

Utilizing non-technological and natural supports with young onset dementia: A guide for employers



Incorporating non-technological aids for employees with dementia into the workplace

This pamphlet will help guide you through the process of determining what types of non-technological aids can be helpful, and under what circumstances they can assist the employee with young onset dementia in his or her employment. It will also give you some ideas of what types of supports are available and have been utilized effectively by employees with young onset dementia. Remember, there is no 'quick fix' available to answer all the challenges that employees with young onset dementia face. What works for one employee with young onset dementia may not work for another. As an employer you may have to try several strategies before finding success.

This paper complements our paper titled, "Employer's Guide to Assistive Technology and Young Onset Dementia."

Why retain an employee with young onset dementia?

Alzheimer's disease, the most common form of young onset dementia, is considered a disability and is therefore covered under the Americans with Disabilities Act (ADA). Therefore, as a covered condition the employer has an obligation to conduct an interview with the employee to discuss any reasonable accommodations the employer may be able to make so that the employee can keep his or her position. Delegating some responsibilities or changing the nature of the tasks of the employee with dementia may be necessary. Retaining an employee with young onset dementia can be beneficial to the employer as well as the employee. Employees with young onset dementia can remain as valuable, experienced and beneficial employees. Often in the early stages of the disease process the person with young onset dementia is high functioning and retains many skills and abilities garnered from years of employment experience. Typically young onset dementia in the early stage affects recent memories far more than memories from the past. While the employee may have difficulty remembering new things or may need memory aids to track time and tasks, the ability to reason and make good decisions often does not decline in the early stages of the disease process.

Utilizing Natural Supports--What are natural supports?

Natural supports in the workplace can be any assistance, relationships, or interactions that allow an employee to work in a job of his or her choice in ways similar to other employees. Use of natural workplace supports can help to allow the employee with young onset dementia to have an impact upon his or her own career and allows the employee with young onset dementia to play an active role in helping to determine the type and amount of assistance they want to receive. Examples of natural supports include co-workers who provide job training for the supported employee or mentoring relationships between the supported employee and others. Co-workers providing natural supports may do so with or without compensation. Natural supports utilize ordinary social

relationships to facilitate a positive, productive and helpful workplace environment for an employee with young onset dementia. However, for natural supports to effectively support employees with young onset dementia it is essential that the employee understand and have a willingness to enter into a partnership with a fellow employee(s).

Determining useful employment strategies for people with young onset dementia

The Alzheimer's & Dementia Alliance of Wisconsin convened a Young Onset Dementia Working Group, whose members all have a diagnosis of dementia and are still working or who had to leave their employment because of their dementia. The work that we have undertaken to produce these strategies would have been impossible without the direct contributions of these individuals. We asked the Working Group what types of employment supports would be most helpful. Those meetings produced some specific strategies that have worked for some people with young onset dementia. Keep in mind that dementia affects employees differently and each case should be handled according to the remaining abilities and current challenges of the individual.

Young onset dementia will affect employees differently. To overcome this difficulty, you may find it helpful to consider trying different strategies to assist the employee in maintaining their employment. Listed below are some strategies that employees with young onset dementia have found successful.

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 and the paper titled "Incorporating Assistive Technology for People with Dementia in the Workplace" 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.

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 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 verbal instruction one step at a time, pause to determine focus and understanding before proceeding.
- 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 their 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")
- Enlist the help of the mentor or a co-worker in seeing that the person with young onset dementia has a regular morning and afternoon break. This will make it easier for the employee to maintain focus throughout the day.
- Consider a modified task list. It should include no more than two choices of what to do when the current task is done.
- Tasks that will take all day or several days are better and more easily accomplished by breaking them down into steps.

An employee with dementia may have problems with organization 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 person maintain function. Keeping the same basic schedule can lessen confusion and frustration. Again, make sure the employee is taking his or her designated breaks.
- Consider a flexible work schedule. An employee with young onset dementia may tire more easily at certain times of the day. Allowing an employee to come in earlier in the day or to work later may help them be successful.
- Nurturing and supporting the employee with young onset dementia. Through nurturing and supporting an employee with young onset dementia, the skills and competencies of the employee with young onset dementia may be enhanced. It's important for the employee to

understand that they have a safe person to go to when they're feeling overwhelmed or unsure.

- Frequent ongoing evaluations of a supportive nature are essential when using assistive technology. The employee's immediate supervisor will have to be involved. We recommend reviewing the situation twice monthly during the trial period and if things are going well monthly evaluations should be sufficient.
- At the end of the trial period, evaluate the effectiveness of the strategies you have implemented. Keep in mind that when an employee has early dementia, cognitive abilities can fluctuate throughout the day and also from day to day.

****Some specific things employers should keep in mind when making accommodations for employees with young onset dementia:***

- Each employee is unique. What works for one employee will not necessarily work for another.
- No one strategy will work in all situations.
- What works today may not work tomorrow. Periodic reviews may be necessary.

Keep in Mind:

Openness and honesty about how you are trying to help and accommodate the employee with young onset dementia is essential. At the same time, it is necessary to realize the person is going through a significant life change and the concepts of the respect and dignity are crucial in the success of your efforts.

Helpful resources:

The Alzheimer's & Dementia Alliance of Wisconsin

<http://www.alzwisc.org>

The Wisconsin Alzheimer's Disease Research Center at the University of Wisconsin

<http://wcmp.wisc.edu/>

Access to Independence, Inc

<http://www.accesstoind.org/>

WorkSource Wisconsin

<http://www.worksourcewi.com/>

Alzheimer's Association

<http://www.alz.org>

Your local Aging and Disability Resource Center

<http://www.dhs.wisconsin.gov/lc/lc/adrc/>

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For further information please contact the Alzheimer's & Dementia Alliance at 608-232-3400 or toll free at 888-308-6251