STAND

Dementia Enquirers Report

STAND
Striving Towards A New Day

Contributing to the new Fife Dementia Strategy

September 2022

Dementia Enquirers

COMMUNITY FUND

iD Innovations in Dementia

Key messages from Dementia Enquirers projects

1. People with dementia can lead their own research projects – both drawing on previous life skills and learning new ones to explore the questions that most interest them.

2. The research questions that people with dementia generate can be different from existing research questions. They are based on lived experience – on topics that will make a real difference in people's lives.

3. "Being in the driving seat of research" doesn't mean that you have to do everything yourself. Team work and support can really help. But controlling the research and leading the way gives people with dementia a huge boost in confidence.

4. Making the language and processes of research more accessible helps everyone!

5. Research *between* people with dementia makes communication and engagement more possible, because having something in common increases trust.

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You can download this report here:
https://dementiaenquirers.org.uk/individual-projects/stand-in-fife/

You can read other Dementia Enquirers reports here:
https://dementiaenquirers.org.uk/individual-projects/

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Introduction

STAND is a peer support group for people who are living with a diagnosis of dementia and their families and friends. The group formed in September 2019 and registered as a charity in March this year. STAND is a member of DEEP which is a network of dementia support groups across the UK. STAND was originally set up for people with a diagnosis of younger onset dementia. This definition meant that membership was only open to people who were diagnosed under the age of 65. However, once the group became more active in the area following the COVID lockdowns, it became clear that there were lots of older people diagnosed with dementia who had similar issues and needed support. When STAND registered as a charity in March this year, their original constitution was amended to allow for membership of any age.

STAND received a grant of £1000 from Innovations in Dementia in November 2020 as part of the Dementia Enquirers programme (funded by the National Lottery Community Fund).

The original purpose of the grant was for STAND members to engage with people with dementia across the Kingdom of Fife to find out what they thought should be included in the refreshment of the Fife Dementia Strategy. Members felt very strongly they wanted to consult with people face to face with a blank sheet of paper and not on a formed strategy, which would have sought “approval” rather than be based on expressed needs.

Group members were prepared to visit established groups in dementia friendly venues across Fife. The funds were required for travel and refreshments.

The Impact of COVID 19

The winter of 2020/21 took us into another lockdown as a second wave of the pandemic affected the whole country. It was April 2021 before groups and activities were able to resume. This meant that opportunities to visit groups were significantly delayed.

By this time the Fife Health and Social Care Partnership, who were leading on the strategy, had employed three User Involvement Workers. STAND was encouraged to work with them to create a framework for consultation on the strategy with a view to face to face consultations taking place in the Autumn of 2021.

Development of the Framework

STAND met the workers in the summer of 2021. It was agreed that the Project Lead for the strategy would develop a questionnaire and a format for face to face workshops.

“Consultation”

STAND was duly consulted on the content of the questionnaire. Sadly, their comments were completely disregarded, and the questionnaire was distributed in its original form. It was made available on-line and paper copies had to be requested electronically.

> *“We could have been listened to more effectively and our feedback used to amend the questionnaire. It was hugely disappointing to be asked then not heard”.* Quote from Irene Donaldson, Chairperson of STAND.

> *“I couldn’t believe the way they talked over us! They brought their own ideas and weren’t prepared to listen to ours!”* Quote from Audrey Ross, STAND member.

The Dementia Friendly Fife Project Manager, who works very closely with STAND, requested paper copies, which she distributed to people directly affected by dementia. She also provided lists of dementia friendly organisations and cafes across the Kingdom in the hope the questionnaire would be distributed to them. It transpired that these lists were not used because of fears around GDPR (data protection), despite the team being reassured that the people on the lists had given their permission for their email addresses to be shared.

STAND members were also consulted on the format for the face to face workshops. Their comments were taken on board and the workshops were adjusted to ensure people living with a diagnosis of dementia had space to air their views separately from their family and friends.

Unfortunately, the effectiveness of the face to face consultations was compromised by a faulty QR code and the need to book online. This meant that the positive opportunity to consult face to face was lost.

Several of the workshops had to be cancelled because of a lack of uptake and those that STAND members did manage to get to were very poorly attended. As a result, not enough information was gained to create a draft of a strategy. This part of the consultation would have been more effective if a working QR code had been in place. Having realised the code was faulty it would have made sense to issue a working code and reschedule the face to face workshops. There was no deadline in place to complete the strategy and rescheduling workshops would have allowed people to gain more confidence to attend group activities as the worst effects of the pandemic abated.

STAND Taking the Lead

STAND held an event on the 18th of June 2022 to celebrate the fact that DEEP had reached the age of 10. The group also wanted to showcase their creative work and let people know about the Dementia Friendly Meeting Spaces (we call them spaces in Fife as they are not going to be purist centres) that are in development across Fife. The main target audience for the event was people living with a diagnosis of dementia and their families and friends. Local organisations were also invited to provide information tables. STAND negotiated with Innovations in Dementia (which hosts the DEEP Network) to use the Dementia Enquirers grant to go towards this event and use it to consult on the Fife strategy.

150 people attended the event on the 18th June, around 50 of whom were directly affected by dementia.

Consultation with the support of the Age Scotland ‘About Dementia’ Team

The Age Scotland ‘About Dementia’ Team was funded by the Life Changes Trust for five years to support people living with a diagnosis of dementia and their families and friends to contribute to eight work streams. These were expected to influence policy and practice. Many STAND members belong to their working groups. When the Life Changes Trust closed in March2022, the ‘About Dementia’ Team were put in place as a legacy partner, with the remit to maintain and further develop the priorities of the Trust. STAND sought the support of this team to run the consultation section of the event because of the expertise they have in “consultation” events. This was felt necessary as STAND members were heavily involved in staging the event and needed to enlist “fresh expert voices” to support them. STAND members also wanted to be part of the conversation and couldn’t lead and do this too.

STAND members had several conversations with the ‘About Dementia’ Team and a format was created for the session.

The original discussion was that attendees were given a blank sheet of paper with the question “What Matters To You About Living With Dementia in Fife?” However, this was felt to be too open a question and potentially unproductive.

> *“This question was too general and we thought people may have felt overwhelmed so we opted for a more structured and step by step approach. His process encouraged dialogue and engagement more effectively.”* Quote from Irene Donaldson, Chairperson of STAND.

STAND members are very clear that their priorities for a Fife Dementia strategy are:

Accessing Self Directed Support at an early stage in the disease process
Accessing peer support
Receiving care at home
Being actively involved in creative and artistic opportunities

The 'About Dementia' Team and STAND members created a discussion approach for all 4 topics that maximised the creativity of the attendees. The Team captured the data and will produce a report that will be used to provide the basis of another stage of consultation.

Learning from the experience and skills development

STAND members recognised very early on in the process that "consultation" has many meanings and can be tokenistic. They learnt that taking a lead in the process can be achieved and they do not have to be passive recipients of statutory processes.

They learnt how to chair events and work in a creative way to gain information and views. They had it reinforced that people living with a diagnosis of dementia need their own space to air their views. They learnt the significant benefit of working with objective experts to create a meaningful process and to provide data based on expressed needs. They also had it reinforced that face to face consultation is much more effective and meaningful than electronic methods. Members developed skills and confidence in using creative methods to stimulate discussion and elicit information and views.

In relation to working together as a group, despite roles and responsibilities being allocated to STAND members, in effect it was a small core group who carried the event.

> *"I expected folk to contribute more and was sad when others didn't realise this. We may need to be much more directive the next time and encourage more active participation."* Quote from Irene Donaldson, Chairperson of STAND.

> *"I enjoyed working with my "demented" colleagues, particularly Irene! We know our individual strengths and weaknesses. We speak for group members, as, through our knowledge of the difficulties, we are constantly trying to improve things for everyone on the journey."* Quote from Gerry King, member of STAND.

There was a range of learning opportunities about ceding power and control, and 'enabling not leading'. For example, there were issues with the sound system on the day. If this had not been resolved it would have had a significant impact on the success of the day. The key "performers" should have been involved in visiting the venue before the event to ensure they knew what was available and how this would operate.

It also became clear that there are some people who do not appear to want to be enabled and seem more comfortable being led. There are also individuals who are prepared to go over and above what is expected of them, which had a significant impact on the effectiveness of the event.

> *"Everyone needs to be encouraged to try new things and not to rely on what they know."* Quote from Irene Donaldson, Chairperson of STAND.

> *"It is important to find a way to balance views, to ensure everyone is heard and given the opportunity to engage regardless of the stage of their dementia. Everyone should find their voice!"* Quote from Gerry King, member of STAND.

Working with other organisations on this occasion was very productive. The Age Scotland 'About Dementia' Team were inspirational in their creativity and approach. They genuinely heard what STAND members said about their plans for the workshops and applied this on the day.

Their experience has given them the opportunity to develop a template that can be used at similar events.

> *"There is a wealth of expertise amongst organisations, and they have been hugely generous in their support of our event. This needs to be acknowledged and celebrated!"* Quote from Irene Donaldson, Chairperson of STAND.

> *"We learned that we need help and support to reach our goals. The 'About Dementia' Team, our writer Jayne and our musician Gus are experts in their fields, and we are blessed to have their support and the benefit of their creativity which allows us to flourish. We are keen to lead the way forward on the Fife Dementia Strategy and are looking forward to working with the Fife Health and Social Care Partnership to do that. We now know how to make sure we are heard!"* Quote from Gerry King, member of STAND.

> *"Working with STAND was a true blueprint for co-production. It was clear that it was important for STAND members to be involved in designing the workshop from the beginning, so we had regular meetings to catch up, swap ideas and check in about progress. STAND members are recognised as real innovators and leading the way in Fife for dementia support. Therefore, we trusted STAND as experts through lived experience to determine which themes should be the focus for the next Fife Dementia Strategy. When feeding back on the day, a STAND member said "The hardest thing in the world to do is respond to an instruction to "discuss the strategy" until the 'About Dementia' fairies organise it". It became evident that there was synchronicity in both the approach of the day and the wishes for the next Fife Dementia Strategy - in particular, the genuine desire for people living with dementia to do this in a creative and truly inclusive way."* Quote from Maxine Meghan and Kainde Manji from the Age Scotland 'About Dementia' Team.

It is clear from the event that asking research questions is a complex process and that different approaches work for different people. The questions need to be truly “person centred” to achieve the best outcomes.

> *“Research questions prompt many responses, depending on circumstances and experiences. Questions need to be kept simple and allow for time to be understood and responses to be formed and articulated. Using a variety of stimuluses will enhance this process.”* Quote from Irene Donaldson, Chairperson of STAND.

> *“It has been difficult to engage with people in a world dominated by COVID. We have shown with our event that, with a bit of creative thinking, some tea, cake and good entertainment, great ideas can be generated. We learnt that you should know the difficulties the people you are targeting face and you should amend your process accordingly. You get a far better response in face to face discussions with people with dementia than with paper/online methods.”* Quote from Gerry King, member of STAND.

Next Steps

STAND are awaiting the written report from the ‘About Dementia’ Team. They aim to negotiate to present this to the Fife Health and Social Care Partnership Joint Integrated Board. They expect to be invited to take the lead on the next phase of the development of the strategy. If this invitation is not forthcoming, then they will forge ahead on their own to ensure the strategy is based on expressed need and accurately reflects what is required.

Thank You!

STAND would like to thank Innovations in Dementia for their patience with this process and for their generosity and flexibility in allowing the grant to be used in a different way from the original application.

> *"We would like to thank everyone who gave up their time and energy to support our event. It was a lot of hard work and I despaired at times that we would achieve our goals. We did, and it was all worth it!"* Quote from Irene Donaldson, Chairperson of STAND
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> *"I loved the day! I am so proud to be a member of STAND!"* Audrey Ross, member of STAND
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> *"I just wanted to thank you for inviting us to be part of this day. It was very uplifting, emotional and inspiring and we met some wonderful people with whom we can hopefully build meaningful relationships moving forward. The format of the day was excellent and I hope we contributed to the success in some way. I always come away from your STAND meetings very much in awe of the positivity of the group. Saturday absolutely blew me away with the passion and integrity shared with us, and I look forward to working with the group in the future."* Quote from Margaret Hamilton, Stakeholder and Community Manager, SGN, Exhibitor and strategy scribe on the day.

Report prepared and submitted by Gerry King and Irene Donaldson, STAND
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https://www.dementiavoices.org.uk/group/stand-kirkcaldy/

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