

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

life changes trust
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.

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

2019: Next Event: Orkney 9th May

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



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 18th, 19th and 20th March 2019, we visited Grampian and brought together people affected by dementia, the statutory and third sectors and the independent sector.

We ran **storytelling** events for people affected by dementia in three locations (Aberdeen, Banchory and Elgin), a community **Boogie in the Bar** and finished with our **conference**, attended by 173 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**; 'Shine a Light on Local', 'Marketplace' and 'People Affected by Dementia - What works for you?' with two roundtable discussion sessions. One of those discussion sessions collected feedback on the local presentations.

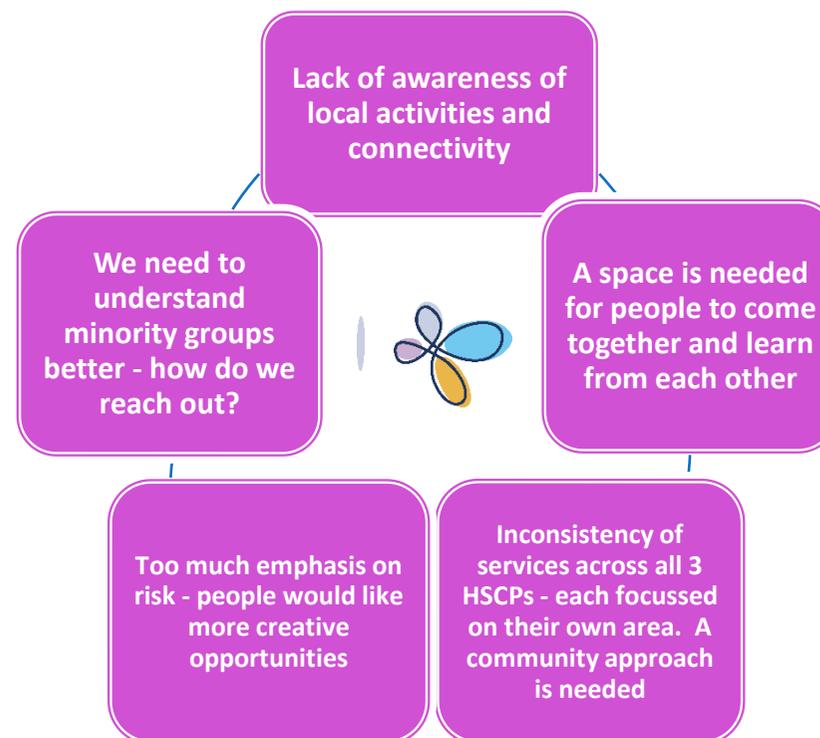
Shine a Light on Local

Part of the conference was 'Shine a Light on Local'. We met Lenny the dementia dog, who has changed the lives of Aberdeen couple John and Jeanette. We heard from Playlist for Life and what they are doing across Grampian to support people living with dementia, and Aberdeen's Third Sector Interface ACVO talked about the progress of their BAME project.

Alzheimer Scotland highlighted the positive benefits of yoga on local people with dementia, and Martin Robertson, an Aberdonian gentleman with a diagnosis of dementia, talked about his personal journey with a particular focus on the gaps in service provision and post diagnostic support.

"Consultants can diagnose and prescribe, but they cannot understand what it is like to live with dementia 24/7. We are the experts on this." Martin Robertson

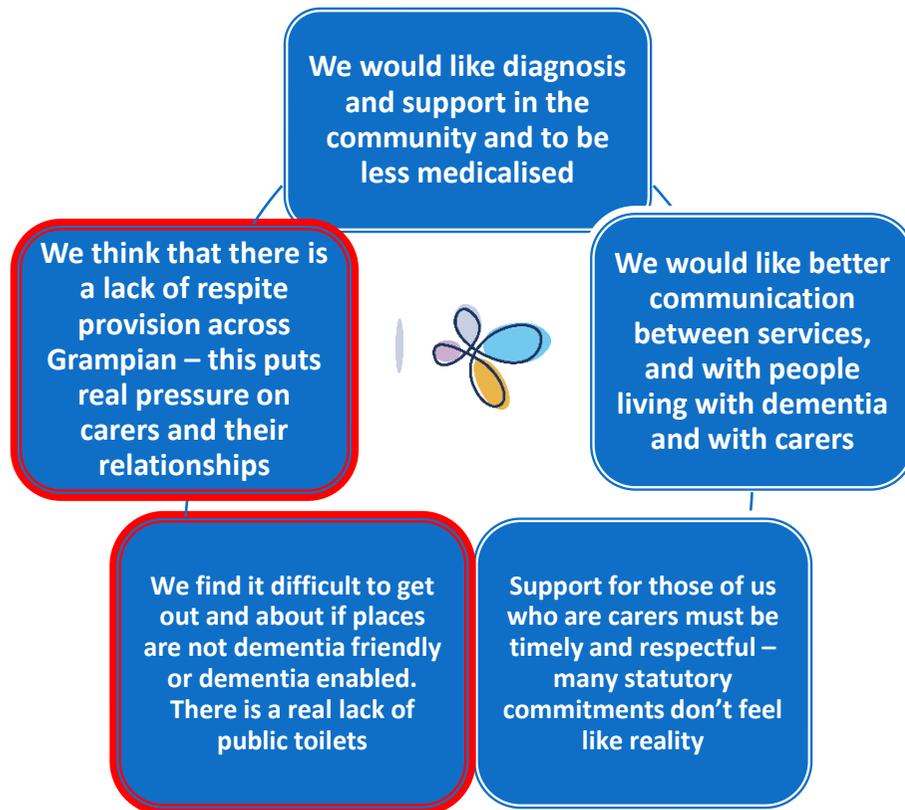
Feedback on local presentations



"It felt good linking up with others working towards the same goal. I didn't appreciate the scale of the different types of work going on in this area."

The second roundtable discussion session was based on **5 Priorities** that emerged from the storytelling events, where people affected by dementia told us what works for them and highlighted some of the challenges they faced. The two most discussed are outlined in red.

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

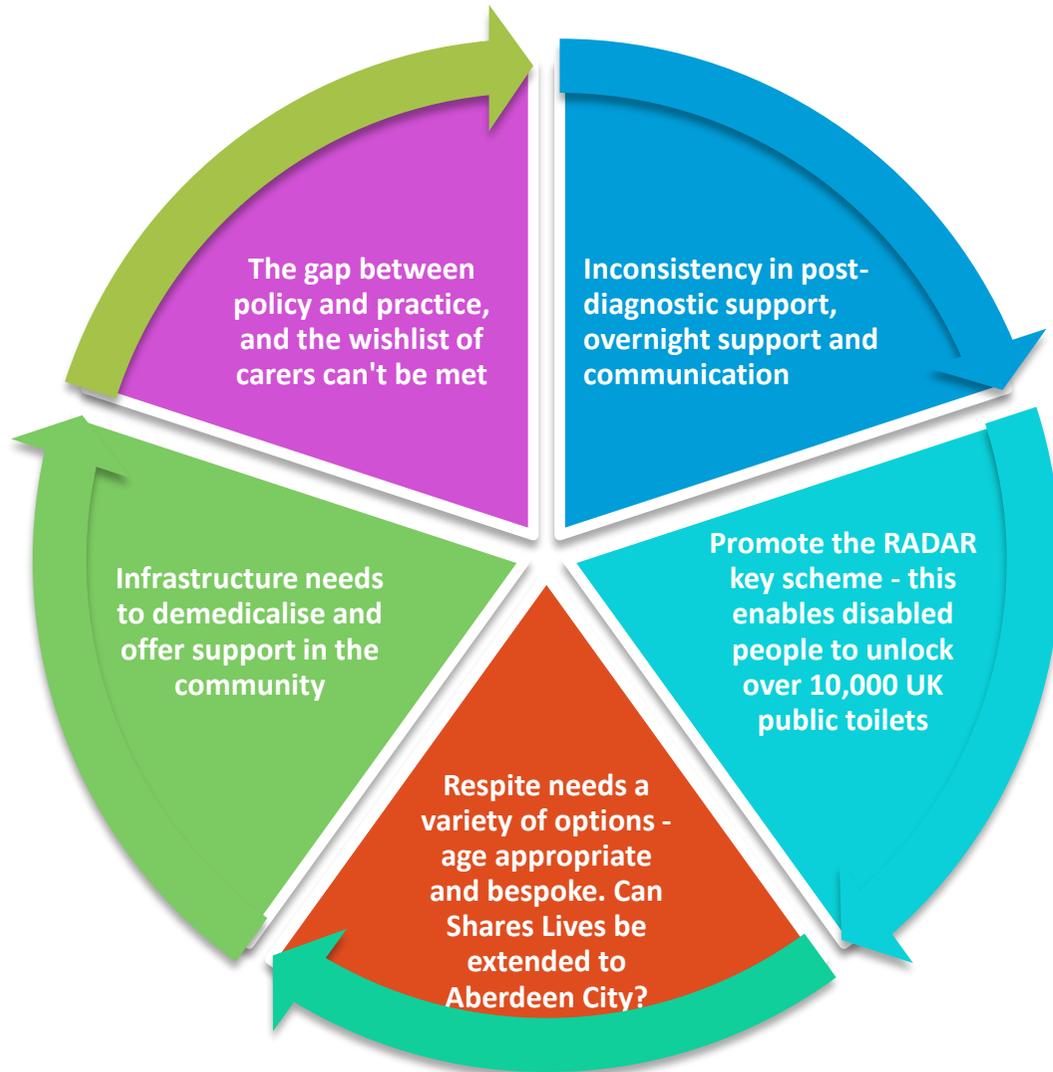


“People get a diagnosis, which is a moment in time, then there is the rest of people’s lives.

“They come out with all sorts of legislation, but we can’t provide them.”

“It’s a bit of a maze, finding what’s out there. Would appreciate not being sent from pillar to post”

Highlights from discussions about the 5 Priorities



NEXT STEPS: Small Grants

Taking this work forward, we are opening [a small grants programme](#) for local organisations across Grampian.

This approach to funding will strengthen confidence amongst local groups who are already 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 reached 2325 people.



What people said about the conference

The majority of delegates attended the conference in order to **improve their knowledge** of dementia, **raise awareness**, to make new connections, and to learn about **new services available locally and in the community**. They also noted the importance of bringing people together who are involved in dementia; not just health professionals but those providing valued services in community organisations and community groups who often go unsung. Many commented on the broad representation of services from both the statutory and third sector and that it had **opened their eyes** to the **forgotten organisations** who are out there and who can support people affected by dementia.



"It's really given me a lot of food for thought about how we look to properly engage with people with Dementia on our new strategy."

"Collective atmosphere of hope and the broad audience that accurately represented what is actually happening on the ground. So often conferences are style over substance, this wasn't."

