



Older People's Commissioner for Wales
Comisiynydd Pobl Hŷn Cymru

Dementia: more than just memory loss

**The experiences of people living with
dementia and those who care for them**

**An independent voice and champion
for older people**

The Older People's Commissioner for Wales

The Older People's Commissioner for Wales is an independent voice and champion for older people across Wales. The Commissioner and her team work to ensure that older people have a voice that is heard, that they have choice and control, that they don't feel isolated or discriminated against and that they receive the support and services that they need.

The Commissioner and her team work to ensure that Wales is a good place to grow older, not just for some but for everyone.

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Contents

Foreword	04
Introduction	06
Key Conclusions	07
Action Required & Next Steps	11
Findings	15
Living with Dementia	15
Services & Support	36
Going Forward	66
Appendix	74

Foreword

Dementia is a devastating illness that is more than just memory loss. It is a degenerative and life limiting brain disease that impacts upon every level of an individual's physical, cognitive, emotional and social functioning. Whilst for some people, its impact is almost immediate, for many others, it leads to a slow and almost unbearably painful decline and loss of all that they hold dear.

The impact of dementia upon individuals, those that they care for and that care about them, and their wider families, is almost impossible to imagine.

That is why we must listen to the voices of the people who generously shared their lives with me and highlighted the significant variations that exist across Wales. They told me that they need to be listened to and for their needs as individuals to be recognised, not only by professionals and services, but also by wider society. They highlighted the difficulties they have in accessing the information, support, and services that can make a big difference to their lives, often feeling alone at the most difficult times.

This report gives a voice to people living with dementia and those that care for and care about them. It provides an opportunity for us to reflect on where we are now in Wales. It has messages for the whole of society and should be used as a challenge to ourselves to not only build upon what we have already done, but also to build upon this in a way that delivers a better quality of life for people living with dementia.

For too many people living with dementia, the consequences of this disease lead to a withdrawal from wider society and the things, often the smallest of things, that give them pleasure and bring value, meaning and purpose to their lives. But it is important that as a society we support people with dementia to be included for as long as possible, that we focus on the skills that they still have or can still learn and that through our actions we ensure that they have the best quality of life for as long as possible.

We need to do more, both within our public services and as a country to support people in its widest sense to stay included, stay within their own homes and the communities that matter to them, and to ensure that our carers have all of the support they need to continue to care for as long as possible. This is good both for individuals with dementia and the public purse.

Within Wales, we now rightly have a strong focus on wellbeing and people with dementia must not be excluded from this agenda. The National Outcomes Framework for Social Services provides a very clear set of outcomes for

individuals in receipt of services, the focus on wellbeing in the Social Services and Wellbeing (Wales) Act lifts this up to a population level and the Wellbeing of Future Generations (Wales) Act sets clear national wellbeing goals, measured by a set of key indicators, that must include people with dementia and the people who care for them.

Dementia is a clinical illness. Whilst it is right that we focus on its prevention, diagnosis and symptoms, we must focus just as much on ensuring that people with dementia are able to have the very best possible lives they can. We must make sure that they feel safe and listened to, valued and respected, can get the help that they need, can do the things that matter to them and live in a place that suits them and their lives.

There will be other things that need to be done, but the issues raised in this report are the things that people have spoken to me about and, if implemented, would go a long way towards ensuring that people living with dementia and their carers maximise their quality of life for as long as possible and that they are no longer excluded and unseen, but rather have the best possible quality of life.



Sarah Rochira
Older People's Commissioner for Wales

Introduction

It is estimated that more than 45,000 people in Wales are currently living with dementia, with this figure expected to exceed 55 000 by 2021¹. The vast majority of people living with dementia are older people, with early onset dementia (under the age of 65) being relatively rare².

The number of people with dementia in Wales is expected to increase by 31% between 2011 and 2021, and by as much as 44% in some rural areas³ and it is estimated that by 2055 there will be over 100,000 people living with dementia in Wales⁴.

Of the total of 45,000 living in Wales, it is estimated that approximately two-thirds of people living with dementia live in the community, with one-third living in residential or nursing care homes⁵. As Wales currently has one of the lowest rates of dementia diagnosis of any part of the United Kingdom (approximately 43.4%⁶), a large number of these people are likely to be living without a formal diagnosis, hindering their access to relevant support and services.

The Commissioner's own engagement and casework, through which she heard from and supported many people living with dementia and those who care for them, also indicates that even in cases where an individual has received a diagnosis, people often feel that they do not have a voice that is listened to and that services often do not meet their needs, something that impacts upon their quality of life.

In order to determine what action could be taken to improve their quality of life, the Commissioner wanted to hear directly from people living with dementia and their carers across Wales about their experiences, both positive and negative, and the challenges they face in their day-to-day lives.

The Commissioner therefore undertook this research, which gives people living with dementia and their carers a voice, to drive the change that is needed throughout Wales to improve support and services for people living with dementia and their carers and ensure they can have the best possible quality of life.

1 Alzheimer's Society (2015), Diagnose or disempower? Receiving a diagnosis of dementia in Wales.

2 Alzheimer's Society. 2014. Dementia 2014: Opportunity for change

3 Welsh Government (2011) National dementia vision for Wales

4 Alzheimer's Society (2015), Diagnose or disempower? Receiving a diagnosis of dementia in Wales

5 Alzheimer's Society (2007). Dementia UK. London: Alzheimer's Society

6 Alzheimer's Society (2015) Wales Dementia Diagnosis

Key Conclusions

Overall, it is clear that a significant number of participants did not feel that their full needs – for care, support, information and advice – are currently being met by services and those who deliver them.

In analysing the findings of this research, a number of themes also emerged from which I have drawn the key conclusions set out below.

There is a widespread lack of knowledge and understanding of dementia amongst professionals and the wider public.

“What really bothers me is that people still have the feeling that dementia is basically just a memory problem, and you think ‘Oh God, if it was just a memory problem, wouldn’t that be easy?’ It’s not, it’s a total life organisation problem.” (Female Carer)

Participants were clear that there is still a widespread lack of understanding about what it is like to live with dementia. The research found that whilst general recognition and knowledge of dementia amongst the general public had increased in recent years, this had not translated into a full understanding of dementia or what it is like to live with the condition. Participants were particularly frustrated that dementia still seems to be widely perceived as being largely related to memory loss.

Although some participants reported that a wide range of organisations and individuals – for example staff in banks and shops – acted in a sympathetic and understanding way, especially when they were informed that a person had dementia, many reported particular issues around interactions with people within their communities and wider society. In many cases, participants spoke about the condition leading to fear and awkwardness rather than stigma or discrimination.

Furthermore, participants had serious concerns about the lack of understanding and knowledge that some health and care professionals had about dementia, and the challenges faced by people living with the condition and their carers. Participants stated that whilst this was expected amongst the wider public, they felt that a more consistent knowledge, attitude and approach should reasonably be expected of people delivering health or care services. It was also clear that basic awareness training and more advanced training on dementia care would benefit professionals working in health and social care.

Dementia services lack the flexibility to effectively meet the needs of people living with dementia and their carers.

“The kind of care he needs is not the traditional care for an elderly person.” (Female Carer)

Many participants shared their experiences of health and social care, stating that there was often a lack of flexibility within the services they relied upon. This often created unnecessary stress and challenges for people living with dementia and their carers.

Frustrations were expressed about public, voluntary, and private care services, with a feeling amongst participants that they were expected to fit into the delivery patterns of formal services, rather than the services being designed to meet their individual needs. This was clearly evident in relation to making or attending appointments, assessments or in arranging medication.

Participants also highlighted issues around the physical locations of some services. This was expressed more often, though not exclusively, by participants living in rural areas, especially north and west Wales and related most often to services delivered in hospital settings.

People with dementia and their carers felt that some of their interactions with services, including assessments and care planning, appeared to be based on ticking a number of boxes rather than listening to them and understanding their needs. Participants also felt that even professionals that they trusted and valued were constrained by a bigger system or a lack of resources.

A common issue highlighted related to activities and other community support services which, where they were accessible, tended to focus on particular types of activities or delivery models – such as day centres, support groups or singing clubs. Several participants noted that the available support is not appropriate or not of interest to either themselves or to the person for whom they care.

Positive comments about services received often related to befriending services and respite that responded to the needs of the individuals. Whilst not all participants had received or wanted befriending, those who had spoke highly of the benefit that it brought, particularly when this was based in or near their homes.

A lack of co-operation between services creates unnecessary difficulties and barriers for people living with dementia and their carers.

“You can’t split a person up into social care and health care needs. The two need to go hand in hand.” (Female Carer)

Participants highlighted a lack of co-operation between the different professionals and organisations involved in their care, often as a result of institutional or professional boundaries.

These boundaries were often exacerbated by an absence of effective or timely communication between professionals and organisations, with many carers often feeling as though they were the linchpin holding everything together and providing the channel of communication between the different agencies involved.

As a result of these difficulties, participants felt that no one person or organisation took overall responsibility for the care and support provided. This led to some participants stating that they did not know who to turn to for advice, or in the event of a difficult situation or crisis, which caused them to feel that they had to take on a ‘care co-ordinator’ role.

Where the issue of responsibility or funding for care services was raised by participants, it was generally felt that discussions had been largely characterised by disagreements over whether the person’s care fell under the banner of health or social care. Some participants believed that people living with dementia were treated less favourably in this respect than those with other health conditions.

Participants experienced a lack of continuity of care due to visits from different professionals, who often needed to be briefed about the exact circumstances of the person they were meant to be supporting. This is a common complaint in relation to care services, but it was felt that it can be even more impactful for a person living with dementia.

The combination of the factors set out above results in significant variation and inconsistency in the experiences of people living with dementia and those who care for them.

Whilst some participants had experienced excellent services and support that had made a positive difference to their lives during a very difficult time, the experiences of others, across every aspect of their lives, were quite simply not acceptable.

There were significant variations in the support, information and response that people living with dementia and their carers received, with participants describing inconsistent knowledge, attitudes and competence of professionals and other staff within the services they encountered. People's experiences highlighted marked differences in the quality of care between different carers working for the same care provider, different GPs in the same practice and different wards in a hospital.

Participants also highlighted the inconsistencies around receiving a diagnosis of dementia, relating to a lack of expertise of GPs and other professionals and the length of time taken to receive a diagnosis.

There were also significant inconsistencies in the level of information and support that people felt they received, or had been able to draw upon. Many participants felt that they would have benefitted from more support, particularly at certain points, although some were happy with the support they had received.

Significant inconsistencies were also identified in relation to the availability of information. Many participants stated that they had found out about something important – a support group, an entitlement or a piece of advice, for example – by chance.

Participants who stated that they had received all of the information they needed, or had been well supported, often attributed this to a particularly helpful member of staff, local group or to individual resourcefulness - often on the part of a carer.

Action Required

The actions set out below need to be delivered over the next three years to address the issues that people living with dementia and their carers have identified as being most important to them.

- All primary care practices in Wales must become dementia supportive and be able to demonstrate that working practices reflect the needs of people living with dementia and their carers. In particular, this should include securing appointments, reminder systems for appointments and the sharing of information about people with dementia with their carers. The NHS in Wales, as part of their work with the Care Council for Wales on the Dementia Learning and Development Framework, must develop a clear set of criteria, based on the views of people with dementia and their carers, to clearly define the term 'dementia supportive'.
- In line with the NHS and Care Council for Wales' Dementia Learning and Development Framework, all clinical staff working within environments where people with dementia receive care, treatment or support must have the skills to ensure they have sufficient knowledge and understanding of dementia to respond to their needs in an appropriate and sensitive manner that protects their dignity and respect and minimises distress. Care and support plans for individuals must explicitly identify how an individual's dignity and respect will be maintained and their rights upheld and this must be subject to regular review and assurance by the ward manager.
- Carers of people with dementia must be fully involved, from the moment of admission to hospital to the moment of discharge. They should be accepted as part of the care team who can provide insight, facilitate communication (and informed consent) and ensure continuity. Carers must have a right to remain with the person they care for and support their care unless this is clearly not in the patient's best interest.
- Should a person living with dementia be admitted to hospital, their carer must be made aware of the support that may be available to them locally and their right, under the Social Services Wellbeing (Wales) Act, to a carers assessment. All hospitals must also make basic information available to people with dementia and their carers, in a manner that is meaningful.

- Where an individual living with dementia is admitted to hospital and does not have a carer, the hospital must ensure that they have access to effective non-instructed advocacy in the most appropriate form, e.g. independent mental capacity advocate, independent mental health advocate, independent advocate.
- Individuals should be able to receive an early diagnosis, if they so wish, that is delivered in a compassionate and sensitive manner.
- All public services in Wales should shape their workforce development plans in line with the national Dementia Learning and Development Framework to ensure that their staff understand that many of the people that they will come into contact with may have a form of dementia or be a carer, and ensure that the service that they provide, either personally or through actions such as providing appointments, proactively responds to challenges that individuals may face in accessing services as a result of living with dementia or being a carer.
- The work that will be undertaken by the newly created Public Services Boards as a result of the Wellbeing of Future Generations (Wales) Act must explicitly take into account the wellbeing of people living with dementia and their carers. Their needs must be fully reflected in the new wellbeing plans and the economic, social, cultural and environmental assessments that will underpin this work and in the national indicators that will be used to assess the overall wellbeing of the population in Wales.
- In establishing their new wellbeing plans, Public Service Boards must work with people with dementia and their carers, as well as the organisations that represent them, to promote positive images of people living with dementia and promote awareness and understanding of dementia and the issues faced by people living with dementia in their daily lives. This must include working to ensure that wider society, including businesses, promotes dementia awareness and a dementia friendly approach.
- Local Authorities and Health Boards, when providing or commissioning health and/or social care services, must ensure that care, support and services are delivered by individuals who have sufficient knowledge and understanding of dementia, as well as sufficient time, to respond to the needs of a person living with dementia in an appropriate and sensitive manner that protects their dignity and respect and minimises distress.

- Following diagnosis, people living with dementia and their carers should be proactively offered a single point of contact who can provide them with information and advice on the services and support available to them, such as independent advocacy, and can help them to secure access to these. This would be delivered most effectively through memory clinics. This system should allow an individual to access this support at any time and should also include annual follow-ups to ensure that individuals do not 'fall off the radar'. These follow-up contacts should also include the offer of a health and wellbeing assessment being organised on behalf of carers.
- Carers of people with dementia should have access to both peer support and specialist counselling to ensure that their own mental health and wellbeing is supported.
- People living with dementia and their carers must have timely access to a range of flexible befriending and respite services that directly meet their specific needs. The range of respite care options offered must reflect that which carers themselves have identified as being most impactful.

In addition, Wales must strengthen its focus on outcomes for people with dementia and their carers, at a strategic, service and, most importantly, personal level. Regular and ongoing review and reporting of achievement against these outcomes should be used to drive continual improvement at the heart of assessment of progress and achievement must be the voices of people living with dementia and their carers.

- The National Outcomes Framework that underpins the SSWB Act must be incorporated into the needs assessment process and used as a supporting framework to underpin wider contacts that people living with dementia and their carers will have with key contacts and the wider health and social care systems.
- Public bodies, working on a collaborative basis, should publish progress of delivery against these outcomes, clearly identifying areas where further progress is required and when this will be delivered. These progress reports should also be subject to formal receipt by the governance bodies of respective public bodies and reflected in their formal annual reports. Included within these should be a commentary on progress from local carers' organisations.
- Public bodies must ensure that they have in place robust and effective mechanisms to continually listen to people living with dementia and

their carers about what is working well and what is not working and be able to evidence that they have used this feedback to drive continuous improvement. They must be able to evidence that their assessments of progress reflect the views of people living with dementia and their carers.

Next Steps

Following the publication of this report, I will seek assurances from public bodies that they have listened, through me, to the voices of people with dementia and their carers and are taking active steps to implement the actions set out above. I will publish a summary of their commitments and keep under review the action that they are taking. However, I expect them to report directly to people living with dementia and their carers on the action they are taking so that as public bodies they are directly accountable to those they are there to serve.

As the Chair of the Ageing Well in Wales Programme, a collaborative partnership of organisations across Wales, I will also continue to encourage and work with others to implement action that promotes the inclusion of people with dementia within wider society.

We should all aspire to deliver the very best for those who are potentially the most vulnerable, and people living with a form of dementia and their carers are some of our most vulnerable – physically, emotionally and at risk of being excluded from so much that matters to them. Unless this is the life that you lead, it is almost impossible to imagine what it feels like. But we must do more than imagine, we must listen and act because the people who shared with me their lives know what needs to change and we must not fail them.

Findings

Section 1: Living with Dementia

Impact upon independence

A key issue discussed by the people living with dementia and their carers who took part in this research was the significant impact that a diagnosis of dementia and the subsequent progression of the disease has upon every aspect of life, leading to a loss of independence.

It was clear that this loss of independence can have a detrimental effect on an individual's wellbeing and quality of life.

Withdrawal

Participants stated that dementia can cause individuals to withdraw from society, highlighting a number of reasons as to why this might occur. In addition to self-imposed withdrawal as a consequence of practical difficulties, such as access to transport or because of particular symptoms demonstrated by an individual, withdrawal may also be the result of the response of the community.

“I stopped taking him because he was getting himself so wound up when we were doing the shopping that it was easier to leave him home, and I'd go and get the stuff and bring it back to him” (Female Carer)

For some, these issues are compounded by the fact that people living with dementia may look perfectly well. As a consequence, it is not always clear to people around them who do not know them, or do not know them well, that there is an illness that is triggering a particular form of behaviour.

“Because he doesn't look as if there's anything wrong with him, he just sounds as if he's behaving like a job.” (Female Carer)

Some people living with dementia, and the people who care for them, are comfortable in declaring the illness, which can result in a more positive reaction and greater understanding from those they are interacting with. For others, however, who are less comfortable sharing information about their illness, this can cause difficulties in certain situations, as it can make it difficult to explain what is happening, especially if the person with dementia can become upset if the condition is mentioned in front of them.

“[He] wanted to talk to a waitress the other day and he just couldn’t and the waitress was waiting for him and I couldn’t say ‘oh sorry, he’s got dementia’.” (Female Carer)

In many cases, as dementia progresses, it appears to become increasingly difficult to engage, either socially or within the community. In some cases, this leads to a self-imposed withdrawal to make life simpler to manage. In this respect, more people being aware of the condition and knowing how to respond appropriately would make a positive difference.

“She withdrew – but people didn’t know what to do to help either.”
(Female Carer)

Social Networks

There was a huge degree of variation in the impact of a diagnosis of dementia upon social networks. Some people with dementia had managed to maintain social contacts, whilst others had lost touch with family or friends. Others also reported that previously they had not had particularly close or extensive social networks and had therefore experienced no significant change in that respect.

One of the most frequent issues that was highlighted was a sense that many people still do not really understand dementia, including among close family and friends. This impression was also reported in relation to broader societal awareness, reactions of people within the community and the ways in which organisations such as banks and shops respond to people with dementia (see ‘Awareness amongst society’ section for further discussion of this issue).

“I think a lot of people are afraid of what he is going to be like...which hurts me big time” (Female Carer)

It is clear that the way in which individuals respond to a diagnosis of dementia is as unique as the progression of the disease itself. In some instances, friends and family took everything in their stride, gradually adapting themselves to the changing circumstances dictated by the increasingly life-limiting nature of the condition. In these cases, people with dementia and carers highlighted a positive response in their close social circles. Some comments suggested a belief that this was tied to being open about the diagnosis.

“It’s the other way round. All the people we know are very helpful and they all know about me now.” (Female with dementia)

“She’s got a really close group of friends...they’re all absolutely brilliant with her, really, really good.” (Female Carer)

“We have friends who come and take his books out and read with him.” (Female Carer)

In other cases, some of those who were formerly close to the person living with dementia – including close family members – were unable to deal with the impact of the condition, which led to a withdrawal from the person with dementia. Even where this wasn’t the case, some carers acknowledged that some family members and friends found it harder to cope, whether with the emotional impact or the practical implications or both. In a smaller number of cases, rifts had become apparent within families and in a very small number of cases, it was believed that some family members had sought to exploit the situation to their own advantage.

“As she got worse, I would say they avoided her.” (Female Carer)

“Oh yes, a lot of friends don’t know how to deal with him so they keep away.” (Female Carer)

“...the younger family were always too busy. My brother was awful...Just stayed away and let us get on with it.” (Female Carer)

“My younger brother struggled with it; manifested in him avoiding seeing her.” (Female Carer)

A few people in the early stages of dementia, as well as some carers, specifically mentioned not wishing to be a burden on their family, especially their children, with the belief that family members also had their own lives to lead. Others had moved home to be closer to family members, although in some cases this had taken place pre-diagnosis in response to a bereavement or another change in family circumstances.

“It’s really my family I feel sorry for, not me. I do, honestly. They’ve got to put up with so much, and they’re all so young, you know.” (Female with dementia)

“They’re loving and caring, absolutely wonderful, but you know they’ve got their own lives and family and everything.” (Female Carer)

Aspects of behavioural change and physical symptoms could also lead to a reluctance to go out on the part of either the person living with dementia or their carer.

The following quotes reflect these experiences at a range of different stages of dementia.

“She’s got no confidence. She is afraid of getting lost.” (Male Carer)

“We can’t go to half the places we used to because she won’t go in the dark now, started this year. So I’m limited.” (Male Carer)

“Because of this toilet thing, I’m very reluctant to take him anywhere.”
(Female Carer)

In addition to the limitations placed upon people’s ability to be independent as a consequence of dementia, additional complications around independence could be created by a reluctance to ask for the help that is available, whether from family and friends or from formal services. Whilst on the one hand this can be viewed as people wishing to maintain their independence on their own terms, it can also impact upon their ability to lead a more fulfilling life with some appropriate support.

“People offer these things – if ever you need anything – but you don’t, you just cope.” (Male Carer)

Transport

Access to appropriate transport is an important issue in facilitating the independence of an individual living with dementia and their ability to continue to engage in the activities they enjoy. In particular, having to give up driving was a significant marker for many who often struggled to adjust to the impact that this had upon their ability to live their life in a way of their choosing.

“I was told I can’t drive, the last four, five months; doctor told me not to try. Since then, I’ve been very, very bad. In other words, I feel I’ve gotten much, much older because I can’t drive.” (Male with dementia who linked this decline to not being able to go out and play bowls and see people that he knew)

“I’ve always attended church but I’m afraid I don’t go as much now.”
(Female with dementia)

In some instances, the impact of access to appropriate transport upon health was highlighted, as people in the earlier stages of dementia felt precluded from staying active and enjoying social interaction. In addition, lack of access to appropriate and/or reliable methods of transport made it difficult to access services, such as appointments with healthcare professionals, attending day

centres or participating in other forms of activity designed to provide social interaction and cognitive stimulation.

“Luckily for us, I’ve driven all my life and done all sorts of different things. Because there are people that we know of in the Forget-Me-Not choirs who’ve got no means of transport now and public transport isn’t brilliant and taxis are an arm-and-a-leg job.” (Female Carer)

For an individual living with dementia, being unable to go out and about at a time of their choosing also increased a sense of dependence upon their carer. If their carer was unable to drive or had difficulty in ensuring safe access to a vehicle for the person with dementia, this could create further limitations upon the ability to go out.

“I miss going out on my own. It’s got to be with [husband] or my son, I can’t do it.” (Female with dementia)

“I used to take her out at least once a week. Go shopping and a bit of lunch, but as I’m getting older, I can’t manage it any more. I can’t get the wheelchair in the car.” (Female Carer)

People in the early stages of dementia sometimes struggled to accept this sense of dependence upon other people to provide transport.

“I can only go if she’s taking me out in the car.” (Male with dementia)

Husband carer: **“It’s the [not] being able to go out when you want with who you want.”**

Wife with dementia: **“That’s hard, that is.”**

In this respect, the Bus Pass Plus One scheme was mentioned positively, but only by a very small number of those spoken to, as awareness of the scheme appears to be extremely limited. Bus Pass Plus One, for those who felt comfortable using public transport, enhanced the sense of independence as the person with dementia could travel with anyone of their choosing and was not reliant upon a primary carer.

“...the Bus Pass Plus One, by allowing my daughter to come with me rather than my wife, I feel more independent.” (Male with dementia)

“You can always ask for concessions for a carer. I’ve even got a Bus Pass Plus One carer, so I can take anybody on the bus with me as my carer, because I could go somewhere and get lost.” (Male with dementia)

“That’s totally new to me, about Bus Pass Plus One.” (Male with dementia responding to a focus group discussion)

There was significant variation in the way in which the issue of giving up driving was handled by people with dementia, their carers and any health or social care professionals involved. Some people gave up driving voluntarily; some had it suggested that this was for the best; some had had their licence withdrawn. One carer received a gentle recommendation that they should take over as much of the driving as possible over the course of the subsequent twelve months, in order to make the transition seem more natural, a piece of advice that they subsequently valued. However, that advice was based upon a medical evaluation of the person with dementia and would not be appropriate in all circumstances.

“...when we went there [memory team], they took me to one side and said it’s unusual for * to still be driving...but from what I’ve seen of him...I can say I think he’ll be alright, but don’t push it, if they do give it you for another year, try and slowly take over the driving and that was a really, really good recommendation.” (Female Carer)

“But he surrendered [driving licence] because the doctor had recommended he did it. But there again, they could have said, well you could have gone for the test.” (Female Carer)

“I have been advised not to drive but I don’t drive because I would be frightened.” (Female with dementia)

“Because the DVLA last year, they took my driving licence in to the medical centre last year, and then they sent it back and said I had a year’s grace, and then this year they took it in April, and I’ve only just heard now they want me to do this assessment before they’ll give it back.” (Female with dementia)

Some people in the early stages of dementia were offered the opportunity to take a driving assessment; others at an apparently similar stage of the disease had not been made aware that a driving assessment was an option. Some of the people living with dementia who took part in this research felt aggrieved at having to surrender their licence and would welcome the issue being discussed and handled in a more sensitive manner.

“I must admit, I would like to be able to take the test and see exactly where I struggle with it.” (Male with dementia responding to discussion of the driving assessment in a focus group)

The impact of decreasing independence upon levels of social interaction was also recognised and some participants mentioned the impact that loneliness had upon their experience because they are unable to go out on their own.

“But I get lonely, that’s the hard thing, the loneliness.” (Female with dementia)

Activity, Meaning and Purpose

Continuing to engage in activities, whether ones that people had previously enjoyed or new ones that had been recently taken up, can be seen as essential in providing meaning and purpose in life and helping people living with dementia to maintain a sense of identity.

Cognitive Stimulation

“The thing is that a lot of people don’t realise that the PWD, that’s me, Person with Dementia, does have cognitive and intellectual needs as well.” (Male with dementia)

A small number of people living with dementia had had access to cognitive stimulation courses that were considered highly beneficial. However, in at least one case, this was a pilot that had not necessarily been rolled out further. There were also questions about what happened when these courses finished, particularly when no follow-up was available, and what the impact of losing an activity might be upon the person with dementia. In some cases, people who had been diagnosed with dementia at a relatively early stage took the decision for themselves to engage in puzzles and other activities that would stimulate their brain.

“I thought I can either stay here and just let things go by or we can do something about it. So I started doing lots of quizzes and puzzles and then I took up sewing to make my brain work.” (Female with dementia)

“It was so much fun, that fifteen weeks.” (Male with dementia, referring to a cognitive stimulation pilot)

Specialist dementia-related groups

Singing with the Brain groups, Forget-me-not choirs and memory cafés were mentioned by a large number of participants, both carers and those with living with dementia, and are among the most widely available forms of activity. Many of these groups and activities are provided, or supported by third sector organisations. These experiences were largely favourable, although some participants felt that they needed them more as the dementia progressed, rather than in the early stages.

“I know everything isn’t perfect up there, but I do have a very enjoyable time.” (Male with dementia)

“When we’ve been to singing, or a concert, or something like that, [wife’s] mood is considerably better altogether, so things like that do help.” (Male Carer)

“These memory cafés I go to with [Alzheimer’s Society staff] is an absolute godsend for me, because when I first came, when we moved to Wales, I didn’t want to go anywhere.” (Male with dementia)

Some carers found that they also benefited from coming into contact with other carers and also the organisers, as they were a source of information, advice and support.

“Armed with these little nuggets [from leaflets]...I got to understand it, and not only that then, by attending different cafés and seeing other people, meeting other people and talking about it with them, and they were telling me about their patient, or their wife, husband, whoever it was, and then I would exchange my experiences and then you would understand, they understand a bit more about it.” (Male Carer)

Some participants, however, found that these activities were not always best suited to their particular circumstances or the likes and interests of the person with dementia. Over-subscription for services or a requirement for a person’s carer to be present, as well as issues around transport, were also highlighted as barriers to access.

“There was nothing to get you going and it was from ten until three.” (Female Carer)

“Some [day centres] bore me to death.” (Female with dementia)

“How am I supposed to get him there if two men cannot get him off a bus, how do they expect me to do it?” (Female Carer)

“All these nice things, the carers have to go with them. So where, when, does the carer get a respite?” (Female Carer)

Sometimes the activities that were available through services were not considered appropriate or relevant to a particular stage in a person’s dementia. Equally, the importance of being able to be with people at a similar stage of dementia, of a similar age, or of the same gender was also noted by some.

“...we find, one of the biggest things we’ve found is that there isn’t enough for early stage Alzheimer’s – to keep motivated to keep things going and being innovative and forward-thinking.” (Female Carer)

“One of [the] things I found about going to the day centres was that she was coming home unhappy because she hadn’t been kept busy enough.”
(Male Carer)

“...no stimulation from a male point of view.” (Female Carer)

Activities and respite

Activities could serve a dual purpose of not only keeping the person with dementia active and engaged, but also, in some cases – where the activities took place with a person or people other than the primary carer – the carer was provided with some respite where they could have time for themselves or attend their own appointments. As noted in ‘What would make a difference’ below, respite care that took the form of admission to a residential care home or a hospital unit was viewed less favourably. Some carers were critical of the fact that spending time outside the home with the person with dementia, attending a dementia café, for example, was considered as respite, even though they were not actually apart or able to get on with other things that required their attention.

“One thing I think is totally underestimated how much it helps, is the befriender service. Because the fact that the befriender can come along and either stay in the house with the person while you go out and do things or takes the sufferer out and allows you to get on with things in the house.” (Male Carer)

“Yes, it’s one of the things of my life now. I really look forward to that [the befriender]. I’m obviously, I won’t say I’m a burden on my wife, but there are times when she needs to have her own home to herself, to be with herself and do things.” (Male with dementia)

“Respite I thought was being totally separate from [husband]. But respite is going to the choir with [husband] because you’re out.” (Female Carer)

Befriending services were often favourably mentioned and participants with dementia who had a befriender appeared to particularly enjoy the engagement that this offered. They felt comfortable, confident and often able to share personal information that they didn’t wish to share with anyone else.

“To me, my befriender is my lifeline.” (Female with dementia)

“I go every week with...the befriender. Absolutely fantastic. We have such a laugh...” (Male with dementia)

“It’s friendship – she [befriender] understands problems, most people

don't." (Female with dementia)

However, a small number of participants experienced difficulties where the befriender was not the same person every week or where a befriending service stopped. Some also found it difficult to access befriending services.

"You look forward to that person coming, and then they don't come anymore." (Female Carer)

"I know that the social worker we have, I had a phone call the other day, because I asked if we could have a befriender service and it came back in the end, I had a phone call from them saying you don't match the criteria...and I think the reason why we don't fit the criteria...is because our daughter lives with us." (Male Carer)

Reluctance

Some participants recognised that they had experienced problems where activities were provided but the person with dementia was not willing to engage with them, placing additional pressure on the carer to keep them occupied. Occasionally the activities available didn't appeal to the carer when the carer also needed to be in attendance. A number of carers recognised that it was difficult to know what to do and where to go when they were having to think of activities on a daily basis.

"I think the facilities are good, the problem I've got is that my husband doesn't want to know, he won't go to any groups...he thinks he can cope on his own..." (Female Carer)

"We need a break and it is very difficult to arrange, not necessarily because of a lack of places to go, but her unwillingness to go there." (Male Carer)

"I can tell you now, there are an awful lot of good garden centres with cafés round here. I think we visited them nearly all!" (Male Carer)

"...he's never been a person for hobbies, so I find it very hard to fill the day with things. I do try and get us out every day, especially for half an hour's walk." (Female Carer)

"There's loads of stuff we could do which [wife] doesn't want to do or I don't want to." (Male Carer)

Likes and dislikes

The value of activities for people with more advanced stages of dementia was also clear. Conversations held with people with dementia, including those in the more advanced stages of dementia where communication had become more difficult, demonstrated it was possible to discern likes and dislikes that meant activities could be organised accordingly. Whilst these preferences might not be consistent over time, it is possible to establish likes and dislikes and create opportunities to engage in relevant activities.

“I like to play games before I get too old, bowls and that.” (Male with dementia, unable to play to bowls because of lack of transport)

“I love playing dominoes. I used to play crib in my younger days but they don’t play it here.” (Male with dementia)

“[Discussing flower arranging] You’ve never liked that? There you are then. I’ve learned something today.” (Activities Manager in a care home)

Impact Upon Carers

“I think carers put up with an awful lot and they are too busy to say anything.” (Male Carer)

Participants caring for people with dementia spoke openly and honestly about the practical and emotional impact of providing care and the non-stop nature of the caring role, especially if the condition was impacting upon sleeping patterns, for example. This was in addition to the burden of finding information, advice, resources and support highlighted in the ‘Information and Advice’ section below.

“The worst thing for me, I think, has been that I hadn’t appreciated how much it took the stuffing out of me.” (Female Carer)

“It’s stressful, it’s a 24/7 job and I think the loss of your life, really, especially if you feel you’re still young enough to have a bit of a life...I can’t leave him at all because he gets anxious if I’m away for just a couple of minutes.” (Female Carer)

“I’d like social workers to actually recognise that whilst my parents obviously have needs, carers have needs as well...” (Female Carer)

“It’s the hardest job I have ever done...because it never stops.” (Male Carer)

Whilst many of the carers who participated clearly felt under considerable pressure, many were nevertheless demonstrating significant levels of resourcefulness in dealing with the circumstances in which they found themselves.

“I think it shows your resourcefulness.” (Female Carer)

Practical impact

“And that bothers me, that they seem to have to get to that breaking point before anything’s done and it should be all in place before it happens.”
(Female with dementia)

One issue that arose for carers, which is reflected in the sections on formal services and information and advice below, is the extent to which they feel responsible for making all sorts of arrangements and following up on meetings and appointments. This is reflected in reports of the time spent contacting different agencies or a complete lack of support.

“I went to a meeting, they were doing something up in [Mum’s care home] about dementia and I was listening to one woman there and she said she could get no help whatsoever, she had to practically beg and she was always on the phone.” (Female Carer)

“You’re constantly on the phone trying to sort things out.” (Female Carer)

Some carers felt they would have benefited from practical support and advice, or some kind of training, to help them deal with the challenges presented by the condition.

“At first, we got it all set up and it was really stressful and I didn’t realise how stressful it was, and she wouldn’t go one day, and I still had absolutely no training, no support.” (Female Carer)

Some carers also spoke about feeling less able to cope as the disease progressed. The importance of support was acknowledged, especially where it was lacking.

“I just came to a point where I didn’t know what to do.” (Male Carer on his wife’s admission to hospital)

“We just seem to go from one crisis to another.” (Female Carer)

“All been a bit of a struggle, all on my own back, I’ve had to do it all.” (Female Carer)

Physical impact

Some carers acknowledged that the responsibilities of caring for a person with dementia left them less able or less likely to prioritise their own needs, including their own health conditions. In addition, the physical impacts of caring are well known, particularly in relation to a lack of sleep or lifting and carrying, for example.

“You don’t have time to be ill.” (Female Carer)

“Because you just struggle on; when you’re in the situation, you don’t think about yourself.” (Female Carer)

“At this stage I am managing. It isn’t always easy. I get very tired.” (Male Carer)

“But it’s wearing, trying to look after yourself and another person and cope with everyday stuff. You can’t really have a minute in the day when

you're not thinking.” (Female Carer)

“I've had three heart operations, going back, so it is hard on me, puts a lot of stress on me at times, it can do.” (Male Carer)

“While he is getting older and worse, I am getting older and I have health concerns of my own.” (Female Carer)

Emotional impact

A number of the carers who participated spoke openly about the emotional impact of caring and the ways in which it had changed the nature of their relationship with the person with dementia. Some also highlighted the difficulty of controlling their emotions given the intensity of the experience.

“With the cancer, I felt I could deal with that – which I have done. But it is the dementia that really got me.” (Female Carer)

“But you don't like saying to other people, because you think everybody cares about other partners. But I just want to come and say, I don't care anymore. I've just had enough. It takes over your life completely.” (Female Carer).

“My Mum is on my mind 24 hours a day really. You function, but it's always on your mind.” (Female Carer)

“...it was either I was going to hit him or the coffee had to go and I just got the cup and I just went ‘psh’.” (Female Carer)

“I'm afraid of something happening when I'm in that brief time when I don't like him – that sounds awful, doesn't it?” (Female Carer)

Peer support

For some of the carers who participated, receiving support from carers who were going through a similar experience was just as important as receiving formal support. Even though some of these carers were still enduring very difficult times, the overall sense was that peer support created a coping mechanism that was not evident in conversations with those who were not involved with groups, whether out of choice or because there was nothing available to them.

However, for working carers, support groups are not always held at accessible times and for others they may be held in locations they find difficult to access,

especially where they are reliant on public transport.

“There’s nothing to be embarrassed about because everyone in that room has the same feelings and the same things going on.” (Female Carer)

“But the biggest, biggest, biggest support I think you get is from other carers, because they know what it’s like and this is one of the problems, is being able to speak to other carers personally, so the only time I can do that is when [husband] is at the day centre, really.” (Female Carer)

“Support groups are great, but they’re usually in work time or they’re at inappropriate times like six or seven o’clock at night.” (Female Carer)

Awareness within society

In general, participants reported that they felt societal awareness of dementia had improved, especially during the last two or three years. This was particularly marked among carers of people who had been living with the condition for a longer period of time.

However, many participants still felt that this increased awareness was not necessarily translating into improved understanding and knowledge among either the general public or professionals who have contact with people living with dementia. A number of carers commented on the lack of understanding demonstrated by family members, including relatives who themselves had a background in health or social care.

“What would get me, this particular [relative], she’d been a sister in the hospital and...she’d ring up and say ‘Is there any improvement?’ [sighs]. He’s not going to improve.” (Female Carer)

When asked whether there was a stigma attached to the condition, many preferred to speak in terms of fear and a lack of understanding of dementia, rather than specifically a stigma. However, others also suggested that there was a large degree of ignorance that still needed to be tackled.

“I think a lot of it is ignorance as well, because there’s, you can’t say you don’t know somebody who’s got dementia. It’s in their family. If it’s not in their family, it’s a friend, it’s a neighbour. There is somebody that they will know at least, more than one, with dementia, and they know nothing about it, and that to me is purely ignorance. They don’t want to know. It hasn’t happened to them, they aren’t interested.” (Male with dementia)

Everyday life

Participants discussed the ways in which the level of societal awareness directly affected their interactions and experiences of doing everyday activities, such as going shopping, catching the bus or going to the bank. Again, these represented a mixture of both positive and negative experiences, and also tended to emphasise the fact that openness about the condition could make a difference.

There were significant variations in people’s experiences with similar types of organisations. This indicates how much of the experience of living with dementia in Wales is down to individual attitudes and responses, a theme which will be developed further in the section on relationships with

professionals below.

“I think there is greater awareness of it now.” (Male Carer)

“I think it’s only recently now that people are more aware of things. In shops, public places, hospitals.” (Female Carer)

However, many participants reflected that although people had become more aware of the condition, this did not necessarily mean that they had a deeper understanding of the disease or its effects.

“Everyone has heard the word dementia, but no-one understands it.”
(Male with dementia)

“That I thought was worrying, he just thought [dementia] was repeating.”
(Female Carer on family friend)

“I think it’s better, it’s got better and is getting better, because of the publicity and, sadly because most people know somebody, even if it’s only the lady down the end of the road.” (Female Carer)

To give an idea of how unique people’s experiences can be, one carer found banks more supportive than supermarkets whilst another experienced difficulties in transferring a current account despite having power of attorney. Such experiences demonstrate how different an experience can be even when dealing with the same type of organisation. Many of the participants shared stories about situations that had occurred while they were out that gave a clear indication how important the attitude and response of an organisation’s staff can be to resolving situations with a minimum of fuss and discomfort, such as a person with dementia wandering in a shop. One carer, who alerted store security because her husband with dementia had wandered off, reported being asked whether he was likely to have thrown himself in the river.

“They know he’s got it and they are absolutely wonderful.” (Female Carer on supermarkets)

“Then there have been times when I have to take longer in a changing room with Mum when she’s trying something on and yeah, there’s difficulty then because they don’t necessarily let you in the disabled changing room.” (Female carer)

“She gave him time [in the bank] and she didn’t have to.” (Female Carer)

Several people in the earlier stages of dementia also reported that they had noticed being followed by store security and one even reported having their bag searched because they were ‘behaving suspiciously’, when they were, in fact, simply trying to remember what they had come in to buy.

“I’ve had security guards following me round shops.” (Male with dementia)

People in the early stages of dementia also spoke about struggling with packing in supermarkets where they felt as though they were being rushed.

“That’s when you try not to panic, you’re holding up the queue, they’re asking for money, I’ve got to pack my bags.” (Female with dementia)

Acceptance

Participants also highlighted issues around the response of members of the public to people living with dementia. Consequently, many of the participants in the research reflected that there were still issues around acceptance of the condition, something they often linked to continuing levels of ignorance. For some, this reflected the fact that many people with dementia do not necessarily look as if there is anything physically wrong with them.

“You’ve got people looking at her up and down as if to say why are you parking in a disabled [bay]?” (Female Carer)

“I don’t think society is very accepting of it.” (Female Carer)

“It confuses other people as well. Why is he acting like this, sort of thing, because he looks so good.” (Female Carer)

Fear

Many participants believed that there was still a fear of the condition, and they often traced this back to a perceived lack of understanding. For many carers, this fear was relevant to both society as a whole and to family members and friends. For some, this apprehension was explicitly linked to a fear of somehow upsetting the situation or making the person with dementia feel worse and/or having a negative effect on their behaviour by saying or doing ‘the wrong thing’.

“I think people are afraid.” (Female Carer)

“There is this fear; she doesn’t like to come unless I’m there.” (Female

Carer referring to family member)

“People, when they realised he would still sit and watch the boxing, they were better.” (Female Carer)

For some participants, there was also recognition that they themselves had lacked understanding of the condition and its implications before they found themselves in the position of living with dementia, or looking after someone with dementia. This was complemented by a belief that it was very difficult, if not impossible, to understand what it was like to live with dementia unless you had direct personal experience of it.

“I’ve seen it now from both sides. My father had dementia so my Mum was his carer...now I know more about it, I deeply regret that I didn’t help my Mum more but that was purely through the fact that I didn’t understand what was happening.” (Male Carer)

“Unless you’ve lived with somebody, or you’ve had a personal relationship with somebody, you haven’t got a clue, you don’t know what it’s like.” (Female Carer)

“People don’t appreciate how difficult it is to live with a disability of any kind unless they’ve had experience of it. You feel sorry but you’ve no idea what’s involved unless you actually live with it.” (Female Carer)

Embarrassment

Some participants commented on a sense of embarrassment attached to the condition, in some cases generated by specific behavioural traits of the person with dementia, but also on a more general level. In some cases, people also felt embarrassed on behalf of the person with dementia.

“They don’t know what to say.” (Male Carer referring to acquaintances)

“Some people find it embarrassing as well, don’t they?” (Female Carer)

Some of the people with dementia who participated expressed a strong preference to be open about their condition, finding social interaction in the community less difficult or awkward if the condition had been acknowledged. Two participants suggested wearing a pin or label badge that would identify them as needing a little more time or some assistance. However, this may only be appropriate for those who are comfortable being open about their diagnosis.

“I prefer people to know I’ve got it; then there’s no atmosphere then.”

(Female with dementia)

“[My husband] is not afraid to tell anybody that he has dementia, which has been a real plus I feel.” (Female Carer)

Others, however, recognised that many people still did not feel comfortable or confident in telling people that they, or the person for whom they care, have dementia. Some of the ways in which it was reported the information was shared with other people also suggested a degree of embarrassment, such as whispering to people in a supermarket queue or a waiting room in order to explain what was happening. However, it was suggested that many people become more accepting or supportive once they know what the situation is.

“I have found talking to other carers that a lot of the time their partners don’t want to say that they had dementia. It’s kind of a hidden thing.”
(Female Carer)

“I think once you say that [the person has dementia], people are quite supportive.” (Female Carer)

“I find it better if you say something, tell people, like when we’re getting in a mess at the checkout and things like that, I’ll say to the person, and luckily he’s quite hard of hearing as well...but I’ll say he’s got Alzheimer’s, and in fairness, most people in shops are ‘oh fine, don’t worry’.” (Female Carer)

Dementia and work

Participants with early onset dementia highlighted that giving up work had also had a significant impact upon their lives, particularly upon their social networks. The way in which their departure from work was handled following their diagnosis was also viewed negatively by a number of these participants, suggesting that there is a need for this issue – as with driving licence withdrawal – to be handled in a more sensitive way.

“I was finished when I had my diagnosis [inaudible] said I wasn’t going to work anymore. I didn’t go through a very good final leave with them and I was working in a pharmacy so they should have been more understanding.” (Female with dementia)

“Yes I was [working], with the civil service. I’d been there for over 25 years and my condition deteriorated, I didn’t know what it was but they were very quick to boot me out which I didn’t take to.” (Female with dementia)

Section 2: Services and Support

Diagnosis

Whilst participants were invited to share their experiences of living with dementia in Wales, they were also encouraged to discuss what was of greatest importance to them. As a result, many conversations focused upon interactions with health and social services. One issue of particular prominence was diagnosis.

Participants highlighted that the process of receiving a diagnosis had proven to be problematic for a number of reasons. These included the length of time taken to receive a diagnosis, the attitude of some of the professionals involved in the process and administrative errors. It was not unusual for participants to report waiting several years for a final diagnosis.

“Because you hear in the national news, they say the facilities for people with dementia are very poor and there’s very little diagnosis, very late; well it’s the exact opposite with me.” (Male Carer)

“Took eight years to get diagnosis, back and forth to our GP and clinic... like knocking your head against a brick wall to get the final diagnosis.” (Female Carer)

“I’ve been diagnosed with dementia for five years, I think, now. It took nearly a year and a half before I got my diagnosis and it was incorrect and I had a second opinion, so all in all it took a year and a half.” (Female with dementia)

“So the diagnosis, I had to ask for, because nobody actually said to me ‘He’s got vascular dementia’.” (Female Carer)

“So I had to make an appointment to go back to the doctor again, and the doctor said ‘you didn’t turn up to the appointment’ – then she looked at the screen and realised the letter had been sent to the wrong person.” (Male Carer)

“In the end, the consultant said it was all in his mind. Well, I said the F word at him and left. And I said to [husband], it’s totally wrong, but if they can’t help us, we’ll help ourselves and carry on as normal as long as we can. And then he got recalled.” (Female Carer)

For some participants, the process worked exactly as it should. Several mentioned that their GPs had been 'brilliant' and knew exactly what to do, such as conducting basic assessments and providing referrals to the memory clinic.

“That particular GP had come across it – knew exactly where the form was.” (Male Carer)

In addition to problems identified in relation to services, in cases where individuals weren't willing to admit, or had failed to recognise, that they were having problems, some participants had experienced difficulties in persuading the person they were caring for to attend the doctor. This was reflected in recollections of difficult experiences setting up appointments, because the surgery wanted the individual concerned to make the appointment themselves, or awkward situations where the person who had raised the concern was effectively forced to explain what they thought was wrong in front of the person who was subsequently diagnosed with dementia.

“When we approached the doctor, it took a lot to get to the doctor. In the end, when we approached the doctor...the doctor said no. The doctor said, you've got to tell her she's got to want to come and see me.”
(Female Carer)

“He [husband] just sat there, really cross with me.” (Female Carer)

Some participants spoke of a lack of recognition of the condition on the part of health professionals, or of inappropriate responses that contributed to the long waiting time that some participants experienced before receiving a diagnosis.

“Can remember [Dad] saying in the end the doctor sat on his desk and said 'well, what do you expect me to do?' Dad said 'well, that's what I've come to see you for; I don't know what's available, I don't know what's wrong with her. I want some help'.” (Female Carer – doctor prescribed breathing exercises)

“My doctor didn't have a clue what my husband had.” (Female Carer)

“My doctor was trying to tell me it was me – indirectly, you understand.”
(Female carer who then took decisive action) **“...took three visits before I said 'I'm not happy with this, either do something about it or refer me to another doctor or send him to the memory clinic'. At that point I was listened to.”**

A small number of participants even indicated that receiving a diagnosis was a relief, despite the nature of the illness, because they had struggled for so long to have the symptoms being experienced acknowledged at all.

“It was a relief for [wife] to get the diagnosis.” (Male Carer, to which his wife responded) **“Because I thought I was going round the twist.”**

The way in which a diagnosis was delivered also had an impact upon participants.

“I thought we’d be put back in an appointment and sat there and told about it, really, not to have to read it in a letter.” (Female Carer, who had gone to receive diagnosis with her mother to find the scans that had been taken at a different location had not been sent through)

“...way delivered was horrendous – consultant said Dad had dementia and gave Mum a leaflet to take away... That was it.” (Female Carer)

“Mum went to the memory clinic for five or six years before the actual diagnosis came through, and as soon as the diagnosis came through, they said ‘Here you go, here’s a pack...’ but nobody to say [this is what you need to know].” (Female Carer)

Information and advice

It was clear from participants' experiences that the availability of information and advice is highly inconsistent across Wales. Whilst some participants felt that they had been almost overwhelmed by the quantity of information that they received, others felt that they had been left to piece everything together by themselves. Where people were in receipt of information and advice, they recognised significant benefits, whether this was from reassurance, emotional support or practical help.

“They were throwing dementia stuff at me that I didn’t blooming well need.” (Male with dementia)

“They [carers’ centre] helped us fill in all the Power of Attorney forms.” (Female Carer)

Carers stated that in many cases they would prefer to be able to speak to someone, rather than simply being handed a leaflet. In a small number of cases, information had been provided in a format that was difficult for individuals to access.

“You get presented with this pack that’s really thick, that you’ve got to wade through, from all different organisations, and at the time what we’re doing is we’re just getting on with life. Actually at the time what we needed was somebody to say ‘We’re going to come and see you and this is what you need to understand’.” (Female Carer)

The importance of peer support and information exchange was also highlighted by participants.

“I’ve found we have to get ideas from everybody else how to help us live with our life, and the same with the carers, how to cope with us and how they cope when we’re stressed, if you see what I mean.” (Female with dementia)

The danger of making assumptions

In some instances, carers felt that professionals [and also other carers and third sector staff] were making incorrect assumptions about their existing level of knowledge and that this was hindering the flow of relevant information. Participants stated that carers groups, day centres and dementia cafés were a valuable forum for the exchange of useful information and advice, whether this related to information about entitlements or tips on dealing with particular

aspects of behaviour that carers were finding problematic.

“Because people think you know these things and you don’t unless you’ve dealt with somebody.” (Female Carer)

“Well, I mean, she [at the memory clinic] never once told me, which I found out later, don’t argue with him...I would try and correct him and he would get more and more nasty. It’s only now that he’s died and I’ve spoken to other people, they’ve said it’s easier to agree with them. Don’t upset them. I was never told this.” (Female Carer)

“But that person has never been in the position of having...to find a care home.” (Female Carer)

Relying on chance

A large number of participants reported that quite often they had found out useful and pertinent information by chance, rather than being provided with information and advice in a systematic way. Often this took the form of a passing comment in conversations, sometimes in carers groups but also in a wide range of other contexts, including supermarket queues. For one participant, it was seeing a road show in a supermarket car park.

“I found it in [supermarket] car park – an awareness programme.” (Female Carer)

“Unless you actually ask about these things, or speak to the right person, either by luck or you seek them out, you won’t get anything.” (Male Carer)

“A lot of it is word of mouth.” (Male Carer)

“It was only this we found through a little notice which said Memory Loss Café.” (Male Carer)

Available services

A particular issue for a number of participants was that they simply did not know what services were available to them in their local area. When some had made enquiries to Social Services as to what was available, they were asked what they wanted – a question they felt unable to answer without some knowledge of what might actually be available.

“We don’t know what is available. We don’t know what to ask for.”
(Female Carer)

“You phone social services up – I did this a couple of years ago because I knew * had got dementia, I thought right, let’s see what is available for the future. I didn’t want any care then – I didn’t want anything. ‘Oh, well, we can’t do anything for you now until you tell us what you want’. Well, it’s the first time I’ve been in touch with Social Services, I’ve never had any dealing with them before – how do I find out what is there?” (Female Carer)

“What do they actually do? What can they provide for you? What can they help you with? Don’t know.” (Female with dementia on Social Services)

Key point of contact

“It’s now getting a little bit trickier, a little bit more of a challenge, and now is the time I would really appreciate someone I could turn to and say, right, what do I do now?...There is nobody!” (Female Carer)

The lack of a key point of contact was reflected in many of the comments of carers who felt that they did not know, and had not been told, who they should contact if they were experiencing issues that they wanted to discuss. As highlighted in the section on formal services below, some individuals found enormous benefit in one particular professional, whether that was a GP, Community Psychiatric Nurse, social worker, or someone else acting as a key point of contact. However, there was no consistency in that professional’s role and often the offer seemed to be driven by the personal qualities of that particular individual. Many simply felt that they did not have a single point of contact to approach for information and advice.

“Who do I turn to? I really didn’t know.” (Female Carer)

“I expected a professional to be giving me the expert opinion, telling me what the options were. I wasn’t getting that and I didn’t know I wasn’t getting that until the event had passed and now I’ve done a lot more research.” (Female Carer)

“You’re ringing around and around – saves all that stress when you’ve got the number.” (Female Carer)

“On one hand, we get bombarded with information. There are all these websites, there are all these organisations, there are all these people offering information, but there isn’t one source that starts you at the beginning and takes you through.” (Female Carer)

In some cases, there was an acknowledgement that information is available, but that it can often be difficult to find. This is especially true for those who are not computer-literate, or do not have IT available to them, given how much information is now only available online.

“What needs to be done for dementia carers is the fact that they needed to be guided more and the guidance is out there, but they’ve got to be guided to how to get the guidance.” (Male Carer)

“There’s too much computerisation for the elderly and they’re expected to be able to cope.” (Female with dementia)

“If you want to look for it, it’s out there. It’s not always that well advertised.” (Male Carer)

A small number of participants had benefited from specific courses that focused on providing advice on financial and legal issues. However, relatively few of the participants had attended such a course as they were either held only in certain areas or were not advertised effectively. One carer reported being unable to attend as the location was inaccessible by public transport.

“I went on the internet and then I found out that there were, Alzheimer’s [Society] did a course for dementia carers that told them, and I went on a six week course and it was very, very helpful.” (Female Carer)

The frustration of having to find things out without assistance was obvious, as was the lack of advice on practical issues.

“...instead of having to rummage around and seek everything out.” (Female Carer)

“In my case I tended to do everything myself because I find people don’t seem to volunteer much information.” (Male Carer)

“I think Dad got a little bit frustrated...and nobody told him how to deal with her.” (Female Carer)

Financial information

The experiences shared by carers highlighted that finding out information about financial issues, ranging from welfare entitlements to Continuing Health Care, can be more problematic than finding out about other services. In some instances, people weren’t sure whether or not they would have to pay for a service.

In one case, for example, a family was not informed that they would be required to contribute to respite costs until after they had accessed the service.

“I talked to the lady at [the day centre] about having to pay; she said you’ll be surprised what you can get funded. I thought nobody’s come along and told me I can get much funded.” (Female Carer)

“That [financial information] was a big vague. You didn’t seem to get anything unless you find out by chance.” (Female Carer)

“If it wasn’t for that talk [by benefits officer, organised by the CPN], we wouldn’t know anything.” (Male with dementia)

“Somebody came from the [local authority] finance department to deal with all, discussed it with me at home – a wonderful person, absolutely lovely – went through everything with me after Dad died, said what Mum was entitled to, not entitled to and what she’d get and it worked like clockwork.” (Female Carer)

Other forms of entitlement

From discussions with participants, it became apparent that there is very limited knowledge about certain entitlements. Participants living within different local authorities, but within the same health board area, had very different levels of knowledge about the services available to them. In particular, it was clear that many participants were unaware of Bus Pass Plus One (the benefits of which are discussed above in the ‘impact upon independence’ section), the Carer’s Card or the Council Tax rebate available for people with dementia.

“There should be a room that they would take you into and explain everything that you’re entitled to.” (Female with dementia)

“It’s [focus group discussion] been a real eye-opener, and to be honest, I’ve never known such information was available.” (Male with dementia)

What lies ahead?

Some carers stated that people should be able to access more information about what to expect and advice on how to handle situations that may arise following a diagnosis of dementia.

“I think it’s essential that people know what’s coming and how to cope with the different stages, because you go through different stages, different things happen, and there are ways and means of dealing with

these things, and it's not something, that is, you've got to do a lot of research yourself..." (Male Carer)

"Not one of the support team turned to me or my sister and [said] 'This is what it is going to mean to you, what you need to do now'." (Female Carer)

Participants with dementia, especially those in the early stages, also said that they felt excluded.

"A lot's said to the carer, but not too much for us." (Female with dementia)

However, comments from other participants indicated that receiving this type of information would not be suitable for them, illustrating the importance of a flexible and person-centred approach and finding out what best suits the circumstances of each individual with dementia and their carers (including the recognition that the wishes of people with dementia and their carers may differ). In a number of instances, individuals with dementia were not, or were no longer, aware of their diagnosis, demonstrating a situation in which professionals would need to be sensitive to differing requirements on the part of the person with dementia and their carer.

Relationships with Professionals

The attitudes and responses of health and social care professionals play a key role in people's experiences of living with dementia in Wales. People with dementia and the people who care for them experienced a wide variation in the quality of their relationships with professionals, ranging from the extremely positive to the very negative. In many cases the attitude of the professionals involved, and also their level of understanding of dementia, was felt to be an important contributing factor to the quality of these interactions. This was also true of the experience of diagnosis, as discussed above.

“It depends on the individual...in the service.” (Female Carer)

“Whether they have the sort of capacity and the skills and the right attitude, personality even, to be able to perform in the best interests of the people in their care.” (Female Carer)

In addition to those cases where strained relationships existed between individuals and the professionals involved with them, there were also a large number of cases where people felt that they had very little involvement with professionals from health or social care, or both. In some instances, participants very much felt as if they had been left without support following the diagnosis.

“We were given the diagnosis and we were sent home. We weren't even sent home with a pamphlet. We had to research everything from that point. There wasn't a phone call, there wasn't anything.” (Female Carer)

“Just one leaflet on dementia: get on with it.” (Female Carer)

The individual level

“That's why this thing about the attitude of professionals is so very, very important.” (Male Carer)

A positive approach on the part of a professional involved with a person with dementia can make a significant difference to the experience of that person and their carer, where they have one. Reflecting the discussion around societal awareness, some participants felt that first-hand knowledge on the part of a professional could be beneficial.

“My diabetic nurse understands because her Mum's got dementia and she's very, she never talks down to me, she talks to me still as a person,

but she understands and what she says to me is very simple, if I can say that, so I can understand what she's saying.” (Female with dementia)

“Our GP now, her Mum has Alzheimer's and she's very, very good. We changed. Still in the same practice, but we changed doctors.” (Female Carer)

“Some of them are very, very special. We had wonderful care from some doctors. Amazing care.” (Female Carer)

“Consultant said to me, if you are worried about her, bring her. I will always see her and I will always see you. I class you as one of my team and my team is important to me.” (Female Carer)

“Regular GP has been amazing...One of the most caring people in the profession that I've ever met.” (Male Carer)

Even where first-hand personal experience was lacking, there was no doubt in the minds of carers about the importance of the attitude and approach of an individual professional to their experience and the experience of the person for whom they cared. Experiences shared by participants illustrated that people can have a very different experience with GPs in the same surgery or professionals in the same team, which suggests that the variation cannot be related to locality, a so-called “postcode lottery”, but can often be attributed to differences in the attitude, awareness and understanding of individual professionals.

“Luckily our CPN, who does the day care, has been excellent with us.” (Female Carer)

“The only issue I had personally was with some of the doctors in the hospital and unfortunately they were the ones who had most influence over what happened to [husband] when he went into hospital.” (Female Carer)

“No obvious support from the doctor or anything.” (Female Carer)

“The arrogance as well around the fact that we were asking lots of questions was quite bad.” (Female Carer)

“I think *, Mum's social worker, is very caring and helpful.” (Female Carer)

Sometimes these positive relationships, particularly those with GPs, were linked to a long-standing relationship that had allowed the doctor to become familiar with the people involved. Negative experiences tended to occur when people with dementia and their carers were registered with clinics where they received appointments with whichever GP was available, rather than having a regular doctor.

“...it takes you three weeks to see the GP who knows what’s going on and...that’s because they’re good. Or you take pot luck and see whoever happens to have a free space and then you have got to go through the whole story, and then it’s difficult, because if they know you and they know the patient, then it’s much better.” (Female Carer)

Listening and communication

Participants stated that an indicator of the quality of the relationship with a professional was the extent to which the carer, or the person with dementia, felt listened to about their concerns.

“Because when you go to your GP, you see different ones all the time, so they don’t understand your condition or give you the time, really...” (Female with dementia)

The same participant later added:

“With the doctors and even the receptionists and that, they talk so quick and they’re telling you something and you don’t understand what they’re saying and you say ‘Pardon? I didn’t quite get that’ and the tone of their voice changes and you can feel the aggression.”

Carers also highlighted the importance of their knowledge of the person living with dementia being recognised by professionals.

“She [psychiatrist] actually said to me what I wanted to hear – you know your husband better than I do...” (Female Carer)

“Right at the end, the doctor did come to the house and he just said ‘I don’t care what you say, Mr *, she’s going to end up in care because that’s what always happens’.” (Female Carer)

“Some members of social services are absolutely arrogant.” (Female Carer)

“I’ve been telling you, telling you for the last two years and nobody ever listened. He said ‘I’m listening to you now’ and he got things moving very quickly.” (Male Carer)

“As far as the people coming to the house, doctors from our practice, going to various places, centres, I think everyone listened. When they didn’t listen was when he went into hospital.” (Female Carer)

Again, the experiences of carers in this respect varied widely. One carer, for example, reported having two opposing experiences from two different hospitals under the same health board. In one, she reported feeling fully engaged, whilst in the other she reported being treated in a very off-hand manner, for example when asking for a Welsh speaker to talk to her parents.

Substantive variations in the way in which professionals interacted with the person with dementia were also highlighted. The same carer referred to above reported one consultant being excellent with her parents – talking to them, gaining their trust and speaking to them in a way they could understand – whilst the professional they saw about continence issues was very different, failing to see her parents as individuals.

Another carer reported feeling caught between different professionals, with a GP being certain that her husband had dementia and the psychiatrist refusing to give a diagnosis of dementia, instead (incorrectly) diagnosing a different mental health issue.

Participants also reported an ambiguity surrounding the nature of the relationship with a professional. Quite often this appears to relate to a major difficulty identified by many carers, which is the issue of who they are supposed to contact for information and support. Whilst it was recognised that a professional had been helpful to them in a particular context, participants were sometimes unsure whether they could approach them for advice or support. Other professionals had no hesitation in offering to be a point of contact.

“I don’t know whether I ring her or not, she didn’t say ‘ring me if you’ve got any problems’. But she was very good.” (Female Carer)

“I know that I can always contact the social worker.” (Female Carer)

“I phoned them again and they said somebody would get in touch with me but nobody has.” (Female Carer on trying to see consultant after husband tried to smother her)

Formal Services

The quality of interactions with formal services had a significant impact upon the experiences of participants, especially carers, who were often required to deal with the health and social care sectors.

Post-diagnosis support

Experiences of the support received post-diagnosis varied widely. As highlighted in the section on relationships with professionals, some participants developed positive, beneficial relationships with individual health and social care professionals, whilst others had more negative experiences. The same variation is evident with regard to the services and support received post-diagnosis.

“In the beginning, I was given a diagnosis and an [Alzheimer’s Society] leaflet and then they said we’ll see you in six months. So if I wanted anything in the meantime, it was up to me to find it.” (Female Carer)

“The way I do feel, to a certain extent, is that you’re given a diagnosis, you’re left to get on with it. Well that’s wrong.” (Male Carer)

Some participants living with dementia reported that they struggled to follow the information given to them because of the way in which professionals spoke to them.

“It’s too much information for you to register in one go. If they slowed down on their speech and talk a little bit slower, it gives you a chance to take it in. You just can’t take it all in. You’re still thinking about what they said three sentences ago.” (Female with dementia)

Communication proved problematic for some who didn’t feel that they were being listened to by professionals who were involved in delivering care to people with dementia. For some, a lack of communication was also a problem, not only between themselves and professionals, but also between the professionals involved. In some cases, this reflected a lack of cooperation between different professionals and organisations, leading people to have to repeat details on a regular basis (see the section on relationships with professionals). In other cases, people reported that they did not feel as though the information they provided was being taken into consideration.

“One, being part of the team; two, being taken seriously; three, I complained, I made a formal complaint and they didn’t bother to go

through the formal complaint procedure.” (Female Carer)

“I feel like I’m listened to, but I don’t feel like I’m heard. I think it’s really different things.” (Female Carer)

“I just expect more awareness of our situation and how we have to manage. They don’t seem to be interested in how people manage.”
(Female Carer)

“...nobody listening to you, that was the other thing.” (Female Carer)

Many carers reported that they ended up feeling isolated whilst caring for the person with dementia, especially in the later stages, rather than feeling supported by a team of health and social care professionals. The support they received was coming from family and friends rather than formal services. One carer commented that it was unclear who was supposed to be doing things, making it possible for different services to blame each other when things were not done, whilst others referred to the length of time it can take for any progress to be made.

“I couldn’t get hold of anybody, nobody would talk about him.” (Female Carer)

“The thing which stands out as being really, really poor, the lack of communication between a mental hospital and a general hospital.”
(Female Carer)

“...whatever we’ve got, we had to shout and jump up and down for.”
(Female Carer)

“It’s so frustrating – you are going round and round in circles trying to get anything.” (Female Carer)

“...you are looking at three months before you get anything done. Just even a return phone call can take three months.” (Female Carer)

The extent of the inconsistency experienced was highlighted in comments made with regard to accessing the system and the support that it could offer. Some felt that if a person with dementia had a carer in the form of a family member or friend, then they were more likely to be excluded from receiving services. Others believed that there was a lack of effective mechanisms for being placed into ‘the system’.

“The usual thing, once you’re in the system, it comes automatically. That’s what they say. But until you actually get into the system...” (Male Carer)

“You get on a conveyor belt and then it all happens.” (Female Carer)

“You shouldn’t have to ask for services. The services should automatically come to you, because it’s one of those things that you don’t really want to admit, that there’s a big problem, but there is a problem there and the earlier you get help, the easier it makes it.” (Male Carer)

Some participants experienced frustration that even when meetings were held, whether with health or social care professionals, they experienced no improvement in their circumstances or the level of support they subsequently received. There was also frustration at feeling excluded from decisions that were being made.

“We had a meeting, but nothing seems to come from it, does it?” (Female Carer)

“...you can rant and tell people what that’s like, but when you see very little come back for you, that’s difficult.” (Female Carer)

“I felt that we’d been disregarded, really, in any decisions that were made about her.” (Female Carer)

“They decided then [after three visits] she had to go into a nursing home. They decided to put her in there” (Female Carer) **“They said here’s a list of homes, you can go and check them out.”**

“[about complaints] I have had nothing back at all, no feedback about the meeting or how they were going to address the situation.” (Female Carer)

Some participants expressed concerns about the level and quality of assessments for both health and social care purposes, and raised questions about the exact nature of the objectives that such assessments were designed to meet.

“A lot of it felt like, you know, when they did the assessments...they had this questionnaire thing to ask my father [with dementia] about how he wanted to improve by three months and by six months and I suppose for my mother [who had suffered a stroke] I could understand it better...it felt like it was wrongly targeted.” (Female Carer)

“They go on about the carer’s assessment, but nobody came and assessed me.” (Female Carer)

A small number of participants were critical of what they perceived to be the shallow nature of the memory test conducted by some GPs, which, in their opinion, had delayed diagnosis. Social care assessments, Carers Assessments and Continuing Health Care (CHC) assessments were also criticised. It should be noted that for most of the carers taking part in this study, the person they cared for was still living at home and CHC had therefore not yet arisen as an issue. However, for carers whose relatives had passed away, or were now resident in care homes, CHC was a clear area of concern.

“I wanted him [the doctor] to realise that Dad had problems and just asking him what his name was and where he lived wasn’t going to show the severity of the silly things he was doing around the house.” (Female Carer)

“My feeling was, filling out those forms, they’d been particularly designed to ensure that the right answers came back that meant you wouldn’t get the financial care.” (Female Carer on both CHC and Social Care assessments, who also commented) **“It doesn’t seem to be designed to help people with Alzheimer’s at all, or dementia, in any way.”**

“When I had a carer’s assessment...quite frankly, I didn’t think it was worth the paper it was written on.” (Female Carer, who also commented) **“It always feels like they’re looking for the easiest and cheapest way out and that’s what it felt like.”**

A small number of participants acknowledged that they had initially been reluctant to access the services that had been made available to them, a choice which had later been regretted. However, they still believed professionals should be doing more to ensure that the necessary support was being accessed.

“One of the things when we got the diagnosis...there was a reluctance on our part to get anybody else involved...I look back at it now, I think that was very naïve of us and that’s why...I do believe the NHS should be more committed to ensuring that somebody who has a diagnosis has the help.” (Male Carer)

For some participants, their location affected their access to services and support. Once again, this was extremely variable across Wales with some participants living in rural locations receiving very good services, whilst

others had to travel in several different directions to get treatment for different conditions, costing time and money, and risking upsets to routine. One person with early-onset dementia in North Wales struggled to access appropriate services having been told by the consultant that he wouldn't see him again until he was 65, whilst in South-East Wales, the services for early-onset were widely praised.

“...being rural just adds complications” (Female Carer who later added) **“I don't think anybody thinks about the difficulties of rural living in this.”**

“If you can't drive, how do you get to the doctor's surgery?” (Female Carer)

“Because I don't know where the specialist will be...” (Male Carer)

“I suppose living in a city is probably easier in a way because everything's that much closer.” (Male Carer)

Some parts of rural Wales were considered to be “forgotten” because they were too far from, or fell in-between, key centres of care. However, even those living in urban areas could experience difficulties accessing services because of their location. For example, one carer reported wanting to attend a dementia café but being unable to as it required catching two buses, something that wasn't feasible for her husband.

Other concerns emerged about the lack of Welsh-speaking services available. One daughter spoke of the difficulty of finding a residential care home with Welsh-speakers for her father and also spoke of the difficulty of finding hospital professionals who could explain issues to her parents in Welsh. Another highlighted the difficulty in conducting a capacity assessment for a patient who was first-language Welsh and one carer commented that she felt lucky that the person for whom she cared was not a Welsh-speaker.

“...the lack of services in Welsh language...” (Female Carer)

For those who had received signposting from within formal services, they were often referred to the third sector for information, advice and support. This can be variable across Wales as different projects receive funding in different localities, which means there is a lack of consistency in some of the services available.

In some cases, services were not appropriate for people with a more advanced stage of dementia, whilst in others, there was a lack of available transport to facilitate access to services.

“If it wasn’t for them, I’d be up the creek without a paddle.” (Female Carer)

“But nobody could manage to give me any help with a night situation. There’s a company or a charity... called * who, the social worker told me, might be able to provide some help. They sit with people while the carer goes shopping and things like that and they can do night situations, but after waiting for eight or nine months, I eventually got a letter from them saying they can’t do anything at the moment, and to ask them again if we still needed help in a little while, so I just gave up...” (Female Carer)

“Yes, when [husband] eventually got diagnosed with vascular dementia, we went to the memory clinic and they directed us to the Alzheimer’s Society...and from that came a lot of redirection if you like.” (Female Carer)

When discussing support from the third sector, references were made to a wide range of organisations that had been contacted and/or involved with people with dementia and their carers. These included both local and national-level organisations, some of which specialised in supporting carers. Such organisations provide a wide range of different services, but these are often not consistent across Wales. Some people found the third sector a great support; others had had a less positive experience or were unable to access the type of support they felt they needed through the sector. In some cases this was due to a lack of funding in their area; in others it was because the available services weren’t suitable for a particular stage or type of dementia, or were targeted at a specific age group. This was felt to be particularly problematic for people with early-onset dementia.

As with other services, comments received were both positive and negative, although comments about third sector services tended to be more positive than for statutory services. However, once again, the attitude and approach of staff was raised as an issue in some cases. The services delivered by third sector organisations are discussed above in the ‘activity, meaning and purpose’ section above.

“It’s people like you [lists charities] and volunteers...they’re the ones that actually do the job.” (Female Carer)

“[some staff members] don’t have a clue about the disease.” (Female Carer)

“She was very well-meaning, very kind and it was nice to have a chat, but in terms of practical advice...” (Female Carer)

“You need to not be giving all the money to one charity, because that’s how it feels.” (Female Carer)

Social Services

“One or two social workers that I’m involved with now, great, but I’ve had one other that was appalling and the attitude on the telephone that was appalling.” (Female Carer)

Several issues emerged that were pertinent to Social Services in particular. Firstly, a large number of participants did not have, and often had never had, any engagement with a social worker.

“I only got a social worker when I broke my foot.” (Female with dementia)

“Nobody’s ever mentioned a social worker to me.” (Female with dementia)

“First of all, of course, I’ve got to be referred to the social care...which I haven’t been.” (Female Carer)

Secondly, some participants had difficulty in engaging with Social Services because they didn’t know what services and support might be available (this issue is explored further in the section on information and advice), whilst others felt able to rely on Social Services for assistance.

Thirdly, a particular area of concern with regard to Social Services was the way in which a case could be closed, even though dementia is a progressive condition and thus support will continue to be required.

“If I needed anything, I would go to the social worker who would have access and would have input. She could facilitate.” (Female Carer)

“I know that I can always contact the social worker.” (Female Carer)

“If you don’t badger them...they take you off the books.” (Female Carer)

“I rang up to speak to someone about [husband]. ‘Oh, his case is closed.’ He was still ill.” (Female Carer)

“And every time I phoned the number for social services, they said, no, your mother doesn’t have a social worker anymore.” (Female Carer, who added) **“So at that point you don’t know who to contact. I can’t tell you how worrying that was.”**

Participants also reported a wide range of experiences with the domiciliary care that was provided. Some of this was delivered under a private arrangement, but some was organised by local authority social services. Experiences ranged from a highly professional service to people reporting that they didn't know when to expect care workers or who was coming. At the more negative end of the scale, carers reported care workers missing appointments and cutting short already brief appointments.

“They’ve been very reliable. They’ve been excellent. They’ve listened to us.” (Female Carer on domiciliary care workers)

“I’m old stock. I’m very modest and I don’t like taking my clothes off in front of youngsters...” (Female with dementia)

“Far too many carers, missed calls, missed medication, overdosing on medication...” (Female Carer)

“If they say they have an understanding of dementia and their call is provide a warm lunch for the lady that they’re seeing, then that’s exactly what they should do.” (Female Carer)

“Some of them don’t give a damn, no. They can’t even make a bed.” (Female Carer)

Lack of cooperation between services

Problems created by a perceived lack of cooperation between health and social services were also reflected in a number of the conversations with participants (also see section on Paying for Care).

“...nothing was joined up. No social worker would talk to anybody else.” (Female Carer)

“We’ve had a series of people come in and out of our lives at different points...but never get to know you, the person with dementia or the family situation, so there’s no join up between health and social care, you’re having to tell your story again and again and again because it’s not noted and it’s not shared, so that’s quite frustrating.” (Female Carer)

“We’re the communication between them, because they don’t talk to each other.” (Female Carer)

“There’s no care coordination on a personal individual level, I don’t think. That’s probably because of the volume of work they have to deal with.” (Male Carer)

“I think coordination of services is shocking.” (Male Carer, adding) **“It’s an absolute mess.”**

Lack of flexibility

Participants highlighted the lack of flexibility that often exists within the health and social care systems and the problems this can cause. A specific example is the difficulties created for many carers, especially those who were still in work, whether this related to attending specific appointments or collecting medication.

“What do you mean, you can’t get here to get the medication between the hours of 10 and 4, Monday to Friday?” (Female Carer)

A particular issue that recurred across a number of discussions was the stress of arranging and making appointments. Some carers reported that they were able to get an appointment with their GP easily, whilst others found this problematic. One GP, for example, agreed to see a patient early so that she wouldn’t have to sit in the waiting room. However, a number of participants were critical of the fact that they were unable to get home visits from the GP surgery, despite the practical difficulties involved in taking the person for whom they care to an appointment, especially where the dementia was more advanced.

“[GP] said ‘look, if you’ve got any problems, you ask to speak to me and I will see you’.” (Female Carer)

“...the doctor said you need to get her to come and see me. I said I can’t get her up out of the chair. ‘I can’t do home visits’. I said if you don’t come now, I can’t see her being conscious in an hour.” (Female Carer)

Both carers and people with dementia found attending appointments stressful and it was also suggested that any assessment taking place when the person with dementia was highly stressed from travelling and being in unfamiliar surroundings could not give a true outcome.

“Now planning for an appointment...is challenging.” (Female Carer)

“It’s just so stressful for him and for me that I don’t think we can go [to the memory clinic].” (Female Carer)

“Can remember taking her to the hospital once and you couldn’t park by the doors of the hospital. I was on my own with her, I’d come out [of work] to pick her up from the care home and take her for a check-up and she wouldn’t have been able to walk the distance from the car park. So what

do you do? Drop her off at the door and hope she's still there when you get back?" (Female Carer)

One carer had specifically requested that the Community Psychiatric Nurse (CPN) call to see her mother on a day when she was either working from home or not in work. The CPN came on a day when the carer was in work and asked the person with dementia if she would like a memory test, which the person with dementia declined and the CPN left. Subsequently:

"And we were sent a letter after saying Mr and Mrs * are coping very well in the community and when I read the letter, I thought 'who are these people?' Because it doesn't sound like our family at all because we're not coping and there's a lot of needs that aren't being met here..." (Female Carer)

A number of participants highlighted concerns about the type of support that they were offered and how appropriate it was to their particular situation. Equally, some reflected concerns about the limitations placed upon the level of support that they received.

"They've told me I've got six weeks respite...I'm thinking if I use my respite up in the first three months, where do we go then?" (Male Carer)

"We have been offered that [support with personal care] and Mum's assessed as needing assistance with personal care. We could have told you that anyway...however, we know what that means, and that means Mum having an agency to come in to help her with her personal care. Mum wouldn't be accepting of that. We're coping fine at the moment. It has its challenges, like everything does...we don't need practical support at this point, and that's the only thing that's been offered." (Female Carer)

Lack of continuity

"I don't like it [different unfamiliar carers]." (Female with dementia)

Another issue that arose regularly with regard to interactions with services was the importance of continuity for people with dementia, and the lack of continuity a number of participants had experienced. It is well known that this is an issue that is frequently raised with regard to domiciliary care workers, but the experiences of participants demonstrate that this is also true of a large number of other professionals. Discussions with participants highlighted significant variation in experiences with regard to continuity: some people had a single point of contact to whom they could turn, whilst others experienced what felt to

them like a constant turnover in terms of the professionals involved.

“That’s lovely, to have that continuity, the same person.” (Female Carer)

“If people have carers coming in, it might not be the same carer, so in that case they’re all strangers as far as [husband’s] concerned.” (Female Carer)

“...one of the problems with using the community nurses is that you never get the same one. You have no say who’s coming and I think in the six weeks, we had 36 people through the front door.” (Female Carer)

“The worst of it, I know which day they’re going to come [district nurses], I never know who’s going to come and I never know what time they’re going to come.” (Female Carer)

“Consistency of care is just...her care plan says no more than three carers a week and normally it’s 10,11,12 different carers every week from the same care provider.” (Female Carer)

For a small number of participants, there were also concerns arising from the prospect of change to what to them seemed like a settled situation. A key focus here was the impact on the person with dementia if a particular care home or day centre be closed, or if they no longer have access to it. Such concerns reflect the recognised importance of continuity and routine for many people with dementia, but also the difficulty of explaining change.

“This is the problem: when they do get settled in a good place, they might have to move on and that’s very, as you can see, emotionally disturbing.” (Female Carer)

“Apparently their policy is that they [domiciliary care workers] shouldn’t get too familiar with any of the clients. But I think people Mum’s age need continuity of care. They need people they know to come. The same people, you know. I don’t think she’d beef if it was five or six people came.” (Female Carer, to which Mum added) **“As long as I got to know them.”**

“When the changeover occurred [local authority domiciliary care], and it did make [mother] very, very anxious, she wasn’t happy in her home, she was frightened basically.” (Female Carer; mother disagrees)

Dignity

Two key issues were highlighted by participants during discussions about treating people with dementia with dignity: continence and the loss of personal items.

The issue of access to appropriate incontinence pads was a theme that occurred regularly throughout the conversations held with those who were caring for someone with a more advanced stage of dementia. There was significant variation in the experiences of participants, with a number highlighting the fact that the products available were not suitable for the person with dementia. This meant that they had to purchase products themselves that could be used more effectively.

“I found it very difficult to find out how to get [incontinence] pads because the district nurse said ‘you don’t’, so I bought my own...but the CPN was excellent, and she arranged it, so I’ve got my pads regularly.”
(Female Carer)

“We’re having to buy more and more things for Mum, including incontinence pads which, although you can get some on the NHS, Mum can’t use them and finds them really difficult and they’re the only ones they do [tone emphasis], so we’ve had to buy things like that.” (Female Carer)

Other participants were concerned about incontinence being developed following admission to a hospital or a care home because people with dementia were placed into incontinence pads on admission, even though they were not incontinent at the time. Some of the carers who had seen this happen to the person for whom they cared felt that the use of incontinence pads was for the convenience and/or time management of the staff, rather than for the benefit of the person with dementia.

“Not incontinent until she went into care at which stage they’d immediately put her into incontinence pads.” (Female Carer)

Another specific issue that was mentioned directly with regard to treating individuals with dignity was the loss of clothing and personal belongings following admission to hospital, or a care home, even when this was only for a short period of respite. Losing personal possessions was viewed as indicative of a lack of dignity and respect in the treatment being offered.

“Quite a frequent thing there, they lose their false teeth.” (Female Carer)

“The other thing that was appalling in that hospital was the clothing; you couldn’t keep track of clothing.” (Female Carer)

“He’d only been in there a fortnight and they’d lost £100 worth of his clothes and all his toiletries, his electric shaver and that. It went. Nobody cared. I spoke to *. ‘It’s not my responsibility’, she said. Well she was the ward manager.” (Female Carer)

“Every time we went [to the respite home] she had somebody else’s clothes on; they weren’t bothered about it.” (Female Carer whose mother returned home with several items of clothing missing)

“They [the hospital] would give Mum a bag of filthy dirty stuff that had been shoved in her locker until Mum came.” (Female Carer)

Finally, some carers noted professionals talking over people with dementia, rather than addressing them directly, or speaking to them inappropriately. One carer noted that the consultant “talks down to him.”

“None of the staff chatting; rather chat round work stations than to the patients.” (Female Carer)

“...absolutely disgraceful the way she [CPN] spoke with my Mum in the care home one day.” (Female Carer)

“...there are some [domiciliary care staff], they come in twos, for the morning visit and to go to bed...if they get on, the tendency is for them to laugh and joke with each other and not include [husband] and I will say to them ‘Could you talk to [husband]? Because you’re here to look after [husband]’.” (Female Carer)

Training and awareness

“The problems are the professionals who have had the same old ideas for donkeys’ years and cling onto them and think that they know best.” (Male with dementia)

Participants also raised concerns about the degree of training and awareness of a range of different health and social care professionals with regard to dementia. The experiences reported demonstrate huge levels of variation, from the very positive to the very negative. One particular area of concern related to the highly individual nature of the condition, meaning that it affects everyone differently. Even where there is generic awareness, this may not be useful for working with all individuals. In particular, carers commented on the apparent

lack of awareness of professionals as to the unreliability of answers they may receive from some individuals with dementia.

“I don’t think even the professionals that deal with people with dementia treat them properly.” (Female Carer)

“I found that they [care company] cover a massive number of people with all different care needs, that they’re not really geared up for people with Alzheimer’s and dementia.” (Female Carer)

“They’re such good nurses, they’re trained, they really know the job and they’re so kind.” (Female Carer)

“The carers [domiciliary care workers] are fine but I don’t think they always understand...that there’s another problem with my Mum and you can’t see it.” (Female Carer)

“The carers that we have – they can say they’ve got experience of dementia, but they’re not tuned into Mum.” (Female Carer)

“She said she could manage – they took her at her word.” (Female Carer)

Concerns were also raised about whether staff trained for other specialities had sufficient knowledge of dementia care to provide appropriate treatment when they were looking after patients as a result of co-morbidities. In some instances, participants felt that professionals refused to consider possibilities other than dementia, whilst in others it was clear that carers didn’t believe that professionals knew how to approach a patient with dementia.

“I still feel lots of those sort of professionals tend to think ‘Right, well, we’ll ignore it anyway and I’ll just do my job’.” (Male Carer)

“I kept saying, well, he was trying to eat but he kept spitting it out and of course, they were taking it that it was end-stage dementia and I said ‘there’s something wrong with his taste buds’. A week later he had thrush like icing on a cake in his mouth and that’s what had stopped him eating and drinking and they should have picked up on that.” (Female Carer)

“...on a surgical ward or a medical ward, no requirement for someone with dementia training to look after him.” (Female Carer)

“She [gynaecologist] just kept asking these questions louder, making Mum more distressed.” (Female Carer who had alerted to the consultant to her mother’s Alzheimer’s)

“I don’t think the A&E departments at hospitals have as much understanding of dementia as they should have, because every time we’ve taken Mum, very few doctors have even considered it. Most of them just talk to her as if she’s normal, ask her date of birth etc.” (Female Carer)

“The ‘listened to’ bit is really important when it comes to dealing with third parties with Mum, because...every time we go for a medical appointment we say ‘Are you aware of Mum’s condition?’...And a couple of times they say ‘yes’ and a few times they’ve been very good. On more than one occasion, though, on her cataract operation as well, it was just dreadful because you go through the same process every time – ‘What’s your name? What’s your date of birth? What’s your address?’ And they’re asking Mum and, God love her, if she’s on a good day, you’d be very lucky to get it now.” (Female Carer)

Unfavourable comparisons

Some participants who had experience of dealing with other life-threatening conditions reported a marked difference between the way in which care is provided for people with dementia and those with other illnesses, such as different forms of cancer. This comparison was almost invariably unfavourable with regard to dementia care and is indicative of the way in which dementia is often perceived as a condition that requires social care, rather than a health care, despite the fact that it is caused by a disease of the brain. Differences in the treatment between mental health and physical health conditions were also noted, as symptoms of dementia are often treated by mental health professionals.

“The first one [Maggie’s Centre] I saw...it was a beautiful place when it was finished and the stuff in there was fantastic.” (Male with dementia who had previously been treated for cancer).

His wife responded **“You got a lot of support from them, didn’t you? And I did as well to come to terms with cancer.”**

“Cancer comes under terminal illness; dementia should come under terminal illness as well, shouldn’t it?” (Female with dementia)

“It’s called a disease of the brain so how can it be social?” (Male with dementia)

“We’re living with someone who’s dying. That’s a fact that’s not considered by services, because it’s hard to think about and actually, if Mum was dying of another illness, our lives would be different and we

would be supported in a different way...” (Female Carer)

“Once diagnosed with cancer, different treatment altogether...she had a medical condition they could deal with...then treated with much more dignity.” (Female Carer)

Paying for care

“The purpose of the discharge meeting was for the medical service and the social services to argue about who was going to pay.” (Female Carer)

Another issue highlighted by some carers in relation to formal services was paying for care. There were a number of dimensions relating to this issue, one of which was a lack of information and advice about what needed to be paid for and by whom. In some cases, carers had not been told whether or not they would have to pay for services, or how much.

“...assume will have to pay for it [respite]...nobody’s actually said it but assume we will.” (Female Carer)

Others felt that once it had been established that they would be self-funding, they effectively received little or no support from formal services. Some carers also reported not having been told about direct payments as an option for managing the care of an individual living with dementia.

“Social services came to see Dad after she [Mum] had gone into care and he said they just got out the clipboard and said ‘do you own the house?’ And he said ‘yes’ and they just closed it and said ‘well, that’s that, then’.” (Female Carer who subsequently added) **“My Dad just couldn’t understand why he was being asked to pay basically all his pension...to do something he didn’t want to do [keep his wife in residential care].”**

Some participants also expressed frustration that they were now being expected to pay for care, as they considered this would not necessarily be the case were the care being provided for other medical conditions. Some explicitly mentioned using savings to pay for care, which raises questions about how carers who are doing this will be able to support themselves in future. One person with early onset dementia was worried about the impact on his family of funding his long-term care needs.

“My kids’ inheritance will be spent on my care which shouldn’t be happening, because I have a disease” (Male with dementia, who later added) **“I feel like it’s my fault...Because of me, because of me, we are potentially**

going to lose everything.”

“If [she] had a stroke, wouldn’t be paying for any of this.” (Female Carer)

“I think about all the expense, because the NHS aren’t going to help...”
(Female Carer)

Section 3: Going forward

What would make a difference?

A number of themes were highlighted repeatedly when discussions were held about what might have made a difference to the experience of living with dementia in Wales and what might make a difference in the future. Broadly, there were six themes that people with dementia and carers believed would have made it easier for them to adapt to the situation in which they found themselves.

However, it must be acknowledged that whilst many of the participants referred to similar themes during this part of the conversations, there was also nuanced differences with regard to exactly what this support would look like for them, reflecting their own particular circumstances.

Single point of contact

One theme identified through discussions with carers and people with dementia, was the desire for a single point of contact.

“And for us to have our own contact person.” (Female with dementia)

“To have one person to accompany you all the way down the journey would be amazing.” (Male with dementia)

Having one person or one contact telephone number to use was also viewed as a fundamental issue by carers, especially by those who do not currently benefit from one. There was a difference of opinion as to whether the single point of contact should be a designated individual or some kind of ‘one-stop shop’ or team holding information, advice and resources.

“You just feel like you need somebody to advise you.” (Male Carer)

“It would be lovely to have a case manager that just holds all of that together and is your constant person that you can turn to. I don’t know if that’s available in other places, but it’s certainly not been offered to us and so I sort of take that role...” (Female Carer)

“You need a one-stop shop for information.” (Female Carer)

“A single point of contact would be absolutely amazing.” (Female Carer)

“I think you should have a dedicated social worker who carries your case forward and who knows you.” (Female Carer)

Practical and emotional support

Some participants were adamant that they would benefit from practical support or training, but didn't feel a need for emotional support. Others expressed a strong preference for emotional support, rather than practical support. For some, there was frustration that the support they were being offered was not the type of support they felt they required.

“...we're not looking for Mum to be taken into care for any period of time. We want to be well supported emotionally in the main, actually, because physically we're coping. We're helping Mum with everyday tasks and her personal care but it's the emotional impact that we could all do with some support on that level and that doesn't happen.” (Female Carer)

Whatever the form of support desired, many felt that they would benefit from a greater level of support than they were currently receiving. For some, this took the form of practical support, but with a recognition that this could be addressed by better advice and training, or any level of advice and training at all.

“But I think even the carers need a lot more help than what they get and a lot more support. I've seen it within the groups that some of the carers are at breaking point.” (Female with dementia)

“Just want more help from the people that are there really. The understanding of what is available and what we can ask for.” (Female Carer)

“Times when I'd have given my right arm to have something there and if you like a tea and whatever.” (Female Carer)

Emphasis was also placed upon taking preventative steps in the provision of support rather than having to react after a situation had reached a critical point, when a much more significant intervention, in terms of time, money and effort, may be required.

“You could fight a lot of fires before they turn into fires.” (Female Carer)

“Carers have [sic] a little bit more support would enable them to continue and save the government money.” (Female Carer)

“It’s the way the system works – you wait for an emergency to happen before [support arrives].” (Female Carer)

For those who wanted greater emotional support, some said they were happy to take part in groups with other carers, whilst others said they would prefer a one-to-one. In the latter case, some expressed a preference for talking to another carer, whilst others would be happy to speak to a professional.

“Only thing I could do with some sort of person I could sit down and talk to – a counsellor, somebody like that.” (Male Carer)

“Yeah [emotional support is important], a counsellor, rather than going to a big meeting.” (Female Carer)

“I would have liked to have a one-to-one with a carer, rather than being in a group; I’d have been sitting there bawling my eyes out.” (Female Carer)

Training

Another area of concern was training, which took two predominant forms. The first, as discussed in the section above on formal services, was the belief that many professionals in both health and social care need to be better informed about dementia, its symptoms and its implications for behaviour.

“I think a lot of people need re-training on dementia care because they’ve got a patronising attitude and they think they know everything when in fact they don’t.” (Male with dementia)

However, some carers also believed that they themselves would have benefited from training to help deal with practical and behavioural issues in particular. Again, a number of carers drew an unfavourable comparison with the way in which other conditions are handled.

“Ideas how to deal with difficult situations and not to, I think he felt now, not to aggravate me by disagreeing with me, if you see what I mean.” (Female with dementia)

“It’s knowing how to deal with those situations. In a way, I feel like you need to go on a course for people to show you how to deal in situations like that.” (Female Carer)

“...I do feel there is a role to be played by people for support...if a support worker can come out and let you know how you can handle it – how to appease, how to agree, how not to disagree.” (Female Carer)

“Some better knowledge, some better skills, some better understanding of what it does to somebody and the way their perceptions change...and the stages people go through, and the things they do and why they do it and the way, as a carer, I needed to react to that and to talk to somebody who knew what that was about.” (Female Carer)

“Why isn’t there something for dementia?” (Female Carer referring to a course upon managing diabetes that she had been offered upon diagnosis)

Listening and communication

Another key issue raised was the importance of feeling listened to appropriately and receiving effective communication from individuals involved in the case. This theme was brought up by both carers and people with dementia. A supplementary issue that emerged was that the agencies involved in providing care needed to improve communication with one another.

“I think they [care professionals] need training on giving people with dementia time, make sure they understand what’s said to them.” (Female with dementia)

“...and listening to the carer, and not assuming that you know everything, not being arrogant...” (Female Carer)

“If I could change one thing, it would be the attitude of social services towards the relatives of patients in care because their attitude is absolutely unacceptable, appalling. Where you need support, advice and reassurance, you are spoken to as if your relative is now a prisoner of the system and you have no say in anything that concerns them.” (Female Carer)

“The outside agencies don’t, in this case, they didn’t communicate with each other at all.” (Female Carer)

Better integration of health and social care

The lack of communication between different services and agencies was highlighted by participants, who also stated that there is a strong need to improve levels of cooperation between those involved in an individual’s case.

“It would be lovely to be able to say that social care and the NHS could link up together, so our doctor could speak directly to social services and all of Mum’s medical records, all of that sort of thing could be brought together...if they could come together as a team more.” (Female Carer)

“I think integrating health and social services is essential, especially in this field.” (Female Carer)

Respite

Respite, whether in the form of a short-term admission or a befriending service, was viewed as an extremely valuable service. However, it should be noted that a number of people raised concerns about short-term admission, the impact it had on the person with dementia and their routines and well-being. Some openly acknowledged that they did not feel this type of respite was suitable for their circumstances. Some also expressed a preference for respite to be made available in the home. Again some unfavourable comparisons were drawn with the way in which other illnesses are supported.

“Things like somebody taking them out...facilities where they could go to, have a meal.” (Female Carer)

“...put her into respite care and I didn’t like it.” (Male Carer)

“Respite is needed at home, not take him away to a residential place.” (Female Carer)

“It’s all right having respite for carers and there’s a lot made of that, but at the end of the day that can cause its own problems [because of losing familiarity and worry].” (Male Carer)

“I’d take on the same thing, but what you need, looking after somebody like that, is a break of some sort, and him going into respite would not work.” (Female Carer)

“What I needed was more than anything, like people with cancer, they can have Macmillan in, and they give you a night to have a good night’s sleep; there’s nothing like that for dementia.” (Female Carer)

Looking to the future

Participants in this study were also asked about their hopes, fears and aspirations for the future. Many expressed fears, rather than hopes, for what might happen. There were two clear trends evident in the way people thought about the future. Some had organised everything they could, such as Power of Attorney (both forms), Advance Decisions to Refuse Treatment and Living Wills. Others felt unable to think ahead in that way and were just taking each day as it comes.

“You make those decisions well in advance of actually needing to.”

(Female Carer)

“When [wife] was diagnosed we said ‘Right – day by day’. But obviously you can’t do everything day by day: we’ve sorted the legal side out, they’re all set, we’ve done the wills, we’ve done the power of attorney...”

(Male Carer)

“We don’t know about the future, so we live to the day.” (Female Carer)

“We need to think about the end...I realise we need to be planning that now. We need to keep her out of hospital.” (Male Carer)

Timely diagnosis

In a small number of instances where there had been early diagnosis, the person with dementia had taken arrangements out of the hands of the carer, in order to be able to make their own decisions about their future whilst they were still able.

“She took it out of my hands. She said when I become 24/7, or I get a bit too much to handle, put me in a home. And she took me looking around homes and said this is where I want to go. I need you to listen to my orders now. This is what you’re doing.” (Male Carer)

“I’ve chosen my own care home. I go to one now so I get used to the environment.” (Male with dementia)

Fears and aspirations

People with dementia shared their fears about the progression of the disease and its potential impact upon themselves and the people around them.

“If I got depressed, my condition would deteriorate rapidly.” (Male with dementia)

The carers who took part most commonly expressed fears around having to admit the person they care for to a residential or nursing home, stating that they aspired to keep that person living at home.

“I don’t think I could ever let him go into a home, or into hospital, as I can’t see how they’re going to look after him.” (Female Carer)

“My one and only fear is that my husband won’t die in his own bed.” (Female Carer)

“...sometimes I will lie in bed thinking, oh God, when is this going to end? Will I have to put him in a home at some stage? That would be really heart-breaking.” (Female Carer)

For some, this reflected concerns about the quality of life based on their experiences of residential care homes.

“I think that her quality of life, although it’s severely limited, it’s not what it was, her quality of life at home is far, far better than it would be in any home.” (Male Carer)

“I know this is not the case for every home, but I’ve visited some homes that I wouldn’t put a dog in.” (Female Carer).

Another significant fear expressed by carers was a concern about what would happen to the person for whom they cared if anything should happen to them. This concern was also shared by people with dementia.

“But look at the people with dementia that are living on their own and it’s quite frightening, you know. And that’s something, I must admit, that does worry me sometimes, what happens if something happens to my husband? What will happen to me?” (Female with dementia)

“At my age, anything could happen, I could pop my clogs in the next five minutes... I don’t want him to go somewhere where he doesn’t know anybody at all, doesn’t know names.” (Female Carer)

“The main thing I worry about is that I will go before him really.” (Female Carer)

“My problem is more what if anything happens to me? That’s probably my single biggest worry. If I had a stroke, I wouldn’t know how to respond.”
(Male Carer)

Some carer participants also recognised that their situation was likely to become more difficult to handle as the disease progressed.

“Maybe it’s time for her to go into a home because we can’t deal with it, awful to say.” (Female Carer)

“It’s just going to get worse and worse.” (Female Carer)

The predicament of paying for care was also raised.

“I think we should start researching the homes and planning what happens financially.” (Female Carer)

“I do worry about the future but I worry about it because of finances.”
(Male with early-onset dementia, concerned about the financial impact on his family)

A few carers also spoke about the pressure on existing services for the future.

“But how are they going to have enough places for everybody?” (Female Carer)

A small number of participants also expressed frustration with the slow pace of research into developing treatments for the disease and interventions to improve quality of life.

“I tell you what I do resent, what I really resent, is that there’s no bloody money going into research on this and that all the money goes into cancer...I resent the fact that it’s not taken as seriously as it should be.”
(Female Carer)

“Somebody was saying to me the other day, the research into Alzheimer’s is where the research into cancer was 20 years ago. There’s a long way for them to go to catch up. What really pees me off – I get so annoyed sometimes – is you hear of things they’ve started to find and they won’t fast-track it.” (Male Carer)

Appendix

Conducting the Research

Introduction

The aim of this research was to explore the experience of daily life in Wales from the perspective of people living with dementia and carers of people with dementia. It sought to examine these personal experiences from a wide perspective, covering wider personal and community life as well as the provision and experience of service provision and delivery. As such, unlike many research projects and reports it is not restricted to exploring health and social care services. Instead research materials were developed with a view to allowing and encouraging participants to comment on any issues that influence their experience of daily life with dementia, or as a carer for a person with dementia.

Process

In May 2015, Age Cymru was contracted to undertake this research on behalf of the Older People's Commissioner for Wales.

A literature review was carried out during May and early June 2015, leading to the design of research materials that were piloted in June 2015. At the same time, project staff received training on dementia and how to conduct the conversations from Age Cymru's My Home Life Cymru project and an Age UK Expert by Experience.

Requests for participants were placed in local newspapers across Wales and resulted in a very positive response, not only in terms of numbers, but also in terms of reactions to the scope and approach of the research.

The research fieldwork was conducted between 14 July 2015 and 15 October 2015 and consisted of detailed conversations with a total of 133 people across Wales, speaking to 50 people with dementia and 83 carers. The research was specifically designed to include people with early-onset dementia and therefore the age range of people with dementia ran from early fifties to early nineties. For carers, there were a number of participants who were adult children and the age range therefore ran from people in their thirties to people in their eighties.

The majority of participants contributed through individual recorded conversations with a member of the research team, either on an individual

basis or with a person with dementia and their carer contributing together. The research team also held five small group conversations with established groups of people with dementia or carers, with 26 participants contributing through these.

Conversations, interviews and focus groups took place throughout Wales, in a wide range of settings, including people's own homes, peer groups, day centres and residential care settings. Whenever possible, participants were provided in advance with a study information sheet, an informed consent form and a short biography, with picture, of the facilitator. Relevant demographic and diagnostic information was collected by the facilitator on the day, together with a consent form signed by the participant and the facilitator. In some instances, carers signed on behalf of the person with dementia after having had the opportunity to go through the research information with them. All conversations were recorded with the consent of the participants. All research took place in accordance with the Age Cymru research ethics statement.

Approach to the research

The research sought to gather the views of people with dementia and carers on key issues including the forms of support that they currently receive; actual and perceived barriers to improving/maintaining their quality of life; and how/whether they feel that their future needs and aspirations can be met by the services currently available and the communities in which they currently live.

Following the literature review (available as a separate document) a principal research question was developed to capture these broader dimensions and shape the framework of the research. The literature review covered both academic and 'grey' literature. It was noted that much of the academic literature adopted a 'medical model' approach and this is reflected in the literature review. However, this research adopted an approach of looking at the barriers and challenges that were preventing people from experiencing a better quality of life with dementia.

The research question is supported by a series of sub-questions intended to capture different aspects of the experience and opinions of those living with dementia and their carers.

Principal question

- How do people with dementia and their carers experience daily living in Wales?

Sub-questions:

- In what ways do forms of service provision impact upon the experiences of people living with dementia and their carers in daily life in Wales?
- What are the positive and negative features of service provision as experienced by people with dementia and their carers in daily life in Wales?
- To what extent has current service provision met the needs of people living with dementia and their carers? To what extent do they believe that existing service provision is capable of meeting their future needs and aspirations?

In order to address these questions, a qualitative approach to the research was adopted. Qualitative methods were chosen as quantitative measures would be unable to capture the depth of subjective experience required to enhance our understanding of how it feels to live with dementia in Wales. The qualitative methods employed helped to unpack what is most important to a person, what the impact of the condition on their lives has been and what meaning this may have for an individual (adapted from Felton, 2005: 223). The qualitative methods employed consist of a combination of informal conversations with observation, semi-structured interviews and focus groups.

Focus groups were used for the purpose of gathering a range of views from a group of carers or people with dementia about key issues or topics that emerged from the conversations held. The use of focus groups can also be seen to provide an additional opportunity for social interaction and peer support and advice for carers. Semi-structured interviews were used for one-on-one interactions with carers allowing key topics to be explored in greater depth.

There are inevitable constraints deriving from circumstances with regard to conducting a form of interview with a person with dementia. It may be difficult to obtain consistently reliable information, but it is possible to gain insight into their subjective experience. The concept of quality of life is often amorphous and vaguely defined (Felton, 2005: 228), but focusing upon the subjective experience will allow for enhanced understanding of how it feels to live with dementia in Wales, or to care for someone who does.

In order to facilitate these less formal conversations, the Talking Points approach was adopted and adapted for the purposes of this research. Talking Points is an example of an outcomes-focused approach, a form of approach that is increasingly important in the study of social work in particular.

“At the centre of the approach is a conversation with an individual using services or unpaid carer that seeks to understand the extent to which they are achieving the outcomes important to them in life.” (Cook & Miller, 2012: 8)

In order to gain insight into a subjective experience of quality of life, it is necessary to understand the components of that life and what is important to the person whose life it is.

The Talking Point approach identifies three types of outcome that are important: quality of life, process and change. These three types of outcome were adapted to reflect the scope of this research, resulting in five themes that will underpin the conversations, interviews and focus groups: communication, processes, attitudes, change and the future. The ‘I’ statements of Talking Points were adapted to fit these extended categories as the basis of conversation points for people with dementia or questions for carers.

The outcomes conversations therefore formed the primary mechanism of data collection. Facilitators of conversations were also encouraged to observe the person with whom they were talking. Facilitators were then asked to note down the themes they felt were important to the participant as soon as possible after the conclusion of the conversation. These observations were then able to be triangulated with analysis of the recorded material. All facilitators received training in communication with people with dementia and the principles of Caring Conversations from a CQC Expert by Experience specialising in dementia care.

Limitations

As with all studies, there are a number of limitations that must be acknowledged. Firstly, there are the limitations inherent in qualitative studies with regard to the extent to which findings can be generalised to the broader population group, in this case the groups of people with dementia in Wales and carers of people with dementia in Wales.

The evidence collected for this research therefore represents the individual experiences of dementia, a condition that affects everyone in a different way, and as such present a snapshot of what those experiences have been to date. The data collected reflects the experiences of people living with all stages of dementia. Valuable insight was gained from across the spectrum, from people in the early stages of dementia about their personal experiences, fears and aspirations and the importance of activity to provide meaning and add value, to carers who nursed partners or parents through the end stages of dementia.

Capturing this range was challenging, as participants were often referring to experiences relating to different stages of dementia, and also to different types of dementia.

Secondly, the sample was largely self-selecting in nature: as outlined above, requests for participants were placed in local newspapers across Wales. Nevertheless, it has to be recognised that this means the majority of participants were those who demonstrated an active interest in being involved with the research and that this may introduce an element of bias into the findings. Efforts were made to balance this possibility by recruiting through a number of other channels. However, the newspaper letters represented a great opportunity to reach potential participants across Wales.

It should therefore be recognised that there is a potentially large group of people who are currently living with dementia in Wales who have not been reached by this research and whose experiences may be similar, better or worse than those who participated. Some of these people will only have limited or no contact with services and may therefore be facing significant challenges as they try to live as well as possible with dementia. As noted above, further research is also required on potentially marginalised groups whose experiences are not explicitly captured within the data collected during this project.

Qualitative research methods also generate questions around the reliability of the information gathered, an issue which is amplified when collecting data from people with dementia. However, insight can still be gained and for those people with more severe communication difficulties, Talking Mats and touch-screen technology were made available to support data collection although were not needed. Whilst helping people with dementia to communicate their views can be difficult, these insights are especially valuable as a result of their under-representation in the existing literature.

The fact that some of the data is also collected retrospectively, (i.e. looking backwards) could also be argued to impact upon reliability, but in the absence of a longitudinal cohort study, represents the best data available. Equally, some participants were reporting experiences that they had in the past and changes may have been made to service delivery subsequently. Qualitative data is sometimes criticised for its narrative or anecdotal nature. However, qualitative methods are those most appropriate to gathering insight into the subjective experience of participants.

Finally, there is no triangulation between the data collected here and the experiences of health and other care professionals, or staff working in the third

sector or wider community, of their experience of delivering services to people with dementia, as this lay outside the scope of the current research.

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