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ALZHEIMER'S DISEASE TREATMENT

HOW IS ALZHEIMER'S DISEASE DIFFERENT FROM NORMAL AGING?

The symptoms of Alzheimer's disease involve more than simple lapses in memory.

People with Alzheimer's have difficulties in communicating, learning, thinking and reasoning that can affect their work, social and family life.

Alzheimer's is a disease that destroys brain cells – which is not a normal part of aging.

HOW DOES A PHYSICIAN KNOW IF IT IS ALZHEIMER'S DISEASE?

There is no single test that can diagnose Alzheimer's disease, but skilled doctors are 80 – 90% accurate. A full evaluation includes:

An accurate medical and psychiatric history

A neurological and physical exam

Lab tests to rule out anemia, vitamin deficiencies, thyroid and other conditions.

An evaluation of the person's ability to do common daily activities such as managing money and medicines.

A mental status exam to evaluate the person's thinking and memory

An interview with the family or someone who sees the person regularly

A brain scan, paper and pencil testing and additional labs as needed

HOW CAN YOU HELP THE PHYSICIAN?

Be prepared for an evaluation with a list of current prescribed medicines and doses, and a list of anything the person is taking or doing for his/her health.

Bring a list of signs, symptoms or situations that indicate a change and a decline in the person's abilities, mood, personality or behavior. For behavior changes, be ready to describe when each behavior started, the frequency of the behavior, the time of day it occurs or what seems to bring it on, and what strategies you have tried already to handle the behavior changes.

WHAT CAN BE DONE IF THE DIAGNOSIS IS ALZHEIMER'S?

Although there is no cure or no stopping Alzheimer's in its tracks, there are ways to treat some of the symptoms.

Use of cholinesterase inhibitors to treat memory symptoms. These medicines may improve quality of life, memory, thought, attention and reasoning.

These medications work most effectively for people who are mildly to moderately affected by the disease. This is why early recognition and diagnosis is so important.

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Vitamin E is an option to help with some symptoms of Alzheimer's disease.

Vitamin E is an antioxidant, and it may aid in the breakdown of free radicals that may be damaging brain cells in people with Alzheimer's disease.

Referral to appropriate activities like exercise or adult day centers.

Prompt treatment of medical or psychological conditions that may add to memory problems or symptoms of confusion.

WHAT CAN BE DONE FOR BEHAVIOR CHANGES?

At times, people with dementia may have changes in behavior such as wandering, paranoia, suspiciousness, hitting or resistance to help with personal hygiene. The doctor may suggest:

Enrollment in the Alzheimer's Association Safe Return Program, an identification program for memory impaired adults.

Modifying the person's environment to reduce confusion caused by overstimulation from noise, glare or other sources

Explaining a task with step-by-step directions

Providing a predictable routine at home, playing music during meals

or bathing, insuring regular light exercise and sleep

Providing reassurance to the confused person without challenging his/her accusations or misperceptions, just redirecting or distracting him/her.

If these strategies aren't enough, the doctor may prescribe medicines for symptoms of depression, restlessness, hallucinations, hostility and agitation.

HOW CAN THE DOCTOR HELP YOU PLAN FOR THE FUTURE?

The doctor may suggest that you start planning now for future health care decisions with an advance directive. An advance directive is a legal document that a patient signs while capable of making sound decisions. It directs how healthcare treatment will be made in the event of future incapacity. There are two types of advance directives:

Living Will states the person's desire to die a natural death and not be kept alive by artificial means.

Durable Power-of-Attorney for Health Care

designates an individual who can make health care decisions on behalf of the impaired person if he or she is not able to give medical consent.

The doctor may also suggest that the family caregiver maintain regular visits to a doctor to insure he/she is in good health.

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TALKING WITH THE DOCTOR

YOU ARE ENTITLED TO

1.

Answers to your questions

2.

Easily understood explanations

3.

Kind treatment

4.

Appropriate referrals to specialists

5.

Appropriate referrals to community
services and support

WHAT SHOULD YOU ASK THE DOCTOR?

1.

What is the diagnosis?

2.

Which tests are needed and why?

3.

What are the treatment options?

4.

Should any foods, activities or other medications be avoided while taking

medicine for memory symptoms?

5.

What is the future course of the disease?

6.

Do you have written information about the disease or treatment?

7.

Are there services available to help or support our family?

8.

Do we need to see another doctor or specialist?

9.

Can we schedule a follow-up appointment?

10. What changes should I call you about? When is the best time to call?

YOU MUST

1. Be organized, clear and concise.

Use visits

to clear up doubts, worries and misunderstandings.

2. Prioritize your top three concerns for this visit.

3. Be prepared to both ask and answer questions.

4. Explain what you think is going on and ask for both written and verbal explanations.

5. Encourage the person with dementia to ask and answer questions as well.

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WHO PAYS FOR MEDICAL CARE?

PRIVATE PAY

Patient or spouse pays based on a contract with a professional, agency or facility.

Long-term care: Most families pay out-of-pocket or savings until money and assets (minus those excluded by law) are spent. A spouse's money and assets (minus spousal protections) must be used to pay for care.

LONG TERM CARE INSURANCE

May pay a daily minimum for home or facility care for those who are eligible and able to pay premiums before need for care.

MEDICARE

Eligibility: Age 65, eligible for Social Security benefits. Adults qualified for disability for two years may be eligible before 65.

PAYS FOR DOES NOT PAY FOR

Hospital care, skilled nursing or rehabilitative care in Most home care or care in assisted living, a "participating" skilled nursing facility adult care homes or nursing facilities

Home health and hospice care Care not considered “reasonable and necessary”

*But duration of care, amount of care covered and “Custodial care” like help with bathing or eligibility have restrictions and limits. walking

Physician’s services given at home, in an office Routine check-ups and immunizations

or clinic, (some exceptions)

After required deductible & co-pay Medicare pays

for:

Medical and surgical care Prescription drugs

Certain x-rays, Diagnostic tests, Medical supplies

Covered physical and other therapies

Covered services provided by social workers,

physician assistants and nurse practitioners.

Routine dental care, vision and hearing

tests, glasses or hearing aids

MEDICARE COVERAGE FOR PEOPLE WITH DEMENTIA

Until 2002, Medicare could deny coverage of people affected by dementia for speech, occupational and

rehabilitation therapies just because of the diagnosis of Alzheimer's disease or a related disorder. A policy

change allows families to appeal unfair denials of rehabilitation services, neuro-diagnostic tests,

medication management and psychiatric treatment for people with dementia. This does not guarantee

that all ordered services will be approved as "reasonable and necessary" or that all denials will be reversed.

There are NO NEW SPECIAL MEDICARE services for people with dementia. This policy change just corrects

an unjust and illegal discrimination against people with a diagnosis of a dementia.

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MEDICAID

Eligibility is based on low income, spent down assets, but there are protections for the well spouse.

See County Department of Social Services for Eligibility.

PAYS FOR:

Some skilled home care

Personal care

Day health services

Most prescription drugs for those financially eligible for Medicaid

and qualified for skilled nursing facility care.

People who are eligible for Medicare and Medicaid can get help

paying Medicare premiums, deductibles and coinsurance.

Skilled nursing facility care after all assets, minus spousal protections,

have been spent down.

Adult care homes and assisted living in certain facilities under

special conditions.

NOTE: LONG waiting lists for non-institutional services.

PRIVATE MEDIGAP INSURANCE POLICIES

Pay some Medicare deductibles and coinsurance and may cover services not covered by Medicare.

GROUP OR RETIREE INSURANCE

May pay for more services at reduced costs through an employer or retiree organization.

VETERANS BENEFITS

Eligible if you are a veteran over 65 and you live near a VA facility.

PAYS FOR:

A wide range of doctors

Home care and facility-based care for those eligible.

NC COUNTY SPECIAL ASSISTANCE FOR AGED AND DISABLED

Eligibility through county departments of social services

PAYS FOR:

Limited home care, day care, adult care, family care and assisted living.

HOME AND COMMUNITY CARE BLOCK GRANTS

Eligible 60+ on a cost sharing basis through county Councils or

Departments of Aging

PAYS FOR:

Some respite, home and day care services

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PRESCRIPTION DRUG ASSISTANCE

MEDICAID

Eligible: Medicaid low income and spent down assets

PAYS FOR:

All prescription drugs with a small co-pay

PRESCRIPTION DRUG PROGRAMS

Contact NC Health Department for local programs

1-800-MEDICARE (800-633-4227)

TRICARE SENIOR PHARMACY PROGRAM

(800) 538-9552 (Press 1)

For retired military personnel and families

PRESCRIPTION DRUG ASSISTANCE PLAN

(800) 662-7030 (CARELINE) or www.dhhs.state.nc.us/prescriptionplan.htm

Eligible: 65+ \$17,180 individual and \$23,220 couple income and no prescription insurance.

PAYS FOR:

60% of drugs for specific conditions (up to \$1000 each year.)

ARICEPT (Free) 800-226-2072 or Pfizer Share Card (800) 717-6005

low income 65+ \$15.00 for 30 day supply

Eligible: patient lives at home, couple income under \$40,000 and no prescription insurance

* MD's office must request and receive medication with patient's last tax return as proof of eligibility

EXELON (Free) 800-277-2254 or Novartis Care Card (866-974-2273)

25% discount

Eligible: Family financially responsible and no prescription insurance.

* MD's office must request and receive medications with proof of need.

REMINYL (Free) 866-736-4695

Eligible: Family is financially responsible and no prescription insurance.

* Caregiver may apply with MD authorization and take card to any pharmacy. Must be renewed every 5 months.

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TALKING WITH PEOPLE WITH MEMORY DISORDERS

Strategies for Communicating with Your Relative

Speak slowly, simply, and concisely, always being mindful of the tone of your

voice. Use concrete, familiar words. Do not use baby talk.

Give one direction or ask one question at a time. "Are you finished?" or "Here is the toilet."

Don't offer too many choices that may make it hard for the person to make a decision. Say: "Mary, would you like to wear the red dress or the green dress?"

Don't avoid talking with the person who is having difficulty. Supply him with the right word or names and other information if you think you know what he is trying to say.

Avoid instructions the person may take literally such as "run down the hall," or "hop into bed." Use direct statements to initiate action or an activity, i.e. "It is time for supper. Let's go to the dining room."

Don't assume the person did not hear you if there is no response. It may take a

while to process what you said and then form an answer.

Watch for signs of restlessness and withdrawal indicating the person does not

wish to communicate. Respect her wishes and try later.

Non-Verbal Communication: When Words Fail

When language becomes more difficult for the person with memory loss, you can help him or her with simple techniques that offer reassurance and encouragement. A smile, eye contact, and attentive listening help support and prompt the individual's efforts to communicate.

Begin by eliminating distractions such as noise from a radio or TV that make it

harder for the person to concentrate on what you are saying.

Let the person see you on his level. If he is sitting, sit facing him. Use touch to get the person's attention. Holding hands or gently touching the individual's arm or shoulder may elicit trust and cooperation. However, be sensitive and respectful of the person who doesn't like to be touched.

Learn to "read" the individual's behavior. The person with Alzheimer's disease may have a flat mood. He may show little expression or emotion. He may also misinterpret situations or the intent of others. Extreme or quick gestures may be seen as threatening. Move slowly and calmly.

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FROM THE PERSPECTIVE OF PERSONS WITH MEMORY LOSS

How To Have A Good Conversation

Talking to an individual with memory loss represents a special challenge. He may have trouble organizing words into thoughts or lose his train of thought in the middle of a sentence; he may substitute or make up words that are incorrect; he may repeat favorite words or tactless curses; and he may misunderstand what you are trying to tell him. Yet, the person with memory loss can and wants to be involved in communicating with those around him. He asks that you be mindful of his difficulty and to remember things from his perspective.

Always treat the person with dignity and respect. He is an adult with adult feelings, still capable of embarrassment, humiliation, and of discerning when others are being condescending, impatient, or not interested in what he or she has to say. He is often aware of his difficulty in communicating. Patience becomes a virtue—patience to listen and the willingness to repeat your answers to his questions. Remember, it is the disease and not the person creating this new and difficult challenge.

“Don’t lose patience if I ask something more than once. It is simply my way of letting you know that I don’t remember what you said the first time.”

“Have a sense of humor. It will help me lighten up about things I may have trouble with.”

“I am not less of a person because I have Alzheimer’s. Don’t feel sorry for me.”

“I am what I am and that’s all that I am. I think of myself as normal.”

“Please don’t ignore me as though I don’t exist. I am a human being. I am not invisible.”

“I think I have to feel like I’m useful.”

“Let me do what I can. Give me a try.”

“Consideration! Be considerate of me and of my feelings. I still have feelings.”

“Just because I have Alzheimer’s does not mean that I should not have a voice in what affects me. Don’t shut me out of decisions that I can still help to make.”

“I still enjoy hearing what goes on in the family. Don’t be afraid to report to me all the happy details. I can also sense when something’s wrong and feel worse when you hide things from me. Don’t be afraid if I cry or become upset. It is better than not knowing.”

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THE TEN ABSOLUTES

Talking To People With Memory Disorders

Never ARGUE, instead AGREE

Never REASON, instead DIVERT

Never SHAME, instead DISTRACT

Never LECTURE, instead REASSURE

Never say REMEMBER, instead REMINISCE

Never say I TOLD YOU, instead REPEAT

Never say YOU CAN'T, instead say DO WHAT YOU CAN

Never COMMAND, or DEMAND, instead ASK or MODEL

Never CONDESCEND, instead ENCOURAGE and PRAISE

Never FORCE, instead REINFORCE

Jo Huey, from the book "Caring for People with Alzheimer's Disease: A Manual for Facility Staff" by Lisa Gwyther, 2001.

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WHAT IS AGITATION?

Irritability, frustration, excessive or uncharacteristic anger

Restlessness, constant pacing, searching or rummaging through drawers

Blow-ups out of proportion to the cause

Constant demands for attention and reassurance

Repetitive questions, requests or telephone calls

Stubborn refusals to go somewhere or do something expected

Insistence on going home immediately after leaving home

Yelling, screaming, cursing, threats

Hitting, kicking, biting, spitting

AGITATION | Helpful Talk

May I help you?

Do you have time to help me?

You are safe here. I'll check the locks for you.

Everything is taken care of. It's all squared away.

I will get right on it.

You can count on me.

I apologize. (Even if you didn't do it)

I am sorry you are upset.

I know this is hard.

I will stay until you feel better.

We're in this together.

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BEHAVIOR BASICS

1. Behavior changes are responses to a confusing world.

These changes

are often beyond the person's control.

2. People with dementia may not know why they are angry, frustrated or suspicious. Don't take it personally.

3. The caregiver is a symbol of security and safety in a shrinking and "scary" world. People with dementia want a family member close by.

They are easily upset by a tense, angry or rushed caregiver.

4. People with dementia are trying as hard as they can.

Reasoning,

pleading or punishing won't change unwanted behavior.

5. Most disruptive behaviors occur because the person is afraid, overwhelmed, forgets what is appropriate public behavior, loses control of impulses or is uncomfortable and unable to express pain, confusion or needs.

6. Brain damage makes it more difficult to plan, start or switch activities.

Tailor activities to fit the person's capacities and energy level and help start the activity. People with dementia will try to avoid embarrassment by refusing to do things they perceive as too difficult or too childish.

7. Use humor, flexibility, acceptance, reassurance and tolerance for best results.

BEHAVIOR | Problem Solving

1. Pick your battles.

Which behavioral symptoms are most disruptive to family life at this point?

2. Describe the behavior.

Is it harmful to anyone? Can you accept it, change expectations or increase tolerance for it?

3. Is there any pattern, trigger or time of day that sets it off? (Caffeine, alcohol)

4. Does your reaction make it worse? Can you just repeat what is asked?

5. Can you change your response to calm or reassure?

(Apologize, sympathize or suggest a walk to a person who is restless or searching)

6. Is the person hungry, tired, scared, overwhelmed, or in pain?

7. Will a change in the environment help? (Turn off TV)

8. Will distraction (ice cream), diversion (ride in the car) or reassurance with calm, relaxed approach, eye contact, gentle touch or soothing music, familiar pleasant activities or security objects help?

9. Is the person cold, over-sedated, hungry, constipated, searching for the toilet, depressed or frustrated by uncomfortable clothing? Try comfort measures.

10. Can routines be adapted to prevent future occurrences?

(Frequent breaks, change time of bath)

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PERSONAL CARE TIPS

Step-By Step Basics of Daily Care

The individual may vary from day to day in what she can do. Planning ahead, remaining flexible, and providing a predictable routine will help with personal care tasks that can be frustrating for her and for the caregiver. Many tasks, however, can be made easier and in some cases, enjoyable.

BATHING

Respect lifelong routines, habits, and preferences in taking a bath. Does the person prefer a bath or shower, in the morning or before going to bed? “Gather everything you will need ahead of time: towels, bath mat, washcloth, soap, shampoo, comb, lotion, and powder. Make sure the room is warm and comfortable.” Be sure the water is at a safe and comfortable temperature. A hand help shower and a shower bench may provide a safety edge for many persons. Recognize that bathing two or three times a week is enough unless the person is incontinent.

If privacy is an issue, drape a towel over your relative’s lap or shoulders and use a washcloth to clean under the towel. If she seems frightened, distract her by talking, singing or asking her to hold things.

It is often necessary to be directive at bath time using such phrases as, “Your bath is ready” instead of asking “Are you ready to take a bath?” Give step-by-step

instruction:

1. "It's time to brush your teeth."
2. "Come with me."
3. "We're going to the bathroom."
4. "I will help you."
5. "Here is the toothpaste."
6. "Take the top off."
7. "Squeeze the toothpaste on the brush."
8. "You're doing great!"
9. Start the motion for him/her by guiding his/her hand.

Pay attention to oral hygiene. Daily attention prevents sore gums and infection. If you find the task unpleasant, using disposal plastic gloves may help. Healthy gums are critical for nutrition.

DRESSING

Evaluate the kinds of clothing used as skills decrease. For example, if a woman is having difficulty putting on a bra and the family does not object, don't bother with it. Also, women may find pantyhose or garter belts frustrating. Socks are a good substitute, especially if she paces a lot, increasing the chance of blisters. Clothing that fastens in the back may keep the person from disrobing in public.

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Men who have trouble with zippers may do well with elastic waist pull-on pants.

Consider jogging suits, slacks with elastic waistbands, shirts that pull over the head or snap up the front. Shoes that slip on or fasten on with Velcro may be easier. Tube socks are excellent because the person doesn't have to find the heel.

Limit choices. Some persons continue to dress themselves if you hand them one article at a time. For some, it is helpful to lay out the clothing in the order that they are to be put on, with underwear on top...

Give the person a clue if it is necessary, "Here is your shirt." Or help by demonstrating or guiding the person, i.e. putting an arm into the sleeve of the shirt. Allow plenty of time for this activity and let the person do as much as he or she can. Respect privacy to the degree possible.

Compliment the person when he is done. You may need to change your standards in allowing the person some freedom while supporting her self-esteem. If your mother is happy wearing an orange blouse with pink pants, let her. In the words of one caregiver, "I finally had to ask myself, 'What difference does it make?'"

If the person insists on wearing the same clothes or seems attached to a particular article, try to have multiples; this solves the problem on washday when he or she refuses to give up

the favorite piece of clothing.

Select a short, easy-to-care hair style. If the person cannot shave himself, ask the barber for tips, including the best shaving tool. Many grooming tasks may be pleasurable and can be considered activities. Women in particular may enjoy make up, manicures, or having their hair done.

TOILETING

Sometimes the person with Alzheimer's will be unable to find the bathroom, unable to position her body to sit, unable to undress to use the toilet or will void in his clothes or other inappropriate places (like waste baskets or outdoors).

Clearly label bathrooms to make them easy to locate even if the person has lived in the same house for many years.

Watch for cues—fidgeting with clothing, pacing, agitation which may indicate the need to use the bathroom.

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EATING & NUTRITION

Serve meals at a consistent time. A calm, comforting atmosphere encourages concentration on the task at hand.

If the person refuses to eat, too many choices on his plate may be the problem. He may not know how to begin the process. Model the eating process for him. Once the process begins, he may continue on his own. Allow him enough time to finish his meal.

If the person eats all the time (or under eats) prepare nutritious finger foods that he can eat throughout the day. Fresh fruits and vegetables are good choices.

Sore gums, poorly fitted dentures, or the food's lack of visual appeal or familiar smell can contribute to the refusal to eat. Correct any of these problems.

Use color and textures as visual clues. Choose dishes, for example, that contrast sharply with placemats or tablecloth.

Remove inedible materials, condiments, and hazardous items when the person loses discretion about use or appropriateness.

Give back some limited control—“Would you like to eat breakfast first or take your bath first? Don’t rush or criticize how well the person does the task.

SLEEPING PATTERNS

Persons with Alzheimer’s disease often appear to sleep less or more. Sleep problems may be caused by pain, medication, lack of exercise, or too much daytime napping.

Have the person evaluated for physical problems which may cause pain or discomfort.

Provide a night light for the person who is afraid of the dark. Fear, hallucinations and confusion may be worse with darkness. Sitting with the person for a while may help.

Is the room too warm? Are the sheets free of wrinkles? Her bed clothes comfortable?

Try white noise which can be soothing—the hum of a fan, soft music.

When the person is restless , try a back rub, brushing his hair, talking softly.

Hunger may be keeping the person awake. Provide a snack but no food or drink with caffeine.

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SAFETY IN THE HOME

Safety in the Home is important to the individual's well being: The person with increased confusion and disorientation because of memory loss is at a greater risk for falls and other injuries during daily personal care tasks.

Have the person checked for hearing and vision. Ask the doctor about medicines that may put the person at risk for falling or other injuries. Monitor the usefulness of the medication.

Take charge when the person can no longer manage his medications safely.

Keep all medications (prescriptions and over the counter) locked. Each should be clearly labeled as to dosage, frequency and expiration date.

Keep all alcohol secured in a locked cabinet. Alcohol can increase confusion and present greater dangers if the person is on certain medications.

2. Insufficient lighting on stairways or hallways,
water that is more than 120 degrees hot,

KNOW THE DANGER AREAS IN THE HOME

3. Missing labels on drawers, closets and other storage areas
that help the person locate needed items,

4. Telephone numbers including emergency numbers when the person is left alone,
5. Urgent health information that is not readily visible to first respondents when the individual is incapacitated,
6. Electrical appliances and tools that the person cannot operate safely.
7. Many persons walk around in their home in socks.

This is a major hazard for falls, particularly on smooth surfaced floors. Provide shoes or slippers that have non-slip soles or slipper socks that can be worn to bed if the individual is in the habit of wearing socks to bed. Getting up from the bed or chair presents its own danger. Encourage the person to get up slowly. Clutter in general creates danger as it adds to the person's confusion.

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HOW TO MAKE TOUGH CARE DECISIONS

“She says she is “fine” and doesn’t need any help, but she doesn’t understand or remember all we do for her. She says “we don’t need to bring strangers into our home—we have daughters.” But how long can I spend 5 hours each day at her house?”

Should I make her see a doctor?

Should I start looking for home care or day programs?

Should I stop her driving or take over the checkbook?

Is it time to consider another living arrangement?

How do you make tough decisions when money is short, there are few affordable quality service choices, no time to look and she “doesn’t want or need help”?

Ask: Is it my decision to make?

If she is able or if she has a husband, you may feel responsible without the power to decide. Consider labeling it “your” need for help or reassurance rather than “her inability to do it herself.”

Dare to think the unthinkable

What would happen if your health takes a tumble?

Change would be forced on you, and you would decide in a crisis. Look now while you still have control.

Listen to those who care about you

If they think you need help, take them seriously. Move

from “if” I need help to “how do I start?”

Decide when to start

If you can't imagine keeping up this pace for 6 more

months, start looking now.

Choose one issue

Choose one need that, if met, will leverage other benefits.

Don't be paralyzed by the magnitude of the task.

Experiment

You don't know whether a care option will work until you try it. Experiment until you find a good fit. Offer your mother a few beauty shop visit coupons for a "Mother's Day" gift, rather than "because her hair is dirty."

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Take one trial at a time

Ask your dad to go with you for a visit to the day center rather than asking him to buy into a program.

Call in the allies

If your relative resists, ask for help from someone she respects. Don't focus on her dependency, limits or needs but on the benefits to her.

Make a friend of crisis

You may have to wait for a crisis, but prepare for the inevitable by considering a "Plan B". Check out services now.

Talk with a professional

Call the Alzheimer's Association (800) 272-3900 or talk to a care manager who can help you clarify your thinking.

Remember

Care decisions involve choices among imperfect options. Just do your best for your relative and yourself, and you

will have acted responsibly

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FAMILY DECISION-MAKING

Do We Really Need A Meeting?

A family meeting is chance for everyone, including the person with a memory disorder, to express concerns and acknowledge different perceptions. Although face-to-face meetings are preferable, don't delay if everyone can set aside time for a conference call or even an email chat. Be inclusive of all concerned, including non-local family members, children and teens who may be affected by decisions about elder care.

Pick a place everyone is most comfortable. It could be the elder's home, a restaurant, or a hospital waiting room if it is an emergency.

If the family is stuck in a disagreement, consider an outside facilitator, professional or expert.

Clarify purpose and priorities: housing, medical care, safety, driving?

Before the meeting, gather information on these areas from the Alzheimer's Association.

Establish that "best care for Mom" is the focus, not long-standing family feuds.

Brainstorm, allowing each family member an opportunity to be heard and submit an idea without criticism.

Develop an action plan – what will be done first, second and third and ask for volunteers before divvying up responsibilities.

Agree to follow-up by phone or email and acknowledge all contributions and good intentions.

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PERSONAL DOCUMENTS

The Basics

When a family member has Alzheimer's, a family caregiver must know how to find important personal documents in an emergency.

1. Check the document list below
2. Have missing items created or replaced.
3. Review, update or change all existing documents as needed.
4. Safeguard the documents—

Make sure you have entry approved and know where the key to a safe deposit box is kept. Make copies of all documents to keep at home in case the bank is closed.

DOCUMENTS

Personal

Birth certificate, social security card, passport, marriage certificate, divorce, naturalization, military or guardianship papers.

Health

Health Care Power-of-Attorney—contact information for agent and alternate; Medicare (Medicaid) cards, Physician’s contact information, current prescriptions, Living Will—where it is filed with addresses and phone numbers.

Legal

Durable Financial Power-of-Attorney, joint ownership deeds, will, cemetery, burial or funeral instructions.

Financial, Credit & Tax Returns

Tax returns, loan records.

Assets

Pensions, IRAs, Certificates of Deposit, bonds, stock certificates, annuities, brokerage accounts, titles or deeds.

Insurance

Policy numbers and phone numbers for life, health/disability, house, car, Medicare supplement, long-term care, funeral or burial insurance.

Household Items

Keep a list of and photos of valuables in a safe deposit box.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

CAN A PERSON WITH ALZHEIMER'S LIVE ALONE??

The following questions may guide decisions about the safety of someone with a memory disorder living alone. It's best to observe the person doing these things rather than rely only on the person's report. Use only the questions that apply to your situation – for example, safe use of power tools may not be an issue for a woman living alone. Some of these questions apply to persons who are left alone during the day. If there are many “yes” answers, the person may need more supervision, support or a change in living situation.

SAFETY CONCERNS | Does The Person:

Have driving accidents, even minor ones?

Get lost driving or walking?

Burn pots or forget to turn off burners or oven?

Forget to extinguish cigarettes?

Let strangers into the house?

Lock him/herself out often?

Forget to secure the house at night?

Have mood swings and suspicious behaviors?

Leave the house and get lost?

Know there are firearms or dangerous tools in the house and how to use them safely?

Know how to operate the thermostat and judge temperature appropriately?

Know what to do in case of emergency?

Have a recent history of being a victim of fraud, telemarketers or a crime?

Risk injury from falls, vision or balance problems?

PERSONAL CARE/OTHER | Is The Person Able To:

Eat well-balanced meals and drink enough fluids?

Dress appropriately for the weather?

Bathe and use the toilet when needed?

Keep up with housekeeping and home repair?

Pay bills on time, handle the checkbook, credit cards?

Shop for, store and cook food correctly?

Use the phone or answering machine?

Take medicine on time and in the right amount?

Know current address and phone number?

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

FRAUD PROTECTION

For Elders Living Or Staying Alone

Remove his/her name from telemarketers' lists and junk mailings.

Set up a P.O. box for mail delivery and screen mail.

Arrange with the bank to allow access only to predetermined amounts of money. Ask the bank to call you if a request for a large withdrawal is made.

Limit credit card access

Look for unusual activity in bank accounts, bounced checks, "maxed out" credit.

Look for checks or documents with signatures that appear forged.

Screen phone calls

Be sure the person's social security number does not appear on checks.

Check the person's credit report yearly

Look for unpaid or overpaid bills

Be aware if someone isolates the person or talks excessively about finances

Notice if a new acquaintance expresses inordinate affection and loyalty.

Look for changes in a will, deed or Power-of-Attorney if the person is not able to comprehend such changes.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

SHOULD MOM MOVE IN WITH US?

Moving Mom in with your family is an instinctive and generous response to her vulnerability, but it is not always the best option when she has a memory disorder that will get worse over time. A move is a serious commitment. Recognize that moves or changes are especially difficult adjustments for people who are confused or unable to learn as easily. Good intentions do not always guarantee good results.

Ask Yourself?

How well do you get along now? How well did you get along in the past? Past problems and irritations can become pronounced when living together again.

What do your spouse, children, brothers or sisters say about your plan? Will there be resentment from all sides?

Is your home large enough for privacy and adaptable to your parent's changing needs?

Are your lifestyles (television and temperature controls) and dietary habits compatible?

Can your parent stay alone or with a paid companion comfortably and safely when you are out or on vacation?

If You Share Your Home

You have limits. You will never be able to care for a parent exactly as s/he cared for you as a child.

Be flexible within a predictable routine. Don't rush.

Share household tasks with your parent by modifying tasks to fit abilities.

Protect everyone's privacy and personal space.

Choose your battles – everyone will have to compromise

Give it time. It's a huge adjustment for all. Be patient but determined.

Know when to quit. Another move will be smoother BEFORE resentment "runneth over".

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

FRETTING FROM AFAR

When Mom Is In Florida And You Are In Durham

If you are caring for someone who lives far away, you are not alone. These suggestions, from other long-distance caregivers, can help you to manage stress and to stay involved.

Assess the situation, identify what needs are being met, and hold a family meeting.

Visit your relative to evaluate health and safety needs (clothes, food, hygiene), daily personal care, transportation, support, and financial needs.

Meet with the primary caregiver, doctor, social worker, attorney, or other service providers while you are visiting.

Establish a relationship with others caring for your relative.

Call a family meeting to address concerns, prioritize needs and assign tasks.

Learn about local services. Services include volunteer helpers.

Get in touch with neighbors, community organizations and churches/synagogues.

Subscribe to the newspaper near your relative to identify new community resources.

Find a local contact to monitor the existing situation.

With assistance from your relative (if possible), select a trustworthy individual to be your “eyes” when you are not there.

Address important legal and financial concerns.

Know the location and contact information for your relative’s documents.

Consult with an attorney regarding durable power-of-attorney for health care and property, living will, and insurance coverage

The Family Medical Leave Act (FMLA) entitles eligible employees to take up to twelve weeks of unpaid leave. Find out if you would be eligible.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

Prepare for crisis situations. Crises can occur suddenly, so be prepared to respond.

Install an emergency response system.

Register your relative for SAFE RETURN through the Alzheimer's Association.

Budget time and money for emergency care and urgent visits

Support the primary caregiver. He or she is the key to your relative's well-being.

Call often, listen supportively, and ask about the person's condition and progress.

Offer to help with bills, phone calls, or respite care.

Respect your relative and stay in touch.

Do not underestimate your relative's capabilities.

If phone conversations are difficult, just send cards and photos often.

Be kind to yourself. You can only do your best, given the present constraints.

Find peers in a support group.

Help defeat Alzheimer's.

Become an advocate for the Alzheimer's Association.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

FINDING THE HELP YOU NEED IN YOUR COMMUNITY

All services may not be available in your community. Begin your search before you think you may need the service.

HOME CARE

Home care may include a variety of care tasks depending upon the qualifications and abilities of the service or individual. Visiting nurses, home health aides, homemakers, private persons and volunteers can provide services at home such as bathing, dressing or companionship while the family is away.

Example: Mrs. G. has used a variety of home care services to support her care of Mr. G through the progression of his illness. Visiting nurses taught her how to lift him as he became bedfast. A volunteer continues to provide a few hours of male companionship to Mr. G each week. She hired a neighbor's daughter to do the heavy cleaning every two weeks.

RESPITE CARE

Refers to a short time of rest or relief. It allows caregivers a break from the day-to-day duties and provides the person with Alzheimer's opportunities to interact with others. Respite can be provided in the home, at an Adult Day Center, in a group respite program or in an assisted living or nursing facility as vacancy allows.

Example: With help from a trained respite worker, Mr. K was able to go back to golf on Friday afternoons. He knew his wife enjoyed doing household tasks with her new “friend,” and that he would feel rested and refreshed when he got home.

ADULT DAY SERVICES

Adult day centers or group respite programs can give the person with Alzheimer’s an opportunity to socialize with others, exercise and engage in meaningful activities. Hours of service may range from a few hours a day to a full-day program.

Example: Mrs. J found the adult day program in her town to be a lifesaver. Her husband enjoyed his day with “those guys” and she was able to keep working full-time.

MEDICAL SERVICES

“Families report they are most satisfied with a specialist who is well-informed about Alzheimer’s disease. This may be a neurologist, geriatrician, psychiatrist or a family doctor who is experienced in treating people with the disease.”

Example: Ms. M reports: “Mother’s doctor has known her for years and insists there’s nothing wrong with her. We know better but she trusts Doc Nielsen”. Ms. M was able to get a consultation for her mother at a Geriatric Clinic and keep her mother’s trusted relationship with Dr. Nielsen.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

MOBILE MEALS

These programs deliver a hot noon meal to the home Monday – Friday. Costs vary widely, and there is usually some subsidy available. For the program nearest your family member, contact the county I & A Specialist.

Example: Mr. B is legally blind. Mrs. B's Alzheimer's disease has gradually erased her memory of how to cook. Mr. B finds that home delivered meals allow him and his wife to remain safely in their home together.

VISITATION PROGRAMS

Volunteers visit on a regular basis to shop, or visit with an isolated elder or couple. These programs are available from churches or voluntary community groups. Start with your church, an interfaith coalition, or your county aging specialist.

Example: Mrs. S is so isolated in caring for her sister with Alzheimer's disease. Few of their friends come by. Now, her church has found a young volunteer who comes weekly to visit. Both Mrs. S and her sister enjoy the young visitor and look forward to their time together.

TELEPHONE REASSURANCE

This program provides volunteers who make or receive a daily phone call from an older person living alone. Contact the county aging information specialist.

Example: Mrs. O lives alone and would like to continue to do so. Her son is concerned, but lives at a distance. The local telephone reassurance program calls her daily and her son registered her with the hospital's Lifeline program.

TRANSPORTATION SERVICES

These programs assist older people in need of medical transport (doctor's visit) and often provide rides for shopping, group meals, or recreation. Call the county aging department.

Example: Mr. N is not able to drive, but thanks to E-Z Rider, he never misses a doctor's appointment or lunch with his friends at the Senior Center.

CAREGIVER SUPPORT GROUPS

These groups are available throughout urban and rural areas. They provide information and support. For referral to a local support group, call the nearest chapter of the Alzheimer's Association at their national headquarters at 1-800-272-3900 or your county aging program.

Example: Mr. W credits the local support group with his becoming more patient with his wife. He was convinced that she just wasn't trying hard enough when she seemed so helpless. He learned good coping strategies for himself as well as good tips on how to take care of her.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

SENIOR CENTERS & CONGREGATE MEALS

Senior Centers offer a variety of social, health, nutritional, educational and recreational services. A hot meal is served at noon and activities such as movies, crafts or guest speakers provide entertainment. Centers are usually open for several hours each day and meals are provided with donations based on the person's ability to pay. No one is turned away. Some centers provide free health checks and some offer transportation.

Example: Mrs. W was still a very outgoing person, even though her memory had failed. She looked forward to going to the Senior Center for lunch with friends once a week.

CHORE PROGRAM

This county social services program provides help in the home with laundry, housekeeping, cooking or shopping. Unfortunately, there are long waiting lists and strict financial eligibility.

Example: Mrs. G was in pain from her arthritis and spent most of her time caring for her husband with memory loss at home. Always a good housekeeper, she really appreciated the few hours on Thursday when the chore worker would come to help her with cleaning and laundry.

HOME HEALTH CARE

Home Health Care provides nursing services for maintaining or improving a person's health at home. Services may include skilled nursing care, help with bathing, physical therapy and speech therapy. The costs vary dramatically, depending on the service provided. It is best to call and compare public and private agencies. If the service is prescribed by a physician following a hospitalization, and is a "skilled" service, Medicare may cover the cost on a short-term basis. Some home health agencies are certified for Medicare and/or Medicaid and some are not. Some agencies will also accept private or work-related insurance. For this reason, it is very important to ask the agency about rates and whether they take third party payment.

Sources of Help

Try the local Health Department (for skilled care prescribed by M.D.). For a listing of home health agencies, call the county aging information specialist.

Example: Mr. K needed good, dependable care for his wife on an inconsistent basis. He found he could call the Home Health Agency in his community and schedule a private duty aide when he needed it on short notice. While he was out of town, he felt secure in the expert care with nursing supervision.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

Medicaid CAP-DA Program

This Medicaid “waiver” program is for Medicaid eligible adults who need intermediate or skilled nursing home care—but prefer to stay at home. There are long waiting lists. Call the county Department of Social Services for more information.

Example: Mrs. S wanted to help her aunt stay home with her as long as possible, but they could not afford to hire help. Her aunt had mild memory problems and severe lung disease. The CAP Program provided a home care aide 20 hours a week.

Adult Care Homes, Assisted Living, Board and Care, Domiciliary, Family Care or Rest Homes

These homes go by a variety of names and can vary in the amount of care provided. They generally provide care for persons needing assistance in meeting day-to-day needs. They offer room and board, personal assistance, supervision of medications and social activities. Family Care Homes are for six or fewer residents. Most of these homes are private pay, and quality and cost vary widely.

Example: Mrs. P’s relatives all lived at a distance and she had no children. When Mrs. P moved to a Family Care Home, she “perked up” around the other women. The family was relieved that she no longer had to cook or risk living alone.

Intermediate Care Level Nursing Home

This care level is for those who do not need skilled care, but usually do need some nursing assistance and supervision. Individual treatment plans are drawn up and followed under the direction of an RN. Intermediate care provides a minimum of 8 hours a day licensed nursing supervision and 24-hour coverage by non-licensed personnel like LPNs or Certified Nursing Assistants. Medicare does not cover these costs. Medicaid will cover cost, if prior approval is received and the facility is Medicaid-certified.

Example: Mr. B needed assistance with every activity of daily living. He could not bathe or dress himself, and he was incontinent. He needed help feeding himself. His wife was too frail to care for him at home and moved him to an intermediate care nursing facility wing. She could visit him to help with meals and to make sure he received appropriate care.

Skilled Nursing Care

This care level is for people who need intensive 24-hour care and supervision by a registered nurse under the direction of a doctor who is available for emergencies. Medicare, Medicaid and some private insurance policies pay for this level of care under certain conditions.

Example: Mrs. R. wandered for much of the day due to her advanced Alzheimer's disease. When she fell and broke her hip, she was placed on the skilled nursing facility floor of the nursing home to receive skilled nursing supervision and physical therapy.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

HOSPICE/END-OF-LIFE CARE

This is a special program for the terminally ill. Hospice supports both patient and family with physical, psychological, social, spiritual and emotional care. Hospice can be provided in the home, assisted living or nursing facility. Medicare covers hospice care, if ordered by a doctor. Hospice staff make a home assessment to determine the appropriate level of care and service needs. Ask about hospice or palliative care services through your physician or county aging information specialist.

Example: Mr. D was determined to keep his wife at home, even when she stopped eating. With the help of a local hospice organization, he was able to make her comfortable, and receive support during her last days at home.

LEGAL SERVICES

Legal planning should begin soon after a diagnosis of Alzheimer's. An attorney familiar with Alzheimer's and aging issues can help draw up a durable power-of-attorney for health care and finances, a living will or guardianship if needed during the progression of the illness. Check listings of local private and non-profit legal services with the county aging information specialist.

Example: Miss A's father had a living will before his illness became severe. Knowing her father's wishes was reassuring in making difficult emotional decisions as his health care power-of-attorney when he was no longer able to speak.

FINANCIAL SERVICES

There are a number of professionals who can give advice on important financial decisions that will have to be made in caring for a person with Alzheimer's. To check eligibility for federal and state financial assistance, use www.benefitscheckup.org or call your county aging information specialist for referral to financial planners.

Example: Mrs. V was not aware that Mr. V was eligible for Veteran's benefits. Now his medical care and prescriptions are covered by the VA, leaving their minimal income for her medical needs.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

LONG-TERM RESIDENTIAL CARE

The Basics For People with Memory Disorders

CONTINUING CARE RETIREMENT COMMUNITIES

Also known as Life Care, these large, campus-like complexes offer life-long care with activities and amenities. Middle to upper income residents must enter before a diagnosis of a memory disorder. Long waiting lists and age minimums. Requires buy-in (which may be partially, fully or non-refundable), entrance and monthly fees, and/or purchase of long-term care insurance. Provides multiple levels of care as needed for those deemed financially able. Have trusted attorney or financial advisor review contract.

ASSISTED LIVING, ADULT CARE, REST HOMES, FAMILY CARE

For persons with memory disorders who require supervision and/or assistance with personal care needs. Services include: assistance with bathing, dressing, grooming, scheduling and transport to medical appointments, administering medicines, all meals, snacks, limited help with eating and modified diets, group and individual activities, mail, laundry, telephone, personal lockable space, but there may be extra fees charged for personal care or nursing care. May include a special wing, program or whole facility dedicated to Alzheimer's or dementia care. May offer hospice or home health services to accommodate aging-in-place. Prices vary widely

with limited funding for low-income persons in adult care and family care homes.

Use Alzheimer's Association guide to evaluating residential care.

SPECIAL CARE UNITS OR FACILITIES

Wing, hallway or self-contained facility of an assisted living or nursing facility specifically for persons with memory disorders, and often for persons at a specific stage of impairment (moderately impaired but mobile residents). Most units separated by secured doors to insure safety of persons who live on the unit.

SCUs should specify services that specifically address the needs of and benefits to individuals with memory disorders. Prices and services offered vary widely.

Ask Alzheimer's Association for help in evaluating such options.

NURSING HOMES OR NURSING FACILITIES

Provides short-term rehabilitative care, "subacute" post-hospital care, short or long-term skilled or intermediate level care with 24 hour RN on duty and physician supervision required. Hospice services may be brought in. Most expensive private, Medicare or Medicaid care. Check with long-term care ombudsman or www.medicare.gov information on evaluating nursing facilities.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

HOW TO GET SERVICE INFORMATION WHEN YOU CALL

“It’s so hard to get through. I tried calling, but the line was busy more often than not. I didn’t know what number to press because I didn’t know what to ask for. When I did get through, I was put on hold and then told to call back later because the person I needed to talk with was out. I just gave up.”

When you call a service agency with a problem or request...

Be specific and to the point.

Be prepared with all the information you might need in front of you. (policy numbers, dates).

Leave a message. If your call is not returned in a reasonable length of time, call back. After several tries with no luck, contact the person’s supervisor.

Get the name of whomever you speak with. Ask by name for those you found helpful in the past.

Be prepared for delays—the system works slowly. Plan ahead when possible.

Try to call early in the morning or right after lunch. Avoid Mondays and Fridays when possible. If the lines are busy, do not give up.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

HOSPITALIZATION HAPPENS

Limit Trauma of Emergency Room Visits

When a visit to the emergency room is unavoidable, the following suggestions can help families make the experience as non-threatening as possible.

Using these suggestions and taking certain steps in advance can greatly reduce the stress and confusion that can accompany a visit to the ER.

Call a friend or family member to meet you at the emergency room. This person can focus on your family member while you are filling out forms.

Be prepared to explain the symptoms, medical history, and recent events many times. You should also write down your relative's symptoms and problems. If you are asked the same questions, you can show what you've written instead of repeating.

Inform the staff about the person's dementia. Provide communication tips; suggest that the staff members use eye contact and talk slowly and calmly.

Be patient, and be prepared to wait.

If your relative is discharged to home, make sure you understand ALL of the

instructions before leaving. Ask questions, and review with your relative.

Pack an “emergency bag”, and have it ready in case of emergency.

The Bag Should Contain

A sheet of paper listing the person’s name, nickname, address, insurance companies (including policy numbers and pre-authorization phone numbers), physicians’ names (including phone numbers) and list of current medications and doses

A list of any allergies and previous bad reactions to medicines and foods

A list of important phone numbers (relatives, friends, clergyperson)

Copies of advance directives, Health Care Power-of-Attorney, &/or a Living Will

Extra adult briefs if your relative wears them

A change of clothes and a plastic bag for soiled clothing.

A card that says, “Please Understand – My companion has a memory disorder. Let me help with specific questions.” Give this card to the health care professional during examinations. Avoid talking about your relative’s memory changes or behaviors in front of him or her. This can be upsetting and embarrassing.

Moist hand wipes.

Reassuring object, portable radio/favorite tape with headset.

A writing pad and pen to jot down information/directions.

Pain medication for you, the caregiver.

A sealed snack (i.e. crackers) and water or juice for you and your relative.

A small amount of cash.

Leave a note on the "Emergency Bag" to bring a cellular phone (if available).

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

PAIN AND DEMENTIA

Studies show that pain is often under-diagnosed and under-treated in people with dementia. They cannot always say how bad they hurt or where they hurt. Their discomfort may be expressed solely by changes in their behavior or observable physical symptoms such as sweating, a tight or tender abdomen, signs of redness or swelling in areas of the body, raised temperature, inability to perform normal physical tasks or decreased ability to concentrate.

Family members, must learn how to recognize non-verbal cues to insure that people with dementia receive the treatment and attention they need to maintain quality of life.

What To Look For:

Noisy breathing or breathing that appears strenuous

Vocalizations suggestive of pain such as moans or groaning or crying not typical of the person.

Facial expressions such as a clenched jaw, grimacing, frowning, or distorted facial expression such as tightly closed eyes or mouth or widely opened eyes or mouth

Clenched fists, wringing hands or grabbing at a body part

Fidgeting, pacing, rocking, restlessness, inability to keep still

Changes in eating including loss of appetite and weight loss

Changes in sleeping patterns

Withdrawal or refusal to participate in usual activities

Anger, yelling, striking out

Consider Causes For Pain:

Pain from an undiagnosed fracture from a fall

Severe constipation or fecal impaction

Urinary tract infection which causes burning pain upon urination

Appendicitis, gall bladder attack, or heart attack which may begin with unrecognized mild but discomforting symptoms the person does not report

How You Can Help

First, insist on adequate medication for pain.

Then, try the following tips for reducing pain and improving quality of care:

Talk, listen to music, or review photo albums with the person

Encourage the person to try deep breathing/relaxation exercises

Apply a cold pack for inflammation

Encourage frequent naps (Pain can cause exhaustion and depression in some persons.)

Use warm tub baths

Try massage as tolerated

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

SUCCESSFUL NURSING HOME VISITS

More than Just Conversation

Things to Do:

Substitute shared activities for limited conversation: manicure, hairdo, massage, watching entertainment, looking at picture albums, writing letters, hand work, watching TV news, volunteer work, walks, outings.

Reminisce: Your favorite Christmas? Your first car? The smell of a wood stove?

Baking at the old home place?

Note: If your relative is very impaired, you need to reminisce further back in time.

Bring a pet or favorite stuffed animal or watch birds, squirrels or children playing

from the windows. Start your own visiting rituals of things you do each time.

Use the arts and your skills: music, poetry, hymns, photos, videos or audios, art work, games (even if your relative can't play well, he or she still may enjoy the activity).

One man found that the slapstick humor of old Jackie Gleason Honeymooners tapes calmed his wife's agitation.

Things to Remember:

You don't have to be busy every moment. Silence can be golden—tender moments watching birds, listening to music, sermons or shared private meditation or prayer can bring enjoyment to your relative.

Respect personal space, possessions, and limited energy. Knock before entering. Ask before moving things around or sitting on the bed. Go slow...keep pace with your relative's concentration and tolerance.

This is your relative's home. Behave as if you were visiting in his or her home.

Your presence is enough. Visit like you really mean it.

Things Not To Do:

Rush in, standing at the door, as if you are on your way out.

Give a litany of your problems or obstacles to visiting.

Apologize or "catastrophize" your guilt or failure—it's not your fault and you and your relative are in this together.

Change the subject when your relative expresses negative or sad feelings.

Give advice, nag or use baby talk.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

FAMILY CAREGIVER AFFIRMATIONS

I did what seemed best at the time.

My choices may be limited and beyond my control.

There are no perfect elder care solutions and no perfect families.

If I had selected another course of action, I might now be having doubts about that as well.

Things probably would have been worse if I had done nothing.

Many others in similar situations have come to similar conclusions.

New problems are not necessarily related to what I did or didn't do.

I know it's easy to second guess or criticize from a distance.

It isn't possible to compare how one person handles things to how

another relative would handle it, if their positions were reversed.

Choices, options and lives are different from what they were 30 years

ago.

I can only do my best and be dependable. I can't do it all.

I must consider "good-enough-for-now" solutions.

Family members have competing needs and loyalties. Compromise is necessary for each to get some of what they need and want.

My elder is not unhappy or upset because of what I have done. She/he

is living with unwanted dependency, loss and/or pain. She/he still needs

to feel useful, dignified and loved.

We must continue to celebrate good times as a family and feel good about what we have been able to do for and with each other.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

10 SIGNS OF CAREGIVER STRESS

1. DENIAL about the disease and its effect on the person who's been diagnosed.

I know mom's going to get better.

2. ANGER at the person with Alzheimer's or others; that there are no cures; and that people don't understand what's going on.

If he asks me that question one more time, I'll scream!

3. SOCIAL WITHDRAWAL from friends and activities that once brought pleasure.

I don't care about getting together with the neighbors anymore.

4. ANXIETY about facing another day and what the future holds.

What happens when he needs more care than I can provide?

5. DEPRESSION begins to break your spirit and affects your ability to cope.

I don't care anymore.

6. EXHAUSTION makes it nearly impossible to complete necessary daily tasks.

I'm too tired for this.

7. SLEEPLESSNESS caused by a never-ending list of concerns.

What if she wanders out of the house or falls and hurts herself?

8. IRRITABILITY leads to moodiness and triggers negative responses and reactions.

Leave me alone!

9. LACK OF CONCENTRATION makes it difficult to perform familiar tasks.

I was so busy, I forgot we had an appointment.

10. HEALTH PROBLEMS begin to take their toll, both mentally and physically.

I can't remember the last time I felt good.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

NINE THINGS TO HELP YOU COPE

1. The desire not to think about what you are facing is normal but you can grow beyond it.

Recognizing that this is a progressive, degenerative disease is painful. One of the biggest challenges you face is to accept what is happening.

2. The process of this disease is unpredictable.

Your loved one will lose functional ability. While change is inevitable, the time line will vary as to when your relative becomes a danger to himself or others. At these times you may need to make decisions for his/her safety.

3. Your family member can still do many things.

Celebrate and make the most of remaining abilities. Help them find enjoyment in the simple things that are still within their capacity. Provide them with as much dignity and control in their lives as possible within their own abilities and limitations.

4. Your relative is doing the best s/he can.

Challenging behavior is a result of their confusion and disorientation. He or she is not doing these things on purpose just to upset or get back at you. People with Alzheimer's disease cannot "just try harder" and it is not realistic to expect them to do what they used to do.

5. Your emotional relationship with you family member will change.

Established roles such as with a parent or spouse will change, but not reverse.

6. Try to put yourself in the position of your relative.

Imagine not being able to remember what you have done, or are supposed to do, or how to do even the simplest things. Recognize the insecurity the person must feel.

Often s(he) may feel perfectly normal. Try to remember that sometimes their actions are reactions to your stress.

7. You, not s/he will have to change.

Your relative's ability to change is extremely limited and will diminish as the disease progresses. This means that you will have to learn to accept the behavior and learn how to alter your expectations and reactions.

8. Beware of the grief that accompanies that process of loss.

You may feel denial, anger, guilt and depression before you can accept what is happening.

Seek the support of a trained counselor.

9. Some families successfully care at home and many successfully place their family members under the care of others.

Don't make promises you can't keep.

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

WHY TRY A SUPPORT GROUP?

“Where else can I say how I feel and have “fellow travelers” understand?

You mean I’m not the only one in the world going through this?

I can be angry at fate’s blows, and no one says, “you shouldn’t feel that way.”

This group is my link to the outside world, adult conversation,

and practical tips.

Only these people know why I can’t do this myself.

I never suspected there were so many “right” ways to get Dad into the tub.

Who would have thought that I would be laughing at the dark and crazy

things that happen to me?

I realized I was out without him, and I didn’t have to be guilty about it.

Compared to these people, I’m doing rather well. Things could be a lot worse.

These folks know how to pace themselves...and go the distance.

My family is totally dysfunctional ...the group is the family I always wanted.

Compassion, laughs and camaraderie – that’s why I keep coming back.

I’m an information junkie – these people know every advance and good deal.

I know we can’t cure her mother, but I’m here because I know y’all can

do something for my wife.

Only here can I whisper, "Will I be next?"

Until I came here, I felt like I was always letting her down and she wouldn't

have let me down.

I never thought I would hear some dignified older lady say,

"Poop is the enemy"

I can see the headlines now – "MAN JOINS SUPPORT GROUP....AND LIVES"

This is the closest I have come to a healing spiritual experience."

He, too, must cross in the twilight dim

Good friend, I'm building the bridge for him.

– Will Allen Dromgoole

For Family Caregivers

A NORTH CAROLINA INFORMATION & ASSISTANCE TOOLKIT

PREPARING FOR THE DEATH OF A FAMILY MEMBER

The following signs and symptoms of impending death may help families understand the natural changes that happen during the dying process and how to best respond. As each person is unique, all of these signs and symptoms will not occur with everyone, nor will they occur in this particular sequence. This information is intended to help with the natural worry and fear that accompanies caring for an individual with end-stage dementia.

Decreased Food and Fluids and Related Effects.

As the body no longer desires or tolerates food and fluids, the person normally eats and drinks less. The person loses weight, and skin becomes thin and tears easily. Urine output decreases and urine becomes more concentrated.

Swallowing problems and choking are common; proper positioning can reduce choking.

Never force food or fluids.

Use glycerin swabs to keep the mouth and lips moist.

Increased Sleeping and Withdrawal.

The person may spend more time sleeping at the end of life or withdraw by

closing his or her eyes.

Never assume that the person cannot hear what is being said in the room.

Sit with the person, hold his or her hand gently; speak softly and naturally.

Incontinence.

People with end-stage dementia lose control of the bladder and of bowels.

Reposition and change pads frequently to avoid use of disposable undergarments.

Breathing Pattern Change and Congestion.

Breathing may become shallow, irregular, fast, or abnormally slow. Changes in breathing patterns or irregular shallow breathing patterns may cause a moaning-like sound when individuals exhale. Congestion is common.

Try elevating the person's head by raising the head of the bed or by using pillows.

Turn the person's head to the side.

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Changes in Temperature and Skin Color.

The person's arms and legs may become cold, hot, or discolored.

Keep the person warm if they appear cold, but do not use electric blankets.

Restlessness and Disorientation.

The person may make restless and repetitive motions such as pulling at sheets or clothing or calling out repetitively. He or she may groan, scream, or mumble loudly. The person may have visions or call out to people long dead and become increasingly confused about his or her identity and the identity of loved ones.

Hold the person's hand or gently massage the forehead.

Talk reassuringly, read to the person, or repeat favorite prayers or music.

At the Time of Death.

At the time of death, breathing ceases, heartbeat ceases, the person cannot be aroused.

The eyelids may be partially open with the eyes in a fixed stare, the mouth may fall open, and bowel and bladder contents may be released as the body relaxes.

When the death occurs, take time to call a supportive person to be with you

before making other calls.

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