

NEAC's Advice on the Use of GPS Tracking Devices in Dementia Care to LandSAR, 30/04/2019

Background

On 23rd November 2018 NEAC received a request for advice from LandSAR on ethical issues in the use of tracking devices.

Concern has been raised around the rapidly growing number of older people who are the subject of Search and Rescue call-outs. These call-outs are usually managed by police, but for certain people 'Wandtrak' technology is employed which can locate them remotely. These are triggered if the person is reported 'lost', and require a qualified person with specific technology to locate the signal from high ground.

GPS cell phone-based tracking devices are now readily available, affordable, and effective. This technology differs from the current standard, insofar as it "always on" rather than working by activation. Further, these new devices can be monitored by family and facilities, with the potential to reduce police involvement. Advice is being sought prior to LandSAR adding such technology to their inventory of recommended support services.

NEAC's Advice on Dementia to the Associate Minister of Health, 5 May 2016

In its 2016 advice to the Associate Minister of Health, NEAC noted the breadth of psychological issues for those living with dementia:

There is a very high rate of behavioural and psychological complications during the course of dementia...including depression, psychosis, disorientation and night walking, and aggression."

The significance of night walking, in particular, is increased by the fact that the majority of people with dementia are living in their own homes in the community. NEAC stated that:

New Zealand can do better in ensuring people with dementia are valued and supported to maintain their independence. We can also do better in recognising and supporting families so that they can provide the best support and care possible.

Supporting people to remain safely in their own homes helps maintain a person's individuality, and also reduces expenditure on residential care. Consequently, ensuring that families, whanau, and friends are well-supported will contribute to better health outcomes and reduced health care costs:

Living well is about much more than physical health. It is also about social inclusion and maintaining independence as much as possible. This is particularly important for people living in the community; there needs to be good access to a range of community and home based services and support to enable the person to live well in the community for as long as possible.

NEAC also outlined the key ethical values and considerations needed in the care of people diagnosed with dementia:

- **Respect/mana** – every person has an inherent value or mana; mana places an expectation on others and New Zealand communities to recognise and uphold the value of each person throughout the course of their life.
- **People first** – knowing the person with dementia and what is important to them is essential.
- **Independence** – doing things for ourselves, doing what we enjoy or find important and making our own choices helps maintain a sense of self and wellbeing; people have a right to make decisions that others might disagree with or think unwise.
- **Interdependence** – we are all dependent on each other in everyday life; the person with dementia and their family, whanau and friends can be more reliant on each other and therefore these relationships are even more critical.
- **Best interests** – any person’s best interests are a balance between what is important to them and what is important for them; there are no absolutes and what is important may change over time.
- **Solidarity** – supportive communities and environments are important for people with dementia and their families, whanau, and friends; everyone has a role to play.

Advice to LandSAR

Of particular interest to NEAC is care based on:

- knowing the person with dementia (a ‘people first’ approach),
- supporting their independence, and
- recognising the interdependence between the person with dementia and their family, whanau, and friends.

Intuitively, perpetual tracking hinders the independence of the individual. For people living with dementia, however, GPS tracking devices offer greater independence for those living in both the community and residential care, as it greatly increases their ability to do so safely. For those in the community, remaining at home strengthens individuality and emphasises social inclusivity and solidarity. NEAC believes that people should be encouraged and assisted to live well in the community for as long as possible, and good access to services such as tracking devices helps facilitate this.

The use of this technology would also be a positive step towards accommodating the needs of the families and carers of those with dementia. We are all necessarily

dependent on others, and the relationship between people with dementia and those who care for them involves a special kind of dependence; the support services made available, therefore, should reflect this. Also of note is that the family, whanau, and friends of people living with dementia are dependent, at least in some sense, on New Zealand's health system. Supporting these groups will produce better health outcomes for both parties, in what is ultimately a reciprocal relationship.

However, it is important to 'know' the person with dementia; and a supported decision-making model (working *with* the person to reach a decision) is preferable to a substituted decision-making model (making a decision *for* that person). It can be difficult to determine the best interests of people affected by a cognitive impairment, and, as outlined above, this will be a balance between what is important to them (established in dialogue) and what is important for them. For example, the person's interest in privacy should always be recognised, but weighed against the reality that extra measures are required to assure their safety. Yet the dignity of risk should also be considered: the right of people to take risks when engaging in life experiences, and the right to fail. Overall, care should be taken not to place too much focus on minimising risk, as this can affect quality of life.

Please note, the above is advice to LandSAR on the issue of adding GPS tracking devices to its inventory of recommended support services. Whether or not these devices should be implemented needs to be determined on a case by case basis, balancing the salient ethical values.