

GANPAIGN TOOLAIT

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Introduction

Rethink Dementia is a new national Scottish Government and COSLA campaign, which will run for five weeks across Scotland, starting from the 4th September.

The campaign has been developed with a National Dementia Lived Experience Panel, as well as a range of partners and key stakeholders, including clinical input. A wide range of different voices and expertise have therefore helped inform and develop the strategy and creative route.

Our insight gathering research (August 2023) showed that the general public associate a dementia diagnosis with people living in the later stages of the disease, possibly confused, occasionally violent and heavily reliant on others. Also, that there is a lack of understanding around dementia being a progressive disease and that in the earlier stages particularly, people can live independent, fulfilling lives.



The stigma attached to dementia stems partly from this misunderstanding: that those with a diagnosis are less capable and possibly unpredictable. Consequently, people with a diagnosis often find their relationship with friends and family can change to become more limited or stop all together as they worry about that person's ability to engage in 'normal' social interactions given their illness.

Rethink Dementia has been developed in response to our insight which shows social contact can help improve overall wellbeing.

Findings have shown that staying socially connected and active with someone who has been diagnosed with dementia, like going for a walk or taking up a new hobby, can help alleviate symptoms commonly associated with dementia, including depression, agitation, sleep disturbance, anxiety and apathy.

The campaign will target people aged between 30-60, living in Scotland to help raise awareness of what they can do when someone known to them has been diagnosed with dementia. Our research identified this audience are more likely to think this campaign is relevant to them as they know someone, or their friends know someone with a diagnosis. However, this campaign is relevant to everyone – younger or older.

The campaign, which will run across multiple channels: TV, cinema, radio, press, digital and out of home advertising, partnerships and supporting PR, encourages our audience to focus on the person, not the condition, with the campaign creative being centred around treating people with dementia exactly as they did before the diagnosis – highlighting the simple ways people can help their family and friends who have been diagnosed to stay connected.

Whilst the main call to action is for people to engage with these key campaign behaviours, the campaign will direct people to nhsinform.scot/RethinkDementia for more information and advice on support.

How you can support the campaign:

stakeholder assets

We would be delighted to have your support. There are a number of ways in which you can help:

- ✓ Share real stories that could support the campaign messages
- ✓ Share this toolkit with your networks (if applicable)
- ✓ Share content included in this toolkit and resource centre on your channels (social, newsletters, website, in your building/venue)
- ✓ Contact the Scottish Government if there are other ways we can work together to share these important campaign messages

We're pleased to be able to give you access to the below assets via this toolkit and our online resource centre.

- · Campaign key messages
- Campaign film
- Social media copy
- Website or newsletter copy
- Real stories / case studies
- Clinician film
- Posters
- <u>Leaflet</u>
- Public information screen assets
- <u>Translated materials</u>

Key messages

If you are writing about the campaign within your networks, here are the key messages to include:

- When a friend or relative is diagnosed with dementia it's natural not to know what to do, but helping someone stay connected, socially active, and doing many of the things you've always done together, can help them stay well for longer
- Making an effort to maintain social contact can help alleviate symptoms of depression, agitation, sleep disturbance, anxiety and apathy that often come with dementia
- Reducing these symptoms could help improve their wellbeing
- For more information visit nhsinform.scot/RethinkDementia

How to help a friend or relative who has been diagnosed with dementia:

- By focusing on the person, not the condition, you can help them get the most from life and stay well for longer
- Be yourself. Your friend or relative haven't changed overnight
- Avoid making assumptions and decisions on that person's behalf ask and listen to their thoughts
- Just popping in for a cup of tea, going to the shops together, going for a walk or continuing to
 enjoy a hobby together, listening to music, inviting them round for dinner these things all help
 people stay connected and socially active

Print and digital assets

We have created a number of digital and print assets to support you with any communications around the campaign.



The campaign film, which is showing on TV, is also available for download **here** and available on YouTube **here**.



The campaign poster is available in A4 and A3 sizes. Artwork can be downloaded from our **resource centre**.



A campaign leaflet is available in A5 for placing in your office or premises. Artwork can be downloaded from our **resource centre**.

Lived Experience Panel – case studies

Danny and Joan Murphy



Daniel Murphy (72), married father of four is living with Alzheimer's.

Joan Murphy (73) is Danny's wife and primary care partner, and the couple live together in Stirling.

Click here to read and share Danny & Joan's full story with your network.

You can access their story on film here



Danny had an official diagnosis of Alzheimer's Disease in 2022. Upon diagnosis, there was a sense of relief for them both and Danny said, "although we didn't tell friends at first, they now all know and are accepting and supportive."

The couple made the decision early on in Danny's diagnosis to remain very active. Joan said, "It's important to both of us to stay active, as I know the benefits this can bring to someone living with dementia." Joan also recognises how much social interaction helps Danny, and the role friends play in helping him live life to the fullest. The couple regularly go on short breaks and also meet up with a small group of friends to chat and play the board game Canasta together, which they both really enjoy.

Danny's friends have been supportive and made adjustments to help him continue to live a full life with dementia. He has a long daily walk and goes to the gym three times a week with a friend. Joan said, "from a care partner's perspective, we've found practical aids a real help. I've set up WhatsApp groups for all his friends, and I'm included in each one to help remind Danny of his plans. His friends all know of his condition and are very accommodating, so will come to the house to meet him here, rather than trying to have him find his way to them. We also have a shared calendar so we can see each other's plans and use the 'Life 360' app so that we always know where each other is."

Danny's advice for someone newly diagnosed with dementia is to continue staying socially and mentally active as much as possible. Danny said, "friends, family and activity are key. I've found that keeping busy, reading, keeping in touch with events in the news, and being with people means that I still have a great life!"

Irene Donaldson



Irene Donaldson (63), mother of one from Kennoway, Fife is living with Early Onset Alzheimer's.

Irene was working as a Deputy Head Teacher at the time of her diagnosis at the age of 53.

Click here to read and share Irene's full story with your network.

You can access Irene's story on film here



"The diagnosis was a bit of a surprise. My mum had lived with vascular dementia, and I could see no similarities between her difficulties and what I was experiencing. My mum had led a good life with dementia, thanks to her family and her close-knit group of friends. So on receiving my diagnosis I was quite positive. I believed my future would be the same but sadly this wasn't the case and my life changed dramatically. The world around me didn't treat me in the same way —it was a very challenging time."

However, Irene's true friends and close family members stood up and made the difference, and Irene thanks social connection for helping her through the incredibly dark times. Thanks to their support, she was able to continue to live her life with some adjustments. "I can still do most of the things that I used to do before, I just do them slightly differently and need people to help me."

Irene was so fortunate to meet a group of like-minded people all living with a diagnosis of Early Onset Dementia and with the help of two very determined ladies they together formed a peer support group called STAND. The group is based on building social connection and engaging in peer support as well as taking part in cognitive activities.

For those who know someone living with dementia, Irene wants to encourage them to see beyond the diagnosis and focus on their family member or friend as the person they know and love to stay connected and to be there to help.

Kenny Moffat



Kenny Moffat (58) from North Lanarkshire, is living with young onset vascular dementia.

He was a Chief Executive Officer in a third sector organisation at the time of his diagnosis in 2016, when he was 50 years old.

Click here to read and share Kenny's full story with your network.



Following his diagnosis, Kenny suffered a heart attack and subsequent stroke which has left him with a left-sided weakness requiring him to use a walking stick or wheelchair.

Today, Kenny has support from both his partner and his personal support assistant, Margaret. He feels lucky to have this support around him but notes the loss of independence has been challenging.

"There have been instances in public settings where I'm out with Margaret and people will speak to her and not acknowledge me. I'm still the same person, but people can sometimes be quick to jump to conclusions or judge."

Leading a socially active life is something Kenny praises for helping him live well with dementia, "I regularly swim, and I am a member of my church. I play an active role in ensuring the services are dementia friendly. I'm also part of a flute group and book club. These social activities have been invaluable in helping me continue to live a full life, and the community's acceptance and support have ensured I remain included and engaged."

For the past three years, Kenny has proudly been a member of the Scottish Dementia Working Group, which is led by, and for people with dementia. The group campaigns to raise awareness and help people live better lives with dementia. Kenny notes, "this group has been so important in helping me stay social, providing me with a support structure and the opportunity to represent people living with dementia and campaign for change."

Ron Coleman

Ron Coleman (66) is from Dundee but now lives on the Isle of Lewis with his wife, where the couple moved initially to raise their children. Ron was a trainer for those undertaking psychosis training courses at the time of his dementia diagnosis seven years ago and would travel often for work.

Click here to read and share Ron's full story with your network.

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Ron dealt with the negative emotions many experience when first diagnosed with cognitive impairment. "I got really depressed. Then I went to Aberdeen and met a group of peers who really changed my outlook on the whole situation. Seeing how they dealt with their diagnosis, how they just got on with it – I knew if they could, I could too. That's all I really needed, to see a future."

Following his diagnosis, Ron also felt that people treated him differently. "Suddenly people are speaking to your wife instead of you, which I found very hard," Ron said. "I'm still the same person, but a lot of society view people living with dementia as not being capable anymore. The diagnosis certainly hasn't stopped me from doing most things that I want to do."

Ron was determined to make the most of life, and he chose to see his cognitive impairment diagnosis as a turning point. "When diagnosed, you go either two ways. You either go into yourself, where you shut off from the world and give up, or you can choose to see this as not as an end, but a new beginning. So that's what I chose." When Ron later had his vascular dementia diagnosis, he became motivated to do more.

Ron is the chair of the board of Deepness Dementia Media, an organisation that is run by people with dementia, for people with dementia. Of the board's twelve members, nine are living with dementia and the remaining three have experience with it. They feel empowered, having the ability to control their own agenda. "If you give people with dementia the right tools, it's amazing what we can do with them."

Ron shared that the importance of family, having a community of support, as well as keeping active and creative, have helped him live well with dementia.

Arvind Salwan



Arvind Salwan (55) is a scientist, charity founder and volunteer from Glasgow. As well as working full time, he is a care partner for his mum and previously cared for his dad who sadly passed away from pneumonia last year.

Click here to read and share Arvind's full story with your network.



Arvind's father had Vascular Dementia, and Arvind said that his dad lived well with dementia until the time of his passing. Arvind spoke of what it means to be a care partner for someone living with dementia, "it is a humbling, emotional and life-affirming experience." With the benefit of hindsight, Arvind feels it gifted them more time together, "caring for my dad was second nature. It was a symbol of my love and compassion, and I didn't feel the need to label it as care, it came naturally".

Being outside and going for walks helped Arvind's father live well with dementia, "I placed importance on continuing to spend quality time together and doing things we would normally do as a family before my dad's diagnosis, such as going on walks to Milngavie reservoirs. It's so important to not let a diagnosis be a hinderance to you or someone you are caring for. Helping my dad live life to the fullest and as normal as he could was integral."

Arvind's dad spoke several languages while he himself is bilingual. Arvind highlights the struggle for those living with dementia who are bilingual, or who have immigrated, "because of the nature of dementia, deep rooted linguistic memories are important, and this was the case for my dad – his native language was what he could remember best. This made it harder for some friends and family and, it was a struggle trying to get support for this need. I'm aware that charity, Playlists for Life, is looking into developing resources to help support this now, but there's always more that can be done."

Social media copy

Below is copy for suggested social media posts that can be shared across your own social media channels. The campaign also has a hashtag, **#RethinkDementia**, so please share in your copy whenever you can:

"It's so important to keep being yourself and do the things you've always done together." Irene lives with dementia and staying socially active has helped her continue to lead a fulfilling life. Find out more - nhsinform.scot/RethinkDementia

It's time to #RethinkDementia. If a friend or relative has been diagnosed with dementia, staying in contact, including them in social activities, and doing many of the things you've always done, can help them stay well for longer. Find out more at nhsinform.scot/RethinkDementia

Social activities like going on a walk or meeting for a coffee with someone living with dementia can help alleviate symptoms of depression and agitation. Reducing these could help them stay well for longer. Go to nhsinform.scot/RethinkDementia for more info

If your loved one or friend has been diagnosed with dementia, staying connected with them makes all the difference. "Friends, family and activity are key. I've found that keeping busy, reading and being with people means that I still have a great life!", said Danny, who lives with dementia. For more information visit nhsinform.scot/RethinkDementia

When a friend or relative is diagnosed with dementia it's natural not to know what to do, but helping someone stay connected and socially active can help them stay well for longer. Find out more at nhsinform.scot/RethinkDementia

Dr. Tom Russ, a NHS Consultant Old Age Psychiatrist and Researcher at The University of Edinburgh, shares the importance of helping those living with dementia stay socially connected. He states, "Research has shown the importance of encouraging those living with dementia to engage socially and keep active, with findings relating to an increase in overall wellbeing." Find out more at nhsinform.scot/RethinkDementia

Editorial copy

Below is example copy for your website or e-newsletters, should you wish to share more information about the campaign:

Scottish Government and COSLA campaign calls on Scots to Rethink Dementia

When a friend or relative is diagnosed with dementia it's natural not to know what to do, but helping someone stay connected, socially active, and doing many of the things you've always done together, can help them stay well for longer. The Scottish Government in partnership with COSLA has launched a new campaign to challenge the stigma surrounding dementia.

The 'Rethink Dementia' campaign encourages people to continue doing the things they always did with friends or relatives diagnosed with dementia. Created in collaboration with a National Dementia Lived Experience Panel, the campaign emphasises the importance of maintaining relationships with those living with dementia. Research has shown that making this effort to stay in contact and include individuals in social activities can help alleviate symptoms of depression, agitation, sleep disturbance, anxiety and apathy that can often come with dementia.

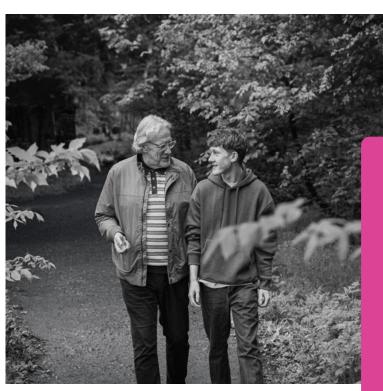


Dementia affects an estimated 90,000 people in Scotland and 3,000 of whom are under the age of 65. Insight informing the campaign highlighted that many people associate dementia with the later stage of the illness and therefore change their behaviour towards a friend or family member who has been diagnosed, some even step away.

The Rethink Dementia campaign will play a key role in getting friends and family to think differently about a dementia diagnosis and provide simple ways they can help a friend or loved one live fulfilling lives with dementia and help them stay well for longer.

Irene, 61, was diagnosed with Early Onset Alzheimer's at 53 and was surprised by the reaction of some of her friends. "When I was first diagnosed my friends weren't being themselves. Some friends just walked away but others stayed, and some were behaving differently. I had to remind them that I was still the same person that loves going to the gym, having fun, and gossiping about the things we always did. Being able to still do these things together really helps me."

For more information around supporting someone with a dementia diagnosis, please visit nhsinform.scot/RethinkDementia.



for your support in helping us to encourage people to Rethink Dementia. Together, we can help those with dementia to stay well for longer.

For more information or to discuss ways to support the campaign, contact Becky Inglis at Scottish Government's Marketing via becky.inglis@gov.scot, Nadine Reilly via nadine.reilly@gov.scot or our PR agency Stripe Communications:

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