

Rural Dementia Top Tips

Learning from a dementia friendly initiative in the Scottish Highlands

Rural Dementia Top Tips was funded by the Joseph Rowntree Foundation and highlights what Dementia Friendly Communities CIC – a pioneering social enterprise established in 2012 and subsequently successfully sustained in a remote, rural area of the Scottish Highlands - learned along their journey.

This process was not without challenges: in particular relating to

- financing the initiative,
- recruiting and retaining the largely voluntary human resources without which it would be unable to function, and
- developing and delivering effective products and services in pursuit of its overarching objectives.

Since these challenges are likely to be common to other rural communities looking to establish similar initiatives, it is hoped these tips may be of use to them.

Introduction

Dementia Friendly Community initiatives are seen both nationally and internationally as having a key role in promoting inclusivity and supporting people affected by dementia to continue to enjoy being part of and feeling valued in their local communities.

To successfully achieve such outcomes – and this is particularly true in remote, rural areas - dementia friendly community (DFC) initiatives need to:

- recognise the great diversity among individuals affected by dementia;
- promote their inclusion in all areas of community life;
- respect their decisions and lifestyle choice; and
- anticipate and respond flexibly to their dementia related needs and preferences.

Top Tip 1: Involve people affected by dementia

Everything to do with any dementia friendly community must be informed by the people you have set out to help

- When developing activities, listen to and be inspired by the experiences of people affected by dementia
- Encourage people affected by dementia to feel confident and competent to participate in society.
- Develop socially inclusive programmes and avoid dementia ghettos which can isolate people even more in rural areas

Top Tip 2: Embrace geographical challenges

Rural isolation, loneliness and stigma are only some of the issues around the profound inequalities that need to be addressed in rural areas:

- Understand that rural areas probably have demographic profiles that impede normal services and support
- In small rural communities there may be a lack of resources and infrastructures may be challenging, but using that situation can work to your advantage – local knowledge and influence often rests by necessity with just a few people wearing a number of different hats, so tapping into the resources of those local pillars of the community can mean connections are made quicker. Also – by working with key personnel who share similar problems and are close at hand - it may be easier to find creative ways around those problems.

- Technology like video conferencing, interactive screens, GPS tracking, use of websites and social media are essential tools to address issues around inequalities in older people

Top Tip 3: Understand asset mapping/networking

Extensive networking and smart asset mapping is key to getting any DFC off the ground.

- Compile a list of local talent: people with influence, skills, strengths, enthusiasm and talents
- Identify resources within the community
- Link the talent with the resources to develop relationships
- Make strategic links with national stakeholders e.g. Local Authority, NHS and Alzheimer organisations to seek support and draw on their contacts and influence
- All the time growing a shared vision

Top Tip 4: Build lasting partnerships

Effective partnering is key to successful DFCs and can be achieved by working with local organisations with common interests as well as acting as a conduit through which others might achieve change.

- Build lasting partnerships with key stakeholders as well as rural voluntary and community organisations
- Make use of Dementia as well as Carer activist groups/individuals
- Remember that people affected by dementia would rather be supported by people who understand their situation i.e. make use of peer groups
- Set up dementia support groups for all people affected by dementia
- Reach far and wide. Local businesses, especially in small communities, will all have clients affected by dementia. NHS and Local Authority personnel often work much of the time in isolation so they may not have the level of knowledge or training around dementia they feel they need. To affect change in communities an initiative needs to cut across the private, statutory and voluntary sectors
- Accommodate strong personalities - bearing in mind that 48% of CICs are dissolved within the first two years and one of the main reasons cited for dissolution is internal disputes. While supporters with strong personalities can help to establish and drive the project forward, tensions can arise when such people have differences of opinion, for example over the core aims of the initiative or how best to achieve them.

- To avoid losing valued supporters, consider altering the organisational structure, commissioning internal reorganisation and/or dividing responsibilities between groups

Top Tip 5: Establish credibility

Organisational credibility – the quality of being trusted and believed in - is essential in building working relationships with key partners and communities. Credibility helps initiatives both to attract support to establish and sustain their activities and to attract key partners to help them to achieve their objectives. In particular, grassroots' community initiatives can struggle to be seen as credible by professional groups.

- Credibility is a quality that can be both hard to develop and difficult to sustain. Support for an initiative can quickly wane if supporters' belief in its ability to deliver change falters
- Ensure that 'successes' are widely communicated to reassure both internal and external supporters that the initiative is being effective and moving forward
- Ensure integrity by endorsing best practice for rural communities
- Gather supporters with individual credibility
- Create organisational credibility by building reliable working relationships with national and local stakeholders.
- Create websites and use social media to convey your messages
- Establish an identity beyond rural areas by working diligently with local and national media, funders, supporters and partner organisations to ensure that positive messages of progress are widely communicated

Top Tip 6: Create a sound organisational structure

Clear organisational structures help an initiative's supporters to understand their roles and responsibilities, but flexibility and willingness to adapt are needed to find optimal configurations.

- Select a legal structure appropriate to the initiative, its aims and the local context
- Understand the different legal forms potentially open to social enterprises, with differing requirements for registration and implications for allowable operational activities, fundraising, the use and transfer of assets, financial reporting, organisational governance, tax benefits, and the personal liability of those directing the initiative.

- Ensure a good range of skills e.g. operational, financial, administrative, communication etc across the organisation
- Ensure board/committee members/staff and supporters clearly understand their roles and relationships to each other
- While evaluation is challenging, it is easier to measure relevant outcomes by setting up an evaluation structure that becomes daily routine and involves small steps of work at a time
- Set up a loosely affiliated *Collaborative* composed of cross-sectoral representation from locally based people affected by dementia, health and social care providers and other dementia specialists to meet periodically to identify service needs and opportunities for developing new support projects for local families affected by dementia.
- Rather than regular meetings, efforts should be made to recruit representatives from all stakeholder groups who can be tapped into when required e.g. inviting members to join problem solving *Task Groups* that identify ways to achieve specific objectives and once reached, move on to the next task

Top Tip 7: Become sustainable

Initiatives will fail without access to funding and sustained support within their communities. Commercial activities not only provide local employment but also offer initiatives an alternative to traditional fundraising activities and/or grant funding. It will however require time and core funding to become established:

- Develop a business plan/strategy to determine how the dementia friendly initiative will operate in practice
- Embrace the idea of core funding to enable resources to be used to achieve outcomes rather than spending precious time generating income
- Work towards financial self-sustainability by involving the entire community in driving forward a vision to put profits back into the community.
- Actively target relevant local and national funding schemes
- Anticipate and prepare for forthcoming funding opportunities
- Avoid longer terms reliance on discretionary funding sources, e.g. charitable grants.
- Set up programmes in collaboration with community clubs around creative activities, support and training etc to generate income
- Sustain enthusiastic support for activities by involving beneficiaries in the decision making : people/communities are more likely to get behind a cause or initiative for which they feel some ownership
- Plan succession to ensure your vision lives on

Top Tip 8: Make change happen

To make change happen, a DFC needs to raise awareness of the experience of living with dementia in a remote rural location by setting themselves up as a model of excellence to inform and inspire others:

- Change often begins with one passionate person wanting change, but more importantly via a 'lightbulb moment' having the vision how to do it.
- To ensure that vision is never lost, it is essential the vision be translated into paper form – sooner rather than later - so that everyone is working to the same end
- Succession is also key, especially in a rural area where people, resources and abilities can be in short supply.
- In today's world, leadership and mentoring can be sought from further afield i.e. via websites, social media and national organisations

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Ann's life took a radical change of direction when her husband Andrew was diagnosed with vascular dementia in 2006. She became his caregiver and has since gone on to become a passionate campaigner on behalf of families affected by dementia.

Ann regularly speaks at national and international conferences and in 2012 inspired the creation of the rural Dementia Friendly Communities social enterprise in East Sutherland in the Scottish Highland.

She is a 2012 Churchill Fellow and also a member of the Prime Minister's Rural Dementia Group, set up in 2014 after the G8 London Dementia Summit to spearhead a global effort to tackle dementia through research. Ann is an advisor to key dementia stakeholders and in 2015 was appointed as a non-executive director to the NHS Highland board.

Ann obtained her MSc (Dementia) from Stirling University in 2014 and her expertise is around rural dementia issues.

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