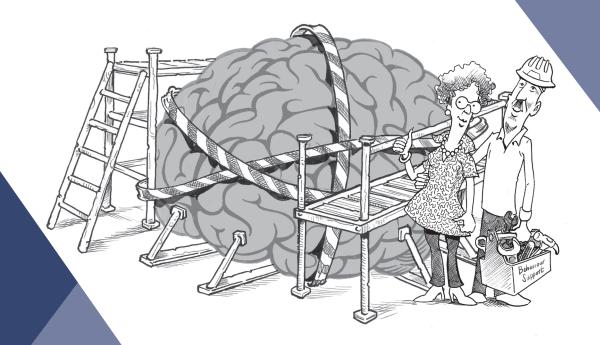# POSITIVE BEHAVIOUR SUPPORT FOR INDIVIDUALS WITH DEMENTIA: A FAMILY EDUCATION WORKBOOK

Alinka Fisher PhD, **Claire O'Connor** PhD **& Olivier Piguet** PhD

FAMILY EDUCATION WORKBOOK ©

FRONTIER

THE UNIVERSITY OF SYDNEY

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UNSW
THE UNIVERSITY OF NEW SOUTH WALES

The purpose of this workbook is to provide families information on common behaviour changes presented by individuals with dementia, and to introduce general principles of behaviour support that can be utilised within community settings.

This workbook is adapted from the educational resource of the FAB-Positive Behaviour Support (FAB-PBS) program (Fisher et al., 2018), and is being piloted with families of individuals with dementia in a study funded by Charles Perkins Centre Active Ageing Research Node, The University of Sydney.

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IMPORTANT NOTE

If you are being confronted with high-risk behaviours, where the behaviour is presenting danger to you or your loved one with dementia, please seek help immediately

Call:

National Dementia Helpline: 1800 100 500

Dementia Support Australia: 1800 699 799

Carer Gateway: 1800 422 737

Lifeline (24 hours): 13 11 14

THANK YOU!

Thank you for participating in this program. We do hope you find the sessions helpful and look forward to your feedback.

YOUR INVOLVEMENT

You will be guided through this workbook over four weekly education sessions. During these sessions, we will discuss common behaviour changes in dementia and introduce general principles of behaviour support. You will be given the opportunity to apply this information to your individual situation, with the completion of activities being an important part of this process.

WEEKLY OVERVIEW

WEEK 1

- Welcome, your involvement
- Module 1: Why do behaviours change with dementia?
- Module 7: what to do in a crisis – Safety First!

WEEK 2

- Module 2: Understanding and responding to anger and irritability
- Module 3: Observing and defining behaviour

WEEK 3

- Module 4: Analysis – *can you identify any patterns relating to the occurrence of behaviour? What might be the purpose/function of the behaviour?*
- Module 5: How can we improve the environment? The importance of positive setting events

WEEK 4
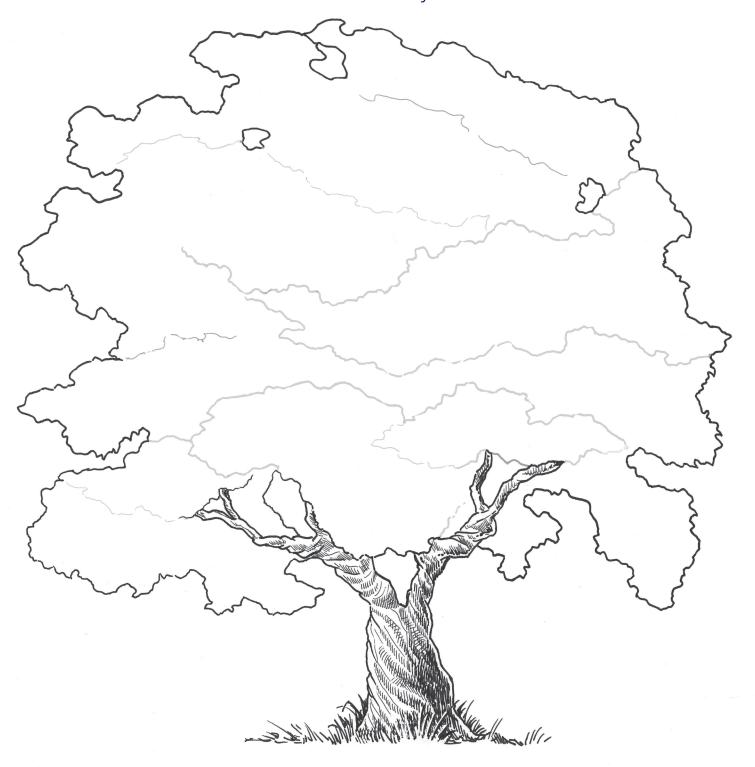
- Module 6: Behaviour support interventions – *what strategies might work for you?*

TABLE OF CONTENTS

THE STRENGTHS TREE

Let's first think about the strengths of your family member with dementia. What are their skills, talents and achievements? What is it about them that you love/admire?

MODULE 1

Why do behaviours change with dementia?

Aim

During this module we will identify common behaviour changes in the presence of dementia. We will also explore how changes to the brain and environmental factors may influence these behaviours.

Outcomes

On completing this module you will be able to:
- understand that behaviour is a product of physiological processes and external factors
- identify what behaviours you find challenging in your current situation, and what factors may be contributing to these behaviours

What are behaviours of concern (or 'challenging behaviours')?

Behaviours deemed 'challenging' will vary between individuals, but may include:

- physical & verbal aggression (e.g. hitting, verbal abuse)
- sexually inappropriate behaviours (e.g. suggestive touching, flashing, sexual propositions)
- socially inappropriate behaviours (e.g. staring at others, using foul language, urinating in public, shoplifting, eating off other people's plates)
- absconding (wandering off)
- apathy (lack of interest or concern)
- lack of initiation
- reduced social skills
- irritability
- mood disorders

Behaviours often become challenging when they are perceived to be of an intensity, frequency or duration that will put personal safety at risk, or if the behaviour negatively influences relationships or community participation.
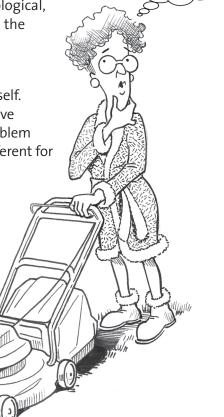
These behaviours may have been present before the onset of dementia, or only appeared afterwards. Coming to terms with and managing these behaviours can present unique difficulties for the individual with dementia and their family.

Why do challenging behaviours occur?

Challenging behaviours often happen as a result of a combination of neurological, reactive (psychological, environmental) and premorbid factors (from before the onset of dementia).

Neurological factors

Challenging behaviours are often a direct result of the change to the brain itself. Damage to the brain can result in a wide range of changes, including impulsive behaviour, reduced tolerance, distractibility and cognitive difficulties (e.g. problem solving, learning, memory, decision-making and reasoning). These will be different for each individual, and will depend on where the brain is damaged.

What changes may occur as a result of changes to the brain?

Attention/concentration:

- Difficulty understanding the meaning of words or sentences
- Difficulty using the right words
- Difficulty pronouncing words (slurred speech)
- Slowed information processing (delayed response)
- Mental fatigue
- Short attention span
- Reduced concentration
- Easily distracted
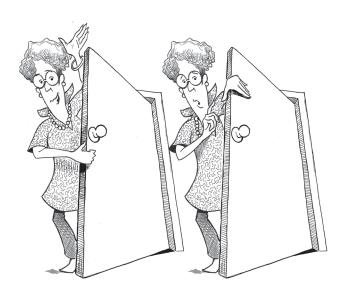
Memory:

- Difficulty learning or remembering new information

Executive function:

- Difficulty following a sequence of events (not knowing what happens next)
- Difficulty working out how to do new things (problem solving)
- Unable to think of a new solution (flexible thinking)
- May repeatedly refer to the same topic or keep returning to that topic
- May start something without considering options or consequences
- Thinking may be rigid and concrete
- May take things literally
- Reduced empathy
- May not pick up on social cues (e.g. understanding non-verbal cues – i.e. someone hinting to finish the conversation
- May be unaware of own limitations and have unrealistic expectations

The information provided here is a guide only.

Each individual will display a different pattern of changes, with varying severity. One person may, for example, have a poor memory, minor problem-solving difficulties, but no change in their personality.

BRAINSTORM

What behaviour changes have you noticed in your family member since the onset of their dementia?

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Reactive factors

Apart from the disease itself, other factors may also affect the person's behaviour, including:

- Feelings of loss and frustration
- Reduced contact with friends
- Financial uncertainty of the future
- Reduced independence and the need to rely on others for day-to-day activities
- Pain
- Fatigue
- Other health issues (e.g. mental health)
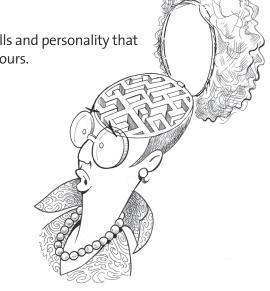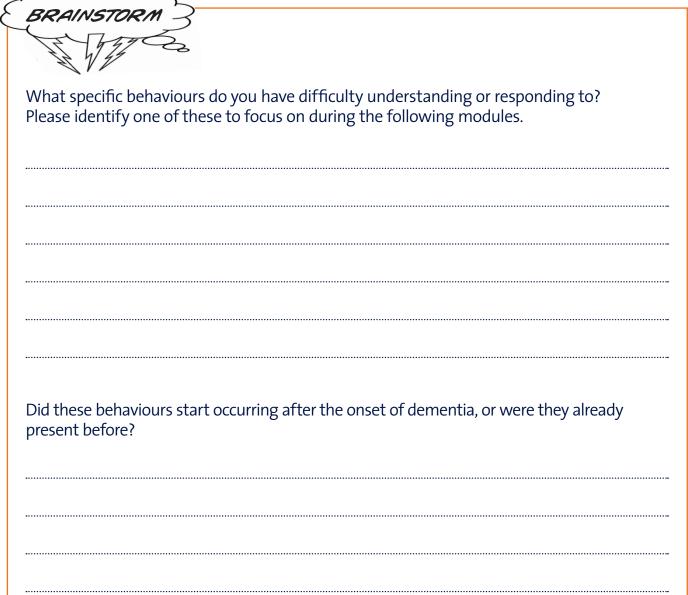
Premorbid factors

It is also important to consider the person's general cognition, social skills and personality that predate the onset of dementia. These can also influence current behaviours.

For example, their previous:
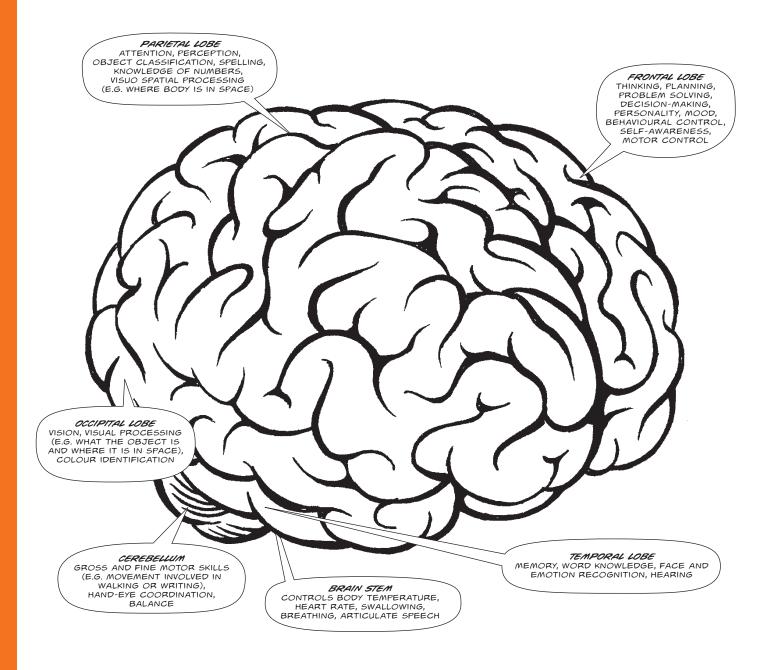
- Problem solving skills
- Personality and coping style
- Interpersonal and communication skills
- Levels of motivation
- Experiences of substance use
- Cultural factors

BRAINSTORM

What specific behaviours do you have difficulty understanding or responding to? Please identify one of these to focus on during the following modules.

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Did these behaviours start occurring after the onset of dementia, or were they already present before?

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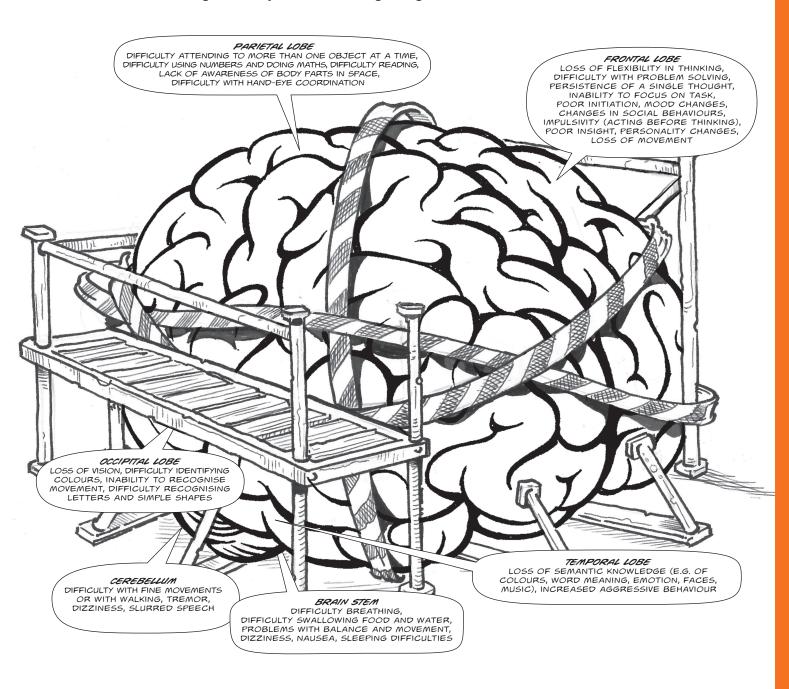
The brain and its functions

This picture describes the main functions of different parts of the brain.

PARIETAL LOBE
ATTENTION, PERCEPTION,
OBJECT CLASSIFICATION, SPELLING,
KNOWLEDGE OF NUMBERS,
VISUO SPATIAL PROCESSING
(E.G. WHERE BODY IS IN SPACE)

FRONTAL LOBE
THINKING, PLANNING,
PROBLEM SOLVING,
DECISION-MAKING,
PERSONALITY, MOOD,
BEHAVIOURAL CONTROL,
SELF-AWARENESS,
MOTOR CONTROL

OCCIPITAL LOBE
VISION, VISUAL PROCESSING
(E.G. WHAT THE OBJECT IS
AND WHERE IT IS IN SPACE),
COLOUR IDENTIFICATION

CEREBELLUM
GROSS AND FINE MOTOR SKILLS
(E.G. MOVEMENT INVOLVED IN
WALKING OR WRITING),
HAND-EYE COORDINATION,
BALANCE

BRAIN STEM
CONTROLS BODY TEMPERATURE,
HEART RATE, SWALLOWING,
BREATHING, ARTICULATE SPEECH

TEMPORAL LOBE
MEMORY, WORD KNOWLEDGE, FACE AND
EMOTION RECOGNITION, HEARING

When the brain is damaged we may see the following changes:

Early stages of dementia

In the early stages of dementia, a person may still show some insight into their changes. As a result, they may experience anger, resentment, depression, emotional lability (constant changing emotions), withdrawal, or loss of self-confidence. These early changes tend to become less prominent as the disease progresses and progressive loss of insight. However, some individuals will remain aware of their difficulties for a long time.

Reduced insight and unawareness of the change in behaviour and effects this has on others is a common feature. This is due to damage to the frontal lobes, which affects the ability to monitor behaviour.

The person with dementia may be unaware of their tactless or inappropriate behaviour. People also may not be able to monitor their behaviours and learn from their mistakes due to reduced insight and memory difficulties.

And what about your adjustment?

Families also go through an adjustment and grieving process. This process will be different for every family, as you come to terms with the dementia and are then faced with the challenges of supporting changed behaviour within your home and community.

Your family dynamics before the onset of dementia will have an impact on how your family cope and adjust to changes. Your role in the family may change. Perhaps you will take on a more leadership role, taking on extra responsibilities. This may include increased pressure on your income, responsibility for transport, managing finances, making decisions and providing emotional/ practical support. Your loved one may also find it difficult coming to terms with this reduced responsibility and increased dependency. As you both learn to adapt to your new roles, there will be a period of adjustment.

The person with dementia may become overwhelmed in crowded environments and may not tolerate noise.

Friends and family may find it difficult to understand and accept the changes in the person with dementia (especially where there is not visible evidence of disability).

They may stop visiting, and the person with dementia may feel isolated. This may place further burden on family relationships.

We have discussed why behaviours change in dementia... so now what?

It is easy to become consumed with 'the problems'. Let's think of the positive attributes you identified in the 'Strengths Tree' at the beginning of Module 1, and separate the person with dementia from their challenging behaviours

Whilst a particular behaviour may be undesirable or offensive, it's important not to make negative judgments about the whole person. Remember to focus on the individual's strengths, as well as their difficulties, and believe that there is capacity to replace the challenging behaviours you have identified with more adaptive ones.

Basic support strategies

There are a few strategies that we can use to minimise the impact of some of the common cognitive changes seen in dementia.

We can:
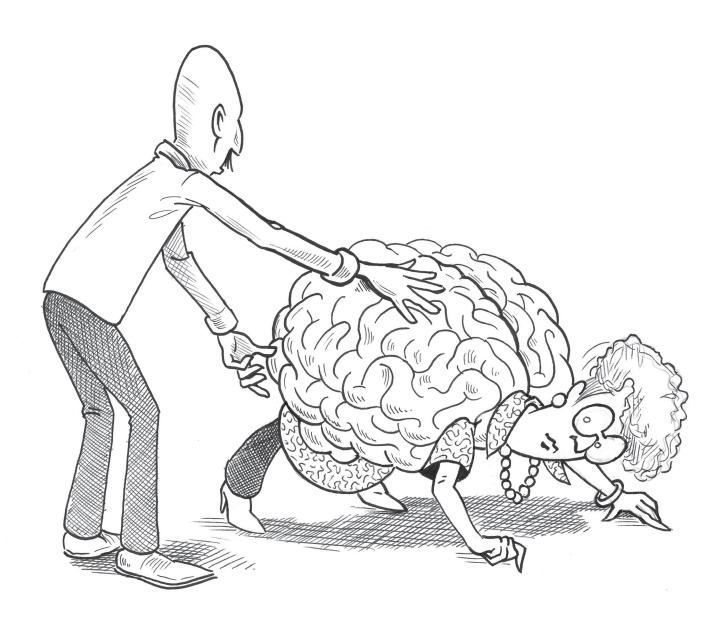
- Speak clearly, using short and simple sentences
- Repeat information if necessary
- Keep activities and instructions short and uncomplicated
- Prompt individuals to the next step in a task (or before moving to the next activity)
- Limit distractions
- Identify achievable outcomes, ensuring there is a purpose or meaning for the person
- Keep the environment organized and uncluttered
- Keep calm and in control, and avoid using emotional undertones (check that you are in the right head space when doing activities – is this the best time for you to be supporting behaviour?)
- Allow plenty of time to do things – limit rushing
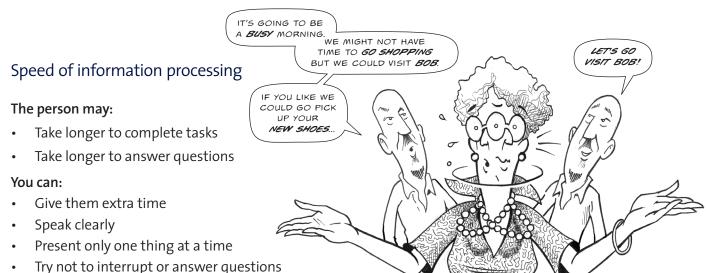
Overleaf is a more comprehensive list of management strategies that apply to specific cognitive changes due to dementia. Try not get overwhelmed by all the strategies presented here, but rather see if any of these might be helpful in your situation.

Sometimes, small changes in the way we respond and interact with a person may significantly change their behaviour. These strategies place importance on allowing time, setting achievable goals/tasks, reducing distractions and communicating in a clear manner (and repeating if necessary). This is not always easy and can take a lot of patience; however, if you keep calm and in control, you will more likely see these behaviours reflected in the individual with dementia.

It may help to circle the strategies that you think could be applied to your situation.

Remember you need to work together to better support the person with dementia!

Speed of information processing

The person may:

- Take longer to complete tasks
- Take longer to answer questions

You can:

- Give them extra time
- Speak clearly
- Present only one thing at a time
- Try not to interrupt or answer questions for them
- Check that they are keeping up with the conversation

IT'S GOING TO BE A BUSY MORNING.

WE MIGHT NOT HAVE TIME TO GO SHOPPING BUT WE COULD VISIT BOB.

IF YOU LIKE WE COULD GO PICK UP YOUR NEW SHOES...

LET'S GO VISIT BOB!

Difficulty following a sequence of events

The person may:

- Have difficulty following instructions
- Lose track of what they are thinking/doing
- Get information mixed up or
- Become confused

You can:

- Keep activities and instructions short and simple; give one instruction at a time
- Ask specific or direct questions
- Provide prompts to the next step in a task
- Set out task requirements in the order of steps required to complete the task
- Reduce distraction by removing any unnecessary items from the activity area

...RIGHT THEN. SO, NOW THAT WE HAVE FINISHED PICKING ALL THE ROSES YOU'D LIKE TO USE...

...THEN NEXT WE CAN PUT THEM IN A NICE VASE.

Fatigue

The person may:

- Get tired quickly
- Have reduced tolerance and ability to cope
- Become irritable easily

You can:

- Encourage them to take rest breaks
- Schedule more demanding tasks when they are at their best (often in the morning)
- Keep activities short

Attention

The person may:

- Appear not to be listening
- Miss details
- Forget what people have said
- Have difficulty concentrating
- Be unable to cope with more than one thing at a time
- Be easily distracted
- Often change the subject
- Get bored easily

You can:

- Use short and simple sentences
- Keep activities short
- Ensure they write down important information
- Encourage them to focus on one activity at a time
- Reduce distractions (noise, other people)
- Bring their focus back to task if they get distracted
- Use different activities to maintain interest

Memory

The person may:

- Have difficulty learning new things
- Be forgetful (what people say, names, appointments)
- Lose things
- Have difficulty recalling what they have learnt

You can:

- Repeat information as necessary
- Encourage rehearsal of new information
- Encourage them to use diaries, calendars, and timetables
- Have 'special places' for belongings
- Give reminders and prompts

Problem Solving

The person may:
- Have difficulty working out solutions to problems
- Be unable to generate new ideas

You can:
- Help identify an achievable outcome for the task, making sure there is a purpose and that it is meaningful to the person
- Avoid giving open-ended tasks
- Help them approach tasks in a more systematic way. E.g. getting out all necessary items before beginning
- Assist them to break tasks down into smaller components
- Introduce one thing at a time – start simple

Reasoning

The person may:
- Have rigid and concrete thinking
- Take statements literally
- Be unable to "put themselves in another's shoes"
- Be resistant to change
- Not understand complex emotions
- Show poor judgment and decision-making skills

You can:
- Use simple language and avoid abstract terms (e.g. using metaphors)
- Explain changes in routine in advance, giving reasons
- if issues occur, think about timing and communication approach (e.g. talk about it later when they are calm)
- avoid using emotional undertones (e.g. say 'yes' but clearly mean 'no')

Flexibility

The person may:
- Be unable to adapt to change
- Become 'stuck in a rut' unable to develop new strategies
- Persist with incorrect/ inefficient methods despite feedback
- Repeatedly refer to the same topic or return to that topic

You can:
- Help them to identify initial signs of frustration and recognise that this is a time to stop what they are doing
- Provide alternative ways of completing a task so a choice is available
- Direct them to another activity if they are continually making errors or consider ways to simplify that activity to match their abilities (e.g. making it less complex)
- If they are talking off topic, direct them back to task by asking a specific question and using visual cues such as pointing or breaking it down into fewer steps

...OK, MUM - HOW ABOUT A CUPPA BREAK?

Planning and organising

The person may:

- Have difficulty preparing for a task
- Be unable to work out the steps or sequences involved in a task
- Not consider the consequences of their actions
- Have difficulty organising their own thoughts and explaining things to others

You can:

- Encourage them to consider what they are about to do before starting an activity
- Provide a written structure or guideline outlining the steps in order
- Give them prompts (e.g. visual and/or verbal)
- Help them to develop a timetable (weekly/daily) to establish a routine
- Keep the environment organised so things are always in the same place
- Encourage them to take time to think about what they want to say

Insight

The person may:

- Be unaware of their cognitive and physical limitations
- Set unrealistic goals and expectations

You can:

- Provide explanation why a proposed action (not their own plan) is useful, and reason through the steps (small steps, start gradually, etc.).
- Help to identify realistic goals – these might be smaller components of a larger plan, but more achievable

Self-monitoring

The person may:

- Often break rules
- Not realise they have made errors because they have not checked their progress
- 'Hog' conversations
- Keep talking when others are no longer interested

You can:

- Reinforce specific requirements of an activity
- Encourage the person to check over how they have performed
- Immediately provide feedback when errors occur or when they talk too much
- Use signals, which have been agreed to in advance, to let them know when they are talking too much
- Encourage turn-taking in conversations
- Let friends and family know about how the person's dementia affects their social skills
- Consider a distraction strategy that could be used in social settings to redirect the person

BRAINSTORM

Did you see any strategies here that might be helpful in your situation?

Reflect on how you currently provide behaviour support, and how you may be able to apply some of these strategies.

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LOOKING FORWARD

During this coming week (before completing Module 2), observe the challenging behaviours you have identified with consideration of neurological factors (changes to the brain – page 7 & 11) and reactive factors (changes to the individual's daily experience– page 8) discussed. Can you see how any of the information presented throughout this module relates to these behaviours?

Next week we will look at understanding anger and irritability, and the importance of observing and clearly defining challenging behaviours.

NOTES/QUESTIONS

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MODULE 2

Understanding and responding to anger and irritability

Aims

During this session, we will identify important factors in understanding and managing anger and irritability.

Outcomes

On completing this module, you will be able to:

- identify early warning signals that an individual is becoming irritated/ angry
- recognise potential triggers of anger
- explain how your own behaviour can exacerbate a difficult situation
- understand the concept of 'anger as a secondary feeling'

Why do people get angry or irritable?

Anger and irritability may be a direct result of dementia, but may also be triggered by other cognitive changes including reduced self-control, impulsivity and lowered frustration tolerance. Issues of sleep deprivation, pain, changed image, changed routine and feeling misunderstood, may also trigger anger and/or irritability.

It is important to be able to:

- identify potential triggers of anger/irritability
- identify 'early warning signals'
- recognise your feelings and
- have strategies for managing anger/irritability

How do we identify the triggers?

Often visible changes occur as a person becomes angry (physical, emotional and/or cognitive). If we can identify these changes early (i.e. before the person loses their temper), we can use them as an 'early warning system'.

The following changes are often used as guideposts to alert a person that they are becoming angry

Physical	Emotional	Cognitive
Muscle tension Temperature change Tremor/shaking Sweating Heart pounding Clenched fists	Irritated Frustrated Moody Unsettled Feeling upset	**Changes to thoughts include:** Racing Jumbled Irrational Jumping to conclusions

(TBI Staff Training: Martin, 2011)

BRAINSTORM

Does your family member with dementia experience anger or irritability?

Can you identify any triggers or 'early warning' signs (physical, emotional, cognitive)?

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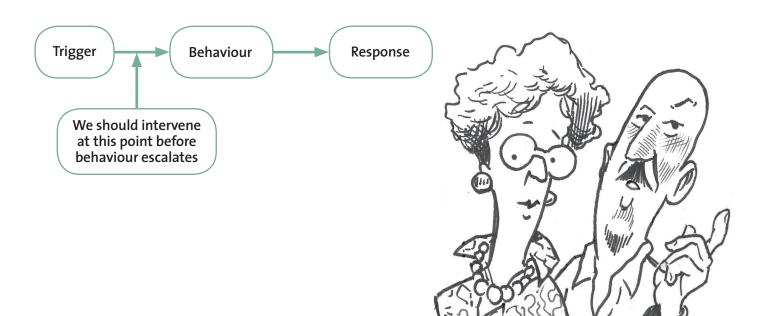
Anger and irritability may be secondary feelings

Anger and irritability may be a secondary feeling, and if so, dealing with the initial feelings may eliminate the 'anger response'.

Pain
Frustration
Fear/Anxiety
Fatigue } Anger/irritability
Guilt
Embarrassment
Humiliation

(TBI Staff Training: Martin, 2011)

When thinking about how people with dementia can change from being calm to being angry/irritable or aggressive, it is useful to think about triggers and responses.

A **trigger** is something that causes a reaction in the person (behaviour), and the **response** refers to the reaction to the behaviour.

Trigger → Behaviour → Response

We should intervene at this point before behaviour escalates

BRAINSTORM

Can you identify triggers of anger in your situation? And how you/or others respond to this behaviour?

Triggers:	Behaviour	Responses:
e.g. being asked to have a bath	→	e.g. let him keep watching t.v. and try asking again in the morning

If you can't think of any right now, don't worry. Perhaps this week you can try identify some of the triggers and responses to behaviours and fill this out then.

It is also important to recognise YOUR feelings

Remember that the behaviour is not necessarily directed at you.

Why you?
Proximity (you are the closest person to them)

What are you feeling?
It is important to recognise and identify your feelings

BRAINSTORM

How do you feel when your loved one becomes angry/irritable (if applicable)?

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What should you do about your feelings...?

- Accept your own feelings about the situation
- Talk to family, staff and friends and discuss how you are feeling
- Recognise that you are only human and that you can also be affected by stress, frustration and anger
- Use stress and anger management strategies yourself

How do we manage anger and irritability?

In any difficult situation, it is important to maintain focus on the underlying issues, not the behaviour.

Below is a more comprehensive list of strategies for managing a situation that is escalating. These strategies place importance on:

- remaining calm
- walking away/removing yourself from situations temporarily (if safe/appropriate to do so) to
- regain composure
- using non-threatening/relaxed body language and tone
- taking slow deep breaths/using a deep breathing technique
- discontinuing a conversation/discussion that is causing a negative emotional reaction in you or the person
- avoiding making the problem worse with the use of alcohol or drugs to 'cope'

What if the behaviour is escalating...?

a) Keep calm and in control
- Avoid mirroring behaviour (e.g. yelling in response to someone being verbally aggressive)
- Controlled breathing (take deep slow breaths)
- Control voice (speak with a calm tone)
- Use non-intimidating body language

b) Maintain a safe distance
- Make sure you are standing outside of hitting and kicking distance (approximately 1 metre away from the person) and be aware of where the exits are in the room in case you need to leave quickly

c) Use non-confrontational body language
- Keep hands open and in full view
- Stand slightly at an angle to the person
- Avoid staring or standing with your hands on your hips
- Avoid making fast movements

d) Think about the situation

- Is there anything reinforcing the behaviour? (e.g. things in the environment or responses to the behaviour)
- Is there anything frightening the person?
- Is there anything frustrating the person? do they have any unmet needs?
- Are they being over or under stimulated?

e) Decide on an intervention (how to respond to the behaviour)

- This may include negotiation, leaving, no action, surprise, distraction, humour, isolating individual, removal of other people from situation, asking for help and self defense (only to be used if under attack / as a last resort)

f) Is the intervention working? Decide on the next step

- If the intervention is not working, you may decide to modify or change your response (for example, if you try to negotiate without success you may feel it is best to remove yourself from the situation).

g) Managing after a crisis

The body's normal reaction to stress is a build up of tension. Tension can be released by:

- Relaxation / breathing techniques
- Physical activity (physical release)
- Talking, laughter, crying (emotional release)

Things to avoid

- Self-administering drugs/ overuse of prescribed medication
- Using alcohol, caffeine or cigarettes
- Comfort eating

Things to remember

- After any crisis, it is normal for a person to experience an emotional or physical change
- Don't label yourself as crazy
- Avoid making life-altering decisions within a few weeks of the crisis

LOOKING FORWARD

During this coming week, try and keep these support strategies in mind and think about the way you are responding to anger behaviours. Can you see how any of the information presented throughout this module relates to your situation?

NOTES/QUESTIONS

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MODULE 3

Observing and defining behaviours

Aim

During this session, we will discuss the importance of observing and recording behaviours.

Outcomes

On completing this module, you will be able to:
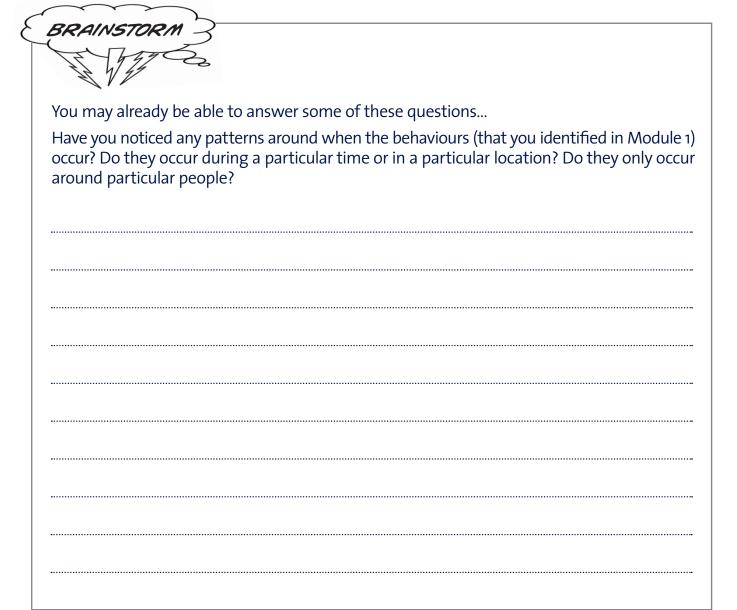
- understand the importance of clearly defining challenging behaviours
- know what to be looking for when observing behaviours
- describe the behaviours you identified in Session 1 in observable terms

Analysing challenging behaviours... where to start?

When analysing challenging behaviour, we need to think about the following:

- **when** does it occur?
- **where** does it occur?
- **who** does the behaviour occur with?
- does it start **suddenly** or build up **gradually**?
- **how long** does it last?
- what is the **history** of the problem?
- what **solutions** have been tried in the past?
- how are people **reacting**?

(TBI Staff Training Kit: Martin, 2011)

BRAINSTORM

You may already be able to answer some of these questions...

Have you noticed any patterns around when the behaviours (that you identified in Module 1) occur? Do they occur during a particular time or in a particular location? Do they only occur around particular people?

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We also need to think about:

- **environmental factors** (e.g. excess noise, overcrowding, appropriateness of environment)
- if the individual treated with **respect**? Do they have **choices**?
- if they are **able to communicate** effectively?
- if they would **benefit** from being **taught coping skills** (e.g. relaxation etc)?

Many of these factors can be recorded through careful observation of the individual. This may reveal patterns of when the behaviours are most likely to occur, in which environment, and in whose company.

If possible, you should also make contact with others who may have been involved in managing challenging behaviour in your loved one (other family members and/or service providers), and find out what strategies have been tried in the past, and what *did* or *didn't* work.

So, what is the behaviour that needs managing?

Before planning an intervention, we need to clearly define the behaviour we want to 'manage'. An accurate and objective picture (not influenced by personal opinion) of the behaviour is best obtained by careful observation and recording.

The behaviour needs to be described in observable terms (exactly what you see).

Not helpful	Helpful
"Bill had an aggressive outburst"	"Bill punched his brother on the cheek with a closed fist"
"John was sexually inappropriate"	"John touched the breast of a female support worker"

When recording behaviours, avoid ambiguous terms, such as "aggressive", "sexually inappropriate", or "disinhibited". This will ensure agreement as to the exact nature of the behaviour, leaving no room for interpretation.

Consider the following example:
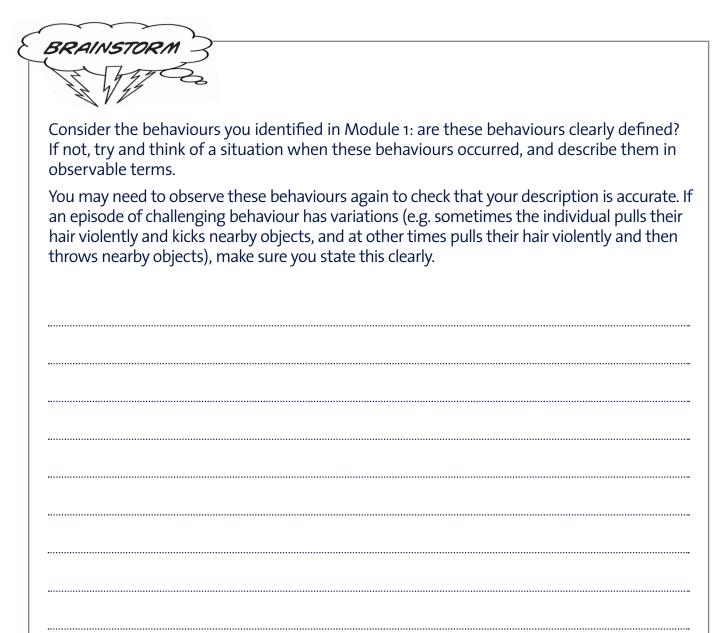
Nathan was eating dinner at the dining room table. He bit his tongue and suddenly turned and grabbed the arm of his partner who was sitting next to him. His nails caused minor bleeding and the force of this action caused significant bruising.

What would best describe this behaviour?

a)   **Nathan became aggressive towards his partner.**

b)   **Nathan firmly grabbed his partner's forearm, causing minor bleeding and bruising.**

Remember, it is important to describe behaviour clearly, leaving no room for interpretation.

The answer (A) above is too ambiguous, stating Nathan's general mood, without explicitly stating what behaviour occurred.

BRAINSTORM

Consider the behaviours you identified in Module 1: are these behaviours clearly defined? If not, try and think of a situation when these behaviours occurred, and describe them in observable terms.

You may need to observe these behaviours again to check that your description is accurate. If an episode of challenging behaviour has variations (e.g. sometimes the individual pulls their hair violently and kicks nearby objects, and at other times pulls their hair violently and then throws nearby objects), make sure you state this clearly.

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LOOKING FORWARD

Now you have a clear definition of the target behaviour, the next step is to record all instances of this behaviour (whenever it occurs) over a specific period, such as a day or week.

This will be your activity next week, so don't get overwhelmed by this now! We will discuss the importance of observing behaviours in Module 4, as it is important that you understand why you are being asked to do this.

NOTES/QUESTIONS

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MODULE 4

Analysis... what it all means.

Aim

During this module, we will discuss antecedents (what happens directly before a behaviour occurs) and consequences (what happens directly after a behaviour occurs), and start identifying whether challenging behaviours are being reinforced.

Outcomes

On completing this module, you will be able to:
- start analysing behaviours by examining the role of antecedents and consequences.
- be able to identify possible triggers of target behaviours.

What is the purpose of the behaviour...? Why does it occur?

Throughout this session, we will identify the function ('purpose') of the behaviour you have identified, and other reasons why the behaviour may be occurring. This may include antecedents and consequences.

Antecedents refer to what happens directly before the behaviour occurs, triggering a response. For example, you may observe that directly before the behaviour occurred, there was a transition to a new activity. This 'transition phase', which involved the individual being asked to change activities, would be referred to as the 'antecedent'.

By identifying the antecedent we can sometimes see what type of replacement behaviour may be appropriate. For example, if an individual becomes aggressive each time they are asked to try something new, it may be appropriate to teach them how to verbalise their concerns/ fears.

> *Antecedents are very important when designing interventions for people with dementia, as individuals often have challenges in understanding and processing information.*

Consequences refer to what happens directly after the behaviour has occurred. So, for example, Jane receives a phone call from her friend who says she can no longer come over for dinner (antecedent), Jane then becomes upset and begins crying and bangs her head against the wall (behaviour), which is followed by her mother giving her a hug and offering to take her out to her favourite restaurant instead. Jane calms down and is happy with this alternative (consequence). Also see the example below.

Antecedent

Bob is playing on his computer. His partner, Jane says it's dinnertime – Bob doesn't respond. Jane repeats herself several times, becoming increasingly impatient.

Behaviour

Bob gets up, takes his plate and throws it on the floor.

Consequence

Bob returns to his computer. His mother quietly cleans up the mess and retreats to her bedroom. She makes him dinner later when he says he's hungry.

In this situation, the behaviour appears to serve an important function: to avoid having to stop playing on the computer to have dinner. Its function in this situation is successful.

Identifying the 'function' of challenging behaviours is not always so easy; however, this example helps us to start thinking of behaviours as having a purpose.

Once we can identify the desired function of a particular behaviour, we can start looking at what may be reinforcing the behaviour. We may also see what other behaviours may serve the same purpose. (e.g. An individual starts yelling when he gets bored, which results in a caregiver's attention. The individual learns skills to request attention or change of activity without yelling).

This is an important first step in developing an effective behaviour management strategy.

Let's consider the different functions of behaviour below:

Behaviour
{
Attention

Access to items
- objects, places, activities, etc.

Escape
- from a person, setting, activity, demand, etc.

Avoidance
- of a person, setting activity, demand, etc.

Automatic reinforcement
- behaviour itself is reinforcing (e.g. gaining particular sensory stimuli)

The two main causes of challenging behaviours following the onset of dementia are:

1. Difficulty controlling (self-regulating) behaviour due to the neurological changes resulting from dementia (e.g. reduced tolerance).

2. A learned response, which has been reinforced in a person's environment (e.g. If I yell, I get what I want).

These factors will be discussed further in the following Modules.

Let's identify the antecedent, the behaviour, and the consequence in the following example:

Michael (63 years) was diagnosed with dementia 6 years ago. He lives at home with his wife and adult daughter, who both assist with his care. Michael has a set daily routine that he follows, and a specific way of doing tasks throughout the house. One evening, while he was washing the dishes, Michael left the tap running on full-volume. After Michael did not react when his daughter asked him to turn off the tap, she leaned past him and turned it off herself. At this, Michael turned around and grabbed his daughter by the throat. Michael's daughter was very shocked, and stayed away from him for the rest of the evening.

Antecedent: Michael's daughter had leaned past him and turned off the tap.

Behaviour: Michael grabs his daughter by the throat.

Consequence: Michael's daughter does not interfere with his task again.

Relevant information: Michael is capable of doing tasks, but has his own specific method of completing activities. His daughter is less likely to interfere with his way of doing things. Michael learns that he can prevent people from interfering with his activities by physically stopping them.

Would you agree with the information presented here?

Let's now consider the following example.

Can you identify the antecedent, the behaviour, and the consequence?

Since her diagnosis with dementia two years ago, Sally (80 years) does not like going out to social events as much. Sally's husband Mick feels lonely as she no longer engages in conversations with him like they used to, and he still enjoys socialising. Last week, they were invited to a mutual friend's house for dinner. Sally said she didn't want to go, but Mick insisted as he felt it would be beneficial to them both to go. Once at the dinner, Sally sat in the corner of the room and did not speak to anyone. As soon as she had finished eating, Sally interrupted Mick's conversation and asked for the car keys so she could wait outside. Mick was embarrassed, apologised to their friends and left early.

Antecedent:

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Behaviour:

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Consequence

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Once you have completed this activity, you can look at the suggested answers on the following page. If you do not feel confident in identifying antecedents, behaviours and consequences, please discuss this with the Program Facilitator.

> ### Suggested answers – Identifying the antecedent, behaviour and consequence for Bill
>
> **Antecedent:**   Sally did not want to attend the dinner. Mick was enjoying himself talking to their friends
>
> **Behaviour:**   Sally ignores everyone at the party, interrupts Mick's conversations and waits outside
>
> **Consequence:**   Mick takes Sally home early
>
> **Relevant information:** Sally did not feel like visiting with friends. She wanted to stay at home. Mick may become more reluctant to visit friends with Sally, and go out less frequently himself. Sally learns she can spend more time at home and avoid seeing friends by ignoring people and waiting outside in the car.

It is not always easy to identify what triggers behaviours, which highlights the importance of recording your observations. This will often show a pattern in behaviours, and possible triggers.

What to observe?

When observing behaviours it is important to take note of:
- **the environment/ setting**
- **time**
- **who was present**
- **the antecedents and consequences (is something reinforcing the behaviour?)**

This will be discussed in more depth in the following modules.

An **Observation Sheet** has been attached (page 45). This week, we will be using this checklist to identify when your identified behaviour/s are occurring.

LOOKING FORWARD

During this coming week, use the Observation Sheet on page 45 to observe the target behaviour you identified in Module 1. Remember to record the Antecedents, Behaviours, and Consequences in objective and observable terms (exactly how you see them). Use the following table to work out how long you should observe your target behaviour.

Approximately how often does the behaviour occur?	Observe the behaviour over the following time period:
Several times a day	1 day
A couple times a day	3 days
A few times a week	1-2 weeks
A couple times a week	2 weeks

For the purpose of this activity (and due to time limitations), it is best to choose a behaviour that happens often, so you get the opportunity to record a number of instances before we catch up next week.

During the next module, we will also discuss the importance of routine. Please record your family member's current routine using the form on page 46. Don't panic if there are gaps in their weekly schedule, just fill it out as accurately as possible.

NOTES/QUESTIONS

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OBSERVATION SHEET

Name of person observed: _____   Observer: _____

Target behaviours: _____

Date	Time	What happens before the behaviour? (Antecedent)	Behaviour	What happens after the behaviour? (Consequence)	Possible Function (purpose of behaviour)/ Comments
15/10/15 (EXAMPLE)	10am	I asked Jane to help with the dishes	Jane picked up her plate and threw it on the floor. She then left the room to her bedroom	I gave her some time in her room and cleaned up the broken plate. We continued with daily activities when she returned we didn't speak of the incident	Avoiding helping with dishes. To let me know she was angry with me? I was irritable which she may have picked up on

Weekly Routine

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
7:30-9:30am							
9:30-11:30am							
11:30am – 1:00pm							
1:00-3:30pm							
3:30-6:00pm							
6:00-8:00pm							
8:00-10:00pm							

LOOKING BACK

You should now have a basic understanding of why challenging behaviours may occur.

So, now what?

Hopefully, your observations (using the Observation Sheet) will reveal some patterns in your target behaviour, including similar times/settings when the behaviours occur, and perhaps consistent consequences that also may play a part in reinforcing the behaviour.

Can you identify patterns in the target behaviour or possible triggers (after completing your observations)?

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In Module 5, we will discuss the importance of positive setting events (antecedent strategies) in behaviour management interventions for people with dementia. We will also start identifying what management strategies may work for you.

Make sure you take note of any questions you have, as sometimes behaviour management strategies sound more difficult than they really are.

IMPORTANT NOTE
If you are being confronted with high-risk behaviours, where the behaviour is presenting danger to you or your loved one with dementia, please seek help immediately
Call Lifeline (24 hours): 13 11 14 or Crisis Care (4pm-9am): 13 16 11

MODULE 5

Creating a positive environment (antecedent strategies)

Aim

During this module, we will discuss the importance of creating a positive environment (antecedent strategies) to support behavioural changes following the onset of dementia.

Outcomes

On completing this module, you will be able to:

- understand the importance of creating a positive environment for your family member with dementia, including environment changes, routines and meaningful activities
- start thinking about why your identified challenging behaviours are occurring and what antecedent strategies may be helpful

As discussed in previous modules, people with dementia often face difficulty with information processing. It is for this reason that antecedent strategies (e.g. environmental changes and identifying warning signals/triggers) are critical to behaviour support strategies for people with dementia.

There are some basic antecedent strategies that are helpful in creating a positive setting for your family member with dementia. These strategies focus on creating a positive and organised environment – you may find by making small changes to your environment, challenging behaviours will decrease.

Environmental changes

During previous modules, we have discussed the importance of an organised and structured environment.

Your observations may reveal a close link between challenging behaviours and environmental factors (e.g. never knowing where the sugar bowl is!). These behaviours can often be resolved by making sure the environment is organised (having specific places for belongings and labeling cupboards) and appropriate to the person's physical abilities.

Even if you do not feel challenging behaviours are directly linked with environmental factors, it is likely that creating an appropriate and organised environment will result in positive outcomes for the individual. Rather than expending their cognitive energy trying to make sense of their surroundings, they can use it to focus on other tasks at hand.

BRAINSTORM

Can you think of how you may make your environment more organised/ structured to suit the needs of your family member with dementia?

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Routine

Routines are important for a person with dementia. A person may have difficulty starting activities, planning how to do them, and maintaining concentration. Routines can help to prompt the person with what needs to be done and in what order. Routines are also helpful if the individual has difficulty transitioning from one activity to the next.

Routine can give the individual with dementia a sense of control over his or her life.

Developing a routine allows your family member with dementia and you, their carer, the opportunity to look at their weekly schedule and make sure activities are appropriate and reflect their interests. When you record their current routine, you may notice that there are certain parts of the week when there are no activities scheduled, which may directly relate to the occurrence of challenging behaviours.

Remember, it is important that the individual helps in setting up their weekly routine, and choosing what activities/tasks they would like to be included.

STRUCTURE and ROUTINE are the keys to independent functioning and success for individuals with dementia.

How to set up a routine

Depending on the cognitive abilities of the individual, assistance may be needed with setting up a routine. It is important to first look at the current daily/weekly schedule and to incorporate the preferred routine – e.g. what time do they usually get out of bed? Do they like to have their shower before or after breakfast?

It is useful to have the routine displayed somewhere central (e.g. the fridge or dining room wall). You could laminate a large table (like the one on page 52) and use a white board marker to fill in the daily/weekly activities. This also enables you to make changes where necessary.

BRAINSTORM

Look at your family member's current routine on page 46. Is there anything that surprises/concerns you? Can you think of how their routine might be adapted to better suit their needs? It may be helpful to develop a new routine using the table on page 52.

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Weekly Routine

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
7:30-9:30am							
9:30-11:30am							
11:30am – 1:00pm							
1:00-3:30pm							
3:30-6:00pm							
6:00-8:00pm							
8:00-10:00pm							

Meaningful activities

So, how does this relate to behaviour support? Consider, how do you feel when you are doing something that you are enjoying or something that gives you a sense of purpose? Now compare that with how you feel when you do something out of obligation, or feel bored and uninspired by what you are doing or by your surroundings.

People who are engaged in meaningful activities are going to feel more positive, and when we are feeling positive, this is more likely to be reflected in our behaviour. Likewise, if we feel a sense of purpose or responsibility, we will feel more important and valued by others.

It is therefore important that meaningful activities are incorporated into the individual's routine. If an individual feels good about their routine, they will be more likely to cooperate when they are required to do necessary but less desired activities (e.g. showering, brushing teeth, dishes etc.).

It might help to consider the following questions:

What are the individual's interests? What do they like/dislike?

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What are their strengths? What are they good at?

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When do they seem most engaged?

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BRAINSTORM

Can you think of any meaningful activities that could be incorporated into your family member's weekly routine?

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Consistency

In this context, consistency refers to all carers and family members having an agreed response to challenging behaviours and maintaining a structured environment. This is very important when implementing behaviour support strategies.

It is not always easy to maintain consistency within unstructured community settings. However, consider these two guidelines:

- responses following challenging behaviours (e.g. ignoring – discussed below) should be consistent amongst carers. If carers respond differently to target behaviours, this will be confusing for the individual, and behaviour management strategies will most likely be ineffective.

- if you decide on 'special places' for belongings, it is important that all carers are aware of this system and understand the importance of maintaining an organised environment.

Let's consider the following example:

Daniel (56 years) was diagnosed with behavioural variant FTD three years ago. He lives with his wife, two teenage children, and their dog, Scratch. Daniel had to stop work as an electrician a year before his diagnosis as he was becoming confused with how to complete jobs, and on two occasions had become angry, swearing at his colleagues.

Since his diagnosis, Daniel has had difficulty with maintaining the tasks he previously managed around the house, and is becoming increasingly reliant on his wife Leah to complete daily tasks such as laundry and washing up. Daniel becomes easily frustrated when something doesn't go to plan or if he becomes confused in the middle of a task. When this happens, Daniel becomes short tempered, swears and may throw something in frustration.

It was suggested that Leah develop a daily routine whiteboard with Daniel to display on the wall next to the clock, to help remind Daniel what activities are planned for each day. When planning the routine, they realised that much of Daniel's day was spent following Leah around or watching TV. So they sat down together and discussed what Daniel might enjoy doing. Daniel said he would like to take their dog Scratch out for walks, and that he would like to do some of the chores that he used to manage, like gardening and washing the car. Although Daniel still needed help with planning his activities, having his new routine outlined on the whiteboard made a big difference to him and Leah.

Daniel's new routine involves a daily walk with Scratch, watering the garden three times per week, and washing the car every Saturday. Initially, Leah went with Daniel and Scratch on their walks, but as they followed the same route each day, Daniel quickly became confident on his own, and Leah was able to use that time for herself. Leah had to prompt Daniel to water the garden in the beginning, but after a couple of weeks, Daniel was going out to the garden on his own everyday to water and collect leaves from the front lawn. Daniel needed help with getting organised to wash the car, but once he had the bucket with soapy water and sponge, Leah was able to leave him to it.

Daniel feels proud that he is contributing to the household again. Daniel becomes frustrated much less frequently now, and if he shows the early warning signs (stalking around the house and grabbing at things Leah might be using), Leah now finds other activities for him to engage with. Sometimes this might be something for the household (e.g. taking the laundry off the line), or if in the evenings, it might be a jigsaw puzzle. Leah and Daniel's friends understand the importance of these new strategies, and have actually enjoyed sitting with Daniel while he works on a jigsaw puzzle.

Now lets apply the information we have covered so far to the following example:

Sam (70 years) lives with his wife Amara. Before he retired, Sam was an engineer but since his diagnosis with Alzheimer's disease, his ability to plan and problem solve have declined. Sam reports having no hobbies, but Amara said that before he developed dementia, Sam used to enjoy playing chess, helping around the house, and doing basic carpentry work.

Sam spends his days watching TV or lying in bed. When prompted by Amara to help with something around the house, Sam yells at Amara and retreats into his room. If Amara did not prompt him in the mornings, Sam would lie in bed all day.

Questions

What is the main problem?

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What do you want the outcome to be?

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Is there anything currently reinforcing this behaviour?

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What potential reinforcers are available to you?

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How might you manage this behaviour?

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Are there other issues you need to consider?

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During the coming week, observe challenging behaviour(s) with these antecedent strategies in mind (environmental changes, routine, meaningful activites & consistency) – do you think any of these may be helpful? You may already be able to apply some of these to your situation...

Throughout this workbook, we have emphasised the use of antecedent strategies, focusing on a 'proactive' rather than 'reactive' approach. However, sometimes contingencies can also play an important role in behaviour support strategies – and even though some people with dementia can learn from consequences, it is still important to create a positive environment.

Desired behaviours ought to be greeted with encouragement and praise, and challenging behaviours should be greeted with efforts to help the person succeed rather than with punishment, which only tends to breed more failure.

In Module 6, we will discuss a variety of consequence-based behaviour management procedures that may be helpful. We will then start identifying what antecedent and consequence strategies might work for you.

NOTES/QUESTIONS

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MODULE 6

Behaviour support procedures

Aim

During this module, we will introduce some basic behaviour support interventions. These strategies can be used individually or in combination with other approaches as part of a more comprehensive behaviour support program.

Outcomes

On completing this module, you will be able to understand and apply one or more of the following behaviour management procedures:

•   Positive reinforcement

•   Extinction

•   Differential reinforcement

(Module adapted from Jacobs, 1995)

Providing behaviour support

Each case and challenge is unique and requires its own individualised approach. Not all individuals with dementia – even those with similar challenges – will have the same response to the same approach.

When appropriate to the situation, some of the behavioural procedures presented throughout this module may be useful. These procedures can be used to maintain or increase particular behaviours, or decrease behaviours.

Please note that these contingency strategies need to be used with caution (and closely monitored) when individuals have difficulties with information processing and memory.

Try not to get overwhelmed by these procedures – they often sound more difficult than they really are! Make sure you take note of any questions you have so we can discuss these as we go.

Positive reinforcement

This is helpful when the aim is to maintain or increase behaviour. A positive reinforcer (reward) is presented immediately following the desired behaviour so the person will see the consequence of the behaviour as something positive. This results in the increased likelihood of this behaviour occurring in the future. Positive reinforcement can be tangible (If I work hard, I will get a raise) or social (praise or smile).

> Example: *Ted cooked his mum dinner every evening. He wanted her to be more helpful with cleaning up after the meal. So he made a point of praising her every time she took her plate to the sink (after prompting). As a result, Mum started taking all of the dirty dishes to the kitchen. She is now responsible for cleaning the table after mealtimes and doing the dishes.*

Description:

Positive reinforcement is one of the most basic, effective, and easy-to-use behaviour support strategies. It is also one of the most popular procedures because it focuses on what a person is doing correctly rather than incorrectly.

The concept is simple: each time the person engages in the desired behaviour, you reward them, which increases the likelihood of this behaviour occurring again in the future. However, using this strategy requires attention to detail.

A reinforcer (reward) is most commonly, but not always, what the person likes, or what someone else thinks the person "should" like. For example, although a person may like chocolate, a block of chocolate is unlikely to be an appropriate reinforcer for someone who is trying to lose weight, or who has just eaten a large meal.

Sometimes, the most preferred consequence may not be appropriate for use as a reinforcer. It may be too costly, inaccessible, or illegal. There are, however, many things that can act as reinforcers, including verbal feedback, praise, money, points, and so on. The opportunity to participate in preferred activities can also be an effective reward for doing less preferred activities. For example, we may be willing to clean out the shed if we can then go fishing, or eat our vegetables to get dessert.

> Example: *Erik liked to go to the cafe but refused to walk there. Telling him that he could go to the cafe whenever he walked there meant he got his desired trips to the café, but also the exercise that he needed.*

Perhaps the most effective and most often overlooked reinforcers are verbal praise and attention. Think of how much we do for just a smile or some other form of acknowledgment from someone who is important to us. It is also important to note that what may be effective with one behaviour in one setting may not work in another.

It is also important for the value of the reinforcer to be equal to the effort that is required to perform the behaviour. A reward that is not worth the effort is unlikely to be an effective reinforcer. Would you mow the entire lawn and do all the weeding on Saturday for a dollar? How about for a thousand dollars? Finding a happy medium or balance between the value of the reinforcement and the behavioural effort is a skill that develops with time and experience.

BRAINSTORM

What do you think would make effective reinforcers for your family member with dementia?

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It is important to have control of the accessibility of the reinforcer. If the reinforcer is readily available to the person, it is unlikely that it will have much effect on the behaviour. For example, using crackers (food) as a reinforcer for putting the dishes away is unlikely to be very motivating after eating dinner. Using tokens that can be exchanged for time watching television, is also unlikely to be effective if the person has unrestricted access to his or her own television. It is also important that the reinforcer is age appropriate.

Controlling the accessibility of reinforcers presents important ethical issues. For example, it is unethical (and illegal) to deprive people of the basic elements required for life, such as water, food, clothing, shelter, and contact with others. However, these things are powerful motivators for all of us, so when used in any behaviour management plan should be carefully monitored and only used in a manner that does not violate personal rights and dignity.

For example, you may use certain types of food, such as special treats, or type of meals as reinforcers.

You may also use food as a reinforcer during the early afternoon, between meals, rather than delaying an individual's lunch.

Finally, reinforcers may stop working. Too much of a good thing can be a problem, as it may no longer be an effective reinforcer. It is then important to think about the amount of reinforcer to provide following the desired behaviour.

It is also important to identify reinforcers that can be used within your natural environment, as they will be available and appropriate to the behaviour. In some situations, the changes in the person's behaviour will determine his or her own reinforcement. For example, although you may use praise and rewards to motivate a person to be more physically active, once they are able to do so, the ability to get around and access activities may be enough to maintain this behaviour.

When and how often do you reinforce the behaviour?

Generally, it is recommended that you reinforce (reward) the desired behaviour every time it occurs. However, once the behaviour is well established, it is not necessary to reinforce it every time.

It is important that you reward the behaviour as soon as you can after it has occurred. If you wait for too long, other behaviours might occur in the meantime, and it may not be clear to the person exactly what behaviour is being reinforced.

Please note: positive reinforcement programs that address high-risk behaviours should only be implemented by specially trained professionals.

When designing a positive reinforcement program you need to:

1. Identify the specific behaviour you want to target. The more specifically the behaviour is defined, the more focused the intervention can be.

2. State how often the behaviour currently occurs, so you can monitor whether the program is working or not

3. Consider other behaviour management techniques – do you think that positive reinforcement is the most appropriate procedure for the target behaviour?

4. Select a reinforcer (reward) that:
   a) is "equal in value" to the behaviour to be reinforced
   b) is readily accessible to you but not the individual
   c) appears to be of interest to the individual

5. Carefully monitor the persons progress – is behaviour improving? Is the reinforcer still working effectively?

Example: *Sally's mother tried to encourage Sally to chew with her mouth closed, but she had been unsuccessful. Sally really liked cats, so her mother set up a program in which they talked about cats during mealtimes as long as Sally kept her mouth closed while eating. When Sally opened her mouth, the conversation stopped and only continued when she closed her mouth again. As a result, Sally now chews her food with her mouth closed 95% of the time, compared to 30% of the time before the intervention.*

Activity

How would you use a positive reinforcement procedure in the following situation?

Graham (58 years) is diagnosed with behavioural variant FTD. His lives with his wife, Amanda. Amanda does most of the housework and house maintenance, and it was agreed that Graham would be responsible for watering the garden. However, he regularly forgets, and Amanda often ends up doing the watering for him. She has tried prompting him in the evening and in the morning before work, but this has not been successful.

In Graham's spare time he loves watching soccer, playing chess and socializing with his friends.

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Extinction

This is helpful when the aim is to reduce a behaviour. Extinction occurs when you do not reinforce a specific behaviour. For example, you may make a commitment to totally ignore inappropriate comments made by an individual. It is common when using extinction to see an initial increase in the behaviour. For example, ignoring inappropriate comments will initially result in the person becoming more vocal and explicit. However, if you continue to ignore this behaviour, it will decrease/ cease over time.

Example: *Allen tried to get his mum's attention by knocking his cup over during mealtimes. His mum would clean up the water, picks up the cup and refill it. This series of actions reinforced Allen's negative behaviour because he was getting the attention he was seeking. To address this problem, Allen's mum started ignoring Allen when he tipped over his cup. At first Allen tried to get her attention by throwing the cup on the floor, but then he stopped engaging in this behaviour because it was no longer resulting in the desired outcome (getting attention).*

Description

This is one of the most basic and powerful behaviour support interventions to help decrease target behaviours. When we present a reward (reinforcer) following a behaviour, it can increase the likelihood of this behaviour occurring in the future. Therefore, by withholding this reinforcement, it is possible to decrease the likelihood of a behaviour occurring in the future. If someone does not receive reinforcement for his or her behaviour, they may be less likely to engage in that behaviour over time. In essence, when applied, this procedure follows the maxim of "ignore something and it will go away".

One of the biggest challenges in the use of extinction is to be consistent. For this approach to be most effective, the reinforcer maintaining the behaviour must be consistently withheld whenever the behaviour occurs. However, it is very easy to slip and reinforce rather than ignore the target behaviour, as we have customarily reinforced this behaviour in the past. For example, when trying not to pay attention to someone so that they will remain focused on task, we may find ourselves inadvertently laughing at that person's jokes. When this happens, the person may learn that although the behaviour is not reinforced all of the time, it is sometimes reinforced. Intermittent reinforcement (sometimes reinforcing behaviours) can be very powerful in maintaining behaviour, and therefore when this occurs during an extinction procedure, it may take longer for the behaviour to stop occurring.

In other situations, all carers or family members/ friends may not be consistent in ignoring the behaviour and the person will simply learn who will and will not reinforce the behaviour. This is similar to a child knowing which parent to go to when they want something.

Finally, you may not be in control of the reinforcer (response) that is maintaining the behaviour, and the person may be able to find other avenues from which to be reinforced for the behaviour. For example, if you decided to no longer pay attention to a person's 'spitting' behaviour, they may be able to find a way for other community members to give them attention. In such situations, extinction may not be effective because you are not able to fully control the reinforcer that is maintaining the behaviour.

Extinction procedures can take time to work, and it is possible that the target behaviour will increase in strength and frequency before decreasing. This is because the person may first try harder for the reinforcer before learning that it is no longer available. If the behaviour starts to increase, don't assume that the procedure is not working and "give in." The rule is to maintain the extinction intervention fully unless you decide to abandon it completely. Otherwise, repeated starting and stopping of the procedure may make the behaviour worse rather than solve the problem.

It is therefore important to think ahead when implementing this procedure, making sure that you (and your family) are able to manage the increased levels of the target behaviours. For example, a person who becomes too aggressive to handle during an extinction procedure may learn to manipulate others through this violence, and a person who initially engages in severe head-banging behaviour may accelerate to the point of potentially causing serious harm. This does not mean that it is never appropriate to use extinction with these forms of behaviour, but that many considerations have to be taken into account before using this procedure for these types of challenging behaviours.

During an extinction intervention, it is important that the person is carefully monitored to ensure his or her safety as well as the safety of others. In addition, other strategies that reinforce appropriate behaviours and engage the individual in meaningful activities should continue.

Once the target behaviour has decreased to an appropriate level, it is important not to reinforce it again in the future. Otherwise, there is a possibility that the behaviour will come back.

Finally, extinction generally works best when it is used with positive reinforcement. In very general terms, this is a process known as differential reinforcement – this is discussed below. In this procedure, one behaviour is targeted for decrease through the use of extinction, while more appropriate behaviour(s) are targeted for increase using positive reinforcement. Although differential reinforcement is preferred, sometime extinction procedures alone may be sufficient.

Please note: extinction programs that address high-risk behaviours should only be implemented by specially trained professionals.

When designing an extinction program you should:

1. Identify the specific behaviour you want to target. Since many behaviours initially increase in frequency before they decrease, it is important to make sure that you and your family can control and manage the behaviour when it is at its extreme form.

2. State how often the behaviour currently occurs, so you can monitor whether the program is working or not

3. Consider other behaviour management techniques – do you think that extinction is the most appropriate procedure for the target behaviour?

4. Identify the reinforcers(s) (responses) that are currently maintaining the behaviour. Make sure you (and others involved) have full control of the reinforcers. If this is not the case, the extinction procedure is less likely to be successful.

5. Carefully monitor the person's progress – is the challenging behaviour decreasing?

Example: *Dianne shouted and screamed at others most of the time when she wanted something. She would shout even when someone was close by. Family members were told to ignore Dianne's yelling. At first, Dianne shouted louder to get their attention, becoming hoarse in the process. She soon learned that her family did not respond to her requests at these voice levels and decreased the amplitude of her voice.*

Activity

How may you use an extinction procedure in the following situation?

Richard had a great sense of humour and was often the life of the party. However, he did not always keep his jokes under control and often embarrassed his family with his off-colour humour. Attempts to talk to Richard about this had not been successful.

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Differential Reinforcement

Positive Reinforcement **+** Extinction **=** Differential Reinforcement

This technique is not as complicated as it sounds. It uses a combination of principles of positive reinforcement and extinction procedures (discussed previously): it involves reinforcing desired behaviours, while inappropriate behaviours are ignored. For example, if your goal is to encourage an individual to socialize with others, you would reward them for just coming out of their room, even if they haven't yet reached the end goal (socialising with others). Basically, this technique involves reinforcing (rewarding) any desired behaviour rather than the 'inappropriate' behaviour.

> Example: *John would prefer his mother to get him drinks of water, bring him fresh towels when he is perspiring, and meet other needs that he is capable of doing himself. His mother would like him to meet his own needs. As a result, his mother ignored requests that he is personally capable of meeting, while at the same time socially acknowledging (praising) his effort to help himself. John soon begins to take greater charge of his daily needs.*

Description

Through using this approach, the person changes a less desirable form of behaviour to a more desirable one. For example, Amy's sister is trying to teach Amy to introduce herself in a more gracious manner. She asks her family members and friends to ignore Amy when she says "hey you!" or "oi", and to only respond to her when she says "hello, how are you?" In most situations, a person will quickly change their behaviour to continue to receive the social reinforcement of your response.

As with other approaches, it is important to be consistent when using differential reinforcement to maximise effectiveness. Otherwise, the person may learn that with certain people they get away with the behaviour, or they may become frustrated/ confused with the lack of direction. It is also a good idea for the behaviours that are going to be reinforced to be of approximately equal (or less) effort as the behaviour you are trying to extinguish. Otherwise, the person may not feel that it is worth the effort to engage in the new behaviour. Furthermore, if you reinforce both the positive and negative forms of behaviour, the person will learn that they can engage in either, rather than just the new and more desirable behaviour.

When using differential reinforcement, it is generally recommended to attempt to replace the challenging behaviour with some other specific behaviour. Usually, you would choose to reinforce the person for a behaviour that is incompatible with the behaviour that you are trying to decrease. For example, it is difficult to pace around the room (the behaviour to be decreased) and sit at the dining room table (an incompatible and acceptable behaviour to be increased) at the same time. Or, you may choose to reinforce a wide variety of other acceptable behaviours, just as long as the targeted challenging behaviour is not reinforced when it occurs.

Please note: differential reinforcement programs that address high-risk behaviours should only be implemented by specially trained professionals

When designing a differential reinforcement intervention you need to:

1. Identify the specific behaviour(s) you want to increase through positive reinforcement and the specific behaviour you want to decrease through extinction

2. State how often the behaviour currently occurs, so you can monitor whether the program is working or not

3. Consider other behaviour management techniques – do you think that differential reinforcement is the most appropriate procedure for the target behaviour?

4. Identify the reinforcer(s) (responses) that are currently maintaining the behaviour that you want to decrease.

5. Carefully monitor the persons progress – is the frequency of the challenging behaviour decreasing?

The specific procedures and requirements of differential reinforcement are the same as the combined procedures of positive reinforcement and extinction. For more detail, please refer to the individual descriptions of these procedures on page 62 and 66.

Example: *George made inappropriate sexual comments whenever his mother had female friends visit. The more she tried to teach George that these comments were not welcomed, the more he said them. His mother asked her friends to ignore all the inappropriate sexual comments, but to readily engage him in conversation when he discussed other topics. At first, George's behaviour became more vulgar, however, after a brief period of time, he stopped all sexual comments towards females and talked about more socially acceptable topics.*

NOTES/QUESTIONS

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LOOKING BACK

Do you think any of the consequence-based procedures discussed (positive reinforcement, extinction, differential reinforcement and overcorrection) may be helpful in your situation?

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There are several other consequent-based (responsive) behavioural procedures focusing on punishment (e.g. timeout procedures) and skill development (e.g. shaping and guidance procedures). However, the procedures discussed here are some of the most basic and powerful behaviour support strategies. Furthermore, you may have found that by implementing antecedent strategies (such as creating a positive environment and routine) that challenging behaviours have already decreased. As stated previously, antecedent strategies are emphasised in behaviour management interventions for people with dementia, as people often experience difficulty with information processing and memory (making it more difficult to learn from consequence-based strategies).

If you have identified that challenging behaviours are related to his or her inability to physically or cognitively complete a specific task, then skill development programs may be appropriate. Please talk to the Program Facilitator about this.

MODULE 7

What to do in a crisis...
And knowing where to get help

Aim

During this module, we will discuss what to do in a crisis, and identify what services are available that may be helpful in supporting you with behavioural challenges following the onset of dementia.

Outcomes

On completing this module, you will be able to:

- know how to respond in a crisis, including;
    - the use of appropriate body language/ communication
    - strategies to keep yourself and the person with dementia safe
    - who to contact in an emergency
- identify what services are available that may be helpful in supporting you to manage challenging behaviours

Crisis Management

In Module 2 (page 31), we discussed what to do if an individual's anger is escalating.

We discussed the importance of:

- keeping calm and in control
- maintaining a safe distance from the person
- using non-confrontational body language
- thinking about the situation – e.g. is there anything reinforcing the behaviour? is anything frightening the person or are they being over or under stimulated?
- deciding on an intervention (how to respond to the behaviour)

It is important to acknowledge the concerns/emotions of the person whether you agree with them or not. This validates their experience, helping them feel 'understood'. For example, you might say "I can understand that (situation) is making you feel upset..."

If danger is present, clear the space if possible and remove others from the scene. Also, make sure you can always see the person – it is important to never turn your back on a person behaving aggressively.

Restraint, medication (if prescribed and available) and self-defense should be used as a last resort.

If the situation seems uncontrollable, keep calm, leave as quickly as possible and go to a safe place.

If you are being confronted with high-risk behaviours, where the behaviour is presenting danger to you or the individual, please seek help immediately:

National Dementia Helpline: 1800 100 500

Dementia Support Australia: 1800 699 799

Carer Gateway: 1800 422 737

Lifeline (24 hours): 13 11 14

After an incident, it is important to debrief. Make time to speak with family/ friends or professionals regarding the incident – can you identify why the behaviour occurred? How did you respond? Can you think of how the situation may be avoided in the future?

After a crisis it is normal for a person to experience emotional and physical changes (both you and your family member with dementia). If these changes persist, seek professional help.

Organisations/ Services

Although there are limited services that specifically support family carers with behaviour support for individuals with dementia, a number of organisations that provide information and counseling exist, and run support groups for familiy carers. These are listed on the following pages.

Dementia Australia
www.dementia.org.au

Government access for funding for services

National Disability Insurance Scheme
(see flowchart below)

My Aged Care
(see flowchart below)

Younger Onset Dementia Key Worker Program
Ph: 1800 100 500.
https://www.dementia.org.au/services/younger-onset-dementia-key-worker-program

Advice regarding behaviour

Dementia Behaviour Management Advisory Service
24/7. Ph: 1800 699 799

Dementia Australia National Dementia Helpline
M-F 9-5pm. Ph: 1800 100 500

Behaviour support planning may be NDIS funded if deemed 'reasonable and necessary'
(see NDIS access flowchart)

Support Groups and Forums

Regional FTD support groups facilitated by health professionals in NSW (North Ryde), Victoria (Hawthorn, Warragul, Geelong) and Tasmania (Hobart);
Referral through **Dementia Australia National Dementia Helpline**
Ph: 1800 100 500

Dementia Support Groups (general) information regarding availability in your area;
Dementia Australia National Dementia Helpline
Ph: 1800 100 500

Younger Onset Dementia forum
www.talkdementia.org.au

FTD Support Forum
www.ftdsupportforum.com

For younger people with a parent with FTD;
www.youngeronsetdementiaandme.blogspot.com.au

Counselling

Carer Gateway
Ph: 1800 422 737

Dementia Australia National Dementia Helpline
Ph: 1800 100 500

If you would like to access face to face counselling in your area, speak to your GP regarding a referral.

Education and Information

Dementia Australia National Dementia Helpline
Ph: 1800 100 500 or www.dementia.org.au
It provides information via phone and website including a library and other written resources. These include Living With Dementia Program & Living With Younger Onset Dementia Program. These programs are available for the person living with dementia and their family/carer.

Frontotemporal Dementia Toolkit
www.ecdc.org.au/ftd-toolkit

The Australian Aphasia Association
www.aphasia.org.au

The Association for FTD (US)
www.theaftd.org

FRONTIER - Frontotemporal Dementia Research Group (Sydney)
www.ftdrg.org

LOOKING FOR ASSISTANCE

Services Which May Be Available:

- Counselling
- Allied Health
  (e.g., physiotherapy, occupational therapist)
- Aids and equipment
- Personal care (showering dressing)
- Nursing Care
- Keyworker

- Transport
- Shopping
- Cleaning
- Gardening
- Respite
- Behaviour Support Planning
  (for people with NDIS)

OVER AGE 65yrs
or
if ABORIGINAL/TORRES STRAIT ISLANDER
OVER 50yrs

UNDER AGE 65yrs
or
if ABORIGINAL/TORRES STRAIT ISLANDER
UNDER 50yrs

Contact **My Aged Care**

Ph: 1800 200 422 (have your Medicare card ready)
Or online www.myagedcare.gov.au

This will initiate an assessment for the types of services needed and eligibility.

If urgent assistance for nursing, personal care, transport or meals, contact by phone which will prompt urgent time-limited service while awaiting the assessment.

For respite, **Carelink**
Ph: 1800 052 222 business hrs
or Ph: 1800 059 059

From October 2019
Carer Gateway will supersede Carelink.
Ph: 1800 422 737
or www.carergateway.gov.au

Contact **National Disability Insurance Scheme (NDIS)**

Ph: 1800 800 110
Or online www.ndis.gov.au

1. This site will guide you to the access form to apply for funding for services. You will need a letter from your specialist providing a diagnosis and request the GP fill out the functional part of the form.

2. You will be advised of your eligibility

3. Prepare for the planning meeting (see www.dementia.org.au or NDIS site above or contact by phone for further information.

4. You will receive the plan after the planning meeting and depending on funding and management you can access services.

(Younger Onset Dementia Key Workers can assist with the NDIS process and provide support coordination if this is funded)
For access, contact
Dementia Australia National Dementia Helpline
Ph: 1800 100 500

If you need assistance prior to accessing NDIS funding, contact
Carelink
Ph: 1800 052 222 business hrs
or Ph: 1800 059 059

From October 2019
Carer Gateway will supersede Carelink.
Ph: 1800 422 737
or www.carergateway.gov.au

Psychologists/ psychiatrists

(Neuro)psychologists and (neuro) psychiatrists can also offer specialised behaviour support, and can help in developing individualised behaviour management plans.

There are a number of private and public (neuro)psychologists and (neuro)psychiatrists. It may be worth asking your GP and other family carers in your support groups/ networks if they can recommend anyone in particular.

Take home messages:

- Following the onset of dementia, a person may experience changes in information processing, memory, cognition (thinking), personality/behaviour, and/or physical ability

- There are specific strategies that can be used to deal with these changes

- It is important to be able to identify potential triggers of anger and 'early warning signals' that a person is becoming angry. To better understand how to manage anger behaviour, it is useful to understand the scale of anger (e.g. from calm to aggressive), and recognise that anger can be a secondary feeling (e.g. resulting from pain, fear or humiliation)

- Behaviour support strategies start with analysing the challenging behaviour, using the observation sheet. This may reveal patterns in the target behaviour, including similar times/settings when the behaviour occurs, and perhaps consistent antecedents or consequences that may play a part in reinforcing the behaviour

- There are behaviour support interventions that can be useful in supporting behavioural changes in dementia

- Managing a crisis involves remaining calm and in control, keeping a safe distance from the person, using non-confrontational body language, analysing the situation, deciding on an intervention, and debriefing following the incident

Thank you!

Thank you again for participating in this program. We do hope you have found these sessions helpful and look forward to your feedback.

Notes