

## Understanding apathy in people with dementia



### Background

Apathy is a common symptom of dementia, yet it is often overlooked in care planning. Knowing how to identify and manage apathy is important. This overview aims to assist in understanding how apathy affects people living with dementia and how carers can respond.

### What is apathy?

Apathy is when a person loses interest in what is going on around them. They can also lose interest in other people. This appears as a lack of motivation or that the person is just not 'getting started'. It can be hard for carers to understand what is happening and this can be frustrating as it can look like the person is just not 'making an effort.' The ability of people with dementia to initiate activities of living is closely linked with carer wellbeing so addressing apathy is important for everyone.

### How to identify apathy?

When identifying apathy, it is important to assess for other possible issues that might look similar, such as depression or hypoactive delirium. The information below may help narrow down what is happening. If in doubt, the person's GP is a great starting point for help.

#### The person with apathy:

- Develops symptoms over months or years.
- Has apparently lost interest in the world around them, and yet may still participate in activities once prompted or encouraged.
- Does not tend to start a conversation.
- May show little interest in friends or family members.
- May have little energy or apparent interest in things.
- Sits quietly without paying attention to things going around them.
- Often does not show joy or happiness over things they normally would.

## How to identify apathy?

### The person with depression:

- Develops symptoms over weeks to months.
- Has feelings of hopelessness and/ or worthlessness.
- Expresses that they feel like a burden to people.
- Does not feel much joy or happiness (sometimes referred to as anhedonia).
- May show recent decreases in appetite, or have difficulty sleeping.

### The person with hypoactive delirium:

- Develops symptoms rapidly over hours to days with symptoms fluctuating throughout the day.
- Experiences lethargy, withdrawal, drowsiness and/or staring into space.

## Impact of apathy on relationships

Although a common symptom of dementia, apathy is often overlooked. People close to the person with dementia such as family and friends notice the decline and can find it very distressing. Family and friends may also experience feelings of being frustrated or concerned at seeing the person 'just sitting there doing nothing', especially if they were previously active.

## What can be done to support someone with apathy?

- Consider why the person can no longer do activities. Is it because they have forgotten how to do the activity, because they have forgotten to do the activity or because their apathy prevents them from initiating the activity?
- Share the interests and hobbies the person has always enjoyed. Informed care staff can then tailor and plan activities that are meaningful to the person.
- Use things that the person is known to enjoy (their interests and hobbies) to help get them started or moving such as:
  - Favourite foods
  - Visits with family (grandchildren)
  - Visits from pets or animal therapy
  - Participation in creative activities such as art
  - Music – listening, playing, singing
- Set up a daily routine or schedule to follow, and keep this visible (e.g. use of calendars, clocks, watches, whiteboard)
- Break things up into smaller steps. You can start the activity with the person until they can continue by themselves (e.g. eating – holding cutlery and supporting plate to mouth motion, folding – folding laundry like towels and/or tea towels, sorting – using items such as nuts and bolts, coins or sewing bobbins). Ensure that you have everything ready before you start.
- Use phrases such as 'It's time to go on our morning walk' and hand the person their shoes or, 'It's time for your shower, the water is running and it's nice and warm' and hand them a towel.
- Seek support if you are struggling or distressed. Others can help in developing strategies for you to feel more confident in providing support.

## What to avoid

- Not engaging with the person – it may feel like we are helping when we don't approach the person concerned but this is not likely to be helpful in improving their quality of life whilst experiencing apathy.
- Relying on one strategy only, as this may not always be successful. It is likely that many things won't work 'first time, every time' so various approaches are more likely to have success.
- Using phrases such as 'Do you want to go for a walk?' and/or 'Would you like your shower now?' – The person experiencing apathy is more likely to say no, adding to carer frustration.

## Useful resources

**Caregiver training: depression/apathy** is a short video that provides some practical examples to supporting the person experiencing apathy.

**My home, My Life: Practical ideas for people with dementia and carers** is an insightful publication that brings together the voice of people with dementia and carers with the best learning from research and care experience to provide tips, strategies and real-life stories to support greater independence.

Health professionals may find the 2012 article by Brodaty and Burns titled **Non pharmacological Management of Apathy in Dementia: A Systematic Review** helpful.