

Common Displays of Unmet Needs

Agitation

Agitation is one of the most common displays in Alzheimer's patients, and it can be one of the most difficult for both you and your loved one. Agitation may be displayed in any of the following ways:

- * Restlessness
- * Pacing
- * Yelling
- * Searching and rummaging around for something
- * Refusing to do something

Triggers that could be causing the agitation include:

- * Your loved one is anxious, scared, depressed, confused, or doesn't understand what is happening in a current situation.
- * Your loved one is having a hallucination or delusion that is frightening
- * If the care partner has left the house, they may be scared that they can't find them
- * Fatigue, hunger, dehydration
- * New person in their environment
- * Too many people or too much stimuli in their environment

Tips for deescalating the agitation:

- * Remain calm and comforting
- * Do not get angry or criticize your loved one
- * Redirect the person's attention to another activity or topic
- * Minimize the stimuli in the environment (i.e. turn off TV or music)
- * Reassure your loved one that you are there, ask if you can help, and let them know they are safe

Combativeness

Combativeness can often come as a result of your loved one being scared, frustrated, or unable to verbalize their feelings or possible discomfort. Triggers that could cause combativeness include:

- * Being tired
- * Unable to communicate they are experiencing pain
- * Too much going on around them (i.e. television, radio, clutter, people)
- * Feeling lost or abandoned
- * Being asked too many questions
- * Frustrated at not understanding instructions or what you are asking them to do
- * They may be picking up on your stress level and irritation

Tips for deescalating combativeness:

- * Reassure in a calm and comforting tone
- * Look for causes of frustration and redirect to a different activity
- * Do not provide explanations. Be encouraging and meet your loved one where they are at in their perceptions
- * Avoid touching them until the combativeness has deescalated
- * Step away from your loved one so that they don't feel trapped
- * Provide a positive distraction

Hallucinations

Hallucinations are false perceptions of things or events. When your loved one experiences an hallucination, they will see, hear, touch, and smell something that is not there. If the hallucination is of something non-threatening and pleasant for your loved one, then you may not need to be alarmed. If they talk to you about the hallucination, you can respond as though you see it too. If however, your loved one experiences hallucinations that are frightening or are happening on a frequent basis, then it is recommended that you contact your doctor to determine the cause.

Tips for dealing with hallucinations:

- * Offer reassurance
- * Do not argue with them about what they see
- * Distract by offering to take a walk or go into a different room, especially if the hallucination is making them anxious
- * Divert their attention to an activity or music
- * Assess the environment for noises that could have been misinterpreted (i.e. television, radio, automatic ice maker, an alarm clock)

Hoarding and Hiding Items

Your loved one may start accumulating or saving items. In the beginning you may notice it and not think much about it. As the disease progresses, you may realize that this is becoming a problem. For example, if your loved one is still able to grocery shop for themselves, they may buy the same box of cereal every time they go the store. They may never throw away an empty coffee can and you find them everywhere in the house.

It may also be common for your loved one to hide things, and not necessarily things of value. Your loved one can get very creative with hiding places. To the opposite extreme, your loved one could leave clothes, papers, and other items lying out in the open so that the items don't get lost.

Whichever hoarding and hiding actions your loved one exhibits, the reasons for this could be any of the following:

- * Progression of the disease which does not allow your loved one to distinguish what is worth keeping and what needs to be thrown away
- * If your loved one tended to collect things prior to the Alzheimer's, then this action will typically intensify with the Alzheimer's
- * Anxiety and fear of loss
- * If your loved one was protective of people and things prior to the dementia, hiding things and placing them in 'safe' places, can be the only way they can still try and protect things.

Here are some suggestions to help with these displays:

- * Be reassuring and do not show irritation or frustration
- * Do not try and remove items in front of your loved one. This can cause agitation and combativeness
- * If you feel the need to remove some of the items, do so when your loved one is asleep. Don't remove all of the items; leaving several of the items still provides your loved one with their possessions.
- * For the items that you take away, please make sure they are completely removed from the home. If you put them in the garbage can, your loved one is likely to find them.
- * Make notes on your loved one's favorite hiding places and check them often.
- * If your loved one keeps stacks of newspapers and magazines, you can cancel the subscriptions

Shadowing

Shadowing occurs when your loved one follows you everywhere. Usually the reason is that as their care partner, they trust you. You are their safety and security in a world that is becoming more and more confusing and unfamiliar. You may think they are following you because they don't trust you, but that is usually not the case. They feel comfortable as long as you are in their direct line of vision.

Some tips to help provide reassurance could include:

- * Give them a hug and tell them you love them
- * Make sure you stick to a routine for yourself, as this will strengthen your loved one's sense of security
- * Make sure they are involved in activities throughout the day as this gives them something, other than you, to focus on
- * Play music that is calm and soothing
- * If you do have to be gone from the home, try to only be gone for short periods of time. Your loved one no longer has the ability to keep track of time so 5 minutes could seem like an hour.



- * Have someone come and be with you and your loved one. This can allow you some privacy to get things done. Try to have them come the same time every day to reinforce the routine for your loved one.

No matter how much you love the person with Alzheimer's disease and you want to be with them, shadowing can make you feel like you're suffocating and can increase your stress and agitation. Having someone relieve you on a daily basis can be of tremendous support, even if it is for short periods of time.

Sundowning & Sleep Issues

Sundowning and sleep issues can be very difficult to handle as they cause such exhaustion for the care partner. It is important to note that not all individuals with early Alzheimer's will suffer from both of these issues. They can commonly occur together, but not always. It is estimated that between 20-25% of individuals, at some point during their disease, will experience symptoms of anxiety, agitation, increased confusion that begin in the late afternoon hours and continue through the night.

Researchers are not completely sure what causes sundowning syndrome, but it is thought to be related to the individual's internal body clock no longer properly functioning. Other possible triggers for sundowning and sleep issues could include:

- * Exhaustion at the end of the day
- * Depression
- * Hunger
- * Changes to hearing and vision, which affect their perception on the time of day
- * Sundowning can occur more frequently in the fall and winter months

The following tips might be helpful to lessen the effects of sundowning:

- * Make sure there is plenty of light in the room
- * Observe to see if other triggers might be causing the sundowning
- * Involve them in an activity late in the afternoon
- * Establish an evening ritual that is soothing and calming. For example, you could provide a hand and/or foot massage or listen to soothing music
- * Make sure that doors and exits are locked and secure to prevent nighttime wandering
- * Provide a light snack before bedtime (no sugar or caffeine)
- * Allow the person to sleep where they are most comfortable. If that becomes a recliner or another bedroom, that's fine.
- * Call your doctor if these actions continue in case your loved one might have a urinary tract infection (UTI) or other medical issue that could be causing sleep problems.

Suspicious (also known as Delusions)

As the disease progresses, your loved one may start making accusations. This occurs as they lose their ability to make appropriate judgments. Suspicious can also occur if your loved one has developed the habit of hiding things. When they are unable to find something, their first thought is that someone stole it. Suspicious/delusions can also take the form of thinking that imposters are in the home, or believing that their care partner and other family members have been replaced by imposters. It is estimated that one in three people with Alzheimer's will suffer from delusions.

Some tips to help move through the suspicious/delusions include:

- * Let the person talk. Be reassuring with them.
- * As much as you will want to reason with them, it will only cause further agitation and frustration.
- * Validate their perception of the situation by asking questions such as "What did they do?" or "When did you notice your jewelry missing?"
- * Do not agree with the accusation, but instead provide reassuring comments that are comforting. For example, "I'm going to help you look until we find your jewelry."
- * Provide reassurance when the missing item has been found. A hug or an "I love you" can help restore their sense of safety.

Wandering

Wandering can be one of the most frightening things to happen to you and your loved one. The Alzheimer's Association estimates that as many as 60% of individuals with Alzheimer's will wander. For this reason, it is important to register with the MedicAlert + Safe Return program. The details on this program are listed below.

As with the other displays of unmet needs, you will need to look for triggers that could cause your loved one to feel the need to get away. Some of those triggers could include:

- * Looking for something that is lost
- * Thinking that they are in a strange place and they need to get back home
- * Looking for a specific person
- * Sundowning
- * Change in environmental stimulus
- * They may be having a delusion, such as the need to go to work or feeling the need to complete something from their past.
- * They may think they are in danger
- * New medications could be causing an adverse reaction
- * Agitation



MedicAlert + Safe Return Program

Three out of five individuals with Alzheimer's will wander during the course of the disease. MedicAlert + Alzheimer's Association Safe Return is a 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia that wander or have a medical emergency. They provide 24-hour assistance, no matter when or where the person is reported missing.

If an individual with Alzheimer's or a related dementia wanders and becomes lost, caregivers can call the 24-hour emergency response line to report it. A community support network will be activated, including local Alzheimer's Association chapters and law enforcement agencies, to help reunite the family or caregiver with the person who wandered. With this enhanced service, critical medical information will be provided to emergency responders when needed.

To get more information and to enroll for the MedicAlert + Safe Return program, please call 1-888-572-8566 or register online at: www.medicalert.org/safereturn