

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

Orkney
May 2019

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Creating better lives.

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.

Inverness
Nov 2018

Aberdeen
March 2019

Perth
May 2018

"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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HUMAN RIGHTS, COMMUNITY AND DEMENTIA: BY LOCAL PEOPLE FOR LOCAL PEOPLE IN ORKNEY

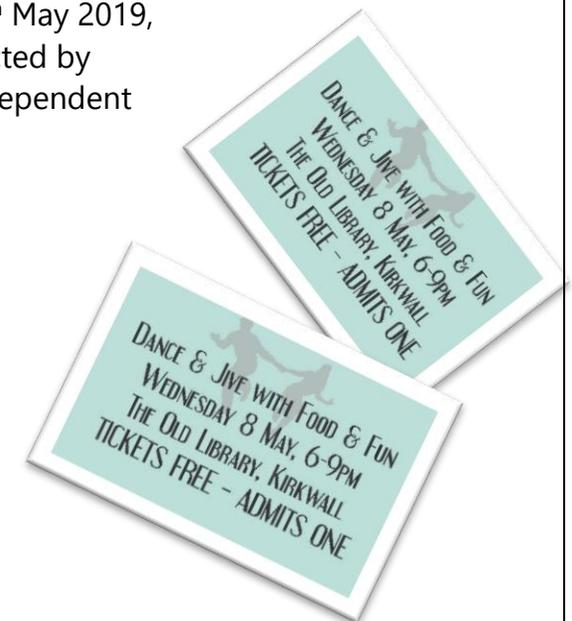
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We know from experience that, very often it is **local, grassroots organisations** which, by their very nature of being local, have the most immediate impact on people living with dementia, their families and unpaid carers.

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 7th, 8th and 9th May 2019, we visited Orkney and brought together people affected by dementia, the statutory and third sectors and the independent sector.

Across the 3 days we hosted **storytelling** sessions for people with dementia and their unpaid carers, a **Screen Memories** session and a **Dance & Jive with Food & Fun** at the Old Library in Kirkwall -featuring the **Bigsy Whalps** and the **Orkney Jivers**- which was attended by 120 people. The **conference** took place at the Picky Centre in Kirkwall and was attended by 109 delegates, including people living with dementia and carers.

These events were planned and delivered **by local people, for local people**, as we believe that collaborating locally will deepen our understanding of what is working well and can offer solutions that can be addressed at a grassroots level.



The main conference was divided into **3 sections**; 'What's going on in Orkney?', 'Marketplace' and 'People Affected by Dementia - What matters to you?' with a roundtable discussion influenced by the 5 Priorities that emerged from the storytelling events.

What's Going on in Orkney?

The morning session included presentations around the theme of community and dementia. Following a rousing performance by the Dementia Friendly Orkney Choir to open the conference, attendees heard from Sally Shaw, the Chief Officer of Orkney Health & Care, Pam Marwick, Occupational Therapy Lead for Orkney Adult Services and Gillian Skuse, Managing Director of Age Scotland Orkney.

Councillor Harvey Johnston then gave his reflections on the day so far, in the form of a touching yet witty poem. Ann Tait & Merle Walls, who are both carers for someone with dementia, then read their self-penned poem about the experience of being a carer. Here is an extract - you can watch the full conference on our Facebook page: <https://www.facebook.com/pg/LifeChangesTrust/videos/>



“A carer's life is very strange, life's dreams go all awry
The things you planned to do together you can no longer try
Dementia sneaks up quite unseen, not always recognised initially
The hardest thing for any carer, is to get it diagnosed officially
If only everyone reacted the same, we'd soon be told what it was
But some people are angry while others forget – it's difficult to find the cause
Where do I go, who do I see, what is the right procedure
Who can assist this loved one of mine, there's help out there I'm sure
We'd like to have a safe space where immediate assistance can be found
If an urgent appointment comes out of the blue and there's no help around

Or what if a carer can't manage short term – do their loved ones go into care?
Making life so confusing as they'd not know why they are there
Rather we could have someone come to our homes, a familiar face that they've learned
To do a night and day home service, giving peace of mind to all concerned
To quote a certain professional, let reality come from rhetoric
Listen to what is being said and do your best to implement it
There's no use having a conference if it's nothing but hot air
Now is the time to put in place what is needed for those who care
We've spelled it out quite clearly and we're willing to do our bit
Prioritise what we need to happen, you have the power
– USE IT! ”

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



Highlights from round table discussions

- ➔ Respite: more collaboration & more flexible approaches needed – dial-a-carer?
- ➔ Diagnosis: not a one size fits all approach – involve the hub to reduce isolation. PDS outwith the mainland
- ➔ Self-Directed Support: more awareness & clear guidance needed
- ➔ Dementia friendly communities: more intergenerational projects, more service-led options
- ➔ Carers: better communication between carers & community awareness of the importance of unpaid carers



NEXT STEPS: Small Grants

Taking this work forward, we are opening **a small grants programme** in August 2019 for local organisations across Orkney.

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.



The main conference was live streamed on the Life Changes Trust Facebook page, and to date, has totalled **3152 views**.

What people
said about the
conference

Over a third of delegates attended the conference as **they currently work in care**, in particular with **people with dementia**. They wanted to get information and to learn more about dementia and what was happening to **support people in the community**. People saw this as a **positive opportunity** to move forward and saw **the importance of working in partnership**. Some people also wanted to know about support for future planning and how to access it. The majority of people said the conference met their expectations, saying it gave food for thought and was more varied than was expected. Words used were "**an amazing event**", "**truly inspiring**" and "**camaraderie**". Overwhelmingly, people said the conference programme was **well organised**, and said it was good to get people together and enable the sharing of information available.

“ There was a real buzz about the place and a sense of a genuine and supportive community ”

“ Real challenges were acknowledged, yet the enthusiasm and passion and vision of attendees was inspiring ”



Another inspiring event by @LifeChangesTrst showing how community has the potential to influence & change the experiences of people affected by dementia. Very moving words from carers Ann & Merle. Here's to 'the Orkney way'! #creatingbetterlives

Really struck by the use of spoken word and poetry all the way through conference today. The power of everyday creativity #creatingbetterlives

What an amazing group! Dementia Orkney are well on their way to being a 'Centre of Excellence' #creatingbetterlives