



# Dementia in rural Wales

The lived  
experiences



**Document purpose:** This report showcases the lived experiences of people affected by dementia in rural Wales, based on interviews and surveys. The report is intended to be used to influence and inform internal and external services, strategies and policies.

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# Introduction

Alzheimer's Society estimates that approximately 17,000 people in Wales live in rural areas and have dementia.<sup>1</sup> This figure represents people living with dementia only and does not include family carers, friends or supporters of people living with dementia. The amount of people affected by dementia living in rural communities is likely to grow, as Wales has a proportionately larger older population than the other nations in the UK.

Despite this, there is very little research available that helps us identify and understand the experiences of people affected by dementia in rural areas. Listening to these experiences can help us to understand the benefits of living in rural Wales for people affected by dementia and the barriers to living well. Without this knowledge, we risk future policies, strategies and service models not meeting the needs of those living in rural areas. This could have a negative impact on their ability to live well with dementia.

To better understand the needs of people affected by dementia living in rural areas, Alzheimer's Society Cymru agreed to pilot a small engagement project from June to August 2016, which created opportunities for people affected by dementia to share their experiences of living in a rural area.

We spoke directly to people affected by dementia from areas across Wales and asked them to share their experiences from the point shortly before they were diagnosed to the period after diagnosis. We also developed a Dementia in Wales survey to understand further the disadvantages of living with dementia in a rural community according to the general public, people living with dementia and their wider carer, family or support networks.

This report showcases the experiences of people affected by dementia through direct quotes. We have not changed or added to their words, except in a small number of instances where we have put minor changes in brackets.

The experiences of people affected by dementia have been grouped into key themes that emerged naturally from these conversations. Each theme has been summarised with a 'What have we learnt?' section and recommendations from the people we spoke to. We hope that these will inform the future development of policy, strategies and services that directly benefit the lives of people affected by dementia.

## People affected by dementia

This report uses the term 'people affected by dementia' to mean people with a diagnosis of dementia along with any partners, family and friends who may be involved in their lives, care and support.

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1 Alzheimer's Society (2016). *Dementia in rural Wales: The three challenges*, [https://www.alzheimers.org.uk/info/20089/campaigns\\_in\\_wales/240/dementia\\_in\\_rural\\_wales\\_our\\_new\\_report](https://www.alzheimers.org.uk/info/20089/campaigns_in_wales/240/dementia_in_rural_wales_our_new_report)

# 1 Defining a rural area

The rural-urban classification used by the Office for National Statistics defines populations of fewer than 10,000 people as rural, and those above 10,000 as urban.<sup>2</sup>

Most of the people affected by dementia we spoke to had a good knowledge of what constitutes a rural area and were able to identify the type of area they lived in. However, when they accessed services for information, most of them were not asked to define the type of area they live in (although they were asked for their address). People affected by dementia agreed that health professionals and service providers should identify the type of area where a person lives and use this as part of their assessment for support.

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**‘You need to consider the individual and their individual circumstances. How can the support you give me help my experience of living with dementia in a rural area?’** Person with dementia

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Identifying the type of area in which a person affected by dementia lives can ensure they are signposted to services that are easily accessible to them, or assessed for transport as a means to attend services. This would be a small change to implement across health and social care and the voluntary sector. Recording the type of area in which a person affected by dementia lives would also provide a more accurate understanding and representation of the prevalence of dementia in rural Wales.

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<sup>2</sup> Bibby, P. and Brindley, P. (2013). *Urban and Rural Area Definitions for Policy Purpose in England and Wales: Methodology*.

‘I have been given so much information on “local services” that are a 40 minute drive away. Maybe if health professionals were aware of the rurality of the area they would understand these aren’t accessible and could use this to evidence the need for drop-in or remote services.’ **Carer**

‘I don’t know if it is any different living in a rural area, because it’s all I know. What I do know is that if I didn’t drive or have good family and friends, I wouldn’t be able to do an awful lot!’  
**Person with dementia**

## What have we learnt?

- The type of area (rural or urban) where a person affected by dementia lives is not asked before or after diagnosis.
- Professionals do not see the need to know the type of area (rural or urban) where a person affected by dementia lives, but for people affected by dementia this information is important
- Rural is a general term – rural areas vary. While some are close to urban areas, some are often very remote.

## Recommendations from people affected by dementia

- When someone receives a diagnosis of dementia, they should be asked whether they live in a rural or urban area.
- The area in which people live should influence the information and support they are offered.
- More time needs to be spent with people affected by dementia living in rural areas to hear their experiences, including creating more opportunities for conversations like those that took place for this report, or an expert reference group.

## 2 Getting a diagnosis of dementia

People affected by dementia in rural areas told us they visited their GP as a first point of contact to discuss or report any concerns about possible symptoms of dementia before being diagnosed. However, the time between noticing symptoms and making contact with the GP varied from one week to two years. There were several different reasons for this.

One reason was the lack of awareness between normal age-related symptoms and symptoms associated with dementia:

‘Thinking about it, I think the symptoms probably started at least two and a half years before, but when you get older you don’t recognise the difference between ageing normally and when something is wrong.’

**Person with dementia**

‘I suppose in bigger areas it’s more widely spoken about and you get to hear about the symptoms and what you should do. I mean, the only people I know about who had dementia were those in care homes or those people who were really old. I was too young to get dementia, so I just thought it was a normal part of ageing.’

**Carer**

However, some people living with dementia did not go to the GP because they were concerned that they had dementia. Worryingly, many people living with dementia told us that the lack of both dementia awareness, and of available dementia-specific support services, made people feel that they would be ‘no better off’ with a formal diagnosis:

‘We just buried our heads in the sand. Maybe because we knew there was no support or presence in this area (rural) and that the lack of awareness about dementia meant it was something to be feared.’

**Carer**

It was generally felt that access to GP surgeries is good, with many within short driving distance or walking distance and flexible with offering appointments. This was seen as good practice and a standard that should be consistent across all GP surgeries.

‘I work full time, so I could’ve easily put it off. The GP has always been flexible and it was really helpful on this occasion as I was able to be seen when I could fit around work.’

**Person with dementia**

People affected by dementia spoke about the importance of having a consistent GP to recognise changes in people who may have dementia and how this ensured a quick referral to the memory clinic. A benefit of living in a rural area for some was the presence of a ‘family doctor’ who has been practising in that community for a long time. Those who did not consistently see the same GP reported more negative experiences such as a delay in referral to get a diagnosis.

‘He (the GP) has been there for ages, so he’s known us since before we had concerns about dementia. Because he knew us, he was able to see the changes and it reassured me that something wasn’t right.’

**Carer**

‘The old GP had retired, so they weren’t able to recognise the differences and changes in him. This was a man who was a mechanic for 30+ years who could no longer understand or be able to do his job.’

**Carer**

Some people told us that GPs were not always able to assess and acknowledge the difference between age-related symptoms and dementia. This was especially true for those diagnosed with young-onset dementia.

'I went to the GP. He asked some questions and told me that because my husband could remember to get dressed he didn't have dementia. A couple of months later, I had a phone call and the GP had asked where he was for his appointment. Well, he'd made the appointment and had forgotten all about it. I visited a second GP and explained all the symptoms and was referred to the memory clinic straightaway.' **Carer**

'I went to the GP initially and they did lots of blood tests. We had to wait for those – they came back all clear. His behaviour was changing more and more and he was sleeping a lot more too. We went back again and they referred him to the sleep apnoea clinic. We even tried relationship counselling because we thought it was something to do with us. When we finally got referred to the memory clinic he had an MRI and it [showed] he had sustained two strokes. The whole diagnostic process then went quite quick from there.' **Carer**

## What have we learnt?

- GPs in rural areas are often accessible.
- Booking an appointment to see the GP in a rural area is flexible.

However:

- Rural areas benefit from having a small pool of longstanding GPs.
- People put off going to their GP due to not recognising their symptoms or because they believe there will be no support to benefit them post diagnosis.
- GPs were not quick in diagnosing dementia or referring to the memory clinic.

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**'We went to the doctors and discussed her memory loss. Because she was only 50, he put it down to the menopause and I was told to come back in a few months once things had settled down.'**

**Carer**

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## Recommendations from people affected by dementia

- People with suspected dementia and those who have dementia should remain with the same GP for as long as this is practical throughout their journey with dementia.
- GPs should be fully trained and confident in recognising the difference between age-related problems and symptoms of dementia.
- All GPs, other health professionals and staff in surgeries and other locations such as memory clinics should be Dementia Friends.
- These GP surgeries and other locations should be dementia-friendly environments.
- The diagnostic pathway should be explained to and understood by people affected by dementia.
- All suspected cases of dementia should be referred straightaway to the local memory clinic.

# 3 Themes from conversations with people affected by dementia

The lived experiences of people affected by dementia, following a diagnosis of dementia was often negative, with only one outwardly positive experience identifying best practice. The areas of support after diagnosis have been grouped into four themes, all of which came directly from listening to people affected by dementia:

Theme 1: Transport

Theme 2: Information and support services

Theme 3: Personal support networks

Theme 4: Dementia awareness



# Theme 1: Transport

At the point of delivering a diagnosis, the health professional has to advise the individual to contact DVLA promptly. DVLA then follow their own processes to determine whether the person is safe to drive. If the diagnosing doctor advises the person not to drive while DVLA is making its decision, this advice must be followed.

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**‘They say he can go to a residential setting for respite, but that I need to take him to it and pick him up. By the time I’ve driven there and back, it’s not really giving me a break or for the purpose it’s intended.’ Carer**

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Most people living with dementia were not aware of the legal requirements about driving following a diagnosis of dementia, nor were their carers, friends or wider support network. Most of the people said they were advised by the doctor to stop driving straightaway. DVLA subsequently referred only one person for an on-road assessment and revoked the licences of the rest.

‘At this point the consultant hadn’t even mentioned to me about dementia and told me to come back in two weeks for my results. As I live in a rural area, the memory clinic was 90 minutes away so I had to drive. When I got there, he dropped this bombshell that I had dementia and told me that I couldn’t drive back. Not only had I received a diagnosis of dementia, I was stranded at the hospital with no idea how I was going to get home.’ **Person with dementia**

For people diagnosed with dementia, no longer being able to drive had a negative impact on their personal lives beyond the practical implications.

‘I remember that afternoon I had made plans to see my friends where I have my caravan, which had been ruined. I then realised that I was not going to be able to keep my caravan – a huge part of my social and personal life. What was I going to do? I can’t get a bus and I can’t afford taxis!’ **Person with dementia**

‘My husband was a mechanic, so he was very upset after having his licence taken away. He did eventually come round to using the bus, but for someone so independent this wasn’t an easy step to make.’ **Carer**

People told us that there appeared to be no clear reason why some people living with dementia were advised to stop driving straightaway and others were told to contact DVLA. In addition, when people’s licences were revoked, they were not fully informed of the reasons why, and were unaware that this was against their rights. These experiences caused great upset and stress for people affected by dementia at an already difficult time. This would often be their first experience of how things would change as a result of their dementia and often left people feeling more negative about their diagnosis.

For those people who could rely on close family members and their wider support network, the lack of transport or losing a licence had little impact as they were able to continue travelling around and outside their rural communities.

‘My daughter comes and picks me up and drops me off to do my shopping. I mean, I suppose I could get someone, or even her, to do it for me, but I’m still able to do it and it’s about still doing the things I can while I can. A taxi wouldn’t be able to help me with my shopping – I’m restricted to times and they can’t come round the shop to help prompt me when I can’t find or remember something.’ **Person with dementia**

Some carers, friends and supporters find the additional need to provide transport for the person with dementia, or enable them to use public transport, difficult – especially in instances where transport is required for the person living with dementia to attend respite.

People affected by dementia often described public transport in rural areas as poor and this increased social isolation. They find that services are not accessible in rural areas because of the lack of public transport available. This is explored further under Theme 2: Information and support services.

‘He loves to catch the bus – always has done. But there’s only one bus a day now from where we live, so he’s limited on what he can do and where he can go. There isn’t anything around here that he can access so it’s difficult for him to keep active/stimulated if there’s nowhere for him to go [that doesn’t require me taking and attending with him].’ **Carer**

‘I can’t access public transport because of my physical disabilities and I can’t afford to keep taking taxis everywhere. So I sit at home most the time. It’s why I’m desperate for a house swap so I can have a garden – at least I can sit outside.’ **Person with dementia**

None of the people we interviewed mentioned the impact and benefit of community transport, which is often an accessible, cost-effective, flexible alternative to public transport run by the community for the community. People affected by dementia were not aware of community transport services locally or that community transport is a support resource for people affected by dementia to use.

## What have we learnt?

- People living with dementia are often underprepared for the impact a diagnosis of dementia can have on their ability to drive.
- People living with dementia need to be given a full explanation of the legal requirements about driving following a diagnosis of dementia.
- Access to transport (public/personal) can impact on social isolation and feelings of loss.
- Carers reported increased pressure as a result of an expectation placed upon them to provide transport.

## Recommendations from people affected by dementia

- A person should be informed of the possible impact on driving prior to the appointment of receiving a diagnosis – so alternative arrangements can be made or someone can be present with them.
- The impact of losing a licence on a person living with dementia should be considered, and practical and emotional support provided immediately (or signposted to).
- Significant investment in community transport is needed within rural areas.
- People living with dementia need opportunities to help shape and influence future transport plans on a local and national level.

## Theme 2: Information and support services

Most people living with dementia and their carers, family and wider support network explained that they were offered a folder of information at the point of diagnosis (though one person wasn't offered this). Professionals in many services clearly recognised that information at this point is beneficial. However, most people with dementia said that they had been overwhelmed by their diagnosis and that the information pack had been stored away to be read at a more suitable time or when needs arose. They were most concerned by the lack of follow-up information and signposting. Many people only received other sources of information and support when a crisis occurred.

'I felt so much stress as a carer, like I had to do everything. I was close to burnout. I phoned social services at this point who put me in touch with carers' outreach who were able to sort some things out for me. Did it need to reach that point? Where was a phone call asking how I was?' **Carer**

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**'The social worker said, 'Were you not given this information when you were diagnosed?' I said yes, I probably was, but I can't say I took much in at that point apart from what the bloody hell I was going to do next!' Person with dementia**

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The information provided at the point of diagnosis, for those who were able and willing to read through it, was not based on individual needs but was general to dementia and what they expected a person to experience and need support with. More so, for people living in rural areas, most of the leaflets regarding services were not relevant or within reach for them to access. This often left people feeling disheartened and not supported.

'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**

'If you keep offloading information, you risk not providing the right services for that person and not meeting their needs. They give you as much information as they can and leave you to get on with it – not taking into account any additional needs like living in a rural area.' **Carer**

'Post-diagnostic support was good, it's just a lot of it was inappropriate for him or us.' **Carer**

Sometimes information in the folders was out of date, or services suggested weren't open for people affected by dementia to access:

'The social worker came out and I'd explained that I'd been struggling to get someone from the village to come and fix the gate and make it secure. The social worker gave me the number for Gofal a Thrwsio<sup>3</sup> – when I phoned up it had been out of service for a few months.' **Carer**

'They suggested befriending as a way to help socially and it made me feel hopeful there'd be something I could access here. When my support worker phoned, they didn't support people with dementia "because we'd forget who the befriender was".' **Person with dementia**

Dementia-specific services were important to all the people we spoke to as they were able to offer dementia-specific advice. They also felt that staff attached to these services were trained to support people affected by dementia and were better aware of support needs.

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3 **Gofal a Thrwsio, otherwise known as Care and Repair in other areas across Wales, offers practical advice and assistance to people over 60 years of age and people with disabilities, who live in the private sector, so that they may live in comfort and safety.**

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**‘I couldn’t grasp the toilet and they (the doctor) kept telling me it was to do with my balance. When a dementia support worker came out they suggested trying a red toilet seat to help me see the difference between the base and the top. It worked!’  
Person with dementia**

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There was a mixed response from people affected by dementia regarding dementia-specific services. People living within rural areas felt that dementia-specific services, including group activities, may ‘segregate’ people from their community or act as an excuse to exclude people affected by dementia from ‘non dementia’ activities. They suggested that we should work on ensuring all activities within the local area are dementia friendly and inclusive, instead of focusing on facilitating dementia-specific activities. This was especially important in rural areas, where relationships within their immediate community are important and a strong component of rural life.

‘As a person living with dementia, I don’t always want to be around other people living with dementia. I want to be able to go to bingo and not feel that I can only go when it’s dementia friendly. I see the merit and benefit of dementia-specific services and activities, but not all the time.’ **Person with dementia**

‘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**

There are fewer services and points of information available for people affected by dementia in rural areas. Services that are within reach to people affected by dementia are not usually dementia specific.

‘If I went to the nearest city, which is about 15 miles away, I’d be able to go to their activity groups. I’m not saying they need a service in every area, but could you not move it around?’  
**Person with dementia**

‘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**

‘So they told me about the nearest care home and it was awful, no dementia awareness at all. Shouldn’t all staff in these places be aware of dementia or does it only occur in cities?’ **Carer**

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.

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’.

‘The caring and coping group (run by a clinical psychologist) has been a great support to me as a carer – we’ve even developed our own peer support group on the back of this where we meet and talk. We have experiences of different dementia, which is useful, and also because we’ve been meeting for a long time we’ve supported each other through the progression of dementia.’ **Carer**

‘Someone takes me shopping, writes my list, puts it away. I can still write, I can still reach and I think I could still walk around the shop. They’re not there to do that with me though, just to do it for me.’ **Person with dementia**

‘For me, [I don’t need carers to come in and] wash, dress and feed [my husband]. [I need them] to sit with him and to take him out – activities are important to him, he likes to keep socially active. I need time for myself too. I used to go to Merched Y Mawr every month, but I can’t go anymore because I can’t leave him on his own.’ **Carer**

‘Day centres have been fabulous, an absolute lifeline. The fact that the council are talking about closing them is criminal.’ **Carer**

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**‘I want to do what I enjoy; I need someone to help me do that.’** **Person with dementia**

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## What have we learnt?

- Information on dementia and services is often only given at the point of diagnosis.
- Some of the information provided at this point is neither specific nor tailored to the needs and interests of people living with dementia.
- Dementia-specific services are important in supporting people living with dementia.
- Accessibility to services in rural areas is poor and often services close by are not dementia specific.
- The needs of the carer and person living with dementia in rural areas are different and are often not assessed separately at different points post diagnosis.

## Recommendations from people affected by dementia

- Information and support about dementia should be timely.
- Any information or support provided should meet the needs and interests of the individual.
- Services should be available in remote areas and be able to move around. For example, drop-in services in local village halls, or an information bus that drives to different areas.
- Carers and people living with dementia need to be assessed individually for care and support – but at the same time.
- Dementia-specific services should be available to everyone who has a diagnosis of dementia.
- Services that are accessible to people with dementia, but are not dementia specific, should be dementia friendly.

## Theme 3: Personal support networks

Both people living with dementia and their informal carers experience a lack of support.

The majority of informal carers we spoke to had at some point experienced carer stress or were close to reaching 'burnout'. Informal carers, most notably spouses, found it difficult to recognise and identify themselves as 'carers' and didn't feel they deserved the support of services.

'I asked [the local councillor] to write down the following and to tell me [the answer]: 168 minus 35 minus 15 equals 118, and she asked what it meant. I explained there's 168 hours in a week, 35 hours is the help my daughter gives and 15 hours is the amount of respite I get. I am left to cope on my own for 118 hours a week.' **Carer**

'It would be a completely different story if I didn't have the help of my family and friends, I don't know what I'd do.' **Carer**

'How can I put myself first? I've spent the past 51 years putting my wife and children first. This advice is good, but people need to adapt the meaning behind the message in respect to dementia, because most things I can't do without neglecting the person I am caring for.' **Carer**

People living with dementia used phrases such as feeling 'like a burden' when they spoke about the amount of support they required from their carer or wider family support network. This sense of guilt appeared stronger in people living with dementia who lived alone.

'They work full time and have a child who has a disability and they have to look after me on top of that. She says she doesn't mind, but it doesn't make me feel any better.' **Person with dementia**

People often reported a much more positive experience of living with dementia where care and support was provided by a family or friend support network.

The role of family and wider support networks in enabling people in rural communities to live well was often not acknowledged by the health sector and social services. Carers often felt they were taken for granted and used as a 'free service' in rural areas, meaning that councils were less likely to commission services if they knew carers and wider family support networks were going to support the person living with dementia.

'We save services a lot of money!' **Carer**

'Without the support, how can I carry on caring for someone at this level? I just need an hour off, not every day.' **Carer**

'If my daughter got paid per hour for what she did, she'd make a fortune, but instead she's working two full-time jobs – one that she doesn't get any support or pay for!' **Person with dementia**

Informal carers of people living with dementia were rarely recognised as needing support and rarely offered a carer's assessment.

Where assessments were carried out, the support offered to the informal carer was often not flexible enough to support the person living with dementia because of the geographical nature of rural areas and the oversubscription to existing services. In these instances, informal carers were declining respite even though they needed it to help reduce carer stress.

'They said they could come in for 20 minutes a day before they had to leave to allow them time to get to the next person. I think this would be more confusing and disorientating for her.' **Carer**

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**‘So, I went to the doctor as I was finding it hard to manage, not with him, but with the carer role. He said I needed a carer’s assessment, the social worker came around and said ‘I’m here to assess him not you’. It’s like I didn’t exist.’ Carer**

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‘They did offer someone to come in four times a day, but no one can ever provide the level of care that me and my daughter can provide – we understand her, respond to her. And that isn’t being disrespectful to organisations or care providers – we just know her better and can support her needs.’ **Carer**

‘Respite [needs investment]. I know there are finances and resources, but this a resource that works well for the person living with dementia and their carer. With more resource and investment it could support more people and be equipped to support people with young-onset dementia as well as those diagnosed when they are older.’ **Carer**

People living with dementia often preferred family and wider support networks to support personal care needs and, more often than not, carers were comfortable supporting these needs. Carers felt they would benefit from carer-specific training courses which focused on personal care and help with eating. Male carers reported managing care needs specific to women difficult and not really knowing who to talk to – most would use their pharmacy as a point of contact for gaining support with these needs.

‘Yes, a woman’s specific problem, I didn’t know what to get or what was most appropriate to use. I’ve learnt how to dye her hair, paint her nails and bathe her – all on my own. I want to do them because they make her feel good. Training or support would’ve been good initially; at least I would’ve felt a bit more confident!’ **Carer**

## What have we learnt?

- Family and wider support networks are relied upon as a form of support in rural areas.
- Being enabled to do the things a person enjoys is more important to the person affected by dementia than having things done for them.
- The level of support required from some support networks can make people affected by dementia feel like a ‘burden’ and impact on their experience of living well with dementia.
- Both the carer and person affected by dementia prefer family and wider support networks supporting personal needs.

## Recommendations from people affected by dementia

- Carers and supporters of people living with dementia should be recognised by health and social care for the support and care they provide to enable people living with dementia to live well.
- Services for people living with dementia should focus on enabling a person to continue doing what they enjoy, rather than doing things for them.
- Practical information and courses for carers and people living with dementia should be available to help equip them with the skills to care for specific needs.
- Services that provide personal and practical care should be more flexible and consistent in rural areas.

## Theme 4: Dementia awareness

The experiences of people affected by dementia suggest a severe lack of dementia awareness in rural areas.

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

‘Well, some charities are reinforcing the lack of awareness. Look at the Memory Walks, our nearest one is Chester or Liverpool. The Wales one is only in Cardiff. I organise my own memory walk every year with over 500 people and I fund most of it myself. I can definitely say it’s helped to raise the awareness.’ **Carer**

‘She said, “I do feel sorry for you” so I said “you don’t need to feel sorry for me, because if I felt sorry for me I wouldn’t cope – just understand and be aware of what I’m going through”.’ **Carer**

Most people affected by dementia acknowledged the importance of encouraging and implementing dementia awareness and dementia-friendly communities in a rural area. They spoke about how this would benefit people with dementia in their local area.

‘Everyone knows everyone and we all like to help out. Once people had that awareness they wouldn’t be scared to help. It’s not out of maliciousness, they just know no different.’ **Person with dementia**

They spoke about the resources available in rural communities, such as village halls, and their unique community spirit and support. People affected by dementia felt we should be making the most of these resources and using them to achieve dementia awareness and help communities to become dementia friendly.

The lack of dementia awareness in some rural areas had a negative impact on people affected by dementia.

‘No one wants to help no more; it’s as if they’re scared to come round the house.’ **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**

People affected by dementia often spoke about their involvement in local communities and how people could be engaged to facilitate Dementia Friends Information Sessions and to encourage a dementia-friendly community steering group.

‘If people want to know what it’s like, they should speak to us, they can know first-hand then how it affects us here and what needs to happen to make it better or keep it good.’ **Person with dementia**

‘This engagement project is a prime example – you know now what needs to work. We need to raise awareness amongst people affected by dementia, professionals and the public about how living in a rural area impacts the experiences of people living with dementia – including what they can do to help.’ **Person with dementia**

## What have we learnt?

- There is a lack of awareness about dementia and the needs of people living with the condition, amongst people in rural Wales.
- This lack of awareness has a negative impact on people affected by dementia, with many of them losing friends as a result.

## Recommendations from people affected by 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.

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**‘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**

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# 4 Dementia in Wales Survey

It can be difficult for people to share their personal experiences using one-to-one interviews. For people with dementia, it can be especially difficult as this can often prompt memories that evoke strong feelings, or can involve discussing difficult situations they are experiencing. Therefore it was important that we used other methods of engagement to ensure people affected by dementia had the opportunity to share their views and experiences. To understand the greater impact of dementia it was also important to understand better the disadvantages and benefits of living in rural areas, as perceived by whole communities – dementia is everyone's business.

The Royal Welsh Show presents a yearly opportunity for Alzheimer's Society Cymru to engage with the people of Wales. During our visit in summer 2016, we rolled out the Wales Dementia Survey and collated over 200 responses. We asked people to identify whether they lived in a rural or urban area. This allowed us to compare the perceived disadvantages and benefits of living in either community.

## Key findings

- Out of 237 responses, 69% of people defined themselves as living in a rural area.
- Only 4% of people in rural areas had only 'heard of' dementia or knew nothing about dementia, 46% knew of someone with dementia in their local area and 29% cared or were caring for a person affected by dementia. This highlights the potential need for dementia-specific support and information in rural areas. Only one person with dementia responded to the survey.
- 77% of people from rural areas would attend their GP for information and support as the first point of contact if they were worried about their memory or if they had a diagnosis. This suggests the development of any support services, local strategies or policies needs to include working closely with local GPs.
- Only 4% of people would contact their local memory clinic. The interviews with people affected by dementia highlighted the difficulty in accessing memory clinics due to their distance from people's homes. In light of this, this result is not surprising – but it highlights the potential need for remote health services within rural communities, especially to provide regular reviews.
- 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. However, this was also identified as the biggest difficulty for people affected by dementia to access services within rural communities (31%). From this, we can conclude that the services people need to live well with dementia in rural communities are not available.

- People within rural communities wanted support services in the community to include peer support, dementia networks, carer support and dementia-specific information.
- Some people affected by dementia in rural communities identified the lack of Welsh speaking staff and information in Welsh as a barrier to accessing dementia-specific support and information.
- Family and friend support was identified as a resource for enabling people affected by dementia to live well in rural communities (27%). Interestingly, this family and friend support was not identified as a barrier, which suggests that family and friend support is currently available for people affected by dementia. These results mirror the experiences shared by people affected by dementia – due to the lack of services and information currently available, people affected by dementia most often only have the support of family and friends. We should value and recognise the support given by family and friend carers, but also be aware of the impact this can have on them. The experiences shared by carers during the interviews were often negative when they were the person's only source of support, with many experiencing high levels of carer stress. It is important that external support and information is accessible for people in rural communities. This will benefit both the person living with dementia and their family and friend support networks by relieving carer stress.
- 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. Targeted awareness-raising campaigns need to be developed and initiated within rural areas, including the development of specific rural dementia-friendly communities.
- Although transport was not the highest-ranking barrier to people affected by dementia living well in rural areas, it was rated as a bigger barrier for rural communities (16%) than for urban communities (6%).

## 5 Moving forward

Firstly, we would like to thank each person who took part in this engagement study, who dedicated time to sharing their experiences.

The purpose of this project was to listen to the experiences of people affected by dementia in rural communities and to use these to influence services, policies and strategies that involve people affected by dementia in Wales. Moving forward, we want to ensure that people affected by dementia in rural communities across Wales are able to access services and information but also that strategies and policy are developed in line with their needs.

With the consent of those who took part, we are going to share this report with our internal managers at Alzheimer's Society Cymru at a national and regional level. We have committed to each of our four localities in Wales adapting something within our current services to better meet the needs of people affected by dementia in rural communities. We are committed to ensuring people affected by dementia in rural areas in Wales live well, and have developed a policy report on Dementia in rural Wales<sup>4</sup> and a Rural Dementia Task and Finish Group.

Outside Alzheimer's Society, this report has been shared with the Welsh Government to enable them to shape their Wales Dementia Strategy to ensure it meets the needs of those living within rural communities. It will also be shared with those responsible for transport to champion, with evidence, the involvement of people affected by dementia in reviews of future transport plans.

In social care, the report has been shared with the Care Council for Wales and will contribute to the training programmes currently being delivered as part of its Good work: A dementia learning and development framework for Wales. The findings from our conversations with people affected by dementia have been shared with local authorities across Wales to enable dialogue and help shape the services they offer to people affected by dementia, to ensure these services meet people's needs.

Memory clinic teams across Wales have also received a copy of the report. We hope that this will increase awareness of the difficulties in accessing the memory clinic pre and post diagnosis for those living in rural areas, as well as resources that can be used to help.

The report has also been shared with the relevant health and social care facilitators in each local authority across Wales to distribute to all third sector service providers in their areas. They have also been asked to share this report with those responsible for rural health development in their areas.

**People affected by dementia in rural Wales require change and by working with them and in collaboration with others, we can achieve this.**

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4 [https://www.alzheimers.org.uk/info/20089/campaigns\\_in\\_wales/240/dementia\\_in\\_rural\\_wales\\_our\\_new\\_report](https://www.alzheimers.org.uk/info/20089/campaigns_in_wales/240/dementia_in_rural_wales_our_new_report)

Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

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