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ABSTRACT

The American Alzheimer's Disease Association reports that the number of people who will be affected by Alzheimer's Disease will increase 350 percent by the middle of this century. This increase will make Alzheimer's not only a disease, but an epidemic. (1) As medical breakthroughs make it possible for people to live and work longer, the number of people exhibiting early signs of Alzheimer's in the workplace is bound to increase. Given this expected surge, it is imperative that managers educate themselves about this devastating disease. This paper addresses several important questions. What is Alzheimer's disease? Who does it affect? What are the early

symptoms? What is the course of the disease? And most importantly for organizations, what is the nature of the employer/employee relationship when an employee wants to work as long as the disease allows. This paper will provide guidelines, both practical and legal, for employers who are unsure about how to deal with an employee with Alzheimer's disease or with employees who are primary caregivers of a family member with the disease.

Introduction

Jim Clarkson, fifty-eight years old, is Director of the Human Resources Department at Franklin Hospital, a medium-sized hospital in Eastern Washington State. He has been with Franklin for more than twenty-five years, starting out as an accountant in the payroll area. He is known for his exceptional communication skills, his sound and logical reasoning, his ability to efficiently handle multiple job demands, and his thoughtful decision making. These skills, in fact, are what led to his promotion to Director of Human Resources five years ago. He is well liked by employees for being fair and even tempered and for not playing favorites.

For the past year or so, several of Jim's subordinates and co-workers have noticed changes in Jim's behavior. Jim seems to be getting more and more forgetful. Twice in the past month, he has forgotten an important meeting, one with an area head and one with the VP of Accounting. Jim gave one employee permission to take a vacation day and then called her at home on that day to demand why she was not at work. Jim has misplaced important reports, one report being found by his secretary in the microwave in his office. Last December, when it was below freezing, Jim showed up to work in a polo shirt and no coat. Things came to a head last week when he sat down with Sue Atkins, Assistant Director of HR to do the calculations for the yearly human resources projections report. Though Jim has been involved in these reports for the past decade, Sue said it was like he had never seen one before. He was confused with even the simplest of calculations. When Sue asked if Jim wanted her to do the calculations, he lashed out at her, stood up grabbing a heavy paper weight and implored her to be quiet if she wanted to keep her job. Frightened, Sue ran out of the room straight to the CEO's office. Like this, top management found out about all the difficulties employees had been noticing over the past several months.

Jim's symptoms are typical of those in the early stages of Alzheimer's disease. Alzheimer's disease affects almost four million Americans. It is expected to afflict over 14 million people by the middle of the next century if a cure or some form of treatment is not found. This projection has led to the 21st Century being dubbed "The Age of Alzheimer's." In 2002, Alzheimer's cost American businesses \$61 billion in medical expenses, productivity loss, and caregiver time off. (2) This number is almost double Alzheimer's costs reported in 1998 and is equivalent to the 2002 profits of the top ten Fortune 500 companies. These costs are expected to soar, as baby boomers reach the age of highest risk of the disease.

As baby boomers age, more and more companies will likely employ individuals who are in the earlier stages of the disease, individuals who may themselves not yet know they have the disease. Yet, even in the early stages, changes in productivity and morale are likely to occur. Given the expected surge in cases of Alzheimer's, it is imperative that managers educate themselves about the disease. There are several important questions. What is this devastating disease? Who does it affect? What are the early symptoms? What is the course of the disease? And, one question that has not been explored in depth, what is the nature of the employer/employee relationship when an employee with an Alzheimer's diagnosis wishes to continue with work as long as the disease will allow?

This paper will explore these questions as well as provide suggestions for employers who are unsure about the best way to deal with an employee with Alzheimer's disease or with employees who are primary caregivers of family members with Alzheimer's.

Plaques and Tangles

Alzheimer's disease is a progressive, degenerative disorder of the brain that results in abnormal brain function with accompanying behavioral problems and eventually, death. The disease was first recognized and described by Dr. Alois Alzheimer in 1907 and has been diagnosed in millions. (3)

Two significant abnormalities occur in the brain of people affected by Alzheimer's: "plaques and tangles", the hallmarks of the disease. (4) Plaques are large, round, sticky balls of the protein beta amyloid. A high level of plaques is associated with a reduced level of neurotransmitters, the brain's chemical messengers; thus memory and learning are progressively destroyed. Tangles are long, menacing strings of twisted nerve cell fibers. They wrap around a cell's nucleus and squeeze it. The tangled fibers are the damaged remains of microtubules that support brain structure. This structure allows nutrients to flow through the nerve cells in the brain; the presence of tangles means the loss of necessary nutrients to the brain. A diseased brain under a microscope shows gooey balls sandwiched between neurons. (5)

Who is most at risk?

Alzheimer's afflicts 1 in 10 people over age 65; therefore, it is not surprising that the most significant risk factor is age. In addition to the elderly, people at higher than average risk are those who have a family history of the disease. (6) Individuals who have lost a parent to the disease have a 50 percent chance of developing Alzheimer's. There is also a distinct link between Alzheimer's and Down's syndrome. Women under the age of 35 who have given birth to a child with Down's syndrome are at a much greater risk for Alzheimer's disease. (7)

What Is the average age of those diagnosed with Alzheimer's?

Alzheimer's develops gradually, with mental changes becoming noticeable typically between the ages of 40 and 60 years. A diagnosis of Alzheimer's generally occurs after the age of 65. Thus, even though an individual may not have yet received an Alzheimer's diagnosis, mental changes that can affect performance may occur quite early, during peak career years. Ten percent of diagnosed Alzheimer's cases are people in their forties and fifties. This early onset of the disease affects an estimated 400,000 people, and most of these cases are known as the familial form that can be passed from one generation to the next. (8)

What impact will Alzheimer's have on baby boomers and their employers?

With the increase of the average life expectancy, if the disease continues to grow at its current rate, the Alzheimer's Association reports that the number of people who will be affected by the disease will increase by 350 percent by the middle of the century. This would make Alzheimer's not only a disease, but an epidemic. (9) One reason for this surge is that one hundred years ago, the average life expectancy in an industrialized country was in the 40s; the number of people who lived long enough to show signs of the disease was not enough to attract attention. (10)

As medical breakthroughs make it possible for people to live and work longer than ever before, the number of workers exhibiting the early signs of Alzheimer's is bound to increase. Because of the epidemic proportions in the growth of Alzheimer's, baby boomers and the organizations that employ them will be affected. Workers who experience early-onset Alzheimer's, as well as older workers exhibiting the early signs of regular-onset Alzheimer's can face a variety of challenges. These challenges include loss of income and insurance when employment ends, reduction in or loss of retirement benefits due to early retirement, delay in eligibility for Medicare benefits, increases in family expenses due to treatment and care, and spouses' being required to work to support the family rather than tending to the patient. Those affected by the disease may still be supporting children in college, making a mortgage payment, or acting as the primary income provider for the family. The burden of care associated with early-onset individuals can be particularly devastating when compared to the care of regular-onset individuals. (11)

Likewise, employers of individuals exhibiting the early symptoms of the disease and employers of the caregivers of such individuals face a multitude of problems. Such problems include a decline in quality and/or quantity of work, interpersonal conflicts with peers, subordinates, supervisors, or customers, problems in coordination and organization of work, and lack of initiative and motivation. Both individuals with Alzheimer's and their caregivers may exhibit tardiness, missed work, and a general decline in work quality.

What are the common warning signs?

There are some common early warning signs of Alzheimer's disease. (12, 13) These are behaviors that an employer or coworkers may witness in the workplace. The

first is memory loss that affects job skills. Occasional forgetfulness is a normal sign of aging, but frequent forgetfulness or unexplainable confusion at work may be a signal of something more. Difficulty performing a familiar task can also occur. Problems with language, such as forgetting simple words or using inappropriate words may make it difficult to understand the individual's sentences. Disorientation to time and place can cause Alzheimer's employees to become lost and not know where they are or how they got there. Poor judgment can make the employee engage in inappropriate actions, such as wearing summer clothes on a freezing winter's day. Abstract thinking becomes difficult, and performing basic calculations may be impossible. (14) Consistently misplacing things is also a problem for the Alzheimer's employee who may put keys or a wallet in the file cabinet without remembering the action. Frequent mood swings for no apparent reason is another warning sign, along with changes in personality. A fairly mild-mannered person can become angry or fearful. And, finally, loss of initiative is generally apparent. Most people get tired but get back into the swing of things fairly quickly. Alzheimer's employees, on the other hand, can remain uninterested in a usual activity or job function indefinitely. (15)

The Americans with Disabilities Act (ADA)

The first decision an employer must make is whether to continue to offer employment to an individual who has been diagnosed with either early- or regular-onset Alzheimer's disease.¹⁶ It is likely that employees are fearful of being discharged if they reveal their diagnosis to their employer. Many employees would probably like to work as long as possible, but how does an employer or employee determine what this time frame should be?

The Americans with Disabilities Act was created to protect people with disabilities from discrimination in employment and in many cases may be used to protect individuals with Alzheimer's disease. The ADA protects any individual who has a disability. An individual is considered to have a disability if he or she has a physical or mental impairment that substantially limits one or more life activities. Major life activities are activities that an average person can perform with little or no difficulty such as walking, seeing, hearing, learning, caring for oneself, and working. Alzheimer's may legally be considered as a disability, and grievances are treated on a case-by-case basis. The crucial question regarding whether an employee with Alzheimer's may be legally considered disabled is whether the disease has become so severe that it affects one or more major life activities. Alzheimer's is a mental impairment that affects activities such as learning, remembering, speaking, working, and caring for oneself. Certainly, some or all of these activities may be considered "major life activities."

According to the ADA, an employer is not required to retain employees who are not qualified to perform the job. To determine whether an individual is still qualified to perform the job, the employer needs to determine whether the employee meets the prerequisites necessary to perform the job. Such prerequisites may include education, skills, experiences, licenses, training, certificates, and other requirements such as using good judgment or being able to work with others. If an employer fails to retain an

individual with Alzheimer's, the employer must show that the individual did not meet a job prerequisite that is related to performing the job and "consistent with business necessity", i.e., the job prerequisite is essential and necessary to performing the job adequately. Employees with Alzheimer's will more likely be discharged on the basis of job requirements (e.g., use of sound judgment, ability to work with others) rather than on the basis of prerequisites such as education, licenses, and training since even with Alzheimer's, an individual still retains such certifications.

Along with determining whether an individual is still qualified, the employer must also identify the "essential functions of the job" and determine whether the employee can perform the functions unaided or with a "reasonable accommodation." These accommodations are modifications or adjustments that would enable the employee to perform the work and are required by the ADA. Modifications may be made to rules, policies, or practices or may be in the form of auxiliary aids or services. For an employee with Alzheimer's, modifications might include more frequent reminders concerning what is to be accomplished on a given day, help on work that requires abstract thinking, training in planning and using a calendar or Palm Pilot, having the employee work as part of a team, rather than alone, or reducing work hours. Another accommodation the company may wish to make is to invite experts in the area of Alzheimer's to educate employees and managers so that they may gain a better understanding of the disease and how they may help a co-worker or subordinate who is in the early stages of the disease. As the disease progresses, the employee may no longer be able to perform the job, and the organization may decide to discharge the individual or move the individual to a less demanding job.

John Wagenaar of George, Iowa, recalled the moment the early-onset Alzheimer's revealed itself in him in 1998. (17) As he had done every day for 11 years, Wagenaar had gone to his job at a manufacturing plant, but on this day he had somehow gotten lost in the plant's new addition. Like many with early-onset, Wagenaar wanted to continue his livelihood and has been fortunate. His employer has allowed him to continue working, and his wife is now employed on the same shift. According to Wagenaar, the Big Sioux chapter of the Alzheimer's Association was a tremendous help. "One of the [Association] people came to my work to talk to everyone about Alzheimer's disease. They helped my coworkers understand more about the disease and how they could help keep me safe at work," said Wagenaar. In Wagenaar's case, the employer became accommodating and took steps to make sure that Wagenaar will remain safe at work.

What else can employers do?

Frequently consulting with employees who have Alzheimer's to learn what is required for them to carry on with normal duty is essential. In fact, the ADA's Provision of Accommodation for Employees with Disabilities requires consultation with employees with disabilities in order to determine their needs and to meet them. Follow up is also necessary to ensure continued need fulfillment. When communicating with the

employee, employers should focus on the abilities that the Alzheimer's employee can perform and restructure the employee's environment based on those abilities.

The Alzheimer's Association has published a set of guidelines regarding work. (18) First and foremost, managers need to educate themselves about the disease in order to effectively work with employees in the early stages of the disease. The organization may want to provide special training for all managers given the future epidemic proportions of the disease. The employee and the company may want to bring in the employee's physician in making decisions about duration of employment after the diagnosis. Also important is a determination of whether any co-workers or clients need to know about the diagnosis for the employee to effectively perform his/her job. The employee might decide to tell co-workers that he/she may have trouble recalling information or finding the right words, occurrences that could lead to frustration for both the employee and the co-workers. Other courses of action an organization might want to take to help the employee with Alzheimer's have already been discussed in the section on reasonable accommodation.

Working with individuals with Alzheimer's is complicated by the fact that many employees decide not to reveal their diagnosis to their employers. In an October 2001 internet poll conducted by the Alzheimer's Association, only 61.4 percent of those questioned thought employers should be informed when an employee has received a diagnosis of Alzheimer's disease. (19) It is likely that employees are fearful of being discharged if their employer finds out that they have the disease. If the organization is committed to employing individuals with disabilities, including Alzheimer's, and to providing reasonable accommodation of such individuals, this commitment should be made publicly known within the company so as to foster an atmosphere of trust. Thus, individuals may be less fearful in revealing their diagnosis and the fact that they may need additional help in getting their jobs done.

Because of the requirements of the ADA, an employee should never be asked if he/she has Alzheimer's disease. If a manager suspects that something may be wrong, the manager should ask only about observed behaviors, (e.g.), "I notice that you have been forgetful lately and have turned in some of your work late. Are you having any sort of problems that are making it difficult for you to carry out your job?" and take care not to mention the suspected Alzheimer's. Decisions regarding conditions of employment can be legally made only on the ability to perform the job and not on the basis of a medical condition. For example, an employee can be discharged if he/she can no longer perform the job, but it is illegal to discharge an employee on the basis of having a particular disease.

Ending employment

Employers dealing with Alzheimer's afflicted employees can be expected to give the same treatment to these employees as the company would to any disabled person. The key is to be accommodating within reason. Generally, an employee with a disability can perform a daily routine indefinitely. In contrast, an Alzheimer's employee's ability to

perform at work slowly diminishes over time, leaving both the employer and employee to decide when work has become too much for the employee or too costly to accommodate. The employer must find a way to terminate employment in a humane way. This can be difficult if the employee wants to continue working. Getting the support of the employee's family can help lessen the blow and it may be helpful to inform the employee of the decision with family members present.

When it is time for employment to end, employers should do everything possible to lessen the burden of the devastating effects of the disease. If an employee is not yet at retirement age, an employer can offer to pay all or some of the retirement benefits until that person reaches the necessary age. An employer may also offer to pay the employee's medical insurance through a Cobra policy if the employee is not yet able to qualify for Medicare benefits. The employer can choose to ease the burden on family members by purchasing helpful items such as a home security system that will let the caregiver know if the Alzheimer's patient exits the home. Other options would be partially subsidizing adult daycare if it is needed; purchasing necessary medical equipment; hiring a home health aide for the employee; or fulfilling a lifelong dream or wish of the employee, such as a trip to Hawaii with a family member, before the disease progresses into later stages.

Not all employers see this as a cost benefit to the company; however, the company may benefit in the public eye. Society highly regards such acts of commitment and kindness and may be more inclined to do business with companies that place great value on employees. Years of service can be taken into account when deciding what benefits to offer the employee. For employees that have been with the company for 20 or more years, the employer may choose to purchase private disability insurance for that employee, thereby making it possible for the employee to receive a paycheck even though his or her disease makes it impossible to work.

When the employee is a caregiver for a family member with Alzheimer's

Employers are also faced with a difficult dilemma when an employee is the primary caregiver of an Alzheimer's patient. Productivity can suffer and absenteeism and tardiness can increase when employees experience conflicts between their work and family responsibilities. Corporations have begun to devote greater resources to childcare issues and have developed effective childcare programs. This, however, has not been the case with the elder care issue. Given the aging of the American population, there is a need for corporations to address this problem. The results of a nationwide study sponsored by Fortune Magazine and John Hancock Financial Services reported that between 25 and 40 percent of employees in America have elder care responsibilities. The study found that corporate executives and employees alike agreed that employers should establish policies or programs that enable employees to deal with family issues impacting on work performance. (20)

The Family and Medical Leave Act (FMLA) of 1993 requires that employers grant up to 12 weeks of unpaid leave to employees during any 12 month period to provide care for an immediate family member with a serious health condition. (12) This piece of legislation is clearly a start in assisting caregivers of family members with Alzheimer's disease. If an employer approves, FMLA leave may be taken intermittently, instead of all at once. This type of schedule may be more appropriate for caregivers of Alzheimer's patients who may need only a couple of hours of time off a day over an extended period of time rather than 12 weeks all at once. Many care giving employees will not be able to take FMLA leave for financial reasons since the leave is without pay. For such employees, the organization may want to consider options such as flextime, job sharing, telecommuting or other work-at-home options.

Conclusion

If the incidence of Alzheimer's disease continues to grow at its current rate, cases like that of Jim Clarkson, presented at the beginning of this paper, will become more and more common. Organizations have much to do to prepare for the possible epidemic proportions of this increase. Managers, and in some cases, employees, need to be educated regarding the symptoms and course of this devastating disease, and how to effectively work with an individual in the early stages of the disease. Managers need a clear understanding of the legal issues such as reasonable accommodation of workers in the early stages of the disease and discharging individuals who can no longer work. Managers should be trained to recognize the early signs of the disease, just as they have been trained to recognize the signs of other disabilities such as drug addiction or alcoholism in employees. The earlier the disease is identified, the more effective the organization can be in providing help and support to the employee so that the employee can continue to effectively function at work as long as possible at work. Morale should also improve as the company demonstrates its concern for employees. Finally, the reputation of the company will be positively affected if the public is made aware that the company is taking proactive steps to deal with this crisis that will affect all aspects of American society.

REFERENCES

- 1 Alzheimer's Association. "Alzheimer's Epidemic to Implode Healthcare System," <http://alz.org/media/newsrelease/current/040103/htm>. 1 Apr 2003.
- 2 Ibid.
- 3 Anonymous, "Alzheimer's: Few Clues on the Mysteries of Memory," *WebMDHealth* http://my.webmd.com/content/dmk/dmk_article_1960956. 9 Sep 2001.
- 4 Anonymous, "What is Alzheimer's Disease?" *WebMDHealth* http://my.webmd.com/content/dmk/dmk_article_3961782. 9 Sep 2001.
- 5 Stout, Frappa. "Alzheimer's: A Conversation About Memories Lost," *USA Weekend Enterprise-Record/Mercury-Register*. 31 Aug – 2 Sep 2001.
- 6 Anonymous, "What is Alzheimer's Disease?" *About.com* <http://alzheimers.about.com/library/weekly/aa040700a.htm>. 14 April 2003.
- 7 Anonymous, "Alzheimer's: Few Clues on the Mysteries of Memory," *WebMDHealth* http://my.webmd.com/content/dmk/dmk_article_1960956. 9 Sep 2001.
- 8 Anonymous, "Question & Answer," *Advances: The Alzheimer's Association Newsletter*. Vol. 21 No. 2 Summer 2001.
- 9 Anonymous, "14 Million Baby Boomers Sentenced to Alzheimer's," *ElderWeb* <http://www.elderweb.com/default.php3?PageID=1795>. 20 Oct 2001.
- 10 Anonymous, "Alzheimer's: Few Clues on the Mysteries of Memory," *WebMDHealth* http://my.webmd.com/content/dmk/dmk_article_1960956. 9 Sep 2001.
- 11 Anonymous, "Question & Answer," *Advances: The Alzheimer's Association Newsletter*. Vol. 21 No. 2 Summer 2001.
- 12 Alzheimer's Association. "Ten Warning Signs of Alzheimer's Disease," <http://www.alz.org/aboutAD/10signs/htm>. 1 May 2003.

- 13 Kuhn, D. & Bennett, D, *Alzheimer's Early Stages: First Steps for Family, Friends, and Caregivers*, Alameda, California: Hunter House, 2nd ed., 2003
- 14 Peterson, R. C., *Mayo Clinic on Alzheimer's Disease*, New York: Kensington, 2002.
- 15 Anonymous, Alzheimer's Disease Guidelines: A Summary for Patients, Family and Friends," *American Academy of Neurology*
http://www.aan.com/public/practiceguidelines/patient_info.htm. 20 Oct 2001.
- 16 ADA Technical Assistance Centers, "What is the ADA: Definition of a Disability,"
<http://www.adata.org/whatsada-definition.html>. 1 May 2003.
- 17 Anonymous, "Question & Answer," *Advances: The Alzheimer's Association Newsletter*. Vol. 21 No. 2 Summer 2001.
- 18 Alzheimer's Association. "Making Job Decisions,"
<http://www.alz.org/IhaveAD/JobDecisions.htm>. 1 May 2003.
- 19 Alzheimer's Association. "Poll Results,"
<http://www.alz.org/PreviousPoll.htm>. 6 Nov 2001.
- 20 Epstein, Becker, & Green, "A Proposal to Assist Employees in Dealing with Problems of Aging and Incapacitated Spouses and Parents,"
http://www.ebglaw.com/article_294.html. 9 Sep 2001.
- 21 U.S. Department of Labor. "Compliance Assistance: Family and Medical Leave Act," <http://www.dol.gov/esa/whd/fmla/>. 30 March 2003.

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