

Employment and financial planning for the future:

A guide for the employee with young onset dementia



If you are an employee diagnosed with dementia in your prime earning years there are many issues to consider when planning for the future. Now is the time to ask yourself, how does my dementia affect my work? How will my dementia affect my work as my disease progresses? What can I do to plan for the future? What changes will I need to make in the future?

Some common cognitive changes you may be experiencing could include:

- Difficulty communicating your thoughts to co-workers or clients
- Difficulty in finding the right words to express yourself
- Finding it harder to concentrate for long periods of time
- Forgetting meetings, appointments or deadlines
- Difficulty in managing tasks or projects

It's important to start planning as soon as possible! Think about how much longer you would like to work, and, how your condition affects insurance issues and your financial planning. By starting the planning process now you are taking control of your future.

It's OK to ask for help! There are many natural supports around you!

- Ask the human resources (HR) office at your workplace about the accommodations available to you so that you remain successful in your work for as long as possible. They'll also be able to suggest other resources to look into
- Family, friends and others can be wonderful sources of support
- A trusted co-worker is a natural support who can be helpful in the workplace
- Many times there are other natural supports within the workplace, such as simple room or equipment arrangements that can be easily adapted
- Your doctor may have some suggestions about how to adjust to life and work
- If you're in a union your union representative may suggest workplace adaptations
- Legal and financial advisors can help you plan for your financial future
- Vocational rehabilitation specialists may provide some services for work related needs
- *See listed resources at the end of this document for links to specific organizations you may find useful*

If you decide to keep working, you may want to consider some of these suggestions:

- Talk with your employer about your diagnosis. You might want to take someone with you to help explain your situation. A family member, friend or a staff person from the Alzheimer's & Dementia Alliance of Wisconsin or the Alzheimer's Association. Your local Aging and Disability Resource Center (ADRC) can also provide you with links to others who may be able to assist you. *(See helpful resources at the end of this document)*
- Discuss with your employer what reasonable accommodations you feel would help you to be successful in your position.
- Think about whom else in your work place needs to know about your diagnosis.
- Do you have clients who would need to know about your dementia?
- Look over your employment conditions, especially sick leave and disability options.
- Consider how long you want to remain employed and when is the right time for you to leave the workforce.

Leaving work

At some point it is likely that you will decide to leave work. This is a big step and should be thoughtfully considered. Make sure you are aware of all benefits available to you through your employer and government programs such as Social Security Disability Insurance (SSDI). Getting good advice at this point is very important! Take your time, discuss the issue with your family and make an informed decision that best fits your situation.

Before making any decisions about leaving work consider the following:

- Have you and your employer have exhausted all accommodations, including natural supports and assistive technology, to help you to continue working? *(See our papers titled: "Assistive Technology and Young Onset Dementia: A Guide for Employers" and "Utilizing Non Technological and Natural Supports and Young Onset Dementia: A Guide for Employers")*
- Do you have sick leave or other benefits through your employer that can be utilized?
- Do you have access to disability benefits or insurance through your employer or through private insurance?
- Will your employer allow you to continue to receive your insurance through your employer after you leave work?
- What government benefits are you eligible for after leaving work? *(See our paper on Dementia and Social Security Disability Insurance)*

Financial Concerns

If you are an employee diagnosed with dementia there are many issues that need to be addressed. One of those issues is financial planning and advance directives. With a disease like Alzheimer's you may eventually lose the ability to think clearly. This makes early financial planning especially important. Listed below are some specific issues to consider.

- **Advance Directives** are legal documents that allow you to convey your decisions about end-of-life care ahead of time. They provide a way for you to communicate your wishes to family, friends and health care professionals, and to avoid confusion later on.

Living Wills are one part of advance directives and describe your treatment preferences in end-of-life situations. A Living Will records your wishes for medical treatment. In the event that you can no longer express your wishes regarding health care the living will can provide direction. The living will may specify the extent of life sustaining treatment you want, protect the physician or the physician's employer for liability for carrying out your wishes, and may specify how much discretion is given to your appointed guardian.

Power of Attorney for Health Care is another part of advance directives and appoints someone to make health care decisions for you when you can no longer do so. The person holding Durable Power of Attorney can agree to or refuse specific treatments, change health providers, remove you from an institution and make decisions about life support.

- **Durable Power of Attorney for Finances** designates someone who can make financial decisions for you when you are no longer able to do so..
- **Living Trust** provides instructions about your estate. The person who sets up the trust is the settlor, trustor, or trustmaker, the trustee is the person who will manage the trust assets.
- **Do Not Resuscitate (DNR) Order** instructs first responders and other health care professionals not to perform cardiopulmonary resuscitation if a person's heart stops or if he or she stops breathing. A DNR order is signed by a doctor and is recorded in your medical records.
- **Will** designates how your assets and estate will be distributed upon death.

Helpful resources:

The Alzheimer's & Dementia Alliance of Wisconsin

<http://www.alzwisc.org>

Access to Independence, Inc

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

Your local Aging and Disability Resource Center

http://www.dhs.wisconsin.gov/lc/lc_adrc/

The Alzheimer's Association

<http://www.alz.org>

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