

## What is dementia?

- More than memory loss
- Not a natural part of ageing
- An umbrella term for symptoms caused by different health conditions
- Major health condition is Alzheimer's Disease – others less common include vascular dementia, frontal lobe dementia and Lewys Bodies. Symptoms vary and different causes means that there will be no one cure – many different approaches and treatments will be needed
- Dementia Friends awareness session – nearly 2.5 million people in the UK now – equips ordinary people to know how to support each other and help people continue to live well and maintain activities
- Research has been under-funded but is increasing now. Looking particularly at prevention in middle-age and building 'cognitive reserve' - it's possible to have an Alzheimer's brain but not have Alzheimer's symptoms – maintaining relationships, activities, connections can prevent deterioration
- Emotional memories remain longer than we thought – need to relate to someone's emotional state rather than their facts

## Dementia: the challenges for rural settings

(Based on Alzheimer's Society research project in Wales)

### 1. Lack of dementia awareness in rural communities

Lack of awareness was the highest ranking factor that people felt would prevent those affected by dementia from living well in rural areas. The most often used word in the survey responses was 'stigma', which reinforces some of the experiences shared by people affected by dementia from the interviews.

Lack of dementia awareness means:

- People don't know what the symptoms of dementia are and how they differ from age-related problems
- People don't know many others with dementia and rely on hearsay, myths and stereotypes
- People don't know the benefits a diagnosis can bring – the help and support – the opportunity to plan and prepare and establish help
- People don't know simple ways they can help each other to continue to live well for as long as possible

**‘Someone may know someone who knows someone else who has dementia and usually that’s a typically negative stereotype.’**

Person with dementia

**‘None of my friends come to visit me no more, they don’t know that I haven’t changed.’**

Person with dementia

**‘Not one of her friends comes round any more. They don’t even call.’**

Carer

We should work on ensuring all activities within the local area are dementia friendly and inclusive, instead of focusing just on dementia-specific activities. This is especially important in rural areas, where relationships within their immediate community are important and a strong component of rural life.

**‘There’s a difference between being dementia friendly and dementia specific. We should encourage dementia friendly, not specific – all activities and groups should be inclusive of people affected by dementia so that we can carry on doing what we enjoyed doing before diagnosis.’**

Person with dementia

Dementia Friends Information Sessions in rural areas need to be arranged for professionals and the public. Dementia Friendly Communities initiatives should be established and promoted within rural areas to enable local communities to become dementia friendly.

**‘We have village halls and we all help each other out. Give us a challenge and we’ll achieve it, especially if it means helping someone in our village out.’**

Carer

## **2. Lack of rural awareness in health and support services**

- Need for more follow up support a few months after diagnosis at memory clinic
- This needs to be more person-centred support rather than broad general advice
- It needs to take into account their rural setting

**‘The thing is, the nearest town to here is also the nearest town to all the other rural areas, so the service is oversubscribed and caters for the majority of older people, without giving those who are younger much thought.’** Carer

Only 4% of people interviewed in rural areas would contact their local memory clinic – due to their distance from people’s homes. Highlights the potential need for remote

health services within rural communities, especially to provide regular reviews. Services need to be organised around the local GP who in rural communities is often a 'family doctor' providing a consistent service – where this happens it is an advantage to regularly see the same GP.

50% of people in rural areas said that in order for people affected by dementia to live well in their rural community they would require community-based support services

Carers in rural areas may not be offered a carers assessment and then it may not take into account their rural setting

Carers want opportunities for more carer-specific training – local and flexible

**Personal support networks** are more necessary and often more available in rural settings with the right awareness and training. Information and support services need to support both the person living with dementia and their family, friends or wider support network and recognise that their needs are different.

People with dementia may say they feel 'like a burden'.

Carers who are spouses or partners or family may not recognised themselves as carers and don't feel they deserve or are eligible for support services.

It was important to people affected by dementia that information and support services shift the 'balance of power' and should be less about 'doing for' and more about 'doing with'.

**'Training or support would've been good initially; at least I would've felt a bit more confident!'**

Carer

**Transport challenges** – driving is more crucial in rural areas

**'You took my licence off me, then suggested I go to a memory café 20 miles away. I would love to go, but how?'**

Person with dementia

Greater clarification about legality of driving

More practical and emotional support for loss of driving and the sudden changes and isolation this may cause

More community transport schemes needed

### **3.Dementia Friendly Communities Rural Guide**

To be launched Thursday 17 May at Devon County Show

Thu 17 May 2018 15:30 – 17:30

During the event, people living with dementia from rural areas will talk about the

challenges they have faced since their diagnosis, and also about the ways they have been supported. We will hear from George Eustice MP, Minister of State at the Department of Environment, Food and Rural Affairs on the governments commitment to support rural communities affected by dementia. As well as Jonathan Owen from National Association of Local Councils and Ann Pascoe from her work creating rural communities in Scotland.

BBC Pavilion, Avenue A, Devon County Show, Westpoint Exeter

To book a place: <https://www.eventbrite.co.uk/e/dementia-friendly-rural-communities-guide-launch-tickets-45440609085>

There are more than 17 towns and villages in Devon working on becoming dementia-friendly including:

### **Dementia Friendly Villages around the Yealm**

The first dementia-friendly community initiative in Devon - five rural parishes around the River Yealm in South Devon came together to improve and change the lives of people with dementia and their carers. <http://www.dementiayealm.org/>

[East Devon Coastal Towns Dementia Action Alliance](#)

[KDFV \(Kenton Dementia Friendly Village\)](#)

[Culm Valley Dementia Action Alliance](#)

[Axminster Dementia Action Alliance](#)

## **4. Dementia Action Week 2018: 21-27 May**

'Challenge dementia' and more resources in this link.

[https://www.alzheimers.org.uk/challengedementia?utm\\_campaign=DAW&utm\\_content=DAW%20marketing%20IG&utm\\_medium=email&utm\\_source=Smart%20Focus](https://www.alzheimers.org.uk/challengedementia?utm_campaign=DAW&utm_content=DAW%20marketing%20IG&utm_medium=email&utm_source=Smart%20Focus)

### **Thinking of you – a resource for the spiritual care of people with dementia,**

by Joanna Collicutt. Both theological and pastoral – recommended.

<https://www.brfoonline.org.uk/9780857464910/>

### **Has your community group or church hosted a Dementia Friends session yet for your community?**

Dementia Friends has done so much to help people living with dementia and carers feel understood and supported. You may have attended a session but has your church and community? You can find a Dementia Champion through the Dementia Friends website

## A personal story

My husband Douglas had vascular dementia for at least 10 years, probably more but so slight that it hardly impacted his life. We married when his first wife died - of smoking related cancer. I was 58 , he was 72.As he deteriorated we had wonderful support from our local GP surgery. He refused to see a consultant as he realised what was wrong and didn't want anyone to spell out the details to us. We quietly adapted our lives to his deterioration, keeping his life as interesting as he could take and gradually doing less and less.

We had wonderful support from St. Swithun's, Sandford, though we lived in Morchard Bishop . We worshipped there weekly and when he became unable to attend church a member of the congregation recorded the servers and brought it out, so we could listen together in the afternoon or evening.

As he became weaker and unable to pray on his own I sang a short, well known hymn to him by memory as he settled for sleep.

When he needed a wheel chair I first hired one from Red Cross and then bought one when I realised what we needed. I always was given help, even by strangers, when it was clear I needed it.

When my husband became bed ridden a kind nurse from the village came in to wash him while I nipped up to the village shop. All the time he was bedridden, the local vicar brought us Communion each week.

I also had a great deal of support from local people - they knew I only asked for help if I really needed it and I always was given it, very willingly.

We continued to share our bed to the very end - I woke at 2.30, realizing he had just passed peacefully over.

That was all 8 years, 4 months ago. I still feel married to him. Although we married late in life it was a perfect marriage. I also was given much support by the village when I moved to a smaller property, in Sandford. Villages are wonderful places.

Pamela



**Robot & Frank** is a 2012 American science fiction comedy-drama film directed by Jake Schreier and written by Christopher Ford.

Light-hearted, it makes some very helpful points about the experience of dementia within a family.

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