

# According to Alzheimer's Society, nearly two-thirds of people with dementia who live on their own feel lonely. What is the solution to loneliness?

**L**oneliness and being alone don't always mean the same thing. So says the musician Roddy Frame who used to be my neighbour in Glasgow. Thirty years ago, I moved from Glasgow to the bonny Black Isle in the Highlands of Scotland. I live in splendid isolation in a traditional highland cottage with a tin roof and 178 hectares of land.

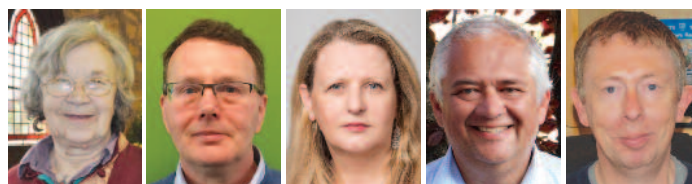
I have had times of loneliness and loss. Getting used to my dementia diagnosis was a lonely time but my family and friends helped me through. I'm not the same person as the person who got the dementia.

Accepting the emotionality of life and dementia can give you that spur to finding your own solutions. For me it's going to choir, being part of a walking group, maintaining friendships and family ties, connecting with other people with dementia. I love my Facebook and Twitter - it keeps me in touch with people and places.

The most important solution for me, though, is the practice of mindfulness. I give it priority in my life. It gives me an inner resource to look at the beauty in life. Mindfulness gives me stillness, peace, it opens up a space that lets other people in, it lets me share my emotional life with others. I'm alone but I don't feel lonely.

**Nancy Macadam is a member of the Scottish Alumni and Scottish Dementia Working Group**

**O**ne person develops dementia every three minutes in the UK and almost everyone knows someone whose life has been affected. Yet too many people



**From left: Nancy Macadam, Tim Beanland, Janet Morrison, Keith Walker and Tony Jameson-Allen**

face the condition alone without adequate support. With two-thirds of people with dementia living in their local community, and many of them living alone, it is vital that the right support is available to enable them to live well with the condition.

Dementia can be an extremely isolating experience. One survey we did found that nearly two-thirds of people with dementia who lived on their own reported feeling lonely and a third said they had lost friends. But initiatives like Dementia Friends are both helping to create a world in which everyone affected is empowered to live a life they want and no one has to face dementia alone. Nearly two million people have become Dementia Friends and more than 300 communities are working to become dementia-friendly.

Our booklet *Living alone* includes practical tips to help combat loneliness. Talking Point ([forum.alzheimers.org.uk](http://forum.alzheimers.org.uk)) is an online community where members can share experiences in confidence.

Alzheimer's Society's national Dementia Action Week will take place 21-27 May. We are calling on everyone to unite and take actions, big or small, to make a huge difference to people affected by dementia. To fend off loneliness and social

isolation, we must all play a part in supporting some of the most vulnerable people to feel part of the community.

**Dr Tim Beanland is head of knowledge management at Alzheimer's Society.**

**D**ementia gradually impacts on people's ability to connect with their loved ones, their friends and their community. People with dementia may start to be reluctant to leave the house, due to the fear of getting lost or confused in public and the stigma surrounding the condition.

At the same time relationships change within families, and there can be a marked decrease in contact with the wider world as people daunted by the condition stop visiting or making contact. And many people living with dementia live alone.

For carers struggling to maintain their relationships, the impact can be doubly painful, especially where they are also facing the loss of wider circles of friendship and support. Dementia-friendly communities have helped make communities more inclusive but there is still much more that we can do.

When people are diagnosed their social and emotional needs should also be addressed – how they can retain confidence and connections with the outside

world for as long as possible. GPs and health workers need to be encouraged to signpost people to dementia clubs and hubs, and to arts and health initiatives.

Even when language becomes a struggle, music can still reach many people, and calm and absorb and reveal the soul within.

Carers should be actively signposted to advice and information, respite and mutual support. And care homes need to invest in activities like music, choirs and the arts to bring joy and engagement and make the walls of the home disappear – linking them to the surrounding community.

**Janet Morrison is chief executive of Independent Age. She is chair of the Campaign to End Loneliness.**

**L**oneliness is a problem that's often in the news, and our knowledge of the potential health impacts is growing rapidly. Alzheimer's Society, in their report *The Hidden Voice of Loneliness*, found that 62% of people with dementia who live alone said they feel lonely, compared to 38% of all people with dementia. Befriending services were named as a priority, allowing people with dementia to have regular contact with a person they trust.

At Befrienders Highland, based in Inverness, we started a pilot to do just that back in 2011 and have since developed that pilot into a mainstream service. Our volunteer befrienders speak with their "friends" every week and we've found that this can make a huge difference in people's lives.

This is perhaps best illustrated by the stories of the

people we befriend, and their carers:

Alistair's carer told us that he frequently forgets who she and other family members are, but he looks forward to his weekly call from his befriender so much that he never forgets who he is.

Fiona lives alone and has a weekly call from her befriender. Because they talk regularly, the befriender was able to notice that she seemed very confused on two occasions. Having raised that with her coordinator, we referred to her GP and on both occasions it was found that she had an infection which might otherwise have gone unnoticed for longer.

Julie's befriender found that she talked a lot about the arts and creativity and helped her to re-engage with that side of herself by sending her a paint set and notebook.

**Keith Walker is executive director of Befrienders Highland.**

**W**e established Sporting Memories Network specifically to try to address a gap in provision for older men, particularly those living with dementia or memory problems. We know men are less likely to access medical services and are less likely to disclose emotions and feelings.

The growing evidence base on the impact of loneliness on

our health underlines the urgency and need for organisations and generations to work together to try to reach the most isolated, to offer meaningful ways to re-engage and connect people to communities.

Time and again we hear stories from people who, on receiving a diagnosis of dementia, have lost confidence, motivation and subsequently their social connections through a combination of factors. Sport is a subject that men are comfortable discussing and can help raise confidence where participants are able to contribute to conversations and meaningful activities.

While sporting memories groups are frequently advertised at GP surgeries and through memory clinics, it is often through relatives, peers and word of mouth that participants are recruited. It is worth emphasising that the groups are open to any sports fan over 50, although the majority of members have so far been male.

Sport can play a significant role in supporting people to live well with dementia. We welcome the appointment of a minister for loneliness, with Tracey Crouch adding the role to her existing portfolio of sport and culture.

**Tony Jameson-Allen is co-founder and director of Sporting Memories Network**

## PERSPECTIVES

### Shifting the emphasis to action is right, but the work of raising dementia awareness will never be done

■ Mark Ivory is editor of JDC



By Mark Ivory

Goodbye Dementia Awareness Week, hello Dementia Action Week. Alzheimer's Society has changed the name, perhaps as a mark of changing times. Surely, everyone is "aware" of dementia after all of those awareness weeks in past years; now is the time to act on that awareness!

Not that Alzheimer's Society makes exactly that argument about Dementia Action Week, which runs from 21 – 27 May. It makes the more modest claim that, while raising awareness and offering support will always be important, we must go further to create change in communities. But then the Society quotes a person called Chris, who lives with dementia and says: "People are already aware. It's action we now need. It's help, it's support. Turning into action week is absolutely the best thing I've heard."

Fair point. It's not the ideas, the concepts and the dreams that we have difficulty with, it's making them real that challenges us. Turning words into deeds and rhetoric into reality is the hard part so it seems right to shift the emphasis from awareness to action. We should always keep in mind, however, that the work of awareness-raising will never be done.

I was struck by something said to me by psychiatrist and social historian Claire Hilton, whose book on Barbara Robb's campaign to make the world aware of the dehumanising treatment of older people in the former long-stay mental hospitals we reviewed in the last issue. "Things go forward and then back again because human beings aren't machines," Hilton said. "We think we've solved something but things that depend on behaviour tend to recur. William Wilberforce abolished slavery, but it doesn't mean we don't have modern slavery. Wilberforce would have had plenty to do today."

Human beings move two steps forward and one step back, and if the net result is that we've still advanced by one step, that's only because campaigners like Wilberforce and Robb never cease to bring injustice to public attention. Mental health is a good example. On 5 July, the NHS will celebrate its 70th anniversary and it can point to the enormous progress that has been made since, in living memory, the old lunatic asylums closed. Public attitudes have altered fundamentally and even the younger members of the Royal Family are talking freely about their mental health and campaigning on the issue.

But we have not suddenly arrived in a land of milk and honey, and (sadly) nor are we ever likely to. We may be more enlightened than we were but people with severe mental illness still die, on average, 15 to 20 years earlier than other people. Employers still discriminate against people with mental illnesses and one in five older people living at home still suffers from depression. The list goes on.

So, three cheers for Dementia Action Week. Let's unite and take actions big and small to make a difference to the everyday lives of people with dementia. But let's keep shining a light on injustice too.

## National Young Dementia Conference 2018

**Achieving Improvements in Young Onset Dementia Support  
Positive, personal and practical initiatives and solutions**

*Journal of Dementia Care* conference in association with



**Thursday 20 September 2018  
The Studio, Birmingham**

Programme available soon at:  
[www.careinfo.org/youngdementia](http://www.careinfo.org/youngdementia)  
or email [events@hawkerpublications.com](mailto:events@hawkerpublications.com)