

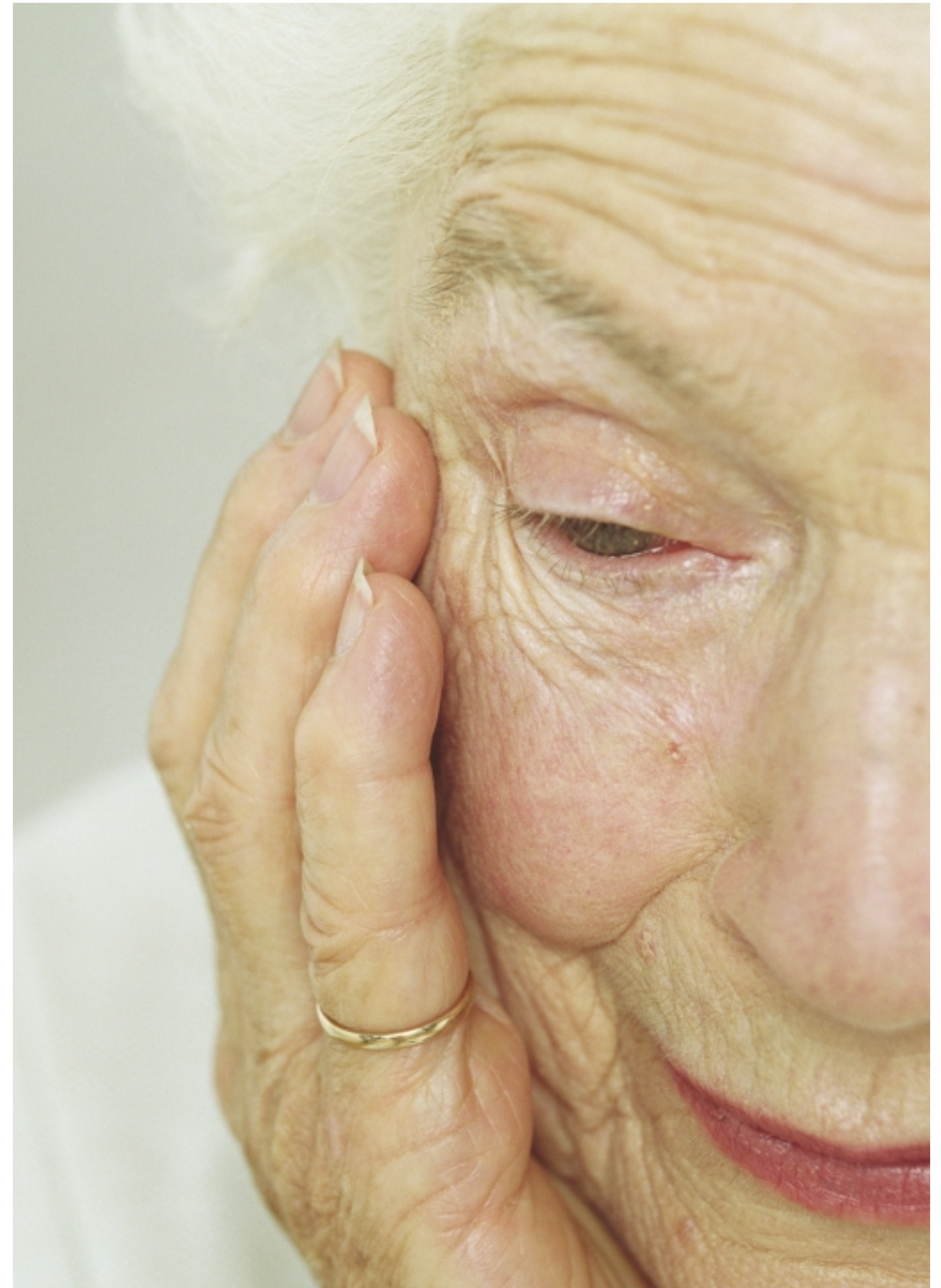


# The Power of Human Touch In, Alzheimer's Care



People suffering from this debilitating disease often can be greatly comforted by massage—if it's done properly.

BY DAWN NELSON





“Hello, Eleanor.”\*  
 “They don’t know what they’re doing.”  
 “You look very nice today, Eleanor.”  
 “The policeman said if they want it they’ll take it.”  
 “It’s nice to see you today, Eleanor.”  
 “I am, too.”

This is a verbatim dialogue with a woman with whom I eat lunch nearly every day. Looking much younger than her 80-something years, Eleanor sits opposite my mother at a four-person table in an attractive, comfortably appointed dining room of an assisted-living facility in northern California.

Although there is a designated wing in the building for those with advanced memory impairment, at least three-quarters of the resident population in the main facility are living with some stage of dementia. My mother’s dementia is stroke-related, while Eleanor’s is likely caused from Alzheimer’s disease. Sometimes my conversations with Eleanor flow in logical sequence, and on other days they follow a path like the one above. Conversations with my mother are always rational, yet she often forgets imparted information in the space of five or 10 minutes.

A few days after the above conversation, Eleanor, who is usually the first to arrive and the last one to leave the table at mealtimes, was nowhere to be seen halfway through the lunch hour. I went to her room, and found her in a confused and agitated state. She was politely resistant about coming to lunch, saying she wasn’t hungry and didn’t need to eat. Putting my arm around her I told her I was sorry she couldn’t find what she was looking for (although I was uncertain what that was). My presence and contact seemed to relax her a little.

As we continued to talk, I gently guided her body toward the doorway, and said we’d really like her company for lunch. She was confused about how to get to the dining room, so I held out my hand to her, and said she could come with me since I was going that way. Eleanor kept a tight grip on my hand as we walked. She then mentioned that her back had been hurting, and we stopped briefly as she guided my hand to a particular area.

I could not sense or feel, externally, anything abnormal on that side of her back, but told her I was sorry she was in pain. I continued to touch and gently massage her upper back as we walked to the dining room. Eleanor’s mood changed once we reached the table, and she ate a hearty meal. When I asked Eleanor later about the pain in her back, she smiled widely and said, “It’s better now.”

Before leaving the facility, I reported Eleanor’s comment about her back pain to a care manager.

Through my years of relating to people living with Alzheimer’s disease and other dementias—whether in the role of massage therapist, friend or relative—I have been continually impressed with the power of touch to make a difference in their lives.

### A Definition Of Alzheimer’s Disease

Dementia is defined as a cognitive decline from a previous level of func-

tioning and memory impairment significant enough to interfere with social or occupational functioning. It is a general term for a variety of disorders. Alzheimer’s disease (AD) is the most common and well-known of these disorders, accounting for about 75 percent of all cases of dementia from various causes. This relentless illness attacks the part of the brain that controls memory, thinking and judgment, eventually affecting the sufferer’s ability to perform routine activities of daily living.

### Conditions That Cause Dementia

Multiple Infarct Dementia is caused by blood vessel disease that results in a series of mini-strokes. This type of dementia may appear similar to Alzheimer’s, and the two types co-exist in 15 to 20 percent of people with dementia.

Creutzfeldt-Jakob disease is a rapidly progressing, rare, fatal brain disease; its characteristics include failing memory, changes in behavior and lack of coordination in early stages. Examination of brain tissue reveals distinct cellular changes unlike those seen in AD.

A hereditary disorder that usually begins in mid-life, Huntington’s disease is characterized by irregular involuntary movements of the limbs and/or facial muscles, and a decline in intellectual processes. The pattern of memory

impairment differs from that seen in Alzheimer’s-type dementia.

Parkinson’s disease is primarily an age-related neurological affliction that can affect movement, balance, walking, speech and muscle tone. Dementia sometimes occurs in the later stages of this chronic, debilitating disease.

Pick’s disease, a rare brain disorder that closely resembles Alzheimer’s, is usually difficult to clinically diagnose. Disturbances in personality, behavior and orientation may precede and initially be more severe than memory defects. Like Alzheimer’s, a definitive diagnosis is usually obtained through autopsy.

Dementia can also be caused by reversible conditions such as head injury, drug reactions, thyroid disorders, kidney disease or even nutritional deficiencies.

Alcoholism, AIDS, brain tumors and meningitis may include dementia-like symptoms.

### Alzheimer’s Disease Affects Millions

According to the latest statistics from the Alzheimer’s Association, AD is now the fourth-leading cause of death in adults, affecting nearly four million Americans, and eight million more people worldwide. Age is the biggest risk factor for AD. The number of cases of Alzheimer’s disease doubles every five years in people aged 65 and older. By age 85, nearly half of all people are afflicted. As the aging population increases, unless more effective methods for prevention and treatment are developed, it is estimated that Alzheimer’s disease will reach epidemic proportions, afflicting 14 million Americans within 50 years. One physician has gone so far as to say that, “In 25 years, the United States will have two kinds of people: those who have Alzheimer’s and those who are caring for someone with Alzheimer’s.”<sup>1</sup>



When the practitioner is at same level as the client, it promotes eye contact and connection that helps build rapport. It is another way of accessing the arm, shoulder and upper back of a client. The pillow serves as a bridge as well as a boundary.

### Cause And Cure Still A Mystery

The exact cause of Alzheimer’s disease remains a mystery. It is generally agreed that there is no one clear “cause” for the disease but likely a combination of responsible factors, which may include genetics as well as environmental and other influences.

There is no cure for AD. The current treatment goal is to slow the progression of the disease and to control symptoms such as depression, agitation, anxiety and insomnia. In spite of intensive research over the past decade, only a few drug treatments have been able to slow the progress of AD, and then only for some people in the early stages. Mamantine was recently approved for use in the United States. Though not a miracle drug or a cure, it is the first drug reported to help some people living with moderate to severe Alzheimer’s maintain their level of functioning for a longer time.

Research is now turning to prevention trials, and a number of studies are

underway to test the effectiveness of various therapies in people without symptoms or who have only slight memory problems. Under scrutiny in these studies are further examination of estrogen and studies of various classes of anti-inflammatory drugs and antioxidants.<sup>2</sup> Complementary and alternatives therapies, including music, massage and aromatherapy, are attracting more and more interest as resources for dementia care.

### Alzheimer’s Disease Difficult To Diagnose

Only a brain biopsy revealing the hallmark plaques and tangles can definitively diagnose Alzheimer’s disease. A number of less-invasive procedures allow physicians to achieve a 90 percent accuracy in diagnosis. Diagnostic tools may include:

- Consultation with closest companion or family member;
- Mental status questioning;
- CT scan or MRI to rule out stroke, brain tumors or brain changes attributable to other diseases;

\* Name has been changed.



This photograph demonstrates attentive touch to legs over clothing. If a client is willing to remove his or her shoes and/or socks, foot massage can be given as the practitioner kneels at end of the client's bed.



PHOTO © BARRY BARANKIN

In 25 years, the United States will have two kinds of people: those who have Alzheimer's and those who are caring for someone with Alzheimer's.



- Blood tests to rule out kidney, liver and thyroid malfunctions, nutritional deficiencies and metabolic imbalances;
- Lumbar puncture to rule out certain brain infections or to look for elevated levels of a specific protein associated with AD.

### A Ruthless Progression Of Symptoms

Alzheimer's disease usually progresses gradually, over a period of years. The Alzheimer's Association divides the progression into seven stages, from no impairment at all to very severe impairment. In this article, the levels are condensed into four stages.

#### Early Signs (Onset)

- Loss of ability to remember recent events;
- Decline in ability to concentrate or to adapt to new circumstances;
- Impaired judgment (inappropriate response to information);
- Intermittent disorientation;
- Difficulty sleeping;
- Emotional mood swings and lack of emotional control;
- Easily distracted or confused;
- Depression.

As Alzheimer's disease advances to an intermediate stage, the symptoms and behaviors that may appear include:

- Language problems, such as illogical verbal expression;
- Repetition of words/phrases;
- Trouble finding right word usage;
- Difficulty in listening/understanding;
- Long-term memory loss;
- Mental confusion;
- Spatial disorientation;
- Impaired depth and spatial perception;
- Visual agnosia (inability to recognize and properly identify objects);
- "Wandering" behavior.

As Alzheimer's disease continues its inexorable advance, a person may have trouble:

- Separating fact from fiction;
- Listening and understanding;
- Consistently recognizing friends or family members.

Eventually he or she may be unable to:

- Communicate effectively through words;
- Recognize self in mirror;
- Dress, undress or bathe without help.

There is a possibility the person will become:

- Paranoid;
- Combative or even abusive;
- Hallucinatory.

He or she may also experience:

- Seizures;
- Muscle cramping;
- Limb rigidity;
- Personality changes.

#### End Stage

In the final stages of a progressive illness such as Alzheimer's, so much of the nervous system is failing that the rest of the body is significantly affected. This most severe stage can have a duration of 12 to 18 months, and is often characterized by:

- Bowel and bladder incontinence;
- Immobility;
- Recurrent urinary tract or upper respiratory tract infections;
- Inability to communicate.

Death is frequently fostered by aspiration pneumonia leading to coma.

### How Massage And Skilled Touch Help

Anger and frustration may arise as a person is forced to adjust to an altered lifestyle, and to a diminishing ability to function in familiar ways. Depression commonly occurs after diagnosis for those in the early stages, who may feel saddened by what is happening to them and by the awareness of the inevitable progression of their disease. They may become emotionally upset and cry easily. Gentle touch, offered unconditionally and in a caring way, can be a great comfort at such times. Inducing a relaxation response through massage therapy may well serve to ease the anxiety that forgetfulness and confusion can cause, and help increase feelings of well-being.

Throughout the progression of AD, the broad, general benefits of therapeutic massage, when appropriately adapted, are beneficial in improving circulation, softening contracted muscles, relieving minor aches and pains, and promoting relaxation.

Perhaps even more importantly, skilled touch sessions provide significant psychosocial benefits to those with AD in residential facilities, including:

- Focused one-on-one attention;
- Companionship;
- Mental stimulation;
- An opportunity for social interaction;
- Skin-on-skin contact;
- Sensory and tactile stimulation;
- Nonverbal communication;
- Nurturing;
- Pleasure.

Intentional, caring touch helps to:

- Reassure those who are confused;
- Calm those who are agitated;
- Increase body awareness;
- Ground the disoriented person in present time and space;
- Provide a touchstone with physical reality;
- Reinforce verbal communication;

- Redirect energy or shift attention;
- Reduce the need for medication and physical restraints;
- Alleviate feelings of isolation, loneliness or abandonment.

I was hired to see Adele twice a week for the purpose of using massage to improve circulation in her legs so she might walk a little more. She was open and responsive to touch. Our sessions lengthened to include back massages and lotioning of her hands and arms. It was clear, however, that the most important benefit of our sessions, for Adele, was the socialization that occurred. She treated me as if I had been invited to high tea in her home, talking excitedly about many things. I began to get a sense of her fascinating life through the vivid images that she presented. The stories were not in logical sequence, so I simply followed whatever twists and turns and leaps she took. She loved to joke and laugh. She sometimes shared her sadness, telling me how difficult it was for her to give up her car. Not being able to drive or go where she wanted when she wanted to was an enormous loss of independence and control over her

K, an 85-year-old woman living with an advanced dementia attributed to Alzheimer's, seemed unresponsive to almost all external stimuli, and often sat in a chair for long hours staring silently into space. Her daughter-in-law, who knew nothing about Alzheimer's and whose task it had become to care for a woman she had never gotten along with, grew increasingly exasperated with K's behavior. Doubtful that she would respond but willing to "try anything," I was invited to visit this once-proud and sophisticated matron. I noticed the rigidity in K's body began to give way immediately as I gently massaged her upper back and shoulders. By our third session, K was answering direct questions with words instead of silence or shrugs. Over time, with gentle support and encouragement, she moved from her chair to the couch so that I could better access her back and legs to massage them. Although her response to the massage may have seemed minimal to an outside observer, I experienced shifts in K's body energy, as well as subtle changes in her demeanor both during and after our sessions.

After observing how much M, who was often unable to communicate through words, loved music and movement, I was able to use this interest of hers to elicit her cooperation during our touch sessions. Staff members in the facility got used to seeing M and me singing and dancing our way down the hall toward her room. Sometimes I could persuade her to stop at a bench in the well-lit, plant-filled hallway to rest. She believed we were sitting “in the sunshine in the park” and would accept her foot massage there while smiling and nodding at the passersby. Once inside M’s room, I was often able to get her to lie down on the bed for a back massage by singing her a lullaby.



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The practitioner places her hand gently underneath the client's so that the client has freedom of movement at any time.

own life. In isolated moments, Adele showed considerable insight and awareness about her own situation. She displayed great enthusiasm for life, at nearly 90 years of age, in spite of her dementia. I always enjoyed spending time with her.

### Benefits Of Skilled Touch In Dementia Care

Although published data of “hard scientific evidence” is still scant, there is a growing body of research to support the efficacy of skilled touch in dementia care, and anecdotal reports from practitioners working with this population are extremely positive.

In a six-month pilot program on the use of massage therapy techniques as an intervention for problem behaviors in

Alzheimer’s patients conducted at the Methodist Home in Chicago, correlations were found. Back rubs were helpful for those confined to wheelchairs, those experiencing chronic pain and those exhibiting irritability or even anger. Foot massage proved helpful for those exhibiting hyperactive behavior or restlessness and “wandering” behaviors. Hand massage or face stroking

seemed to calm those exhibiting anxiety, worry, sadness and fearfulness. Massaging the temples, scalp and forehead helped relieve headaches and tension. Shoulder and neck massage seemed useful in alleviating tiredness, irritability or mild upset.<sup>3</sup>

Since the inability to communicate normally with language increases anxiety and frustration for people living



Utilizing touch as therapeutic modality and as a form of nonverbal communication, such as massage, for inducing relaxation would certainly make sense.

with dementia, utilizing touch as a form of nonverbal communication and a therapeutic modality, such as massage, for inducing relaxation would certainly make sense. In one study, people with AD who received hand massages and were spoken to in a calming manner had a reduction in pulse rate and in inappropriate behavior. Health-care professionals have speculated that massage may be beneficial in dementia care, not only because it is relaxing, but because it provides a form of social interaction and a moderate form of exercise.<sup>4</sup>

### Specialized Skills Required

It is important to have a thorough understanding of the symptoms and characteristics of dementia, and to develop the ability and patience to respond to those people in a compassionate and supportive way. Appropriate communication skills are essential. In addition to being trained in a variety of massage techniques, which can be adapted to non-table work with the frail elderly and ill, practitioners must learn to be very clear and concise to communicate effectively without being condescending. Assistance must be offered in such a way that the person with dementia is not made to feel incompetent. Some useful guidelines are listed below:

- Get the person’s attention before speaking. Make eye contact if possible;
- Call the person by name and gently touch his or her shoulder, arm or hand (if he or she seems open to physical contact);
- Communicate one idea or give one instruction at a time;
- Eliminate questions that require abstract thought, insight or reasoning;
- Avoid changing the subject abruptly;
- Speak slowly, calmly and in a normal tone of voice;
- Use simple and positive phrasing;
- Be patient! If an answer is required, give

## Reagan’s Death Puts Spotlight On Alzheimer’s

Ronald Reagan’s decision, five years after leaving the presidency, to reveal his diagnosis did more than any other single event to increase public awareness of Alzheimer’s disease, and to accelerate medical research and patient education.

By talking about it, Reagan literally brought Alzheimer’s disease “out of the closet.”

The recent death of the former president has, once again, highlighted for the general public the heartbreaking path of Alzheimer’s, and the desperate need for a cure. There is little doubt that whatever people thought about Ronald Reagan’s politics, he became a champion for people with Alzheimer’s disease and their caregivers throughout the world.

While wealth cannot stop the inexorable downward spiral of Alzheimer’s, Reagan’s experience was in some ways atypical, partly because he was in otherwise excellent health at the time of his diagnosis, and partly because he had 24-hour medical care throughout the years of his struggle. It is not known whether the role of any of his live-in nurses included that of a massage therapist. However, it is certain that he had unlimited access to any and all alternative and palliative care therapies available during what has been referred to as his “Long Goodbye.”

Nancy Reagan seems poised to become an advocate for those who suffer the burden of caregiving while bearing witness to the devastating effects of the disease on a loved one, without the benefit of her funds and resources. She has become increasingly vocal and active in promoting any research that can help “save other families from this pain.”

In 1995, the Reagans joined with the Alzheimer’s Association to create the Ronald and Nancy Reagan Research Institute, dedicated to accelerating the progress in Alzheimer’s research. The Institute awards \$15 million in research grants each year. For more information go to: [www.alz.org/Research/Reagan/overview].—Dawn Nelson



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The massage therapist builds rapport with resident Adele Fell, while offering hand massage.

the person plenty of time to respond;

- Reinforce necessary instructions with gentle physical guidance.

When making physical contact:

- Assume an equal or lower position when with the person;
- Make sure your contact/touch is conscious, caring and focused;
- Never force or persist in physical contact if the person is not open to receiving it;
- Treat the person the way you would want to be treated if you were in a similar circumstance.

A person diagnosed with Alzheimer's disease becomes progressively more frail and vulnerable in both body and mind. In addition to the ravages of a primary disease such as Alzheimer's, he or she may be experiencing other age-related changes, such as impaired eyesight or hearing, and may have one or more secondary conditions as well. It is not uncommon, for instance, to find a stroke survivor or someone with a lung or heart disease, who also has Alzheimer's.

As Alzheimer's and other dementia-related diseases progress, the activities that the confused person is able to engage in become more and more limited. At some point the person with dementia may be unable to remember even the most recent events or to anticipate future ones. The mind may be unable to follow the action or correctly interpret the images on a television screen or to understand the words of an audio story tape. The person may be unable to organize his or her thoughts enough to carry out even the simplest activities of daily living, such as bathing, dressing, teeth brushing and so on. Eventually, the person may do little else than sit with endless, vacant time and empty thoughts. Gentle, nonintrusive massage can engage the attention of such a person, temporarily drawing him or her back into present time and space.

### Specific Challenges For Therapists

Remember that the person with AD may not be able to recognize even the most

familiar people, may not be able to remember anything for more than a few moments and may not be able to carry on even a short conversation. At some stage in the disease process, the person may not want to sit down or sit still, for more than a few moments. Logic and reasoning are useless forms of communication. Moods may change from moment to moment. In the middle of a massage or touch session, the person may begin to laugh, swear, break into song or simply get up and walk away. Interacting with such a person requires patience, persistence and creativity!

The touch practitioner must be prepared for the unexpected, and develop the ability to remain calm and centered no matter what happens. It is critical to accept the way things are and drop any ideas or agenda of "doing" something that might "help" the person.

Skilled touch can be incorporated into a simple relating session in various ways such as lotioning dry skin, applying a soothing cream to itching skin on the face or elsewhere, warming cold

hands or feet, or giving a back rub while walking beside a person "on the move." At some point, any physical contact that resembles what many people usually think of as "massage" may need to be set aside in favor of a conscious, attentive presence and intentional touch as simple as holding the person's hand.

### Benefits For The Touch Practitioner

In his keynote address at an Alzheimer's conference I participated in a few years ago, a UCLA researcher, Dr. Jeffrey Cummings, made the following point: "Comprehensive care includes helping people with AD maintain contact with other people and reality because that contact is central to being human."<sup>5</sup>

The opportunity to relate to this particular group of men and women by sharing the gift of touch has been deeply rewarding for me in myriad ways. I feel I am contributing to an enhanced quality of life for those suffering from a devastating disease, such as Alzheimer's, in the moments we share. Yet I always feel I receive much more than I give. Sometimes it is drinking in the wisdom of a lifetime. Sometimes it is getting to know another human being on a level beyond verbal communication. Perhaps the greatest gift in relating to people with Alzheimer's and other forms of dementia, who have limited capacity for remembering the past or anticipating the future, is that our interaction compels me to reside in the present.

There are so many undertouched and touch-deprived individuals living out their days in care facilities. They cannot ask for the kind of conscious, caring physical contact for which they yearn. They cannot create it for themselves. It is imperative for our culture to meet the challenge of finding ways to accept and respond to those among us who are living in the advanced stages of a dementia such as Alzheimer's disease, despite their inherent dependency. As social worker

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Lisa Snyder exhorts in her book, *Speaking our Minds*, "It behooves us as a society to examine our approach to the care of people with Alzheimer's because the extent to which our communities embrace those afflicted is the extent to which we can ensure our own care."<sup>6</sup>

Dawn Nelson, founder of Compassionate Touch® for those in Later Life Stages, is an internationally recognized speaker, author and touch educator. Her most recent book is entitled, *From The Heart Through The Hands: The Power Of Touch In Caregiving* (Findhorn Press, Inc., 2001).

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### Useful Resources

The Alzheimer's Disease Education and Referral Center of the National Institute on

Aging. Call 800-438-4380, or send an E-mail to [adear@alzheimers.org](mailto:adear@alzheimers.org). Or, go online to [\[www.alzheimers.org\]](http://www.alzheimers.org).

**The Alzheimer's Association.** Call 800-272-3900 for information or support or to find a local chapter. Or, go to [\[www.alz.org\]](http://www.alz.org).

**National Cell Repository for Alzheimer's Disease.** A study on genetic factors in Alzheimer's is recruiting 1,000 families with at least two living siblings with the disease. To find out more, or to volunteer, call 800- 26-2839, or send an E-mail to: [alzstudy@iupui.edu](mailto:alzstudy@iupui.edu).

**AARP.** Caregivers of Alzheimer's patients can get online guidance at: [\[www.aarp.org/life/caregiving\]](http://www.aarp.org/life/caregiving).

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