

Dementia and Wandering: Suggestions for family caregivers

*This document is the transcript of the video: Dementia and Wandering: Suggestions for family caregivers; the video can be viewed on youtube at: <http://www.youtube.com/watch?v=zD8PEyZZbhI>
The video and the transcript have been prepared by Swapna Kishore.*

Introduction

We often hear of cases where elders wandered and got lost. A confused elder got off a train at night when the family was sleeping. Or at a fair, a son left his mother on a bench to buy her a soft drink and returned to find her missing. A parent walked out of home. The wandering of a loved one with dementia can traumatize the entire family. Sometimes the person returns after a while, or is brought back by an alert neighbor, but sometimes the person remains missing for days, weeks, months, even years. Or is found injured, or worse...

Wandering is a common problem amongst persons with dementia. Alzheimer's Association USA estimates that "More than 60 percent of those with dementia will wander, and if a person is not found within 24 hours, up to half of individuals who wander will suffer serious injury or death."

This video discusses wandering. It discusses some reasons that make dementia patients wander, and provides some suggestions and approaches to tackle wandering. However, please note that every person with dementia is different, and there is no foolproof way to understand why a person wanders and how to prevent it. A tip may work for one person one day, and fail for that person the next day. It may work for one person but not another. Family members, given their knowledge of the person's likes and dislikes, past habits, childhood and youth, and so on, are in a position to think of creative solutions, but in spite of all their precautions, the patient may still wander, and they need to be prepared to search for the person.

When we talk of wandering, here are some aspects to consider:

- 1> **Reduce the need to wander:** Patients who step out of the home, or the train, or vanish into a crowd do so because they have some need. They don't *want* to get lost. Understanding the patient's need and the context of the patient's wandering enables family caregivers to come up with ways to reduce the wandering.
- 2> **Reduce the chances of exit:** Wandering happens when a patient leaves a safe, familiar space. We can consider approaches to stop the person from leaving the home or compound
- 3> **Be prepared for wandering:** Howsoever alert we may remain, the patient could wander off some day. We need to be prepared for this possibility
- 4> **Get them home safely as soon as possible:** Use multiple ways to locate the patient, and also make it easier for others to contact the family if they spot the patient

Reduce the need to wander:

What sort of unmet needs could make a patient wander?

Maybe Amma wants to go to the toilet, or is hungry or thirsty. Maybe she wants to watch TV. Or she wants to have a relaxed, friendly chat with a family member or friend.

Maybe she is uncomfortable. Too hot, too cold, clothes too tight. She wants to change. She may be wanting to sit in the sun. General restlessness is another possible cause. Sometimes, the patient is restless or frustrated or angry and starts pacing. Or maybe the patient needs fresh air and opens a door expecting a nice green garden.

Some needs come from patterns of their old life, from what they used to do years ago. They are disoriented about where they are, which year, which city. A retired manager sees the clock or hears a bus or has just finished breakfast, and remembers that he must rush to office. Or a voice in the corridor or the ring of the doorbell makes Amma think her friend has come to meet her. Or a vegetable seller calls out, and she wants to buy tomatoes.

Maybe the home looks unfamiliar because the patient is thinking of the past. Or the disorientation makes the room look somehow wrong, and so the patient gets up to find a safe and familiar place. Or a temple she likes to visit, or a park.

Often, patients just want to "go home", but their image of "home" is a vague one from the past. The home she wants maybe from another city, years ago...

We cannot understand all reasons that could make someone with dementia pace restlessly or get confused and open a door and step outside. We may not always know why a patient wants to climb over a compound wall. But if we understand the common reasons why the patient wanders, that may help us reduce the chance of such wandering. For this, we can observe the patient before he or she tries to wander. Did he squirm? Maybe he wants to go to the bathroom, or is constipated, or physically uncomfortable. Did he look bored, angry, concerned, confused? When he got up, was his walk purposeful, like he knew what he wanted, or was it confused, as if he didn't know what he wanted, or didn't know where to find it? Did he look up suddenly at a sound? Does he tend to wander at the same time every day? Was there a change in his routine that day, or the previous day--for example, too many visitors, an outside trip, anything that could have disturbed or confused him? We can keep records for a few days to try and understand why the patient heads for the door. Look for connections, patterns, clues. As family members, we can use our knowledge of the patient's likes and dislikes, past habits, etc., to think of the likely needs and triggers.

We can also ask the patient what he wanted, but he may not know or remember, and may get agitated if he feels probed, so we keep our questions gentle and don't insist on answers.

Always check for medical reasons. Could the person be unwell or in pain, or needing new spectacles or hearing aids? A review of the medicines he is taking may also help.

And how we can reduce the need to wander?

Telling Papa not to wander does not solve the problem, because Papa was not wandering. He was trying to meet some need, and so he won't understand our explanations or will forget them. We can explain, but we cannot **depend** on that explanation to stop the wandering. Getting angry or upset at Papa does not help either.

Our understanding of why our loved one wanders helps us make changes so that our loved one can fulfill a need without getting lost, or maybe he or she remains peaceful and engaged and does not get restless enough to wander, or maybe he or she can walk in a safe zone without getting hurt or lost.

We can make home safer and easier for patients. Signs help. Even a simple arrow can make a difference. Good lighting helps. We can remove clutter. TVs confuse many patients, because they cannot distinguish between make-believe and reality. Switch it off, move it to another room, or reduce the volume. Mirrors in bathrooms can frighten some patients.

If Amma is often looking for company, seat her at a place from where she can see other family members so that she doesn't need to walk around to locate you. Surround her with comfortable, familiar objects. Or employ an attendant who provides her company and keeps her safe.

Basically, we use creative changes to give our loved ones a home where they can do things they want, where they are comfortable, safe, and loved.

We can also find ways to reduce boredom, anxiety, restlessness. Most patients feel less stressed if they have a daily routine and a structured day. Enjoyment can be added through fun activities like games or simple jigsaws. Or give the patient a box of interesting objects to fiddle with, albums to see, etc. These reduce boredom and restlessness. Some patients enjoy tasks they consider useful, like shelling peas or sorting papers. Some love music. We must select an approach that works well for our patient.

Relaxing together can also reduce restlessness. We can sit with them in the balcony and watch children play outside.

Some patients like to pace, and all patients need physical exercise, so create safe zones at home where they can walk without feeling hemmed in. Or take them out for a walk as part of their daily routine.

Restlessness and pacing at night is a common problem. Night lights can reduce disorientation and chances of injury. Lock the doors at night. Consult the doctor for possible changes in diet and other factors to reduce pacing at night, such as reducing evening fluids and caffeine.

When outside home--a market, road, or train--don't leave the patient alone even for a few minutes. Outside settings often confuse and alarm patients, increasing their chances of wandering. Night travel is particularly risky. Even vacations can stress patients, especially new places, lots of people around, noise, festivities, and days packed with fun. The patient may enjoy for some time, but then blank out or become anxious.

We also need creative solutions to handle patients who are determined to leave home for some task. Papa wants to go to work. Can we remove the clock that reminds Papa of office? Or keep him occupied at the time he usually thinks of office, so that he does not check the clock? If Amma thinks the doorbell means she has a visitor, can we switch to a bell that sounds like a bird chirping, which Amma will not recognize as a doorbell?

For some patients in the initial stages, reality orientation can help remind them of where they actually are, but such reminders backfire for patients who are more disoriented or confused. If you tell Papa that he retired ten years ago so he can't go to work, he may not believe you, so maybe you can convince him that it is a Sunday and even show him a Sunday newspaper as proof. Distractions or explanations work mainly if patients believe them and they fit well in the patients' "reality".

One possibility is to remove objects that patients need while going out. Hide their outdoor footwear, the handbag or briefcase they carry. When they pause and start looking for this object, this may distract them and stop their urge to leave.

Different persons respond differently to various solutions. Also, something that works on one day may not work on another day. Caregivers have to keep thinking of solutions, and also remain gentle with themselves and the patients if their solution does not work.

Reduce the chances of exit

When a patient roams inside the home, that is walking or pacing. The danger begins when he or she steps out of the door (or out of a compound).

We need to prevent the patient actually stepping out. How can we do that? We can try to distance them from the door, or make the door less visible or attractive, or do things so that they hesitate to open the door, or they cannot open the door even if they try.

Moving the patient to a room farther inside an apartment can help.

A door is also less visible if painted the same color as the surrounding wall.

Some patients who are confused or restless may open a door not because they want to go out, but just because they happen to see the door. A stop sign on the door may stop them because they automatically respond to the cue.

A black painted stripe or black foot-mat could stop many patients, because they think those black patches are holes, and won't try to cross them.

An interesting technique sometimes suggested is placing a mirror on the door. The patient sees her reflection, thinks of it as another person and steps back, or starts talking to "that old lady." Of course, like any other technique, this can backfire. Another patient may get angry (a rude old woman is staring at me) or even say, "Why is there a mirror on the door?"

Some families place a basket of attractive objects near the door to distract the patient who start playing with them instead of going out.

Think about the door's knob or latch. Can it be made less visible, more difficult to open? Or placed higher up, beyond reach? Or can you use "childproof" knob which the patient cannot open? Can an alarm be arranged so that it rings if the door opens?

Often all these help, but are not foolproof, and the families lock the door to prevent wandering. Locking a door seems a good strategy, but it cannot be the only strategy because family members

forget to lock the door when in a hurry or when going out for "just one minute". Many cases of wandering happen in those few minutes of a door left unlocked.

Prominent locks on the door may agitate some patients (they protest, am I a prisoner?) though some patients may accept such locks as a matter of fact. Consider a smaller lock placed well above eye level. Or maybe lock the door from outside.

If your home has a lawn and compound, it allows the patient open space for a stroll, but make sure the patient cannot climb over the walls and gate, and lock the gate. If that is not possible, accompany the patient when she is walking in the compound.

If you see the patient walking out, calmly guide the patient back to safety. Don't get agitated. Don't argue with her or contradict her or tell her she was doing something wrong. Remember she was only trying to fulfill some need. You may need to walk with her for a while and distract her to bring her back safely. Later, think of ways to reduce future such incidents.

Be prepared for wandering

Chances are, howsoever hard you try, a patient may someday wander out. Be prepared for this.

Ensure that the patient always carries some identity. Use multiple ways to do this, so that at least some of them work. You can tell the patient to carry a cellphone or wallet, but do not expect him to remember that, or depend on that. Other options are tags and necklaces, but they should be difficult to remove or the patients may take them off. Some countries have identity bracelets, but very few people in India know about such bracelets and people trying to help a confused elder may not spot the contact number on a bracelet, so don't let bracelets be the only form of identity that the patient carries. Keep visiting cards in the patient's pockets. Stitch labels with your name and phone number prominently on Papa's kurtas or Amma's nightgowns, in places not visible to the patient so that it does not bother or anger them, but so that these labels are visible to anyone who might notice the patient wandering and then alert you.

If your city has a "safe return" program for dementia patients, or some GPS tracking or radio device, see if you can enroll.

When a patient wanders, locating them fast is very important to get them home safe. Once outside the home, the patient is likely to find the surroundings very different from what she expected. She may have expected a compound with an outhouse, a garden, a muddy road with cyclists or village children. Instead there may be an apartment corridor with lift and stairs, or a crowded road. There are skyscrapers instead of trees. Even if the patient reaches a familiar garden or temple, she can get confused about how to return. Or she may board a bus or fall in a ditch or get hit by a car.

Remember, most dementia patients do not ask for help. Even if someone tries to help them, they cannot remember their name or address, or they give some old address or city name.

Locating a missing patient alone is not possible; we need help from neighbors, friends, relatives, others, and all these people must be told beforehand about the chances of the patient wandering. When the patient goes missing, we don't have time for comments like, *But Auntie was fine last*

week, she even offered me tea, or Why can't you let your mother go for a walk, are you her jailor, or Why worry, Auntie is not a child. We don't have time to convince people that the problem is genuine.

Let friends know that if the patient visits them alone, they should inform you so that you don't worry. Tell everyone nearby--neighbors, shop keepers, security guards--that if they see the patient alone they must stop her and contact you. Explain about confusion and memory loss. Tell them not to let the patient keep walking alone. The patient may otherwise walk past them and instead of stopping her, they may even help her get into a bus if they think that's what she wants.

Have an identification kit ready to help tell people what Amma or Papa look like. This includes basic information, physical description, recent photograph, and when the patient wanders off, all you can do is just add the last clothes worn, time and place of getting lost, and circulate copies immediately. Keep important numbers handy: persons and organizations for help, police station, etc. Maybe even torches to hunt at night. Gather what you think you'll need, so that you won't waste time collecting them when the patient goes missing.

Get them home safe and fast

Suppose Amma walks out, what then? Skip investigating who forgot to lock the door. Skip the anger, the scolding, guilt, blame, and panic. Focus on the search.

Tell the security guards and neighbors immediately. Quickly check what Amma has taken along, because that might tell you what she wanted to do. Pull in everyone who can help--family members, friends, colleagues, neighbors, nearby shopkeepers, rickshaw drivers; give them the photograph and information, request them to help, and ask them to spread the word using phone calls, social media, organizations, whatever. Make one person stay home in case the patient comes back. Start the looking around. Look at the patient's favorite places: the park, temple, friends nearby. Look at dangerous places. Look in directions she may have gone in, especially places that may have seemed familiar to her, more like "home" or her favorite temple or market. Or the road she typically used to take, or that you have often driven her on. Ask at bus-stops and autorickshaw stands whether she was seen boarding a vehicle. Check the ditches near the home; sometimes patients fall down and don't think of shouting for help, or are too injured. Try to trace the path Amma took by showing her photo and asking at shops, bus-stops etc. Ask your friends to fan out through the city. Sometimes patients keep walking and are found several kilometers away. Involve organizations that can help. Notify the police and make sure that the police have the photo and particulars in case Amma is brought to the police station. Stay calm, but work with speed.

And when you find her, be gentle and reassuring, and avoid extreme emotions that could baffle or unsettle her. Thank everyone who helped, accepting their comments gracefully, even if some of them are critical. Remember you needed their help, and may need it again. Then, when you are calmer, see how you can handle things differently to reduce the risk of more wandering next time.

Conclusion

Most family caregivers are tense that their loved ones may wander, and with over 60% patients doing so at some time or the other, this risk is very real. Yet every family and the situation is different, and every family has to find its own creative solutions to tackle this challenge.

To reduce the chances of the patient's wandering, it helps to understand what the patient wants, or what is causing restlessness. The patient is less likely to wander if it is easy and safe to meet the need. Or families can look for various ways to reduce the patient's restlessness. Be especially careful at night, or when the patient is outside home.

The chance of actual exit can be reduced by making exits like doors or gates less visible and attractive, by using ways that discourage the patient from wanting to open them, and by making these exits difficult to open. Having multiple strategies helps.

Patients still manage to wander in spite of all our efforts, so it is necessary to be prepared for such events. Ensure that the patient always carries some identity, and tell everyone about the wandering problem. Keep necessary information handy for emergencies.

Getting patients back home safe and fast is the focus when the patient wanders. Tell everyone, ask everyone for help, spread the word, look everywhere. And when you find our loved one, be reassuring and gentle with them, while also thanking everyone you asked for help.

Being creative, being flexible, being gentle with themselves and the patient is key for families coping with the wandering problem. Please contact support groups and dementia associations for more tips and advice. We hope you succeed in keeping your loved one safe. We also hope you remain alert about noticing and helping other dementia patients who may have wandered.

Thank you for watching this video.