

Loss of initiative is one of the most distressing parts of Alzheimer's disease for families. It can also be distressing to patients, but commonly people who lose initiative also lose the insight that their initiative is less. As a result, their families are often left to carry the burden as they watch the person they care for "sit around" or become "less engaged" or "switched off".

## Understanding the Symptom

Although loss of initiative sometimes is present before the diagnosis of Alzheimer's disease, it generally occurs in early dementia and becomes worse as the disease progresses.

Loss of initiative can be seen in many ways. The person you care for might become less interested in daily tasks and activities, even ones that they are still physically able to perform such as reading the newspaper, visiting a neighbour, or going for a walk. They may show little interest in current events and in the lives of those around them. As the disease progresses, they might even appear reluctant to complete personal care tasks such as bathing or dressing.

Getting out of bed and starting the day, or going out with friends for coffee requires motivation. While the person you care for may appear "lazy" or "apathetic" to others, remember that they have suffered damage to specific parts of the brain which has resulted in this change. That is why they cannot simply be "talked into" showing interest, although they can be prompted to do specific tasks.

## Managing Loss of Initiative

It can be very difficult to watch the person you care for lose interest in things that they once enjoyed. You might feel as though there is nothing you can do, but DementiaGuide's online resource has a few tips that can help:

- **Create a routine.** Giving the person you care for something to do each day can help encourage them in various activities. When creating a routine keep the following in mind:
  - **Schedule activities that they enjoy.** Most people enjoy some activities over others. Consider the type of work or activity that they used to do. For example, if they used to play football they may enjoy going to watch a local game.
  - **Be mindful of the time of day.** If the person you care for has difficulty getting going in the morning, or if they like to eat meals at certain times, schedule activities around these times.
- **Provide rewards when possible.** To help motivate the person you care for, you could offer a reward if they leave the house, such as a walk in the park or an outing for lunch.
- **Bring stimulation to them.** The smell of coffee or breakfast in the morning helps some people to get out of bed in the morning. You might try this, or similarly, you could play music or bring the newspaper to them.
- **Bring aspects of their social life to them.** Invite friends or relatives over to their house. This might encourage them to go visiting next time.
- **Lack of initiative can also be a symptom of depression. If it persists for an extended period of time, or is accompanied by a low mood, weight loss or problems with sleeping, it is important to speak with the family doctor.**

### About the Symptom:

A person with Alzheimer's disease or dementia may:

- Spend a great deal of time sitting in a chair or in bed doing nothing and staring off into space
- Show less interest in daily tasks or activities (i.e., cooking, bathing, watching TV)
- Be uninterested in the lives of others or current events

### Doctor's Notes:

Loss of initiative is part of a dysexecutive syndrome and indicates damage to the frontal lobes. This common complaint in Alzheimer's disease is hard on families and frustrating to watch.

Recovery of initiative is common with treatment and much appreciated by families.

This response to treatment is not often tracked by the standard ways that drugs are evaluated.

### Additional Resources:

Sarah Voss and Roger Bullock. In Rockwood K, Gauthier S (eds.) *Trial Designs & Outcomes in Dementia Therapeutic Research*. (London: Taylor & Francis, 2006).

