

Freedom to roam for people with



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Dementia and Human Rights

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A little background...



Helmsdale –

Remote and rural Scottish Highlands

Latitude 58°N

Population 740

Nearest city 70 miles away



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A little background...



Dartmoor –

Extreme environment

Area 368 square miles

Nearest city 7 miles away



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FREEDOM TO ROAM

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Who has the right to decide?



Who has a say in deciding?

- ▣ People with dementia
- ▣ Dementia families and carers
- ▣ Health Care professionals



Human Rights

- ▣ The right of privacy vs the right to roam freely

The fundamental principles of The European Convention on Human Rights (ECHR) remain the same regardless of the laws of any signatory nation

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Trial of GPS tracker

- ▣ Helmsdale 4 month pilot – May-Aug 2014
- ▣ Dartmoor – test with Search & Rescue – November 2015
- ▣ GPS Tracker and SOS alarm
- ▣ Monitored 24/7 365 days per year
- ▣ *Locate Me* can say where a person is and how they are travelling in under a minute
- ▣ SOS alarm connects user to monitoring centre directly via satellite



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Key Results of Trial - Helmsdale

- ❑ One person with dementia did not have insight to understand wife's concern when he was gone for long periods – **she no longer worries.**
- ❑ The other person with dementia had been too afraid to go out alone – he now feels secure enough to go out without his wife, **his independence has increased, giving him a new lease of life.**
- ❑ Semantics are important – **people don't want to be tagged, they want freedom to roam.**

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Key Results of Trial - Dartmoor

- ❑ Dartmoor Search and Rescue found the person very quickly
- ❑ Even if the person had taken it off, it would narrow the search parameters, which is helpful for Search and Rescue

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The Law



- The issue is about
 - Protecting the **Right to Life** (article 2)
 - **And balancing it against the other rights**
 - **Right to Liberty** (article 8)
 - **Right not to be subjected to degrading treatment** (article 5)
 - **Right of assembly and association** (article 11)

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The Ability to Choose

- **For those with cognitive ability** they can choose to wear the GPS tracker or not.
- **For those without capacity** the carer must be satisfied that it is in the person's best interest to wear a GPS device. If there is a dispute, the Court can be asked to make a decision.

"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." David

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Ethics



- ❑ For safety – not to check up
- ❑ Risk enablement vs Risk aversion
- ❑ A person with dementia is still a person and has human rights
- ❑ A person with dementia is entitled to live as well as they can – and has the right to make unwise decisions

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CONCLUSION

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- Any person with dementia should be entitled to live their life freely, balancing their wish to go where and associate with whom they choose with the risk of harm – *including getting lost*.
- The location should only be disclosed when the balance has moved sufficiently to the risk of harm... This is **not surveillance but FREEDOM TO ROAM**

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Today's Speakers:

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let's do this together...
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