

# Not feeling motivated?



## **Study shows how pervasive — and problematic — the issue can be among people with MS.**

by Aviva Patz

Lydia, who lives with MS, knows that just 10 minutes of stretching in the morning can help control her spasticity, but she can't seem to get started. Then, she doesn't take her medication, doesn't return her best friend's call and doesn't wash the dishes still piled in the sink from the night before.

### **Is she depressed?**

Possibly, but a new study suggests she might be struggling with apathy, a lack of interest, enthusiasm or motivation that affects many people with neurological conditions, including multiple sclerosis, Alzheimer's disease, stroke, Parkinson's disease, Huntington's disease, HIV and schizophrenia.



**Apathy can be frustrating for those who have it because completing important tasks — both large and small — becomes difficult.** Photo: iStock

“While apathy and depression are often studied together in clinical samples, the two have been found to be distinct symptoms in many neurological populations,” explains Jeannie Lengenfelder, PhD, assistant director of traumatic brain injury research at the Kessler Foundation, and lead author of the study. “Apathy and depression may, therefore, present themselves independently of one another and have independent effects on daily functioning.”

Lydia may be a hypothetical case, but apathy in MS is real, and understanding it is important because it can sabotage a person’s self-care, which may contribute to worsening symptoms and diminished quality of life. According to Lengenfelder, people with MS who struggle with apathy fail to keep appointments, take their medications, participate in their treatment or show concern for their health. They may also end up dropping out of community life or damaging their various relationships.

Understanding apathy and finding ways to overcome it are critical for successfully managing MS symptoms and maintaining relationships and quality of life.

### **The research**

In the study, presented at the 35th Annual Meeting of the Consortium of MS Centers in Orlando, Florida, in November 2021, Lengenfelder and her team sought to determine the prevalence of apathy among people with MS.

To measure apathy, characterized as “lack of initiation, lack of interest, reduced spontaneity, indifference and reduced self-awareness,” they asked 41 people who have been living with relapsing-remitting MS for an average of 14 years to answer questions on an apathy evaluation scale. They also asked those people’s significant others to fill out a companion version of the questionnaire.

The results showed that 39% of the study participants with MS have significant apathy.

“This was an interesting study, although not entirely surprising,” notes clinical psychologist Meghan Beier, PhD, a part-time assistant professor at Johns Hopkins University School of Medicine in the Department of Physical Medicine and Rehabilitation. “As the researchers mentioned, in medical conditions where there is an impact on the brain, we often see a subset of individuals who have challenges with ‘get up and go’ or with initiating tasks.”

### **Origins of apathy**

While you might suspect that dealing with MS symptoms and treatments for over a decade could lead to burnout, that’s not the cause of apathy.

“It’s not a lack of desire, not a lack of effort, not laziness,” Beier says. “It is a lack of, or reduced volume on, the part of the brain that internally prompts the person to act.”

Specifically, according to Lengenfelder, it’s disruption in the frontal-subcortical circuits — a part of the brain that allows you to act on your environment.

Beier explains it this way: “Our brains need to plan an action, then send a signal to the body to initiate the action. If our brains don’t send or have trouble sending the ‘initiate’ signal, the person doesn’t act.”

### **Effects of apathy**

In her clinical experience, Beier sees people with apathy knowing the list of tasks they’d like to accomplish but having difficulty getting started. “It can sometimes feel like being overwhelmed with where to start or thinking about a task but realizing 10 minutes later you still haven’t started it and not quite knowing why,” she says.



**There are several things people with MS can do to help treat apathy, including reporting symptoms to their care team, medication and simple lifestyle strategies, such as setting alarms or voice alerts to prompt action.** Photo: iStock

As confusing and frustrating as apathy is for people who have it, it's also mystifying to their families. "They may feel frustrated because they perceive the person as being able to accomplish these tasks and not understanding why they aren't starting or completing them," Beier says.

Relatives may interpret it as depression or severe fatigue and may overcompensate by doing more for the person with apathy. That's potentially problematic, according to Beier, because the more others do for us, the less we do for ourselves, and over time, the less we're capable of doing.

Apathy can also be confusing to healthcare professionals, who may attribute its symptoms to depression or fatigue, which can lead them to suggest treatments or interventions that aren't as targeted or helpful.

### **Treatments for apathy**

The first step is to report symptoms to your caregiving team, says Lengenfelder.

"Education for patients and caregivers on the difference between depression and apathy is important so that individuals can be aware when features of apathy exist, even when treated for depression," she says.

Some medications — including those that boost dopamine-related activity in the brain — may help with apathy. Healthcare providers can offer more information about the various options.

But simple lifestyle strategies also can help. Beier recommends setting up external triggers and prompts. “Sometimes, having an outside person prompt an action — ‘Can you please come into the kitchen?’ — can be enough to get the person moving,” she says.

Because apathy often stems from cognitive challenges, she also recommends working with a speech pathologist or occupational therapist, both of whom have experience with cognitive rehabilitation and, more specifically, can help you figure out and set up external reminders.

Beier suggests setting alarms on a smartphone, which can be particularly useful if they go off near where the action should take place. For example, set it next to the sink, so you have to go there to turn it off, which can initiate enough momentum to get you engaged in the task of cleaning dishes. You might also set an Alexa/Siri/Google voice alert prompting a particular action at a particular time.

“In apathy, people lack the internal prompt to initiate an action,” Beier says. “So, setting up an external prompt can be enough to overcome that internal hurdle.”

Next up for Lengenfelder’s team is investigating whether the presence of apathy can affect emotional processing and facial recognition in people with MS.

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