

Best Practices in Addressing Hallucinations

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Bugs crawling up your legs and under the bed; glass shards floating in your drinking water; phones that keep ringing but when you answer there is no one there; people barging into your room, keeping you up in the middle of the night... Hallucinations can be scary!



Unfortunately, hallucinations are a common symptom of dementia. Up to 53% of patients with Alzheimer's disease will experience hallucinations, most frequently during moderate-to-late stages (5-6) of the disease. Patients experiencing sundowners have an increased incidence of hallucinations. In Lewy Body disease, hallucinations are often the first noticeable symptom affecting up to 65% of patients. In other dementia-related conditions, such as vascular dementia or Parkinson's, hallucinations may or may not be present at any given stage.

Differing from delusions, which are a set of unshakable false beliefs, hallucinations are sensations that appear real but are created by the brain. Hallucinations are frequently visual, but auditory, olfactory and tactile hallucinations have also been observed. While some hallucinations are neutral and non-threatening, and some patients are even amused by them (one of our clients used to enjoy lounging in her backyard to watch *all the little children play and frolic around*), others can be very threatening and trigger defensive behaviors that may be harmful for the patient and others. It is not uncommon to find patients running from their homes in the middle of the night to escape from *intruders*, or refusing to drink or eat a meal because of the *bugs!* Hallucinatory experiences may also include sensing the presence of people or animals as well as feelings of floating or falling. Patients suffering from hallucinations are at increased risk for anxiety, panic attacks,

agitation and behavioral problems.

Hallucinations often blend fragments of real past experiences, one's own memories, with events seen on the news or TV programs. These fragments are bound together by strong feelings such as love, fear or hate. A Santa Barbara resident who insisted on hiding under the bed because she kept hearing *bombs exploding*, it turns out, had actually lived in London during German WWII aerial attacks. Even though the bombing was a hallucination, the fear related to it was a very real memory.

Watching a loved one suffer from hallucinations is extremely distressing for caregivers. Their first instinct is to explain to the patient that what they are experiencing is not real. This often just increases the patient's sense of urgency and agitation. To them, in the moment, the hallucinations are real. *Bombs ARE falling! Bugs ARE crawling! Intruders ARE here!* Caregivers often feel powerless in combating an imaginary enemy while coping with the very real anxiety and fear they cause.

When confronting someone suffering from a frightening hallucination, first of all KEEP CALM. Try to understand the nature of the hallucination and the feelings associated with it. Do not attempt to debunk or explain away the hallucination. Instead, try to insert yourself into

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alzheimer's association®

California Central Coast Chapter

Santa Barbara County
1528 Chapala St., #204
Santa Barbara, CA 93101
Tel: 805.892.4259

120 E. Jones St, #113
Santa Maria, CA 93454
Tel: 805.636.6432

San Luis Obispo County
71 Zaca Ln Suite 110
San Luis Obispo, CA 93401
Tel: 805.547.3830

Ventura County
2580 E. Main St Suite 201
Ventura, CA 93003
Tel: 805.494.5200

24-Hour Helpline:
800.272.3900

alz.org/CaCentral



Tips

Biggest mistakes when dealing with hallucinations:

- ◆ Trying to convince them it is not real
- ◆ Ignoring it
- ◆ Failing to provide comforting reassurance
- ◆ Waiting too long to seek medical assistance
- ◆ Following advice of under-qualified medical professionals
- ◆ Not adjusting expectations
- ◆ Not titrating
- ◆ Overstating risk of medications
- ◆ Failing to follow-up with reevaluations as dementia progresses.

When visiting the doctor bring notes:

- ◆ The kind and nature of the hallucination(s)
- ◆ Time of day it occurred and during what event (nap, meal, exercise)
- ◆ How long it lasted
- ◆ How the person responded (if they were distressed) and the words they used to describe what they experienced
- ◆ Current medications and dosages (including supplements and over-the-counter medications)
- ◆ Medical history, including any previous hearing or vision conditions and mental health issues
- ◆ Use of alcohol or other recreational drugs.

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the hallucination, make it believable for you as well, so that you may act as a trusted ally to your loved one against the perceived threat. They will welcome your reassurance and companionship and accept whatever creative means you employ to neutralize the threat. Step into their hallucination, then guide them out.

If *intruders are here*, you may want to hide with your loved one in a safe place and, in a convincing manner, *call the sheriff's department*. If *bugs are crawling around* you may get a spray bottle full of water and, with the help of your loved one, use it to *kill them*. If *bombs are falling* you may want to crawl under the bed together and offer a safety hat, which could be used for continued comfort even as the *bombardment slows down and ceases*.

Every hallucination is unique. Be creative. Find your own way of neutralizing the threat, and provide support and reassurance. And as soon as the person feels safer, offer their favorite treat. In this situation, an ice-cream cone is far more effective than Prozac!

Although sometimes benign, hallucinations can have serious, real consequences and vary greatly. Therefore patients should be evaluated for treatment by a specialist. Conventionally, hallucinations are treated with anti-psychotic drugs. Given the complexities of dementia and the plethora of dementia-related diseases, make sure the prescribing doctor is indeed a specialist with ample experience in dementia care, preferably a neurologist.

Do not wait too long to seek medical treatment. The sooner treatment strategies are implemented, the better chances of a positive result. Do not wait for a crisis to seek assistance: most treatments require titration (starting with minimal doses and increasing in small increments



until optimum dosage is achieved) which cannot be done in an emergency. Medications must also be meticulously re-evaluated on a regular basis as dementia-related changes in the brain continue to occur potentially affecting the appropriateness and efficacy of treatment.

Some families are reluctant to use medications to help alleviate the psychological symptoms of dementia. Although it is true that there are no drugs approved by the FDA for this specific use, experts have identified several medications that are remarkably safe and effective WHEN USED PROPERLY. The right combination can soothe a mind affected with hallucinations and greatly enhance well-being.

Above all, do not underestimate the problem. A calm, friendly approach from caregivers and medical assistance from experts are essential in keeping hallucinations under control and your loved one safe and comfortable.



Tools:

ALZ.org - Vast array of information about the disease.

Support Groups (listing on page 5) - As no patient with dementia has the same experiences as the next, caregivers learn valuable information in support groups regarding how to prepare for and respond to daily challenging dementia symptoms.