Caregiver Classes

Sponsored by the University of Chicago Memory Center

7101 South Exchange
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Class 1:
What is Dementia and How Does Dementia Progress?

A. Dementia – What it is and is Not...

Myth #1: Dementia is a normal consequence of aging.

Dementia is a term used to describe a progressive deterioration of cognition (memory, judgment, new learning, recognition and or behavior) which is significant enough to interfere with social and occupational functioning. Alzheimer’s disease is the major cause of dementia, accounting for 50-60% of dementias. It is a medical condition, just as hypertension or diabetes are abnormal conditions which occur in select individuals and is not a consequence of age.

Myth #2: There is no need to go thru an evaluation for dementia.

There are multiple causes for dementia. Multiple diagnostic tests can help us rule in/out the cause of individual cases of dementia.

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<tr>
<th>1</th>
<th>Causes of Dementia (Irreversible)</th>
<th>Examples</th>
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<tr>
<td></td>
<td>• Alzheimer’s disease</td>
<td>• Lewy Body Dementia</td>
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<td>• Multi-infarct or vascular dementia</td>
<td>• Jakob-Creutzfeldt disease</td>
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<td>• A combination of Alzheimer’s disease and vascular dementia</td>
<td>• Fronto temporal Dementia</td>
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<td>• Parkinson’s Disease</td>
<td>• Primary Progressive Aphasia</td>
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<td>• Huntington’s Disease</td>
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<td>• Multiple Sclerosis</td>
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<td>• AIDS</td>
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<th>2</th>
<th>Mimics of Dementia (Reversible)</th>
<th>Examples</th>
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<tbody>
<tr>
<td></td>
<td>• Depression</td>
<td>• Various Anemia’s</td>
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<td>• Brain Tumor</td>
<td>• Normopressure Hydrocephalous</td>
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<td>• Thyroid disease</td>
<td>• Neurosyphilis</td>
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<td>• Pituitary deficiency</td>
<td>• Encephalitis</td>
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<td></td>
<td>• Vitamin B-12 Deficiency</td>
<td>• Malnutrition</td>
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**Myth #3:** If my mother had Alzheimer’s disease will have it? There is no need doing an evaluation.

The biggest risk factor for dementia is age, not genetics. Some forms of dementia such as Alzheimer’s may run in families; however, genetic testing is generally not recommended unless strong history early onset (<65 years) disease. The primary factors in evaluation are comprehensive history, physical examination and diagnostics:

**What is Involved in the Evaluation Process?**
Evaluation for a dementia must be comprehensive including history, examination and diagnostic test to rule in/rule out various causes of dementia. The evaluation should include the below:

1. A history of the patient symptoms of cognitive/functional decline from the patient perspective and that of a close family member or friend. This should include when symptoms occurred and how they have progressed over time.

   **10 Warning Signs of Dementia:**
   - Memory Decline (Trouble recalling appointments, medications)
   - Trouble planning or problem solving (Trouble making decisions)
   - Trouble doing familiar tasks (Trouble operating washer)
   - Trouble with time or space (Unaware of date)
   - Trouble with understanding visual images (Not understanding signs)
   - Trouble with language (Forgetting names)
   - Misplacing things (Odd locations items)
   - Decline in judgment (Impulsive behaviors)
   - Withdrawal from work (Decline hobbies, social outings)
   - Change personality (Depressed, Irritable)

2. A complete physical examination including a neurological exam.

3. A complete history of the patient’s medical and surgical conditions, as well as those medical problems present in the patient’s family (like dementia).

4. A complete drug profile (prescription, herbal and over-the-counter medications) and alcohol history.

5. Blood tests that include a complete blood count, vitamin B-12 and folate levels, syphilis testing and thyroid function testing.

6. Other testing at the discretion of the physician that can include chest x-ray, EEG, EKG, spinal tap, brain scans (either MRI or CT scan).

7. Neuropsychological Testing. Generally reserved for patients with atypical or unclear causes of dementia. Should be considered with initial diagnosis and repeated over time to assess for progression to new stages of disease.
**Myth #4:** There is no need to diagnose dementia because there is no treatment. —or— Dementia is curable.

Dementia is a long-term, non-curable disease which progresses over time. However, there are various forms of therapy to assist in the care, safety and symptom progression of individuals living with dementia.

**After completion of a comprehensive evaluation, individuals and families with dementia should undergo the following treatment plan:**

1. An educational meeting to inform the patient and family of the cause of their dementia. This meeting should also address what stage the patient is exhibiting and (drug, social, exercise) treatments appropriate during this time.

2. The physician should address safety in the community:
   - Driving
   - Medication administration
   - Ability to cook, manage finances, pay bills
   - Ability to live in current setting vs. additional safety (home aide, meals on wheels, safe return)

3. Medications for dementia (Not a cure, delay progression speed)
   a. Acetylcholinesterase inhibitors (SE: nausea, anorexia, dizziness)
      i. Donepezil (Aricept) 5mg daily → 10mg daily chronically → Consider 23 mg if stable on 10mg >6 months
      ii. Rivastigmine (Exelon) 4.6mg patch daily → 9.5mg daily chronic
      iii. Galantamine (Razadyne ER) 8mg daily → 16mg daily chronic
   b. NMDA receptor antagonist (SE: drowsiness, constipation, dizziness)
      i. Memantine (Namenda) 5mg night->5mg ->
          5mg/10mg night-> 10mg 2 times daily chronically
   c. Blood thinning medications if history of stroke disease
   d. Other medications to treat related problems-depression, vitamin deficiencies, ect.
4. Establishing Advance Directive (Health Care Power of Attorney-The person you trust to make decisions when you are no longer able. Living Will-your wishes about focus of medical care should your physical condition decline to a point you are actively dying). Dementia is a progressive condition, which at end stage is terminal and can result in death due to inability to eat, walk, manage oral secretions. Your loved one may not be able to express their wishes late in disease so addressing what they do and don’t want as medical care early is critical.

5. Treatment of behavioral/personality changes existing with dementia (depression, anxiety, pacing, wandering) If there are concurrent behavior problems, the physician may consider placing the patient on medications specific to the behavioral problems. In some cases treatment may improve some of the behavior problems.

6. Recommendations for physical, social activity. These recommendations may involve referral to an adult day health program, senior center, senior exercise group or taking a class with instructions/teaching adapted for memory impairment.

7. Reevaluate stage of disease and Treatments annually-Mental state testing, assessment of functioning in community, safety either by your physician or via neuropsychology follow up).

8. Optimizing the stability of other medical conditions and establishing a plan for management and screening of other medical conditions based on prognosis/staging of dementia. As dementia progresses it may no longer be appropriate to continue with specific medications or preventive health treatments based on the overall prognosis (duration of remaining life) based on dementia and other chronic illnesses. It is important to patients and families with dementia to arrive at a decision based on the individual patient and physician discussion.
Myth #5: Medications like Aricept are appropriate for all dementia patients at all times

Consider stopping dementia medications in the following situations:
- Limited benefit over period of years
- Side Effect intolerance (severe weight loss, dizziness or anorexia)
- Risk>Benefit
- Compliance Issues: (Cost, swallowing, behavior escalation)
- Not consistent with patient goals for care

Myth #6: All patients with dementia will be upset and distressed by the diagnosis.

How to Tell Someone they have a “Dementia” Diagnosis
- Some families are very concerned about how the patient will respond to the diagnosis of dementia. Many people are afraid of the “word” Alzheimer’s disease just like the way they are frightened of the “word” Cancer.

- Many patients who are told that they have a dementia illness accept it without problems. They are grateful that they have a “real” problem that accounts for the memory problems they are experiencing.

- More often the actual symptoms of dementia lead to a lack of insight of the person experiencing the illness. Therefore, they may have difficulty understanding the seriousness and implications of their diagnosis. They may deny symptoms and refuse recommendations necessary for safety such as “NO DRIVING.”

- Other patients may become depressed at the final diagnosis because they are still intact enough to understand all of the repercussions of their condition. These patients may need additional help such as counseling, anti-depressant medications, and attending support groups.

- It is best to treat the patient with respect and allow as much autonomy and independence as possible, while still balancing safety.

- It is crucial not to get into disagreements about who is right or wrong, often patients with dementia lack the insight or the retention of information to know what actually occurred or was said. “Agree to disagree.”
**Test Your Caregiver Knowledge**  
*(Go thru Answers to above and these questions)*

**Answer True or False to the following statements:**

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<table>
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<tbody>
<tr>
<td>1.</td>
<td>Alzheimer’s disease is a psychiatric illness.</td>
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<td>2.</td>
<td>You can catch Alzheimer’s disease from your relative.</td>
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<td>3.</td>
<td>Senility is to be expected when you get older.</td>
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<td>4.</td>
<td>Alzheimer’s disease can be cured if treated early.</td>
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<td>5.</td>
<td>You will get Alzheimer’s disease if either of your parents had it.</td>
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<td>6.</td>
<td>The only way to definitively diagnose Alzheimer’s disease is on autopsy.</td>
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<td>8.</td>
<td>Alzheimer’s disease patients can live up to 15 years after they get the disease.</td>
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<td>9.</td>
<td>Incontinence is an early sign of dementia.</td>
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<td>10.</td>
<td>You can diagnose Alzheimer’s disease with a blood test.</td>
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<td>11.</td>
<td>Alzheimer’s disease patients lose their emotional feelings early in the disease.</td>
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<td>12.</td>
<td>People who are sweet and kind all of their life never develop behavior problems.</td>
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<td>13.</td>
<td>Alzheimer’s disease is always physically painful.</td>
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<td>14.</td>
<td>Persons with dementia have control over their behavior.</td>
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<td>15.</td>
<td>You should always defend yourself if a person with Alzheimer’s disease accuses you of stealing.</td>
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<td>17.</td>
<td>Memory loss that interferes with daily functioning is a normal part of the aging process.</td>
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<td>18.</td>
<td>If the person with memory problems wants to continue driving, he should be allowed to.</td>
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<td>19.</td>
<td>It is all right to allow the person with dementia to watch whatever he wants to on television.</td>
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<td>20.</td>
<td>All persons who develop dementia will develop difficult behavior problems.</td>
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<td>21.</td>
<td>The demented person will be able to tell you when something is bothering him.</td>
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<tr>
<td>22.</td>
<td>It is more helpful to speak to a demented person in short sentences using only one direction at a time.</td>
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People with dementia do better when they are taken on long relaxing vacations away from familiar surroundings.

It is best to break down more complex tasks into smaller tasks to avoid frustration for the person with dementia.

If the person with dementia has never gotten lost, it is all right for them not to wear a Medic-Alert bracelet or necklace.

Urinary and fecal incontinence develops early in the course of dementing diseases.

Demented persons do not need to attend church/temple any longer.

B. Myth #7: Dementia is a stable disease and does not progress. “He just has a touch of dementia.”

Stages and Symptoms of Dementing Diseases

Separating the course of these diseases into “stages” helps caregivers to know approximately where the patient is at and what to expect. Just for the purpose of this class, we will divide dementing diseases into four stages. Movement thru the stages of disease is not always clear. Individuals may exhibit symptoms of more than one stage at a time.

Stage 1 – Early Stage – Mildly Impaired

This stage lasts approximately 1-3 years.

It is characterized by recent memory changes, especially in the person’s ability to remember the names of people, appointments, and dates.

Language Skills

The person may have difficulty finding the right word to use in a sentence and may substitute other words. Reading comprehension may begin to decrease and the ability to actively participate in a conversation may begin to diminish. The same questions may be asked several times in an hour and may progress to more often than that.

Social Skills

There may be subtle changes in the personality. The person may become more Withdraw and less sociable. Difficulty starting new projects or conversations.

Cooking and Feeding

Meals may go uneaten or the person may eat several meals in a row, not remembering whether or not he has just eaten. This is especially noticeable when the person lives by himself. If the person cooks, pots may be burnt and water may be left running.

Handling Money

Checkbooks may show incorrect or forgotten entries. Bills may go unpaid until the various companies send notices. Bank notices and other financial papers may pile up.

Operating Machinery/Tools

Handling machinery may become dangerous, especially when critical decisions have to be made such as shutting off the lawn mower to remove a branch that is stuck in the blades.
Travel
If the person is driving, there may be minor car accidents even driving out of the driveway. Judgment and reaction times are affected leading to driving problems. Getting lost in unfamiliar surroundings becomes routine (driving, bus route).

On-the-Job
Handling multiple responsibilities in a job setting becomes very difficult and may require that the person stop working until a diagnosis is made.

Making up the Difference
The person at this first stage may have an uncanny ability to cover-up deficits by using sociable phrases like, “It was so nice to have met you.” Even some physicians may be fooled into thinking that there is no problem at this time. Yet there may be an inability to initiate meaningful conversation.
The person may still be able to enjoy all previous activities, but they may have increasing difficulty being able to independently perform or initiate them.

Stage 2 – Middle Stage – Moderately Impaired
This is the longest stage and may last from 3-10 years.
The patient repeats questions, forgets new information and later in stage may have more difficulty with remote memory. It is the time when the person is no longer able to adequately manage by himself and needs the assistance of another individual to survive. Activities of daily living may begin to be compromised at this point.

Daily Living Skills
At this stage the person may need reminders to bathe and assistance in selecting clothing from the closet. The person may need help with putting the clothing on in the correct order and may wear clothes that are not appropriate for the season such as not wearing a winter coat when it is very cold outside.

Medications
All medications will need to be administered by another person to ensure adequate and consistent dosing.

Language Skills
The person begins to have even more difficulty with using and comprehending the spoken word. Watching television may become less enjoyable, because it may become difficult to follow any story line.

Behavior Difficulties
This is the stage during which behavior problems may occur such as aggression, agitation, and sundowning. Sun downing is a term used for people who become more restless and irritable later in a day and towards the evening. You may also observe wandering, pacing, rummaging, paranoia, delusions, hallucinations. Difficulties with bathing, dressing, sleeping, incontinence of urine, and eating problems may become more pronounced. Television programs with violence and aggression may result in agitation.
**Point to Remember**
Although it may seem as if the problem behavior is intentional, it is really due to the pathological changes in the brain that the person is experiencing. As a caregiver, you will have the challenge of trying to change the way you approach these problems, rather than having the patient change his behavior.

Myth #8: He just has a touch of dementia not cancer or something than can cause death.

**Stage 3 – Late Stage – Severely Impaired**
This is the last stage and can last from 1-3 years. The patient demonstrates profound deficits in short-term and long-term memory. It is the time when the person becomes incapable of caring for himself and need 24 hour care. This is the time when the caregiver may need physical assistance for the patient. It is a time when the patient has severe deficits in ability to express their needs and may express needs with gestures or aggressive behaviors.

*Language and Communication Skills*
These skills may become very limited. However, the person with dementia can still respond to the tone of voice, but not necessarily understand the words spoken. The ability to speak deteriorates to only a few basic words.

*Daily Living Skills*
All functions become more difficult. The brain can’t get the message to the body to swallow, chew or walk. Disinterest in food and difficulties with chewing and swallowing result in weight loss. Swallowing may become a problem and choking can occur. The person’s ability to walk becomes more difficult and falls may occur. Muscles and joints become rigid. However, the strength of upper and lower extremities can be surprisingly intact and sometimes uncannily strong. Incontinence of feces, as well as, urine occurs regularly.
Terminal Stage - (Final Weeks-Months before death)
Death can and usually occurs from an infection such as pneumonia (due to uncoordinated swallowing), malnutrition, vascular events (strokes, heart attacks) or infected bedsores. This stage is not reversed by intravenous fluids, stomach tubes, breathing machines or antibiotics.
Class 2
Caring for the Caregiver
Plans for your life and future might not have included being a caregiver. Realistically, however, you may presently or in the near future be caring for an elderly or disabled loved one. Not having a choice about being a caregiver, having to learn many needed skills “on the job,” feeling out of control about what will happen next, and being filled with conflicting emotions can easily leave you physically and emotionally drained.

To guard against what is known as “caregiver burnout,” you need to remember that caregivers need care too, and find for yourself ways to nurture your own physical and emotional health and energy levels.

This class will explore the nature of your care giving career with its rewards and challenges, how to manage your workload by setting limits and having realistic expectations, feelings related to care giving, how to care for yourself, and moving on through the care giving process.

Caregivers Need Care, Too!
Since taking care of yourself might seem like an impossible task at a time when your energy supply is already depleted, here are some methods that you can use to meet your own self-care needs.

Expand Your Support Network
Although at first it might seem like “just one more thing to do,” join a caregiver support group. At the group meeting, you can share feelings, learn new ways to cope, find out about available community resources, and just feel less alone. A safe, supportive environment can be a comfortable place for you to relax, share a good laugh or cry, and leave with a renewed sense of strength about making sensible decisions concerning your life and the life of the person you care for. Because your time with others is so limited, make sure the people you choose to be with make you feel valued and cared about.

Maintain Your Own Physical Health
An adequate amount of sleep, eating well, and some exercise will replenish your body’s energy level. If it seems impossible to find extra time for any of these activities, look at the time you do have, and resolve to make good use of it. Can’t get a full eight hours of sleep? Take a couple of short naps. Can’t go to an exercise class? Do some leg lifts in front of the TV or take a short walk with a neighbor. Can’t always find the energy to cook a balanced meal? Go out to eat instead, perhaps with a friend, a member of your support group, or just by yourself with a good book to read. Taking your thoughts off of care giving for a while is good for the body and the mind.
Build Your Own Self-Esteem
Some days, talking to yourself might be the only “conversation” you have. Strive to make your “self-talk” positive rather than negative or demeaning. Give yourself compliments on the good job you’re doing or for your gentle caring ways. Work toward affirming yourself and your actions at least once every day. You deserve to hear these positive statements, and they might as well start coming from within yourself!

Strive for Balance in Your Day’s Activities
During the time you are a caregiver, you probably will not get to play as much as you work. Maybe it’s hard sometimes to imagine having fun anymore or even to remember the last time you did something you enjoyed. It may be very difficult for you to schedule “time out” to have fun. Well, you need and deserve a break! Make it a habit to do something you enjoy by building it into your routine. It will renew your patience and your sense of humor, which will enable you to continue more effectively in your role.

Learn to Set Priorities
You’re well on the road to self-care when you learn that dusting the coffee table daily or doing the breakfast dishes by 9 AM isn’t nearly as important as a much-needed afternoon nap, a walk with a friend, or watching the sun set. The dust and the dishes can wait. How can you take good care of someone else if you put everything and everybody before yourself? Think about have you would like to feel (rested, healthy, calm, etc) and decide how you can work towards that feeling. Start with an activity that is manageable, both time- and energy-wise. Set your goal so you can achieve it daily or weekly! Remember, care for yourself because caregivers need care too!

Excerpts from Jayne Royce, trainer/consultant at Community Care Resources, St. Paul, MN. Reprinted with the permission of the author and Good Age, September 1988.
Self-Test: Are You an Overachieving Caregiver?

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<th>Answer True or False to the following statements:</th>
<th>Answer</th>
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<tr>
<td>1. Do you feel that no one else can look after your relative as well as you can?</td>
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<td>2. Do you go for weeks without taking even an hour off?</td>
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<td>3. Would you feel you had abandoned your relative if you took him or her to a day respite program?</td>
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<td>4. Do you feel that only you can understand him or her and that letting others provide care would hurt, frighten or otherwise damage your relative?</td>
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<td>5. Do you feel anxious, exhausted or irritable most of the time?</td>
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<td>6. Do you secretly feel angry with your relative, and then feel ashamed of your unnatural feelings and become obsessed by guilt?</td>
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<td>7. Have you dropped all your previous hobbies, friends, and interests?</td>
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<td>8. Would you rather die than let your relative go into full-time professional care?</td>
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<td>9. Do you avoid going to support groups because you could never share your feelings with strangers, and/or you are sure such groups are full of people who just make each other miserable?</td>
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<tr>
<td>10. Do you keep all your fears, needs, and feelings to yourself because you aren’t the kind of person who shares such things with others?</td>
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<td>11. Are you sure that no good caregivers can be found?</td>
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Managing Stress

Both normal and unusual events produce stress in our lives. Stress is a part of living. You can’t avoid it. How you adapt to the stresses of life is something that you can change. If stress in not handled properly over a long time, it may have unhealthy effects on our bodies causing diseases and the breakdown of body functions. Stress management is the mastery of specific skills that help reduce the negative effects of stress on the body. Techniques of stress management include diaphragmatic breathing, mental imaging, and progressive muscle relaxation.

Symptoms of Stress

Symptoms of stress vary from person to person. When you experience an unusual level of stress, certain warning signals occur. Stress can become debilitating. Recognizing the source of your stress can help effectively deal with its destructive effects. Taking care of yourself starts with identifying the unhealthy ways that you may deal with stress.
Self-Quiz: Are You Experiencing Care-giver Stress?
Answer Yes or No to the following questions Answer

1. Do you feel a loss of energy or zest for life?
2. Do you feel out of control, exhibiting uncharacteristic emotions or actions?
3. Do you lack interest in people or things that were formerly pleasurable?
4. Are you becoming increasingly isolated?
5. Are you consuming an increased amount of sleeping pills, medications, alcohol, caffeine, or cigarettes?
6. Are you having increased health problems, for example, high blood pressure, ulcers, or difficulties with digestion?
7. Do you have difficulty falling asleep at night, awakening early, or sleeping excessively?
8. Are you experiencing appetite changes?
9. Do you have problems with concentration or memory?
10. Are you increasingly irritable or impatient with others?
11. Do you have thoughts of suicide?
12. Does your body have pain or feel achy even when you haven’t exercised?
13. Have you noticed a change in your bowel or bladder habits?
14. Do you feel like you’re tired all of the time?

Causes of Stress
What creates stress for you may not create stress for someone else. The causes vary with the responsibilities and with the individual caregiver. This self-quiz will help you to identify some of the common sources of caregiver stress.

Self-Quiz: What’s Causing Your Caregiving Stress?
Answer Yes or No to the following questions.
Space is provided for comments.

1. Are you experiencing multiple demands on your time, energy, or money? What are they?
2. Do you feel that your responsibilities conflict? Which ones?
3. Is there a difference in expectations between your family, your boss, your dependent relative, yourself? What are they?
4. Do you feel a lack of understanding about the person’s mental or physical condition?
5. Do you have difficulty meeting your relative’s physical or emotional needs?
6. Are you pressured by financial decisions and lack of resources?
7. Do you feel a loss of freedom?
8. Do you feel a sense of being trapped?
9. Is there disagreement among family members?
10. Do you feel that other family members aren’t doing their share?
11. Does the older person place unrealistic demands and expectations on you?
12. Is there a lack of open communication?
13. Do other family members have negative attitudes that you have trouble contending with?
14. Is there an observable deterioration in your family member that is painful to watch?
15. Are there other problems with children, marriage, employment, or health? What are they?

**Caring for Yourself**

Once you can recognize unhealthy reactions to stress, you can try a healthier approach. The following recommendations are some of the ways you can reduce the effects of stress on your life:

**General**

- Exercise for 30 minutes at least three times a week.
- Recognize the things that upset you and develop a positive attitude toward those you cannot avoid.
- Develop methods for relaxation. For example, talk with supportive people, listen to music, watch movies, or take walks.
- Get adequate and regular amounts of rest and sleep (6 to 10 hours a night).
- Eat three to six small, balanced meals a day.
- Use positive thoughts and humor to overcome negative thoughts.
- Seek professional help for dealing with especially stressful events in your life. Learn to use relaxation techniques, such as diaphragmatic “deep” breathing, mental imaging, and progressive muscle relaxation.
**Deep Breathing**

Deep breathing is a method of relaxation that removes tension from your body. It can be done practically anywhere. It is also called diaphragmatic breathing. Begin this exercise by sitting in a comfortable chair or lying on the floor with a pillow under the small of your back.

- Breathe in slowly and deeply, pushing your stomach out as you breathe in.
- Say the word “relax” silently before you exhale.
- Exhale slowly, letting your stomach come in.
- Repeat this exercise 10 times in a row without interruption.
If you can do this exercise five times a day, you will notice a feeling of relaxation, quietness and fewer symptoms of distress.

**Mental Imaging**

This technique consists of mental exercises that create feelings of heaviness and warmth in your muscles. This relaxation technique is also called “antigenic training.” Begin this exercise by sitting in a comfortable chair or lying on the floor in a quiet room with your eyes closed. Concentrate on a specific muscle group, then visualize and feel this muscle group relax. For example, while you visualize and feel the muscles in your forehead and scalp relax; say to yourself, “My forehead and scalp feel heavy, limp, loose, and relaxed.” Each exercise session should last 5 to 10 minutes. Do this exercise twice each day for each of the following muscle groups:

- Forehead and scalp
- Eyes
- Nose
- Face
- Tongue
- Jaws
- Lips
- Neck
- Right arm
- Left arm
- Right leg
- Left leg
- Back
- Chest
- Stomach
- Buttocks and thighs
**Progressive Muscle Relaxation**

In these exercises you focus on physically relaxing specific muscle groups, one at a time, tensing and relaxing each group while breathing slowly and deeply. As you concentrate on your muscles, you aren't thinking about problems and events that cause stress and anxiety. Audiotapes that teach this technique are available at many bookstores.

Begin this exercise by sitting in a chair with your back straight, head in line with your spine, both feet on the floor, and hands resting on your lap. Tighten each muscle group and hold the tension for 15 to 20 seconds.

Starting with your head, work down the body or start at the feet and work up. The muscle groups to tighten and relax are:

- Forehead and scalp
- Eyes
- Nose
- Face
- Tongue
- Jaws
- Lips
- Neck
- Upper arm
- Lower arm and hands
- Chest
- Stomach
- Back
- Buttocks and thighs
- Legs
- Feet

Each exercise session should last 12 to 15 minutes. If you exercise each muscle group twice a day, you'll notice the difference between tension and relaxation.
Class 3

Behavior Problems

Behavior is a result of a person’s interaction with the environment. When a person with dementia does not understand the environment, it can result in a problem behavior that can be disruptive and difficult to manage by the caregivers. If a person with dementia is not feeling well (either emotionally or physically) and is unable to find relief from those feelings, problem behaviors can result. Medications and medication interactions can also result in problem behaviors. Problem behaviors can also result from chemical changes in the brain. Common medical conditions that can result in acute worsening behavioral problems include dehydration, constipation, respiratory infections, urinary tract infections, depression, and/or anxiety. This acute fluctuating worsening which occurs over days-weeks and distinctly differs from baseline behaviors is called delirium. Delirium should be evaluated by the primary doctor immediately and often improves to baseline once the underlying condition is treated.

Common behavior problems of dementia include agitation, aggressiveness, sun downing, pacing, wandering, refusal to bathe or brush teeth, refusal to dress or change clothes, and problems with eating, incontinence, anxiety, and depression.

Myth #9: Patients with dementia escalate behavior for no reason.

The following factors may initiate, result in, intensify, or aggravate behavior problems:
1. Fatigue
2. Change of routine
3. Change of caregiver
4. Change of environment
5. A perceived increase in demands
6. Overwhelming, over stimulating or competing stimuli
7. Under stimulation or boredom
8. Physical illness
9. Pain
10. Medication reactions.

Points to Remember

It is important that the caregiver try to determine the possible cause of unwanted or problem behaviors. In this way, perhaps the behavior can be eliminated or prevented the next time. New onset behavior problems may be the result of a physical problem and should be brought to the attention of a physician for evaluation. While we will try to help you manage these problems, please remember to call your health care professional if you are unable to manage these behaviors. Medications can be provided if behavioral management techniques are not successful.

Coping Skills

Try to incorporate the following concepts into the daily care giving of persons with dementia:
1. Never confront the person with their memory loss.
2. Never talk about the person in front of him.
3. Never respond to the person's accusations.
4. Never get into a power struggle with the person.
5. Never put the person on the spot, contradict him, or argue with him.
6. Never put the person through a memory test. Only the physician or psychologist should do this.
7. Never assume that the person is doing things just to be difficult.

**Communication Skills**

When communicating with a person with dementia, try to do the following:

1. Avoid asking questions that rely on memory.
2. Try not to reason or rationalize with the person.
3. Try not to express your own anger verbally or with physical threats such as point a finger.
4. Speak slowly.
5. Use short, simple sentences.
6. Try one-command sentences using only one noun and one verb.
7. Complete one step at a time before going on to the next step.
8. Avoid pronouns such as he, she, that, or there.
9. Use names of people and names of objects like, “I would like you, Sarah, to come and sit on the chair next to me.”
10. Try not to make demands, only requests.
11. Avoid questions like "do you remember?" They probably don't and may become upset.
12. Use repetition. Frequent reminders may reassure the person.
13. Allow adequate response time to requests to perform any activity.
14. Limit choices to avoid confusion. This pertains to mealtime and dressing.
15. Provide challenging and diversional activities so that the person may enjoy them and avoid becoming frustrated.
16. Above all, speak in a soft, reassuring, accepting tone of voice. The feelings behind the tone will be conveyed to the person immediately.
**Talking to a Person with Alzheimer’s**
People with Alzheimer’s disease deserve our respect. Strive to learn the language of dignity. This list of Do’s and Don’ts helps to guide our visits with them.

<table>
<thead>
<tr>
<th>Don’t Say</th>
<th>Do Say</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What did you have for lunch today?</td>
<td>How was your lunch today?</td>
</tr>
<tr>
<td>2. What time is it?</td>
<td>The day’s really going by, isn’t it?</td>
</tr>
<tr>
<td>3. What did you do today?</td>
<td>How is it going?</td>
</tr>
<tr>
<td>4. Was today rough?</td>
<td>How was your day?</td>
</tr>
<tr>
<td>5. What would you like to do now?</td>
<td>Would you like to take a walk?</td>
</tr>
<tr>
<td>6. Is that a new sweater?</td>
<td>What a nice sweater. I don’t remember it.</td>
</tr>
<tr>
<td>7. Who’s that sitting over there?</td>
<td>That person looks nice. Let’s go meet him.</td>
</tr>
<tr>
<td>8. Do you know who I am?</td>
<td>Hi, I’m glad to see you.</td>
</tr>
<tr>
<td>9. You just told me that!</td>
<td>That’s interesting. I didn’t know that.</td>
</tr>
<tr>
<td>10. I already know that.</td>
<td>Thanks for telling me.</td>
</tr>
<tr>
<td>11. What kind of music do you like?</td>
<td>Want to go listen to some music?</td>
</tr>
<tr>
<td>12. Do you want to watch Wheel of Fortune?</td>
<td>How about seeing if there’s anything good on TV?</td>
</tr>
<tr>
<td>13. We talked about this last time.</td>
<td>That sounds interesting. I’d like to know more about it.</td>
</tr>
<tr>
<td>14. I just explained that.</td>
<td>Let me show you.</td>
</tr>
<tr>
<td>15. I know how to do that!</td>
<td>That’s a good idea. Thanks for telling me. I will have to try it.</td>
</tr>
<tr>
<td>16. Why do you always have a comeback</td>
<td>I wish I could come up with quick answers like you do. I never think of them until the next day.</td>
</tr>
<tr>
<td>17. I’m an adult, not a child.</td>
<td>You always look out for me. I love you for that.</td>
</tr>
<tr>
<td>18. I don’t understand why you say things like that.</td>
<td>I’m not sure I got that. Could you explain it again?</td>
</tr>
<tr>
<td>19. What did you do all day?</td>
<td>Did you have a “regular” day today?</td>
</tr>
<tr>
<td>Problems</td>
<td>Examples</td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Sleeping</td>
<td>• Insomnia&lt;br&gt;• Sleeping all the time&lt;br&gt;• Night/day disruption</td>
</tr>
<tr>
<td>Eating</td>
<td>• Spitting&lt;br&gt;• Pocketing food&lt;br&gt;• Refusing to sit down&lt;br&gt;• Refusing to use utensils&lt;br&gt;• Unable to eat independently</td>
</tr>
<tr>
<td>Dressing and Bathing</td>
<td>• Refusal to bathe&lt;br&gt;• Refusal to change clothing&lt;br&gt;• Fear of water</td>
</tr>
<tr>
<td>Toileting</td>
<td>• Incontinence&lt;br&gt;• Using closet, wastepaper, basket or bathroom sink to relieve himself&lt;br&gt;• Forgetting to go to toilet</td>
</tr>
<tr>
<td>Verbal Noises</td>
<td>• Screaming</td>
</tr>
<tr>
<td>Sun downing</td>
<td></td>
</tr>
<tr>
<td>Hallucinations and Paranoia</td>
<td>• Seeing dead relatives</td>
</tr>
<tr>
<td>Wandering</td>
<td></td>
</tr>
<tr>
<td>Pacing</td>
<td>• Walking back and forth from room to room</td>
</tr>
<tr>
<td>--------------------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td>Wanting to go home</td>
<td>• Insisting they don’t live in the place they are living. Remembering only their old home</td>
</tr>
<tr>
<td>Agitation</td>
<td></td>
</tr>
<tr>
<td>Anger</td>
<td></td>
</tr>
<tr>
<td>Other aggressive acts</td>
<td></td>
</tr>
</tbody>
</table>

**Activities for the Memory Impaired**

Activities designed for the memory impaired involve repetitive actions and using skills developed when the person was younger. The most important part of these activities is that they should give the patient a sense of accomplishment without a sense of frustration.

If the patient finds the activity to be upsetting, stop it and attempt something else. Try activities when the patient is well rested. Keep the environment as low key as possible and avoid other distractions. Praise the patient for a job well done. The job doesn’t have to be done expertly. The patient may have a shorter attention span, so the length of each activity may need to be shortened as well. Here are some general guidelines for activities appropriate for the memory-impaired patient.

**Activities for the Memory Impaired (Continued)**

<table>
<thead>
<tr>
<th>Domestic Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Dusting</td>
</tr>
<tr>
<td>• Vacuum cleaning</td>
</tr>
<tr>
<td>• Mopping the bed</td>
</tr>
<tr>
<td>• Folding laundry</td>
</tr>
<tr>
<td>• Changing bed linen</td>
</tr>
<tr>
<td>• Setting the table</td>
</tr>
<tr>
<td>• Clearing the table</td>
</tr>
<tr>
<td>• Washing fruit</td>
</tr>
<tr>
<td>• Washing salad vegetables</td>
</tr>
<tr>
<td>• Tearing lettuce leaves</td>
</tr>
<tr>
<td>• Raking leaves</td>
</tr>
<tr>
<td>• Sweeping the sidewalk</td>
</tr>
<tr>
<td>• Gardening</td>
</tr>
<tr>
<td>• Watering flowers or plants</td>
</tr>
</tbody>
</table>
### Caregiver Education Course

<table>
<thead>
<tr>
<th>Physical Activities</th>
<th>Mental Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sorting Socks</td>
<td>Watch television. Some of the most popular programs are:</td>
</tr>
<tr>
<td>Whipping cream</td>
<td>- Children’s education</td>
</tr>
<tr>
<td>Beating Eggs</td>
<td>- Animal programs</td>
</tr>
<tr>
<td>Washing dishes</td>
<td>- The Price is Right</td>
</tr>
<tr>
<td>Folding napkins</td>
<td>- Wheel of Fortune</td>
</tr>
<tr>
<td>Winding balls of yarn</td>
<td>- Comedies</td>
</tr>
<tr>
<td>Knitting</td>
<td>- Sports</td>
</tr>
<tr>
<td>Crocheting</td>
<td>- Avoid programs with violence, fighting, arguing, shouting, or hitting:</td>
</tr>
<tr>
<td>Wood working</td>
<td>- Soap operas</td>
</tr>
<tr>
<td>Sanding wood</td>
<td>- Jerry Springer</td>
</tr>
<tr>
<td>Petting the dog</td>
<td>Play games. All games provide recreation. They do not have to be played using the accepted game rules.</td>
</tr>
<tr>
<td>Playing with grandkids</td>
<td>- Go Fish</td>
</tr>
<tr>
<td>Note: Avoid babysitting!</td>
<td>- Old Main</td>
</tr>
<tr>
<td>Walking</td>
<td>- Bingo</td>
</tr>
<tr>
<td>Exercising while seated</td>
<td>- Lotto</td>
</tr>
<tr>
<td>Dancing to old music</td>
<td>- Simple board games</td>
</tr>
<tr>
<td>Pushing a grocery cart</td>
<td>- Cut pictures of objects in half.</td>
</tr>
<tr>
<td>Walking stairs</td>
<td>- Ask the person to match the two halves.</td>
</tr>
<tr>
<td>Tossing a ball</td>
<td>- Dominoes</td>
</tr>
<tr>
<td>Batting a balloon</td>
<td>- Put together simple puzzles, those with less than 100 pieces.</td>
</tr>
<tr>
<td>Catching a bean bag</td>
<td>- Sort objects into different plies. Use items like:</td>
</tr>
<tr>
<td>Bowling</td>
<td>- Buttons</td>
</tr>
<tr>
<td>Shuffleboard</td>
<td>- Coins</td>
</tr>
<tr>
<td>Basketball using a small ball and wastebasket</td>
<td>- Keys</td>
</tr>
<tr>
<td>Bathing</td>
<td>- Shoes</td>
</tr>
<tr>
<td>Shampooing hair</td>
<td>- Combining or brushing hair</td>
</tr>
<tr>
<td>Brushing teeth</td>
<td>- Shaving with an electric razor</td>
</tr>
<tr>
<td>Combining or brushing hair</td>
<td></td>
</tr>
<tr>
<td>Shaving with an electric razor</td>
<td></td>
</tr>
</tbody>
</table>

### Updated March 2011
| Ask the patient to solve some simple math problems. Write simple addition or subtraction problems on paper | Evoke Old memories and encourage discussion by looking over catalogs:  
- Clothing  
- Sporting goods  
- Camping  
- Vacation brochures | Play old music popular when the person was younger. Check with record stores for appropriate selections. Encourage the person to dance and sing. Playing soft, light music that is soothing may relax the patient. |
|---|---|---|
| Ask the patient to give the opposite word for simple things:  
- Up (down)  
- In (out)  
- High (low)  
- Black (white)  
Ask the person to tell you all the words they can think of that begin with the letter “S” or any other letter. | Reminiscence. People with moderate to severe memory loss may still be able to recount events of long ago. This enables the person not only to communicate, but helps them validate their life and contributions they have made throughout their lifetime.  
- Look over photo albums  
- View old movies  
- Run 8mm films | Keep a memory box. Fill a shoebox or carton with objects and memorabilia that the person once used. Reviewing these items periodically can stimulate discussion of attached memories. Asking the person to select and then identify items with closed eyes also stimulates memory. |

### Activities for the Severely Impaired Patient

As the disease progresses, the activities listed in the previous chart may have to be modified or made simpler. There may be times when the patient may no longer be able to participate in any of the activities. However, even the most severely demented patient should have some stimulus. Here are some activities that you can provide to help the patient maintain a connection with the world around them through sound, touch, and sight:

- Play their favorite “soft” music.
- Use a sound machine to play soft gentle sounds.
- Speak to the patient in soothing tones.
- Gently touch the patient while bathing, brushing their hair or applying skin cream.
- Give the patient a cuddly stuffed animal or baby doll to hold.
- Hang brightly colored mobiles from the ceiling above the patient’s bed.

### Managing Aggressive, Agitated Behavior

Aggression and agitation is a way that some people deal with frustration and anxiety. It is associated with not being able to accomplish something or not being able to fulfill a need. Cognitive disorders such as Alzheimer’s disease and vascular dementia are often associated with aggressive behavior. There are a number of factors that are related to and often trigger aggressive and agitated behavior in the person with dementia. The caregiver needs to determine what triggers aggressive and agitated behaviors in the individual before they can attempt to resolve the problem. If aggressive or agitated behavior is not checked, it can escalate rapidly. Be aware that a catastrophic reaction can ensue.

### Common Causes of Aggressive Behaviors
• Frustration
• Direct provocation from others
• Exposure to certain stimulants in the environment (i.e. TV violence, loud music)
• Many people talking at the same time
• Boredom
• Illness
• Lack of sleep
• Inability to understand or follow through with directions or commands
• Pain
• Overheated environment

Responding to Aggressive Behaviors

Assess
Separate the person from what seems to be an irritation. For example, turn off the TV or loud music. Close windows if there is noise from outside.

Body Language
• Approach the person in a non-threatening manner.
• Smile and be friendly to the person.
• Keep a proper distance from the person.
• Allow them plenty of space.
• Maintain eye contact.
• Try to remain at the person’s body level (sitting or standing)

Voice
A severely impaired person may not understand the actual words, but will pick up on the tone of voice quickly. Insure that the tone of voice you are communicating in cannot be construed as threatening or pressuring the person.
• Speak slowly and calmly in a normal tone of voice.
• Don’t scold or threaten.

Validate
Validate the fact that something seems to be upsetting. Tell the patient that you want to help. Assure the patient that you love them.

Redirect
• Redirect the person to an activity that they may like.
• Offer some food that the person enjoys.
• If the patient was asked to do something, but cannot carry through, drop the request and try again later. (i.e. Take a bath, change clothes, eat a meal)
• If you seem to be the source of the problem, leave the room for a period of time.

Prevent
• Try to insure the person gets adequate rest throughout the day.
• If the person is bored, they are more likely to have difficult behaviors. Try to engage the person in some form of diversional activities. (i.e. playing cards, walking, looking at magazines.)

Point to Remember
Contact your physician or nurse if the aggressive or agitated behavior does not respond to the above suggestions. Medications may be prescribed to help reduce the occurrence of these behaviors.
Class 4
Community Services for the Caregiver
We all acknowledge that “it takes a whole village to raise a child.” This class will remind us that it takes the same kind of commitment and energy to care for a loved one with Alzheimer’s disease. Reaching out to our families, friends, healthcare, legal and other community resources will help us to manage this disease process to the best of our ability.

Alzheimer’s Association
The best defense is a great offense to use a football analogy. Taking care of a loved one starts with education. Every bit that we learn about the resources that are available eliminates the stress associated with such an awesome responsibility.
The Alzheimer’s Association (www.alz.org) and its individual chapters provide a wealth of services.
Here are some services offered by the Greater Illinois Chapter.
Helpline 800-272-3900
A telephone service that offers emotional support to the caller and provides information about Alzheimer’s disease, chapter services and community resources. The Helpline operates 24/7 and is available in 140 languages. This service will connect you with the following resources.

Support Groups
A support group is a formal gathering of caregivers, family and friends of persons with dementia to discuss issues relating to Alzheimer’s disease. The purpose of the support group is to provide an opportunity for family members, friends, caregivers, and other interested individuals to meet regularly for mutual emotional support and to exchange coping skills and resources with one another. The reasons people attend support groups vary. People may attend to gain a better understanding of the disease, because they are in crisis or because they have specific caregiving struggles. They may be looking for advice on a particular subject or just want to be with people who are having similar experiences.
Meetings are held throughout the communities of our service area and are held monthly and run approximately 1 ½ hours.

Early Stage Support Groups
Early stage support groups are designed to provide an opportunity for persons with early symptoms of dementia, who are aware of their memory loss and are concerned about their illness, to meet with others who are experiencing similar problems. There are 8 sessions, 1 ½ hours each, during which the participants will exchange information, share feelings and gain support in an informal group discussion setting. There is a concurrent group offered at the same time for the caregiver of the early stage individual. These groups are time limited and offered twice a year at various locations. Prescreening is required prior to attendance. Please contact the Helpline for additional information and start dates for the groups.
Safe Return
The Safe Return program assists in the safe and timely return of individuals with Alzheimer’s disease or a related dementia who wander and become lost. Safe Return is a nationwide identification, support and registration program working at the community level. Safe Return benefits include: personalized identification products; national information/photo database; 24-hour toll free crisis line; fax alert notification system, local chapter support, wandering behavior information and training. There is a $49.00 registration fee, in addition to a $25.00 annual renewal fee.
Call the Helpline to obtain a registration brochure and tips to prevent wandering.

Education Programs
Workshops, seminars, and conferences on Alzheimer’s disease are offered year-round in the Chapter area. These programs, designed to increase knowledge of the disease, are appropriate for family and professional caregivers. Program topics include research development, caring for the Alzheimer’s individual, and coping strategies.

Publications
In order to foster a more informed public, a variety of educational materials is available for purchase through the Chapter.

Speakers Bureau
Speakers are available on a variety of topics including an overview of Alzheimer’s disease, research trends, and Chapter programs and services. Call the Helpline for speaker availability.

Advocacy
The Greater Illinois Chapter is dedicated to influencing policy on the local, state and national levels to increase Alzheimer’s research, and quality and accessibility of care in community and institutional settings.

Internet Resources for Alzheimer’s Disease

Replace with current chart at

Alzheimer’s Discussion Group
This is an e-mail group for professional and family caregivers sponsored by the Alzheimer’s Disease Research Center at Washington University in St. Louis (314-362-2882). It is open to anyone and the subscription is free. There are hundreds of subscribers worldwide, generating 30-50 messages daily. To subscribe send e-mail to majordomo@wubios.wustl.edu and in the body of the message, send the command: subscribe ALZHEIMER

Virtual Career Support (Chat Group)
Every Wednesday evening beginning at 8:00 P.M. CST, there is a live interactive chat session among family caregivers. A moderator arranges a topic for each session. This is based in London.
http://dementia.ion.ucl.ac.uk.candid/chat.htm

Updated March 2011
The Rush Alzheimer's Disease Center
Explains the clinical, educational and research activities of the Center and provides information about local community resources in the Greater Chicagoland area.
http://www.rush.edu/Med/RADC

The Alzheimer's Association
Explains the activities and resources of this national organization based in Chicago with over 200 chapters throughout the United States and a leader of Alzheimer's Disease International.
http://www.alz.org

The Alzheimer's Disease Education and Referral Center
A federally funded clearinghouse for information about resources throughout the United States.
http://www.alzheimers.com

Alzheimers.com
Written and maintained by medical writers and supported by the Bayer Corporation.
http://www.alzheimers.com

Doctor's Guide to Alzheimer's Disease Information & Resources
Although primarily for physicians, this site may be useful to others too.
http://pslggroup.com/alzheimer.htm

Alzheimer's Web
http://dsmallpc2.path.unimeb.edu.au.ad.html

Alzheimer's Disease Resource Page
A joint effort of the Alzheimer's Disease Center at Case Western Reserve University in Cleveland and the Cleveland Chapter of the Alzheimer's Association.
http://www.cwru.edu/affil/adsc/intro.html

Alzheimer's Research Forum
This site is mainly for researchers, but there are good articles and resources.
http://www.alzforum.org

University of Chicago Memory Center Caregiver Classes

Internet Resources for Related Dementias

Other Dementias
This site is a large selection of another site, Alzheimer's Outreach. It is devoted to the array of related dementias
http://home.sufia.net/user/outreach

Lewy Body Disease
Lewy Net is a comprehensive information source on Lewy Body Disease or Dementia with Lewy Bodies including abstracts of numerous scientific papers on this form of dementia.
http://www.ccc.nottingham.ac.uk/~mpzjlowe/lewy/lewyhome.html

Parkinson's Disease
National Institutes of Health based in Bethesda, Maryland.
http://www.nih.gov/ninds/healinfo/disorder/parkinso/pdhrt.htm
American Parkinson’s Disease Foundation based in New York, New York.
http://neuro-chief-e.mgh.harvard.edu/parkinsonsweb/main/pdmain.html
National Parkinson Foundation based in Miami, Florida.
http://www.parkinson.org

Pick’s Disease
The Pick’s Disease Support Group based in London, U.K.
http://dementia.ion.ucl.ac.uk/candid
e-mail:candid-dementia-request@mailbase.ac.uk
The Hoffman Family Home Page is a personal story loaded with facts and anecdotes about a woman diagnosed with Pick’s disease at age 50 who is currently cared for at home by her
husband, Bob Hoffman.
http://www.isl.net/~hoffcomp/

**Creutzfeldt-Jakob Disease**
CJD Voice is a growing advocacy group of family members and professionals founded in 1997.
http://members.aol.com/larmstr853/cjdvoice/cjdvoice.html
The Creutzfeldt-Jakob Foundation
http://www.members.aol.com/crjakob/intro.html
Mad Cow Home Page
http://www.mad-cow.org/~tom

**Primary Progressive Aphasia**
The Primary Progressive Aphasia Newsletter is based in Chicago, Il. The newsletter started in 1996 by Nancy Johnson, Ph.D., at Northwestern Alzheimer’s Disease Center.
http://www.brain.neu.edu/ppa/

**Huntington’s Disease**
The Huntington’s Disease Association is based in London, U.K.
http://www.connect.org.uk/merseyworld/glaxo/huntsfacts1.html

**Other Rare Disorders**
National Organization for Rare Disorders, Inc. is based in New Fairfield, Connecticut
http://www.nord-rdb.com/~orphan/

<table>
<thead>
<tr>
<th>PROGRAM</th>
<th>ADMINISTERED BY</th>
<th>SERVICES OFFERED</th>
<th>CRITERIA</th>
<th>REFERRAL METHOD</th>
<th>NOTES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare</td>
<td>US Dept of Health and Human Services</td>
<td>Medical care; Rx coverage, medical equipment, in-home medical treatment, hospice, short-term nursing home stays</td>
<td>must be eligible for Social Security; each service has separate criteria</td>
<td>Apply prior to retirement or age 65</td>
<td><a href="http://www.medicare.gov">www.medicare.gov</a> 1-800-Medicar(e)</td>
</tr>
<tr>
<td>Medicaid</td>
<td>IL Dept of Human Svcs</td>
<td>LINK (food stamps), medical benefits and transport, long-term nursing home placement</td>
<td>Must meet income guidelines</td>
<td>Apply at local DHS office</td>
<td>Office determined by zip code</td>
</tr>
<tr>
<td>Community Care Program (CCP)</td>
<td>IL Dept on Aging</td>
<td>Homemaker, Adult Day Services, respite, Home Delivered Meals (MOW)</td>
<td>Must be over 60yo and meet financial guidelines</td>
<td>Contact Chicago Senior Services intake unit (312) 744-4016</td>
<td>Most services are also available on a private pay basis</td>
</tr>
<tr>
<td>Circuit Breaker/ Pharmaceutical Assistance</td>
<td>IL Dept of Aging</td>
<td>Tax rebate; pharmaceutical assist</td>
<td>Must meet income guidelines</td>
<td>Complete application from Dept of Revenue</td>
<td><a href="http://www.cbrx.il.gov">www.cbrx.il.gov</a></td>
</tr>
<tr>
<td>Indigent Patient Program</td>
<td>Pharmaceutical Companies</td>
<td>Free or low-cost meds; Off-label</td>
<td>Varies according to specific company</td>
<td>Medical staff applies on patient’s behalf</td>
<td><a href="http://www.needymeds.org">www.needymeds.org</a></td>
</tr>
<tr>
<td>Department of Family and Support Service Chicago</td>
<td>Chicago Dept of Family and Support Services</td>
<td>Case management, legal services, activity, and volunteer programs. Phone reassurance</td>
<td>Must be a resident City of Chicago resident over the age of 60</td>
<td>Contact Chicago Senior Services intake unit (312) 744-4016</td>
<td>Suburban townships have similar programs</td>
</tr>
<tr>
<td>Program</td>
<td>Contact</td>
<td>Services</td>
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<tr>
<td>ADA Paratransit Program</td>
<td></td>
<td>Offers van and/or taxi services</td>
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<tr>
<td>Alzheimer’s Association</td>
<td>Contact</td>
<td>Dementia education, phone reassurance, support groups, ID pgm for persons who wander</td>
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<tr>
<td></td>
<td>local chapter</td>
<td>For persons with dementia and their families and caregivers</td>
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<td></td>
<td>(847) 933-2413</td>
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<tr>
<td>Small Accessible Repairs for Seniors (SARFS)</td>
<td></td>
<td>Housing repairs; installation of safety equipment</td>
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<td></td>
<td>Contact</td>
<td>Must be a City of Chicago resident and meet income guideline</td>
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<td></td>
<td>area Alderman's</td>
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<tr>
<td></td>
<td>office</td>
<td>Formerly known as H-RAIL Program</td>
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<tr>
<td>Rehabilitation Services</td>
<td>Contact</td>
<td>Homemaker services; services for low-vision patients; job training</td>
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<td></td>
<td>local DHS office</td>
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<td></td>
<td></td>
<td><a href="http://www.dhs.state.il.us">www.dhs.state.il.us</a></td>
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<td></td>
<td></td>
<td>Includes Brain Injury Program</td>
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<tr>
<td>Adult Protective Services</td>
<td>Contact</td>
<td>Investigates suspected abuse, neglect, and/or exploitation by caregiver or other</td>
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<tr>
<td></td>
<td>24 Hour Hotline</td>
<td>Must be over age 60</td>
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<tr>
<td></td>
<td>1-866-860-1409</td>
<td>24 Hour Hotline</td>
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<td></td>
<td></td>
<td>Can also access through 311 or 911</td>
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<tr>
<td>Guardianship</td>
<td>Contact</td>
<td>Protection and oversight of person and estate</td>
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<td></td>
<td>Guardian's</td>
<td>Assets &gt;$25,000 Must be totally incapable of managing independently</td>
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<td></td>
<td>intake office</td>
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<td></td>
<td>(312) 603-0800</td>
<td>Medical staff are mandated reporters Must file a report if pt is physically or mentally unable to do so or if assistance is requested</td>
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<td>State</td>
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<td>Guardian's Office</td>
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<td></td>
<td>(312) 793-5900</td>
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<td>Elderly in Distress</td>
<td>Contact</td>
<td>Community outreach crisis intervention</td>
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<td>Hospital</td>
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<td>(773) 271-9040</td>
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<tr>
<td>Bureau of the Blind</td>
<td>Contact</td>
<td>Mobility and safety training; resource location</td>
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<td></td>
<td>CRIS</td>
<td>Visual Impairment. Must meet income and age guidelines</td>
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<td></td>
<td>for application</td>
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<td></td>
<td>(312) 541-8400</td>
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<tr>
<td>Chicagoland Radio Information Service</td>
<td>Contact</td>
<td>Daily radio programming that includes reading of story serialization, local newspapers, many other offerings</td>
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<td>(CRIS Radio)</td>
<td>CRIS</td>
<td>Must have visual or physical impairment. Physician must certify disability</td>
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<td></td>
<td>for application</td>
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<tr>
<td></td>
<td>(312) 541-8400</td>
<td>Provides, on free loan, a radio. Program is free. monthly program guide costs $15 annually</td>
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Updated March 2011
### Talking Books
- **Description:** The Library of Congress Nat'l Library Service for the Blind and Physically Handicapped
- **Materials:** Recorded materials provided on free loan to visually and/or physically handicapped
- **Eligibility:** Must have visual or Physical impairment. Physician must certify disability.
- **Contact:** Contact the Talking Book Center at the H. Washington Library (312) 747-4001
- **Program Information:** Program provides on free loan, a tape player and free postage for tapes.

### Little Brothers, Friends of the Elderly
- **Description:** Little Brothers, Friends of the Elderly
- **Services:** Services focused on isolated seniors. Home visitors, holiday and social gatherings, summer camp
- **Eligibility:** Age 65 and older. No active family resources
- **Contact:** Contact Little Brothers intake (312) 455-1000
- **Additional Information:** All services are free www.littlebrothers.org/chicago

### Low Income Home Energy Assist Prog (LIHEAP)
- **Description:** Community and Economic Development Assn (CEDA)
- **Program:** One-time grants to assist with winter energy bills
- **Eligibility:** Determined by income levels
- **Contact:** Contact CEDA (800) 252-8643
- **Website:** www.CityofChicago.org/LIHEAP

### Supportive Living
- **Description:** IL Dept of Human Svcs/ Dept of Public Aid
- **Program:** Assisted Living with partial to full state financial support available
- **Eligibility:** Determination of Need screening by DOA. Medicaid application.
- **Contact:** Contact individual supportive living residences or Dept on Aging (312) 744-4016
- **Website:** www.sifillinois.com

### Lions Club
- **Description:** Lions of IL Foundation
- **Program:** Eye exams, eyeglasses hearing evaluation, reconditioned hearing aids
- **Eligibility:** ages 0-18 and 55+ criteria varies from club to club
- **Contact:** Contact Lions of IL Foundation for app. (800) 955-5466

### Dental Care (low income)
- **Description:** Medicaid
- **Program:** Dental exams, extractions fillings, crowns, root canals (on front teeth only) full dentures (partials are not covered)
- **Eligibility:** Medicaid Eligible
- **Contact:** Contact Denta Quest (800) 417-7140 www.dentaquest.gov.com
- **Referrals:** Referrals made by zip code

### Ramp Up Foundation
- **Description:** United Cerebral Palsy of Greater Chicago and public and private partners
- **Program:** Provide home access to those who own their own home but lack resources to purchase home ramps or do needed modifications
- **Eligibility:** Mobility and physical disability; income/assets
- **Contact:** Ramp Up Foundation (708) 444-8460 x272

### Grandparents Raising Grandchildren
- **Description:** IL Dept on Aging
- **Program:** Support groups, information, referral, training
- **Eligibility:** Grandparent raising grandchildren <18
- **Contact:** IL Dept on Aging or Chicago Senior Services Intake Unit (312) 744-4016
- **Referrals:** Referrals made by Planning Areas of IL Dept on Aging

### Emergency Food
- **Description:** Chicago Dept of Family and Supportive Services
- **Program:** Free emergency food boxes and infant formula
- **Eligibility:** Resident of Chicago
- **Contact:** Chicago Senior Services Intake Unit (312) 744-4016
gov.cityofchicago.org