



FAMILY/CAREGIVER GUIDELINES: WANDERING & EXIT SEEKING IN PEOPLE LIVING WITH DEMENTIA

Introduction

Dementia causes disorientation and this can lead to wandering and exit seeking. People with dementia who wander are moving about in ways that may appear aimless but often have purpose. They may wander in response to an unmet basic need like human contact, hunger, or thirst; a noisy or confusing environment; or because they are experiencing some type of distress, like pain or the need to use the toilet. Wandering can be dangerous and as such, it is our priority to set out this guideline to educate family members/caregivers in ensuring the safety of their loved ones.

WARNING SIGNS OF WANDERING & GETTING LOST

- Return from regular walk or drive later than usual.
- Talks about fulfilling former obligations such as going to work.
- Appears restless with repetitive movement or pacing.
- Forget the way to access to familiar places.
- Searching for home even he/she is at home.
- Unable to locate the familiar places in the house like bathroom or living room.
- Asks the whereabouts of past friends, relative or family members.
- Appears anxious in crowded areas like shopping malls, markets, or restaurants.
- Acts as if doing a hobby or daily routine activities, but nothing gets done.

FACTORS CONTRIBUTING TO GETTING LOST

- Wandering Tendencies - A person with dementia tends to go missing during routine daily activities such as going for walks or a drive. At times, he/she may have direct access to exits of his/her home. While unnoticed by family members/caregivers, he/she may impulsively leave home and head to an unknown venue.
- Absence of supervision - Due to absence or lack of supervision, he/she can go missing within minutes
- Searching - He/she may wander and get lost while searching for something or someone, such as past friends.
- Basic Needs - He/she may search for a bathroom or food or want to go outdoors.
- Past Routine - He/she may follow past routines and try to go to work or run errands.
- Visual-spatial problems - He/she can get lost even in familiar places because dementia affects the parts of the brain important for visual guidance and navigation.

TIPS OF PREVENTION WANDERING & EXIT SEEKING

- Create a daily plan.
- Daily reality orientation to time, place and surrounding family members/caregiver.
- Provide exercise and physical activities to reduce stress and boredom.
- Identify the cause of restlessness and triggers of wandering. Ensure all basic needs of him/her are being fulfilled.
- Speak to his/her doctor for a physical check up to identify any pain or discomfort that may trigger the need to wander. Discuss about the possible side effects of medication which might increase confusion or possible incontinence.
- Identify his/her dominant hand. Wandering patterns generally follow his/her dominant hand. He/she tends to go to the right if he/she is right-handed, or to the left if he/she is left-handed.
- Provide a safe and supervised space at home or in the yard for walking or pacing. Going for walks especially in the evening can reduce the anxiety and wandering.
- Avoid crowded places that are confusing and cause disorientation.
- Keep car keys or any other door keys out of his/her reach.
- Make sure he/she carries some kind of ID, GPS tracking device or wears a medical bracelet.
- Involve neighbours and local community members. It is helpful to have them keep friendly eye on your loved one from time to time.
- Identify wandering and exit seeking behaviors. Keep a record or diary about patterns of wandering behavior including certain times of the day, frequency, and responses to certain situations.
- Home modifications:
 1. Use signage to orientate him/her to his/her home environment such as bathroom, bedroom etc.
 2. Distract attention from entries and exits by painting the doors the same color as the wall.
 3. Place a red 'STOP' signs on the door if painting on the door is not allowed.
 4. Alarms or sensors on exterior doors and windows.

WHEN A PERSON WITH DEMENTIA IS MISSING

1. Stay calm Search in the house especially in areas like closets and the yard.
2. Think of clues as to where he/she may have gone.
3. If you can't find him/her after 15 minutes, begin search-and-rescue efforts immediately.
4. Have an updated photo and current medication list. Be prepared to share information about where and when he/she was last seen, what he/she was wearing when last seen, and if he/she likes to be called by a preferred name or nickname. If he/she is believed to be in a car, a description of the vehicle with plate number should be provided.
5. Create a "missing person" post on various social media platforms.
6. Return to where your loved one went missing and look for witnesses who might have seen him/her.
7. Contact all nearby hospitals to inquire about him/her.
8. Be aware of the dangerous places in your neighborhood that need to be searched first.
9. To contact the Alzheimer's Disease Foundation Malaysia hotline at: +603-7931 5850 who has an extensive network of personnel that can help. The hotline is available during office hours. After office hours, you may post on their Facebook page <https://www.facebook.com/adfmpj/>
10. Call to make police report is more than 24 hours. Reinforce to the police officer that the missing person has dementia.

When A Person With Dementia Returns Home

- Inform police immediately if a police report was made.
- Inform neighbours and all parties involved in the search-and-rescue effort.
- Do not scold or show anxiety or how worried or inconvenienced you have been. He/she may have been confused and frightened him/herself.
- Provide reassurance and return to normal routine as soon as possible.
- Kindly share your story on social media to increase the awareness in this issue among families with people with dementia.