Dear Friend:

When a parent or other relative develops Alzheimer’s disease or other dementia, it is a frightening time for the whole family. The Alabama legislature, through its Dementia Education & Training Act (DETA), and the staff of the DETA training program, wish to help you understand dementia-related diseases and connect you with resources in your community that can support you in caring for an Alzheimer’s or other dementia patient.

Currently in Alabama, about 52,000 individuals have Alzheimer’s disease. Ten percent of Alabamians over he age of 65 and almost one-half of people over age 85 will develop dementia. These statistics are frightening when you consider the aging of Alabama. By the year 2030, more Alabamians will be over the age of 65 than under the age of 18.

This packet of information is designed to provide you with pointers in caring for Alzheimer’s patients, as well as to acquaint you with several new services designed to help both professional and family caregivers manage Alzheimer’s and other dementia patients.

First, the state DETA program has established a toll-free information and referral number, 1-800-457-5679, which individuals can call and receive basic information about Alzheimer’s disease and other dementias, referral to local caregiving resources, and referral to local experts who can answer legal and medical questions.

Second, the DETA program, housed in Tuscaloosa within the Bureau of Geriatric Psychiatry, has developed a number of informational videotapes. One of these entitled, “Alzheimer’s Disease: A Practical Guide”, is available in every public library in the state. Other tapes, which target high school and middle school students, sitters, law enforcement personnel, and pastors, are available through local Alzheimer’s support groups and by calling the 1-800 H.E.L.P. Line.

Third, the DETA program has developed a speakers’ service, which is comprised of volunteers from throughout the state, who have received specialized training in Alzheimer’s disease and dementia.

I ask you to take advantage of this comprehensive array of services and to encourage your state and local officials to develop more resources to care for elderly Alabamians with Alzheimer’s disease or dementia.

Sincerely,

Richard E. Powers, MD
Director, Bureau of Geriatric Psychiatry/DETA
The Dementia Education and Training Act (DETA) Speakers’ Service is made available to groups and organizations throughout the State of Alabama. The purpose of this service is to increase public awareness and enhance individuals and family education regarding Alzheimer’s disease and other dementias.

Speakers available through this service represent a number of areas of professional and personal expertise. They may be family caregivers, professional caregivers, support group members, health professionals, or have a combination of these experiences.

It is through the Dementia Education & Training Act, passed by the Alabama Legislature in 1993, that this service is available to the citizens of Alabama. Civic clubs, church groups, schools, and other organizations are encouraged to review the list of topics and to contact the DETA program about scheduling a speaker.

To schedule a speaker or trainer to address your group, please contact the DETA office, Bureau of Geriatric Psychiatry, Tuscaloosa, AL at (205) 759-0820.

ALZHEIMER’S & DEMENTIA H.E.L.P LINE --1-800-457-5679

TOPICS:
• WHAT IS DEMENTIA
• ALZHEIMER’S: A PRACTICAL GUIDE
• THE FOUR A’s OF ALZHEIMER’S
• TIPS FOR THE CAREGIVER OF THE DEMENTED PATIENT
• BEHAVIORAL MANAGEMENT OF THE ALZHEIMER’S PATIENT
• RESOURCES IN ALABAMA: WHERE TO GO FOR HELP
• EPIDEMIOLOGY OF DEMENTIA
• DEMENTIA: FINANCING CARE
• LEGAL ISSUES AFFECTING THE ELDERLY WITH DEMENTIA
• DEMENTIA IS EPIDEMIC: SPREAD THE WORD (Tips for Promoting Public Information)
  • LONG-TERM CARE
Family caregivers must speak for patients who lose the ability to comprehend healthcare issues. These family caregivers have certain rights including:

1. The right to receive complete, unbiased information about every procedure proposed for their patient.


3. The right to seek a second opinion about diagnosis and treatment.

4. The right to insist that healthcare professionals obey the patients’ written advanced directives.

5. The right to assume the role as the expert on the patient’s unwritten wishes about end-of-life issues.

6. The right to respectfully disagree with the medical team.

7. The authority to have the wishes of the patient honored.
FACT SHEET ON MENTAL HEALTH IN THE ELDERLY

- More than 80% of all nursing homes patients have some form of mental impairment.
- Sixty percent (60%) of all nursing home patients have dementia.
- Most mental illness is unrecognized or untreated in the elderly.
- Alabama has a serious shortage of geriatric mental health professionals.
- Nursing home staff needs detailed training to deal with patients with mental illness.

THE THREE D’S OF MENTAL ILLNESS IN THE ELDERLY
- Depression
- Delirium
- Dementia

DEPRESSION IN THE ELDERLY

- Depression is a biological brain disorder.
- Depression is not a normal part of aging.
  - Depression is treatable.
- Seven to 12 percent of all people over the age of 65 become depressed.
  - Suicide is one of the 10 leading causes of death in the elderly.
- Thirty to 40 percent of all seriously medically ill elderly individuals suffer from depression.
  - Most depressed patients cannot make themselves well.
Seventy to 90 percent of depressed elderly patients will improve with medication and other therapy.
• Most elderly depressed patients can be treated as an outpatient.
• Many medications such as antihypertensives cause depression.
• Some depressed elderly individuals need three or four types of therapy before they improve.

DELIRIUM
• Delirium is temporary confusion or intellectual impairment from medical problems.
• Delirium is reversible and common the elderly.
• Delirium is frequently caused by prescribed drugs such as sleeping or nerve pills, and other mind-altering drugs.
• Delirium is very common in brain damaged individuals like Alzheimer or stroke patients.
• Major problems like strokes, pneumonia or major surgery can cause delirium.
• Minor problems like fecal impaction, bladder infection, and over-the-counter medications can cause delirium.
• Delirious patients often act out.
• Delirious patients often manifest psychiatric symptoms.
• Delirium is easy to treat – simply fix the medical problem or stop the drug.
  • Most delirious patients get better when appropriately treated.
• The average nursing home patient is prescribed eight medications and receives between four or five medications.
• Delirious patients frequently do not get better because the delirium is unrecognized.
• The longer a patient remains delirious, the more likely there will be serious complications.

DEMENTIA
• Dementia is the permanent, progressive loss of many intellectual capabilities.
  • There is no treatment for dementia.
• Ten percent of all people over the age of 65 will suffer from dementia.
• Forty-seven percent of all people over age 85 will suffer from dementia.
  • Fifty-two thousand Alabamians suffer from dementia.
• Forty to 60 percent of all demented persons develop psychiatric complications.
• Fifty percent of individuals with dementia will wander or become aggressive.
  • Alzheimer’s disease is the most common type of dementia.
DEFINITION OF DEMENTIA
- (De mens) Latin for “out of mind”.
- Permanent loss of multiple intellectual functions.
- Alois Alzheimer first described this disease in 1906 in a brain specimen from an autopsy.
- Alzheimer’s disease is one type of dementia, although it is often used synonymously with dementia.

EPIDEMIOLOGY OF DEMENTIA
- Approximately four million Americans are afflicted with Alzheimer’s disease. In Alabama, over 60,000 people suffer from dementia.
- Approximately 10% of individuals over age 65 years, and 47% of persons over age 85 years, have dementia. Dementia afflicts both men and women in all racial, religious, and socioeconomic groups.

TYPICAL SYMPTOMS OF DEMENTIA

**Intellectual Symptoms:**
- **Amnesia:** Loss of memory function
- **Aphasia:** Loss of ability to understand spoken or written word (receptive) and/or the inability to speak (expressive)
- **Apraxia:** Loss of the ability to perform remembered motor tasks, for example, buttoning a shirt, turning a door knob, eating, or walking.
- **Agnosia:** Loss of the ability to recognize sensory messages, e.g., what things look or feel like, or visual agnosia, e.g., the face of a close relative or the feel of car keys.

**Psychiatric Symptoms:**
- Depression – 25%
- Hallucinations (seeing things) 25%, and delusions (false beliefs) 30%
- Poor judgment, irritability, inappropriate behavior
- Major personality changes

**Behavioral Symptoms**
- Wandering, hoarding, undressing
- Resisting care, hostility
DAMAGE OUTSIDE THE BRAIN
- Only the brain is damaged by Alzheimer’s disease.
- Other organ systems are not damaged.
- Patients frequently appear quite healthy.

REVERSIBLE CAUSES OF INTELLECTUAL DEMENTIA
Five to 20% of the elderly patients who appear demented have treatable diseases such as depression, hormone imbalance, i.e., hypothyroidism, or drug-induced confusion (medication).

CAUSES OF DEMENTIA
Dementia is caused by the death of nerve cells. Once a nerve cell dies, it cannot be replaced and its function may be lost. Nerve cell death is caused by many diseases.

COMMON CAUSES OF DEMENTIA INCLUDE:
- Alzheimer’s disease – 60-70%
- Diffuse Lewy body disease – 10-20%
- Multiple small strokes – 5-10%
- Multiple other causes – 10-15%

CAUSES OF ALZHEIMER’S DISEASE
The cause of nerve cell death in Alzheimer’s disease is unknown. Inheritance plays some role:
- Five percent strongly inheritable (autosomal dominant).
- Twenty to 60% of patients may have a genetic vulnerability.
- There is no fool-proof genetic test for Alzheimer’s disease.
- Damage may result from accumulation of a toxic brain protein called amyloid.

TESTS FOR ALZHEIMER’S DISEASE
- There is no fool-proof test that predicts your risk for Alzheimer’s disease.
- Diagnosis requires a good clinical history and mental status examination.

TREATMENT FOR ALZHEIMER’S DISEASE
Prevention:
- Estrogen therapy may help women after menopause.
- Vitamin E may slow onset.
- Gingko Biloba has not been proven to be beneficial.

Current Treatment:
- Early treatment offers some hope.
• Medications slow progression in early stages, i.e., Aricept, Excelon, and others.
• Psychiatric symptoms usually respond to medication.
• No treatment stops nerve cell death in Alzheimer’s disease.

**Future Therapy:**
• Future therapy will prevent the death of nerve cells and maximize the function of surviving nerve cells.
• Vaccines may reduce damage from amyloid.
• Brain cell implants offer limited promise.

**THE COURSE OF ALZHEIMER’S DISEASE**
• Most patients survive 8-10 years, but can live much longer.
• Each patient has a different mixture of symptoms.
• Patients have long survivals because other organ systems are not damaged.

**Early Stage (2 to 5 years)**
• Mild amnesia (memory loss), good function at home, few psychiatric symptoms.

**Middle Stage (3 to 5 years)**
• Many intellectual impairments, poor function at home, many psychiatric/behavioral problems.

**Late Stage (2 to 5 years)**
• Multiple, severe intellectual impairments.
• Minimal function at home.
• Problems with walking, talking, chewing, and swallowing.
• Loss of bowel and bladder function.

**END-OF-LIFE CARE**
• Most patients die from complication like infection.
• Quality of life is more important than length of survival.
• Feeding tubes can produce discomfort and complications.
• End-stage patients do very poorly on life support machines.
• Hospice may be available to help.

**WAYS TO PROTECT YOUR BRAIN OVER AGE 65**
• Stay mentally and socially active.
• Stay physically fit.
• Control blood pressure and heart disease.
• Visit your doctor on a regular basis.
• Treat Depression.
FINANCIAL CARE
• Dementia costs Alabama over 2.7 million dollars per year.
• Fifty to 60% of all nursing home residents are demented. The annual cost of nursing home care is between $42,000 and $50,000 per year in Alabama. Most expenses are paid by patients’ families.
• Families provide 70% of the care given Alzheimer’s victims. The total cost to society in caring for the AD patient averages $47,000 per year for each patient.
• Paying for Alzheimer’s disease – including cost of diagnosis, treatment, nursing home care, informal care, and lost wages – is estimated to be more than 80 billion dollars each year in America.

MOST OFTEN CALLED TELEPHONE NUMBERS IN ALABAMA
• Alzheimer’s Association, North Alabama Chapter (Huntsville) – 256/880-1575
• Alzheimer’s Resource Center (Dothan) – 334/702-2273
• Alzheimer’s Foundation of the South (Mobile) – 334/438-9095
• Alzheimer’s of Central Alabama (Birmingham) – 205/871-7970
• Morgan County Mental Health Association – 256/353-1160
• UAB Alzheimer’s Disease Center, Memory Disorders Clinic – 1-800-333-6543
• Division of Healthcare Facilities—Elder Abuse Hotline – 1-800-356-9596
• Department of Human Resources – Adult Protective Services – 1-800-458-7214
• Coalition of Alzheimer’s and Related Disorders of NW Alabama (CARD) – (Florence) 256/757-8771
• Senior Advantage (Montgomery) – 334/286-3400
• Tuscaloosa County Mental Health Association – 205/752-2689

DEMENTIA EDUCATION & TRAINING PROGRAM MATERIALS
VIDEOTAPES: (Available in ALL Public Libraries in Alabama)
• Alzheimer’s: A Practical Guide to Community Resources
• Alzheimer’s: A Practical Guide for Pastoral Care Volume I&II
• Alzheimer’s: A Practical Guide for Sitters Volume I&II
• The DETA Brain Series. May also be purchased from the University of Alabama Center for Public Television and Radio (1-800-463-8825).
- The DETA Care Series. May be purchased from the University of Alabama Center for Public Television and Radio (1-800-463-8825).

SCHOOL PROGRAMS ON DEMENTIA
- All In Your Mind (High School videotape produced for a teenage audience with custom teacher guide).
- All In Your Mind (New Middle School videotape with custom teacher guide). Program available FREE to Alabama teachers. May be purchased from University of Alabama Center for Public Television and Radio – 1-800-463-8825.

ALZHEIMER’S PICTURE BOOKLETS FOR ALABAMA CITIZENS*
- “Alzheimer’s: A Broken Brain
- “Vascular Dementia: An Explanation of Dementia Caused by Multiple Brain Strokes”
- “Psychiatric Complications of Dementia”
- “Crossing the River of Life with Alzheimer’s Disease”
- “Parkinson’s Disease: A Disorder of Movement, Mood, and Thought”

*Booklets are free to Alabama citizens. Out-of-state individuals may purchase by sending check or purchase order and shipping information to: The University of Alabama Supply Store, Attn: Jeff Smith, Box 870291, Ferguson Center, Tuscaloosa, AL 35487. ORDER BY PHONE: (MasterCard, VISA, and Discover Card Accepted). Call 1-800-825-6802 (Ask for Jeff Smith).
ALZHEIMER'S SUPPORT GROUPS

For more information on a support group in your area, call the Dementia Education & Training Program at 1-800-4578-5679 or visit our support group listing on our website at www.alzbrain.org
ALZHEIMER'S / DEMENTIA HELPLINE

Understand Problem Behaviors, Receive Tips & Referrals on the Alzheimer’s Toll-free H.E.L.P Line 1-800-457-5679

Your questions can be answered more quickly if you can provide the following information about the patient(s):

H – How long have you noted change in behavior?
E – Examples of behavior/environmental change.
L – List of medications/diagnoses/recent lab work.
P – Physical problems – UTI, impaction, infection, pain?
TIPS FOR THE CAREGIVER OF THE DEMENTED PATIENT

APPROACHING THE PATIENT

1. APPROACH THE PATIENT SLOWLY AND CALMLY.

2. USE A FRIENDLY TONE OF VOICE AND FACIAL EXPRESSIONS.

3. MAKE EYE CONTACT WITH THE PATIENT.

4. FACE THE PATIENT WHEN YOU SPEAK TO HIM.

5. DO NOT TOUCH THE PATIENT FROM BEHIND.

6. SPEAK SLOWLY, CLEARLY AND DISTINCTLY.

Demented patients do not understand complex speech. Speaking slowly, and facing the patients will increase the chance that the patient will hear and understand you. Remember, even though patients may not understand, written or verbal communication, they do respond to the emotions of your voice and face. Do not ask the demented patient, “Do you remember me”? Tell the patient your name.
INSTRUCTING THE PATIENT

1. USE ONE-STEP COMMANDS.
   Patients with dementia cannot comprehend complex instructions.

2. USE GESTURES TO SUPPLEMENT WORDS.
   Example: Don’t say “It’s time to eat Mrs. Jones. Let’s get up and go to the dining room. Where is your walker?” This conversation is too lengthy. The demented patient cannot understand all of this. It will be frustrating to him. You might say instead, “Mrs. Jones, stand up”. After she stands, “Mrs. Jones, here is your walker” then, “Mrs. Jones, it’s time to eat”. Then begin leading her down the hall. These are one-step commands. This patient is told one thing at a time.
DRESSING THE PATIENT

1. USE ONE-STEP COMMANDS.

2. GIVE THE PATIENT A LIMITED CHOICE OF CLOTHING TO WEAR IF THE PATIENT CAN STILL CHOOSE.

   Limit the choices to two items. Too many choices confuse and frustrate the patient.

3. USE A CONSISTENT METHOD OF DRESSING THE PATIENT EVERY DAY.

   For example: Dress the patient’s upper body first, and then go to the lower body. If the patient can still dress himself, hand him the articles of clothing in the same order – only one item at a time.

4. USE GESTURES AND ENCOURAGEMENT.

   SHOW THE PATIENT WHAT TO DO.
BATHING THE PATIENT

1. TRY TO BATHE THE PATIENT AT THE SAME TIME EACH DAY.

2. USE ONE-STEP COMMANDS AND GO SLOWLY.

3. TALK TO THE PATIENT REASSURINGLY DURING THE BATH.
   Explain what you are going to do in short, simple terms.

4. IF THE PATIENT IS AFRAID OF THE SHOWER, TRY THE TUB; IF HE IS AFRAID OF THE TUB, TRY THE SHOWER.
   If the patient continues to resist bathing, look at the patient’s past. Ask the family members about the patient’s past bathing habits.

5. REMEMBER TO PROVIDE PRIVACY.
FEEDING THE PATIENT

1. MAKE SURE THE PATIENT IS IN AN UPRIGHT, COMFORTABLE POSITION AND READY TO EAT.
Make sure his/her mouth is empty, particularly if the patient is known to hoard food or cigarette butts.

2. FOR PATIENTS WHO ARE POOR EATERS, OBSERVE THE PATIENT.
Is the patient fearful at meal times? Does the patient say or think that the food is poisoned? Can the patient handle and use her own silverware? Does the patient spill food? Does the patient eat only sweets? Does the patient fill up on fluids? Consider moving food to a different location of the tray.

3. CONSIDER PAST EATING HABITS WHEN YOU CAN.
Ask family members if the patient always ate sweets first, or liked food cut up a certain way, etc.

4. GIVE THE PATIENT PREFERRED FOODS WHEN POSSIBLE.
Give the patient one food item at a time if she seems confused by too many foods on the tray. Serve the drink last if the patient drinks too much and won’t eat. Whenever possible, let the patient eat with other patients to increase socialization and make mealtime more pleasant.

5. OBSERVE THE PATIENT TO DETERMINE IF SHE HAS DIFFICULTY SWALLOWING.
REMEMBER! Patients with advanced dementia will eventually forget how to swallow.

6. IF THE PATIENT APPEARS TO THINK THE FOOD MAY BE POISONED, MEDICINE MAY HELP.
Continue to reassure the patient that the food is safe.
DEALING WITH THE WANDERING PATIENT

1. ALLOW THE WANDERER AS MUCH FREEDOM AS POSSIBLE.

2. PLACING A LARGE LINE, STRIP OF TAPE OR VELCRO ON THE DOOR OR FLOOR MAY STOP SOME PATIENTS FROM GOING PAST THAT POINT.
   A large “STOP” or “DO NOT ENTER” sign, or a mirror on the exit door may also help.

3. REMEMBER! THE PATIENT MAY BE LOOKING FOR SOMETHING OR SOMEONE.

4. TAKE THE WANDERER TO THE TOILET AT LEAST EVERY TWO (2) HOURS.
   Needing the bathroom is a major cause of wandering.

5. NO MEDICATION WILL STOP THE PATIENT FROM WANDERING.
   Medication will only sedate the patient, making them physically stiff and more likely to fall.

6. TRY TO REDIRECT THE WANDERING PATIENT BY GIVING THEM SOMETHING TO DO.
   Examples include allowing the patient to fold towels, sort laundry, work jigsaw puzzles, put pennies in a jar, etc. The patient who wants to “take care” of other patients may respond to taking care of a teddy bear, doll, etc. REMEMBER! No two patients are alike. Different things work for different patients.
DEALING WITH THE HOSTILE PATIENT

REMEMBER! There is a reason for every behavior. Try to determine the cause. Ask yourself the following questions:

1. **IS THIS NEW BEHAVIOR?**

2. **IS THE PATIENT MEDICALLY ILL?**
   Check for fever, impaction, pain, and shortness of breath. Always check the patient’s vital signs. Check the chart for past health problems.

3. **DOES THE PATIENT HAVE ANYTHING NEW IN HIS ENVIRONMENT SUCH AS A NEW CAREGIVER, NEW HOUSEKEEPER, NEW ROOM OR ROOMMATE, OR CHANGE IN ROUTINE?**
   Is there noise or work going on in the unit, e.g., workmen, etc? Consider the cause of the behavior and correct it if you can. Continue to watch and observe for the cause of the patient’s behavior.

4. **IS THE PATIENT ON A NEW MEDICATION?**
   Try not to over-react. Stay calm and reassuring. Look for signs that the patient may be responding to voices or things only the patient can see or hear. The patient may have strange, untrue beliefs, such as thinking he is at home and seeing staff members as intruders in his home. These are examples of behaviors that may be helped by medication.
DEALING WITH THE RUMMAGING PATIENT
(The patient who gets into others’ things)

1. TRY DIRECTING THE PATIENT BY GIVING HIM SOMETHING TO DO, SUCH AS OFFERING DOLLS, STUFFED ANIMALS TO HOLD, MAGAZINES OR BOOKS WITH PICTURES TO LOOK THROUGH, SIMPLE PUZZLES TO PUT TOGETHER, PAPER CUPS TO STACK, TOWLES OR LAUNDRY TO FOLD, OR PENNIES TO PUT IN A JAR.

2. GIVE THE PATIENT A DRAWER OR CLOSET WITH THINGS FOR HIM TO RUMMAGE THROUGH.

3. REMEMBER TO IGNORE BEHAVIOR THAT IS CAUSING NO HARM.
THE PATIENT’S ENVIRONMENT

1. DEMENTED PATIENTS NEED A QUIET, ORDERLY ENVIRONMENT.
They may be frightened or confused by change and loud noises such as telephones, intercoms, loud music, etc.

2. FOR SAFETY, MAINTAIN UNCLUTTERED ROOMS AND HALLWAYS.
This is very important as dementia progresses.

3. DOORS OF DIFFERENT COLORS MAY HELP THE PATIENTS IDENTIFY THE BATHROOM AND DINING ROOM.

4. AVOID HIGH GLOSS, SLICK FLOORS.
Patients tend to mistake the gloss for water. Patients may fall trying to avoid the “water”.

5. AVOID USING SCATTER RUGS, ESPECIALLY DARK COLORED RUGS.
Older patients see bright colors well. Avoid prints.
Demented patients have brains that are dying. Most of the time, they cannot help behaving the way they do!
COMMUNICATION TIPS WHEN INTERACTING WITH DEMENTIA PATIENTS

It has been noted widely that non-verbal communication, such as body language, voice tone and facial expressions relay great amounts of information to the cognitively impaired adult. As their ability to process verbal information is impaired, the way in which we use language is extremely important when working with cognitively impaired adults.

Clear communication, verbal and non-verbal alike, is the essence of any quality interaction. The following suggestions will enhance your effectiveness with your family member or patients.

1. In your interactions with the patient, try to:
   * Be calm and reassuring
   * Speak slowly and distinctly
   * Use simple words

2. Remember that the patient is dealing with:
   * Confusion
   * Anxiety
   * Loss of self-esteem
   * Irritability
   * Feeling of depression (when he is aware enough)

3. Before asking the patient to do something, address him by name to get his attention. While you are speaking, maintain eye contact to help maintain his attention. Non-verbal gestures help in communicating to the patient what you want him to do.

4. Ask only one question at a time and give the patient time to respond. If the patient does not seem to understand, repeat the question using the same wording. If this does not work, after a few minutes try to rephrase your question. (This will require that the patient process new information).

5. Approach the patient from the front. It may startle and upset him if you touch him unexpectedly or approach him from behind.

6. Allow the patient adequate time to respond in conversation or when performing an activity. Rushing the patient will increase his confusion.

7. Use humor whenever possible though not at the patient’s expense.

8. Always remember the importance of love and affection. Sometimes holding hands, touching, hugging and praise will get the patient to respond when all else failed.

9. The feelings expressed in your voice when speaking to the confused patient are as important as the words you say.

10. Try to maintain a regular daily routine. An Alzheimer patient has difficulty coping with change. A structured routine will help the patient maintain his abilities. It may also save you time and energy.
11. Involvement with his daily tasks helps to maintain the patient’s self-esteem. Also, disruption in the patient’s usual habits may result in his no longer being able to perform that activity. For example, if you begin dressing the patient, he might soon forget how to perform this function.

12. Keep your expectations of what the patient can do realistic given his degree of impairment. There will be less frustration on both your parts if expectations are realistic.

13. Break down all tasks into simple steps. Tell the patient one step at a time what to do. Giving too many directions at one time, or giving them too quickly, will increase the patient’s confusion. If the patient gets upset and becomes uncooperative, stop and try again later.

14. When the patient wakes up from a nap or a night’s sleep, he may be more disoriented than usual. Expect this and be prepared to orient him through general conversation.

15. Do not disagree with made up stories. Instead, gently correct the patient to avoid increasing his anxiety. If the patient mumbles incoherently or rambles, attempt to reduce this by directing him with an activity.

16. Be consistent. If you say that you are going to do something, follow through with it.

17. If the patient repeatedly asks a question, remember that he cannot remember the answer you have just given him. Instead of answering the question after a second or this repetition, reassure the patient that everything is fine and that you will be with him and will help him.

18. Repeating the same act may be meaningful for the patient and provide relief of tension. For example, the patient may spend 20 minutes contentedly wiping the kitchen counter. If the activity does not seem to be upsetting the patient, let him continue. If it upsets you, try to gently redirect his activity by giving him something else to do.

19. Use gestures when appropriate. Point to objects or demonstrate an action, such as brushing your teeth.

20. Do not argue over the correct answer. Relatives are often confused. He may call you his mother and mean his wife. Also remember he may be speaking his reality. If he says it is winter even though it is the middle of July, it may feel like, look like, and be what “winter” is for him.

21. If you do get angry, use “I” statements as opposed to “you” statements. Example: “I’m feeling angry, I need to rest now,” instead of “You make me so angry, I can’t stand to be here.” Accusing him of causing your bad feelings is fruitless. He can’t change his behavior for you. Also, he is frightened to see you angry at him when he feels so helpless. Talk to a friend when you need to blow off steam. Support groups are a great place for this. You will be relieved you did not yell at him after things have settled down.

22. When he is no longer able to communicate verbally, keep talking to him about those things that were important to him, such as yourself, family member, etc.
FACT SHEET ON DEMENTIA AND DRIVING

1. Most dementia patients continue driving for about two years.

2. Many demented drivers will crash (30%-47%).

3. Most demented drivers insist they are safe.

4. Dementia patients can renew driver's licenses by paying the fee at the courthouse.

5. Dementia victims and families are liable for damages caused by their driving.

6. Dementia patients should not drive without an evaluation by a knowledgeable clinician.

7. Dementia patients who cannot dress themselves should NOT drive a car.

8. Older drivers (over age 60) have more crashes than middle-aged drivers (40).
From A to Z

A. Converse with a resident.
B. Help a resident with a lacing project.
C. Initiate a group parachute game or ball toss.
D. Play a word game with 2-3 residents.
E. Initiate a discussion group on a subject that rekindles fond memories.
F. Lead a sing-a-long.
G. Talk with a resident about an old photograph.
H. Play a game of ring-toss with several residents.
I. Have a resident identify various scents.
J. Play a game of balloon volleyball.
K. Play a familiar music tape and have residents "name that tune."
L. Give a resident a hand massage.
M. Initiate a similes word game, i.e., as fresh as a ____________.
N. Play a game of adapted bingo where participants cover pictures instead of numbers.
O. Allow a cognitively impaired resident to unravel yarn.
P. Cut pictures into simple shapes and have a resident put them together.
Q. Play a bean-bag toss game.
R. Present items of different textures and have resident describe feel.
S. Read a newspaper story to alert resident with visual impairment.
T. Arrange residents in circle and have a game of kick-ball.
U. Have a group discussion on old cars, favorite dinner or movie.
V. Have a resident match colors using color cards.
W. Dance with a resident.
X. From a chair, lead residents through various stretches.
Y. Have residents pass a ball to each other while in circle.
Z. Use your own ideas - Adapt to level of resident.
FACT SHEET ON END OF LIFE ISSUES FOR DEMENTIA PATIENTS

1. Dementia is a progressive disease that kills the brain.

2. Most older patients understand fatal illnesses and want control over their care.

3. Families must prepare for terminal care while the patient is still healthy.

4. Advance directives such as living wills afford patients the opportunity to make choices.

5. Families must discuss issues in advance to avoid conflicting instructions to medical teams.

6. Doctors will use all means available to treat patients when families cannot agree on a plan of care.

7. End-stage Alzheimer patients deserve the care and comfort afforded by hospice services.

8. Most end-stage dementia patients do very poorly when placed on life support machines.

9. Dementia patients may experience pain and deserve appropriate pain medication.

10. Most Alzheimer patients will choose dignity and respect over longevity.
TIPS ON MEDICAL VISITS FOR YOUR DEMENTIA PATIENT

1. Keep a record of your patient’s physical complaints between visits (e.g., chest pains, shortness of breath, etc.)

2. Bring all their medicines -- including prescriptions and over-the-counter preparations to every doctor visit.

3. Insist on providing history and symptoms directly to the doctor.

REMEMBER: Many doctors do not realize your patient has trouble with memory and communication.

4. Insist that the doctor explain medical conditions and medications to you as well as the patient.

5. Ask the doctor about whether any new medicines may increase confusion.

6. Attend every medical appointment with your patient or send a family member to be present throughout the entire examination.

7. Doctors frequently don’t talk to each other. Inquire about communication among each physician treating your patient.

8. Tell the doctor when specific instructions like exercise, diet, smoking cessation, etc., are not realistic for your patient -- Example: bed rest for a wandering patient or expecting that a patient unable to communicate will ask for chest pain pills (nitroglycerin).
FACT SHEET ON DELIRIUM IN THE ELDERLY

1. Delirium is temporary confusion or intellectual impairment from medical problems.

2. Delirium is reversible and common in the elderly.

3. Delirium is frequently caused by medications such as sleeping and nerve pills, or over-the-counter medications (e.g., antihistamines or cold preparations).

4. Delirium is very common in brain damaged individuals like Alzheimer or stroke patients.

5. Major problems like strokes, pneumonia or major surgery can cause delirium.

6. Minor problems like fecal impaction and bladder infection can cause delirium.

7. Delirious patients can become hostile or agitated.

8. Delirious patients often develop psychiatric symptoms.

9. Delirium is easy to treat - simply fix the medical problem or stop the drug. Delirious patients get better when appropriately treated.

10. Delirious patients frequently do not get better because the delirium is unrecognized.

11. Patients who remain delirious have a higher risk for serious complications.
FACT SHEET FOR DENTIST ON DEMENTIA

• 10% of patients over the age of 65 may have dementia.

• Dementia is the loss of multiple intellectual functions including memory, (amnesia), language (aphasia), motor skills (apraxia), and recognition (agnosia). Most dementia patients hide and deny cognitive loss.

• Dementia patients will not remember symptoms or home-care instructions.

• Dental disease may cause agitation, hostility or weight loss in dementia patients.

• Dementia patients may not understand verbal directions.

• Dementia patients may forget how to use a toothbrush, properly insert dentures, or open their mouth.

• Patients may not remember you as their dentist.

• Dementia patients frequently become more confused with narcotics and benzodiazepines.

• Dementia patients are not intrinsically dangerous but do require patience and time to assure compliance.
FACT SHEET ON DEPRESSION IN THE ELDERLY

Depression is a biological brain disorder.

1. Depression is not a normal part of aging.

2. Depression is treatable.

3. Seven to 12 percent of all people over the age of 65 become depressed.

4. Suicide is one of the 10 leading causes of death in the elderly.

5. Thirty to 40 percent of all seriously medically ill elderly individuals suffer from depression.

6. Most depressed patients cannot make themselves well.

7. Seventy to 90 percent of depressed elderly patients will improve with medication and other therapy.

8. Most elderly depressed patients can be treated as an outpatient.

9. Many medications such as antihypertensives cause depression.

10. Some depressed elderly individuals need three or four types of therapy before they improve.
1. A common cause of dementia.

2. Produced by long-term heavy drinking.

3. Frequently accompanied by other neurological damage, e.g., unsteadiness, decreased sensation in legs, etc.

4. Neuropsychological evaluation is helpful.

5. Memory problems are common.

6. Dementia may stabilize with sobriety.

7. Other alcohol-related health problems worsen confusion.

8. Treatment includes good nutrition and sobriety.

9. Psychiatric problems such as personality change and hostility are common.

10. Alzheimer medications do not help.
MEDICAL CAUSES OF SKIN TEARS IN THE ELDERLY

1. NEUROMUSCULAR:
   - Frequent Falls Explained by Dementia or Motor Impairment
   - Muscular Weakness
   - Seizures

2. HEMATOLOGICAL:
   - Low Plateletts
   - Anticoagulant Therapy, e.g., coumadin
   - Frequent Drawing of Blood or IV’s

3. DIETARY:
   - Low Protein
   - Significant Weight Loss
   - Poor Skin Integrity

4. BEHAVIORAL:
   - Dementia
   - Fighting/Struggling Behavior
   - Wandering Behavior
FACT SHEET ON FRONTO-TEMPORAL DEMENTIA

1. FTD includes several diseases.
2. Personality changes precede intellectual decline.
3. Memory and language impairment is less severe than Alzheimer’s disease.
4. Apathy and personality changes are common.
5. Neuropsychological testing helps distinguish FTD from Alzheimer’s disease.
7. FTD has minimal genetic risk.
8. FTD has no known prevention or treatment.
9. Alzheimer’s drugs don’t work for FTD.
10. FTD requires an autopsy for absolute diagnosis.
FACT SHEET ON VASCULAR DEMENTIA

1. Vascular dementia is the second most common cause of intellectual loss.

2. Vascular dementia and Alzheimer’s disease have similar clinical features.

3. Many types of strokes can cause dementia.

4. Strokes in many brain locations produce dementia.

5. Severe hypertension increases the risk of dementia.

6. Poor heart function will increase the risk of intellectual loss.

7. Post-stroke depression occurs in almost half of patients and produces symptoms like dementia.

8. Many patients with strokes will also develop Alzheimer’s disease.

9. Strokes are preventable, but the dementia is not treatable.

10. Vascular dementia is avoidable by stroke prevention.
FACT SHEET ON DIFFUSE LEWY BODY DISEASE (DLBD)

1. DLBD is the second or third most common cause of dementia.


3. Most patients have visual hallucinations.

4. Confusion and hallucinations often vary on a day-to-day basis.

5. Many patients develop parkinsonism with stiffness, slowness and tremor.

6. Many patients develop depression.

7. DLBD is not inherited.

8. There is no prevention for DLBD.

9. DLBD patients are very sensitive to antipsychotic medications, e.g., Haldol.
10. Diagnosis requires brain autopsy examination.

DEMENTIA EDUCATION & TRAINING PROGRAM-1-800-457-5679

**PSYCHOSIS FACT SHEET**

1. Hallucinations and delusions are common in dementia.
2. Auditory hallucinations are when patients hear voices or sounds when none exists.
3. Visual hallucinations are when patients see animals, people or images when nothing is there.
4. Auditory or visual impairment worsens hallucinations.
5. Hallucinations are caused by brain regions misfiring and the patient cannot distinguish misconceptions from reality.
6. Delusions are fixed false beliefs with no basis in fact.
7. Many dementia patients have delusions.
8. Delusions frequently patients to accuse family or caregivers of misconduct.
9. Delusions are not a reflection of past beliefs.
10. Patients can be terrified by hallucinations and delusions.
11. Antipsychotic medications improve hallucinations and delusions.
12. Arguing or reasoning with psychotic patients doesn’t help.
13. Ignore hallucinations or delusions, distract the patient, and focus on pleasant topics.
14. Some delusions and hallucinations are quite convincing, but all come from brain malfunction.
1. FALLS ARE COMMON IN THE ELDERLY
   - About 5% of community-dwelling elders have serious falls each year.
   - 1% of elders fracture bones each year.
   - Some hip fractures occur with minimal or no trauma.
   - Many (40-60%) Alzheimer patients fall each year.
   - Fractures are more common (x3) in dementia patients.

2. PATIENT RISK FACTORS FOR FALLS
   - Advanced Age
   - Previous History of Falls
   - Psychotropic Medications
   - Confusion or Dementia
   - Recent Weight Loss

3. FALL PROTECTION PROGRAMS INCLUDE:
   - Physical Therapy Assessment and Treatment
   - Cane or Walker
   - Meri-Walker
   - Maximize Vision and Hearing

4. CONSEQUENCES OF PHYSICAL RESTRAINTS
   - Increased Agitation
   - Weight Loss
   - Increased Patient Suffering
   - Patient Injury
1. The most common reason for weight loss is due to inaccurate weighing procedures.

2. Abnormal weight loss in Alzheimer’s patients includes more than five pounds in one month, 7.5% of body weight in three months, or 15% of body weight in six months.

3. Weight loss causes skin tears, wound healing problems, falls, and agitation.

4. Weight loss from Alzheimer’s disease is slow and subtle.

5. Weight loss in early dementia is caused by depression, anxiety, or medical problems.

6. Weight loss in mid-stage dementia is caused by psychosis, depression, agitation, medical problems, and failure to correctly feed the patient.

7. Weight loss in end-stage dementia is caused by the patient forgetting how to chew and swallow.

8. Trouble with teeth, gum, and dentures can produce weight loss.

9. Patients who lose weight need evaluation by the nurse, doctor, and dietitian.

10. The first step in treating weight loss is to identify the cause of weight loss.
11. Weight loss is produced by mental problems, behavioral problems, medical problems, chewing and swallowing problems, and failure of staff to appropriately nourish the patient.
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LEGAL DEFINITIONS

CONSERVATOR: An individual appointed by the probate court to manage the financial assets, property of an incapacitated person. The responsibilities of the conservator are spelled out in the court order of appointment but there are a requirement that the conservator posts a bond and make periodic accounting settlements to the court. Preference of those who are entitled to be considered for appointment as conservator, including a relative who has resided with the incapacitated person prior to the filing of the petition, are determined by the court.

GUARDIAN: A person appointed by the probate court to make decisions concerning “the body” of an incapacitated person. The guardian is responsible for the health, personal care and maintenance of the ward. The responsibilities of the guardian are spelled out in the court order of appointment. Preference of those who are entitled to be considered for appointment as guardian, including a relative who has resided with the incapacitated person prior to the filing of the petition, are determined by the court.

GUARDIAN AD LITEM: A special guardian (attorney) appointed by the court to represent the interests of an individual declared to incompetent who is part to a suit or certain litigation. An individual will have a Guardian Ad Litem appointed to represent them in guardianship, conservatorship, commitment, etc., proceedings.

PROTECTIVE SERVICES GUARDIAN: A person 18 years of age or older whose behavior indicates that he/she is mentally incapable of adequately caring for himself and his/her interests without serious consequences to himself or others, or who, because of physical or mental impairment, is unable to protect himself from abuse, neglect or exploitation by others, and who has no guardian or relative or other appropriate person able, willing, and available to assume the kind and degree of protection and supervision required under the circumstances. (Outlined in the Adult Protective Services Act). This action is usually taken after a report to, and an investigation by the Department of Human Resources.

INCOMPETENCY: A legal term synonymous with “incapacitated.” An “incapacitated person” means any person who is impaired by reason of mental illness, mental deficiency, physical illness or disability, physical or mental infirmities accompanying advanced age, chronic use of drugs, chronic intoxication, or other cause (except minority) to the extent of lacking sufficient understanding or capacity to make or communicate responsible decisions.

LIVING WILL: Signed, dated, and witnessed document which allows the person to state in advance wishes regarding the use of life-sustaining procedures when dying. It comes into play only after the person becomes unable to make decisions concerning his/her care and is certified as being terminally ill by two (2) physicians, and death will occur whether or not such procedures or intervention is utilized.

POWER OF ATTORNEY: Signed, dated, and notarized authorization that someone gives to another person to act in his/her behalf. It may be general or limited to a specific action. The law requires ongoing mental capacity on the part of the maker for the agent’s action to be valid. This power of attorney will expire automatically upon the INCOMPETENCY, disability, incapacity or death of the maker.

DURABLE POWER OF ATTORNEY: A signed, dated and notarized authorization that someone gives another to act in his/her behalf. It may be general or limited to a specific action. This durable power of attorney remains effective even after the maker has become incompetent, disabled, or incapacitated. Most attorneys believe the act is broad enough to include the granting of a durable power of attorney for healthcare decisions and are preparing such documents. The durable power of attorney expires at the death of the maker.

WILL: A signed, dated, witnessed, and notarized document that says how a person wants his/her assets divided after death. It must be drawn up and executed while the person is legally competent. A will may be found “invalid” (not binding) if written too late in a person’s illness.
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**BOOKLETS**
- Alzheimer’s: A Broken Brain
- Alzheimer’s: Psychiatric Complications
- Alzheimer’s: Vascular Dementia
- Crossing the River of Life with Alzheimer’s
- Parkinson’s Disease

**BOUND BOOKLETS**
- A Short Practical Guide for Psychotropic Medications
- Assessment Packet for Dementia Evaluation
- Management of Serious Mental Illness in the Elderly
- Managing Behavioral Symptoms of Dementia

**HANDOUTS AVAILABLE**
- Activity Ideas (from A to Z)
- Alcohol-Induced Dementia
- Asking A Dementia Patient to Stop Driving
- Assessment and Management of Delirium
- Assessment of Agitation in the Nursing Home Patient
- Bathing and the Dementia Patient
- Comprehensive Assessment and Management of Schizophrenia in the Elderly
- Comprehensive Management of the Elderly Patient with Mania
- Comprehensive Multidisciplinary Assessment of the Demented Nursing Home Resident with Weight Loss
- Creutzfeldt-Jakob Disease
- Dementia
- Dementia and Driving

**FACT SHEETS AVAILABLE**
- Aggression Fact Sheet
- Aging and Mental Retardation Fact Sheet