

Human rights, community and dementia... let's keep the discussion going!

HUMAN RIGHTS, COMMUNITY AND DEMENTIA: CREATING BETTER LIVES IN THE WESTERN ISLES

We know from experience that, very often it is **local, grassroots organisations** which have the most immediate impact on people living with dementia, their families and unpaid carers.

The Life Changes Trust is holding a series of 14 collaborative learning events across Scotland to find out **what matters most to people with dementia and those who care for them**, at a **local level**. On the 16th, 17th and 18th September 2019, we visited the Western Isles and brought together people affected by dementia, the statutory and third sectors and the independent sector.

On the 16th September we hosted **storytelling** sessions on **Benbecula** for people with dementia, their unpaid carers, and professionals working in the field of dementia. The sessions were attended by 35 people, including **Alasdair Allan MSP**.

Day 2 focused on community connections with a **Garden Party at Tagsa Uibhist**, which saw 83 people celebrate the official opening of their Sensory Garden.

The **conference** took place at **An Lanntair** in Stornoway on the 18th September, and was attended by 48 delegates, including people living with dementia and carers.

On 1 May 2018 the Life Changes Trust held a conference on human rights, citizenship and dementia in Perth. The conference set the scene for a series of local events across Scotland.

These collaborative learning events will support local areas to think more deeply about how communities can uphold the human rights of people with dementia and unpaid carers.

"The destiny of human rights is in the hands of all our citizens in all our communities" (E. Roosevelt)

2019:

Next Event:
Western Isles
18th September

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These events were **planned, designed and developed in partnership with local stakeholders in the Western Isles**, highlighting the importance of taking a local approach to supporting people affected by dementia within a national policy context.

The conference - what's going on in the Western Isles?



The conference was chaired by **Myra Lamont** and **Agnes Rennie**, both of whom have experience of and an interest in dementia and how those who are affected by it are supported across the Western Isles.

The day started with **Ron Coleman**, who gave a riveting presentation on 'virtual assistant' Alexa and dementia, followed by a round table discussion during which delegates discussed the **five priorities** identified during the storytelling sessions (see below). Each table focused on a priority, and considered what they could do **locally** and **collaboratively** to make it a reality in their community.

The morning session ended with **Rhoda Grant MSP** reflecting on the conference so far, looking at what matters most to people with dementia and to carers in the Western Isles.

For the first time since we started these regional events, we asked the delegates to think about how they would pitch the idea and/or key messages that came out of their morning discussions around one of the five priorities to the Chief Officer of the Health & Social Care Partnership, **Dr Ron Culley**, in just 2 minutes. The pitches took place in the afternoon, and delegates did a fantastic job!



We also took a 'A Focus on Local...' where **Deborah MacVicar** shared her experience of caring for her father in a beautiful and emotional presentation, followed by a fantastic short film showcasing the diverse work of **An Lanntair's Ciallas Project**. Dentist **Ella Wronecka** gave a talk about dementia friendly dentistry, and **Cuimhne** screened an interview with carers Rachel and Colin about the impact the project has had on their lives and their loved ones. To close the event, **Dr Ron Culley** reflected on the five priorities and what was said, and talked about the way forward. You can see videos of the pitches and presentations on our [Facebook page](#).



5 PRIORITIES: What people affected by dementia told us...

Priorities from Western Isles Storytelling Sessions



Priority 1: We want: diagnosis to be delivered in a supportive and timely manner; better information and access to post-diagnostic support; and for this to be available in local communities

Priority 2: We want access to sustainable, regular and reliable transport, allowing us to be better connected to activities and services in our local communities.

Priority 3: "Carers have rights too" - we would like to see more emphasis on the support and services we need to better enable and empower us.

Priority 4: "Dementia is not just about the individual, it is about the community and its response" - we want to see a stronger focus on improved partnership working to provide sustainable services.

Priority 5: We want to see a long-term approach to commissioning services for people with dementia and unpaid carers.



Priority 1

Failure / reticence to diagnose due to lack of resources. There needs to be better support, collaboration from the start, and wiser use of resources.

Priority 2

Not enough buses / accessibility. Need to raise dementia awareness with transport companies. Communities & organisations work together to fund transport.

Priority 5

How can we make continuity more attractive to funders? There needs to be a better recognition of local work & more partnerships.

Priority 4

Tackle stigma, raise awareness in the community. Use technology like WhatsApp for networking & support. Expand DEEP groups.

Priority 3

Need for more advocacy, more information: what are carers entitled to? More imagination needed surrounding the issue of respite beds.



Next step: Small Grants

Taking this work forward, we are opening a **small grants programme** in December 2019 for local organisations across the Western Isles.

This approach to funding will strengthen confidence amongst local groups who are already providing or are looking to provide support to people affected by dementia in their community.

We want to see communities get the financial support they need to really deliver on what local people affected by dementia say would make the biggest difference to their everyday lives.



Most talks and presentations were filmed and uploaded on [Facebook](#) throughout the day, with **1041 views** to date.

What people
said about the
conference

Some delegates attended the conference to **demonstrate the impact of the projects they are working in** and to **influence statutory bodies around funding issues**. Others were there to **support awareness of dementia, to learn, and to gain a better insight into what was available in their communities**.

Though, due to ferry timetables, some people felt that the afternoon was a bit rushed, **67%** of those surveyed said that the event **met their expectations**. They particularly enjoyed hearing from people with dementia and from carers, as well as the friendly atmosphere.



Community and Dementia Conference: fascinating insight into the complex needs of people with dementia. Dementia friendly dentists, things we all take for granted but without thought can be made accessible to those with dementia @lifechangestrst

The work of Cuimhne in Uist has been highlighted a number of times at @lifechangestrst Dementia Conference. An example of what can be achieved when people come together

Some of the challenges are the same across Scotland but rich insights today about those that are unique to remote and rural areas

“A really humbling experience to listen to presenters”

