



Wellbeing for Life Changed Behaviour



Learning Outcomes

- To understand what are the common changed behaviours that you may see as Dementia progresses.
- Understanding that all behaviours are a form of communication.
- Find out ways to support a person to understand their behaviour.
- To identify ways to support each other within the workplace.

Remember: There are 11 mini booklets all about different changed behaviours that accompany this eBook.

How 'Behaviour' is Viewed

Do's and Don'ts –

- 'Behaviour' in general has a very negative association in relation to dementia, with the term 'Challenging Behaviour' often used. This terminology does not represent good practice and should be avoided.
- Equally, 'behaviour' in relation to people with a learning disability is often also viewed negatively and can be used as an excuse for why a person is conducting themselves in a particular way. Using behaviour as an excuse in this context is not helpful, and can mask the development of dementia and delay a diagnosis.
- It is important to remain open-minded about all changed behaviour that you might see in relation to supporting a person with dementia. The causes can be many and varied, and the response(s) needed are often likewise.

Think about the Words you Choose to Use

P246

Not just a “Challenging Behaviour” • Kate Swaffer • Residential Care Models of the Future • Australia

Not just a
“Challenging
behaviour”



The words you choose to say about a person, says more about you than the person.

Always think about the words you choose to use.

Remember behaviour is normally a sign of an unmet need.

It is our job to work out what need it is that is not being met to support the person the best we can.

What is Changed Behaviour?

- One of the most recognised symptoms of any type of dementia are changes in the person's behaviour that were not present prior to the person developing dementia.
- Changed behaviour can happen early in the onset of the person's dementia, acting as a sign that the person needs to be assessed for dementia, or at any point in the person's life after a diagnosis of dementia.
- Changed behaviour post-diagnosis does not necessarily mean that a person's dementia has advanced – it may just be manifesting itself in a different way, perhaps because of other factors like the person's environment or restrictions that are being placed upon them.





Changed Behaviour Mini Books

Below is a list of common changed behaviours that are associated with dementia:

- Verbal Aggression – e.g. shouting, swearing,
- Physical Aggression – e.g. pushing, hitting out, kicking, throwing objects
- Repetition – e.g. asking the same questions repeatedly
- Paranoia/Accusations
- Walking
- Restlessness
- Anxiety
- Tearfulness/being emotional
- Wakefulness/disturbed sleeping
- Losing/hiding or hoarding objects/items
- Losing sexual inhibitions

This list is not exhaustive. You should approach any new behaviour that you see as potentially resulting from the person's dementia and, if concerned you should seek professional advice.

Remember: Each of these changed behaviours has its own mini booklets – that goes into each changed behaviour in more detail with examples and how to support the person.



There are so many potential changed behaviours, where do I begin?

- It is important to stress that it is very unlikely that you will see every changed behaviour in every person with dementia whom you support.
- You may not see any markedly changed behaviours; you may see a few different changed behaviours which may come and go, or the person may have longer periods of changed behaviour.
- Over time, you may notice some commonality between the behaviours of different people you are supporting with dementia. However, whilst some commonality in your response may be appropriate, it is important to see each person you support as an individual and explore the solutions that are right for each person.

How changed behaviour is likely to make the person feel...

Because changed behaviour is such a broad topic, many different feelings and emotions are associated with them for each person experiencing them.

These can include:

- Fear
- Sadness
- Embarrassment
- Shame
- Confusion
- Anger



Always put yourself in the shoes of the person you are supporting. All of these feelings and emotions can be difficult to cope with for anyone, but particularly for a person with a learning disability and dementia.



Why do Changed Behaviours happen?

- Changed behaviours can have a **physical cause** – being the result of additional damage in the person’s brain, or as a result of another health condition, for example undiagnosed pain.
- Changed behaviours can have an **environmental cause** - a new reaction to the world around the person (ie the person’s home or their workplace), even if it hasn’t changed.
- Changed behaviours can have a **human cause** – they can be the result of how we, or someone else, is communicating with or responding to the person with dementia.
- Changed behaviours can also appear to have no obvious cause. However, that doesn’t make them any less real or any less distressing for the person.



What do Changed Behaviours mean?

- It is a common misconception that changed behaviours are the person being 'difficult', 'manipulative', 'awkward', 'deliberately misleading', 'lying', 'trying to make life difficult' or being 'troublesome'. All of these viewpoints are wrong and unhelpful.
- Changed behaviours are a form of communication – they are often the only way the person with dementia can express themselves when they are experiencing something that they cannot explain to you in any other way.
- In practical terms, the person may be trying to communicate an unmet need that you should respond to in a sensitive and timely way.

Changed behaviour = Communication

Understanding that changed behaviours are a form of communication is important because it:

- helps you to understand how the person is feeling.
- helps you to understand the person's viewpoint and what they might be trying to tell you or trying to do.
- helps you to remain calm and focused on responding to the person appropriately.



How to Respond – Do's

- First and foremost, you need to respond with kindness and compassion, being respectful to the person at all times
- Be patient. You may need extra time with the person to support them – this may mean colleagues will need to help with other people you support to give you this time with the person
- If appropriate, try to guide the person into an occupation/activity that they enjoy to alleviate their distress
- Always support the person with their best interests at the heart of your response

How to Respond –Tips

- Avoid confrontation and never mimic the person. There is no room for frustration or anger in your response.
- Avoid restraint or restriction – this is a negative response that is only likely to make the person's changed behaviour more negative in return.
- Remove yourself from any situation if you do not feel able to control yourself; it is better to ask a colleague for their help rather than respond to the person inappropriately.



Responding in Specific Situations

- Be polite when responding to verbal aggression – do not shout or swear back at the person and be aware that reprimanding in inappropriate language is a very parental response that is usually inappropriate unless the person actively seeks this type of relationship with you.
- If aggression is physical you need to protect the person and yourself from harm – reassure the person in a calm and understanding way, removing anything in the person's personal space that they may feel is threatening to them.
- In situations of repetition, treat every time you answer as the first time you have answered. If repetition is because of the need for factual information (i.e. wanting to know the day/time), consider enhancing the person's environment with technology that will provide the answer the person is looking for (like a dementia clock for example).
- If the person is making accusations or becoming paranoid, avoid arguing with them or allowing the situation to become hostile. Reassure the person, exploring with them how they are feeling and what is prompting those feelings, using your knowledge of their life history, or gently orientate them into the present reality if you feel this is more appropriate for the person.



Responding in Specific Situations

- If the person's changed behaviour involves a lot of walking, help to facilitate this to support their mobility whenever possible. Never view walking as 'wandering' – 'wandering' is a negative term that suggests the person has no purpose in what they are doing, which is not the case: there is a purpose to them it is just that you do not yet understand that purpose.
- If the person is restless, try to give them something to hold or move with their body to help them focus themselves away from their restlessness – an occupation or activity might also help the person to focus on something other than their restlessness.
- If the person is very anxious, emotional or tearful, respond gently and with appropriate touch. Create a warm and comforting environment to alleviate their distress.



Responding in Specific Situations

- If sleeping is a problem, help the person to gradually change their sleeping routine/environment to support more restful sleeping habits – this might involve changing their bedtime routine, their bedroom environment, or how you or your colleagues respond to the person in the evening/night time.
- If the person is hiding or hoarding other housemates' belongings, support the return of these items to their owners and consider substituting any items that the person has formed a strong attachment to (i.e. if the person likes a particular magazine or jumper, try to give them their own version of this).
- In situations involving sexual behaviour, preserve the person's dignity and ensure that they, and you, are not compromised.



Reflecting on your Response

It is important to take some time after supporting a person with changed behaviour to consider if your response was the right one.

Think about what worked and what did not work.

Specifically Reflect Upon:

- Whether your response alleviated the person's changed behaviour.
- If the person's changed behaviour later returned, reflect on what might have caused this and how the return could have been delayed or avoided.
- How you felt supporting the person – confident? Intimidated?
- What you would change in the future.
- Building your confidence.



Reflecting on your Response

- Confidence is a really important factor in how you respond to changed behaviours. If you do not feel confident in any given situation, you are more likely to respond negatively, or reflect negatively afterwards.
- Crucial to building your confidence is your knowledge of the person you are supporting. The more you know about the person, their likes and dislikes, routines, and any trigger points for their changed behaviour, the better you can support them.
- Equally, improving your knowledge of specific changed behaviours that a person you are supporting is experiencing can also help you to feel more confident. Take responsibility for your knowledge and do some research if you feel you need to know more.



The Importance of Teamwork

- Positive teamwork is very important when you are supporting a person who is experiencing changed behaviours.
- Sharing ideas as a team is crucial for identifying good practice and replicating it consistently for the person you are supporting. Use the person centred thinking tool “learning log” to help identify solutions that work.
- Sharing ideas as a team also helps each staff member to improve their individual practice, thus contributing to their own personal development.





Good Teamwork in Practice

- Regularly discuss changes in a person's behaviour with colleagues – they may have ideas or positive ways to support the person who is experiencing changed behaviours, or can tell you about interventions they have tried that have helped the person.
- If a person is currently experiencing changed behaviour, think about your interpersonal relationship with the person. If it is not as positive as a colleague's, ask your colleague to help support the person in this moment if this is possible.
- When you reflect on a person's changed behaviour, make sure you include colleagues – discuss as a team anything you might be able to try that will alleviate the person's changed behaviour.

Final Tips

Best practice to support a person with changed behaviours would be to ensure that:

- Support is person-centred at all times
- The person has access to activities or occupation that is purposeful and meaningful to them
- The person's environment is responsive to their needs
- The person's individuality and independence is preserved
- The person is not experiencing any undiagnosed pain or symptoms of another health condition
- The person's wellbeing is supported and they have positive relationships with the staff who support them

Looking after Yourself

- Supporting a person who is experiencing changed behaviours is often cited as one of the most difficult aspects of dementia care and support.
- As well as doing your utmost to support the person through what is likely to be a difficult and confusing time for them, it is important to look after yourself too.
- Regular reflective practice with colleagues can help you to work through any difficulties you are experiencing, but also ensure that you speak to your line manager if you are feeling overwhelmed, vulnerable or out of your depth.

When everything you have tried doesn't seem to help.

The person you support may be offered medication by a doctor to help to manage their changed behaviours. However, this should only be considered when all other available therapies and interventions have been tried.



Produced by the MacIntyre Dementia Project with the support of an Innovation, Excellence and Strategic Development Fund Award from the Department of Health

A special thank you to Beth Britton, and for all her hard work on the MacIntyre Dementia Project.

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