

Diagnose or disempower? Receiving a diagnosis of dementia in Wales



Document purpose **Diagnose or disempower?** presents new evidence about the experiences of people receiving a diagnosis of dementia in Wales. The report aims to provide an accurate overview of the process of receiving a diagnosis of dementia and the support available to people with dementia in the first year after diagnosis. It makes recommendations about the changes that most urgently need to be made in order to improve the experience of receiving a diagnosis of dementia.

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Foreword



Over half of the people with dementia in Wales have still not received a formal diagnosis. Even those who have received a diagnosis have most likely not received the information and support that they need in order to live well with dementia. This is simply unacceptable.

People with dementia have a right to a diagnosis. A diagnosis empowers people to make decisions about their lives and future care. In some cases it enables access to medication that can slow down cognitive decline, and it helps individuals and their families to understand the changes that they are experiencing.

A diagnosis of dementia should also open doors to appropriate services, but this report demonstrates that very often these services are simply not available. With appropriate support, people with dementia can continue to have a good quality of life. However, far too many people are still not receiving the support they need.

Diagnose or disempower? is the first report to take a detailed look at the situation in Wales. It shows that far too many people with dementia have a negative experience of diagnosis, but it also demonstrates the necessary steps towards lasting change.

Alzheimer's Society has a vision of a better Wales for people with dementia: a Wales where people with dementia are empowered to be active partners in their care, where people with dementia are informed about their condition and provided with the support necessary to maximise their quality of life. We believe that this Wales is achievable by 2021, but there is much that needs to be done and no time to lose.

The time to act is now. Together we can and must make Wales a truly dementia-friendly nation.

Sue Phelps
Director of Alzheimer's Society in Wales

Executive summary

Dementia is a national challenge in terms of its scale and impact. There are currently 45,000 people living with dementia in Wales. One in five people in Wales has a close family member or friend who has dementia. It is estimated that by 2055 there will be over 100,000 people living with dementia in Wales. Dementia now costs the Welsh economy £1.4 billion a year and the costs of dementia are increasing as the numbers of people with dementia increase.

Receiving a diagnosis of dementia empowers people to make decisions about the care and support they receive; it opens the door to accessing services and, in some cases, medication. It offers economic benefits to the health and social care system, through improved clinical management and reductions in crisis admissions.

In a poll of the Welsh general public (aged 18+), half of the people in Wales thought the Welsh Government should be doing more to respond to dementia in Wales. Diagnose or disempower? sets out some of the most urgent changes that need to be made so that 75% of people with dementia in Wales receive a diagnosis and everyone diagnosed with dementia receives at least a minimum standard of support.

Diagnosis rates in Wales

In Wales, diagnosis rates are among the worst in the UK, with little improvement in recent years. The diagnosis rate in Wales is currently 43.4%, an increase of only 0.6% on the previous year. No local health board (LHB) in Wales achieves a diagnosis rate higher than 50% and the lowest is just 37.2%. Some LHBs even experienced a reduction in their diagnosis rates this year. It is not acceptable that so few of the people estimated to be living with dementia in Wales have received a diagnosis.

In April 2015, the Welsh Government announced that it had set the Welsh NHS a challenge: increase the dementia diagnosis rates to 50% by the time the figures for 2015-16 are published. This is the first time that there has been a specific commitment to raise the dementia diagnosis rate in Wales and, as such, it is very welcome. However, far more needs to be done and it is essential that the Welsh Government commits to concerted action to raise the diagnosis rate in Wales. Local health boards should commit to an annual minimum increase of 5% in the diagnosis rate for their area. This should enable an increase in the national diagnosis rate to 75% by 2020.

Improving diagnosis rates involves more than just improving numbers – it involves designing a diagnostic pathway that takes people from their first appointment with their GP through to the support they receive in the years following a diagnosis. This requires investment and joint working across the health and social care sectors and strategic leadership from the Welsh Government. As such, the overarching recommendation of this report is that the Welsh Government commit to an adequately resourced and fully accountable national dementia strategy for Wales.

Alzheimer's Society believes everyone with dementia should be able to access a timely diagnosis. A timely diagnosis can be understood as a diagnosis at a point where the symptoms of dementia are starting to have an impact on daily life.

Receiving a diagnosis of dementia is important both for individuals with dementia and for the health and social care system. A diagnosis allows people with dementia to access services and, in some cases, medication. It also gives them the knowledge and time to make critical decisions about the care and support they receive, while they have capacity to do so. For the health and social care system, a timely diagnosis helps with planning and the avoidance of future admissions, and it contributes to improved clinical management.

Despite this, there are still many barriers to receiving a diagnosis of dementia. These include: low public awareness of dementia; fear and stigma; poor understanding of dementia by health and social care professionals; under-resourcing of memory services; and disinclination to diagnose in areas where support services are not available.

- Just over half of people with dementia, before they received their diagnosis of dementia, thought that their symptoms were a normal part of ageing.
- Polling conducted by YouGov also indicates a widespread lack of general knowledge about dementia.
- One in five people with dementia who experienced a delay in their referral for an assessment reported that this was because their GP did not think that their symptoms needed further investigation.

The range of barriers that exist to obtaining a diagnosis of dementia means that any action to improve diagnosis rates will have to be approached from several different directions. Post-diagnosis services, investment in memory clinics, training for healthcare professionals and campaigns to raise awareness and understanding of dementia all have their part to play in the change that it is required.

Receiving a diagnosis of dementia

Despite improvements, there is still much that needs to be done to improve the experience of being given a diagnosis of dementia in Wales. One in ten people with dementia reported that their diagnosis was not given to them in a sensitive way. Less than half of people with dementia were given enough information about dementia when they received their diagnosis and only 38% were given enough information about services in their area.

Post-diagnosis support

Many people with dementia are left without support following a diagnosis. However, appropriate support and advice is essential for people with dementia to gain the maximum value from their diagnosis. With the right care and support, people with dementia can still enjoy a good quality of life. Post-diagnosis support consists of information, advice and support for people with dementia and their carers within the first 12 months of their receiving a diagnosis of dementia. Many of the services described may continue to be helpful to a person with dementia for several years. However, services received in the first year of diagnosis have a particular role to play in setting someone on the right track for the years to come. Accessing appropriate services in the first year after diagnosis can make it more likely that a person with dementia will continue to learn of appropriate services at each stage of their condition, providing that appropriate services are available.

Access to services after diagnosis is currently very limited for many people with dementia in Wales. In the first year after receiving a diagnosis of dementia:

- only 39% were given a named support worker
- only 35% attended a social or support group
- only 15% were matched with a befriender
- nearly 1 in 10 received no support at all.

This is simply unacceptable, especially when it is considered that the sampling for this survey is biased towards those who are more likely to have received support. The disparity between the services people want and the services people are actually able to access is a clear demonstration of the levels of unmet need that currently exist.

Alzheimer's Society commissioned a poll of GPs across the UK to seek their views on access to post-diagnosis support. When looking at the responses to this poll from GPs in Wales, it is clear that many believe that the level of support on offer from statutory services is not sufficient.

- 56% disagreed or strongly disagreed that their patients with dementia received enough support from the NHS.
- 72% disagreed or strongly disagreed that their patients with dementia received enough support from social services.
- 34% agreed or strongly agreed that they would be less likely to refer people with suspected dementia for a diagnosis if there isn't enough local support for people with dementia.
- When asked what they think the one main barrier to support is, over half of GPs in Wales believed it to be the lack of accessible local services.

Minimum provision of support

One of the most striking findings of this report was the wide variation in the quality of care received by people with dementia across Wales. Stories of support, or lack of support, varied from clinic to clinic, as well as by type of dementia. It is quite clear that there is currently a postcode lottery when it comes to the receipt of appropriate support for people with dementia.

Excellent services for people affected by dementia do exist across Wales. However, there are still too many people who are not adequately supported. As a result, we need a national consensus on a guaranteed minimum level of post-diagnosis support. Sufficient resources should be prioritised and made available to fund this in every geographical area. Within the framework of a minimum standard, support can remain flexible and adapted to the individual and their family.

A guaranteed minimum provision of support for both people with dementia and carers is vital to ensure that in future all people with dementia in Wales receive sufficient support.

Alzheimer's Society believes that all people newly diagnosed with dementia in Wales should be offered a tailored, nationally-assured package of post-diagnosis support. This should include, as a minimum:

1. comprehensive information on all aspects of the condition and access to universal support services, such as a helpline
2. access to a named support worker who can provide expert practical guidance on how to navigate services, support and decisions
3. support to manage and live well with dementia. This can be delivered individually and/or in a group, depending on an individual's preference.

Particular investment will be needed to guarantee that all people diagnosed with dementia receive access to a support worker. Although over half of people with dementia said that they were given a named person to contact for advice and support when they were diagnosed, when this issue was explored in the focus groups it was clear that many people with dementia had been given a named contact who they did not actually feel able to contact for advice and support. There is a considerable need for further investment in this area. At least 45 new dementia support roles will need to be created each year until every person with dementia has access to someone who can provide this expert practical guidance.

Recommendations

There is a very clear choice in the provision of care for people with dementia: provide a diagnosis and open the door to appropriate support, or keep people with dementia in the dark and disempower them from shaping their own future.

Diagnose or disempower? shows that there are still far too many people with dementia in Wales for whom the experience of receiving a diagnosis has been a negative one. People with dementia who have not received a diagnosis, or who have not received adequate support after diagnosis, are essentially being denied the opportunity to take control of their lives. Alzheimer's Society calls on the Welsh Government to take urgent actions to ensure that the following recommendations are implemented swiftly.

1. **All local health boards to set targets to improve diagnosis rates by a minimum of 5% per year until they achieve a diagnosis rate of 75%.**
2. **The Welsh Government should run a sustained public awareness campaign on dementia, with a particular focus on reaching Welsh language communities.**
3. **All GP practices in Wales should complete the 'Managing dementia in primary care' training.**
4. **The Welsh Government to allocate additional resources to memory services so that they have the capacity to support the numbers of people with dementia in Wales who are yet to receive a diagnosis of dementia.**
5. **Commissioners across Wales to explore innovative practices for memory services that include support from local providers of advocacy and emotional support, such as Alzheimer's Society or other charities.**
6. **Every person diagnosed with dementia to receive a named support worker who they can easily contact with any questions and who can signpost them to appropriate services.**
7. **The Welsh Government to establish a guaranteed minimum provision of integrated post-diagnosis support for people with dementia and their carers.**
8. **The Welsh Government to commit to an appropriately resourced national dementia strategy.**

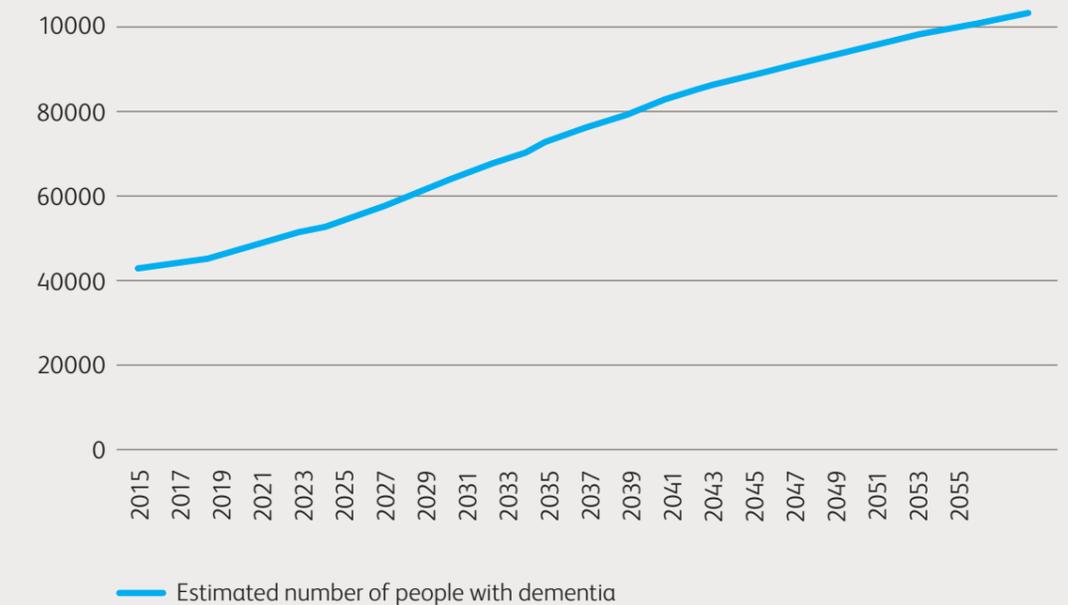
Introduction

Dementia in Wales

Dementia is not a disease in its own right. It is the name given to a collection of symptoms including memory loss, mood changes and problems with thinking and reasoning. It is caused by damage to the brain as a result of Alzheimer's disease or one of a number of other causes. While it is not a normal part of ageing, it predominately affects older people, though younger people can also be affected by it.

Dementia remains a national challenge in terms of its scale and impact. It is estimated that there are currently nearly 45,000 people living with the condition in Wales, and one in five people in Wales has a close family member or friend who has the condition (YouGov). These numbers are continuing to rise each year and it is estimated that by 2055 there will be over 100,000 people living with dementia in Wales. The costs of dementia are also increasing as the numbers of people with the condition increase. Dementia now costs the Welsh economy £1.4 billion a year and this price tag is set to rise.

Figure 1 People with dementia in Wales



Two-thirds of people with dementia live in the community (Alzheimer's Society, 2007). One third of those living in the community live alone in their own homes (Mirando-Costillo et al, 2010). The other third of people with dementia live in care homes (Alzheimer's Society, 2007), and up to 70% of care home residents in the UK have dementia or significant memory problems (Prince et al, 2014).

Dementia is therefore an issue that Wales cannot afford to ignore. This policy report sets out some of the most urgent changes that need to be made in order for people with dementia to have a better quality of life both before and after receiving their diagnosis.

Policy context

National dementia vision for Wales

The National dementia vision for Wales was launched in 2011 with the aim of promoting the creation of dementia-supportive communities across the country. The vision identified six strategic priorities:

1. Improving joint working between health and social care
2. Improving information provision
3. Improving awareness
4. Improving training
5. Supporting research
6. Developing a long-term vision.

Within these broad headings there are commitments to reducing the time people spend waiting for a diagnosis, improving care on general hospital wards and ensuring appropriate use of antipsychotic drugs. Unfortunately, progress on achieving the ambitious aims of the Vision have been hampered by a lack of resourcing, monitoring and ownership of the action plans, also developed in 2011.

1000 lives plus

1000 lives plus is the national improvement programme that supports organisations and individuals to deliver good-quality, safe healthcare in Wales (1000 Lives Plus, 2010). It sets out five intelligent targets for dementia, including reducing the time between the onset of symptoms and diagnosis. They have also produced a 'how to' guide for health professionals, to help them lead change in this area from the bottom up.

Together for mental health

The Strategy for mental health and wellbeing in Wales contains several measures to improve dementia care in Wales. These are very welcome and the progress that has been made is to be commended. However, the strategy does not specifically commit to raising the diagnosis rate in Wales, nor does it attempt to tackle many of the issues raised in this report.

Wales: A dementia friendly nation

In April 2015, the Minister for Health and Social Services announced his priorities with regards to dementia in the year ahead, as well as the steps they will take to support each of following priority areas:

- Dementia risk reduction.
- Dementia diagnosis rates.
- Post-diagnosis support.
- Care in general hospital settings.
- Public awareness and support.

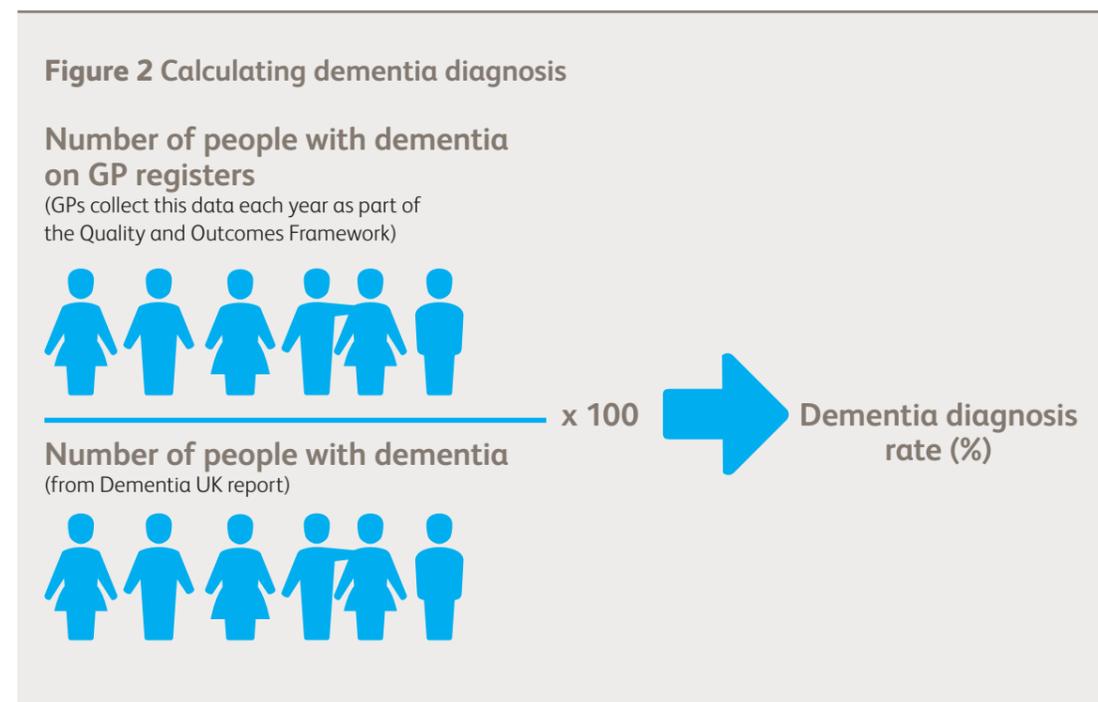
Alzheimer's Society welcomes these commitments, particularly the commitment to increase the diagnosis rate in Wales to 50% and to provide funding for 32 new primary care support workers. However, these are only the beginning. There are more changes that need to be made and far more that needs to be done. This report outlines some of the most urgent areas for action.

Diagnosis rates in Wales

In Wales, diagnosis rates are among the worst in the UK, with little improvement in recent years. The diagnosis rate in Wales is currently 43.4%. No local health board has a diagnosis rate higher than 50% and the lowest is 37.2%.

Dementia diagnosis rates are calculated by comparing estimates for the numbers of people with dementia with the number of people with dementia who are on GP registers. Alzheimer's Society estimates the numbers of people living with dementia using the prevalence rates determined by the Delphi Consensus exercise. More information about the process of determining the prevalence rates can be found in the Dementia UK: Update report published by Alzheimer's Society in 2014 (Prince et al, 2014).

When calculating the diagnosis rates for Wales in 2014–15, the prevalence rates were applied to the ONS mid-year population estimates in Wales for 2014. This gives the total estimated number of people living with dementia in Wales. Full information about the current diagnosis rates in each local health board can be found in the appendix of this report.



The following table shows just how little improvement there has been in diagnosis rates in Wales over the previous years.¹

Table 1 Diagnosis rates in Wales 2012–2014

	Number of people on QoF dementia register (number with a diagnosis)	Estimated number of people with dementia (diagnosed and undiagnosed)	Diagnosis rate
2012-13	17,661	42,980	41.1%
2013-14	18,591	43,478	42.8%
2014-15	19,239	44,362	43.4%

In April 2015, the Welsh Government announced that it had set the Welsh NHS a challenge: increase the dementia diagnosis rates to 50% by the time the figures for 2015–16 are published. This is the first time that there has been a specific commitment to raise the dementia diagnosis rate in Wales and, as such, it is very welcome. In order to meet this target, there would need to be a 7% increase in the diagnosis rate over the next year. This is more than triple the increase that has been seen over the previous three years combined. Alzheimer’s Society believes that this scale of change is achievable but it will require concerted action.

¹ Please note that the diagnosis rate for 2012–13 is different from that which was published at the time. This is because in 2014 Alzheimer’s Society published new estimates for the number of people living with dementia in the UK (Prince et al, 2014). In order to compare changes in diagnosis rates, the new estimates have been used when calculating these diagnosis rates.

Even if the target of 50% is reached by next year, there will still be far more that needs to be done. Alzheimer’s Society believes that we should ultimately aim for a diagnosis rate of 75% in Wales. There are currently several areas in the UK which are reaching this level. A national diagnosis rate of 75% would therefore bring Wales in line with best practice in the UK.

Diagnose or disempower? outlines the necessary steps to take us to a situation in Wales where 75% of people with dementia in Wales receive a diagnosis and where all people diagnosed with dementia receive at least a minimum standard of support.

Methodology

Diagnose or disempower? examines the experiences of people receiving a diagnosis of dementia in Wales. The report also draws on existing research and current work in dementia. This includes a range of public policy documents and research literature, as well as learning from good practice and existing indicators. It focuses on the experiences of people with dementia, but also includes contributions from their carers and some professionals who support them. It presents new findings about how well people with dementia are being supported in Wales.

Data collection methods are described in more detail in the appendix, but included:

- a survey of people affected by dementia in Wales, referred to as ‘Survey’
- focus groups of people affected by dementia in Wales, referred to as ‘focus group’
- a poll of the general public aged over 18 in Wales, carried out by YouGov, referred to as ‘YouGov’
- a survey of GPs, carried out by MedeConnect, referred to as ‘GP poll’
- two roundtable events with professionals who support people with dementia.

It is worth mentioning that the respondents to the survey of people affected by dementia reported receiving their diagnosis between 1995 and 2015. However, most responses were from people who had been diagnosed fairly recently. The median year of diagnosis was 2012 and the modal year of diagnosis was 2013. Most responses (56%) indicated that they were given their diagnosis in 2012 or later (Survey). This is significant as the National dementia vision was published in 2011. The Vision aimed to improve the experience of diagnosis and we can reasonably assume that these changes should have started to come into effect by 2012.

1 Receiving a diagnosis of dementia

This chapter includes:

- Why it is important for people with dementia to receive a diagnosis, and the benefits it can bring to both the individual and the health and social care system.
- Possible barriers to receiving a diagnosis of dementia, such as: lack of knowledge about dementia and the stigma that still surrounds the condition; GP attitudes and delays in referral to memory clinics; the difficulty diagnosing dementia given the assessment tools currently available; inadequate resourcing of memory clinics; and the shortage of services available to people with dementia after diagnosis.
- The experience of receiving a diagnosis of dementia and the sensitivity with which it is communicated.
- Actions necessary to improve access to a diagnosis of dementia in Wales.

Why a diagnosis is important

It is important that people with dementia receive a diagnosis, both for them and the health and social care system. A diagnosis allows people with dementia to access services and, in some cases, medication. It also gives them the knowledge and time to make critical decisions about the care and support they receive, while they have capacity to do so (APPG, 2012). For the health and social care system, it helps with planning and the avoidance of future admissions, and it contributes to improved clinical management (Bannerjee & Wittenberg, 2009).

Alzheimer's Society believes everyone with dementia should be able to access a timely diagnosis. A timely diagnosis can be understood as a diagnosis at a point where the symptoms of dementia are starting to have an impact on daily life (Brooker et al, 2013).

The benefits of a timely diagnosis for people with dementia

Quality of life for a person with dementia depends on receiving a timely diagnosis. Every day we hear from people with dementia who tell us of the difference that their diagnosis has made to them. The majority of research on the topic has indicated that many people with dementia want to know their diagnosis and do have the potential to live well with dementia (Bamford et al., 2004; Pratt & Wilkinson, 2003).

In the first instance, a diagnosis of dementia rules out other conditions which may be curable. Symptoms similar to dementia can be caused by several different diseases and conditions, some of which are treatable and reversible, including infections, depression, nutritional deficiencies or the side-effects of medication.

For those who do have dementia, receiving a timely diagnosis allows them to get prompt access to medications and medical attention. There is evidence that the currently available medications for Alzheimer's disease may be more beneficial if given in the early stages of the disease. In some people, these medications can help to maintain daily function and quality of life, as well as stabilise cognitive decline, meaning that they can continue recognise their loved ones, drive or play with their grandchildren. A diagnosis can also help in the management of other symptoms that may accompany the early stages of dementia, such as depression or irritability.

In many cases, a diagnosis of dementia also enables a person to access appropriate support services, where these are available locally. If dementia is diagnosed early enough that the individual has the capacity to participate in medical, legal and financial decisions, this makes it easier to involve the person with dementia in the planning of medical and psychosocial interventions, suited to their needs both in the present and through plans for future care. There is currently a very positive emphasis on the co-production of care in Wales. Alzheimer's Society welcomes the increasing opportunity for people to shape the services they receive. However, a co-production approach to delivery of care for people with dementia is simply impossible if people with dementia do not receive a diagnosis.

The early recognition and detection of dementia enables people with dementia, their families and clinicians to plan more effectively for the future (NICE, 2013). Receiving a timely diagnosis empowers people with dementia to participate as fully as possible in planning their own lives following diagnosis, and in making important decisions about their future treatment and care.

'I was relieved. She said to me, "Well, I've got to tell you something. I don't know how you're going to take it". She said, "But you've got something called PCA." I said, "Well what is PCA?" She said "It's a form of Alzheimer's." I said, "Oh my God, thank you very much!" I smiled and I said "Thank you, because I know what I'm dealing with now. And now I know what I'm dealing with, I'll deal with it."

Person with dementia, focus group

A person with dementia has a right to an accurate diagnosis, and it can answer many of their questions. It provides them with knowledge of what is happening to them, and this greater understanding and self-awareness can itself positively impact on them.

‘I think the thing of having a quick diagnosis is much better. Cos then you don’t get into a part where you really, really think “oh my God, am I going mad?” Cos a couple of times I had that, didn’t I? I was crying.’

Person with dementia, focus group

A diagnosis of dementia also provides a framework within which family and friends can understand their loved one’s changes in personality or behaviour. A diagnosis may reduce the tendency to blame or be impatient with the person with dementia, thus improving relationships.

A lack of diagnosis can also have an adverse impact on carers. If dementia is not diagnosed early, carers can become demoralised because they lack recognition and support, and have to cope with apparently unexplained personality and behavioural changes.

‘The diagnosis helped family members to plan how they could all help out, or to plan for the future despite [person with dementia] being in complete denial.’

Survey respondent

‘My mum was very distressed to learn she had Alzheimer’s. She said when she was diagnosed she was happier getting on with it without knowing. But as a family the diagnosis helped us to come to terms with what was happening and to know how to deal with the illness and to know where and how to seek support.’

Survey respondent

For younger people with dementia (those under 65) who are more likely to still be in employment, a timely diagnosis can encourage a person to explore their options, either in terms of accommodations that can be made for them at work, or early retirement before reduced performance jeopardizes their employment and financial security.

The benefits to the health and social care system

For the health and social care system, a timely diagnosis facilitates:

- full involvement of the patient and caregivers in planning medical, educational and psychosocial interventions suited to their needs and expectations.
- early symptomatic treatment and the potential to keep the disease at a less-advanced stage for longer
- improved clinical management of multiple, complex conditions
- accurate population-level planning thanks to an accurate understanding of the numbers of people living with dementia in a certain area.

Improvements in the quality of life of the person with dementia and delaying the progression of the disease can reduce the overall costs of their care to the health and social care system. The costs of care increase with the severity of the disease, so the ability to delay its progression may have substantial economic implications, as would reducing crises and emergency admissions to hospital and delaying the time to nursing home admission.

According to Alzheimer’s Disease International, the available evidence suggests that governments should ‘spend to save’. Economic models suggest that the costs associated with an earlier dementia diagnosis are more than offset by the savings as a result of the benefits of anti-dementia drugs and services to support people with dementia and their carers (ADI, 2011).

There has been evidence of the potential savings to the health and social care economy from timely diagnoses since 2009 (Banerjee & Wittenberg, 2009). The APPG report, *The £20billion question*, also found that diagnosis is a key element in providing cost-effective dementia services (APPG, 2011). In a time of economic austerity, and given that dementia already costs the Welsh economy £1.4 billion per year, this is an imperative we cannot afford to ignore.

The impact of delayed or missed diagnosis

Despite all of these benefits associated with people receiving a timely diagnosis of dementia, it is still far too common for a person with dementia to live with the condition and never be given a formal diagnosis. Currently over half of the people with dementia in Wales have not received a diagnosis.

When a diagnosis of dementia is significantly delayed, it can cause substantial distress for people with dementia and their families. In most cases, people with dementia and their families will know that something is not right. When a person’s symptoms remain unexplained, it can cause a great deal of anxiety as they do not know what is causing them. It keeps the person with dementia in a situation of powerlessness where it can be difficult for them to know what to do.

‘[It] would have been nice to have been diagnosed earlier as [it] would have cut down on anxiety.’

Survey respondent

Unnecessarily long waiting times can cause undue stress to people already experiencing difficulties. It can also cause a great deal of frustration with the medical profession.

‘It took 4 years to get to be diagnosed. We went through hell for four years. It started off with strokes in 2006 – small TIAs – and nobody told me that TIAs can bring on dementia... When [person with dementia] started forgetting things and was losing memory and he started walking as if he was half drunk, and we went for tests for a year, that was in 2008. At the end of 2008 it was confirmed that he didn’t have multiple sclerosis. Well, I knew he didn’t have multiple sclerosis! I was so mad when the consultant said “you haven’t got multiple sclerosis,” and he wrote to the doctor and said I didn’t seem pleased. Well he’d had tests for a year, they told me he didn’t have multiple sclerosis but they didn’t tell me what it was! And then we left and we decided to carry on with our lives as best we could and accept what was happening day to day. Then in 2011 we got called back to [clinic name] and within three months you were diagnosed in [clinic]. But we suffered all the time it took, and things were going downhill, weren’t they?’

‘...When he was told he didn’t have MS he was [told he was] making it all up. They sent him to a psychiatrist in the Royal Infirmary and he went for one visit and she said “There is nothing wrong with you, mentally there is nothing wrong with you.” But that’s what the consultant said: “You haven’t got MS”, so I said “What is it?” And he looked at me and he said “He’s making it all up.”’

Carer, focus group

Undetected dementia places older adults at risk of delirium, motor vehicle accidents, medication errors and financial difficulties, as well as many other things.

Reasons for this include:

- medications being prescribed which can exacerbate dementia symptoms, eg anticholinergics
- memory problems interfering with a person’s ability to remember to take important medications, such as those for diabetes, heart disease or high blood pressure
- not having the knowledge, information and insight to risk assess environments and patterns of behaviour before accidents or emergencies occur.

A delayed diagnosis also means that the diagnosis is given later in the progression of the dementia. This can make it much harder for an individual to come to terms with their diagnosis. An early diagnosis of dementia may have made it easier for individuals and their families to understand what was happening and to make plans accordingly. Having the mental capacity to make key decisions at the point of diagnosis about their financial affairs and future care, in the form of advance directives and powers of attorney, for example, can be crucial in ensuring person-centred care later in life.

‘My mother didn’t understand her diagnosis. It was explained to me at the memory clinic, but my mother seemed to ignore this and didn’t want to talk about it. By the time she was diagnosed her short term memory was significantly impaired, [as] was her ability to take on new information, although she could still hold conversations. She became very suspicious of neighbours and friends.’

Survey respondent

Delayed diagnosis also denies people with dementia access to medications which may have been able to slow the progression of their dementia and keep them at an earlier stage of the disease for longer.

‘Delayed diagnosis caused distress for the immediate carer and huge family problems. Delayed medication resulted in many distressing/sleepless nights for both my mother and myself (as carer). An earlier diagnosis could have enabled the family to find appropriate help and access services more quickly.’

Survey respondent

The audit of memory clinics in Wales, which was carried out in 2014, found that under half (42%) of people diagnosed with dementia over the past 12 months were in the early stages of the condition, though estimates varied widely between clinics (from 3% to 86%). However, no services routinely recorded the staging of dementia at diagnosis and interpretation of ‘early stages’ was likely to have varied a lot. One of the recommendations made by the audit, therefore, was that consistent definitions be adopted for future use (Public Health Wales, 2014).

In order to mitigate against the barriers to receiving a diagnosis of dementia described later in this chapter, it is essential that the Welsh Government commits to concerted action to raise diagnosis rates in Wales. Diagnosis rates in some areas of Wales are very low and this will not change overnight. All local health boards should commit to an annual minimum increase of 5% in the diagnosis rate for their area. This should enable an increase in the national diagnosis rate to 75% by 2020.

The people with dementia in Wales who are currently living without a diagnosis will be at every stage of the condition. Therefore, increasing the number of people with dementia who are able to access a diagnosis will require concerted action from a variety of different organisations, as well as greater collaboration between organisations. For example, when an individual has an assessment for domiciliary care, or indeed a residential care placement, one of the first things that should happen is that they should have a medical diagnosis as to why they need to access these services.

The range of barriers that exist to obtaining a diagnosis of dementia means that any action to improve diagnosis rates will have to be approached from several different directions. Post-diagnosis services, investment in memory clinics, training for healthcare professionals and campaigns to raise awareness and understanding of dementia all have their part to play in the change that it is required.



Recommendation 1

All local health boards to set targets to improve diagnosis rates by a minimum of 5% per year until they achieve a diagnosis rate of 75%.

Barriers to diagnosis

There are many barriers to receiving a diagnosis of dementia. In this section we consider barriers such as: low public awareness of dementia; fear and stigma; poor understanding of dementia by health and social care professionals; under-resourcing of memory services; and disinclination to diagnose in areas where support services are not available. These were some of the issues most frequently mentioned by people with dementia, their carers and professionals in the field of dementia care during the data collection for this report. It is likely that all of these factors, as well as others not listed, contribute to the low diagnosis rates in Wales. Breaking down these barriers to diagnosis will require ambitious and strategic leadership from the Welsh Government, as well as greater partnership between health and social care providers.

People not discussing their concerns with their GPs

GPs say that people are simply not presenting with the symptoms of dementia in order for them to be referred on to memory clinics in sufficient numbers to boost diagnosis rates. The findings presented below show that this may be one of several factors which are contributing to the low diagnosis rates in Wales.

Research indicates that many people experience cognitive changes for at least two years before discussing their concerns with a healthcare professional (Chrisp et al, 2011). Our survey respondents were split evenly between those who delayed discussing their symptoms with a GP and those that didn't. When asked 'Did you wait more than a year after first experiencing symptoms before discussing them with your GP?', 44% said yes and 44% said no, with the remainder saying that they did not know or could not remember (Survey).

We did not ask people who responded 'yes' why they waited so long. However, it is worth noting that people who didn't think that their GP would take their concerns seriously were far more likely to wait more than a year before discussing their concerns with them.

Table 2 Diagnosis rates in Wales 2012–2014

Did you wait more than a year after first experiencing symptoms before discussing them with your GP?	People who said they did not think their GP would take their concerns seriously	People who said they did think their GP would take their concerns seriously	All respondents
Yes	61%	36%	44%
No	29%	57%	44%
Don't know	10%	7%	13%

Note: Figures may not add up due to rounding.

This does not necessarily mean that GPs' attitudes are preventing people from seeking assistance. However, it may indicate that in a culture where fear and a lack of awareness of dementia is still pervasive, it is difficult for people to judge at what point individuals worried about their memory should take their concerns to their GP.

Public attitudes

Our research shows that, although things are improving, there is still a generally low level of understanding of dementia. Just over half (51%) of survey respondents said that before they received their diagnosis of dementia, they thought that their symptoms were a normal part of getting older (Survey). Polling conducted by YouGov also indicates a widespread lack of knowledge about dementia.

- Over one in five (22%) were not aware that there are medications that can sometimes slow the progression of Alzheimer's.
- Nearly half of people in Wales (49%) don't know whether all people with dementia are provided with professional social care free of charge.
- There was substantial confusion about the relationship between dementia and Alzheimer's disease, with 58% of people incorrectly stating that dementia was a common form of Alzheimer's disease, rather than the other way round.
- Only 40% of people in Wales know that dementia is a terminal illness.
- Only 28% of people in Wales know that dementia can affect a person's vision.
- 15% of people in Wales think that dementia is a natural part of ageing.

The poll also indicated that, in general, levels of knowledge about dementia were lower among respondents who spoke Welsh (YouGov). This suggests that there may be a need for a public awareness campaign specifically aimed at Welsh-speaking communities.

Misunderstandings about dementia can make people less likely to discuss their symptoms with their GP and so may contribute towards low diagnosis rates.

Alzheimer's Society's public awareness campaign, *Worried about your memory?*, is ongoing and aims to improve public and professional understanding of dementia. We also run the Dementia community roadshow, which has been touring since June 2011. The roadshow provides members of the public with information, advice and support. Visitors are able to receive free, tailored, and confidential advice from local trained Alzheimer's Society staff, either if they are worried about their memory or that of a loved one, or if they are living with or caring for someone with dementia. We are also working to improve community understanding of dementia through our Dementia Friendly Communities and Dementia Friends programmes.

Case study

Dementia Friends in Wales, Alzheimer's Society

Dementia Friends is an Alzheimer's Society initiative which aims to give people an understanding of dementia and the small things that can make a difference to people living with dementia in their community.

Free information sessions aim to improve public knowledge and understanding of dementia, and to encourage everyone to think about the small changes that could be made within their communities that would make a difference to people affected by dementia. These information sessions are run by volunteer Dementia Friends Champions. People who want to become a Dementia Friends Champion can sign up on the Dementia Friends website and attend an induction day. More information on how to become a Dementia Friend or a Dementia Friends Champion is available on www.dementiafriends.org.uk.

Dementia Friends was launched in Wales in February 2014 with the support of the Welsh Government. Since then, over 27,000 people in Wales have become Dementia Friends. Individuals and organisations across Wales have embraced the Dementia Friends initiative. A particularly good example of this is NatWest bank in Wales (NatWest Cymru).

Every NatWest Branch Manager and Deputy Branch Manager in Wales has now participated in a Dementia Friends information session as part of their leadership development. Branch Managers have put the information they learned to good use and when some branches were refurbished, they enlisted the help of an Alzheimer's Society Service User Review Panel. This group of people with dementia provided feedback to NatWest staff on the accessibility of the NatWest branches. They also did some mystery shopping to test how well staff responded to someone who may have forgotten their PIN. The review panel was impressed with the changes that had been introduced at NatWest and the lessons from the exercise have now been shared with all NatWest branches in Wales. The whole process has supported staff at Natwest Cymru to have a greater understanding of how they can help people living with dementia to live independently and confidently for as long as possible.

The impact of stigma on people with dementia

Negative attitudes towards dementia remain a significant barrier to people with dementia living well with the condition. Low levels of understanding of dementia, and the stigma that still surrounds the condition, can impact on people who have dementia in a variety of ways.

It can mean that people with dementia are less likely to come forward for a diagnosis. This may be because they do not recognise their symptoms as being caused by dementia and think it is just a natural part of ageing. It may be that they are so frightened of dementia that they would rather remain in denial than acknowledge their symptoms. Or it may be that they are simply too embarrassed to acknowledge their symptoms.

Even after a diagnosis has been given, the stigma surrounding dementia may mean someone with the condition is less likely to tell friends, family and neighbours about their diagnosis. When we asked people with dementia who they told about their diagnosis within the first six months of receiving it, 11% said that they did not tell friends, and 3% said that they did not tell anyone.

We asked people why they did not feel able to tell certain people. Sometimes there were specific reasons for this, such as illness of close friends or family, but very often it was related to the stigma that still surrounds dementia. Responses included ‘embarrassment’, feeling ‘too ashamed’, being ‘worried about gossip and stigma,’ and because ‘I think they would treat me differently’ (Survey respondent).

Stigma can make it harder for a person with dementia to come to terms with their diagnosis.

‘Alzheimer’s to me was something, as everybody says, sitting in a wheelchair and, you know, you can’t speak, isn’t it? Everyone thinks that, don’t they? So I was like, “My God, I’m never going to live with this. This is awful. I can’t go to work. I can’t go here, I can’t go there.”’

Person with dementia, focus group

It can also make it harder for people with dementia to get the support they need from their friends and family.

‘I had a happy childhood. I go back and I talk about my mum and the other day my friend said “Will you stop wallowing.” And I said “Oh sorry, I didn’t know I was wallowing” and then I shut up. And my brother tells me off cos, he says, you know, cos I forget things, forget words and I say “oh it’s the condition,” because I accept that I’ve got Alzheimer’s and I just get on with me life. It annoys me because they go – people say, well, my brother says “oh well we all do that” and I know as you get older you forget, but it’s not. And I have got Alzheimer’s! I have been diagnosed, you know – the scans and things that have been done – and I just wish they’d accept it and stop arguing with me that I haven’t.’

Person with dementia, focus group

This shows a clear need for strong public messaging and information on the symptoms of dementia, when someone should feel concerned and the benefits of getting an early diagnosis. This should not just be ‘awareness’, but should also have an emphasis on ‘understanding’, with clear messages on what the symptoms of dementia are and a positive message that it is possible to live well with dementia. This would help to reduce the stigma that is unfortunately still associated with the condition.

There is a need for initiatives to raise the general levels of knowledge about dementia in Wales. This should include initiatives aimed both at the general public and at professionals.

The Dementia Friends programme has been very successful in Wales, but there is a need to take this further and ensure that more people have to the opportunity to participate in this awareness raising initiative. A public awareness campaign on dementia is also needed in Wales. This should come from a public health perspective and particularly consider the needs of Welsh language communities.



Recommendation 2

The Welsh Government should run a sustained public awareness campaign on dementia, with a particular focus on reaching Welsh language communities.

Delays in referral to memory clinic

Currently, where dementia is suspected, GPs carry out an initial review of a person’s cognitive and physical health and refer them to a specialist secondary service (a memory clinic/service) for full diagnostic assessments. From the survey and focus group responses it is clear that for those who did experience a delay in their diagnosis, it was most likely to occur in trying to get a referral to a memory clinic. And for the majority of people, this would therefore mean the delays occurred when they visited their GP. For 82% of survey respondents, the first professional who they discussed their symptoms with was a GP (82%), although for a significant minority (8%) it was with hospital staff during an inpatient stay (Survey).

It is encouraging that around two-thirds of people who discussed their symptoms with their GP were referred to a specialist straight away. However, for around a third of people this did not happen. Common reasons for this include: ‘The doctor thought I had a different condition’ (23%), ‘The doctor wanted to wait to see how my symptoms developed’ (19%), and ‘The doctor did not think that my symptoms needed further investigation’ (18%) (Survey).

While dementia can sometimes be a difficult condition to diagnose, delays in referrals have caused serious anxiety and problems for people with the condition. As we have already seen, the impact of a delayed diagnosis can often be substantial for the person with dementia.

There is evidence that the knowledge, attitudes and skills of healthcare professionals can act as a barrier to timely diagnosis of dementia, and that improving the knowledge and skills of primary healthcare professionals is essential for improving the experience of receiving a diagnosis of dementia (Belmin et al, 2012; Hansen et al, 2008; Koch & Iliffe, 2010; Martinez-Lage et al, 2010; Mitchell et al, 2011) (BPS, 2014b).

The memory clinic and assessment audit also found that there is a need for GPs to become more confident about case finding for dementia, more knowledgeable about the process of assessment, and more skilled in communicating a dementia diagnosis to patients and families (Public Health Wales, 2014).

Dementia confused with other conditions

One quarter of our survey respondents said that their referral for further assessment was delayed because their GP believed that their symptoms were the result of a condition other than dementia. This was particularly the case when the individual had a rarer form of dementia such as Pick's disease or posterior cortical atrophy (PCA), or when the person had early-onset dementia. This was particularly likely if they were a woman as their symptoms were very commonly attributed to the menopause (Survey).

'Dr tried to say it was low Vit[amin] B12. Then it was said to be delay in shock, even though that was years before. They then said menopause, and then depression.'

Survey respondent

'[I] have a rare form of dementia and didn't show the classic symptoms associated with dementia. [I'm] also still very young, it could have been diabetes.'

Survey respondent

While an essential part of the diagnostic process is ruling out other reasons for a person's symptoms, for many people who go on to be diagnosed with dementia it is experienced as an avoidable delay to receiving the support that they need.

'We had to fight health care professionals for over five years to be referred to specialists as they did not believe that my mum was having memory problems so young and, even though we did not know at the time of the genetic link, we told the professionals that we had lost other family members and they told us that it was impossible to have a genetic form of Alzheimer's. Of course this was untrue, yet this was only 10 years or less ago and the information was available. It was just ill-informed and sometimes ignorant GPs who would not listen and put mum's symptoms down to the menopause and depression. We could have started treatment earlier and maybe held our mum at a manageable stage of the disease.'

Survey respondent

Symptoms not taken seriously

Every day people who have received a diagnosis tell us of the benefits it has brought to their lives. Health and social care professionals need to recognise the importance of diagnosing and supporting people with dementia from early on in the condition through to the advanced stages. Unfortunately, this is still not universally accepted. Some of the most worrying responses came from the large numbers of people who simply said that their GP did not take their symptoms seriously.

'My concerns were just brushed aside – early stages, so I wasn't really listened to.'

Survey respondent

Some of these people were only able to get a referral to a memory clinic because they managed to get another appointment with a different GP.

'[They] said it was old age. [I] took my husband to another GP a couple of weeks later for another ailment and told him my feelings. He listened and referred him straight away.'

Survey respondent

Several survey respondents indicated that they had only been able to get a referral to a memory clinic because they had family members who were willing to keep asking the GP for a referral. They reported that sometimes this process could take as long as 18 months. This raises the question as to what would have happened to these individuals if they had not had a family member available to pursue a referral on their behalf.

'[I] only got a referral as my grand-daughter is a nurse and she insisted I was referred, otherwise I wouldn't have been.'

Survey respondent

While there are many examples of excellent care, it is also clear that a significant minority of people with dementia find that their GPs are barriers to appropriate care rather than people who can signpost them to the care they need. It is simply not acceptable for there to be so many people with the symptoms of dementia who are not being taken seriously.

'It's annoying. You sit in the doctors, and you know they've got all this electronic stuff. "Do you suffer from...? Have you got any of these symptoms?" And all the dementia symptoms you go "tick, tick, tick." And then when you get to the doctor he's umming and ahing, you know, before referring you.'

Carer, focus group

The Wales Mental Health in Primary Care training package, Managing dementia in primary care, was designed to respond to some of these concerns. The training aims to allow primary care teams to deliver the best quality care to patients with dementia and their carers. It lasts for two hours and is aimed at the whole practice. In 2013, all practice managers in Wales received a copy of the Managing dementia in primary care DVD and a hard copy of the Facilitators workbook. Since then 144 practices are known to have completed the training.

Training for healthcare professionals should be evaluated to see whether they are being adequately prepared. The Wales Mental Health in Primary Care GP training package should be rolled out to all GP surgeries in Wales and incentives should be put in place to support this. Similar packages should also be developed for other healthcare settings.



Recommendation 3

All GP practices in Wales should complete the 'Managing dementia in primary care' training.

Case study

Dementia RED, Alzheimer's Society, North Wales

Dementia RED (respect, empathy, dignity) is a volunteer-led service run by Alzheimer's Society. Volunteers staff Dementia RED care information centre points within GP practices and health centres across Wrexham, Flintshire, Denbighshire, Conwy, Gwynedd and Anglesey.

The information points provide a service to all people with queries about dementia, including people who are worried about their memory, people with dementia, and carers, friends and family of people with dementia. Volunteers offer relevant information and signpost to appropriate community support services. They are people with knowledge of dementia who can respond to queries and offer referrals to a dementia support worker if required.

This ease of access to information, which would otherwise be difficult to obtain, is vital in supporting people to live well with dementia. The service helps people to understand dementia better and supports people to access appropriate community support services, thus reducing isolation and loneliness.

Not everyone is ready to ask for information immediately after receiving a diagnosis of dementia. Nonetheless, it is still important that they have the knowledge of where to go when they are ready for the appropriate information. The regular presence of the Dementia RED care information centre point in the GP surgery goes some way to address this.

The information points also raise awareness of dementia and offer support to people who may be concerned about their memory, encouraging them to speak to their GP in order to seek a diagnosis, thus helping to increase the overall diagnosis rates in Wales.

The Dementia RED team currently works with approximately 20–30 volunteers, but the hope is for the project to expand to hospitals, memory clinics, community centres, supermarkets and other locations that are easily accessible and visible. As a new project it has not yet been evaluated, but feedback forms from people accessing the service show that the need for the service exists, and the value of the high levels of information being distributed.

Problems with assessment tools

Making a diagnosis of dementia is often difficult, particularly in the early stages. This is because there isn't one simple test for the condition, and because the early symptoms of dementia can be similar to those of several other common conditions. A diagnosis of dementia will usually involve:

- taking a history of the individual experiencing symptoms
- physical tests and examinations
- tests of mental abilities
- scans.

The tests of mental abilities used during the assessment could range from a short, simple test that can quickly identify marked cognitive impairment to long, complex neuropsychological assessments that give the most comprehensive indication of a person's cognitive abilities (BPS, 2014b).

A GP may use a brief test, such as the abbreviated mental test score (AMTS) or the General practitioner assessment of cognition (GPCOG), to inform their decision as to whether or not to refer someone for further assessments. In a memory clinic, however, tools such as Addenbrookes cognitive examination-III (ACE-III), Montreal cognitive assessment (MoCA), or the Mini mental state examination (MMSE) may be used. The earlier in the progression of a person's dementia that a diagnosis is attempted, the more likely it is that there will be a need for a complex assessment of cognitive functioning (BPS, 2014b).

In the UK and several other countries, the Mini Mental State Examination (MMSE) is the most commonly used test for complaints of problems with memory or other mental abilities. It consists of a series of questions and tests, each of which scores points if answered correctly. It tests a number of different mental abilities, including a person's memory, attention and language. It can be used by clinicians to help diagnose dementia and to help assess its progression and severity

These tests are essential elements of the diagnostic process, but they do have their limitations. Many have a limited ability to distinguish between dementia and other causes of poor cognitive performance, or to differentiate between different forms of dementia. They also have particular difficulties identifying rarer forms of dementia. Furthermore, cognitive decline can be overestimated in people who have sensory impairments, limited education, or those from a different culture or with a different language (BPS, 2014b). The test can also be inaccurate as some people find out the questions that will be asked in order to revise and get the best possible score (BPS, 2014b).

When giving evidence to the All Party Parliamentary Group (APPG) on dementia, many GPs explained the deficiencies of the tools available to them. Issues included the cognitive tests being inaccurate in picking up a decline in function in articulate people, or people with a high IQ before the onset of dementia. The Faculty of Health Sciences at the University of Southampton suggested that there were difficulties because the tools focus on cognition, and therefore other symptoms of dementia, such as changes in mood or visuospatial skills, are missed. The Royal College of GPs also highlighted this problem. In addition, specific problems were reported with the Mini Mental State Examination, including problems with the copyright. (APPG, 2012)

These types of problems were apparent in some of the stories heard during data collection. For example, this story demonstrates the type of situation where cognitive decline may be underestimated:

‘My mother wasn't aware of the extent of her symptoms initially and put her 'forgetfulness' down to old age. It took several visits to the GP, with me in attendance as her daughter, for the GP to begin to take my concerns more seriously. It was only when the GP asked more probing questions that the extent of my mother's memory loss became clear, as she was able to 'pass' initial mini memory tests focused on some arithmetic or words. My mother had been a comptometer operator when she was younger and then had been a librarian, so seemed to hang on to her ability to do crosswords or count back from 100 in 7s, long after her day-to-day functioning was significantly impaired.’

Survey respondent

Another story, this time from a participant in a focus group, indicates some of the problems that may be encountered when attempting to diagnose a rarer form of dementia:

‘It took three years, three or four years to diagnose me, cos mine is PCA [posterior cortical atrophy] and it's a very rare form. I worked in an office running a team and it started that I couldn't find things. The doctor did a little test for me, I didn't know what he was doing the test for. He just said "Can you do this and do that for me: remember this name, remember this address." I said, "Oh yeah, I can do that!" And then I was like, "No, I can't do that." We did it a couple of times and he said "What I'll do, I'll send you up to [clinic]." And that was about three years before I was diagnosed.

‘And then, it just went on from there. But they didn't know what it was, what form of Alzheimer's it was.

‘I went there one day on an appointment and I had my purse by the side of me. And I dropped a couple of coins on the floor, but I couldn't see the coins on the floor and I couldn't pick them up. And she said, "try to pick them up." I thought "that's horrible, telling me to pick them up myself!" She just put her hands up and said "Diagnosis done, it's PCA!" She said, "I've had suspicions, but now I saw you do that with your handbag." It was just as easy as that, but it took four years.’

Person with dementia, focus group

There may also be specific issues around diagnosis if the person's first language is Welsh. The memory clinic audit found that Welsh language assessment was available in all clinics, but usually only by involving a Welsh speaking colleague from another service (Public Health Wales, 2014). The Addenbrookes cognitive examination-III (ACE-III) has been translated into Welsh. However, it is a direct translation from the English and the translated version has not been subject to thorough testing. As a result we cannot know whether the cognitive impairment that may be indicated by different scores is the same in Welsh as it is English. Given that these assessments can be subject to cultural bias, and given that in many instances the assessment may be being carried out by someone who is a specialist in another field, this is a cause for concern.

Current assessment tools can therefore be a potential barrier to the process of diagnosis. There are numerous potential solutions, and there would be great benefit in exploring these further. In their response to the APPG, Alzheimer's Research UK called for greater research into tests that could diagnose dementia more accurately (APPG, 2012).

According to the British Psychological Society, a good cognitive assessment is one that is a supportive and informative experience for the person being assessed. As well as providing an accurate diagnosis, it should also help the individual to understand and make the most of their strengths (BPS, 2014b). They also suggest that when early-stage dementia or a rarer form is suspected, such as frontotemporal dementia or dementia with Lewy bodies, it is essential for the individual to have access to specialist assessment services. This might be a comprehensive neuropsychological assessment by a trained psychologist.

Lack of resourcing in memory clinics

Memory clinics, where professionals specialising in dementia perform assessments, are a key part of an effective diagnosis service. The inquiry into diagnosis rates by the 2012 All Party Parliamentary Group on dementia heard evidence that high diagnosis rates in Northern Ireland could be a result of having adequately established and resourced secondary care services, such as memory clinics, which were able to deliver quality services tailored to the needs of the population. Dr Simon Hughes from Royal Victoria Hospital, Belfast, stated:

‘Quality has been key for the service. This is the quality of the referrals and the requests that we get, the quality of the scans themselves delivered on a day-to-day basis and the scanning service, and the quality of the reporting as well. All of this has bred confidence in both the referrers and the patients in the services. We have also developed one of the things that I think has been absolutely crucial, which has been a regional multi-disciplinary team for dementia.’ (APPG, 2012)

It is clear that this situation is not the case everywhere in Wales. The 2014 audit of memory clinics in Wales found that, in the previous 12 months, each assessed an average of 299 new patients (6.5 per week) and saw an average of 697 patients in total, though some services estimated numbers as data are not routinely recorded. Despite the increasing volume of patients being referred to memory clinics, the average time between memory services receiving a referral and starting assessment is 5.2 weeks, with the maximum waiting time being 16 weeks.

Nearly one third of clinics in Wales are currently failing to meet the standard set by the Memory Services National Accreditation programme, which states that people should wait no more than 4-6 weeks between the receipt of referral and their first appointment (PHW, 2014). This implies that there are currently many areas in Wales where memory services either do not exist in sufficient number or are overstretched.

‘[The] GP referred my husband for neurological tests on 10 March 2009. Following delays in the commissioning of [the new memory clinic], investigations did not start until October 2009, resulting in a seven-month delay before undergoing initial assessment, by which time his condition had noticeably worsened.’

Survey respondent

A common concern expressed to the APPG inquiry, including by the British Medical Association, was that with such a large number of people living with undiagnosed dementia, memory services will be ‘overwhelmed’ if all those people who are currently undiagnosed are identified and referred at once. Initiatives to improve diagnosis rates can be met with hesitance due to this fear. Increased emphasis on diagnosing dementia is going to place additional pressures on memory clinics. It is therefore essential that appropriate investment is made at the outset to ensure that the resulting improvements in access to diagnosis services are sustainable.

Timely diagnosis of dementia requires sufficient resources to meet growing demand. Health service commissioners should prioritise investment in memory services when designing dementia pathways. Few existing memory clinics have the capacity at present to cope with the numbers of new patients needing assessment (PHW, 2014). This will be a growing problem if more people are to be diagnosed at an early stage of the condition, and if the present diagnosis rates in Wales are to improve. Plans need to be made to deal with this increasing workload, and significant additional investment in memory services will be required if we are to reach an average diagnosis rate of 75% in Wales.



Recommendation 4

The Welsh Government to allocate additional resources to memory services so that they have the capacity to support the numbers of people with dementia who are yet to receive a diagnosis.

Limited access to services

While there have been improvements in information provision, support following a diagnosis is still not available to everyone as there is no mandatory minimum provision of such support. This means that too often access to appropriate post-diagnosis support is dependent on where the person with dementia lives.

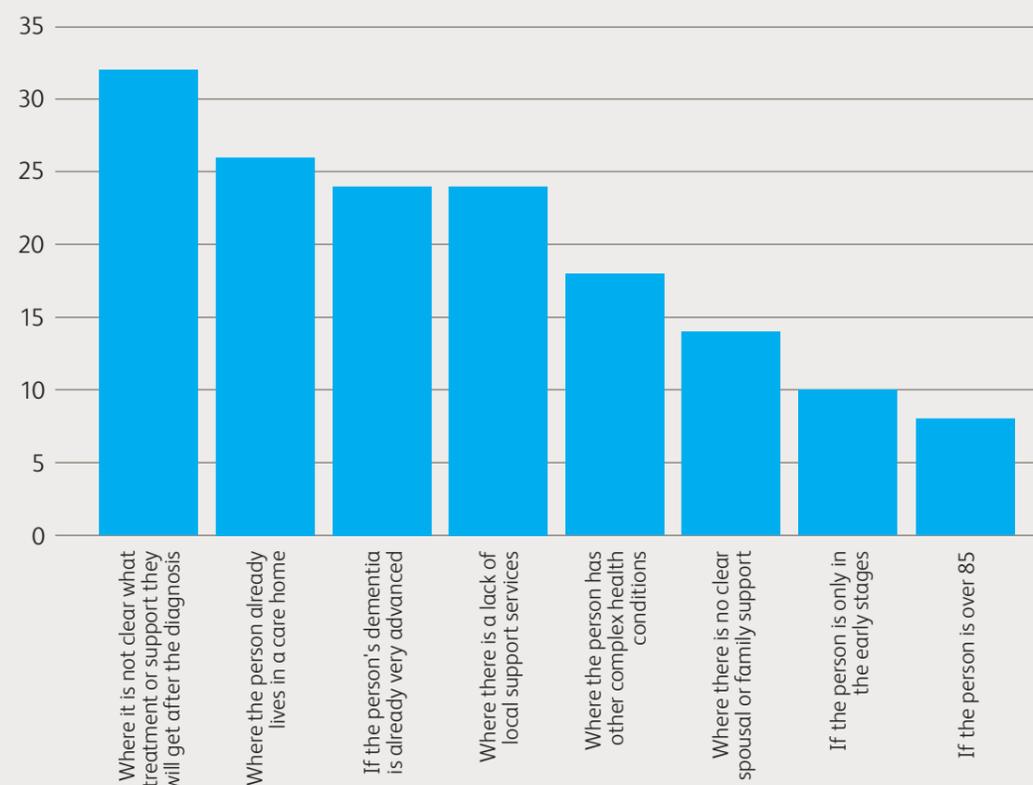
Alzheimer’s Society commissioned a poll of GPs across the UK to seek their views on access to post-diagnosis support. When looking at the responses to this poll from GPs in Wales, it is clear that many believe that the level of support on offer from statutory services is not sufficient.

- 56% either disagreed or strongly disagreed that their patients with dementia received enough support from the NHS.
- 72% either disagreed or strongly disagreed that their patients with dementia received enough support from social services.
- 56% either disagreed or strongly disagreed that there were integrated services for people with dementia in their area that deliver effective person-centred care.

It has been suggested that a lack of local services available to people with dementia will contribute to the feeling that there is no value in receiving a formal diagnosis, and therefore may contribute to low diagnosis rates in some areas. Nearly a quarter (24%) of GPs in Wales either agreed or strongly agreed that they would be less likely to refer people with suspected dementia for an assessment if there wasn’t enough local support for people with dementia.

Figure 3 Reasons why GPs may be less likely to refer for diagnosis someone presenting with the symptoms of dementia

Which of the following, if any, will reduce the likelihood of you deciding to diagnose or refer for diagnosis someone presenting with the symptoms of dementia?



Alzheimer's Society believes that a wide range of post-diagnosis services should be available in all areas of Wales. However, even in areas where this is not currently the case, a diagnosis can still offer benefits to people with dementia.

Receiving a diagnosis of dementia in Wales

For the majority of people with dementia in Wales, the barriers to diagnosis are too great and as a result they do not get to the stage of receiving a diagnosis of dementia. However, even for the minority of people who do receive a diagnosis, their struggle is far from over. This section considers the experiences of people with dementia in Wales when they received their diagnosis. It includes: waiting times for a diagnosis; the sensitivity with which the diagnosis was communicated; and possible ways of improving the experiences of receiving a diagnosis of dementia.

Waiting times for a diagnosis

Survey respondents were asked in which year they began experiencing symptoms of dementia and in which year they received their diagnosis. These two numbers were then subtracted from each other to give an approximate length of time from the onset of symptoms to diagnosis.

The calculations are only approximate, but they paint a picture that is consistent with what staff at Alzheimer's Society regularly hear from the people they support. While most people received their diagnosis within a year or less, the average length of time from the onset of symptoms to receiving a diagnosis was nearly two years. A small number (2%) of respondents indicated that it took a decade or longer to receive a diagnosis, presumably meaning that the dementia was fairly advanced by the time the diagnosis was received.

In addition to the time spent between the onset of symptoms and getting a referral from a GP, many people spend a long time between referral and diagnosis. As stated previously, the memory clinic audit found that nearly one-third of clinics in Wales are currently failing to meet the standard set by the Memory Services National Accreditation programme which states that people should wait no more than 4–6 weeks between the receipt of referral and their first appointment. On average, people in Wales wait 5.2 weeks for this to happen, and an additional 9.6 weeks from the point of having the assessment to receiving the diagnosis (PHW, 2014).

Once people have had their first appointment, they may also have to wait to receive their diagnosis. In the period between the first assessment and diagnosis, the person will often have a brain scan, have blood tests taken, sometimes undergo more detailed neuropsychological assessment, and then wait for the diagnosis to be delivered, which is most often done by senior medical staff in a second clinic appointment. Sometimes a diagnosis cannot be made immediately and the person will need to be reassessed after a few months. However, for some patients the time between assessment and diagnosis can be reduced if their blood tests and brain scan are ordered at the time of referral and are therefore available at the time of their first visit. If this happens, it may be possible for the diagnosis to be delivered on the same day as the first appointment, without any additional appointments or tests (PHW, 2014).

Waiting times for memory clinics need to be kept under regular review. A national performance target should be set, to consistently meet the Memory Services National Accreditation programme minimum standard of six weeks. However, the focus on reducing the wait for an initial appointment is not enough, given that for most people the wait between initial appointment and diagnosis is longer than between referral and initial appointment. The time that the whole diagnostic process takes needs to be standardised. Where clinically appropriate, people with dementia should expect to wait no longer than 12 weeks from initial GP referral to receiving their diagnosis.

People with dementia should not wait for longer than necessary for appointments and diagnosis. This causes undue and avoidable stress. A prompt, efficient diagnostic process of no longer than 12 weeks from referral to diagnosis should be available to all, where this is clinically appropriate. Further time may be needed to determine the sub-type of dementia in particularly complex cases, but an initial diagnosis should still be given within 12 weeks. At present, long waiting times are far more likely to be a result of inadequate resourcing and pathway design than a lengthy clinical process.

In order to keep waiting times and other key quality standards under regular review, Alzheimer's Society recommends that the audit of memory clinics in Wales be repeated at least once every two years.

Sensitivity of diagnosis

Receiving a diagnosis of dementia isn't just about being told the results of a medical test. The way in which the news is conveyed to the individual can make all the difference to how the person goes on to cope with their dementia. Alzheimer's Disease International suggests that the impact of a diagnosis on someone with dementia depends greatly upon how it is made and imparted. Evidence suggests that when people with dementia and their families are well prepared and supported, initial feelings of shock, anger and grief are balanced by a sense of reassurance and empowerment (ADI, 2011).

A diagnosis that is given sensitively and provides appropriate information and signposting gives the person with dementia the best chance of finding the support that they need. However, a diagnosis that is given poorly can leave the person with dementia extremely distressed and with a poor level of understanding of their condition. Diagnosis needs to be seen as the opportunity to set someone off on the right track for the years to come.

For most people with dementia in Wales, their diagnosis will be given to them at their local memory clinic after having been referred by their GP. 71% of survey responses indicated that they were given their diagnosis at a memory clinic. However, 8% were given their diagnosis by their GP and a further 8% were given their diagnosis by their community mental health team. There may have been some confusion in these responses though, as in Wales 86% of memory clinics are provided as part of a wider service, such as a Community Mental Health Team for Older People (CMHT-OP), and not as a stand-alone clinic. Community mental Health Teams were included within definition of memory clinic in the memory clinic audit (PHW, 2014).

When asked whether their diagnosis was given to them in a sensitive way, 78% said that it was. This is encouraging. However, it is unacceptable that 11% of respondents did not feel that their diagnosis was given to them in a sensitive way. Some of the stories revealed in the survey and the focus groups demonstrate unacceptable levels of care.

'When I first went, my doctor said I had to go and have an MRI on me brain and I had to go back two weeks later and me daughter was with me and they done a test with me. First of all it was [with] the nurse, it was – where I had to say things, write things, and then when I went in to see the doctor she said she'd have to look at the scan. So she had a look at everything and then she come back. She said "I think it is Alzheimer's Dementia." Well, you could have knocked me over the floor. I said "Beg your pardon?" [and she said] "That's my findings. What I'll do is get a second opinion and get back in touch with you." So I thought "Right, she got that wrong!" I was convinced that she'd got that wrong, so weeks went by, well maybe three, but it seemed a lifetime to me. So I wrote to her and handed it in in [the memory clinic] to say "Was it yes, or was it no?" You know, I needed that knowledge. I got a phone call [when I was with my husband in the car] and the phone call was the doctor's secretary, just to tell me that her findings were true. Well, you can imagine, me in the car on speaker. Me husband had to stop the car and he said "What did she just say?" so then you can imagine – went home, told the other children, then it was weeks after that I had to go to see a psychologist.'

Person with dementia, focus group

Several other stories, while less shocking, reveal that many people with dementia felt that they were told about their condition in a way which did not really acknowledge the impact that the news would have on their life. It would appear that many health professionals underestimate the emotional impact of a diagnosis of dementia.

'[The diagnosis was given] slightly matter of fact. [There was] no real opportunity to discuss issues, except advice to obtain power of attorney.'

Survey respondent

'The delivery was interrupted with a knock on the door hurrying us along. I felt like we were given a death sentence with no hope.'

Survey respondent

A diagnosis that is given sensitively is one which is responsive to the effect that the news is having on the person with dementia. They may be upset and afraid, or they may be relieved to finally know what is happening to them. People will also have varying degrees of knowledge about dementia. It is important to give people the opportunity to ask any questions that occur to them as well as to signpost them to people who can respond to any questions that may occur over the coming weeks and months.

A diagnosis of dementia should not be experienced as coming out of the blue. It is important that the individual with suspected dementia understands why they are doing the tests and what the possible diagnoses are. There can be a role for pre-diagnosis counselling here. More is said about this in the next section.

A diagnosis that is given sensitively is also one that empowers people to understand their diagnosis. It is not acceptable that there are people who felt that their diagnosis had been delivered in such a way that they may not even have realised that they were being diagnosed with dementia. It is important that medical professionals feel able to actually use the word 'dementia.'

'If [my father] could have acknowledged that he had dementia when it was first diagnosed then I think all our lives would be easier. Therefore, if the giving of a diagnosis could be followed up in quick succession by more information, given repeatedly, emphasising that he did have an illness that wasn't just old age, rather than 'not wanting to upset him' it would have been better. More honesty and directness is needed.'

Survey respondent

'The memory clinic said there was a problem but [the social worker] told me what it was – dementia.'

Survey respondent

How diagnosis could be improved

A consultation of people with dementia run by the British Psychological Society found that people's preferences for how a diagnosis is delivered varied greatly (BPS, 2014b). However, people in the focus groups were clear that one thing that what was needed was more time to process the news and to ask questions. Within that there were considerable variations, but people felt that this additional time would better enable the diagnosis to be delivered in a way that was suitable to the individual. For some people with dementia, the opportunity to ask questions needed to be at the appointment itself.

'Someone to take you into a room, not just sit at the desk, sit you in a room, and say right, "This is the worst scenario, this is best scenario, this is how long it might take." I know everyone's different, but it would have been nice to have somebody in the room, just a nurse, to sit outside and wait for you to come out, especially when they are telling you the diagnosis.'

Person with dementia, focus group

For others, there needed to be someone who could answer questions and who was available several hours or even days after the appointment at which they were given their diagnosis.

'Then when I got home and I started reading the leaflet, that was when I needed the support. Because up until that point I'd been very positive about the whole thing, but when I got home...'

Person with dementia, focus group

'Yeah, we were [given time to ask questions], but you don't think about them then, do you? It could be like you've gone home and you've read the leaflets and it would be perhaps even more helpful if the following day you had a call from somebody to say "You had your diagnosis yesterday, you've been given the leaflet. And how are you feeling today? Have you read the leaflets? Can we answer any questions?"'

Carer, focus group

Alzheimer's Society therefore recommends that memory clinics should consider partnerships with third sector organisations to have people on site who can answer questions about dementia and provide emotional support.

Case study

Dementia support service, Alzheimer's Society, Ystrad Mynach

Some memory clinics have very close links with Alzheimer's Society's dementia support service. One such example of this is the dementia support service in Ystrad Mynach who have been working in partnership with the memory team at Ysbyty Ystrad Fawr for over five years.

Alzheimer's Society's dementia support service provides one-to-one support to people with dementia, carers and family members. It can also provide information to professionals working within the field of dementia. The service is tailored to each service user as it is based upon their personal circumstances, information and support needs. The service can be provided face-to-face, over the telephone, via email or by written communication. It provides accessible and relevant information, guidance, sign-posting, practical and emotional support to promote and maintain independence and to enable and empower the person with dementia to live well with the condition.

The consultants and nursing staff at Ysbyty Ystrad Fawr can direct people diagnosed with dementia and family members to the dementia support service. The majority of referrals are received from the dementia coordinator following a post-diagnosis visit. This enables the person with dementia and their carer to have access to services immediately following diagnosis.

The dementia support service consider attending the memory clinic to be a big benefit because it enables them to work closely with the memory team to promote suitable services for those recently diagnosed. It means that dementia support workers can meet people with dementia and their carers face-to-face. This allows these people to feel comfortable accepting services from Alzheimer's Society, as they can put a face to the name before home assessments commence.

The excellent working relationship between Alzheimer's Society and the memory assessment team at Ysbyty Ystrad Fawr has enabled collaborative working at awareness raising sessions, workshops and support groups. Representatives of the dementia support service regularly attend multi-disciplinary team meetings and joint home visits with the memory team support worker. They have also, with appropriate consent, attended consultations and diagnosis appointments. Alzheimer's Society and health board dementia coordinators are continuing to build on this initiative and are working towards establishing a consistent approach to collaborative working. This would provide high quality services to people living with dementia throughout Gwent and South Powys.

Pre-diagnosis counselling

There is good evidence to suggest that pre-diagnosis counselling can help people to have a better experience of diagnosis. Good pre-diagnosis counselling should set the scene for successful engagement with services in the future, and it enables people with dementia to maximise the advantages of an early diagnosis. A consultation run by the British Psychological Society found that pre-diagnosis counselling was essential for many and helpful for most (BPS, 2014b).

Pre-diagnosis counselling involves providing the opportunity for the person with suspected dementia and their families to fully understand:

- the reasons for the referral
- what assessment will involve
- the possible outcomes of an assessment
- the implications for other areas of life, including driving, work and insurance
- the opportunity to discuss their concerns and fears (BPS, 2014b).

It is important that people understand why they are having tests done and what the possible findings might include. The earlier this is explained, the better.

Pre-diagnosis counselling can help make sure that people's experience of diagnosis is helpful to them. For example, the individual can decide beforehand whether they want someone to accompany them to the assessments or diagnosis consultation. This can be particularly helpful for people with dementia who do not have a carer. In these instances, it may be appropriate for an advocate to accompany the individual to support them in gaining the information they require.



Recommendation 5

Commissioners across Wales to explore innovative practices for memory services that include support from local providers of advocacy and emotional support, such as Alzheimer's Society or other charities.

2 Post-diagnosis support

This chapter includes:

- The importance of post-diagnosis support for people with dementia.
- The types of support that should be available in the first year after receiving a diagnosis of dementia.
- Barriers to accessing appropriate support services.
- The impact on people with dementia if they do not receive sufficient support.
- Actions necessary to ensure all people with dementia and their carers are guaranteed a minimum level of support after receiving a diagnosis.

The importance of post-diagnosis support

Post-diagnosis support consists of information, advice and support for people with dementia and their carers. For the purposes of this report, we are defining post-diagnosis support as support that is offered to people within the first 12 months after receiving a diagnosis of dementia. This does not mean that it is any less important to offer support in the following years. Indeed, many of the services described may continue to be helpful to a person with dementia for several years. However, services received in the first year following diagnosis have a particular role to play in setting someone on the right track for the years that follow. Accessing appropriate services in the first year after diagnosis can make it more likely that a person with dementia will continue to learn of appropriate services at each stage of their condition, providing that appropriate services are available.

Many of the benefits of receiving an early diagnosis of dementia, both in health and economic terms, can only be fully realised if the individual successfully comes to terms with their diagnosis of dementia and learns to live well with the condition. Post-diagnosis services have a crucial role in supporting people to adjust successfully. Post-diagnosis support is particularly important for those for whom medication is not an option. However, these can frequently be the people who are least likely to know about or have access to appropriate post-diagnosis support as they are more likely to be discharged quickly from memory clinics (BPS, 2014b).

Some people with dementia feel relief at getting their diagnosis because they finally know what is happening to them and can deal with it accordingly.

'It was a relief after wondering what was wrong. It explained a lot of the problems I'd been experiencing, particularly at work, and the stress disappeared.'

Survey respondent

However, others can be devastated by the news.

‘I was terrible when I was first diagnosed. I was in a hell of a state; depression, crying – no, not crying, sobbing.’

Person with dementia, focus group

If people are properly supported, some of the difficulties following a diagnosis can be lessened. It is important that everyone receives the support necessary to help them live well with their condition. However, good quality post-diagnosis support can be particularly beneficial to those who are struggling to come to terms with their diagnosis.

When talking to people with dementia in the focus groups, it was clear that one of the most important factors in helping someone to live well with their dementia was their sense of humour. Good quality post-diagnosis support can help people to find the resilience to face their condition with a positive outlook.

‘The thing is, all of us, you’ve got two choices. You either sit in the house and look at the four walls, or you go to a place where you’ve got activities and you enjoy it.’

Person with dementia, focus group

Good quality post-diagnosis support should help people to make the positive choice.

Early therapeutic interventions can be effective in improving cognitive function, treating depression, improving the mood of the person’s carer and delaying institutionalisation. Some of these interventions may be more effective when started earlier in the disease course, adding to the importance of a timely diagnosis. (ADI, 2011)

The support that is currently available

It is clear from the survey that access to services after diagnosis is currently very limited for many people with dementia in Wales. When asked what happened in their first year after diagnosis, the only option that more than half of respondents selected was that they were prescribed medication.

Table 3 Support received in the first year after diagnosis

I was prescribed medication	78.21%
I was given a named support worker	38.89%
I attended a social or support group	34.62%
I received support from an occupational therapist	20.09%
A domiciliary care package was set up for me	15.38%
I was matched with a befriender	15.38%
Nothing	8.97%
I was referred for counselling	8.55%
Other	8.12%

Common themes from the ‘other’ responses include: being assigned a social worker or community mental health nurse; support from family, friends and the wider community; home alterations through Care and Repair; and support from various other charities.

Even in the case of the prescribing of medications – the most common form of support received after diagnosis – there were several stories of people either waiting an unacceptably long time to receive their medication or of people being prescribed medication without being told what they were being given the medication for.

‘No one actually said you had dementia but tablets were prescribed.’

Survey respondent

‘No medication was received until about 12 months after diagnosis.’

Survey respondent

There were also several stories of people receiving virtually no support at all in the first 12 months after receiving their diagnosis.

‘Too long to wait for diagnosis. Staff not understanding enough in memory clinic. Not enough staff at memory clinic. Only one consultant and he was on bereavement leave. GP not got enough expertise on dementia. Without [Alzheimer’s Society staff] I would have been in a terrible place and my family wouldn’t have been supported.’

Survey respondent

Nearly one in 10 respondents to the survey reported receiving no support at all during this time. This is simply unacceptable, especially when it is considered that the sampling for this survey is biased towards those who are more likely to have received support.

It is currently far too difficult for people newly diagnosed with dementia to access appropriate forms of support and substantial investment is required in this area. When people with dementia are not able to access appropriate services, it can have a devastating impact on their health, wellbeing and general quality of life.

‘My father, after having to push for a proper diagnosis, was told he [had] vascular dementia. We were sent away from the memory clinic with not even a leaflet, no phone call, no GP phone call, nothing. My father lived with us. Everything we found out about dementia we had to research ourselves. Nothing was offered to us in way of support for Dad. He was already going to day care prior to dementia (which was excellent) twice a week. As [the] dementia worsened he was made to change, and the day care provided [was] terrible in the local council EMI unit. It was the loneliest journey for our family and for poor Dad. An admiral nurse or support worker would have made all the difference.’

Survey respondent

Another common issue people faced was having problems actually travelling to services. Sometimes, this was because public transport was either not accessible to people with dementia or simply not available at all. At other times, it was because respondents lived in rural areas and the services were simply too far away for them to be able to attend.

‘We would like to attend more groups but most are morning sessions and some distance to travel from our local town [...] We do feel rather isolated as [we] have no close relatives and have had to chase up support which is much lacking in the town.’

Survey respondent

While there have been improvements in information provision, further support following a diagnosis is not available to everyone as there is no mandatory minimum provision of support. It is also unclear whether the responsibility for providing services should sit with the NHS or social care, or both. This means that too often access to a diagnosis and appropriate post-diagnosis support is dependent on where the person with dementia lives.

The services people wanted

Unsurprisingly, information came top of the list of services which people with dementia would have found most useful in the first year after their diagnosis.

Table 4 Support people with dementia would have wanted to receive in the first year after diagnosis

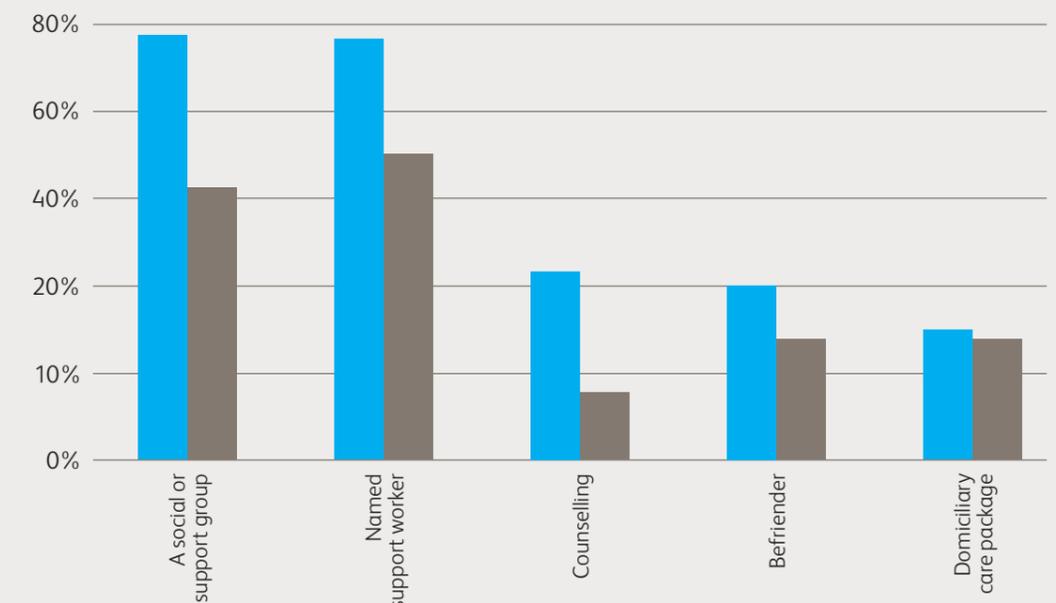
Information about services in my area	71.43%
Information about dementia	64.98%
A social or support group	53.92%
Named support worker	53.46%
Support for my carer	52.07%
Regular meetings with my GP	24.42%
Counselling	23.96%
Befriender	22.12%
Domiciliary care package	16.59%
Other	13.36%

‘Other’ responses included: respite care; transport; advocacy; financial advice.

When the responses to the two questions ‘What support did you receive?’ and ‘What support would have been most helpful to you?’ are compared, it is clear that there are currently significant levels of unmet need. The disparity between the numbers of people who would have wanted to access a particular service and the numbers of people who were actually able to do so is indicative of the large numbers of people who are not receiving the support they need.

Making comparisons between responses to these two questions is difficult, however, as there was not an exact overlap between the options available in response to each question; both questions contained possible responses which were not available in the other question. However, when the options that were given in both questions are compared in the chart below, it is clear that for every service there are more people who could benefit from it than are currently able to access it.

Figure 4 The differences between the support people with dementia want and the support they receive



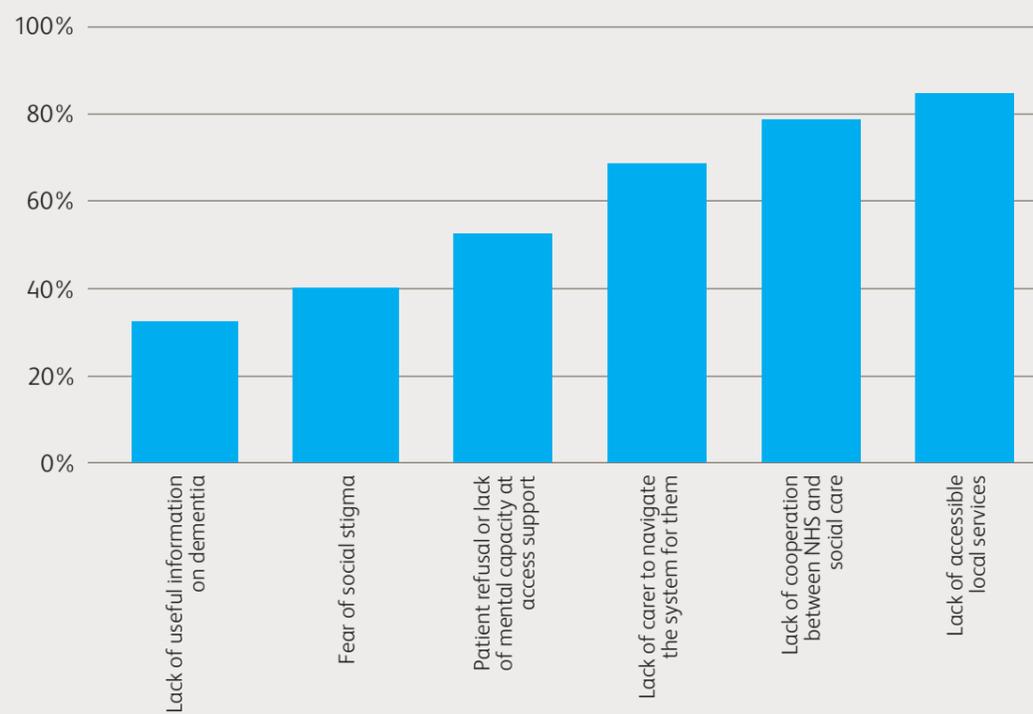
The barriers to accessing support

Support following a diagnosis is critical in helping people with dementia to live well with the condition and has been identified as important by the Welsh Government. However, at present there is no guidance on a minimum provision of support and it is unclear whether the responsibility for commissioning services lies with health or social care providers. As a result, access to support after a diagnosis is inconsistent.

Currently, many people with dementia struggle to find information about services in their area. Even where support does exist, there are no quality standards and health and social care professionals are often unsure of how to make referrals into services. This is unacceptable. Everyone affected by dementia should be guaranteed support to live well following a diagnosis. This should be the focus of public policy on diagnosis over the course of the next Welsh Assembly term.

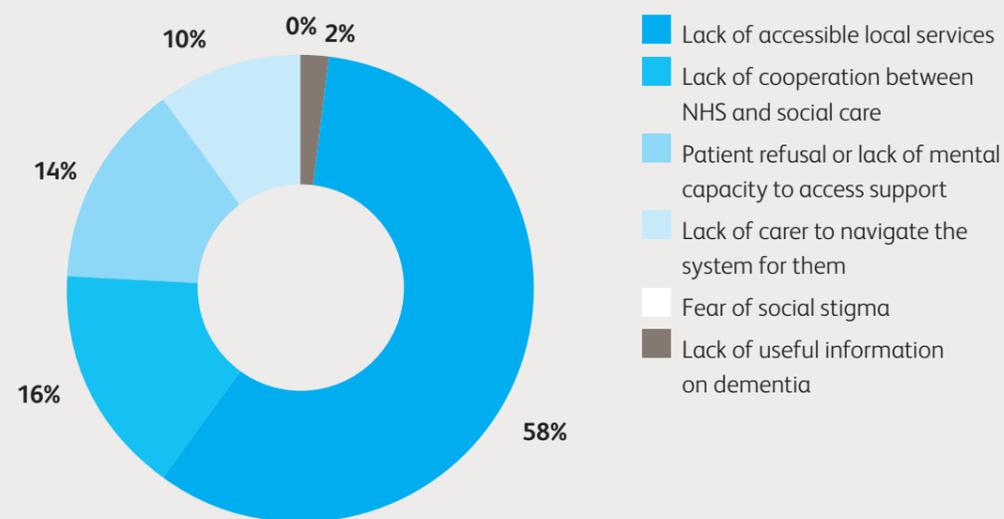
Alzheimer’s Society commissioned a poll of GPs to seek their views on dementia diagnosis and access to post-diagnosis support. One thousand GPs were surveyed across the UK, of whom 50 came from Wales (GP poll). The following table shows the reasons why those GPs in Wales felt there were barriers to people with dementia getting the support they need following a diagnosis.

Figure 5 Barriers to post diagnosis support, according to GPs in Wales



When asked ‘Where is the main barrier for people with dementia getting the support they need following a diagnosis?’, over half of GPs in Wales believed it to be the lack of accessible local services.

Figure 6 The main barrier to post diagnosis support, according to GPs in Wales



It is therefore clear that GPs in Wales believe the main barrier to people with dementia accessing appropriate post-diagnosis support is that these services are simply not available.

The responses from our survey and focus groups broadly back up this assertion. Even though the sampling was heavily biased towards those already in receipt of services, there were still substantial gaps between what they received and what they wanted.

Types of support that should be available

People with dementia come from a wide variety of backgrounds, have a variety of personalities and will be affected by their dementia in a variety of different ways. There can therefore be no ‘one-size-fits-all’ approach to post-diagnosis support. It is important that every person with dementia in Wales, no matter where they live, can choose from a selection of different services in order to access the support that will be beneficial to them. People with dementia should always be able to make choices about the type and intensity of services that they access. A consultation by the British Psychological Society found that while post-diagnosis support and psychosocial interventions were essential, it was also necessary for the individual to have choice in terms of the type of intervention and whether it was delivered individually or in groups (BPS, 2014b). Having a selection of services to choose from can help to empower a newly diagnosed person with dementia at a critical point in their dementia journey.

The British Psychological Society’s A guide to psychosocial interventions in early stages of dementia contains a comprehensive list of services which may be of benefit to people with dementia (BPS, 2014a). This section is not designed to be a comprehensive list of services that should be available to people with dementia after their diagnosis. It has however been structured around the types of support that people with dementia told us would have been most helpful to them in their first year after diagnosis.

Alzheimer’s Society believes that key support services, such as those described below, should be available to each person diagnosed with dementia, as well as their carers. These should be appropriate for the individual, tailored to their specific needs and written into a formal care plan. This plan should be reviewed at least annually, reflecting the changing needs of people with dementia and carers as the condition progresses.

Information about dementia and local services

In recent years there have been various attempts to improve information provision for people newly diagnosed with dementia. Most notably, in 2011, Alzheimer’s Society was given funding to produce information packs to be distributed to people newly diagnosed with dementia across Wales. The information packs contained bilingual information about dementia and relevant services; it could also be tailored to provide information about the services in each local area. However, it is clear from survey responses that not everyone received a copy of the pack when they were diagnosed. Additionally, the funding for this initiative has now run out.

Only 47% of survey respondents said that they were given enough information about dementia when they were diagnosed (Survey). In focus groups, when asked what information they were given about dementia when they were diagnosed, several participants said ‘nothing at all.’

Given the low levels of public understanding of dementia, the level of stigma that still surrounds the condition and the fact that many people diagnosed with dementia may not be comfortable finding information on the internet, it is essential that people who are diagnosed with dementia are given good quality information about the disease that they are living with.

‘I suppose in the beginning I was, I’m ashamed to say this, I didn’t know anything about Alzheimer’s. So it took a long time for me to even work out what it was... That was hard.’

Person with dementia, focus group

One survey respondent even said that the reason why there were people who they hadn’t told about their diagnosis of dementia was that they ‘didn’t know enough about Alzheimer’s to explain to them’ (Survey).

All people receiving a diagnosis of dementia should receive information about the specific condition that they have been diagnosed with, as well as the opportunity to ask questions to help them to understand the information that they have been given. The YouGov poll indicated that there was substantial confusion about the relationship between Alzheimer’s disease and dementia, with 58% of people incorrectly stating that dementia was a common form of Alzheimer’s disease, rather than the other way round.

‘I was just told I had Alzheimer’s disease and vascular dementia. No one explained the difference.’

Survey respondent

Providing information in writing not only helps the person with dementia to refer back to the information that they have given, it also means that this information can be more easily shared with family and other people who are important to the person with dementia.

‘It also would have helped the family if written information was provided so that they could understand the disease process and give appropriate responses to our mother’s behaviour.’

Survey respondent

Only 38% of survey respondents said that they were given enough information about services in their area when they were diagnosed. Access to good quality services is essential to enabling people to live well with their condition and to maintain their independence for as long as possible. Three quarters of GPs in Wales feel that it is confusing for people with dementia and carers in their area to navigate the health and social care system (GP poll). If people with dementia are not signposted to appropriate services at the time of their diagnosis, there is an increased risk that they will become isolated and at risk of reaching crisis point before they access services.

‘As a social worker myself I was aware that she was entitled to a community care assessment. However, we were not advised of this as a family. I knew she needed a package of care and the process, however no one told me this.’

Survey respondent

The limited range of post-diagnosis services that are currently available are provided by multiple organisations, and this fragmented landscape can make it difficult to find information about what is available.

‘When diagnosed we were just told and didn’t know what to do or who to turn to. If it wasn’t for Google and finding the Alzheimer’s Society web site we still would not have a clue.’

Survey respondent

Even when information is provided, this may not necessarily be done sensitively. Care needs to be taken not to overwhelm the person with dementia.

‘Once we eventually got to [the] memory clinic help was there, but even so, so much in information you can’t take it all in. Perhaps some six months later we started to follow things up.’

Survey respondent

While some people with dementia find it helpful to be given large amounts of information when they are diagnosed, others may need more time to come to terms with their diagnosis and giving them information at the wrong time may even be unhelpful (BPS, 2014b). Research has highlighted that the need for personally tailored, timely information is crucial as needs will evolve over time (Bunn et al, 2012; Durcharme, 2009; Lecouturier et al, 2008; Manthorpe et al, 2011; Moniz-Cook et al, 2006; Werner et al, 2013) (BPS, 2014b). Alzheimer’s Society believes that providing all people newly diagnosed with dementia with a named support worker would enable provision of information to be far more tailored to the individual than is currently the case for most people with dementia in Wales.

When providing information about dementia to people who have been newly diagnosed, Alzheimer’s Society believes that it is essential to consider three principles.

1. Provide information in writing so that the individual can consider it later or share it with family members.
2. Make sure there is time at the appointment for the person with dementia to ask any questions that they wish to ask at that time.
3. Give contact details for someone who is available to respond to questions the individual may have at a later date.

These are simple principles, but it is clear that they are not currently being universally applied across Wales.

Case study

An Insider's Guide to Dementia, Cardiff and the Vale University Health Board, Cardiff

In Cardiff and the Vale, clinical psychology services have worked with service users to produce An insiders' guide to dementia. This booklet, which is written by people with dementia, for people with dementia, provides tips on coping with a diagnosis. People who have received the booklet have found it helpful to know how others have coped and value knowing that they are not alone. The booklet addresses emotional issues around coping with a diagnosis of dementia, as well as more practical tips, and is printed in both English and Welsh. An evaluation of the booklet found that the majority of service users found it helpful and easy to read and 80% felt it should be given to other service users after a diagnosis of dementia. The booklet is often appreciated by service users as something written for them in a healthcare context, where the focus is often on care partners.

Social groups

Examples of social groups include, but are not limited, to the following:

- Dementia/memory cafés – regular groups which provide a safe, comfortable and supportive environment for people with dementia and their carers to socialise. As well as offering a range of fun and engaging activities, they give both carers and people with dementia a chance to get information and advice and talk to others with similar problems.
- User involvement groups – groups of up to eight people with dementia who are involved in influencing issues beyond their own care, through reviewing informational materials, forms and questionnaires, or informing priorities for service or strategic development.
- Singing for the Brain – structured group sessions which use music to encourage communication and participation, and include opportunities to talk to other people. Each session includes a range of activities including vocal warm-up and singing a variety of familiar and new songs.
- Peer support groups – facilitated sessions which provide the opportunity for people to share their experiences and learn from peers in a safe, non-clinical environment. People with dementia can ask questions, receive information and express themselves.
- Activity groups – these may include, for example, art and craft groups, drama workshops, walking groups, yoga or tai chi classes etc.

More than half (54%) of people with dementia said that they would have appreciated attending a social or support group in their first year after diagnosis (Survey). Such groups were also highlighted as extremely positive by several members of each of the three focus groups. While social groups may not be appropriate for everyone, it is clear that they are a lifeline for many people.

The benefits of attending a social group include the opportunity to meet other people, gaining more information and support, and reducing the risk of isolation.

'When I was going back and forward to [memory clinic], they asked me if I would like to attend a group and it took me about three months. "Will I go? Will I go? Are they going to be talking about Alzheimer's? Are they going to be doing this? Are they going to be doing that?" And I thought "You can only go once and you don't have to go again." And it was absolutely fantastic. Fantastic. Everybody was there and we don't talk about Alzheimer's unless somebody has got an issue... And I go in there sometimes when I have had a really bad week and I come out of there and I feel lighter I feel as if "That was nice, I've talked to different people" and [my husband] goes out with some of the carers in the lounge and makes a cup of tea and takes his quiz book with him. So he's having a couple of hours peace as well and... it's a really nice comfortable place.'

Person with dementia, focus group

Some people find that the groups are an essential aspect of coming to terms with their diagnosis of dementia.

'You can ask "What I was like when she first met me?" I was totally different person wasn't I? I just sat there, didn't really answer you, did I, properly? My wife was answering the questions she was asking me, because I just didn't want to. I was so down and um... I went to see the specialist, and the specialist nurse said to me about the groups and I started to go to these memory cafes. I've just come on fantastic. I've got back in to myself.'

Person with dementia, focus group

There is particular evidence that music therapy can improve cognition, behaviour and social interactions for people with dementia.

'I love singing. To be able to sing with a crowd, it really is good actually. They give us the words there. A lot of songs I can remember. I can remember them because I can remember what happened many, many years ago, not what happened yesterday actually. I thoroughly enjoy singing. It's something that is really good.'

Person with dementia, focus group

Case study

Try Something New, Alzheimer's Society

The Try Something New project provides formal and informal learning activities for both people with dementia and their carers in South West Wales. Working with community learning, it aims to reduce social isolation, increase confidence, help people to learn new skills and develop existing ones, and most importantly be fun!

Try Something New offers a wide range of activity courses ranging from arts and crafts, local history, film clubs, singing, chair aerobics, bowls and gardening to Zumba, ukulele, mosaics, tea dances, yoga, relaxation, iPad and woodwork. The sessions are run in community venues, care homes, hospitals and learning centres.

The ambition is that by attending a course, individuals will feel more confident and encouraged to attend similar courses in their local area. To date, 175 activity groups and taster sessions have been delivered, with 1,408 direct participants, 981 of which were people with dementia and 427 were carers. There have been 310 secondary beneficiaries – that is, carers receiving respite as those they care for attend the sessions.

The project has been externally evaluated by Bangor University. This evaluation reported that:

- 94% of participants enjoyed taking part in activities at the groups
- 83% said they felt that coming to the groups gave them more opportunities for socialising
- 79% said that coming to the groups helped them to have a more positive outlook on life.

Comments from participants include: 'I could forget I have dementia'; 'Enjoyed trying something different and learning a new skill'; 'I did something I didn't know I could do before'; 'I came out of the group happy and felt like I had really achieved something.'

A named support worker

52% of people with dementia said that they were given a named person to contact for advice and support when they were diagnosed (Survey). However, when this issue was explored in the focus groups and the question was asked in a different way ('In the days and weeks after your diagnosis, when you thought of questions you hadn't thought to ask at the meeting when you were given your diagnosis, was there anyone to whom you could ask those questions?'), the answer came back from almost every participant as a resounding 'No.'

Participants in the focus groups reported being given people from a variety of different roles as their named support worker, but the most common was a member of staff at the memory clinic. It was clear from the focus groups that many people with dementia had been given someone who they did not actually feel able to contact for advice and support as their named contact. In most cases, this was because people with dementia are very aware of the busy workloads of most memory clinic staff and did not feel that their queries were sufficiently important for them to bother such busy people. In other cases, people with dementia had attempted to contact their named support worker but had found that they were difficult to contact or that their busy schedules meant that meetings were promised but never arranged.

'I've not been assessed since I've had my diagnosis I don't think, but she was supposed to come about two months ago to assess me and she never came and I've not heard from her. She seems to be spread very thin. She's very nice but I think she has so much to do. You sort of get lost on a list somewhere.'

Person with dementia, focus group

Alzheimer's Society believes that every person diagnosed with dementia in Wales should have access to a named support worker, such as a dementia adviser or a dementia support worker. This type of dementia support is often provided by voluntary and community sector organisations. A dementia support worker is normally a non-clinical professional with knowledge of dementia and the local services available. People with a diagnosis of dementia need to have access to a dementia support worker, or equivalent, immediately after their diagnosis to help them understand their diagnosis and make plans for their care. A dementia support worker should also be available to meet with people with dementia on an ongoing basis as their needs change.

Widespread access to dementia support workers would be a cost-effective investment by government. It would ensure that people with dementia are prepared for the future and aware of the services available in their area (Department of Health, 2013). It could also avert health crises further down the line (APPG, 2012). Support from a dementia advisor is recommended by the Royal College of Psychiatrists and is included in the criteria for the Memory Service National Accreditation Programme (Royal College of Psychiatrists, 2014b).

Alzheimer’s Society dementia support workers were frequently mentioned by survey respondents and focus group participants as being some of the most useful sources of support they had accessed since receiving their diagnosis of dementia.

‘[Dementia Support Worker] has been a great support. Initially through the dementia café/therapy for both of us/advice on care packages/someone wonderful to talk to.’

Survey respondent

‘I am alright as [name of Dementia Support Worker] has helped us with everything.’

Survey respondent

A dementia support worker can help to solve some of the issues around information provision for people with dementia. When information is in a written format, it can be hard to know how much information to give and at what time. This can particularly be the case when a person with dementia is reluctant to access services because they are still coming to terms with their diagnosis.

When a person with dementia is given a support worker, the support worker can respond to their questions as and when they need that information. They can support the person to access the services that are most appropriate to them at that time.

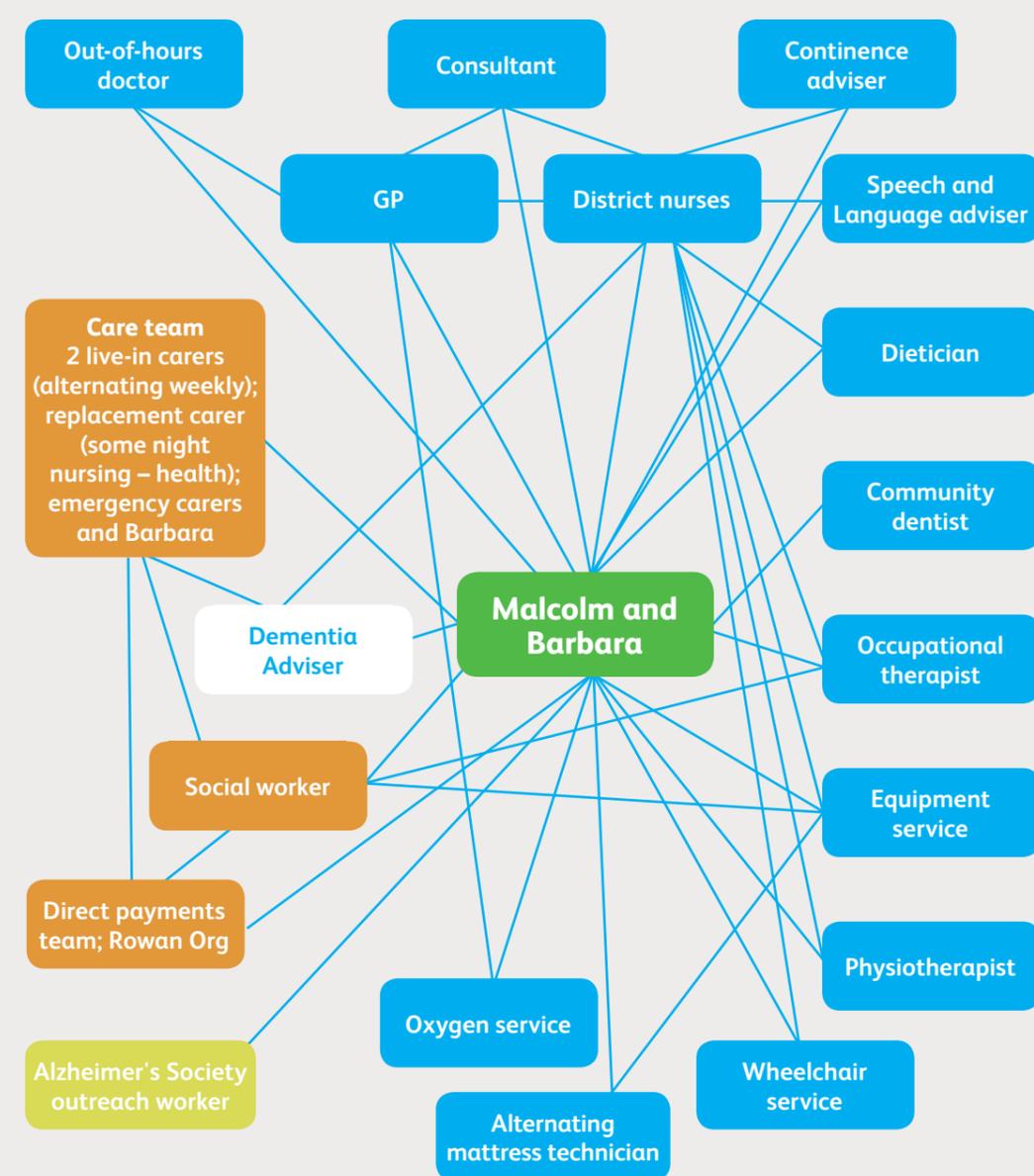
‘I think there is a lot to be said about choice and the information that is there. You know what groups there are and support if you need, and if you don’t need it that’s your choice. But as long as it’s there, it’s personal preference.’

Person with dementia, focus group

Alzheimer’s Society welcomes the Welsh Government’s additional funding for 32 dementia support workers in Wales. This is a step in the right direction but is unlikely to eliminate the issues around people with dementia being unable to get hold of their named support worker in order to access the support they were promised. Further resources are therefore necessary.

Alzheimer’s Society believes that everybody diagnosed with dementia entitled to an extensive package of post-diagnosis support. In our Right to Know campaign we call for everyone to be able to receive such a package, which includes access to a dementia adviser or dementia support worker. These roles offer personalised support from the point of diagnosis and help people with dementia and their carers navigate the health and care system. They also help to make use of community resources and pre-existing social networks. It is vital that dementia advisers or dementia support workers have specialist knowledge of dementia and the services that are available, because the nature of dementia presents specific challenges to navigating the system.

Figure 7 Barbara Pointon’s ‘web of care’ (last 7 years)



National Voices www.nationalvoices.org.uk/webs-care

The experiences of people with dementia and their carers depict a complex web of health and care services and staff. People with dementia must attempt to navigate this web and interact with many different people in order to get the care and support they need. Much of this complexity stems from the differences between the types of care and the range of services that they need. This can range from day-to-day care to managing personal budgets or direct payments, accessing out-of-hours doctors and other practical aspects like equipment services. The complexity of navigating such an array of services is compounded by the fact that many people with dementia will have several other health conditions. The diagram above reflects this ‘web of care’.

It highlights the complexity that people with dementia and their carers face in trying to access to vital services and support. In contrast to this, having one named person as a point of contact for the person with dementia and carer has the potential to transform this experience for the better and significantly improve access to care and support. A support worker could play this important role.



Recommendation 6

Every person diagnosed with dementia to receive a named support worker who they can easily contact with any questions and who can signpost them to appropriate services.

Carer support

Carers of people with dementia living in Wales today save the Welsh economy £622 million every year (Alzheimer's Society, 2015). Without the right support, carers are unable to care for the person with dementia. If carers are identified and supported, the potential savings to the health and social care could be significant.

Informal family carers provide a large proportion of care for people with dementia. 84% of GPs in Wales either agreed or strongly agreed that their patients with dementia had to rely on family members as they did not receive enough support from the NHS or social services (GP poll). It is therefore crucial to provide education to all carers to enable them in their role, and to support them to ensure that carer burnout does not occur.

The contribution of carers, without which the health and care system could not function, can often come at a high personal cost to the individual caring for the person with dementia. Caring for a person with dementia is unlike caring for a person with any other condition and many will experience high levels of stress and even depression (Carers Trust, 2013). Many carers report not being provided with information and advice on basic practical issues (Carers Trust, 2013). It is therefore not surprising that services which support their carers also emerged as an area where further support services are needed.

The memory clinic audit found that all memory clinics in Wales stated that they provided access to education and support for carers (PHW, 2014) However, it is clear from the evidence gathered for this report that not all carers feel like they have received sufficient and appropriate support. Alzheimer's Society therefore recommends that the minimum provision of support should also extend to carers of people with dementia, as well as the people they care for. This minimum provision should include access to an independently evaluated carers education programme, such as the Carer Information and Support Programme (CrISP), as well as access to short breaks and suitable respite care.

Alzheimer's Society's Carer Information and Support Programme (often referred to as CrISP) is an information programme for carers, family members or friends of a person with dementia, and is delivered throughout Wales. It aims to improve the knowledge, skills and understanding of those caring for a person with dementia by providing effective support and up-to-date and relevant information. The programme consists of two separate parts: CrISP 1 and CrISP 2. Each programme is delivered to small groups of up to 12 people. CrISP 1 has been designed specifically for carers, family members and friends of people with a recent diagnosis of a dementia. CrISP 2 has been designed specifically for carers, family members and friends of people who have been living with dementia for some time. An independent evaluation of CrISP found that the support and access to information that the programme delivers to carers improved care for themselves and for the person with dementia (Barnes et al, 2013). As this carer said in one focus group:

'I wanted to know how to cope and what help, and progressively what sort of things [to expect]. And I went to the Alzheimer's Society six-week course with [DSW name] [CrISP]. It was a very, very good course. It was a very useful course. I would like to say that I found it really helpful.'

Carer, focus group

Case study

Caring and Coping with Loss in Dementia, Betsi Cadwaladr University Health Board, North Wales

Caring and Coping with Loss in Dementia are groups for carers of people with dementia that have been running since Autumn 2013 in North Wales.

The groups are facilitated by clinical psychologists, community psychiatric nurses, occupational therapists and social workers, and they meet weekly for 2.5 hours, for a period of eight weeks. Each group is facilitated by two professionals and one observer, and each group can have up to eight carers. The facilitators are trained in the model that is used in the group, and the role of the observer is one of a trainee facilitator.

This support programme for carers was originally developed in Sheffield, where the groups have been running since 1997. The course content is based on five theoretical models: the family support model, attachment theory, positive aspects of caring, bereavement theory and cognitive behavioural therapy.

Carers of people with dementia can face particular challenges as they come to terms with the changes in the person they are caring for. The carer can grieve for the loss of the person as they were, while at the same time having to manage the daily demands of caring. Change and loss are therefore important processes for carers to explore and address. When carers attend a Caring and Coping with Loss in Dementia group, they are provided with space to share their experiences, feelings and emotions around these changes and losses, and to explore issues related to their experience of caring.

Carers reflect on how they cope with difficult situations, and are also encouraged to explore positive aspects of caring. The aim of the group is to improve a carer's awareness of their own needs and abilities, and to reduce any negative emotions they may be feeling, such as isolation or hopelessness.

Feedback from the groups has been very positive, with carers indicating that although it can be difficult to explore certain issues, it had been a worthwhile and enjoyable experience. Many reported feeling more confident, more able to relax and better able to cope with their caring role after attending the group. Carers have also reported feeling less frightened of thinking about what lies ahead and more confident in planning for the future after attending the group. Formal evaluation found that participants' level of anxiety, depression and feeling of being burdened had significantly decreased by the end of the eight-week period. The largest improvement in psychological well-being was seen in people caring for a parent with dementia.

Regular ongoing care

One theme which emerged from the focus groups was a lack of clarity over who was responsible for the regular ongoing care of people with dementia. Many memory services will discharge people for whom medication is not an option. This then means that these people with dementia do not receive any follow-up care or ongoing contact with specialist services. This is a particular risk for people who have been diagnosed with vascular dementia.

'After several attempts at trying medications I gave up because of side effects. I currently receive no medication at all for my dementia, therefore the memory clinic do not see me at all anymore. I have not had a brain scan.'

Survey respondent

However, it is also quite likely that a person with Alzheimer's who has been prescribed medication will be discharged from the memory clinic once their response to the medication is stable. The care of the person with dementia is then transferred back to their GP. However, focus group participants often felt that, even when GPs were supportive, they were often not able to provide the specialist information and advice that they needed.

'But it always seems to [be] "Go back to your GP." Well our GP is brilliant, but he's not an Alzheimer's GP. He's general. He's doing thousands of other things as well.'

Carer, focus group

'I had to go see my doctor, that's what they said, "Go see your doctor." I don't know what they thought he would do! Cos when I went to see him he said, "Well, I can't do anything." He said, "The thing is I'm not qualified. If you've got any other medical problems..."'

Person with dementia, focus group

Medication is only a part of the ongoing care that people with dementia need. It is important that ongoing support takes into consideration the full spectrum of factors that will impact on the quality of life of a person with dementia and how that may change as their condition progresses.

'It's an ever changing situation and therefore support with dealing with the "latest" stage is helpful.'

Survey respondent

Many people felt like they were slipping between the cracks in our health and social care systems or being bounced between different professionals with very little continuity of care.

'[It would be helpful] to be able to have contact with the same consultant, CPN etc, or a small group of professionals rather than being ushered between different people.'

Survey respondent

The fact that a quarter of survey respondents wanted to have more regular meetings with their GP shows the extent to which people feel that there is insufficient regular management of their medical needs. However, focus group participants often felt that even when GPs were supportive, they were often not able to provide the specialist information and advice that they needed. They wanted their first port of call to be the memory clinic, and yet the memory clinic often did not feel that this was part of their role and tended to refer people back to their GP.

'I did try the memory clinic last year, [person with dementia] had hallucinations, panic attacks, total rejection of the pill that they altered six weeks before we went on holiday. And I thought "Well I'll ring the memory clinic and see if they could help" and they said "Oh, you'll have to go through your GP". So I didn't bother.'

Carer, focus group

Focus group participants often felt that their experiences at the memory clinic had been positive, but not sufficiently regular to be helpful to them. The participants did not want something substantially different from what was already being provided, but simply more contact of the kind that they had already experienced.

The memory clinic audit found that all clinics in Wales are able to offer home-based assessments when needed (PHW, 2014), and it is clear that this is something that is welcomed by people with dementia.

‘I don’t remember when I went last, but what they decided was, rather than... to put pressure off me, that rather than me go to the hospital, they came to my house. And two people, which was a cracking idea, it was lovely. The doctor and someone came and my wife and the assistant, whatever it was, went up the garden, had a cup of tea. And the doctor came to see me in the house. And I bet that’s been two years. I’ve got to go again now as it happens, but I bet it’s been two years since I went for a check-up.’

Person with dementia, focus group

Many people at the focus groups reported experiencing significant delays in check-ups. This was despite the fact that the majority of the focus group participants had a form of Alzheimer’s rather than vascular dementia. They were therefore more likely to be in receipt of medication and to have more regular check-ups.

‘We’re going back to the memory clinic in June, that’s the first time in four years.’

Carer, focus group

Ongoing support is essential to maximise the value of receiving a timely diagnosis of dementia, but it is clear that this not yet reliably happening across Wales. Part of the problem is that there is a lack of clarity over the role of memory clinics in the ongoing support of people with dementia. There is little agreement over whether the responsibility for the ongoing care of people with dementia should lie with memory clinics, a named keyworker, or with primary care providers. Currently there seems to be a wide variety of different approaches, with the ratio of follow-up patients to new patients at memory clinics in Wales ranging from about four to one, to less than one to one (PHW, 2014).

Alzheimer’s Society is not necessarily recommending that all memory clinics should take on this responsibility, but it is clear that people with dementia need to receive this support and that the current system is not providing adequate levels of it. Therefore, it will be necessary to have a conversation about who should be providing this support. There will either need to be significant upskilling of GPs so that they can provide this support, or there will need to be a significant increase in resources allocated to memory clinics so that they have the capacity to provide a greater level of ongoing care to people who have been diagnosed with dementia.

Counselling

Counselling is not something which is routinely offered to people newly diagnosed with dementia. However, a quarter of survey respondents said that it was one of the services that they would have found most helpful in their first year after diagnosis. It was also the service where there was the largest difference between the people who received it and the people who would have liked to receive it.

Post-diagnosis counselling is a process of providing support to help people come to terms with a diagnosis of dementia. It involves thinking about needs and working out the next steps in terms of treatment. It can be offered to a person after their diagnosis as an opportunity for them to discuss the diagnosis, have their questions answered and receive information about further advice and support. It can be a useful way of helping an individual to come to terms with the emotional side of receiving a diagnosis. It provides a solution to some of the issues identified by the focus groups about not having enough time to talk things through when they were given their diagnosis. It is therefore an important part of the diagnosis process and should be offered at the time of diagnosis.

The British Psychological Society has found that talking therapies, such as counselling and psychotherapy, can reduce depression and anxiety for people living with dementia (BPS, 2014a). These therapies may be useful for people with dementia and their carers, or for both together in the form of family therapy.

There is a particular need to provide specialist post-diagnosis counselling to people who have rarer diagnoses, familial conditions or a particularly adverse reaction to their diagnosis. Despite the fact that, according to the memory clinic audit, 93% of memory clinics in Wales stated that they have access to specialist post-diagnosis counselling, the availability of specialist counselling described here is currently uncommon in Wales. It is possible that the question in the memory clinic audit may have been misinterpreted as meaning provision of general support and advice following a diagnosis (PHW, 2014).

Befrienders

Befriending services provide personalised companionship for people with dementia or carers, either in their own home or during outings and activities in the community. Befriending is provided by volunteers who are supported and managed by staff. Activities will be specific to a person’s needs and will be decided in agreement with the person with dementia.

Befrienders are frequently named as one of the most beneficial services for people with dementia. Almost a quarter of people (22%) said that they would have benefited from a befriender in the first year after their diagnosis (Survey).

‘My befrienders, I love them to bits. They are my best friends. I’d be lost and I admit that, I’d be lost. I know it’s only two hours but it makes my week.’

Person with dementia, focus group

Minimum provision of post-diagnosis support

Excellent services for people affected by dementia do exist across Wales. However, there are still too many people who are not adequately supported. As a result we need a national consensus on a minimum level of post-diagnosis support. Sufficient resources should be prioritised and made available to fund this in every geographical area. Within the framework of a minimum standard, support can remain flexible and adapted to the individual and their family.

Each individual will have different needs that change over time, and not all diagnoses will be given early in the course of the condition. It would be inappropriate to stifle innovation through a prescriptive framework of support. Health and social care professionals must ensure that any interactions with, and care provided for, a person with dementia is personalised to ensure the care meets the individual's needs. It is also essential to address the needs of the carer as part of this support. However, a guaranteed minimum provision of support for both people with dementia and carers is vital to ensure that in future all people with dementia in Wales receive sufficient support.

One of the most striking findings of this report was the wide variation in the quality of care received by people with dementia across Wales. Stories of support, or lack of support, varied from clinic to clinic, as well as by type of dementia. It is quite clear that there is currently a postcode lottery when it comes to the receipt of appropriate services and support for people with dementia.

Memory services are commissioned according to local need and to complement existing structures and services. However, variability in form should not lead to variability in function, as is currently the case.

Alzheimer's Society believes that all people newly diagnosed with dementia in Wales should be offered a tailored, nationally-assured package of post-diagnosis support. This should include, as a minimum:

- comprehensive information on all aspects of the condition and access to universal support services, such as a helpline
- access to a named support worker who can provide expert practical guidance on how to navigate services, support and decisions
- support to manage and live well with dementia. This can be delivered individually and/or in a group, depending on an individual's preference.

Local health boards and local authorities should be required to provide annual reports to the Welsh Government detailing what has been commissioned. When measuring the success of post-diagnosis support, it is important to measure it against the aspirations and expectations of the person with dementia and their families, benchmarking it against a standardised national package of post-diagnosis support. It is therefore clear that information should not only be collected on what is being provided, but also on the outcomes of these services for the people they are working with.

A named support worker

Access to a named support worker, such as a dementia support worker or dementia adviser, is an essential part of any minimum provision of post-diagnosis support. The support they provide has a vital role in making it possible for the person with dementia to access information and services which are appropriate to their needs.

While there are roles within Wales that currently meet this description, there is considerable variation in both job descriptions and pay packages. There are also not enough roles to support all the people with dementia in Wales. The Health Minister's recent announcement about an additional 32 roles is welcome, but still not sufficient to enable the scale of change that is necessary to ensure everyone dementia receives this minimum standard of support.

Working on the assumption that each support worker can support 50 people with dementia at any one time², 385 dementia support workers would be required to support all those people in Wales who have currently received a diagnosis of dementia. There are therefore not yet sufficient numbers of support workers available to work with the numbers of people who have already been diagnosed with dementia. If the target of a 75% diagnosis rate is reached, this would require at least 650 dementia support workers in order to maintain a basic level of support. Working on the assumption that increases in the diagnosis rate can be achieved at a rate of a minimum of 5% each year, an average of at least 45 new dementia support roles would need to be created each year. Extra resources are therefore urgently needed in order to ensure that this basic standard of support can be provided throughout Wales.



Recommendation 7

The Welsh Government to establish a minimum standard of integrated post-diagnosis support for people with dementia and their carers

National dementia strategy for Wales

This report has identified a range of needs and made suggestions about how to meet them. Improving the experience of receiving a diagnosis of dementia will require concerted action from a range of organisations. Strategic leadership will be required from the Welsh Government in order to encourage the range of actions that will be required. As such, the overarching recommendation of this report is that the Welsh Government commit to an adequately resourced and fully accountable national dementia strategy for Wales.

In order to achieve system-wide improvement, there is a need to change the way that health and social care professionals think about caring for people with dementia. Existing commissioning guidance needs to be applied to redesigning systems and workforce development, and will require appropriate investment if transformational change is to be seen. Improving diagnosis rates involves more than just improving numbers – it involves designing a diagnostic pathway that takes people from their first appointment with their GP through to the support they receive in the years following a diagnosis. This requires investment, joint working across health and social care, and leadership.

² The exact number of people with dementia who a support worker can support would depend on the level and intensity of need as well as the case management approach adopted. An Alzheimer's Society dementia support worker would normally support far fewer people than 50. However, 50 is perhaps still a useful benchmark to use for these initial calculations as to the levels of unmet need.

The evidence about the barriers to diagnosis again demonstrates the importance of a joined-up approach for dementia, both locally and nationally, designed to achieve change across the whole system. GPs do not work in isolation and it is clear that the issues that they see in the rest of the system are having an impact on what should be a clear-cut decision to refer for diagnosis. Of GPs polled in Wales, 78% believed that the lack of cooperation between the NHS and social care was one of the barriers to people with dementia receiving the support they need after a diagnosis (GP poll). Any national dementia strategy would therefore need to cover the full range of services that people with dementia regularly need to access.

The National dementia vision (2012) and Wales: A dementia friendly nation (2015) announcements both included a number of commitments, but it is important to move from commitment to transformation and planned action. In a Welsh poll of the general public, half of the people in Wales (50%) thought the Welsh Government should be doing more to respond to dementia in Wales (YouGov). A national dementia strategy would enable change in all of the areas described in this report, as well as others outside the scope of this project.

The Welsh Government's reaffirmed commitment to dementia will only suffice if it is turned into meaningful action, funding and agreed specific outcomes in meeting the objective of improving dementia care and support in Wales. A national strategy is now needed to deliver real improvements for people affected by dementia. This national strategy should include:

- actions on diagnosis rates and post-diagnostic support as identified in this report
- information on how each action will be implemented and funded
- clear lines of accountability for the delivery of key aspects of the action plan
- a delivery assurance group with representatives from the health and social care sectors, as well as the third sector.



Recommendation 8

The Welsh government to commit to an appropriately resourced national dementia strategy.

A message from people with dementia

Throughout this report, we have tried to keep the voices of people with dementia at the heart of all of our recommendations. It is fitting therefore that they should have the final word. At each of the focus groups, people with dementia were asked the following question: 'If you could give one message to politicians or the people who commission services, what would that message be?'

The following quotes are representative samples of the types of responses given to this question.

'Early diagnosis, because they can do it when they want to.'

'More funding, that's the biggest thing, I think, because there is not enough to go around.'

'To listen to us.'

'To put more money into research.'

'They've just closed one centre. Just fund the centres [for] people to go to. It's not us so much cos we've all got family and friends, but these people who haven't, they need that place.'

It has always been unacceptable for people with dementia to be kept in the dark about changes that are happening to their own body. However, the increasing emphasis on co-production in the delivery of health and social care services means that the unacceptably low diagnosis rate in Wales is growing ever more untenable. Many people with dementia are eager and capable of engaging with the co-production agenda, but in order to do so they need to be adequately supported, and the first step to receiving adequate support is receiving a diagnosis.

There is a very clear choice in the provision of care for people with dementia: provide a diagnosis and open the door to appropriate support, or keep people with dementia in the dark and disempower them from shaping their own future.

Conclusion

As we approach the 2016 Welsh Assembly elections, Alzheimer's Society is concerned at the lack of long-term national commitment on dementia. There has been insufficient monitoring of the funding allocated from the 2011 stakeholder action plans, and there is an urgent need for a national dementia strategy with clear lines of accountability and adequate resourcing. The initiative Wales: A dementia friendly nation has been a step in the right direction but there is still a clear and urgent need for robust national prioritisation of dementia. Without a national focus, the lives of individuals affected by the condition cannot improve.

This report has shown that there are still far too many people with dementia in Wales for whom the experience of receiving a diagnosis has been a negative one. People with dementia who have not received a diagnosis, or who have not received adequate support after diagnosis, are essentially being denied the opportunity to take control of their lives. Alzheimer's Society believes that increases in the number of people receiving a diagnosis of dementia are achievable over the course of the next Assembly term. We also believe that a guarantee that all people diagnosed with dementia will receive at least a minimum provision of support, regardless of where they live or what form of dementia they have been diagnosed with, will empower people with dementia to achieve the best possible quality of life at each stage of the condition.

Alzheimer's Society looks forward to working with all relevant stakeholders to implement these changes and make Wales a truly dementia-friendly nation.

Recommendations

1. All local health boards to set targets to improve diagnosis rates by a minimum of 5% per year until they achieve a diagnosis rate of 75%.
2. The Welsh Government should run a sustained public awareness campaign on dementia, with a particular focus on reaching Welsh language communities.
3. All GP practices in Wales should complete the 'Managing dementia in primary care' training.
4. The Welsh Government to allocate additional resources to memory services so that they have the capacity to support the numbers of people with dementia in Wales who are yet to receive a diagnosis of dementia.
5. Commissioners across Wales to explore innovative practices for memory services that include support from local providers of advocacy and emotional support, such as Alzheimer's Society or other charities.
6. Every person diagnosed with dementia to receive a named support worker who they can easily contact with any questions and who can signpost them to appropriate services.
7. The Welsh Government to establish a minimum provision of integrated post-diagnosis support for people with dementia and their carers.
8. The Welsh government to commit to an appropriately resourced national dementia strategy.

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Appendix

Methodology

Survey of people affected by dementia

Alzheimer's Society surveyed people with dementia in Wales to find out about their experience of receiving a diagnosis of dementia. The survey was distributed via Alzheimer's Society services, made available online and promoted by partner organisations. People were invited to complete the survey between March and June 2015.

The total number of respondents to the survey was 257. The majority of respondents (62%) were people with dementia, either filling in the survey alone (10%) or with support (52%). The number of carers completing the survey on behalf of someone with dementia was 35%. The majority of respondents were aged 65 and over: 16% were under 65 years; 63% were 65–85 years; and 20% were over 85. Responses came from all across Wales.

This is a significant number of people with dementia to complete a survey in Wales, and this provides an important evidence base from which to establish how well people are being supported at around the time of receiving a diagnosis. This is the first time that Alzheimer's Society has run this type of survey in Wales alone and it represents a significant step forward in our understanding of the experiences of people with dementia in Wales.

However, there are limitations to the sampling on which it is based. This is a self-selecting survey sample and the majority of respondents were already in contact with Alzheimer's Society and therefore accessing some level of support. The survey was also aimed at people who had received a diagnosis of dementia and therefore does not capture the experiences of people who are still struggling to get a diagnosis. Furthermore, the questionnaire format also means that it is likely that evidence is collected from people who are predominately less affected by symptoms, as they need to be able to understand and respond to the questions. However, the use of carers as proxies does mitigate this in some cases.

For these reasons, it is likely that the survey responses represent 'best case scenario' evidence of the experiences of people with dementia who have received at least some form of support. The evidence provides a robust snapshot of the experiences of these particular people, rather than a definitive evaluation of the experiences of all people living with dementia. The experiences of those who have not received any support or who may not even have received a diagnosis are likely to be even more negative than those presented in this report.

Focus groups of people affected by dementia

The survey allowed Alzheimer's Society to reach out to a large number of people with dementia; many more people than could be reached through interviews alone. However, it does not provide detailed information into the experiences of people who live alone with dementia. To gain a more detailed picture, Alzheimer's Society spoke directly to people with dementia living alone.

Between May and August 2015, Alzheimer's Society ran three focus groups in different locations across Wales. Focus groups were primarily aimed at people with dementia, but carers were also welcome to attend if they wished. In total, 11 people with dementia and 6 family members participated in the focus groups. The opinions expressed at these meetings have informed this report and quotes from participants have been included where appropriate.

It must be noted that these participants were already in contact with the Society or using its services.

Public poll

Alzheimer's Society commissioned a YouGov poll of UK adults. In August 2015, over 1,000 individuals in Wales were asked a range of questions about dementia. Of the 1,327 people polled, 415 were Welsh speakers. The survey was carried out online. The figures have been weighted and are representative of all Welsh adults (aged 18 and over).

Roundtables with professionals

Alzheimer's Society held two roundtable events to which a range of professionals were invited, one in South Wales in February 2015 and one in North Wales in April 2015. The opinions expressed at these meetings have informed this report and quotes from participants have been included where appropriate.

GP survey

Alzheimer's Society commissioned a poll of 1,013 GPs through MedeConnect Healthcare Insight to seek their views on access to post-diagnosis support. The survey results were originally published at a UK level by Alzheimer's Society in *Dementia 2015: Aiming higher to transform lives*. Fifty of the respondents were GPs in Wales and their responses are used in this report.

Diagnosis rates in Wales

Progress on improving diagnosis of dementia 2014–2015

Area Name	Number of people on QoF dementia register (number with a diagnosis) 2014	Estimated number of people with dementia (diagnosed and undiagnosed) in 2014	Percent of people with dementia with a diagnosis in 2014	Number of people on QoF dementia register (number with a diagnosis) 2015	Estimated number of people with dementia (diagnosed and undiagnosed) in 2015	Percent of people with dementia with a diagnosis in 2015	Number of people without a diagnosis 2015	Percent of people without a dementia diagnosis in 2015	Percentage improvement since 2014
Wales	18,591	43,478	42.8%	19,239	44,362	43.4%	24,239	54.6%	0.6%
Betsi Cadwaladr ULHB	4,572	10,726	42.6%	4,614	10,985	42.0%	6,112	55.6%	-0.6%
Powys Teaching LHB	984	2,376	41.4%	1,013	2,448	41.4%	1,363	55.7%	0.0%
Hywel Dda ULHB	2,357	6,218	37.9%	2,369	6,368	37.2%	3,849	60.4%	-0.7%
Abertawe Bro Morgannwg ULHB	3,133	7,222	43.4%	3,305	7,359	44.9%	3,917	53.2%	1.5%
Cwm Taf ULHB	1,497	3,720	40.2%	1,531	3,752	40.8%	2,189	58.3%	0.6%
Cardiff & Vale ULHB	2,673	5,553	48.1%	2,799	5,652	49.5%	2,754	48.7%	1.4%
Aneurin Bevan ULHB	3,375	7,663	44.0%	3,608	7,798	46.3%	4,055	52.0%	2.2%

Dementia prevalence rates

The estimated numbers of people with dementia were calculated by applying the following prevalence rates to the corresponding age groups to mid-year 2014 population estimates:

30–34 years:	0.0094%
35–39 years:	0.0077%
40–44 years:	0.014%
45–49 years:	0.0304%
50–54 years:	0.0583%
55–59 years:	0.1368%
60–64 years:	0.9%
65–69 years:	1.7%
70–74 years:	3.0%
75–79 years:	6.0%
80–84 years:	11.1%
85–89 years:	18.3%
90–94 years:	29.9%
95 years+:	41.1%

Prevalence Rates were established in the Dementia UK (2014) report.

This can be found at www.alzheimers.org.uk/dementiauk

Mid-year population estimates for 2014 were obtained from the Statistics Wales website (www.statswales.wales.gov.uk/)

Dementia diagnosis rates

The number of people diagnosed with dementia was taken from data on the 2015 NHS Quality and Outcomes Framework (QOF) indicator number DEM1.

This can be found online:

www.wales.gov.uk/statistics-and-research/general-medical-services-contract/?lang=en

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 3,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

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