

# *Island Voices*

*Tiree*



**CONNECTED CARING COMMUNITIES PROJECT**





The Cohesion Team wanted to find out if there were particular challenges for people with dementia, their carers, and primary care teams related to living on an island. Our journey took us to Tiree, a small island of around 700 people off the West Coast of Scotland, where we spoke to Dr Holliday, the recently retired local GP and Fiona Grant, who runs the Tigh-A-Rudha Care Home on the island.

There are between eight and ten people living in Tiree with a dementia diagnosis, however, there may be more people with dementia who have yet to be diagnosed, given the estimated 1 in 5 of the UK population over the age of 65 thought to have the condition.



## PRIMARY CARE

**“It’s a very old fashioned practice, we’re here every day... 24 hours a day. There aren’t many doctors who work in that sort of way anymore.”**

GPs and their primary care teams on Tiree provide 24-hour wraparound “cradle to the grave” care for their patients. From assisting with the delivery of children, to end of life care, the primary care team are responsible for all. There is no dedicated specialist medical support on the island, so the doctors and nurses are required to handle all manner of situations. The nature of the care that they provide means that they have excellent knowledge of the people and their individual medical needs. Because Dr Holliday was the GP on Tiree for 35 years he got to know his patients very well, however, this made it more difficult for him, as a human being, to tell people that they had dementia, “how do you tell someone that?”.

**“We feel fairly remote from best practice.”**

Dr Holliday feels that Tiree is remote from mainland networks who could advise on available technologies and dementia best practice. They are a small team and as such,



are not always able to keep up with new developments. He had limited knowledge of available technology and was unsure of some of the ethical questions surrounding the use assistive technologies like GPS trackers. He feels that he would have benefited from access to support around issues such as this in the past.

*Despite regular contact with the mainland and good internet access, we discovered in Tiree a lack of connectedness: to information and good practice and to secondary care and to multi-disciplinary teams. Communication between the island and the mainland has never been easier, however, the systems and processes required for effective care and remote monitoring have yet to be put in place. Without this connectedness, people on this island – and others in remote locations, are at risk of not receiving the specialist care and support that they need to live safe and fulfilling lives with a dementia diagnosis.*



## ACCESS TO SECONDARY CARE

**“Coll aren’t allowed to refer to the hospital in Glasgow... That’s the postcode lottery in action. They go to Oban by ferry and then to Paisley, whereas we fly to Glasgow.”**

Access to secondary care on the island is a real problem. There is a clear disparity between the care available in Tiree and the services available to people on the mainland. A general psychiatrist (not island-based) treats dementia patients, rather than a dementia specialist. Professionals from Alzheimer’s Scotland, physiotherapists and occupational therapists visit the island occasionally, but these visits are very rare.

People from Tiree are required to fly to Glasgow see consultants, have scans, and receive emergency medical care, or travel to Lochgilphead for psychiatric care. This can present challenges for older people with multiple conditions who often require specialist care. Those who are older, frailer, and more cognitively challenged often elect not to have specialist treatment, even when it’s available to them, because of the challenges associated with travelling, overnight stays and their requiring an escort.



While these issues present barriers to accessing secondary care for people living on Tiree, Dr Holliday believes that they are in a relatively fortunate position in comparison with their neighbouring island, Coll. Patients are flown to Glasgow for treatment in the new Queen Elizabeth hospital in the city, while people in Coll, which is less than a mile from Tiree, must travel by ferry and road to Paisley.

Geography becomes more important as people become older and it becomes more difficult to get around. While the physical isolation of the island is less of an issue now than it was a hundred years ago (island dwellers often take the twice daily plane to Glasgow), for those who are frail, the distance required for access to specialist treatments is prohibitive.



## ISLAND CULTURE

**“Tiree was so different 100 years ago, it was isolated, it had a strong language tradition, a very distinctive culture.”**

This tight-knit island community look out for each other and neighbours are often the first responders in times of crisis. Similar to what we learned about Highland culture, the islanders are fiercely independent and are sometimes unwilling to admit that they need help, which often prevents them from seeking the assistance that they need early on in their dementia journey.

People with dementia on Tiree, as is often the case, find it easier to communicate in their first language, and often revert to speaking mostly in Gaelic as their condition progresses. Dr Holliday believes that his ability to speak Gaelic helped him to connect with these patients, while Fiona believes that she is at a disadvantage because she cannot speak the language.

Many people with dementia on the island tend to live more in their past than their present and can be reached through the mediums of language and song and an awareness of the island’s history. Awareness of this and learning about ‘their Tiree’ could



well improve communications between older people with dementia, younger generations and those providing their care.

A deep-rooted mistrust of “outsiders” can present additional problems. There are some who won’t accept home carers from another area, or the home carer won’t go to that area, because of the mistrust that has developed between communities over the years.



## *RESIDENTIAL CARE*

**“It’s about knowing your residents, and knowing if they do go out wandering and what they would have normally done previously.”**

Local attitudes towards residential care can be problematic. It is not seen as a positive choice - nobody wants to ‘end up’ there - it is viewed as an end-of-life predicament, somewhere somebody goes when they have no choice and can no longer live an independent life. This view may create a barrier to islanders seeking help early on in their dementia journey, instead struggling on, trying to cope by themselves.

Having no specialist residential dementia unit, people with dementia live in a mixed care home environment, where it can be difficult to manage people with challenging behaviours in the same environment as other residents. Residents are often transferred to the mainland when they are no longer able to be managed in the care home on Tiree, a situation which is at present unavoidable, but likely to be distressing for people as they move and lose connections with their home, community, history and self. Having to move to the mainland for care was described as “everyone’s worst fear”.



Worryingly, there is a risk to the ongoing operation of the care home, given the running costs, which are relatively high for the number of residents being cared for. There is pressure to find a solution on the mainland.

*Are people with dementia on an island suffering from inequality of provision compared to the mainland? Is this the price of staying on an island?*

*Dementia and the practicalities around caring for someone with dementia can present difficult ethical questions. There is no doubt better equipped, more advanced care on the mainland, but people’s reluctance to leave their island throws up important questions for policymakers and care providers.*



## TECHNOLOGY

**“We’re at the edge of a huge health board, and we’re very rural. I think that is quite a big factor in looking after people as best we can.”**

While Tiree has access to all of the technology that services have on the mainland, there are no dedicated response teams to monitor and respond to telecare systems, so there is a reliance on family and friends to do this. When they cannot help it often comes down to the nurses and doctors if something goes wrong. There is some discussion about setting up a dedicated response team on the neighbouring island of Coll, which has a population of around 2500, however, it is unlikely that a small island like Tiree could support such a service.

Limited knowledge about the different assistive technologies available and ethical concerns about tracking people are complex issues where the primary care team require support and advice. These issues have been barriers to the adoption of assistive technologies.

While remote-monitoring of long-term conditions has been attempted, this has met with limited success thus far.



Communication between primary care providers and consultants is often difficult to achieve in a timely manner, due to competing priorities. Dr J suggest that useful technologies could be developed to make it easier for consultants to respond to enquiries from primary carers and support interaction between care providers on the island and mainland.



## HOME CARE

**“...you can't have every level of care in a community of this size.”**

The lack of family carers on Tiree is a real problem, stemming from the “hollowed-out” middle age population; compounding this is the lack of paid employees for the provision of homecare services. Recruitment is a real problem and the island's lack of capacity has worrying implications – a care crisis can be triggered if just one carer becomes ill. There is little capacity to provide homecare beyond visits four times a day and there is nobody to provide the all-day low-level care that many people with dementia need. Because of this, people often end up in residential care prematurely.



## CONCLUSION

*What does the lack of specialist care on islands and in remote communities say about inequalities in healthcare and the overall approach of decision-makers to designing inclusive healthcare services?*

*Self-directed support is of course intended to offer choice and control over how care is delivered and the Scottish Government's policy is for person-centred care in a community setting, however, choice on an island of this size is limited because of structural issues related to the availability of care and support services. If we look at dementia care through the lens of a rights-based approach, it becomes clear that current health and social care systems are not fit-for-purpose in remote areas. Policymakers must look for solutions that support the right of people in rural and island settings to live where they are happiest.*

*While the NHS faces ever increasing costs, growing demand and reduced budgets, remote monitoring of long-term conditions offers a cost-effective way of ensuring that people get the specialist support and treatments that they need, without having to travel to the mainland, while also reducing the need for expensive journeys by healthcare practitioners to islands and*



*remote rural areas.*

*We need to think differently about healthcare. The integration of health and social care offers real opportunities to address this unequal situation. Integrating technological solutions into the design of health and social care systems is essential to their success and will offer real possibilities to keep people safe at home and to allow them to access specialist care in different ways.*

*What makes us who we are? The importance of place, identity, culture and belonging cannot be underestimated. Songs and stories, language and even food can have positive effects on people with dementia, stimulating conversation and improving communication and mood. Such strong emotional and psychological bonds to place require that we put support in place that allow people to be cared for where they are and where they want to be.*



WITH THANKS TO:

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**Journey of Voices**

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