

# How to identify, approach and assist employees with young onset dementia: A guide for employers



## What is dementia?

Dementia involves the decline of cognitive functions. Young Onset Dementia, also known as Early Onset Dementia, means having symptoms of dementia prior to age sixty-five. Young Onset Dementia isn't a disease itself but is a group of symptoms that can accompany some diseases or physical conditions. In the early stages an employer is most likely to see memory loss as the first symptom.

## Is dementia reversible?

Some forms of dementia can be reversible. Dementia caused by chronic drug or alcohol abuse, depression, low blood sugar or thyroid levels, metabolic disorders can all frequently be reversed to varying degrees by addressing the underlying issue.

Other forms are not reversible. The most common form of non-reversible dementia seen in younger employees is Alzheimer's disease. Alzheimer's disease accounts for the majority of young onset dementia cases. There are drugs available that can alleviate some of the symptoms associated with Alzheimer's disease and which can delay the onset of Alzheimer's type symptoms but the disease process can not be reversed. Other non-reversible forms of dementia include multi-infarct dementia, Frontal-Temporal Dementia, Creutzfeldt-Jakob disease, dementia associated with the AIDS virus and dementia associated with Parkinson's disease to name a few.

## What kinds of dementia am I as an employer likely to see in my employees?

Although we generally associate dementia with older employees, dementia symptoms can appear in younger employees as well. It is estimated that more than a half a million people in the United States have what is known as young onset dementia.

Dementia is a general term that is defined as a global change in cognitive performance that may include difficulty with memory, judgment, planning ability, language, way-finding, calculation and performing one's everyday activities. There are a number of specific diseases that cause dementia, such as Alzheimer's disease.

When an employee at any age experiences changes in memory, thinking and reasoning ability, it is important to discover the cause of these changes. A change from baseline ability, such as decreased ability to perform one's usual job tasks, is never normal. There are many potential causes of cognitive changes such as stress, depression, a new medication, a physical illness or undergoing chemotherapy for cancer treatment or dementia to name a few.

If you have an employee whose job performance has declined significantly, it is vitally important that the employee receive a thorough work-up to determine the cause. Employees who have Young Onset Dementia need a specific diagnosis, treatment plan, education and support, help to get legal and financial affairs in order and when leaving employment will need assistance in applying for Social Security Disability Insurance (SSDI) and other benefits. (See our paper titled: "Social Security Disability Insurance and Young Onset Dementia: A Guide for Employers and Employees")

## **How does young onset dementia in general affect an employee?**

*An employee with young onset dementia may become frustrated in his or her job.*

### **What you can do:**

Employers can address this understandable emotion in two ways. First, be aware of matching tasks with remaining abilities. Making use of the suggestions on this page will go a long way in alleviating frustration. Second, seek out a fellow employee who will "partner" with the person with dementia to provide an understanding ear and offer encouragement. In this way frustrating situations can be addressed before they interfere with work. (See our papers titled: "Incorporating Assistive Technology for People with Dementia in the Workplace" and "Utilizing Non Technological and Natural Supports and Young Onset Dementia: A Guide for Employers")

*An employee with young onset dementia may begin to have problems with acquiring, storing and recalling information.*

### **What you can do:**

Employers can address this issue with the use of memory aids such as reminder notes, calendars, to do lists, and electronic memory aids such as electronic calendars to provide reminders to the worker, recording devices and other assistive technology. (See our paper, "Incorporating Assistive Technology for People with Dementia in the Workplace")

*The employee with young onset dementia may begin to have difficulty learning new things.*

### **What you can do:**

- Provide simple written instructions for the worker and offer increased or additional instruction.
- Use the employee's over-learned and over-remembered skills. Use the employee's long term memories-past experiences, habits and knowledge to aid functioning.
- Routine and structure will also help the employee with young onset dementia function at their highest possible level.

***The employee with young onset dementia may have difficulty paying attention.***

**What you can do:**

- Limit distractions. Try to limit noises and extraneous activity as much as possible to make it easier for the employee to focus on the task at hand. Ear plugs or headphones have been used by some employees with young onset dementia to help limit distractions.
- Limiting or eliminating work space clutter will also help the employee maintain focus.
- Choose tasks that fit the person's ability. They are more likely to gain and hold attention than those that are too complex or too simple.
- Frequent stopping and starting of a task may be difficult for an employee with young onset dementia. Try to avoid interruptions as much as possible.

***The employee with young onset dementia may have difficulty starting, maintaining or stopping a task.***

**What you can do:**

- Don't assume the worker is tired, lazy or uninterested.
- Encourage and assist the employee. Verbal or visual cues may also be helpful to signal to begin or end a task. (See paper "Incorporating Assistive Technology for People with Dementia in the Workplace")

***An employee with dementia may have problems with organization, judgment or reasoning. They may find it difficult to organize their time, set goals and follow plans.***

**What you can do:**

- Help plan and organize daily activities. Consider a daily written schedule or check list for the employee.
- Maintain a structured routine in the day to help the employee maintain function. Keeping the same basic schedule can lessen confusion and frustration.

## Common diseases that cause dementia in younger employees

### Young Onset Alzheimer's Disease

The most common cause of dementia in younger employees is Alzheimer's disease. Symptoms can appear as young as in the thirties or forties. It is a progressive disease that is ultimately fatal. A change from baseline ability is key: if an employee has never been able to do a task, inability to perform it now is not a symptom of a cognitive change. Employees who have Alzheimer's disease always have impairments in their short term memory. Other young onset Alzheimer's disease symptoms and examples include:

<u>Primary Symptom</u>	<u>Examples</u>
Impairment in short term memory	Forgetting appointments, work deadlines
Changes in judgment ability	Making poor decisions, behaving irrationally, difficulty deciding on a plan
Changes in executive function	Difficulty carrying out a plan, failure to complete tasks
Loss of energy and motivation	Extreme fatigue, need for more sleep, losing interest in enjoyable activities
Language deficits	Difficulty coming up with certain words they want to say, becoming quieter, decreased writing skills
Calculation deficits	Change in ability to handle math problems, lack of understanding of the meaning of money, not being able to handle finances
Orientation to time	Not knowing the date, missing deadlines
Way-finding	Getting lost in either familiar or unfamiliar places, inability to follow directions or a map
Mechanical ability	Difficulty managing familiar tools
Recognition of objects or people	Not recognizing people, not knowing the purpose of an object, such as a remote control

## Frontal-Temporal Dementia

The second most common dementia in younger people is Frontal-temporal dementia. Frontal-temporal dementia, which is also a progressive fatal disease, can strike as young as the twenties and is less common in people older than age sixty-five. Frontal-temporal dementia affects one's judgment, social behavior and language. There are a number of causes of Frontal-temporal dementia, but they have similar symptoms and behavioral examples. Persons with Frontal-temporal dementia do not exhibit all of these symptoms. Frontal-temporal dementias are a group of brain disorders that share many clinical features. The hallmark of this disease group is a progressive decline in behavior and/or language skills.

### Symptom

Changes in short term memory

### Examples

Difficulty remembering what has been said or done recently. Persons with Frontal-temporal dementia generally do not have as much short-term memory impairment as those who have Alzheimer's disease

Changes in judgment

Making strange decisions, behavior that is not typical of the person's previous actions: driving without a license, getting into financial difficulties, scrapes with the law, a new onset of substance abuse or alcoholism

Language impairment

May become quieter or have difficulty with expression of language and problems with word meanings, may use the same phrase over and over: "Whatever." Language may not make sense—a lot of words, but no coherent thoughts, may echo back the last few words someone else says, or, have fluent speech but lose the understanding of words or ability to recognize and name devices

Loss of insight

Loss of ability to judge oneself, inability to see changes in one's behavior and personality, belief that "there is nothing wrong with me—it's your problem"

Loss of social skills

Becoming crude, thoughtless, saying or doing anti-social things, saying or doing whatever pops into one's head

Attention problems

Difficulty concentrating, restlessness, distractibility, apathy, inability to focus on a task, perseverating: doing or saying the same thing over and over

Changes in hygiene

Becomes slovenly, wears dirty clothes, refuses to bathe

Hyperorality	Puts everything in the mouth, grabs food without using utensils, has an intense craving for sweets
Hypersexuality	May become sexually aggressive, doesn't know the proper time or place for sexual activity, may grope others

### **CADASIL: A Young Onset Vascular Dementia**

CADASIL (Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy) is an inherited disease that is quite rare. If a parent has the disease, children have a fifty-fifty chance of developing the disorder, which can be detected with genetic testing and a skin biopsy. Persons with the CADASIL gene will develop the disease, with fifty percent showing symptoms by age fifty. Persons with CADASIL may have the following symptoms.

<u>Symptom</u>	<u>Examples</u>
Strokes or Transient Ischemic Attacks	Periods of confusion, impairment in use of a limb, speech difficulties, a droop of the eye or mouth, visual impairment
Migraines	Very painful headaches, may be one-sided, may have auras
Loss of short-term memory	Difficulty remembering what has been said, forgetting appointments or family events
Attention impairment	Difficulty focusing and concentrating, difficulty completing tasks
Executive function impairment	Difficulty making decisions, carrying out a plan
Mood disorders	Depression, irritability, aggression

### **Lewy Body Dementia**

Lewy Body dementia can occur in younger people, but it is most common over the age of sixty-five. Like the other forms of dementia, it, too, is a fatal disease. Common symptoms and examples of Lewy Body dementia are as follows:

<u>Symptom</u>	<u>Examples</u>
Waxing and waning cognition	Normal behavior and thinking and then sudden periods of acute confusion: “Where am I? Who are you? What’s going on?” May wake up confused, may stay confused from minutes to hours to sometimes days and then returns to baseline cognition
Movement disorders	Impaired balance, shuffling slow gait, bent-forward posture, falls, may have a “drop attack”- falls to the floor when walking, lack of facial expression, Parkinson’s-disease-like symptoms
Visual or auditory hallucinations	Seeing things that are not there—often very detailed visions such as small children or animals, hearing sounds that are not real—a

radio playing in the room or having a conversation with a photograph

Variable attention

Staring spells, “spacing out,” may begin a sentence and stop speaking before finishing the thought

Poor sleep

Restless legs, sleep walking, waking multiple times

***For further information, contact the Alzheimer’s & Dementia Alliance  
at 608.232.3400 or toll free at 888.308.6251***