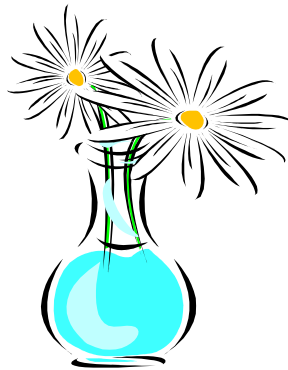


alzheimer's  association™

the compassion to care, the leadership to conquer

Especially for Caregivers: LATE STAGE CARE

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Visit our website: www.alzwa.org

Especially for Caregivers:

Late Stage Care

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Especially for Caregivers: Late Stage Care

Alzheimer's Association Services

Alzheimer's disease (pronounced Alz'-hi-merz) continues to affect the lives of millions of families. In the United States more than 4 million people live with Alzheimer's disease, and an estimated 100,000 live in Washington State. Yet there is a lack of public awareness about AD, and in general, only a vague understanding of what it does to the individuals affected, and to their families and loved ones. For all families, meeting the care needs of a loved one with Alzheimer's is a tremendous challenge.

Our mission is to educate, support and advocate for individuals, families, and communities affected by Alzheimer's disease and related disorders.

The Western and Central Washington State Chapter of the Alzheimer's Association serves 23 Washington counties, helping individuals and their families, as well as other service providers in the community who need information about Alzheimer's disease and related disorders. Alzheimer's HELPLINE Services are available to assist with a variety of needs and can help from the beginning for those suspecting Alzheimer's who need information on its warning signs, how it is diagnosed, and referrals to physicians for diagnosis and treatment of the disease. Once a diagnosis is made, there is information available on Caregiver Support Groups and other community resources that can help, as well as educational information and advice for caregivers on some of the specific challenges of caring for a loved one with Alzheimer's or a related disorder.

The Alzheimer's Association is a privately funded, non-profit organization. Services are provided without cost, although donations are always gratefully accepted. **Memberships are available that include such benefits as:**

- A quarterly newsletter to keep informed about the latest information on Alzheimer's and Alzheimer's care
- Free use of educational videos from our resource library
- Discounts on the purchase of books and other educational publications
- Information about training conferences
- Notification of special programs and events
- Discounts on events and programs (e.g. Education Conference)

Getting the Support You Need to Care for a Loved One at Home

When providing care at home, it is important to know about community resources that can help you to provide the best possible care, and to prevent the caregiver from "burning out".

Programs available through the Alzheimer's Association include:

HELPLINE, staffed by trained professionals who are knowledgeable and experienced in issues related to Alzheimer's disease and related disorders, have a variety of articles available for caregivers, and can provide information about the range of available local community resources that can help you.

SUPPORT GROUPS for caregivers and family members that provide a safe, non-judgmental group setting to talk about the challenges of caring for a loved one with Alzheimer's.

CARE COORDINATION through the *Connections* program to assess the care needs of your loved one, and to recommend programs and services that will support you.

The RESOURCE LIBRARY, providing books, pamphlets and videos on a wide variety of topics related to Alzheimer's care.



CONTACT HELPLINE

206-363-5500 or 1-800-848-7097

The HELPLINE is available 24 hours a day, seven days a week. Whether you need information on community resources for patients and families, support groups and classes, articles on a wide variety of topics related to caring for someone with Alzheimer's or a related disorder, or information on coping with the challenges of caregiving, the Alzheimer's HELPLINE is available to assist you.

Contact HELPLINE for information about:

- **Warning Signs of Alzheimer's**
- **Related Disorders**
- **Diagnosis & Treatment**
- **Physician Referrals**
- **Current Research**
- **Stages of Alzheimer's Care**
- **Caregiver Support**
- **Resources & Services**
- **Respite Care Options**
- **Case Management Services**
- **Counseling Services**
- **Home Safety Concerns**
- **Driving & Alzheimer's**
- **Long Term Care Options**
- **Residential Care Options**
- **Financial & Legal Concerns**
- **Education & Training**
- **Safe Return Program**

**...and other questions related to
Alzheimer's & related disorders**

FAMILY SERVICES & SUPPORT GROUPS

Coping with Alzheimer's disease does not have to be a lonely experience. The Family Services Program provides support to family and friends from the beginning through the Early Stage Memory Loss Seminar, as well as ongoing support through more than 100 caregiver support groups in Western and Central Washington. In addition to support, practical information about caregiving and community resources is provided. Contact HELPLINE to connect with a support group.

THE CONNECTIONS PROGRAM: ALZHEIMER'S CARE COORDINATION

PROGRAM GOAL:

The Connections Program provides direct assistance to families and individuals throughout the course of the disease through an interactive process. It helps caregivers to implement the actions necessary to improve the health of the family and its members.

The Care Consultant is available by phone or in person to meet with families at home, in a care facility, or at the Alzheimer's Association office. She will discuss your needs, provide individualized information and connect you to services and resources. She will also set a plan for follow-up on a regular basis so that you can be assured of getting the help you need.

This service is confidential and there is no charge (although contributions are always gratefully accepted).

ALZHEIMER'S RESOURCE CENTER

Books, pamphlets, newsletters and videos are available through our Resource Center. These materials cover a wide range of topics to inform families, health professionals and individuals diagnosed with Alzheimer's or a related disorder.

Books can be reviewed and purchased through the Resource Center. As mentioned previously, books are offered at a discount for chapter members.

Videos can be rented for a week for \$5.00 each. You may rent two videos at a time. Video rental is free of charge for chapter members.

EDUCATION & OUTREACH

Keeping health care professionals, families and friends informed is accomplished by such events as our **Annual Education Conference** and through a series of classes throughout the year for families and friends of Alzheimer's patients.

Dementia Care Trainings can be arranged for professional groups; and public education forums enhance caregiving skills and keep health care professionals, families and friends informed.

Our **Speaker's Bureau** provides presentations on a variety of topics related to Alzheimer's to inform and educate families, professionals and community groups.

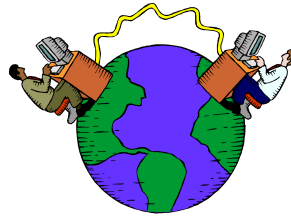
PUBLIC POLICY & ADVOCACY

The Alzheimer's Association, Western and Central Washington State Chapter, supports state and national policies that promote respite care, long-term care, research funding and other issues affecting the well-being of people with Alzheimer's and their families.

An **Annual Legislative Outreach Day** provides families and others impacted by Alzheimer's disease an opportunity to meet with legislators and advocate for legislation that addresses the needs of people with Alzheimer's.

If you or someone you know would like to join us in this effort to make a difference locally and nationally, call us at 1-800-848-7097 for more information!

VISIT OUR WEBSITE



Our chapter's website can be visited at www.alzwa.org. You will find several articles available, as well as additional information on our many programs and services.

WAYS YOU CAN HELP

Care Partners

Make a difference in the lives of people living with AD and their families through a *Care Partners* monthly pledge. It's simple: you pledge a monthly amount that is automatically deducted from your checking account or charged to your credit card. It's an easy way to touch the lives of so many, every month of the year.

Membership

Your annual membership helps provide financial support for **critically needed services**. You can play a vital role in helping families impacted by Alzheimer's disease. Benefits include our quarterly newsletter, discounts on trainings, conferences, books and materials, and free access to our video library.

Bequests, Memorials & Other Gifts

Your gift of a memorial, honorarium or special occasion tribute is a wonderful way to mark a special date or event. Bequests through your estate have a lasting impact. You can also designate the local Alzheimer's Association through your employee giving programs such as United Way, Employee Combined Fund Drive, or if your employer has a matching gift program.

Consider Volunteering

Volunteer your time and talents in many ways:

- To assist callers on the HELPLINE
- In the Resource Center
- Providing clerical support or computer skills
- Helping with Memory Walk, the Annual Auction or other special events
- Participating in the Annual Legislative Outreach Day
- Serving on committees

We have several interesting volunteer opportunities. Call (206) 363-5500 or 1-800-848-9707 for information.

LATE STAGE CARE

- **In the late stage of Alzheimer's disease, the brain is no longer able to tell the body what to do.** The person cannot walk or eat without assistance, and becomes incontinent of bowel and bladder. There is severe cognitive decline and all verbal abilities are lost. There is little purposeful activity. Loved ones are no longer recognized. Since at this time patients are immobile, they are at great risk for skin breakdown, contractures, elimination problems, pneumonia, and other infections. As Alzheimer's disease usually advances quite slowly, the patient might be 10 or even 15 years into the disease process before they reach this stage.
- **At this time, families are also at risk because of emotional overload.** Families may be caring for a person who can no longer respond (even those feisty comments are missed at this stage) and may not want to visit a person in a fetal position, whose hands and arms might be contracted. The time is approaching to let go of this person who has been slowly dying and whose unique personality has been changing.
- **It becomes necessary for family discussions about medical issues.** If the person with Alzheimer's does not have a living will, the family must agree on what comfort measures or medical procedures this person would have wanted.
- **The late stage is a sad time but also a time to prepare for a comfortable and dignified death.** Nursing home placement is very common at this time. If home care is the choice of the caregiver, daily help is needed and hospice care can be explored.
- **Hospice is a program of nursing care that is covered under Medicare and provides comfort measures only for those in the end stage of any terminal illness, including Alzheimer's disease.** Not only do nurses provide care but also they talk and counsel with the family. The family counseling continues for one year after the death of the patient. The patient is never transferred to a hospital for aggressive treatment but is allowed to die either at home or in the nursing facility.
- **There are important medical decisions to be made by the family at this time.** When death is inevitable, many choose to provide comfort measures only, such as pain medications and oxygen. This includes choosing to forego antibiotics to treat infections

since they will only prolong the dying process and will not cure the underlying problem – Alzheimer’s disease.

- **Eventually the swallow reflex no longer operates and the person with Alzheimer’s disease cannot swallow food or water without choking.** The issue of placing a feeding tube in the stomach becomes a real point of discussion. If there is no artificial feeding, the person will die of dehydration.

“Research and clinical evidence reveals that death by dehydration is a very compassionate and comfortable way to die. On the other hand, hydrating by a feeding tube or IV prolongs the dying process and may make it more uncomfortable by filling the body with fluids which can gather in the throat and lungs.” (1998 Dunn, H., *Hard Choices for Loving People*, A&A Publishers, Inc.).

This is a very emotional time for families. It is strongly recommended that families read materials and discuss planning options long before major decisions need to be made. Attending support group meetings can be extremely beneficial at this time. Only those facing these same decisions can understand the agony of making such difficult choices. Letting go is always difficult, even when someone has been ill for a long time.

Greater Pittsburgh Chapter, Alzheimer’s Association, revised 7/2000

THE FINAL ACT: PROMOTING COMFORT & DIGNITY UNTIL THE END

In his book, *The Dying of the Light*, Arthur Olson poignantly describes his wife Aila in the end stage of Alzheimer’s disease. Aila “remains in a world of her own, thankfully a peaceful world.” She cannot walk. She is moved each day from her bed into her wheel chair or recliner by a hydraulic lift. Her back from the waist up is frozen in a rigid position. Alia’s speech is limited to a few words. She often repeatedly speaks the word “happy.”

Alzheimer’s disease is a terminal disease; there is no way to slow or reverse progression of the destruction of the brain. As patients reach the final stage of Alzheimer’s disease, they become completely disabled and must rely on the care of others, even for the simplest tasks.

A recent study suggested that dementia patients who have a family caregiver receive a significant proportion of their care at home in the 90 days before death. Understanding the intricacies of care of an Alzheimer patient is essential to provide quality care. Treatment should be care-oriented (as opposed to cure-oriented) and focus on the patient’s immediate needs. Management strategies should strive for symptomatic relief of physical, emotional, and psychological discomfort. Treatments that seek to prolong life may not always be appropriate.

End stage disease process

By the end stage of Alzheimer’s disease, individuals require full-time care and assistance with all activities of daily life. They usually cannot ambulate, are incontinent, and therefore become susceptible to pneumonia, urinary tract infections, and decubitus ulceration. Myoclonus (clonic spasm or twitching of muscles), dyskensia (involuntary movements), seizures, and/or primitive reflexes (grasp, tactile suck, snout response) become increasingly more frequent. Individuals may have occasional moments of lucidity, when some recognizable component of their identity

surfaces. Eventually they may fall into a persistent vegetative state – severely physically debilitated, unable to move, swallow, or communicate.

Predicting the length of survival time once a person is considered at the end stage of the disease is often difficult. Recent studies, using the presence of severe dementia (stage seven in the Global Deterioration Scale and the presence of significant medical complications due to dementia (aspiration pneumonia, decubitus ulcers, etc.), point toward the possibility of predicting death within six months.

Whether in a long term nursing facility or in the home, health care professionals and caregivers can do much to promote the quality of life of the Alzheimer patient.

Satisfying basic physical and comfort needs

In the end stage, Alzheimer patients need complete personal care such as bathing and toileting, as well as dressing, grooming, and feeding. Patience is essential in providing good personal care; any sense of urgency may well transfer to the patient and could result in aggression or agitation.

To delay flexion contractures and preserve mobility, the caregiver can passively (while changing clothes for example) and, if possible, actively move the patient's arms and legs in the range of motion for all joints. However, this should not be done against strong resistance. Also, a comfort checklist, which includes such things as vocalizations, facial expressions, or behaviors, may be helpful in assessing the patient's comfort level. Finally, concurrent illness should be treated if it is contributing to the patient's discomfort.

Because disturbances of sleep and other daily rhythms often reflect the underlying damage to the brain, achieving "normal" sleep patterns may not be possible. An agitated patient, or even one with a flat affect, may be suffering from lack of sleep. If mild, transient nighttime restlessness appears, then the patient may be calmed with a warm drink, massage, or soothing touch. If this doesn't work, medications to promote sleep or emotional comfort may be indicated.

Preserving skin integrity

Pressure, environmental irritants, malnutrition, or incontinence can damage a patient's skin. Judicious daily inspection of the patient's skin is essential for preventing pressure ulcerations and for managing existing skin conditions. Massage and repositioning is helpful, as well as alternating pressure or egg crate mattresses. Diapers must be checked thoroughly and changed quickly.

Providing oral hygiene

Maintaining moisture and integrity of the gums and oral mucosa will preserve optimal dental function, assist in adequate nutritional uptake and therefore optimize patient comfort. This means brushing the patient's teeth twice daily with ingestible toothpaste and moistening the mouth with artificial saliva. Also regular cleanings from a dental hygienist are invaluable for total oral health maintenance.

Promoting optimal nutrition

Nutrition can be furnished in a variety of ways, but most likely is provided by either soft or pureed diets. Soft diets consist of fresh fruit, salad, nuts, and meat, cut or chopped into small pieces, for minimal chewing. Pureed diets are foods pulverized to a semi-liquid consistency that require no chewing.

The patient's weight, hydration status, and oral intake should be monitored. If a patient is prone to choke or aspirate, more semi-solid foods should be included in the diet (Liquid flows into the pharyngeal cavity quicker so solid food is easier to control) and less milk-based food, which may increase respiratory mucus. If oral intake is low, then vitamin and mineral supplements can be added to the diet.

In spite of careful planning and consideration, Alzheimer patients may encounter problems with eating such as difficulties in swallowing, esophageal obstruction, depression, or concurrent illness. Or they may lose the ability to feed themselves, or do not recognize what is offered as food. Optimal nutrition is thereby compromised and weight loss may ensue. If skillful hand feeding or dietary adjustments cannot stop weight loss, then a nasogastric (NG) tube or a gastrostomy tube may be considered, but the best evidence suggests that tube feeding is not helpful to the patient and can prolong the dying process.

Managing elimination needs

In Alzheimer's disease, patients will become incontinent. Incontinence does not occur because the patient forgets how to locate the rest room facilities or is unable to communicate this need; it is an eventuality of cortical damage. Urinary incontinence can be managed with the use of disposable, adult-size diapers. Diapers must be checked regularly and changed expeditiously when soiled. Male patients can use a condom catheter. Foley catheters should not be used to manage incontinence; they are generally not well tolerated and often require the use of hand restraints, which may compromise a patient's dignity and comfort.

As for bowel elimination, Alzheimer's patients often experience constipation. Medications, decreased food and liquid intake, and lack of motor activity decrease intestinal motility. Patients can be given bulk-forming substances such as bran or diet substitutes rich in whole grains, vegetables or fruit. Adequate oral fluid intake (a minimum of 1500 to 2000 ml/day) is a good preventative measure. A gentle laxative such as milk of magnesia is commonly used to promote morning bowel elimination (1 to 2 tablespoons every other evening). Care must be taken to ensure that the patient doesn't become dehydrated in the process of treating the constipation. Enemas and harsher chemical cathartics should be avoided because these may only increase pain or discomfort to the patient.

Maintaining safety with neurological manifestations

Seizures occur in 10% to 20% of patients in the end stage of disease. Anticonvulsants such as phenytoin (Dilantin) are most commonly used to control seizures in Alzheimer patients. Phenytoin can also be relatively toxic, affecting neurological function (loss of muscle coordination, rhythmical oscillation of eyes), behavioral features (hyperactivity, drowsiness, and hallucinations), and causing gastrointestinal problems (nausea, vomiting, anorexia, or epigastric pain).

Some patients develop myoclonus or myoclonic jerking. These involuntary movements are not life-threatening or indicative of an impending seizure. Primitive reflexes may emerge in some patients and could interfere with direct caregiving. There are no pharmacological treatments for either myoclonus or primitive reflexes. All the health care professional can do is to protect the patient from physical injury.

“The Final Act: Promoting Comfort and Dignity Until the End”, *Research & Practice*, Volume 4, Number 2

TUBE FEEDING IN PATIENTS WITH ADVANCED DEMENTIA

Researchers at the Johns Hopkins Geriatric Center in Baltimore, MD, report on their review of existing data and studies about tube feeding in patients with advanced dementia. They looked for evidence that tube feeding can prevent aspiration pneumonia, prolong survival, reduce the risk of sores or infections and improve function or keep the patient comfortable.

The researchers found no data to suggest that tube feeding improves any of these clinically important outcomes. Further, they found that the risks of tube feeding are substantial.

The researchers also say they believe that a comprehensive, motivated, conscientious program of hand feeding is the proper feeding for severely demented patients with eating difficulties. They conclude that the best evidence suggests that tube feeding will not help late stage Alzheimer’s patients who are declining and that the practice of tube feeding should be discouraged on clinical grounds.

Background

Patients with advanced dementia (including Alzheimer’s) frequently develop eating difficulties and weight loss. Feeding tubes are often used in this situation, even though the benefits and risk of this therapy are not clear.

The Alzheimer’s Association continues to take on the treatment of patients with advanced dementia:

“When the severely demented patient has previously made his or her wishes known and when there is co-existing illness, it is ethically permissible for the physician to withhold treatment that would serve mainly to prolong the dying process. When there is no prior expression or living will, responsible family members or the patient’s guardian should indicate their wishes regarding treatment...severely and irreversibly demented patients need only care given to make them comfortable. If the patient rejects food and water by mouth, it is ethically permissible to withhold nutrition and hydration artificially administered by vein or gastric tube.”

ACTIVITIES FOR THE PERSON IN LATE STAGE ALZHEIMER’S

For our purposes here, a person in the late stages of Alzheimer’s disease is someone: 1) whose mobility is compromised and who may even be bedridden; 2) who is incontinent; 3) who is dependent on others for all activities of daily living, including eating; 4) who has both a strong oral reflex (putting things in her mouth) and a tendency to choke easily.

Everything you do with someone who has Alzheimer’s disease is an activity, because everything takes brainpower. As the disease progresses, there is less the person can do for herself, but that

doesn't need to diminish the pleasure in the activity. Focus on strengths. Even in the late stage of Alzheimer's, when people are bedridden or close to it, most still respond to music, a friendly voice, and loving touch. Most of the activities for late stage residents are centered on ADL's (activities of daily living): bathing, dressing, grooming, feeding and changing. So fill them with music, a friendly voice, and your loving touch. Concentrate on the person, not the task at hand.

A few suggestions:

- Wake her up with a tape of singing birds, or a favorite hymn. A person who was in the military may respond to reveille. Or sing. Make awakening pleasant with a warm greeting.
- When you sit her up to feed her, use a nurturing touch, one that says, *I'm happy to be here with you*, not a custodial touch that conveys, *let's get this job over with*.
- If visiting in the nursing home, introduce yourself. In late stage she is unlikely to remember who you are, and her vision may have deteriorated so that she cannot recognize you, but your friendly voice may be familiar.

One of the strengths that long remains intact is the ability to laugh. Amazingly, most people in the late stage of Alzheimer's don't lose their sense of humor and the ability to smile until they are very near death. They continue to enjoy jokes, laughter and gentle bantering as well. People respond to the tone of your voice even when they can no longer beat you to the punch line or even understand why it's funny.

Although the deterioration of the brain has robbed them of the ability to speak coherently, we cannot know how much is still understood. Who knows what thoughts they may have and be unable to articulate? That's why reminiscing is still appropriate, too. If this is your relative, you know the person's life story. If your loved one is being assisted by a professional caregiver, make sure she or he knows her life story, and uses it to communicate.

Open the window and talk about how sweet the earth smell in spring, how gentle the morning light looks, what it was like in spring (or another season) where she once lived. Use this same communication technique throughout the day. Try asking questions that can be answered with a yes or no, such as *Do you remember when...* If you get a verbal response, that's terrific. If not, look for signs of recognition in the eyes, a smile or hand gestures. Discuss fashions and fabrics while dressing. Talk about food and how it's changed at mealtimes. At bath time, talk about claw foot tubs and what it was like long ago to get ready for a Saturday night date. In brief, use your environment to stimulate interest and pleasant responses.

When you don't know what to say, read aloud from her favorite book (if you know of one) or read something that has a pleasant rhyme or rhythm, such as poetry or limericks.

A person in the late stage of Alzheimer's may also suffer tremendous sensory losses. A man may keep his eyes closed to shut out all the confusion caused by skewed vision. This doesn't mean he's sleeping, and it doesn't mean he is trying to shut you out. Trying to correct eyeglass prescriptions at this stage is futile.

Similarly, someone with a hearing loss will be unable to participate – and may be frustrated if he cannot hear clearly what is going on. Hearing aids have a tendency to be more bothersome than helpful at this point, which adds to the difficulty.

A few hints:

❖ **Music in the Late Stage**

The theory is that as the brain deteriorates in Alzheimer's, simpler music is better – a single voice, unaccompanied, or a single instrument. Sometimes lullabies are appealing because the rhythm is similar to a mother's heartbeat, which infants heard in the womb; or a person may be soothed by the vibrations of a low drumbeat. Experiment with sounds that seem soothing.

❖ **Touch in the Late Stage**

Touch is a way that we get attention and pay attention. When we are daydreaming, someone touching our arm can quickly bring us back to reality. Touch helps to "ground" a person with Alzheimer's in the same way, helping him to attend to the task at hand. Many older people don't feel they are touched enough. They love receiving hugs and having their hands held. But be respectful of personal space. Some people may be uncomfortable with displays of affection. Their body language will tell you if you have overstepped their bounds.

Massage therapist Dawn Nelson says, "...Simple, care-filled touch of the human hand is one of the most ancient and effective means for relieving discomfort in the body, reducing stress, and inducing a state of relaxation."

The easiest way to begin for those of us who are not experienced in massage is to start by gently rubbing lotion into the body. Older skin tends to need more moisturizers, and soothing motions tend to come naturally as we work the lotion into the skin. Use a lotion that is smooth, not sticky. Avoid a startling or chilling effect by pouring a little into your palm and rubbing your hands together to warm both the lotion and your hands before touching the person's body.

A hand massage is a good intergenerational activity. Pour a little lotion into a child's hand, and tell her to gently rub it into her grandmother's hand until all the lotion has disappeared. But recognize that a person with arthritic hands may not welcome this. Be watchful for signs of pain or discomfort such as grimacing or pulling away.

Research is beginning to show the many positive benefits of massage beyond muscle relaxation. Loving, calming touch can reduce agitation and make a positive difference in the relationship between the caregiver and the person with dementia.

❖ **Exercise.** Massage is also a way to gain some of the benefits of exercise (improving circulation, decreasing muscular contraction), but if you can help a person with late stage Alzheimer's to use his muscles independently, that's even better. By the time he is bedridden, he may lack the physical coordination to play games such as tossing a ball, but consult a physical therapist for ideas on range of motion exercises to practice daily.

❖ **Group Activities.** In the home setting, group activities are not likely to be an option. In a long-term care setting, even if the person is bedridden, it may be possible to help him into a Geri-chair and wheel him into the activity room. But ask yourself first, *who benefits?* It is easy to over stimulate someone in the late stage of AD with too many people, too much noise, clutter, or a complex activity. Again, notice body language. If you bring him into a sing-along and you see him tapping his toes in rhythm, that's a good sign. On the other hand, clenched fists or jaws, a grimacing face or tense limbs will indicate signs of discomfort, and it's best to remove him from the group if he is over stimulated. If he's simply falling asleep, he may be taken back to his room to get a more comfortable rest, or may remain where he is if awakening in the group setting is not disturbing for him.

- ❖ **One-on-one Activities.** These are likely to be more consistently successful. Two keys to planning a successful activity are: 1) individualizing activities that fit his interests, and 2) experimenting to expand the list of his enjoyable activities.

A person with Alzheimer's always knows who loves him and is always comforted at some level by that loving care!

Adapted from "Activities For The Person In Late Stage Alzheimer's"
Cleveland Chapter, Alzheimer's Association

LEGAL & FINANCIAL ISSUES

At this stage, you have probably done your long-term care planning and addressed legal and financial concerns. However, if you need additional assistance, don't hesitate to contact HELPLINE. Copies of "Understanding Long-Term Care Options" and a list of Elder Law Attorneys are available upon request.

WHEN STAYING AT HOME IS NO LONGER AN OPTION: FINDING A NURSING HOME FOR SOMEONE WITH ALZHEIMER'S

There are many reasons why a person may need residential care. Although many families may be able to provide care themselves or to hire 24-hour care when the time comes, this is not possible in all situations. Often families feel tremendous guilt when they realize they can no longer manage without finding an assisted living facility or a nursing home that can care for their Alzheimer's patient.

Promises that a loved one will never have to go to a nursing home should be avoided! Instead, reassure your loved one that you will make certain that she or he will always receive the best possible care.

When the time comes that a person with Alzheimer's disease requires skilled care, and those needs cannot be met with either family or through paid homecare services, it is time to find a nursing home.

Skilled Nursing, also known as nursing home care, provides an intermediate or skilled nursing setting for those who require more intensive care. There are Skilled Nursing Homes that can provide specialized care for persons with Alzheimer's or related disorders.

There are many factors to consider in choosing residential care. A booklet entitled ***Residential Care: A Guide For Choosing A New Home*** is available upon request. If you would like a copy of this guide, contact the HELPLINE, and a copy will be mailed to you.

It is a good idea even if think you'll never need residential care, to familiarize yourself with the options available in your community. Remember that many long-term care residences have long waiting lists. It is better to have a plan and not need it than to urgently need residential care and not know where to turn. Examine all of your available options well ahead of time. Do all of your information gathering early on to be as prepared as possible.

NURSING HOME RESIDENTS' RIGHTS

- The Right to Be Fully Informed.
- The Right to Participate in Care
- The Right to Make Independent Choices
- The Right to Privacy and Confidentiality
- The Right to Dignity, Respect and Freedom
- The Right to Security for Possessions
- The Right to Remain in the Facility
- The Right to Raise Concerns or Complaints

"Know Your Rights to Care and Treatment in a Nursing Home", Alzheimer's Association, October 1997

"A ROOM IS AVAILABLE" HOW TO MAKE THE MOVE TO RESIDENTIAL CARE

What do I tell Mother? How can I make it easier for us all?

Gain Consensus

Try to involve all concerned family members in making the decision.

If the family is not in agreement, it can hinder the person's adjustment to the facility.

Keep It Brief, Simple

When you tell your family member about the move, the simple facts work best. "It's not safe for you to live alone anymore; we've found the best place we could for you." Long explanations or trying to convince the person, only increase their resistance. It is usually best to tell the person only a few days in advance of the move.

Acknowledge Feelings

It is crucial to acknowledge whatever feelings the person expresses. Anger and/or sadness are normal reactions to anticipation of a move and loss of independence. If the person expresses sadness, perhaps crying, join them in sorrow; allow your own tears and give your family member a hug. You may not need to do anything else.

If the person expresses anger, e.g. "I don't want to move; I want to stay in my own home," acknowledge these feelings by saying, "I know you don't want to move" or "I know you wish you could stay in your own home." This will help neutralize the anger, because the person feels understood. Then add, "We don't have a choice."

It is difficult to listen to feelings of anger, especially if they seem directed at you. Remember that sadness and anger are normal and healthy responses. The more your family member is able to express these feelings, the easier their adjustment will be to the move. Your allowing and listening to these feelings may help avoid depression after the move.

Reassure

“We love you and we’ll always be here for you.”

“We’ll do everything we can to help make it easier.”

Reassurance is what the person with memory loss seems to need most.

Redirect

The shock and intensity of feelings are great. Both your family member and you need time and space. Distract the person with food, a change of room, activity.

MAKING A SMOOTH TRANSITION

Moving a person with Alzheimer’s to a long term-care facility can be a traumatic experience for both the individual and the caregiver. There are several things that can be done to make this transition go more smoothly. In approaching ways to make the transition a more positive experience, look for signs from him to determine how much information is helpful. Generally, telling a person several days or weeks ahead of time results in increased trauma and anxiety. Consider sharing information on the person’s upcoming move based on the person’s ability to understand what is happening to handle stress.

Generally, the transition is easier if a family member or another familiar person spends time with the person at the time of admission. Many care facilities will make arrangements for you to have the first meal together, which can make him more comfortable.

There are other steps you can take before and during the transition to help the person adjust more easily. To smooth the transition for your loved one:

- **Personalize the room before admission.** Decorate your loved one’s room with personal items such as pictures, a favorite chair, end tables or a bedspread. Familiar items provide reassurance.
- **Choose the right time for the move.** Try to arrange the admission time during the individual’s “best” time of day. Avoid staff shift changes or mealtimes when facilities tend to be loud and hectic. Mid-morning hours are usually best because generally more staff is present and there is an activity he can attend right away.
- **Try not to show fear or sadness.** Do your best not to appear upset. A person with Alzheimer’s can be very perceptive of the emotions of others around him.

To prepare yourself for the transition:

- **Plan ahead.** Research the care that is available in your community soon after you receive a diagnosis. Many long-term care facilities have long waiting lists. It is important to get your name on the waiting list before a crisis occurs. Becoming familiar in advance with the staff will also help you to become more familiar with the facility.
- **Define your new caregiving role.** Your role changes (but doesn’t end) when a loved one moves into a care facility. You may want to come in for meals or do an activity together. This change can be very difficult, so you will want to stay active and pursue some of your own interests, as well. Enjoying yourself in no way means that you are abandoning or forgetting your loved one.

- **Talk with others about your feelings and emotions.** Many people find it helpful to join a support group sponsored by the Alzheimer's Association. You may also want to spend time getting to know other family members who visit loved ones at the care facility. Talking to others who are experiencing similar situations can be very helpful.
- **Maintain good communication with staff.** Share your concerns and suggestions with staff so they can provide a safe and comfortable environment for your loved one. Your information can not only help the staff to better understand your loved one as an individual, but improve his quality of life in his new home.
- **Develop a visitation schedule that is comfortable for you.** At first you may need some time away to define your new role and to accept the changes. When you visit, you may want to take along a friend or a family member if it is too difficult to visit alone at first. Encourage other family members to visit with you or at times when you are not able to visit. This is a good way to involve the family in the person's care.

EMOTIONAL FACTORS IN LONG TERM CARE PLACEMENT

Love is ordinarily associated with acts of nurturance, generosity, attentiveness, steadfast devotion, and active, heartfelt support. Placing a loved one in an assisted living facility or a nursing home requires some degree of separation and estrangement, while the nurturing care is provided by professional staff at your loved one's new home. Even though you know intellectually that is your best remaining choice, the emotions of guilt a caregiver often feels can create painful emotions during this time of transition.

The high costs of out-of-home placement can also produce turmoil and guilt when balancing how to help to cover these expenses while safeguarding your own life savings and financial future. It is a good idea to discuss and evaluate this decision with those who are knowledgeable and supportive (other family members, an Elder Law attorney, members of your support group, the family doctor or social worker).

Caregivers can assuage their feelings of guilt and better cope with their feelings by understanding that the eventual placement of a loved one when the care needs can no longer be met at home is an act of love and genuine caring. Sometimes feelings of envy and competition with professional caregivers can emerge when one has been the primary caregiver for a long time.

Another factor that often makes the adjustment process for the family caregiver difficult, is the common confusion and fear their loved one feels, and the initial resistance to his new environment. However, many of these initial fears and the accompanying resistance are overcome relatively soon simply through his familiarity with his new home, the caregiving staff and other residents.

Placing a loved one can be a cause for relief for an exhausted caregiver. Feelings of relief can also bring feelings of grief and guilt when the family caregiver confuses these natural feelings with a lack of love or caring. Social pressures can increase the stress when others, due to ignorance, a lack of empathy or just plain cruelty, harshly judge the caregiver who places a loved one in a long-term care home. Support groups can be enormously helpful in counteracting the negative effects of these kinds of pressure.

In general, spouses have the most difficult and complicated feelings about placing a wife or husband in a new home. This is related to the interdependency of spouses, as well as the deeper level and longer time of the commitment that exists in the spousal relationship than generally exists in the parent/child relationship.

Garner all of the support that you can at this critical time. *When you find yourself listening to that nagging internal voice that is making you feel guilty, recognize it as a negative feeling that is interfering with your well-being and causing you additional pain.* Refuse to listen to that negative refrain, and when you catch yourself listening, and feeling guilty, tell yourself “Stop!” and remind yourself that this difficult period of adjustment will be over soon, and it is *keeping you from a healthy adjustment* that will come given time. Reach out to friends and family who are supportive of you, and who have empathy. Push yourself a bit to begin to resume some of the activities you once enjoyed, and explore new activities.

Adapted from “Emotional Factors In Nursing Home Placement”, Gerald Amanda, PhD, Lincoln/Greater Nebraska Chapter Newsletter, October 1999, Alzheimer’s Association



Help Care Providers Get To Know Your Loved One Better By:

- **Providing photographs**
- **Sharing stories or memories**
- **Preparing a written personal history**
- **Explaining favorite hobbies, activities & interests**

VISITING IN THE NURSING HOME

There are multiple benefits from nursing home visits:

The Patient Benefits:

“ I forget, but I am not forgotten”

“My family is here. I am loved, valued, and still important to them.”

“My daughter will remind me what to do so I won’t be embarrassed.”

“Only my wife knows how I like my clothes done.”

The Staff Benefits:

“Visitors become friends and make our jobs more interesting.”

“Families offer the personal attention and time that we can’t provide.”

“It’s the families that remember to thank us for special attention.”

The Visitor Benefits:

“I know the staff and what they can do, and they know my husband deserves the best.”

“I can keep Mom going and check in on Aunt Bessie at the same time.”

“I feel closer to my husband now that it’s not me fighting with him to bathe.”

“I promised ‘til death do us part and I have not abandoned her.”

What Do I Say/Do When There Is Nothing to Say/Do?

- Tell her you love her, you came to see her and you’ll be back again (regardless of her reaction to your visit).
- Sit close, away from the window glare, at eye level and touch or hold as preferred by her.
- Listen for clues to feelings in body language, eyes or repeated phrases.
- Gentle teasing or joking provides a sense of continuity and pleasure to those who have always communicated this way in their families.
- Silence can be golden...tender moments watching birds, listening to music, and shared private meditation or prayer.
- Respect personal space and possessions. Ask before moving things around or sitting on the bed. Go slowly. Keep pace with her concentration and tolerance.
- Substitute shared activities for limited conversation: manicures, hairdos, massages, watching entertainment, looking at photos, writing letters together, walks and outings.
- Start your visiting rituals: reading favorite passages, verses or stories from a treasured book; visiting other residents together.
- Reminisce about a special life event or holiday gathering, her first car, the smell of a wood stove, baking at home. (With severe memory impairment, go back further in time, as the earlier memories are the ones we lose last).
- Use the arts and your skills: music, poetry, photos, video or audio tapes, artwork, games (even if she can’t play as well, she may still enjoy the activity).
- Bring along holiday decorations or special foods or holiday items from the past.
- Bring out of town family or friends, and take pictures of them visiting with her at the nursing home.

- Organize a private coffee hour and invite friends and family to visit. Make sure she has something to wear that day.

“Visiting The Memory Impaired Nursing Home Resident”, Lisa Gwyther, MSW, *PERSPECTIVES*, Western and Central Washington State Chapter Newsletter, Alzheimer’s Association, Winter 1997.

CONSIDER THE BENEFITS OF HOSPICE SERVICES

The primary concept of hospice is to assist persons with terminal illness and their loved ones to live as fully as possible the time they have left together. Hospice programs recognize dying as a normal process that should neither be hastened nor prolonged.

Hospice in the United States began in the early 1970’s and the first hospice opened in 1974. Public acceptance has been remarkable and today over 1700 programs exist nationwide to provide compassionate care to people in the last few months of their lives.

Most hospice care is provided at home, assisting persons to live as comfortably as possible, and helping their loved ones through this challenging time of life. The vast majority of hospice care is Medicare-covered when one’s physician has given a prognosis of 6 months or less.

Hospice programs offer:

- Respect for personal philosophy, privacy, life style and needs of the patient and family.
- Information and assistance for the patient and family members related to personal care, nutrition, pain management, symptom control, medical diagnosis and other concerns.
- Participation in the decision-making process related to living and the process of dying.
- Committed professional team of registered nurses, nurses’ aides, social workers, chaplains, physical therapists and a medical director.
- Physical comfort and care, including management of pain
- Planning and coordination of care between home and hospital including help with insurance and financial concerns.
- Counseling and spiritual comfort to deal with the human needs of the patient and family both during the time preceding death and in bereavement.
- Dedicated trained volunteer caregivers to help with transportation, household tasks, companionship, relief care and emotional support for the patient and family.
- Availability of hospice registered nurse staff, 24-hours a day, 7 days a week, as needed by the patient and family.
- Hope and the possibility to live life and the end of life as fully as possible.

“Hospice As A Way Of Caring”, Alma Stanford,
Washington State Catholic Conference publication

PREPARING FOR APPROACHING DEATH

When a person enters the final stage of the dying process, two different dynamics are at work, which are closely inter-related and interdependent. On the physical plane the body begins the final process of shutting down, which will end when all the physical symptoms cease to function. Usually this is an orderly and undramatic progressive series of physical changes which are not medical emergencies requiring invasive interventions. These physical changes are a normal, natural way in which the body prepares itself to stop, and the most appropriate kinds of responses are comfort-enhancing measures.

The other dynamic of the dying process is at work on the emotional-spiritual-mental plane, and is a different kind of process. The “spirit” of the dying person begins the final process of release from the body, its immediate environment, and all the attachments. This release also tends to follow its own priorities, which may include the resolution of whatever is unfinished of a practical nature, and the receiving of permission from family members to let go. These events are the normal, natural way in which the spirit prepares to move from this experience into the next dimension of life. The most appropriate kinds of responses to the emotional-spiritual-mental changes are those responses that support and encourage this release and transition.

When a person’s body is ready and wanting to stop, but the person is still unresolved or not reconciled over some important issue or with some significant relationship, he/she may tend to linger even though uncomfortable or debilitated in order to finish whatever needs finishing. On the other hand, when a person is emotionally-spiritually-mentally resolved and ready for this release, but his/her body has not completed its final physical process, the person will continue to live until the physical shutdown is completed.

The experience we call death occurs when the body completes its natural process of shutting down, and when the “spirit” completes its natural process of reconciling and finishing. These two processes need to happen in a way appropriate and unique to the values, beliefs and life-style of the dying person.

As death approaches, it is important for you to know what to expect and how to respond in ways that will help your loved one to accomplish this transition with support, understanding and ease. This is the great gift of love you have to offer your loved one as this moment approaches.

The physical and emotional-spiritual-mental signs and symptoms of impending death which follow are offered to help you to understand the natural kinds of things that may happen and how you can respond appropriately. Not all these signs and symptoms will occur with every person, nor will they occur in this particular sequence. Each person is unique and needs to do things in his/her own way. This is not the time to try to change your loved one, but the time to give full acceptance, support and comfort.

The following signs and symptoms described are indicative of how the body prepares itself for the final stage of life.

1. **Coolness:** The person’s hand and arms, and feet and then legs may be increasingly cool to the touch. At the same time, the color of the skin may change. The underside of the body may become darker and the skin more mottled. This is a normal indication that the circulation of blood is decreasing to the body’s extremities and being reserved for the most vital organs. Keep the person warm with a blanket, but do not use an electric one.

2. **Sleeping:** The person may spend an increasing amount of time sleeping and appear to be uncommunicative or unresponsive and at times be difficult to arouse. This normal change is due in part to changes in the metabolism of the body. Sit with your loved one, hold his hand, and do

not shake or speak loudly, but speak softly and naturally. Plan to spend time with him during those times when he seems most alert or awake. Speak to him directly as you normally would, even though there may be no response. Never assume the person cannot hear. Hearing is the last of the senses to be lost.

3. **Disorientation:** The person may seem to be confused about the time, place and identity of people surrounding him, including close and familiar people. This is also due in part to the metabolic changes. Identify yourself by name as you enter the room rather than asking him to guess who you are. Speak softly, clearly and truthfully when you need to communicate something important for his comfort, such as “It is time to take your medicine”, and explain the reason for the communication, such as, “...So you won’t begin to hurt.” Do not use this method to manipulate the patient to meet your needs.

4. **Incontinence:** He may lose control of bowel and bladder as the muscles that control these functions begin to relax. Discuss with the hospice nurse what can be done to protect the bed and to keep him clean and comfortable.

5. **Congestion:** The person may have gurgling sounds coming from his chest as though marbles were rolling around inside. These sounds may become very loud. This normal change is due to the decrease of fluid intake and an inability to cough up normal secretions. You may also gently wipe the mouth with a moist cloth. The sound of congestion does not indicate the onset of severe or new pain.

6. **Restlessness:** He may make restless and repetitive motions such as pulling at bed linen or clothing. This often happens and is due in part to the decrease in oxygen circulation to the brain and to metabolic changes. Do not interfere with or try to restrain such motions. To have a calming effect, speak in a quiet, natural way, lightly massage his forehead, read to him or play some soothing music.

7. **Fluid and Food Decrease:** The person may have a decrease in appetite and thirst, wanting little or no food or fluid. The body will naturally begin to conserve energy expended on these tasks. Do not force food or drink on the person, or try to use guilt to manipulate him into eating or drinking something. To do this only makes him more uncomfortable. Small chips of ice, frozen Gatorade or juice may be refreshing in the mouth. If he is able to swallow, fluids may be given in small amounts by syringe (ask the hospice nurse for guidance). Glycerine swabs may keep the mouth and lips moist and comfortable. A cool, moist washcloth on the forehead may also increase physical comfort.

8. **Urine Decrease:** The person’s urine output normally decreases and may become “tea” colored, indicating concentrated urine. This is due to decreased fluid intake as well as decrease in circulation of the kidneys. Consult with the hospice nurse to determine whether there may be a need to insert or to irrigate a catheter.

9. **Breathing Pattern Change:** The person’s regular breathing pattern may change with the onset of a different breathing pace. A particular pattern consists of breathing irregularly (e.g., shallow breaths with periods of no breathing of 5 to 30 seconds and up to a full minute). This is called “Cheyne-Stokes” breathing. He may also experience periods of rapid shallow pant-like breathing. These patterns are very common and indicate decrease in circulation in the internal organs. Elevating the head and/or turning him on his side may bring comfort. Hold his hand. Speak gently.

NORMAL EMOTIONAL- SPIRITUAL- MENTAL SIGNS & SYMPTOMS WITH APPROPRIATE RESPONSES

1. **Withdrawal:** The person may seem unresponsive, withdrawn, or in a comatose-like state. This indicates preparation for release, a detaching from surroundings and relationships, and a beginning of “letting go.” Since hearing remains all the way to the end, speak to your loved one in your normal tone of voice. Identify yourself by name when you speak, hold his hand, and say whatever you need to say that will help him to “let go.”
2. **Vision-Like Experiences:** The person may speak or claim to have spoken to persons who have already died, or to see or have seen places not presently accessible or visible to you. This does not necessarily indicate an hallucination or a drug reaction. He is beginning to detach from this life and is being prepared for the transition so it will not be frightening. Do not contradict, explain away, belittle or argue about what the person claims to have seen or heard. It is real for your loved one. Affirm his experiences. They are normal and common.
3. **Restlessness:** The person may perform repetitive or restless tasks. Things that may be helpful in calming him are comforting conversation, soothing music and reassurance that it is okay to let go.
4. **Fluid and Food Decrease:** When he wants little or no fluid or food, this may indicate that the person is ready for a final shutdown. Do not try to force food or fluid. You may help your loved one by giving him permission to let go whenever he is ready. At the same time affirm the person’s ongoing value to you and the good you will carry forward into your life that you received from him.
5. **Decreased Socialization:** He may only want to be with a very few or even just one person. This is a sign of preparation for release and an affirming of who the support is most needed from in order to make the appropriate transition. If you are not able to be a part of this “inner circle” at the end, it does not mean that you are not loved or not important. It means that you have already fulfilled your task with him and it is the time for you to say “Goodbye”. If you are part of the “inner circle” of support, he needs your affirmation, support and permission.
6. **Unusual Communications:** The person may make a seemingly “out of character “ or non-sequitur statement, gesture or request. This indicates that he is ready to say goodbye and is “testing” to see if you are ready to let him go. Accept the moment as a beautiful gift when it is offered. Kiss, hug, hold, cry and say whatever you most need to say.
7. **Giving Permission:** Giving permission to your loved one to let go without making him feel guilty for leaving or trying to keep him with you to meet your own needs can be difficult. A dying person will normally try to hold on, even though it brings prolonged discomfort, in order to make sure that those left behind will be all right. Therefore, your ability to release the dying person from this concern and to give him assurance that it is all right to let go whenever he is ready is one of the greatest gifts you have to give your loved one at this time.
8. **Saying Good-Bye:** When the person is ready to die and you are able to let go, this is the time to say goodbye. Saying goodbye is your final gift of love to the loved one. It achieves closure and makes the final release possible. It may be helpful to lay in bed with the person and then say everything you need to say. It may be as simple as saying, “I love you.” It may include saying “I’m sorry for whatever I contributed to any tensions or difficulties in our relationship.” It may also include saying thank you for what he has given to your life.

Tears are a normal and natural part of saying, "Goodbye." Tears do not need to be hidden from your loved one or apologized for. They express your love and help you to let go.

Adapted from "Preparing For Approaching Death", Hospice of Hillsborough

AFTER YOUR LOSS

Many families wish to have a brain autopsy to confirm the diagnosis of Alzheimer's. This information is also helpful to Alzheimer's research. Contact HELPLINE for information about brain autopsy resources.

Two publications that may be helpful for you in handling funeral, legal and financial arrangements are: "**A Guide To Dealing With Death**" a booklet available through the Washington **State Office Of The Attorney General** at **1-800-551-4636** or **1-800-276-9883 (TTY)** or "**What To Do When A Death Occurs**", available through the **Senior Rights Assistance Program** at **206-448-5720, 1-800-972-9990** or **1-800-448-5025 (TTY)**.

GRIEF AND BEREAVEMENT

Every person has his own way of dealing with loss. When feelings of loss cannot be shared, one feels very isolated and emotionally neglected. Taking the time to allow each family member to share feelings about loss may help to strengthen family unity, and alleviate deferred or buried grief, and facilitate healing.

All hospice programs include grief and bereavement services for families and loved ones, and other resources may exist in your community that will help you to heal.

10 STEPS: PARTICIPATING IN YOUR OWN HEALING

1. Talk about what happened, and how it felt to you. Find other people who understand.
2. Talk about your loved one – the good, the fun, the sad things that have happened.
3. Laugh without guilt. If he or she survived you, wouldn't you want them to laugh.
4. Cry with abandon. Allow yourself to cry, require yourself to cry. This is a part of your healing.
5. Exercise daily. Exercise provides a natural source of endorphins. Endorphins are the natural substances in the body that mediate our perceptions of pain.
6. Sleep as naturally as possible. Do without medication if you can. Natural sleep allows you to dream. REM sleep (when dreaming occurs) is important, and should not be disrupted.
7. Eat well. Nourish your body with healthy foods.

8. Tend to your spirit. Take a walk in the woods or along the beach. Spend time with friends. Write in a journal about your feelings, and how your life is changing.
9. Think about the things you are going to do for yourself that are special. Make a list!
10. Do some special tending to yourself! Your heart is broken – tend gently and lovingly to yourself.



We hope this guide about late stage care has been helpful in meeting your need for information at this time.

Other key informational booklets are available with information you may need:

- **Facts About Alzheimer’s Disease**
- **Especially For Caregivers: Early Stage Care**
- **Especially For Caregivers: Middle Stage Care**
- **Understanding Long-Term Care Options**
- **Alzheimer’s: No Cure Yet, But Reasons For Hope**

In addition, we have extensive topical files with articles on a wide variety of concerns related to providing dementia care.

If you need additional information, contact our 24/7 HELPLINE at (206) 363-5500 or 1-800-848-7097.