How people with dementia achieved their dream to roam free and safe in the remote, rural Scottish Highlands

‘I can now also live a life because my husband is no longer fearful of going out alone’
Who has the Right to Decide?

A key issue that the East Sutherland Dementia Friendly Communities (DFC) grappled with is, who has the right to decide when a person with dementia may wear a GPS tracker.

A number of issues come into play:

- **People with dementia** (particularly in rural areas) want freedom to roam
- **Dementia families** (particularly carers) need the assurance and peace of mind that the people they are caring for can be found if they lose their way while roaming
- **Search and rescue organisations** generally support the use of GPS trackers to assist in the task of finding people with dementia who might get lost and need to be found by emergency services
- **Risk aversion** is a contributing factor to people with dementia not being able to roam as they wish

**Freedom to Roam Safely**

The debate around freedom to roam safely was raised at the Prime Minister’s Rural Task and Finish Group in 2014 where human rights’ concerns from a legal and ethical point of view were addressed.

While it was noted that the Scottish laws on incapacity differ from those in England and Wales, it was agreed the fundamental principles of the European Convention on Human Rights (ECHR) remain the same.

After careful examination of the various issues, particularly around human rights, the East Sutherland Dementia Friendly Community Technology Task Group (comprising people affected by dementia) undertook a four month pilot (May – August 2014) using the Bob Technology GPS Tracker system. Two dementia families were involved and key to this were weekly diaries summarising the journey from both the person with dementia and the carer points of view.

**Key Results**

- One person with dementia did not have insight enough to understand his wife’s concern when he was gone for hours on end: knowing she can find him if required, she no longer panics when he is not home at an appointed time.

- The other person with dementia who had been too afraid to go out alone now feels secure enough to go anywhere without his wife with the result that his independence and increased sense of well-being has given him a new lease on life.

- Semantics are important i.e. people don’t want to feel tagged, they want freedom to roam.

“Taking Bob along with me means I have my independence and quality of life back again. I can go down to the harbour on my own – something I’ve not done for nearly two years”

“I can now roam the Highland hills to do my photography”
What is Bob?

Bob was developed for those affected by dementia by listening and working with potential users, their family and carers, health professionals, NHS Telecare monitoring teams, and by working with police and emergency responders to implement all their needs into the Bob journey to locate a missing person.

It is an all-in-one SOS Alarm and Personal GPS Locator monitored nationwide 24/7 365 by an NHS Trust with accredited Telecare status and direct links to Police and emergency responders.

The equipment is supplied free of charge to any person with dementia and a monthly monitoring fee is applicable.

- Bob works across 98% of the UK population on the largest telecoms service (satellite technology) currently available.
- Bob also works internationally enabling many people living with dementia to travel and still enjoy family holidays and trips away from home with renewed confidence.
- Bob weighs and is approximately the size of a small matchbox.
- Bob may be worn on the lanyard supplied or attached to keys, walkers, bags or items that the user would not leave home without.
- He is water resistant not waterproof, so no swimming or showering for Bob!
- He will stay active for 60 hours during which time he will track for 10 hours of movement, but it’s recommended his battery be topped up daily.

Bob is fully configured on arrival. No technical knowledge, computers, laptops, smartphones or apps are needed: simply charge and register the user’s details with the NHS monitoring centre using a Freephone number provided and Bob is ready to go! Should a Locate Me or SOS situation occur, the user and carer is no longer alone. Bob ensures they have a full NHS Telecare team just a phone call away day or night and there to support them no matter what the situation.

How does Bob work?

Bob reports his position when moving every 30 seconds to his monitoring platform which is triggered once Bob moves a meter. When Bob is not moving he will report the time he is ‘parked’ and the time he moves off again.

These reports may be shared with responders in a geo tagged location or street name format saving valuable time when looking for the person.

During a Locate Me incident, operators are able to ascertain what speed Bob is travelling, enabling them determine the mode of transport being used. They will monitor Bob live and relay updated information continually to responders while also working with family and/or carers to achieve the best possible outcome.

When an alert or Locate Me request is received at the monitoring centre, operators will generally locate the Bob user on screen in under a minute. Up to this point the user’s privacy is protected, as operators do not have open access to their screens to see the Bob user’s movements or location. They only see Bob when an alert is created. Operators are also able to change their views on screen to show potential hazards such as a railway line, water or main road, which helps them formulate the best recovery options.

Holding the SOS alarm down firmly for 5 seconds will directly connect Bob to the monitoring centre for a two-way conversation. The operator will stay on line to manage the situation. The Bob user will not be able to end the call, ensuring the monitoring centre has an open link between them and the user until the situation is resolved.

“I have my dignity back again because I know my wife will only try and find me if she believes I’m lost”

“I am no longer afraid to go out alone because I know I too can use Bob to call for help if I’m lost. This makes me feel very safe”
Who can Activate Locate Me?
Where practical the user will select those they wish authorized to locate them in the event of concern for their whereabouts. Where this is not possible, this authorization will be undertaken by the user’s Power of Attorney or family or health professionals.

Authorization is activated by providing each person chosen with the user’s unique Bob ID number and registering their details with the monitoring centre.

Anyone concerned about the user may still call and raise an alarm but the user’s whereabouts will not be disclosed directly to them. The monitoring centre will use their discretion to contact the Bob user, first responders or the emergency services.

Ethics and the Law
Search and rescue organisations support the use of GPS trackers to assist in the task of finding people with dementia who might get lost and need to be found by the emergency services, thereby protecting their Right to Life (Article 2).

The following Articles of the European Convention on Human Rights (ECHR) are also relevant to this debate:
- Right to a private and family life (Article 8)
- Right to liberty (Article 5)
- Right not to be subjected to degrading treatment (Article 3)
- Right of assembly and association (Article 11)

For those with Cognitive Ability
If the Adult with dementia is given a choice while they still have cognitive ability, then they can choose whether or not to wear the GPS tracker. If the Adult chooses to wear the tracker then there is no issue whilst they retain capacity.

For those without Capacity
When the Adult does not have capacity to consent to the wearing of the GPS tracker then in Scotland the power for this should be sought by way of a welfare guardianship order application under the Adults with Incapacity (Scotland) Act 2000 and the principles of the 2000 Act are then engaged.

In granting such a power to a welfare guardian, the court must be satisfied that the power to insist on the wearing of the GPS device is in the Adult’s best interests and the least restrictive option. It is through the court granting the welfare guardianship that the human rights of the person with dementia are protected and the proposed guardian’s reasons for seeking such a power are properly scrutinised.

The least restrictive option would be to do nothing. However, consideration should be given to the level of the risk of harm, or even death, if nothing was done. The assessment of the risks to the person with dementia should be carried out firstly by the individual making the application, e.g. the family member, the carer, the local authority etc, and then by the court (potentially with a report from a Safeguarder). The court will also consider any views previously or currently expressed by the Adult, but, ultimately the power will be granted if it is deemed to be in the best interests of the Adult.

If the court is satisfied that a power to insist on the wearing of a GPS tracker is necessary to safeguard the well-being of the Adult, then the welfare guardian will have this power conferred on them. It will then be for the welfare guardian to make the decision as to whether or not the power is used.

If a person with dementia uses the device, they should be advised that the use of the device is for their own safety and not to check up on them. It is also key that carers adhere to this.

“With my husband out and about every day, I now have more ‘me time’ at home alone. It’s mini respite!” - Hilary Cragg, Solicitor
Consent
If a carer is an Attorney under a Power of Attorney, then the carer/Attorney may consent on behalf of the person with dementia to the use of the tracking device without recourse to a court application.

It is recognised that while the use of such devices could be abused, generally there may be a family or other special bond between the person with dementia and the carer/Attorney which should preclude such behaviour. Above all else, besides giving the carer/Attorney peace of mind, if the device is used for the care of that person and if it is in that person’s best interests to use such a device, then using such a device is likely to be lawful.

Risk aversion is a contributing factor to people with dementia being kept in their homes, sometimes under lock and key. Since quality of life invariably entails taking risks, using such a device would require a risk enablement mentality on the part of both professionals and dementia families.

If someone who lacks capacity is to wear a GPS tracker, as indicated above, the question around a person’s best interests will always turn on its own set of facts and be an individual decision in every case. However some general guidance can be considered:

- There should be a protocol in place, which reflects the section 1 principles of the 2000 Act, which include that anything done should be in the best interests of the Adult and be the least restrictive of their rights and freedoms.
- The least restrictive option is to do nothing, but this could lead to harm occurring to a person with dementia and who is at risk of wandering.
- Any protocol for the wearing of a GPS tracker device should be on the basis that it is worn and used in the least restrictive manner (in accordance with the 2000 Act), which would therefore indicate that it should only be used when the individual is at real risk of being lost, at risk of harm and in danger, and not simply to check up on them.

- Once the person is located and it is considered that the location is safe, then no further enquiries should be required and the individual should not be necessarily removed from their location.
- The individual is entitled to have their Rights of Assembly and Association (Article 11) respected. If the individual is in a place that the guardian does not consider safe, then they can be located and their safety established and if necessary returned home or to hospital or to wherever is appropriate in the circumstances.
- While there is a risk that this could be used for an oppressive level of either monitoring and/or control over the life of an individual, it must be remembered a person with dementia is still entitled to live as well as they can and to make wise decisions, provided they have sufficient capacity to make such decisions and that they are not at risk of harm, even if the carer does not always agree with their decision(s).

It should be noted that, providing the Adult lacks capacity and has not previously granted a Power of Attorney, the only individual in Scotland with the power to make a decision regarding the Adult wearing a GPS tracker is a welfare guardian appointed under the 2000 Act. The specific wording of the power may be “to make the decision to allow the Adult to be fitted with a GPS tracker device”. However, as this power could ultimately amount to a deprivation of liberty in terms of Article 5 of the ECHR, the basis for such a deprivation must be narrated in the application and justified in the circumstances. The guidance/protocol discussed above could also be relevant.

“A lot of people think that using a GPS tracker is like tagging prisoners. That’s a lot of nonsense. We can switch it on and off when we feel like it, which prisoners can’t do!”

“Being free to roam, Andrew has put colour back into our lives with his wonderful photography”
Conclusion

Any person with dementia should be entitled to live their life freely and this can be done by balancing their wish to go where they choose and associate with whom they choose with the risk of harm - including the many risks arising from becoming lost - from doing so. The actual location should only be given to the carer/Attorney/Guardian when the balance has moved to the risk of harm in order to avoid a surveillance situation.

It will be lawful for a person with dementia who lacks capacity to consent to wearing a GPS tracker, to have one placed on them by their Attorney under a Power of Attorney or by their Guardian under the 2000 Act with the likelihood of such a power being granted if the protocol for locating them is clearly stated. It is essential that the device be used for their own safety and not to check up on them. It is key that the guardian and carer adhere to this principle.

Acknowledgment

Our thanks go to all those special people who have supported us so very well in the production of this booklet. It has been a long road to freedom!

Contact details

Dementia Friendly Communities CIC
hello@dementia-friendly.com
01431 821655

Bob Technology (GPS tracker)
laurence@bobtechnology.co.uk

Prime Minister’s Rural Task and Finish Group
Ian Sherriff
ian.sherriff@plymouth.ac.uk

Freedom to Roam Ethics
Catriona Watt (Scottish legal)
Anderson Strathern LLP
catriona.watt@andersonstrathern.co.uk

Having read this leaflet you may now be considering the value of creating a Welfare Guardianship, Lasting Power of Attorney, Power of Attorney, a Will, or you may need other legal advice

- Here for you and your family 24/7, 365 days a year
- Unlimited access
- Our helpline advice is free
- Peace of mind we have all legal areas covered

England / Wales: 0344 245 4381
Scotland: 0344 245 4380

A confidential service provided by Parabis Law LLP in conjunction with The Help and Information Service
Bob is monitored nationwide - even worldwide for those on holiday - 24/7 by an accredited NHS Telecare Centre with direct links to the Police and Emergency Responders.