

## **Dementia, Alzheimer's disease, and Parkinson's disease**

### **Dementia and Alzheimer's disease**

Dementia is a loss of brain function that occurs with certain diseases. It affects memory, thinking, language, judgment, and behavior. Alzheimer's disease (AD), is one form of dementia that gradually gets worse over time. It affects memory, thinking, and behavior.

The early symptoms of dementia and AD can include:

- Language problems, such as trouble finding the name of familiar objects
- Misplacing items
- Getting lost on familiar routes
- Personality changes and loss of social skills
- Losing interest in things you previously enjoyed, flat mood
- Difficulty performing tasks that take some thought, but that used to come easily, such as balancing a checkbook, playing games (such as bridge), and learning new information or routines

As the dementia or AD become worse, symptoms are more obvious and interfere with the ability to take care of yourself. The symptoms may include:

- Forgetting details about current events
- Forgetting events in your own life history, losing awareness of who you are
- Change in sleep patterns, often waking up at night
- More difficulty reading or writing
- Poor judgment and loss of ability to recognize danger
- Using the wrong word, not pronouncing words correctly, speaking in confusing sentences
- Withdrawing from social contact
- Having hallucinations, arguments, striking out, and violent behavior
- Having delusions, depression, agitation
- Difficulty doing basic tasks, such as preparing meals, choosing proper clothing, or driving

People with severe dementia and AD can no longer:

- Understand language
- Recognize family members
- Perform basic activities of daily living, such as eating, dressing, and bathing

Other symptoms that may occur with dementia:

- Incontinence
- Swallowing problems

Someone with dementia will need support in the home as the disease worsens. Family members or other caregivers can help by trying to understand how the person with dementia

perceives his or her world. Give the person with dementia a chance to talk about any challenges and participate in their own care.

Tips for reducing confusion in people with dementia and AD include:

- Have familiar objects and people around.
- Keep lights on at night.
- Give frequent reminders, notes, lists of routine tasks, or directions for daily activities.
- Stick to a simple activity schedule.

Regular walking with a caregiver or other reliable companion can improve communication skills and prevent wandering.

Calming music may reduce wandering and restlessness, ease anxiety, enhance sleep, and improve behavior.

The person with dementia should have their eyes and ears checked. If problems are found, hearing aids, glasses, or cataract surgery may be needed.

Supervised meals and help with feeding. People with dementia often forget to eat and drink, and can become dehydrated as a result.

### **Parkinson's disease**

Parkinson's disease is a disorder of the brain that leads to shaking (tremors) and difficulty with walking, movement, and coordination. Parkinson's disease most often develops after age 50. It is one of the most common nervous system disorders of the elderly. Sometimes Parkinson's disease occurs in younger adults. It affects both men and women.

Symptoms include:

- Automatic movements (such as blinking) slow or stop
- Constipation
- Difficulty swallowing
- Drooling
- Impaired balance and walking
- Lack of expression in the face (mask-like appearance)
- Muscle aches and pains
- Movement problems
  - Difficulty starting or continuing movement, such as starting to walk or getting out of a chair
  - Loss of small or fine hand movements; writing may become small and difficult to read; eating becomes difficult
  - Slowed movements
  - Stooped position
- Rigid or stiff muscles, often beginning in the legs
- Shaking, tremors
  - Tremors usually occur in the limbs at rest, or when the arm or leg is held out

- Tremors go away during movement
- Over time, tremor can be seen in the head, lips, tongue, and feet
- May be worse when tired, excited, or stressed
- Finger-thumb rubbing (pill-rolling tremor) may be present
- Slowed, quieter speech and monotone voice

Other symptoms:

- Anxiety, stress, and tension
- Confusion
- Dementia
- Depression
- Fainting
- Hallucinations
- Memory loss

To help a person with Parkinson's disease maintain his independence for as long as possible, there are many simple changes a caregiver can make around the home. Consider the following:

- Keep walking areas free of clutter.
- Make sure chairs have firm backs and armrests to support the person's weight when he gets up or sits down.
- Get a telephone with big buttons to make dialing easier, and help the person program their phone so they can easily dial commonly used numbers.
- Provide easy-to-use remote controls with large buttons for operating the television and stereo.
- Install large, easily toggled light switches and purchase lamps that are activated by touch or sound.
- Secure all electrical and phone cords so they don't pose a tripping hazard.
- Install a grab bar beside the bed to provide extra stability as the person gets in and out of bed.

The bathroom can be a hazardous place for people with movement disorders like Parkinson's disease. Here are some tips to protect them from bathroom accidents:

- Install railings to make it easier to sit on the toilet or step into and out of the bath or shower. You may also want to consider buying a raised toilet seat for easier accessibility.
- Think about replacing the bathtub with a shower, so the person with Parkinson's disease doesn't have to step over the high edge of a tub.
- Place a non-skid mat in the tub and think about buying a bath bench or chair with non-skid feet as well.
- Attach extended levers to sink and bath fixtures to make them easier to use.

- Provide liquid soap and a terrycloth glove or mitt to minimize the person's risk of slipping while bending over to pick up a bar of soap or washcloth.
- Cover the majority of the bathroom floor with a large rug and secure it in place instead of using small, slippery, area rugs.
- Provide an electric razor and electric toothbrush to reduce the movements required for the person to shave and brush their teeth.

Similarly, there are steps you can take to make the kitchen a more manageable place to get around for a person with Parkinson's disease. You might consider:

- Attaching extended hand levers to the faucets in the sink to make them easier to use
- Reorganizing the kitchen so food, utensils, and cookware are in easy reach. A countertop turntable can also make supplies more accessible.
- Replacing the controls on the stove with large buttons or dials for easier use
- Making sure the refrigerator, cabinets, and drawers can be easily opened. Install larger handles if necessary
- Always keeping flammable items away from the stove

Caregivers can use a number of helpful strategies when communicating with a person who experiences speech problems due to Parkinson's disease. Try:

- **Sitting face-to-face.** This will allow you to maximize verbal and non-verbal communication to enhance your understanding of what the person is trying to say.
- **Keeping questions basic.** Ask questions that can be answered in simple ways, with very little elaboration.
- **Encouraging the person to speak slowly and carefully.** Teaching the person to talk slowly is very important. Keep in mind that the person may also need extra time to process information and respond appropriately.
- **Following up if you only understand part of a statement.** Don't be shy about asking the person to clarify a statement. For example, you may understand that the person wants you to go to the store for them, but you may not get the rest of the sentence. Follow up with pointed questions like: "What would you like me to get you at the store?" or "Which store are we talking about?"
- **Being creative.** Work with your friend or family member with Parkinson's disease to develop shorthand verbal and nonverbal codes that will help get the point across, particularly regarding common subjects. Sometimes people will use pictures or gestures to better express what they are saying.
- **Limiting distractions.** When speaking with the person, turn off the television and minimize background distractions as much as possible.

## The Older Person

It is important to recognize that people age differently, so what is presented here may not be exactly what you or your loved one experience. Also, even though there are many challenges of aging, these can often be addressed through simple steps that improve communication and make the environment safer and easier for the older person to navigate. These steps may also help to make it easier for the older person to live independently for as long as possible.

### ***Sensory Changes***

Humans receive and process information from the environment through hearing, vision, taste, smell, and touch. With aging, these senses are often diminished and incoming information may be distorted or difficult to understand. As a result, the older person may give up some enjoyable activities or lose contact with friends and family who are important sources of support. These problems can be reduced or overcome by following the suggestions described in the sections below.

### **Hearing**

About 30% of people over 60 have a hearing impairment, but about 33% of those 75 to 84, and about half of those over 85, have a hearing loss. Hearing loss affects the older person's ability to talk easily with others. For example, older people often have trouble hearing higher pitched tones. They also may not be able to make out sounds or words when there is background noise. Conversations may be difficult to hear, especially if the speaker has a high voice or there is background interference.

Older persons may be frustrated or embarrassed about not being able to understand what is being said. They may have to ask people to repeat themselves, or endure shouting when a speaker tries to be heard. Older persons may hold back from conversation out of a fear of making inappropriate comments. They may tire from concentrating and straining to hear. As a result, the older person may withdraw from friends and family and outside activities.

Hearing loss doesn't have to cause social isolation and emotional distress. Simple changes in behavior and the home environment can increase the elder's ability to carry on a normal conversation.

- Speak clearly and in a normal tone of voice. Don't speak too fast or too slow. Hold your head still. Do not shout.
- Get the older person's attention before speaking.
- Look directly at her or his face and at the same level.
- Stand or sit with the light above or toward you, not behind you. Keep your hands away from your mouth.
- Eliminate background noise from radio and television.
- Try using different phrases with the same meaning if you are not getting your point across.
- Build breaks into your conversation.
- Use facial expressions or gestures to give useful clues.
- Repeat yourself if necessary, using different words.
- Ask how you can help.
- Include the hearing-impaired person when talking, do not exclude them.

There are many different devices that can be used in the home to help a hearing-impaired person. Special phones work with hearing aids and ring louder than a standard phone. There are alarm clocks, smoke detectors, and doorbells that have flashing lights and vibrations to alert the hearing-impaired.

## **Vision**

Even though changes to the eye take place as a person ages, many older people have good-to-adequate vision. Nevertheless, beginning in the late 30s and early 40s, an individual may begin to notice some changes. She or he may have to hold the paper farther away to read it due to changes in the ability of the lens to change its shape to accommodate to distance.

With aging, peripheral vision is reduced. A person may need to turn her or his head to see to the sides. The flexibility of the eye decreases and it takes an older person more time to accommodate to changes in light. Adaptations in lifestyle and behaviors must be made to cope with this change. An individual might give up driving at night. Placing more lights evenly around the room so that the entire room is lit is also helpful.

Degeneration of eye muscles and clouding of the lens are associated with aging. Several changes in vision result from this. Older people tend to have trouble focusing on near objects, but eyeglasses may correct this problem. In addition, the ability to see colors changes with age as the lens yellows. Red, yellow, and orange are easier to see than blue and green. This is why fabrics in warmer shades may be more appealing to the older person.

Serious vision impairments such as cataracts, glaucoma, and blindness affect between 7% and 15% of older adults. If someone you know must learn to cope with blindness or near blindness, you can play a critical role in helping them maintain their independence.

To help a person with any visual impairment, or to make your own life brighter:

- Light the room brightly and use more than one non-glare light in a room.
- Use blinds or shades to reduce glare.
- Keep a night light on in the bedroom, hallway, and bathroom to maintain an equal level of light.
- Increase lighting on stairwells and steps.
- Use concentrated light for sewing and reading.
- Turn lighting away from the television to avoid glare.
- Provide printed materials with high contrast between the background and lettering.
- Use contrasting colors in the home, such as colors between the doors and walls, and between the dishes and table coverings.
- Mark the edge of steps with a brightly colored tape or different colored paint, and paint the handrails.
- Provide audiotaped books and music for the elder's cognitive stimulation, entertainment, and relaxation.
- Wear a hat with a wide brim and sunglasses while outside. This will protect the eyes against too much sunlight, which can lead to cataracts.
- Know the warning signals of possible vision problems, including pain in or around the eyes, excessive tearing or discharge, double vision, dimness or distortion of vision, flashes of light, halos or floating spots, swelling of the eyelids or a protruding eye, changes in eye color, and changes in vision or movement of one eye.

- Make sure the older person has regular eye exams, including a glaucoma screening, at least once every 1-2 years.

## **Taste and Smell**

Some loss in taste sensitivity takes place with aging. However, the loss is minor and does not seem to occur in most people until well after 70. There is also a loss of smell, but this is not severe.

Nevertheless, older people often complain that their meals are tasteless or that they no longer like their favorite foods. Most experts feel that these complaints are caused by a sense of loneliness at meals, or an unwillingness or inability to cook. Also, older persons may not buy more enjoyable foods when they have difficulty chewing due to poor dentures or dental problems, or are stretching their food dollars due to a limited budget.

To help the older person enjoy mealtime:

- Offer familiar, well-liked foods.
- Invite or encourage the elder to share meals with friends and family, in his or her home or at congregate meal sites.
- Experiment with different seasonings and flavorings.
- Prepare a variety of foods each day.
- Make the table colorful and inviting with bright napkins, mats, and flowers.
- Encourage exercise, when possible, which stimulates the appetite.

## **Touch**

The skin serves a protective function by buffering us from the environment. Skin changes leave the older person vulnerable to discomfort and harm. Due to reduced sensitivity, heat sources such as heating pads, hot water bottles, and pot handles can hurt the skin before the elder realizes that damage is occurring.

An older person may develop a greater sensitivity to cool temperatures and drafts. This is caused by a decline in sweat gland activity, a decrease in the ability to maintain a normal body temperature due to poorer circulation, and a thinning of the skin. Wrinkling, drying, and scaling also occur. The skin tears and breaks more easily, increasing the chance of injury and infection.

To cope with these changes, the older person should:

- Avoid extreme exposure to sun and wind, which speed up the aging of the skin.
- Avoid daily baths or showers, as these tend to dry out the skin.
- Moisturize the skin with body oil after a bath, gently patted on with a washcloth.
- After bathing, pat the skin dry.
- Drink one to two quarts of fluid daily to maintain normal body temperature and functioning.

The sensation of touch connects us with others no matter what our age. Thus, touch is important in maintaining the elder's emotional well-being. Use touch to communicate that you are there for support and that you care.

## ***Changes in Bones and Muscles***

Aging adults, especially the very old, are vulnerable to broken bones. In addition, joints stiffen and connecting ligaments between bones lose their elasticity. Hand and foot pain may result.

Although there is no known way to prevent sometimes painful changes in aging muscles, bones, and ligaments, regular exercise helps to assure continuing mobility in old age. Most physicians feel that walking, along with adequate rest and a nutritious diet, are tremendously valuable for maintaining mobility and fitness in the later years.

It is very important to prevent falls. Due to changes in bone mass and strength, falls often result in injury, hospitalization, and continued declines in health.

The suggestions covered under vision and hearing, as well as those listed below, will help the older person take the necessary precautions to prevent falls.

- A no-slip bath mat and grasp rails are installed in the shower or tub.
- A seat is placed in the shower if standing is difficult.
- If scatter rugs are used, they should have no-slip backing or mats underneath.
- Chairs are sturdy and do not wobble, break, or tip over.
- A safe, sturdy step stool is available to reach high places.
- The telephone is placed in a convenient location.
- Chairs and sofas are at a height that permits easy sitting.
- Floors and stairs have non-skid surfaces.
- Railings line all staircases.
- Staircases and walkways are uncluttered.
- Front and back steps, and inside flooring and carpeting are in good condition.
- Instructions for the proper use of medications are followed carefully, as improper types or dosages often cause falls.

## ***Digestion***

### **Teeth and Mouth**

Older adults are more likely to lose teeth to gum disease than to problems with the teeth themselves. However, with proper personal care, regular checkups, and improved dentistry methods, older people are more able to retain their natural teeth throughout their lives. Older people who do lose their teeth may now expect and demand comfortable, well-fitting, and durable dentures.

### **Digestion**

The digestive system is very sensitive to emotions. An older person may experience an upset stomach or lack of appetite when lonely, depressed, or worried. Regular contact with friends and relatives, through visits and telephone calls, can help prevent these problems.

It is fairly common for older people to have less frequent bowel movements and to suffer from constipation. This is due to changes in tissue and muscles and reduced thirst. Regular exercise, such as a daily walk, can prevent constipation. A well-balanced diet that includes adequate fiber and fluid intake also encourages normal bowel function and minimizes the need for laxatives. In contrast, self-prescribed laxatives are an expensive substitute for foods that naturally keep the gastrointestinal system running smoothly, such as bran cereals, fruits, and vegetables. Overuse of laxatives can interfere with the availability of nutrients for healthy body functioning.

Adequate fluid intake is essential for maintaining proper body temperature and functioning of the digestive system. However, some older people make the mistake of limiting their fluid intake in order to avoid frequent urination. Dehydration is a serious problem for the elderly. This is due to their decreased sense of thirst and reduced capacity to conserve water. In addition, laxative abuse, diuretic therapies, infections, immobility, or excessive use of alcohol or caffeine tend to promote dehydration.

Caregivers and older adults should follow the guidelines below to assure proper gastrointestinal functioning.

- Get some form of regular exercise that is appropriate to the level of physical ability.
- Maintain a well-balanced diet that includes natural sources of fiber such as whole grains, fruits, and vegetables.
- On a daily basis, drink eight cups of water and other fluids.
- Watch for signs of dehydration, such as mental confusion, decreased urine output, constipation, nausea, lack of appetite, dryness of lips, and elevated body temperature.
- Pay special attention to fluid intake during hot weather.
- Monitor the fluid balance in older people with special medical problems, such as congestive heart failure or kidney disease. Discuss the appropriate methods to monitor fluid intake and output with your doctor.

## ***Circulation***

The older heart slows down and is less able to pump blood through the body than the younger heart. This results in older people having less energy and stamina for physical work. Decreased circulation also contributes to cold sensitivity, particularly in the hands and feet. Because oxygen necessary for proper physical and cognitive functioning is carried through the blood, the elder with poor circulation may experience forgetfulness and other symptoms of poor cognition.

Blood vessels, which play an important role in the circulation of blood throughout the body, lose elasticity as we age. This causes blood to tend to "pool" in the feet and legs. This means that swelling (edema) may occur in the extremities. Consequently, the heart, which undergoes muscle changes as we age, must pump harder in order to carry the blood to all parts of the body.

Changes in circulation make the older person more susceptible to the development of "little strokes" (TIAs) than when younger. Symptoms of such episodes include headache, vision disturbances, loss of balance, confusion, and dizziness when standing quickly from a sitting or reclining position. Because "little strokes" can be harbingers of a larger stroke, consult with the older person's primary health care provider, should these occur.

Many older people are on medications that impact circulation. Be familiar with these medications, and their side effects. This may prevent complications, which may arise from their use.

Pressure ulcers, a skin problem found in people with limited mobility, are due to impaired circulation. When an older person is unable to move about, tissue may die due to lack of an adequate blood supply to the skin. Areas particularly susceptible to these ulcers are those over bony prominences such as hips, shoulders, elbows, knees, ankles, and the heels of the feet.

To facilitate proper circulation and its effects:

- Prop the feet on a footstool or other appropriate stable object when sitting.
- Change the person's position at least every two hours to prevent pressure ulcers of the skin.
- Develop an activity routine which conserves energy and yet includes opportunities for movement.
- When the elder is sitting, rotate her or his feet at the ankles frequently to promote circulation.
- When the elder is rising from a reclining position, help her or him sit on the edge of the bed for a few moments before standing.
- Be familiar with the older person's medications and their side effects to prevent falls and other complications.
- Be alert to sensitivity to cold in the older person. Make certain there are sweaters, blankets, and other warm materials available.

## ***Conclusions***

The aging body does change. Some systems slow down, while others lose their "fine tuning." As a general rule, slight, gradual changes are common, and most of these are not problems to the person who experiences them. Sudden and dramatic changes might indicate serious health problems. A program of regular, thorough health check-ups and self-examinations will identify changes that may be cause for concern.

Many of the once-disabling problems of aging can be managed through improved health care and the use of assistive devices. Simple but effective changes in the home environment can be made that prevent problems and enable the older person to maintain independence.

The person who has had good health habits when younger and who maintains these habits throughout life can expect to age with a sense of well-being and continued enthusiasm for living. A healthy lifestyle includes getting plenty of appropriate physical activity, such as simple stretches and walking. Research confirms that physical activity prevents problems as people age such as increased weight gain and risk of cardiovascular disease. Activities that increase strength and mobility can also help older adults remain independent.

To stay healthy, older adults also need adequate sleep, sufficient fluid intake, nutritious foods, and a healthy and comfortable body weight. For more information about aging, meeting nutritional needs in the later years and maintaining a healthy lifestyle, contact your Cooperative Extension Service county agent.

## What Caregivers Should Know About HIPAA

In 1996, the U.S. Department of Health and Human Services began enforcing the HIPAA Privacy Rule. HIPAA, also known as the Health Insurance Portability and Accountability Act, has become an integral component of the U.S. health care system. The intent of this privacy rule is twofold—to provide federal protections for personal health information; and secondly, to outline patients' rights in regard to their personal health information.

### What Does HIPAA Do?

HIPAA is designed to provide individuals with control of their personal health information and how this information is used. For this reason, HIPAA only allows the release of the minimum information necessary. HIPAA sets boundaries in regard to personal health information disclosure, and those that violate HIPAA protections can be held accountable for the violation of a patient's rights.

Caregivers should be aware of the following:

- Adult children, friends, or other caregivers can have access to patient information if authorized by the patient.
- Patient authorization allows caregivers access to personal health information.
- Participation in doctor's visits is allowed with patient authorization.
- In the event the aging parent is unable to make their wishes known, the doctor may determine with whom to discuss the patient's options — typically an adult child caregiver.

Violating privacy is now punishable, and HIPAA's privacy policy is enforced by the Office of Civil Rights.

- Any information that can identify a patient is considered "Protected Health Information" (PHI). Exposing this information either written or oral is a violation.
- Conversations with patients should not include questions about their diagnosis, insurance coverage, or anything else that deals with their health information.
- Do not listen to any conversations between patients and medical staff.
- Never discuss anything about a patient unless it is in the performance of your assignment and then only to the proper person and in a manner and location, which insures that the conversation will not be overheard.
- Never discuss anything about a patient outside of the host facility. This includes knowledge of admittance, and emergency treatment. This also pertains to family members, neighbors, friends, church members, etc. who are patients and whom you might see while volunteering. Unless they give you permission to tell someone else, **DO NOT TELL ANYONE**. (This can be difficult at times, because you are caring individuals and would want others who care to know so that they can send a card, say a prayer, etc. However, it is the Law and you must comply. It is also the patient's right to privacy, no matter how good your intentions might be.)
- Key: remember **WHAT** you are saying, **WHERE** you are saying it, and to **WHOM** you are saying it. These three W's can determine whether or not you are being compliant with HIPAA regulations.