ethical guidelines

TRACKING DEVICES

Background

As Alzheimer's disease or a related dementia involves different areas of the brain certain abilities will be affected. Many of these symptoms can leave the person at risk of getting lost. Whether going out for a daily stroll, driving to the grocery store or leaving home in search of quieter surroundings the potential for getting lost is there.

Research has shown that when a person with Alzheimer's disease is lost for more than 12 hours, there is a 50 per cent chance of finding the person injured or dead.¹ Therefore it is vitally important to prevent people from getting lost, or to find him or her quickly.

People who provide care, whether at home or in a long-term care facility, are often concerned about this risk of getting lost and interested in options that can help to ease this concern.

The technology

Tracking devices are technological tools that can be used to observe a person's movements or to identify a person's location and thus can help find people who are lost. A transmitter carried by a person relays radio signals back to a receiver that identifies the location of the carrier. Depending on the particular technology used, there are limits to the range of coverage and the source of power (such as batteries). The cost of purchase and maintenance can vary greatly.

These technologies include:

- Global Positioning Satellite (GPS) -- both personal devices and those built into some models of cars
- Homing devices (radio tracking)
- **Cell phones** -- technology is growing at a rapid rate. On newer models, the user can activate a locating system, usually by dialing 911.

The issues

For people with Alzheimer's disease:

Loss of privacy: Tracking devices have the potential to be used for ongoing surveillance in addition to locating a person who is lost.

Loss of freedom: People have the need to walk around and access the outdoors freely. Caregivers concerned about the risk of a person getting lost may impose restrictions. These may limit the size of person's environment, or the ability to go outside. The use of a tracking device may also increase the person's freedom

Loss of contact with caregivers: Relying on technology may decrease the amount of interaction a person has with caregivers. For example, if a person wore a device that alerted caregivers when he/she was exiting the building, caregivers might not check in as regularly as they would when the person was not wearing a device.

¹ Koester R.J. (1999) Lost Alzheimer's Disease Search Management. dbS productions, Charlottesville, VA.

For those who provide care:

Limits of technology: No single technology can guarantee a person with Alzheimer's disease will not leave a building or that they will be found.

Costs: Purchase and maintenance costs of these devices may be unaffordable.

For police and search and rescue personnel:

Government monitoring its citizens: Police do not want to use the technology to monitor citizens' activities, only to facilitate search efforts and help people with Alzheimer's disease get home safely and quickly. However, some people may feel that the use of tracking devices is an invasion of privacy and that police and others are acting as "big brother."

Preferred choice

The recommended approach is to prevent people with Alzheimer's disease from getting lost. If the person becomes lost, there should be a plan in place to find the person as quickly as possible using a multi-faceted approach.

Prevention:

To decrease or eliminate opportunities where the person is at risk for getting lost:

• **Develop strategies** -- whether at home or in a long-term care facility, develop a plan that keeps the person as active as possible and engaged in meaningful activities. Provide the freedom and opportunity to walk. For example, a regular walking routine may help reduce the desire for the person to leave.

Identify triggers that may cause the person to want to leave. Explore possible strategies to prevent the person from wanting to leave. Try different approaches, keep track of what works and what doesn't and share the information with others.

• Adapt the environment -- create a safe environment that accommodates the person's need to walk. This may include finding ways to prevent people from going outside unsupervised by disguising doors, or identifying when people do leave by using door alarms.

Planning:

In case the person gets lost/goes missing safeguards can be put in place to facilitate the search and location of the person.

• Register the person with Safely Home™ -- a nationwide program designed to help find a person who is lost and to assist in a safe return home. Developed by the Alzheimer Society of Canada in partnership with the Royal Canadian Mounted Police, the registry stores vital information confidentially on a police database. Police anywhere in Canada and the United States can access the information. All people with Alzheimer's disease who are at risk of getting lost should be registered with Safely Home.

- Learn what to do if the person gets lost. Those who provide care need to involve police and search and rescue personnel as early as possible. For families at home, the Safely Home registration package includes information on steps to follow. For organizations that provide care, the Alzheimer Society has produced a pre-plan manual, SEARCH is an Emergency, to help them prepare should a person in their care get lost.
- **Tracking devices** are one option to consider when a person is at risk of getting lost. In determining if tracking devices are an option, the benefits, risks and costs of different technologies must be weighed along with the safety needs of the person. Those who consider tracking devices must do so only to locate and rescue, and must have the permission of the person or his/her designated decision-maker. Getting lost can be a frightening experience for both people with Alzheimer's disease and those who provide their care. Recognizing the person's risk of getting lost and preparing for it can help get people safely home.

Resources:

- 1. <u>Safely Home Program</u> -- contact your local Alzheimer Society or visit the Safely Home section.
- 2. SEARCH is an Emergency -- pre-plan manual for the search and rescue of missing people with Alzheimer's disease and related dementias. Contact your local Alzheimer Society.