



**STAND DEEP Gathering – 18th June 2022 – Script for
Gerry and Irene
1345**

(Irene) On behalf of STAND a very warm welcome to you all. We are delighted to have your company at what we hope will be a creative, innovative and informative afternoon.

We have a busy few hours ahead of us where we are aiming to do three things. We're going to tell you about STAND, celebrate Deep and our relationship with the network and have a discussion about what you think should go into the next Fife Dementia Strategy. We're also aiming to wow you with our entertainment!

As this is a unique moment in time and the history of STAND we are recording this in a variety of ways. We fully understand if you do not want your image captured and shared. Do please make it clear to the people running around with cameras that you do not want to be filmed. Simply holding up your hand or covering your face will be enough guidance for them.

(Irene) I'm Irene Donaldson, the current chairperson of STAND.



(Gerry) I'm Gerry King, the driving force behind the creation of STAND.

STAND first met in September 2019. I was doing quite well following my diagnosis of younger onset Alzheimer Disease at the age of 55. I had met Ruth McCabe and became an activist in the Dementia Friendly Fife Project. I was surrounded by the love and support of my family. However, I felt there was something missing and that for me was connecting with other people who were also living with a diagnosis of dementia. I approached my support nurse, Maggie Simpson, and asked if she could link me up with my peers. From the very first meeting the group gelled and we now have opportunities for people living with a diagnosis of dementia and their families and friends to meet on a regular basis.

(Irene) I am very grateful to Gerry for instigating the group. I too am living with a diagnosis of younger onset Alzheimer's Disease. I was diagnosed 7 years ago at the age of 53. While I was determined to embrace the diagnosis and live my life as fully as I could I found the world around me unaccepting and dismissive of me. I wasn't particularly keen to go to a group. My



mum had vascular dementia and was taken away in a bus to a group. I never knew what took place there and she could never tell me. I didn't want to have that kind of experience. What is vastly different about STAND is that family and friends are core members of the group and we do things together.

In March this year STAND became a registered charity and as Gerry says we now have activities going on across the Kingdom. We'll hear more of that later on this afternoon.

(Gerry) STAND had met on 6 occasions before the COVID Pandemic hit. When the first lockdown was imposed on us STAND was lost. If it hadn't been for DEEP STAND would not have survived.

DEEP stands for The Dementia Engagement Empowerment Project. DEEP is a network which is coordinated by Innovations in Dementia. Rachel Niblock is the person who brings all the groups together and facilitates their connections. DEEP is a place where people living with a diagnosis of dementia come together to share their thoughts, feelings and experiences. It is a network which emphasises that people with dementia do have



a voice and that this should be heard and can contribute to shaping the way they are nurtured and supported.

STAND had joined DEEP at its inception and Rachel came to visit the group in the Autumn of 2019.

At the very start of the first lockdown, in recognition that the group didn't have the expertise to move smoothly into an on line format, Rachel invited STAND to meet with her on a weekly basis on ZOOM.

STAND jumped at the chance and has had a myriad of very positive experiences which have shaped the way we are today.

(Irene) On the ZOOM calls Rachel introduced us to activists like Wendy Mitchell and Keith Oliver. These people, both of whom are living with a diagnosis of dementia, had written books. We were so in awe of them! I was invited to participate in a poetry project with Keith and a group of our peers from across the UK. This led to the publication of a book called Time and Place.

Through the link with DEEP we were "consulted" by the Scottish Government, the Life Changes Trust and the Age Scotland About Dementia Team about the impact COVID was having on our lives. Like everyone else we were stuck at home so were



delighted to have a conversation that was meaningful, valuable and that would make a difference to the way the pandemic was being handled.

Rachel linked us up with other groups across the network and we had regular visits with each other. This included a 4 nations group called Voices Across the Lands which still meets today. Sadly, many of our members could not participate on ZOOM so as soon as the rules allowed, we met up again. In the early days of emerging from lockdown this had to take place outside. The Scottish weather ensured that would be a huge challenge which DEEP solved by donating a gazebo to the group.

Rachel prompted us to write our story in the hope we would inspire other people to embrace life and peer support in the way we were doing. The result of this was the creation of the Recipe For Life booklet. This publication has been distributed far and wide across the UK and indeed the wider world with copies going to Australia, New Zealand and the USA.

The group was also involved in developing the Knowledge Is Power booklet. The first publication of its kind in English and Gaelic.



Do please pick up copies of these from the STAND information table.

(Gerry) Rachel also introduced us to Damian Murphy from Innovations in Dementia who supported STAND members to write a self-management course aimed at people who were newly diagnosed with dementia. This is an offer unique to Fife in that the course has been designed by people who are living with a diagnosis of dementia and facilitated by them. STAND received funds from the Alliance and has run two courses with a third in progress this month. The courses have been so successful that NHS Fife has committed to investing funds in the group to run 8 courses over the next 2 years as part of their offer of post diagnostic support.

Through DEEP we met BOOM Saloon and Irene and I participated in an online poetry project. This has resulted in a relationship we hope to take forward in a way that many more people can benefit.

In summary DEEP and Rachel are our very best friends and can take a huge amount of credit to what we have achieved and where we are today.



A big part of today is celebrating the fact that DEEP is 10 years old. Congratulations to Rachel and all the individuals and groups which make up the network and enrich lives across the UK. Cheers Rachel! Thanks to you and DEEP for everything you have brought to our lives.

Please come up and take a bow and say a few words – over to Rachel!

(Irene) We are conscious we are talking a lot but just a few more minutes until we bring on the entertainment.

At this point we need to introduce you to the Life Changes Trust. The organisation has now closed but has left a huge legacy for us in Fife and indeed throughout Scotland. The entertainment you are about to experience has been created by funds mostly donated by the Trust through their peer support grants and the evidence of the success of this influenced a Fife collaborative bid for some of their legacy funds. STAND has secured £119,480 so that you too can have similar opportunities to meet with your peers and get the benefit of working with writers, artists and musicians in the Dementia Friendly Meeting Centre spaces that are being developed across Fife.



(Gerry) When the STAND group was set up we based it on the principles of a Meeting Centre. This is a model based on a Dutch service which has been growing in the UK through the efforts of Worcester University. The basic principles of the model are that it works best when it is used by people who are in the early to moderate stages of dementia. Family and friends are welcome too and there is an emphasis on peer support, physical and creative activities.

What we are going to do now is introduce you to some of the creative efforts of STAND.

To do this we are going to hand over to our creative writer Jayne Wilding our musician Gus Harrower and St Marie's Primary School Choir. Over the last few months STAND has supported around 250 young people in the school and their teachers to become dementia friends. This gave them the expertise to work with our musician Gus and learn the STAND songs so that they could perform with us today. What you are about to hear is original material created by STAND. We share this with you in the hope you will be inspired to visit a Dementia



Friendly Meeting Centre space near you. Over to Jayne, Gus and St Marie's Choir.

1415

Jayne, Gus and choir take over from here.

1445

(Irene) Well I hope that has inspired you! STAND is hoping to have 7 dementia friendly meeting centre spaces set up across Fife. They are already established in Kennoway, Kinghorn and St Andrews and plans are in place to set them up in Rosyth, Dunfermline and Kirkcaldy. We'll keep you up to date about our progress.

We're now going to have a break for tea and cake. At the end of this we'll be led into the session on the Fife Dementia Strategy by the Age Scotland About Dementia Team. Maxine Meghan and Kainde Manji will take us through this.

(Gerry) More tea/cake and visiting information tables – ask people to fill in feedback postcards and leave them on the table for us to collect



1515 – Dementia Strategy – what should it include? –

About Dementia Team, Age Scotland

1630

(Gerry) We hope you have all had a great afternoon. It's been about celebrating what has been achieved and looking forward to what we still have to do to make sure people who are diagnosed with dementia and their family and friends get gold standard opportunities to live their lives as well as possible with what is likely to be a challenging condition.

As always there are a lot of people to thank for making this afternoon possible.

Fife College who gave us the venue free of charge and has supplied us with wonderful hospitality and technical support.

Our creative writer Jayne, Gus our musician and St Marie's choir for inspiring us and supporting us to be at our creative best.

To DEEP and the Life Changes Trust for supporting us to maximise our lives and to influence how support can be provided across Fife. Thanks again to DEEP and Innovations in Dementia for providing the funds for the food and refreshments.



To Maxine, Kainde and all the people who acted as scribes for the strategy session.

To all the people who gave up their time to provide information tables.

To all the STAND members who have supported the day in a variety of roles.

To Scotmid who provided the sweets on the tables.

To Tanya at NY Creative who pulled out all the stops to supply us with the booklets and all the kit we needed to make today such a resounding success with takeaways that will help you to keep in touch with STAND.

To Ro Pengally who gave us financial support for the STAND business cards.

(Irene) The most important people to thank are all of you who are living with a diagnosis of dementia for having the courage to come along today and thanks to all the family and friends who have supported you to do this today and to get through every day!

We hope you have filled in the feedback cards and left your contact details so we can keep in touch.



Do please keep your name cards in your in the lanyards. There is a QR code on them that if you scan takes you to the STAND page on the DEEP website. Please leave the lanyards and plastic envelopes attached to them at the reception desk. You never know we may just be crazy enough to do this again!

If you have enjoyed today and would like to contribute to the work of STAND, please drop a donation in the buckets that STAND members will be holding at the door.

Thank you so much for a wonderful afternoon. Safe journey home. See you all again soon!