GPS Systems for people with Dementia: The Human Rights Issues

Background
There are a number of GPS systems available on the market. Some are simple GPS trackers (which work with a SIM card, like a mobile phone), others have additionally functions, such as phone, panic/distress button or watch. Some devices are similar to pagers and some are like watches that can be worn on the wrist, amongst the designs available. Some devices have a location service associated with them, which has a pre-set protocol that will be agreed upon when the device is set up with the company, others may just work from an App and the individual can be located whenever the carer (App user) wishes.

It has been agreed by search and rescue organisations that this would be helpful in the scenario that a person with dementia (or possibly a learning disability or other cognitive impairment) gets lost and needs to be found by the emergency services, thereby protecting their Article 2 - Right to Life. The issue relates to the process of tracking an individual and their legal rights to wear it or have it put on them, their Article 3 right – Freedom from degrading treatment, their Article 5 – Right to Liberty and their Article 8 - Right to Private and Family Life.

Mental Capacity
The Mental Capacity Act 2005 indicates that an individual is assumed to have capacity to make a decision unless it is proven that they do not. The capacity to make any decision is specific to the complexities of that decision and the time at which the decision needs to be taken. The Mental Capacity Act 2005 indicates that if an individual lacks capacity to make a decision, but will regain the capacity, as capacity can fluctuate, and the decision can be postponed, then it should be.
Scotland
Within Scotland, the legislative framework is the Adults With Incapacity (Scotland) Act 2000, a different legislative framework than England & Wales with the Mental Capacity Act 2005. Within the Scottish legal framework, the principles discussed in this paper are consistent to the Adults With Incapacity (Scotland) Act 2000.

Consent to wearing a GPS Tracker
In the situation where the individual has capacity to consent, in accordance with the test of capacity of the Mental Capacity Act 2005, then they can consent to wearing it themselves (or not if they so choose). In the scenario where the individual has a Health and Welfare Attorney or a Health and Welfare Deputy, then the Attorney or Deputy can consent to them wearing it.

Refusal to wear a GPS Tracker
If someone has indicated that they do not wish to wear one, then if they have capacity then it should not be placed on them. If they lack capacity, but have expressed the wish not to wear a tracker, then their previously expressed wish should be taken into account in making any best interests decision. It is therefore unlikely that it would be in the best interests of someone who has expressed the wish not to wear a GPS tracker for one to be placed on them, after the loss of capacity.

The Issue
The remaining issue then relates to someone who lacks capacity, and is without an Attorney or Deputy for Health and Welfare. What is in a person’s best interest will always turn on its own set of fact and will be an individual decision in every case. However some general guidance can be considered.

Firstly there should be a protocol, which reflects the Principles of the Mental Capacity Act, that anything done should be the least restrictive of their rights and freedoms. Clearly the least restrictive is to do nothing, but this could cause serious harm to an individual at risk of wandering, which may be a risk to their Article 2 – Right to Life. Therefore any protocol for wearing one of these devices should be on the basis that it is worn and used the least restrictive manner (in accordance with Principles of the MCA), which would therefore indicate that it should only be used when the individual is at real risk of being lost and in danger and not simply to check up on them. Therefore once they are located and it is considered that the location is safe, then no further enquiries should be made and the individual should not be necessarily removed from their location. The individual is entitled to have their Article 11 –
Rights of Assembly and Association respected. If the individual is in a place that the carer 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.

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. A person with dementia is still entitled to live as well as they can and to make unwise decisions, if they have sufficient capacity to make such decisions, even if the carer does not agree with their decision/s.

The individual with dementia should therefore be entitled to live their life freely, go where they choose, associate with whomsoever they choose and should only have their location told to their carer, when the balance between the risk to their life is so great that it take paramount precedence over their right to their many freedoms.

The issue still remains, is it acceptable that a carer makes the decision that a person with dementia should wear a GPS tracker? MCA s.5 indicates that any act done in the care of an individual for their care is lawful if it is considered to be in their best interests. MCA s.5 is primarily aimed concerned at medical decisions, however does include the wording “care or treatment” [emphasis added], which could extend to the wearing of a GPS tracker for safety reasons, in the same way that “piper alarms” can be used in the home and considered part of their care.

Alternatively, it could be considered under the Research sections of the MCA (s30-34). These sections relate to “intrusive research”, as part of a “research project”, which would need “approval” by the “appropriate body”. These Research sections are primarily aimed at clinical trials, however on the basis that the research is the individual’s location, then these may be the applicable sections. In which case, in order for the research (into the individuals location) to be lawful, it would have to have approval by the Secretary of State in the case of England and the National Assembly in the case of Wales. If therefore opinion is such that these GPS trackers are considered Research rather than Care, then approval for them to be worn should be sought, on the basis of a defined protocol, that they would only be used to the extent that the risks to life outweigh the risks to rights and freedoms. The remaining issue is that of a “research project”, however if a protocol can be agreed, then the body making the application for approval can do so on behalf of individuals and companies for this research project.
The potential problems
The 2 main issues are firstly that someone with dementia will wander and have a serious accident or will be killed. Just because someone has dementia, they should still be allowed to take a certain amount of risk. It is about balancing the risk, but to be too risk averse just because someone has dementia would be to interfere too much with their privacy and freedom. If it is important to the person with dementia that they can have freedom to roam, then there must be an acceptance that is the price they pay to retain that freedom is a certain amount of risk.

The second issue is that the carer will use the tracker too oppressively. A good example of this is a husband and wife, if one of them were to roam and have an affair, then s/he should have freedom to do so, even if their spouse and carer, doesn’t want them to. Having an affair isn’t illegal and the spouse should not use the GPS tracker to interfere with their freedom of association, to do so, would be a breach of their human rights. But it’s very hard for the spouse / carer not to interfere, as there is a conflict in their role of carer and the role of spouse. The issue may not be an affair, but the person with dementia has freedom of association, so should be allowed to go where they want and meet with whomsoever they want, as long as it isn’t illegal.

Summary
It is likely to 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 carer if the protocol for locating them is followed and it is considered to be in their best interests to wear it. Approval by the Secretary of State or Welsh National Assembly may be required. In every case, it still has to be considered in the best interests of that particular individual with dementia to wear it, by their carer.