



**Older People's Commissioner for Wales**  
**Comisiynydd Pobl Hŷn Cymru**

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# **Rethinking Respite for People Affected by Dementia**

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**April 2018**

**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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# Foreword

My ‘Dementia: More Than Just Memory Loss’ report<sup>1</sup>, which was published in 2016, looked at how services across Wales need to improve to ensure that people living with dementia and those who care for them can access the services, support, information and advice that they need. One of the major issues that emerged related to the lack of timely, meaningful and impactful respite, an issue that was significantly and unnecessarily undermining people’s physical, mental and emotional health.

This was such a significant issue that I made a commitment to look again at it in greater depth and this report gives a voice to people affected by dementia, organisations that support them, public service providers and a wide range of professionals, setting out what needs to change. It is clear that much needs to change in terms of respite: a fundamental shift in the way we think about respite is needed, and that change in thinking needs to both underpin and drive forward new models of support that directly respond to the issues that people who use respite have and continue to raise.

The key messages contained within this report make clear both how our thinking and practice needs to change. We need to rethink the language and terminology we use around respite; we need to rethink how we engage with people living with dementia and carers and use their knowledge and experiences to develop new models of care and support. We need to align the outcomes that we are trying to achieve with the National Outcomes Framework, ensuring that people are empowered to have a voice and control over the nature of the respite support they receive.

Respite should be so much more than ‘a break from the burden of caring’, too often having to be booked months in advance. It should be seen as a way to support families in maintaining important relationships, maintaining and developing new skills, and should underpin and sustain the overall wellbeing of both individuals and families. Respite must be a flexible and individualised continuum that runs alongside the entire dementia journey.

If this change does not take place, then our ability to deliver the outcomes that people have a right to, outcomes that sit at the heart of the Social Services and Well-being (Wales) Act 2014, will be compromised. People affected by dementia will continue to face unacceptable and avoidable pressures upon their physical, mental and emotional health, at huge detriment to themselves, and an unnecessary cost burden will be placed on public services due to increased demand for more complex and lengthy care and support.

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<sup>1</sup> Older People’s Commissioner for Wales (2016) Dementia: More Than Just Memory Loss; The experiences of people living with dementia and those who care for them

I have broadly welcomed the Welsh Government's Dementia Action Plan for Wales, in particular the document's clear commitment to learn from the findings and recommendations that I have laid out in this report. It is my expectation that the Welsh Government, and public bodies, will now listen to the voices of people affected by dementia and take the action that they need to maximise their wellbeing.

Whilst this report has focused specifically on people affected by dementia, many of the key messages are equally applicable to other people who need respite. It is also relevant not just to our current generation of older people and their families, but to future generations and potentially each of us, as few can predict when we might need respite in the years to come. It is in all of our interests to rethink respite.



**Sarah Rochira**  
**Older People's Commissioner for Wales**

# Acknowledgements

I would like to extend my thanks and appreciation for the support and effort of all the people living with dementia and carers of people living with dementia who participated in the engagement work and shared their experiences with me. Their voices are at the heart of this report.

I would also like to thank all of the agencies and professionals who helped to make the engagement work a reality - in particular Dementia GO, the University of South Wales, Dementia Matters Powys, Me Myself I and the Chepstow Methodist Church Singing Group who helped to host some of the engagement events.

Further to this, the engagement work would not have been possible without the numerous organisations who helped to share information about what was happening, and in some cases provided practical support for people to be able to attend - not least DEEP, the Alzheimer's Society, Carers Wales, Carers Trust and the many carers organisations across Wales.

# Key Messages

The term 'Respite' can have negative connotations, implying that people must have time apart or that caring is a burden. Alternatives such as 'replacement' or 'alternative' care can also imply a carer focus and fail to take into account the wellbeing outcomes and needs of people living with dementia, 'doing to' rather than 'working with' individuals to find out what matters to them.

While 'traditional' forms of respite in day services and care homes are important options of choice for some people, meaningful occupation, quality and flexibility are fundamental for these to be genuine options. Rethinking respite means moving beyond 'care' and 'sitting' services to ensure that the wellbeing outcomes of everyone affected by dementia are given meaningful consideration. When this happens, people affected by dementia are supported to maintain physical, mental and psychosocial wellbeing in ways that are meaningful to them. Social networks are rebuilt, interest in life extends and 'caring' relationships can be sustained and rebuilt as the therapeutic benefits of new opportunities, happiness and laughter rekindle mutual engagement and connection. The paradigm has already shifted in our legislative and policy frameworks; we now need to rethink respite to ensure that wellbeing outcomes are available to people living with dementia and carers.

Current systems for monitoring, measuring and evaluating levels of 'respite' are not fit for purpose, relating to a narrow and one-sided definition of respite (e.g. the Welsh Government respite performance indicator only relates to overnight stays). The evidence base for 'quality' respite is currently unclear because the research and evaluation measures employed often relate only to carer experiences and frame the caring role as a 'burden'.

Effective respite is also key to delivering on the National Outcomes Framework, both for individuals and at a population level. If respite is not reframed, people affected by dementia are in danger of being excluded from these outcomes.

## Sustaining the physical, mental and psychosocial wellbeing of people affected by dementia

- Respite is often primarily considered as something for the benefit of carers. However, it is essential that respite is also regarded as an opportunity for people living with dementia to sustain and maintain their physical, mental and psychosocial wellbeing in line with what matters to them.
- Flexibility and choice is vital to accommodate the different needs and circumstances of people living with dementia and carers.

- The importance of people living with dementia staying active, learning new skills and being enabled to sustain social networks, volunteering opportunities and employment is not sufficiently understood, either in terms of individual wellbeing or the wider cost benefits to the health and social care system. Such opportunities can help to build confidence and self-esteem, and empower people living with dementia to adapt and adjust to living as well as they can with dementia.
- Meaningful and flexible respite options need to be available for people with multiple and complex needs and be responsive to fluctuations and changes. People's understanding about what constitutes a meaningful break will change throughout their dementia 'journey' as well as in response to external events and day-to-day functioning.
- There is a clear need for more creative forms of respite, in partnership with a range of sectors – covering hospitality, the environment, sports, arts and leisure – to meet the wellbeing outcomes of people affected by dementia. The current one-size-fits-all approach of 'traditional' day and care services does not serve the diverse population of people living with dementia and risks creating passive recipients of care and a culture of early dependency or disengagement with services.
- Health and social care systems are not sufficiently responsive to people with multiple caring roles, such as where people may be caring for other disabled relatives or friends and children as well as the person living with dementia, or situations where there is a caring 'network' and not just one main carer. This often inhibits the availability of meaningful respite to meet people's needs.

## Information and Empowerment

- People affected by dementia often find it difficult to navigate the health and social care system to access respite and self-funders do not feel they are being given adequate support or information to arrange their own respite.
- Opportunities for families and individuals to talk about personalised solutions to meet their 'wellbeing outcomes' in relation to current and future 'respite needs' are frequently limited by the awareness amongst professionals of meaningful alternatives to traditional respite options. Accessible information about respite options is not sufficiently accessible, delivered at the right time and in the right format, and there is insufficient support to make sense of the options available.
- Direct payments can be an important vehicle to enable flexibility, choice and control in relation to respite. However, more work is required to make this a



widely offered and meaningful alternative.

- The importance of empowering people affected by dementia, families, carers and individuals to adapt and create innovative solutions to their own unique respite needs (for example, people with early onset dementia) is not sufficiently considered in frontline practice or at a strategic level. Furthermore, some people felt that their suggestions of how their needs could be met were not welcomed or given sufficient status.

## The central importance of respite to restoring and sustaining individual resilience and personal relationships

- People need opportunities to have breaks together and apart, within the home and away from home in line with their views, wishes and feelings.
- The traditional respite option of a night or nights away in an external care setting for the person living with dementia is not always restorative or helpful to building resilience within caring relationships. Many people reported how a loss in physical, mental or social functioning due to institutional practices or the stresses of not knowing if their loved one was being well supported could make things worse.
- Stigma and myths about dementia continue to persist in many local communities, which impacts on people's confidence and willingness to 'get out and about'. Social inclusion and a wide range of dementia friendly and supportive environments are therefore key to the availability of respite options to ensure that people affected by dementia are not limited to 'special' segregated provision.
- There is clear evidence concerning the risk of social isolation of people affected by dementia. Respite offering social contact and befriending opportunities is an important aspect in supporting the wellbeing of people living with dementia and carers.
- Peer support is particularly valued, not only by carers, but by people living with dementia; it is an important aspect in people feeling understood and supported and in helping to build emotional resilience.

# Introduction

My ‘Dementia: More Than Just Memory Loss’ report, which was published in 2016, set out some of the key issues affecting people with dementia in Wales, in particular:

- A widespread lack of knowledge and understanding of dementia amongst professionals and the wider public.
- A lack of flexibility to effectively meet the needs of people living with dementia and their carers.
- A lack of co-operation between services creates unnecessary difficulties and barriers for people living with dementia and their carers.

I called for a range of actions to address this, and there has been some progress, particularly in relation to public awareness and staff training, with the publication of and ongoing work to roll out ‘Good Work: A Dementia Learning and Development Framework for Wales’<sup>2</sup> and the growth of Dementia Friendly and Supportive Communities. However, despite a range of changes across society at a policy, practice and community level, there is still a long way to go to transform services and drive the cultural change needed to effectively meet the needs of people affected by dementia.

I have consistently focused on the importance of meaningful outcomes for people with dementia and their carers, to ensure that their lives have value, meaning and purpose. This is fundamental to ‘Rethinking Respite’ and to delivering the Welsh Government’s vision of ‘a dementia friendly nation that recognises the rights of people with dementia to feel valued and to live as independently as possible in their communities’<sup>3</sup> as outlined in the new Dementia Action Plan for Wales 2018-2022.<sup>4</sup>

The commitment of ‘experts by experience’ in helping to develop the Welsh Government’s Dementia Action Plan must be acknowledged, including people affected by dementia, who freely gave of their time alongside organisations and professionals. Their input ensured that the final Action Plan was based on real life experiences and the Welsh Government’s pragmatic approach in describing the Action Plan as a ‘live document’ provides a basis for us all to work and learn together in translating people’s aspirations into reality. As part of this, I welcome the commitment made by the Welsh Government to consider the findings of this Rethinking Respite report.

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2 Care Council for Wales (2016) Good Work: A Dementia Learning and Development Framework for Wales <<https://socialcare.wales/resources/good-work-dementia-learning-and-development-framework>>

3 Welsh Government (2018) Dementia Action Plan for Wales 2018-2022 <<http://gov.wales/about/cabinet/cabinetstatements/2018/dementiaactionplan/?lang=en>>

4 See Appendix 1 on Welsh Policy

There is much in the Dementia Action Plan that I have welcomed, in particular the commitment to promoting the rights, dignity and autonomy of people living with dementia and the use of personalised outcome statements. However, more work is needed if a rights-based approach is to be embedded throughout the plan. For example, I would have liked to have seen a stronger link made to older people living with dementia in care homes, in particular the way in which services and support are commissioned, including respite. I had also expected to see more prominence given to the wellbeing of carers and to the promotion of opportunities for peer support.

An additional £10m funding has been made available on an annual basis to support implementation of the Dementia Action Plan, and a key delivery agent of this will be the Social Services and Well-being (Wales) Act 2014. The majority of funding will be made available via the Integrated Care Fund to develop the Dementia Action Plan proposals for a 'Team around the Individual', and it is important that this resource is used productively and transparently.

The Social Services and Well-being (Wales) Act 2014 provides the legal framework and duties on Local Authorities, Health Boards for 'promoting the well-being of people who need care and support, and carers who need support', and to give people stronger voice and control. Key principles and duties<sup>5</sup> include:

- People have control over what support they need and should be involved in making decisions about their care and support as an equal partner
- Easy access to information and advice is available to all
- A preventative approach to meeting care and support needs is practised
- Carers have an equal right to assessment for support to those who they care for

Critical to this transformation is embedding the 'What matters' approach across all points of contact for people affected by dementia - from information and advice services, to social worker and other professional involvement. Otherwise, there is a risk that the 'What matters' approach becomes a one-off conversation that is unable to sustain the cultural change needed to promote individual wellbeing through supporting people to achieve the outcomes that matter to them.

The National Outcomes Framework<sup>6</sup> has set a clear national direction for promoting the wellbeing of people who need care and support and carers through a series of simple 'I statements'. These statements clearly resonate to the wellbeing outcomes

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5 Welsh Government (2015) Social Services and Wellbeing (Wales) Act 2014: The Essentials <<http://gov.wales/docs/dhss/publications/160127socialservicesacten.pdf>>

6 Welsh Government (2016) Social Services: The national outcomes framework for people who need care and support and carers who need support <<http://gov.wales/docs/dhss/publications/160610frameworken.pdf>>

that people affected by dementia have told me matter most to them, such as:

- I know and understand what care, support and opportunities are available and use these to help me achieve my well-being.
- I can access the right information, when I need it, in the way I want it and use this to manage and improve my well-being.
- I engage and make a contribution to my community. I feel valued in society.

The challenge of Rethinking Respite is to make these outcomes real for everyone affected and impacted by dementia.

Whilst it is clear that the application of policies and legislation are critical to rethinking respite, significant scientific and academic advances have also contributed to a more nuanced understanding of the brain and of dementia, as has the development of a global dementia friendly movement and personal stories shared by dementia activists.

Whilst there is now increased public awareness and understanding of dementia as a progressive disease of the brain, misinformation, stigma and discrimination are still prevalent in the public domain, and continue to impact on the wellbeing of people affected by dementia.

Challenging this is a welcome and growing voice and influence of people affected by dementia. For example, the DEEP (Dementia Engagement & Empowerment Project), which is now becoming more established across the UK, including Wales, aims to transform the way people think about dementia with a view to changing the services and policies that affect them<sup>7,8,9</sup>. National work has also been driven through the Alzheimer's Society's service user review panels (SURPs)<sup>10</sup>, the carers call for action led by the Dementia Alliance<sup>11</sup> and 'Together in Dementia Everyday'<sup>12</sup>, an involvement network that recognises family carers of people with dementia as experts by experience who can influence policy and help to shape and improve commissioned services.

The need for change is essential, not least to transform people's lives but for public bodies to effectively respond to the size and significance of this issue. Current

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7 Williamson T (2014) A stronger collective voice for people with dementia York; Joseph Rowntree Foundation

8 Dementia Engagement and Empowerment Project (DEEP) <<http://dementiavoices.org.uk/>>

9 Mental Health Foundation (2015) Dementia, rights, and the social model of disability Policy Discussion Paper <<https://www.mentalhealth.org.uk/publications/dementia-rights-and-social-model-disability>>

10 Alzheimer's Society / Living With Dementia Magazine (2017) How people with dementia are having influence through Alzheimer's Society's service user review panels <[https://www.alzheimers.org.uk/info/20082/living\\_with\\_dementia\\_magazine/280/how\\_people\\_with\\_dementia\\_are\\_having\\_influence\\_through\\_alzheimers\\_societys\\_service\\_user\\_review\\_panels](https://www.alzheimers.org.uk/info/20082/living_with_dementia_magazine/280/how_people_with_dementia_are_having_influence_through_alzheimers_societys_service_user_review_panels)>

11 Dementia Action Alliance (2015) Carers Call to Action <<https://www.dementiaaction.org.uk/carers>>

12 <http://www.lifestorynetwork.org.uk/tide/> (accessed 20/04/2018)

estimates suggest that there are over 45,000 people with dementia living in Wales; by 2021, the number of people with dementia across Wales is projected to increase by 31% and by as much as 44% in some rural areas<sup>13</sup>. Dementia is one of the main causes of disability later in life, ahead of cancer, cardiovascular disease and stroke.

Around 370,000 people are carers in Wales, of which approximately 11% care for someone with dementia<sup>14</sup>, and carers of people living with dementia spend significantly more hours per week providing care compared to carers of people with other conditions<sup>15</sup>. The age profile of carers also has far reaching consequences, with nearly half aged over 75 caring for someone living with dementia. In addition, 65% of older carers (aged 60–94) have long-term health problems or a disability themselves<sup>16</sup>. The number of carers aged over 85 is also increasing rapidly. For example, comparison of the 2001 and 2011 UK census figures shows the number of carers aged over 85 has increased by 128%, compared to 25% for those aged 60–64 years.

Respite is a crucial form of support that is of relevance to a wide range of people with different conditions or illnesses and at different life stages, and the findings of this report will have wider resonance in terms of its key messages. However, as already stated, dementia particularly impacts on older people and there is evidence that people affected by dementia are less likely to take up the current ‘offer’ of respite services, in part because they are often so ill-fitted to their needs<sup>17</sup>.

This report sets out to reshape thinking about respite and provides evidence of how respite can be positively transformed. The approach to the study has included:

- Engagement with over 120 people affected by dementia, undertaken in partnership with My Home Life Cymru (Swansea University).
- A literature review of related research, undertaken by the University of Worcester Association for Dementia Studies
- A call for examples of practice, undertaken in partnership with the University of Worcester Association for Dementia Studies

The methods employed are outlined in more detail in Appendix 2 and the literature review produced by the University of Worcester Association for Dementia Studies is included as a separate Annex on the Older People’s Commissioner for Wales website.

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13 Marie Cure Cancer Care & Alzheimer’s Society (2015) Living and dying with dementia in Wales

14 Carers Trust (2015) Key facts about carers and the people they care for <<https://carers.org/key-facts-about-carers-and-people-they-care>>

15 Brodaty, H. and Donkin, M. (2009) Family Caregivers of People with Dementia. *Dialogues in Clinical Neuroscience*, 11, 217-228

16 Carers UK and Age UK (2015), *Caring into Later Life: The Growing Pressures on Older Carers* Carers UK and Age UK

17 Older People’s Commissioner for Wales (2016) *Dementia: More Than Just Memory Loss; The experiences of people living with dementia and those who care for them*

This report brings together the key findings from all of this work, to aid policy makers, commissioners and providers to deliver change, and to aid people affected by dementia to have a broader knowledge of some of the wider respite options that might – or should – be open to them.

# Exploring Respite

In order to ‘rethink’ respite, it is helpful to explore how people understand it. Whilst this report will demonstrate that perceptions, policy and practice are shifting, it is clear that too often respite is narrowly defined and understood.

## What is respite?

Respite is often considered in traditional forms, such as day services and overnight stays in care homes. Where these are able to provide positive outcomes, they can be a positive choice for people. However, there are many alternative forms of respite which can be equally, if not more, impactful and can be provided at a lower cost. Examples of these varied and creative examples are provided throughout this report.

The people involved in the engagement sessions thought about respite in a wide range of ways, not necessarily linked to specific types of services:

**“[Respite is] about being able to make a new memory.”** (Person living with dementia)

**“For me and my dad a good break would be spending time with someone who’s interested in him. Someone fresh and new who asks him questions.”** (Carer)

**“It’s a rest or a break from something – not necessarily from Mum. It might be from the chores.”** (Carer)

It is often assumed that respite means having a break apart, and it was highlighted in ‘Dementia: More Than Just Memory Loss’<sup>18</sup> that many people affected by dementia did not want this. This was a point frequently raised in the Rethinking Respite engagement activity:

**“Horrible to think you have to have separate breaks when you have a certain condition and you get to a certain stage.”** (Carer)

**“To go away as a family. It’s difficult surroundings for me. I want my loved ones with me. That’s respite, isn’t it?”** (Person living with dementia)

**“I tried respite in a care home but it didn’t work. Not everyone wants to leave their loved one in a care home for respite.”** (Carer)

**“My mother has dementia and my father has physical needs. They can’t get**

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<sup>18</sup> Older People’s Commissioner for Wales (2016) Dementia: More Than Just Memory Loss; The experiences of people living with dementia and those who care for them

**respite together it has to be separate. I'd want them to stop looking at mum and dad separately but as a couple and also us a family. They want respite together and a chance to go on holiday together.”** (Carer)

Fundamentally, people wanted a range of choices and meaningful options and consistently highlighted the importance of personalised approaches.

## **Who is respite for?**

Respite is typically considered as being for the benefit of the carer<sup>19</sup>. However, there is an increasing emphasis in policy and practice guidance that respite should be an enjoyable experience that supports the wellbeing of people living with dementia, rather than being about their ‘containment’<sup>20</sup>. People with dementia themselves need quality forms of respite:

**“It’s something to give you a reason to go out of the home - to recharge your batteries”** (Person living with dementia)

**“You need to get away – so you’re not stuck within four walls.”** (Person living with dementia)

**“[My mother] knows what she wants. They always say that when you’ve got dementia you need more routine, but she wants change.”** (Carer)

**“That’s the important thing, that it’s something you’re both comfortable with.”** (Carer)

**“He occasionally needs a break from me, likewise I need a break from him.”** (Carer)

Not only has respite traditionally been focused on the carer, but ‘the carer’ is often assumed to be one person. Whilst this may be the case for some, the reality for many people is that caring relationships can be complex and dynamic. During the engagement sessions there were many examples of multiple caring networks, including family members, neighbours and friends, plus several people described carers at a distance who were providing critical support.

Furthermore, in much of the research and in practice, the carer is often assumed to be in a familial relationship, which is not always the case. Neighbours and friends can be a significant (even main) carer, particularly for people living alone, and it is estimated that up to one third of people living with dementia live alone<sup>21</sup>. During the

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19 Rethinking Respite Literature Review Bibliography available as a separate Annex on the Older People’s Commissioner for Wales website <http://www.olderpeoplewales.com/en/Reviews/respite.aspx>

20 Social Care Institute for Excellence (2018) Preventative support for adult carers in Wales: rapid review commissioned by Social Care Wales

21 Mirando-Costillo et al (2010) People with dementia living alone: what are their needs and what kind of support are they receiving. *International Psychogeriatrics*, 22(4) 607-617



engagement, one person described how they had been the sole carer for their friend for many years, and it had been difficult to get statutory services to recognise and understand their situation. Another person living with dementia (alone in her own home) described how help with some practical tasks (organised by Social Services) had provided a form of respite to her; she said it had transformed the nature of her relationships and improved her quality of life:

**“I am able to get my friends and neighbours back [as they used to be] because I am not having to rely on them so much.”** (Person living with dementia)

## Language and terminology

It can be seen from the references included in Appendix 3 that respite has traditionally been defined as providing some sort of break or ‘temporary relief’ for the carer. It has been identified that not only is respite generally based on the carer’s point of view but also that the term tends to be used interchangeably as a service (something that is used) or as an outcome (something that brings benefit)<sup>22</sup>. There is no agreed definition of respite within academic literature and no agreed consensus around the outcomes for respite<sup>23</sup>.

It is not uncommon to read and hear negative language related to respite<sup>24</sup>, such as carers experiencing ‘burnout’, ‘strain’, ‘stress’ and ‘anxiety’. Similarly, the Dementia Engagement and Empowerment Project (DEEP) has identified that the word ‘burden’ is commonly used in the context of dementia and has included this in their list of words to avoid<sup>25</sup>. Whilst there is no doubt that carers can be under considerable stress<sup>26</sup>, the language applied to respite often fails to take into account the varied nature of caring relationships and the perspectives and experiences of people living with dementia.

Because of these negative connotations, different terms to ‘respite’ have been suggested over the years, largely emerging from research and engagement with carers, for example: ‘restorative care’, ‘short breaks’, ‘replacement care’, ‘alternative care’, but some of these terms fail to take into account the perspectives of people living with dementia and imply something being done to them, rather than engaging with individuals as fully as possible to ensure their quality of life is supported.

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22 Chappell, N., Reid, R. & Dow, E. (2001). Respite reconsidered: A typology of meanings based on the caregiver’s point of view. *Journal of Aging Studies*, 15(2), 201-226.

23 O’Shea, E. & Monaghan, C. (2017). An Economic Analysis of a Community-Based Model for Dementia Care in Ireland: A Balance of Care Approach. *International Psychogeriatrics*, 29(7), 1175-1184.

24 O’Shea, E., Timmons, S., O’Shea, E., Fox, S. & Irving, K. (2017). Respite in dementia: An evolutionary concept analysis. *Dementia*.

25 DEEP Guide (2014) Dementia words matter: Guidelines on language about dementia <<http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>>

26 Newbronner, L., Chamberlain, R., Borthwick, R., Baxter, M. & Glendinning, C. (2013). *A Road Less Rocky - Supporting Carers of People with Dementia*. Carers Trust.

Different terminology is currently used across the UK to describe what is widely known as respite (for example, the term ‘replacement care’ is used in England and ‘short breaks’ are used in Scotland). In Wales, despite the Welsh Government Carers Strategy (2013-17) stating that ‘The Advisory Group recommended that we drop the elastic term ‘respite care’ and instead refer to ‘alternative care’ or ‘replacement care’’, the term respite is still widely used.

Language, definitions and terminology are fundamental issues in challenging discrimination, oppression and stereotypes and it is important to respect the perspectives of people that terms are applied to. Language and terminology changes over time - and will continue to do so – as marginalised groups of people are empowered to gain a voice and have those voices heard. In rethinking respite it is therefore crucial to think about the term ‘respite’ and what this means.

# Challenges and Enablers

People affected by dementia face a number of challenges in obtaining quality respite when they need it. These are outlined in this section, evidenced through the literature review and our engagement work, together with suggestions of enablers to overcome these, which draw upon people's experiences and examples from practice.

Many of these challenges will not be specific to people affected by dementia, but in many ways they can be more acutely experienced. For example, continuity is something most people would want from a quality service, but it is of particular importance where someone is affected by memory loss and may be confused and distressed by different people visiting them.

There are ways of meeting these challenges, and throughout this section examples from practice have been used to illustrate how this can be achieved, using information gathered from the good practice call and through further information searches.

The challenges and enablers are described under the following themes:

- Navigating the health and care system
- Availability
- Quality, flexibility and choice
- Information, advice and advocacy
- Meaningful occupation
- Home or away?
- Complex needs and keeping people active
- Safeguarding and positive risk taking
- Diversity
- Maintaining and building relationships
- Social inclusion and having an 'ordinary' life

# Navigating the health and care system

**“It’s like a spider’s web... Too many organisations who don’t speak to one another – there’s too many and they don’t communicate.”** (Carer)

Many people affected by dementia involved in the engagement activity talked about the problems they had understanding and navigating the health and care system in order to access respite. This is considered below in relation to diagnosis, care management and care pathways.

## Diagnosis

A diagnosis of dementia is life changing but it can also provide the opportunity for people and their families to make choices and lifestyle adjustments that will build resilience for the long term, including access to respite support. If people are enabled to make positive psychosocial and practical adjustments in the early stages of dementia, then it is likely that they will experience fewer distressing symptoms later and will be able to live at home for longer with a better quality of life<sup>27</sup>.

Whilst early diagnosis has been a priority for the Welsh Government, set out in the National Dementia Vision for Wales (Welsh Government, 2011) and also reflected in the new Dementia Action Plan for Wales, the current dementia diagnosis rate in Wales is around 54 per cent, which is the lowest in the four countries of the UK<sup>28</sup>. Whilst it is stated in the Dementia Action Plan that work to improve rates will continue, this means just under half of the people in Wales living with dementia do not have a formal diagnosis and are at risk of not gaining access to support. This was raised in ‘Dementia: More than Just Memory Loss’ and was an issue of concern in our engagement activity with people saying it could block access to respite:

**“The council has raised the gateway. I know the diagnosis isn’t done by the social worker, but health aren’t helping here.”** (Carer, who said access to a support services was denied without evidence of diagnosis)

**“I needed access to respite and support before official diagnosis.”** (Carer)

## Care management and access to respite

Most people involved in our engagement activity had had contact with a memory clinic, linked to specialist diagnostic support, and some had been referred to different sources of support through this (including, for example, Social Services, Dementia Support Workers and the Alzheimer’s Society). However, many people

27 Brooker, D., La Fontaine, J., Evans, S., Bray, J. & Saad, K. (2014). Public health guidance to facilitate timely diagnosis of dementia: Alzheimer’s Co-operative Valuation in Europe recommendations. *International Journal of Geriatric Psychiatry*, 29(7), 682-693

28 Alzheimer’s Research UK Dementia Statistics Hub <<https://www.dementiastatistics.org/statistics/diagnoses-in-the-uk>>

said they did not have much ongoing contact with anyone after their diagnosis and/or were confused by the wide range and roles of different practitioners involved. This was highlighted in ‘Dementia: More Than Just Memory Loss’, where it was recommended that a ‘key worker’ role should be established. The Dementia Action Plan for Wales also makes a commitment to reviewing the role of the dementia support workers in relation to this function<sup>29</sup>.

In some areas, people said it could be difficult to access a social worker due to pressures on services, resulting in long waits. There were also many examples where people said they were told they did not meet the eligibility criteria for support from Social Services because their needs were not considered to be high enough. This was especially the case where people did not require personal care:

**“There’s nothing for people who don’t need washing and dressing – because they’re in that ‘bubble’ then they’re discounted.”** (Carer)

**“Early intervention never happens with dementia.”** (Carer)

There was a real frustration about this, because people living with dementia can live for many years without their ability to self care being affected, yet their cognitive decline can profoundly impact on their lives (and that of carers) in ways that require support, including respite. Whilst there is evidence that early intervention and support can enable people to live well for longer and help to sustain caring relationships<sup>30</sup>, some carers felt that the more they did, the less would be offered to them:

**“I feel like social services think, she’s bumbling along and not complaining much - we’ll just leave her to it.”** (Carer)

**“I’d been asking for respite for months and months and in the end I just told them ‘I am going on holiday’ to make them help my Mum.”** (Carer)

Even where respite was offered or provided, many people complained that social workers only provided information about a narrow range of respite alternatives. Several people involved in the engagement activity said that assessment and care management processes did not really help them access the respite they needed and did not offer a fair system for self-funders.

**“The social worker said I had to go through her but the care home [manager] told me you can ring her up directly. It all comes to knowing the system.”** (Carer)

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<sup>29</sup> See Appendix 1

<sup>30</sup> World Alzheimer Report (2011) The benefits of early diagnosis and intervention Alzheimer’s Disease International, London

**“I am often telling the social worker more than she knows.”** (Carer)

**“People can’t seem to access the same [respite] services if you choose not to go via the social services route – even if you self-fund.”** (Carer, talking about day services)

**“There needs to be a parallel system to support people where you don’t need to go through social services. Getting the information and signposting and help so that you know where to go.”** (Carer)

**“Everything is so traditional. When we make these suggestions the Local Authority looks aghast at us.”** (Carer)

NHS Continuing Healthcare funding does not specifically provide respite to carers but, if the person needing support qualifies, it may help pay for the cost of care at home or in a care home. NHS funded nursing care may also be able to pay for the nursing or medical care that the person receives in a care home<sup>31</sup>. Only a couple of people involved in the engagement said they had been able access NHS funding to contribute to respite at home, and one said this had been “a fight”.

As GPs are pivotal to obtaining a diagnosis, several people said that they should be more proactive in informing people and enabling support for respite.

**“You see your doctor. You are told what’s wrong with you. Then it’s goodbye.”**  
(Person living with dementia)

However, there are examples of primary care services that are providing a more active respite offer:

### **Practice example: Surrey GP Carers Prescription Scheme (Incorporating the GP Carer Breaks Service) in partnership with Action for Carers Surrey and Surrey Independent Living Council, England**

The Surrey GP Carers Prescription Scheme provides primary healthcare staff with a solution to support carers who need a break. Primary Healthcare staff within GP practices affiliated to the programme can make referrals to a number of organisations and a range of services relevant to carers across Surrey. The support can be provided directly to the carer, or to the person being cared for, to help the carer have a better balance between their caring role and their life outside caring.

A Carers Wellbeing Tool is available to staff to help them to informally assess whether a carer is under particular strain and whether a referral to support services may help. Referrals may be made to Social Services for a carer assessment. One off cash payments to help secure a break are also available to carers who are

<sup>31</sup> See Appendix 4

eligible, up to a maximum of £300.

This project is provided as part of a broader package of measures to support carers within primary care and as part of the Carers Care Pathway. The project is funded through the Better Care Fund (England based).

**See website for more information: <https://www.actionforcarers.org.uk/professionals/general-practitioners/forms-information-and-other-downloads-gps/>**

Social prescribing is another way of linking individuals to sources of non-clinical, community-based support, such as exercise, horticulture programmes and community arts. Social prescribing has been active for a number of years, but there were not many examples of social prescribing provided during our engagement activity. Some people using the Dementia GO service had accessed this through an 'Exercise on Prescription' scheme operated by their GP practice, and people who knew of this scheme said it should be extended to other activities. This view is supported by a recent report published by the Arts Council of Wales, which called for arts activities to be available on prescription, funded by health boards, based on evidence of the positive impact of the arts on health and wellbeing<sup>32</sup>. It should be noted that there is currently no agreed definition encompassing what is prescribed or to whom, and organisations other than primary care may operate these schemes, although information about social prescribing projects is available and a list of projects by area across Wales has been produced by Primary Care One<sup>33</sup>.

A summary of 'Routes to Respite' is included in Appendix 4.

## Dementia Care Pathways

**"Everyone goes through this diagnosis process but once you've got this you're given a huge amount of information but none of it's relevant at the time. But when you need it, it's where do you go? There's no information at that stage about what's going on locally... you see a consultant or whatever and you don't get anything back. You get to crisis point before help is offered."**  
(Carer)

Dementia care pathways have been introduced in a number of countries and this features in the Dementia Action Plan for Wales 2018-2022<sup>34</sup>.

The aim of a care pathway is to enhance the quality of care across the care 'journey' with a view to improving outcomes, promoting safety, increasing satisfaction, and

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32 Arts Council of Wales (2018) Arts and Health in Wales A Mapping study of current activity Volume 1: Analysis, findings and proposals <<http://www.arts.wales/arts-in-wales/arts-and-health>>

33 Primary Care One Wales(2018) Social Prescribing <<http://www.primarycareone.wales.nhs.uk/social-prescribing>>

34 See Appendix 1

optimising the use of resources<sup>35</sup>. Care pathways can operate within complex organisations (such as the NHS) and/or across a range of agencies.

Research evidence shows that respite should be an integrated element available throughout the dementia care pathway, with a recognition that different types of respite will be appropriate for different people at different points in time<sup>36</sup>. Several people involved in the engagement activity stressed that it is vital that respite is not considered as a 'late stage' point:

**“At the diagnosis stage - build a picture of the patient’s history, work with family and friends and this will empower everyone involved in the journey.”**  
(Carer)

**“Respite options should start earlier – before it gets to the last stages. Quality of life can be maintained for the person with dementia and carer before it gets to a crisis.”** (Carer)

Where people live is also important. Cross border issues were raised by some participants, either between Welsh public bodies or between Wales and England, where support services and assessment processes could be in different localities and/or the carer might live in a different area. There was concern that there should be a more joined-up and consistent approach:

**“All the [respite] services we access are Chepstow based, but Mum lives a quarter mile over the border in England.”** (Carer)

**“What can we expect? We have a dilemma because where do we go?”** (Carer on border of Gwynedd)

**“We’re a small country. We have 22 different ways of doing things. It’s ridiculous.”** (Carer)

**“We have pathways and action plans coming out of our ears – what is not happening is services on the ground. Staff are not properly trained. They’re not implementing what they say....There’s a huge disconnect between social policy and the reality.”** (Carer)

As the comments above demonstrate, if developed from an organisational perspective, dementia care pathways risk excluding or failing to support people who do not have a diagnosis or who are not actively engaged in the health and social care system, who are considerable in number. It is critical that any dementia

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35 Guus Schrijvers, Arjan van Hoorn, Nicolette Huiskes The care pathway: concepts and theories: an introduction Int Journal Integrated Care. 2012 Jan-Dec; 12(Special Edition Integrated Care Pathways): e192. Published online 2012 Sep 18.

36 Newbronner, L., Chamberlain, R., Borthwick, R., Baxter, M. & Glendinning, C. (2013). A Road Less Rocky - Supporting Carers of People with Dementia. Carers Trust



care pathway is considered from the perspective of people living with dementia and carers and addresses routes to information, advice and advocacy at all stages, including prior to diagnosis.

## Availability

Access to respite is influenced by a wide number of factors, and many of these are addressed in the following sections. What is addressed here covers levels of provision and affordability, and access to emergency and planned respite.

### Levels of respite

The availability of appropriate respite care is one of the most frequently raised carer issues<sup>37</sup>. It is difficult to know the level of 'traditional' types of respite provision in care homes and day services across Wales, for a number of reasons:

- For local authority funded respite, the definition of respite used in the performance data collected specifies it as overnight care for the care recipient<sup>38</sup>. However, much of the respite care provided (such as day service support) does not involve an overnight stay.
- Respite data collected from Local Authorities is broken down by age, but it is not disaggregated by condition, so it is not possible to link it to dementia.
- Respite support funded or provided by Health Boards will not necessarily be described as 'respite' and is therefore not recorded/reported as such.
- As respite support is given directly to the care recipient but the break is also beneficial to the carer, this is also not adequately captured in the current system of data recording at a national level.

To help gain a more detailed understanding of the types of respite that should be available and the demand for it, Carers Trust Wales has been commissioned by the Welsh Government to undertake research which will be published later this year. This work will include dementia, but is not dementia specific.

More meaningful outcomes-based performance indicators for public bodies to monitor levels of respite were recommended in a report to the Welsh Government in 2010<sup>39</sup>. As highlighted in this report (in the section 'What is Respite?'), these outcomes need to relate to the person living with dementia as well as carers.

Ensuring that outcomes for people with dementia are considered alongside outcomes for carers also has implications for the ways in which respite services are evaluated, as this is essential for learning about what works and ensuring high quality services are made available. Limited research has been undertaken on

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37 Carers Trust Wales (2017) Response to the Finance Committee call for information – Welsh Government draft budget proposals for 2017-18.

38 Welsh Government (2017) Adults receiving care and support 2016-17; Statistics Guidance Notes, p12 <<http://gov.wales/docs/statistics/2017/171031-adults-receiving-care-support-2016-17-en.pdf>>

39 London Economics Wales (2010). Respite Care in Wales: Final Report to Welsh Assembly Government.

respite as a person-centred outcome, and a number of factors have been identified that undermine studies of effectiveness, including:

**“poorly designed and overly narrowly focused studies; variability and uncertainty in outcome measurement; lack of focus on the perspectives of people living with dementia and supporters; and failure to understanding the complexities of living with dementia.”<sup>40</sup>**

However, efforts have been made to address this. For example, an Expert Panel on Respite Research has made recommendations for how to structure and organise future research in ways that will improve understanding of respite care and maximise its benefits and resources<sup>41</sup>, and Shared Care Scotland has produced a short break evaluation toolkit<sup>42</sup> to enable providers to evaluate short break services based on outcomes for carers, outcomes for people receiving care and outcomes for services and society.

## Emergency and planned respite

A distinction is made in practice between ‘planned’ and ‘emergency’ respite<sup>43</sup>. Whilst this is useful to a point, it does not reflect the reality of people’s lives. Through our engagement work, carers in particular highlighted many circumstances that fall between ‘planned’ and ‘emergency’. For example, if they needed to do something at short notice, such as attending a doctor’s appointment, people said they were often unable to get the respite support they needed. People also wanted to be able to behave in normal, spontaneous ways, without having to plan everything well in advance.

**“I need to be able to pick up the phone and get ad hoc care.”** (Carer)

**“Some things can be planned but sometimes they are unpredictable.”** (Carer)

In some areas, people said ‘planned’ respite was far too inflexible and/or could not meet their needs:

**“I have a situation where I can’t book Mum in [to the care home for respite]. I can’t book her in until the day before. So that means I can’t book anything – a holiday or a ticket to go somewhere. I had to cancel a weekend away I had planned.”** (Carer)

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40 Dawson, A., Bowes, A., Kelly, F., Velzke, K. & Ward, R. (2015). Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach. *BMC Geriatrics*, 15(1), 59.

41 RS Kirk and Associates and Jill Kagan (2015) A Research Agenda for Respite Care; Deliberations of an Expert Panel of Researchers, Advocates and Funders ARCH National Respite Network and Resource Center

42 Shared Care Scotland (2013) Short Break Easy Evaluation Toolkit <<https://www.sharedcarescotland.org.uk/resources/tools/evaluation-toolkit/>>

43 Carers UK offers advice on emergency planning: <https://www.carersuk.org/search/planning-for-emergencies> (Accessed 20/04/2018),

**“I was told I had to book a place in the care home a year ahead.”** (Carer)

**“You don’t get anything unless there’s a crisis.”** (Carer)

Some people also wondered what ‘emergency’ respite actually meant:

**“How do I know what makes it a crisis? What’s the threshold?”** (Carer)

**“It’s hard to know when it’s bad enough.”** (Carer)

There were also examples of emergency respite provision not being available, and the costly implications of this to all concerned:

**“Without crisis respite, people end up in hospital.”** (Carer)

Whilst social workers need to ensure effective contingency plans are in place, including signposting to emergency schemes and cards that carer organisations and some Local Authorities have in place, many of the carers who took part in the engagement activity said they had not had any discussions with professionals about contingency planning.

## **Affordability**

Several people remarked how expensive traditional forms of respite could be, especially if they are self-funded; one person said they had paid £928 per week as a self-funder for nursing home accommodation. There was an appreciation that public services have had to make difficult funding decisions and are constrained by limited resources, but people could not understand why so much money was spent on expensive traditional forms of support, when much cheaper alternatives might respond to their needs more effectively:

**“Two days in a [care] home is more expensive than a holiday.”** (Carer)

**“Dementia friendly hotels may be expensive but they are probably cheaper than care homes.”** (Person living with dementia)

**“The local authority tend to have day centres in residential homes as it’s cheaper – or more like they think it’s cheaper. And it’s not individual people’s care – it’s just about containing people and that’s why people don’t want to go. It’s seen as the cheap way, but that’s wrong, rather than investing in things that are relatively low cost compared to some of the stuff they provide.”** (Carer)

**“They’re not seeing the economic case. They’re not looking at it logically and it’s not person centred....They talk about rights, but there’s no eligibility or they don’t give you the information.”** (Carer)

**“It’s a waste of money, it’s no good for anyone.”** (Carer)

**“More flexible options would be more cost effective – spend the money on what people need and save money.”** (Carer)

Some engagement participants who were accessing respite through Social Services were confused by charges for this. Within the current system, Social Services are likely to charge the respite care recipient for any respite care services provided; Local Authorities must follow guidelines about how income/capital is taken into account and the recommendation is to use discretion if it is a service provided for the carer<sup>44</sup>. However, this means there may be variations concerning how this is applied locally. There are also possibilities that people may refuse support (both people living with dementia and/or carers) based on affordability and/or the principle that the family unit should not be charged in order for the carer to have a break from their unpaid caring role. A report by the Local Government Association (England) demonstrated that charges/potential charges to carers do not represent value for money and are likely to result in increased costs to the Local Authority<sup>45</sup>.

## **Providers and the respite ‘market’**

Through our engagement activity across Wales, people described significant variation in terms of their access to the more traditional forms of respite (including day services and residential care). A relatively small number of people had positive experiences and were able to access support without too much difficulty (this could be self-funded/organised or through Social Services):

**“My mother enjoys the social interaction in the care home. She asked for a few more days. She said she liked seeing more people – she’s fed up with me!”** (Laughing) (Carer)

However, a larger number of people who had been seeking this form of provision were frustrated by the limited availability, sometimes having to wait months, or even years, for care home respite beds to become available:

**“You have to wait months to get anything – by the time you’ve got there, things have moved on and then there’s too much information and you’re completely overwhelmed.”** (Carer)

**“I had to apply for respite 7 months in advance.”** (Carer)

**“Pre-bookable respite is extremely difficult to find.”** (Carer)

We were informed that in one county there were no designated respite beds and an example was provided where a person with complex needs was placed in a care

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<sup>44</sup> See Appendix 4

<sup>45</sup> London Economics Wales (2010). Respite Care in Wales: Final Report to Welsh Assembly Government.

home in Nottingham for respite because it was the only provider who could be found by Social Services.

In some rural areas and small towns, there might be just one care home or day service presented as the only available respite options, and several carers commented that independent sector providers tend not to offer respite beds. During our engagement activity, one carer suggested that a way of overcoming this could be through families clubbing together to 'time share' a self-funded respite room, and that care home providers should be encouraged to consider more creative approaches such as this.

However, many people said they wanted different forms of respite to traditional day services and care homes, something that is being recognised in creative alternatives to day and overnight respite being established across parts of the UK, such as the examples below:

### **Practice example: TRIO scheme, Person Shaped Support (branches in England and Wales)**

Unlike conventional one-to-one or group support services, TRIO works with one (formal) carer and two service users, allowing more opportunities to meet others in the local area with similar interests and make friends through social interaction. This is facilitated by one of the Trio care team.

TRIO is provided by trained Shared Lives carers who deliver a flexible service in which carers and their families can receive a break from their caring role and users of the service can be supported to remain independent.

There is a branch of TRIO in Conwy.

**For more information: <http://psspeople.com/how-pss-can-help/get-out-and-about-and-meet-people/who-are-also-living-with-dementia>**

### **Practice example: Dementia Care Respite, Newcastle, England**

Dementia Care, a charity based in Newcastle, offers a range of services to people living with dementia and carers, including overnight respite support, which is directly linked to their dementia Day Club. The Centre has five en-suite bedrooms, all with accessible toilets and hand basins and two with showers. All rooms are fully accessible and have dementia-friendly furniture and electrically-operated beds. There is a separate bathroom in the Centre with dementia-friendly fittings and an electronic Jacuzzi bath.

To assist with people's orientation the same dementia-friendly design is used in the

respite rooms as it is in the Day Club, which is on the same site. People are able to use all of the Day Club facilities, including taking meals in the restaurant. However, if people want some quiet time away from Day Club activities, there is a separate lounge and kitchen/dining room in the Respite Centre. This can enable people to have a quiet break away or join in activities with a wider group of people, who may already be known to them.

**For more information:** <http://www.dementiacare.org.uk/services/residential-respite-care/>

Several people commented that self-organised ‘holiday-type’ options (generally spent together with family or friends) offered a better alternative for them:

**“A holiday is as good as medication – without the side effects!”** (Carer)

**“I call respite a holiday. It’s not anything exotic, it’s just a change of scene.”** (Carer)

**“I like bus trips. It’s nice to go out and about.”** (Person living with dementia).

**“My husband and I like to go on a coach holiday and that’s respite. My husband enjoys it so much... We put the case on the bus and that’s it. We enjoy the views. You don’t have to think about food. And that’s respite.”** (Carer)

**“I have been on trips to Edinburgh and Ireland with my friends. I’m so lucky.”** (Person living with dementia).

A couple of participants had stayed in accommodation specifically tailored for people living with dementia, which they found very helpful and enjoyable. In Scotland, a ‘respitality’ scheme is providing further opportunities for people to access holiday-type breaks:

### **Practice example: ‘Respitality’ in Scotland**

Respitality (Respite + Hospitality) originated in the USA. The hospitality sector ‘gift’ short breaks, which can be overnight stays, dinner reservations, spa days, beauty treatments – whatever gift the business chooses to donate. The breaks can be made available during quieter periods, when it suits the business.

Carers Centres and the Scottish Hospitality sector have worked together to introduce this scheme to provide short breaks to unpaid carers.

Respitality is currently available in 14 different Local Authority areas across Scotland. Carers can only access Respitality through their local carers centre, and current coverage is being expanded. Businesses wishing to donate a break can do so whether their Local Authority area delivers Respitality or not.

Personal stories are included on the Respitality website, including an example from MindforYou, which provides supported holidays for people living with dementia and their family or friends; they donated a Respitality break to allow an Angus couple living with dementia to have a holiday in Grantown-on-Spey.

**For more information: <https://www.sharedcarescotland.org.uk/respitality/>**

The above examples illustrate only a small number of the creative alternatives that can expand the possibilities for more local, personalised respite. A number of further examples are provided in this report, including those that were recommended through the good practice call. These projects and services are all listed in an Annex on the Older People's Commissioner for Wales website<sup>46</sup>.

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<sup>46</sup> <http://www.olderpeoplewales.com/en/Reviews/respite.aspx>



## Quality, flexibility and choice

The quality of experience for the person living with dementia is fundamentally important – both to them and to the carer:

**“Carers want the person with dementia to be happy with that support.”** (Carer)

Where people had had a poor experience, this could have lasting impact and could be a barrier to accessing support again:

**“If you have had one bad experience then you don’t forget that.”** (Carer)

**“When I telephoned the care home to raise my concerns the person at the other end said ‘People who come in to respite expect too much.’”** (Carer)

**“If my mum didn’t like the day centre then she would come home in a bad mood.”** (Carer)

If respite services were declined because there were concerns that they could not effectively meet needs, there was frustration that this could be linked to the label ‘service refusal’ or ‘service refuser’ and block access to further support:

**“It comes back to needs. It’s not service refusal. It’s that they don’t meet your needs.”** (Carer)

‘Dementia: More Than Just Memory Loss’ highlighted the importance of quality for people to have meaningful respite breaks. How ‘quality’ is experienced is dependent on a number of factors, and this largely relates to personalisation, consistency and reliability, dignity, staff knowledge and understanding, and this has been evidenced in wider research<sup>47</sup>. These themes featured throughout the Rethinking Respite engagement activity.

People particularly valued respite support where there was flexibility and choice in terms of whether the carer could join in or not, how long people chose to stay (such as drop-in services), and options at different times of the day and week:

**“We need choice of what we do.”** (Person living with dementia)

**“[Respite is] rigid and off-the-shelf...They need to tailor the service – not off-the-shelf [services] like we are little dolls.”** (Carer)

**“People need something short. Something for half an hour not two hours.”** (Carer)

**“It’s Monday to Friday. What happens on Saturday and Sunday?”** (Carer)

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<sup>47</sup> Neville, C., Beattie, E., Fielding, E. & MacAndrew, M. (2015). Literature review: use of respite by carers of people with dementia. *Health & Social Care in the Community*, 23(1), 51-63.

This particularly impacted on carers sustaining their jobs or supporting young families:

**“It really affects my working day. I have actually reduced my [work] hours because I am becoming depressed.”** (Carer)

**“I need a service that can look after my Mum while I do my parenting role. I couldn’t go to sports day because Mum didn’t want to go and I didn’t have support for her...I said that I had to work around the school holidays but all the dates had been booked up.”** (Carer)

**“Day services need to fit around school and playgroup times.”** (Carer)

People’s experiences across the UK demonstrate the choice and flexibility that direct payments can offer in relation to respite (see description in Appendix 5), yet there is still very limited uptake of this option, particularly amongst older people and carers<sup>48</sup>.

The majority of people involved in our engagement activity were unfamiliar with this route to support and said they had not been informed about direct payments by their social worker:

**“Direct payments are the best kept secret in Wales.”** (Carer)

**“Direct payments - here you have to fight for it.”** (Carer)

**“The advocacy [to help people manage direct payments] and the will is not there.”** (Carer)

**“I have heard the Council now say that they will not pay carers direct payments now and that’s illegal.”** (Carer)

**“Often Social Services keep the whole thing about direct payments quiet. They don’t want people to know about it, even though it could save them money.”** (Carer)

**“For some reason some Social Workers just don’t want to go through [direct payments].”** (Carer)

A small number of people had used the direct payments option to organise respite support. A couple of carers said their experience of this had not been positive, either because they did not feel adequately supported to manage them, the amount of money provided by Social Services did not cover the costs or because they could not find anyone to provide the service.

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48 Newbronner, L., Chamberlain, R., Bosanquet, K., Bartlett, C., Sass, B. & Glendinning, C. (2011). Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their carers. Social Care Institute for Excellence

However, other people provided positive examples that demonstrated the flexibility that this option can offer, as outlined below:

### **Practice example: Using Direct Payments for respite (Wales)**

Through our engagement activity, the examples of people using direct payments for respite included:

Direct payments for people living with dementia:

- Paying for overnight respite in a place of choice, either on their own or as a family (either in a care home or within the hospitality sector).
- Employing three personal assistant carers who work in rotation, and who operate flexibly to allow the carer to go away for extended periods of time.
- Paying for fuel costs to enable someone to stay with a family member for few days, and also paying the family member to provide support, thus giving a break to the main carer.
- Paying for a 'buddy' volunteer for a few hours or days a week, to help support the person living with dementia with what they wanted to do, in or outside of the home.

Two of the groups who supported our engagement activity (Me Myself & I and Dementia GO) also described how some of their members pay for their support and/or transport through direct payments and group organisers are active in telling members about this option.

Direct payments for carers:

Carers are also entitled to seek support for themselves in the form of a direct payment. One example of this was provided during our engagement work where a carer had used the payment for someone to mow the lawn, which was something he found difficult due to health reasons. It met the outcomes of having a break and sustaining him in his caring role: "Helping with some of the difficult things I was finding to do – things that might alleviate that."

### **(Information about direct payments is included in Appendix 5)**

All of these people said organising respite through this route was much cheaper than the alternative of an overnight stay in a residential home.

Research evidence demonstrates that direct payments can deliver positive outcomes for older people, including people with dementia and carers, as long as Local Authorities put the right support infrastructure in place<sup>49</sup>. There is also

<sup>49</sup> Age UK (2013) Personal Budgets work for older people

guidance available on how to make direct payments work effectively, both for recipients of direct payments<sup>50, 51</sup> and for Local Authorities<sup>52</sup>.

Furthermore, there is scope for people to come together and pool their direct payments and in Wales the Direct Payments & Citizen Directed Support Scheme is promoting and supporting this:

### **Practice example: Direct Payments & Citizen Directed Support Scheme, Wales**

Direct Payments are payments for people to organise their own care and support and Social Services have a duty to make direct payments available under the Social Services and Well-being (Wales) Act 2014 (see description in Appendix 5).

Direct payments can be used individually or pooled with other people in similar circumstances, which can offer greater 'critical mass' to enable new services to be established, including those that might offer respite.

Disability Wales, in partnership with Wales Co-operative Centre, established a Direct Payments & Citizen Directed Support Scheme, based on evidence of the benefits this can offer<sup>53</sup>. The scheme provides support for the development of citizen directed co-operatives as a new way to manage Direct Payments.

**For more information: <http://www.disabilitywales.org/projects/citizen-directed-co-operatives-cymru-project/>**

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50 Age Cymru (2017) Direct payments for social care services in Wales Factsheet 24w August

51 Social Care Wales Direct Payments and personal assistants <https://socialcare.wales/learning-and-development/personal-assistants-and-direct-payments?record-language-choice=en-cy> (Accessed 20/04/2018)

52 Alzheimers Society (2016) Making personal budgets dementia friendly, A guide for local authorities

53 Roulstone, A and Se Kwang Hwang (2013) Co-operation and Co-operatives in the Development of Direct Payment Schemes in Wales A Report for Wales Co-operative Centre and Disability Wales

# Information, advice and advocacy

## Information and advice

Information is critical to people being able to access the support they need, including respite, as highlighted in ‘Dementia: More Than Just Memory Loss’. Access to information is associated with a number of issues, including:

- Confusion about multiple information sources and multiple agencies
- Information in unsuitable and limited formats (for example, some people are not computer literate)
- Information either lacking or people reporting being ‘swamped’ by information at times they cannot absorb it
- Information not keeping pace with changing circumstances and a deteriorating condition
- Information not always being available in people’s own language (including Welsh) and plain language

This was evidenced in a UK wide qualitative and quantitative study, A Road Less Rocky<sup>54</sup>, which emphasised the need to provide information – including information on respite - throughout the care pathway for people affected by dementia. Information related to making information more accessible for people living with dementia has also been developed by DEEP and is included in their DEEP Guides<sup>55</sup>.

During the Rethinking Respite engagement activity, information about respite was a significant issue:

**“We don’t know what’s available.”** (Person living with dementia)

**“There must be a lot of people who are not availing of these facilities. They don’t know that these groups exist.”** (Carer)

**“My husband and I just found out [about this exercise class] by chance from the practice nurse. We were in the right place at the right time.”** (Carer)

**“I find there’s nobody at the group whose been told by their GP. We don’t all look at the posters that are there, do we? But they don’t have time to think about it.”** (Carer)

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54 Newbronner, L., Chamberlain, R., Borthwick, R., Baxter, M. & Glendinning, C. (2013). A Road Less Rocky - Supporting Carers of People with Dementia. Carers Trust

55 DEEP (The Dementia Engagement and Empowerment Project) Guides <<http://dementiavoices.org.uk/resources/deep-guides/>> (accessed 20/04/18)>

**“Social workers and GPs should have a list of every single activity or at least a list of who to approach, a guide to dementia caring, it’s so disjointed.”** (Carer)

Many people said they had heard of the services they used through word of mouth, not through a professional body:

**“It was the window cleaner who told me about a day centre in the hospital because his wife worked there.”** (Carer)

**“People from other groups have been much more supportive [in providing information] than the services who are supposed to be helping.”** (Carer)

Dewis Cymru<sup>56</sup> is available as an online portal for information about wellbeing and related services being rolled out across Wales; it includes respite care and this is ongoing in its development.

In Scotland, a range of respite options are brought together on a dedicated ‘short break’ website hosted by Shared Care:

### **Practice example: Short Breaks Fund, Shared Care Scotland**

In Scotland, the Short Breaks Fund provides grants to third sector organisations that support unpaid carers to take a break from their caring role. The fund aims to increase both the range and availability of short breaks across Scotland.

Shared Care Scotland operates the Short Breaks Fund on behalf of the National Carers Organisations and the Scottish Government, and the Scottish Government currently funds the Short Breaks Fund on a rolling annual basis.

As well as administering the fund, Shared Care Scotland provide:

- a range of support and guidance for funded projects
- a learning platform of ‘Short Break Stories’
- information on holiday-type short breaks
- a Short Breaks directory and planner

**For more information see: <https://www.sharedcarescotland.org.uk/about-us/>**

This programme of work is not dementia specific, but does include dementia short break options.

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<sup>56</sup> Dewis Cymru <https://www.dewis.wales/> (Accessed 20/04/2018)

Whilst such information platforms can be very useful, many engagement participants said they wanted more bespoke advice and guidance and assistance to navigate the system, ideally under one roof or through one port of call. There are examples of services in Wales which are providing information as part of a wider range of support, where it can be delivered in a more supportive and personalised way (for example, Dementia Matters Powys, described in the Annex of practice examples<sup>57</sup>).

## Advocacy

Several carers during the engagement sessions said they were exhausted by their attempts to gain access to support and respite, and people often used words and terms related to a 'battle':

**"I had to fight every inch of the way."** (Carer)

**"You must fight for respite because the availability is so low. There are only two respite beds in the local care home."** (Carer)

For many, dealing with agencies was a significant element of the stress they were experiencing as carers:

**"It's exhausting finding support, it's exhausting doing it."** (Carer)

**"I have had no carer assessment. I've got so much going on I feel like I need a secretary."** (Carer)

**"So much of the system is actually creating more stress...if the [basic] services that were supposed to be delivered were actually delivered that would be respite."** (Carer)

**"If the care system worked properly respite would be less urgent."** (Carer)

Advocacy - both formal and informal - is a critical element for families seeking help where they do not feel they have a voice or are not being listened to. One carer described how an advocate linked to a service provided by the Alzheimer's Society had been invaluable in getting to know the person living with dementia and representing his needs in meetings with professionals:

**"[The advocate] looks after Colin's best interests and that is his sole focus... To me that's important – he has the bigger picture... I think [the social worker] takes more notice of the advocate and I can see it changes things – [the social worker] knows that he knows the ropes. [The advocate] has probably made a difference more than anyone else we have to do with."** (Carer)

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<sup>57</sup> <http://www.olderpeoplewales.com/en/Reviews/respite.aspx>

However, even with this valued support, the carer was frustrated that they did not have an advocate for themselves, and did not feel their voice was being heard in their need for respite:

**“I am really much too near the edge.”** (Carer)



## Meaningful occupation

In 'Dementia, More Than Just Memory Loss', the need for people to have meaningful occupation was a clear message. Supporting a person living with dementia to remain active and feel involved in life is key to maintaining quality of life. However, many of those engaged with through Rethinking Respite said this was still not happening for them:

**“[In the day centre] they don’t do anything, they just talk.”** (Person living with dementia)

**“You sit with a load of people with no conversation. Day centres need more activities. It would be an answer for so many of us.”** (Person living with dementia)

**“My husband absolutely hated [the day service]. They said they do quizzes, they do bingo and he doesn’t want that... I know they haven’t got much money but it’s not about the cost. They can buy a CD or do karaoke and there’s other things they can do.... It’s making sure everyone’s enjoying what they do during that time...I told them this and they said ‘We can’t accommodate everyone’.”** (Carer)

**“They [day services] should have something to stimulate people. They have TV. They have board games. They have quizzes – but that isn’t everyone’s cup of tea.”** (Carer)

**“I was in this place [day centre] and they were all sitting around on a Monday doing nothing and I thought this was boring, so I got up and started dancing. I love dancing, I love to boogie woogie. I love getting with it.”** (Person living with dementia)

**“They need to share best practice about day services within Wales so that you don’t have the variation in what’s provided.”** (Carer)

Many people living with dementia said they wanted more opportunities to do things that made a difference to them:

**“My brain goes back to when I was a child. I can’t do things I used to do two or three years ago – but I try to get what I can out of things. You need to do what you can... It’s just finding a key to give the person with Alzheimer’s a difference.”** (Person living with dementia)

**“The more stimulation you get – it helps.”** (Person living with dementia)

**“It’s about keeping the brain active, keeping mobile, socialising. There’s a lot out there but you have to look for it.”** (Person living with dementia)

People provided many examples of the kinds of activities they liked to do, such as cookery, snooker and bowls, crafts and fishing. Intergenerational opportunities were also important to some people:

**“I love playing with children. I like to see their imagination coming out.”**

(Person living with dementia)

**“I like watching football and watching the kids play.”** (Person living with dementia)

Contact with animals also featured:

**“Loved the woods and walking my dog. Can’t go there now on my own. I’d love to walk a dog.”** (Person living with dementia)

**“We looked after a puppy for a friend and my Dad who has dementia loved him...I think animals lift people’s spirits with dementia.”** (Carer)

A Dementia Dogs scheme<sup>58</sup> is available through a collaboration between Alzheimer Scotland and Dogs for Good, providing assistance dogs and community dogs to increase confidence and reduce social isolation.

There is also an increasing body of evidence about the therapeutic benefits of arts activities for people living with dementia<sup>59, 60</sup> and creative arts featured strongly amongst people we spoke to, in particular dancing and singing:

**“I like dancing. We used to go sequence dancing and I miss it.”** (Person living with dementia)

**“There are dance sessions at Caernarfon once a month. We enjoy them.”** (Person living with dementia)

The benefits of music for people with dementia are well evidenced<sup>61</sup>. One of our engagement events was held with a singing group linked to Chepstow Methodist Chapel, and participants said how much they enjoyed it:

**“Music helps me relax.”** (Person living with dementia)

**“Singing is so valuable because we are on an equal footing. Even if mum didn’t want to come I would still come because I get a lot out of it.”** (Carer)

Having opportunities to enjoy the outdoors was also really important to people:

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58 Dementia Dogs <http://dementiadog.org/> (Accessed 20/04/2018)

59 SCIE All Parliamentary Group (2017) The Role of the Arts in Social Care

60 Windle G, Newman A, Burholt V, et al. Dementia and Imagination: a mixed-methods protocol for arts and science research. *BMJ Open* 2016;6:e011634. doi:10.1136/bmjopen-2016-011634

61 Howell, S & Bamford S.M. (2018) What would life be - without a song or dance, what are we? A report from the Commission on Dementia and Music. The International Longevity Centre and Utlely Foundation

**“There has to be a chance to go outside.”** (Person living with dementia)

**“I love to go walking.”** (Person living with dementia)

There are programmes in Wales to enable people living with dementia to access the natural environment (for example, Dementia Adventure<sup>62</sup> and Active Woods<sup>63</sup>) and evidence of the benefits to health and wellbeing through being connected to the wider environment is growing<sup>64</sup>.

Support to help people get out and about was particularly valued by carers, whose abilities to support this might be compromised:

**“Some people living with dementia are very active and like cycling or hiking, but it can be very tiring for a carer.”** (Carer)

**“Simon would be off like a shot if there was a walking group.”** (Carer)

**“I would like someone to come to the house to take my husband to the garden centre or Tintern Abbey for a walk and a coffee. We used to have this, but it stopped.”** (Carer)

**“Someone coming into the house to help them continue to do the things they enjoyed like visiting the Wetlands Centre, especially when he could no longer walk. His world got smaller and the whole family’s world got smaller and external support coming into help them would have opened up their world again.”** (Carer)

**“That would be respite if the person with dementia who likes walking could go to a walking group or have a one-to-one support worker to go walking with him.”** (Carer)

Meaningful occupation needs to be promoted within all types of respite service provision. One-to-one support, to enable tailor-made activities can be achieved through direct payments (by employing a ‘buddy’<sup>65</sup>, for example) and some projects are being established to provide this kind of personalised support:

### **Practice example: ConnectEd, Onside, Worcestershire, England**

Onside provides a range of support and advocacy schemes in Worcester, including ‘ConnectEd’ where experienced mentors provide person-centred activities for people with early onset dementia, diagnosed under the age of 65, as well as support for their carers. Mentors work one-to-one with users, with the aim of stimulating

62 Dementia Adventure [http://www.dementiaadventure.co.uk/research/visit\\_woods](http://www.dementiaadventure.co.uk/research/visit_woods) (accessed 20/04/2018)

63 Coed Lleol <https://www.coedlleol.org.uk/partners-in-the-actif-woods-wales-project/> (accessed 20/04/2018)

64 Mapes, N Think outside: positive risk-taking with people living with dementia Working with Older People, 21(3), 2017, pp.157-166.

65 see Appendix 5 and section on Quality, flexibility and choice

and maintaining their skills and interests, enabling them to engage with their local community and to develop social networks.

'ConnectEd Plus' is now available offering the same support for people diagnosed with dementia over the age of 65.

**For more information: <http://www.onside-advocacy.org.uk/what-we-do/community-services.html>**

Several people said they did not just want stimulating activities, but also wanted to feel they were being productive and making a contribution:

**“This means Mum is flourishing because she feels she’s helping others. It’s about involving Mum’s skills and she still has so much to offer the community.”** (Carer)

**“I live with memory loss but now I like to know other people’s problems so I can help them.”** (Person living with dementia)

Many of the people at the Me Myself & I club (where one of the engagement events took place) spend time making things that are offered for sale to support the finances of the club:

**“I really enjoy doing the woodwork. I can just sit in the corner and make things and they’re for sale.”** (Person living with dementia, who makes a range wooden items)

A project in Japan provides opportunities for people living with dementia to do some paid work:

### **Practice example: DAYS BLG, Tokyo, Japan**

Days BLG is a not-for-profit day centre for people with dementia. Daily activities and ideas focus on making choices, working in the community and supporting people to carry on their 'ordinary' lives for as long as possible.

Each member of the day centre can decide what they want to do that day, such as, cooking lunch or going shopping for ingredients. Members can, if they wish, undertake paid tasks around the city, such as washing cars at a local car dealership, delivering leaflets and assembling products. In return, they receive a small wage. Some are also able to give lectures about what they do.

The emphasis is on giving members freedom and responsibility. The centre's view is that the people who spend the day there are not passive people, but active members of society.

**Sourced from Pathways to dementia care in Japan (2016)<sup>66</sup>**

Further examples of projects and services that provide a range of activities and experiences for people living with dementia are included throughout this report and were also provided through our good practice call. These are listed in an Annex on the Older People's Commissioner for Wales website<sup>67</sup>.

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66 Dr Mayumi Hayashi Pathways to dementia care in Japan Care Talk 14th July 2016 published online <http://www.caretalk.co.uk/pathways-to-dementia-care-in-japan/> (Accessed 15/03/2018)

67 <http://www.olderpeoplewales.com/en/Reviews/respite.aspx>

## Home or away?

Respite at home can be a positive option for some people living with dementia, offering a familiar environment where going somewhere else could have a negative impact:

**“When they go into [residential] respite when they come out they’re disorientated.”** (Carer)

Some of the people involved in the engagement activity had used formalised befriending support at home, and in large part these experiences were positive. For example, one carer described how a young befriender had spent time with the person living with dementia compiling a photograph album and listening to music together; the befriender also started to share new music and accompany them to occasional concerts. It was stressed that befrienders need to be properly selected and matched:

**“They do not always check what suits people and match accordingly – they’re not always using common sense.”** (Carer)

There were also frustrations with long waiting lists, turnover, inflexibility and the small amount of time made available, but it was appreciated that organisations could be restricted by the limited number of volunteers available.

A small number of people also said they had organised overnight stays at home, though it was difficult to get funding for this:

**“A carer came to live in for a period so my husband could stay in his own home... Important for me to be able to pre-book it well in advance so that I could take advantage of a coach holiday for a few days.”** (Carer who had self organised and funded)

**“I needed to have a break from being constantly interrupted – it’s the lack of sleep.”** (Carer who had obtained health funding but said she had to “fight” for this)

Whilst staying in the home can be an essential element in making respite a reality, many people described how much they valued the opportunity to get out of the house:

**“When I get home I get the doldrums until I get out again.”** (Person living with dementia)

**“I sit in the house all day doing nothing. I go for a walk but I am on my own, but here I go with the walking club and I have got company.”** (Person living with dementia)

**“The more dementia took hold the more important those bits became... because it gave her a group to go to and sense of wellbeing - getting out of the flat was important.” (Carer)**

## Supporting Transitions

Carers described situations where the person they cared for did not want to access any external forms of support (either within or outside of their home). A variety of reasons were given for this, linked to fear and anxiety, cultural expectations, difficulties coming to terms with the diagnosis, or concerns about quality or lack of privacy:

**“[Going outside] is a big fear for Mum. I don’t know what to do. We’re coasting at the moment. There’s no social worker involved. We’re afraid if we take her out. We tried, but Mum refused point blank on the day.” (Carer)**

**“I’ve looked after my Mum and husband...I didn’t sleep for five years. We’ve tried to book two nights away, it’s happened three times so far, but hasn’t worked out, he didn’t like it... My only respite is meetings and carers coffee mornings. ... I can’t go too far from home. I have the room set up for him, but he won’t have anyone else in to help out.” (Carer)**

Carers may decline support for similar reasons, and some carers described how they felt guilty asking for support:

**“It’s making me feel guilty leaving him. He wants me there.” (Carer)**

These issues can cause conflict and pressure, and there were suggestions that more family support and mediation is required in such circumstances to enable people to think about different forms of respite that could work for them. In some areas there are dementia outreach services (NHS or independent sector<sup>68</sup>) that may be able to support this kind of situation and, in Australia, a respite specific service has been established:

### **Practice example: Bega Valley Mobile Respite Team, New South Wales Australia**

The Mobile Respite Team in Bega Valley includes two support workers working as a team, one with a focus on working with the carer to provide education and support and the other simultaneously working with the person living with dementia.

Through home visits, respite is provided to the carer as one of the two workers spend time with the person living with dementia. In addition, the Mobile Respite Team provide information about local respite available and assistance in applying for

68 See examples in Annex on the Older People’s Commissioner for Wales website

financial assistance for respite. Different respite options are discussed concurrently by one worker with both the carer and person living with dementia and then together. They explain the importance of respite for self-care and in supporting the relationship.

In a personal story from an evaluation report, the Mobile Respite Team assisted a carer in filling out paperwork to receive financial carers allowance entitlements and for financial assistance for respite and informed him of respite services available in the region. They arranged for the person living with dementia to be transported to regular once a week respite. The carer said he wouldn't have done this on his own.

[https://www.dementia.org.au/files/AA121303\\_FINAL\\_REPORT\\_ON\\_EVALUATION\\_OF\\_MRT\\_ALZHEIMERS\\_AUSTRALIA\\_NSW\\_JAN\\_7\\_2014.pdf](https://www.dementia.org.au/files/AA121303_FINAL_REPORT_ON_EVALUATION_OF_MRT_ALZHEIMERS_AUSTRALIA_NSW_JAN_7_2014.pdf)

Further to this, some people involved in the engagement activity said they valued opportunities to 'try out' services as this could be the key to help build trust, confidence and familiarity and help to make external support an option:

**“There’s no transition into respite – there could be opportunities for people to visit – to go and have tea – to join in some activities – just to become familiar with the place.”** (Carer)

Quality services that offered a range of opportunities (for example, care homes that offer overnight respite and day service options) were also valued because of the continuity and transition support this could potentially offer:

**“It’s a good place and he’s familiar with it, and there are familiar faces when he gets there.”** (Carer commenting on a respite bed in a care home which also operates as a day centre)

## Transport

As highlighted in 'Dementia: More Than Just Memory Loss', transport can be a significant factor for many people, affecting their ability to access respite away from home, where attendance at day centres or other forms of respite activity is reliant on domestic, private (taxis), public or community transport. This can be at unhelpful times, stressful and costly, and sometimes undermines any benefits from the service<sup>69</sup>. It may also affect whether someone actually accesses respite at all<sup>70</sup>.

Amongst the people we engaged with, transport was a particular issue for those living in rural areas:

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69 Older People's Commissioner for Wales (2014) The Importance and Impact of Community Services within Wales  
70 Blackstock, K., Innes, A., Cox, S., Smith, A. & Mason, A. (2006). Living with dementia in rural and remote Scotland: Diverse experiences of people with dementia and their carers. *Journal of Rural Studies*, 22(2), 161-176.



**“The bus is going like this for hours. For some who are poorly it’s awful.”**  
(Person living with dementia, jolting her whole body to illustrate)

**“Transport is a big issue for everybody. We had people who were paying £20 for a taxi to come to the group – it’s a lot of money.”** (Person living with dementia)

**“Even though it was meant to be respite for me, I think he got more out of it than me. Transport was provided and he was picked up between 8:30 and 11:00. But you know what it’s like - I started picking him up because the transport took so long. It wasn’t respite for me then.”** (Carer)

**“Respite should be local. I don’t want to send them miles away.”** (Carer)

Community transport connects people to respite opportunities and complements the development of dementia friendly communities<sup>71</sup>. Support for community transport helps to tackle loneliness and isolation, keeps older people connected<sup>72</sup> and contributes towards the national wellbeing goals within the Well-being of Future Generations (Wales) Act 2015. It also helps older people to remain as workers, volunteers and carers within their communities.

There are over 100 organisations across Wales delivering community transport services<sup>73</sup>, and in addition to their traditional door-to-door services, community transport operators are increasingly running demand-responsive local bus services. These include ‘Grass Routes’ (Monmouthshire), the ‘Green Dragon’ (Pembrokeshire), Neath Port Talbot CT and DANSA (Western valleys), ‘Bws Bro’ (Ceredigion), and ACT and Connect2 (south Wales valleys). As well as responding to individual calls from eligible people, there are examples of community transport services operating under contract to Wales Ambulance Services Trust, such as in Neath Port Talbot where people living with dementia are picked up from their home and transported to the Dementia Day Centre at Tonna Hospital.

Many of the people we engaged with said how much they valued community transport where it was available, but said there could be problems with availability and accessibility of some services, which they felt needed to be expanded.

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71 Ageing Well in Wales <http://www.ageingwellinwales.com/en/themes>

72 Older People’s Commissioner for Wales (2014) The Importance and Impact of Community Services within Wales

73 Community Transport Association (2014) A CTA State of the Sector Report: Wales 2014

## Complex needs and keeping people active

Dementia is a progressive and life limiting disease. Each person is unique and will experience dementia in their own way, but people may have physical symptoms such as muscle weakness and difficulties with speech, especially in the later stages. There are also numerous forms of dementia, which manifest differently, and might include difficulties with movement or impaired visuospatial skills<sup>74</sup>, for example.

**“My husband’s condition varies, he’s got good days and bad days – the support needed varies.”** (Carer)

Given the age profile of people with dementia, they are also likely to be affected by other health conditions, such as heart disease, stroke and diabetes, where the risks increase with age. There is also clear evidence of an association between visual impairment and dementia, and age-related hearing loss and dementia<sup>75</sup>.

**“Dementia doesn’t come on its own. My husband has many different needs and several other conditions and things have to tie in with all that stuff.”** (Carer)

Some people will have disabilities that may be long standing, including learning disabilities, mental health problems or physical and sensory impairments, which will all impact in unique ways with dementia, and must be fully supported.

As health conditions progress and people age, there may also be a requirement for palliative care, and there is a good example of this working for people living with dementia in Wales:

### Practice example: Hospice of the Valleys, Blaenau Gwent, Wales

Hospices have traditionally specialised in supporting people with cancer. If people with dementia are referred to them it tends to be at the very end of life rather than helping them to remain as comfortable as possible before that. In 2014, the Hospice of the Valleys launched the Challenge Project in partnership with Alzheimer’s Society to improve support for people affected by dementia in Blaenau Gwent, South Wales.

At a weekly group in the hospice’s day centre, people living with dementia and their carers enjoy games, gardening, conversation and other activities, with clinical support and dementia support workers close at hand. Carers are also welcome to attend.

<sup>74</sup> Alzheimer’s Society (2017) Factsheet 400LP: What is dementia?

<sup>75</sup> SCIE Living with dementia and sensory loss <https://www.scie.org.uk/dementia/living-with-dementia/sensory-loss/> (accessed 20/04/2018)

The hospice provides education and support to people with all types and stages of dementia, their families, professionals, volunteers and the public. There is also a linked befriending service, so that people can also be supported in their own homes.

**For more information: <http://hospiceofthevalleys.org.uk/dementia-services/>**

However, throughout our engagement activity, many people described situations where the particular impact of dementia and/or other health conditions/disabilities were not always taken into account in relation to the types of respite being offered:

**“They said ‘It’s taken three people to get your dad up’, but I had told them what his needs were and the routine that he knows... that one person would need to talk to him when they were getting him up... It’s about communication, about knowing the person.”** (Carer)

**“My husband was supposed to have respite in a nursing home for two weeks but they sent him home within the first few days saying they could not cope with him.”** (Carer)

**“[The day service staff] were hopeless at realising that he had difficulty doing certain things.”** (Carer)

There was also concern that where people living with dementia might become distressed, this was not always understood or managed appropriately:

**“If we were suddenly in a strange place like that [day centre or care home] we’d be quite nervous.... then people are labelled as challenging and aggressive if they react negatively.”** (Carer)

Several carers of people with higher support needs said access to services was denied, or services were withdrawn, linked to reasons such as mobility levels, personal care requirements, related conditions and/or perceived behavioural issues:

**“My husband was refused entry – he needed two carers, and was rejected on health and safety grounds.”** (Carer talking about care home respite)

**“They [the care home] have to fit [Joe’s] criteria, it’s not [Joe] fitting their criteria.”** (Carer)

There were concerns that people could be labelled as having so-called ‘challenging behaviours’ and excluded from services, instead of providers dealing with these issues through listening to carers, training staff and adapting environments, with specialist inputs where necessary.

A lack of sufficient support could also leave carers at risk. For example, one person described how she was left to manage lifting and moving her 19 stone husband because it was deemed too risky for the paid carers to carry on providing support.

Helping people living with dementia to stay physically active is vital to help slow its progression and avoid people's needs becoming unnecessarily complex, and evidence of the benefits of physical activity is growing<sup>76</sup>. Prevention work is also especially important, given the risks associated with muscle weakness, including reduced mobility and falling. During the engagement activity, people living with dementia and carers who were participating in an exercise class said how much they benefited from this:

### **Practice example: Dementia GO, Gwynedd County Council, Wales.**

Dementia GO is a weekly session delivered by staff and volunteers, which provides chair-based exercises based on improving strength, balance, coordination and stamina for people living with dementia. Two different classes are available, aimed at people with different levels of functioning. Carers are able to join in or not, whatever they prefer, and the classes are supported by volunteers. People living with dementia who attended described how much they benefited from it:

**“We know what’s good. I never knew there were so many exercises you could do sitting down in a chair!”** (Person living with dementia)

**“It’s the people who do it so well. With new people they introduce things slowly and let them sit and do whatever they want to do. It’s all about the people.”** (Person living with dementia)

A carer also described the physical health benefits she had seen in her husband since he started – including the health professionals:

**“The specialist said ‘It’s Dementia GO helping out the health service’ – his health has improved hugely over the last few months.”** (Carer)

The classes are held in 14 locations throughout Gwynedd, some based in Council leisure centres and others in community halls, and extra Care housing facilities. In the leisure centres, people are encouraged try out other activities, for example:

**“I’ve never played table tennis in my life, but now I’m a champion!”** (Person living with dementia)

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76 Morris JK, Vidoni ED, Johnson DK, Van Sciver A, Mahnken JD, Honea RA, et al. (2017) Aerobic exercise for Alzheimer’s disease: A randomized controlled pilot trial. PLoS ONE 12(2): e0170547.

Refreshments are provided and people use this as an opportunity to socialise after the class, which they clearly value:

**“With the café here it’s gelled us into a very good group. There’s the exercise and the getting to know, supporting each other.”** (Person living with dementia)

This was also reflected by carers who attended, who enjoyed the social support in particular:

**“It’s normality. You can share support. You can have a cuddle. It’s the highlight of my husband’s week and sometimes, I think, mine.”** (Carer)

## Safeguarding and positive risk taking

“It’s not respite if I don’t know she’s safe... I always have to anticipate her needs and others need to do this.” (Carer)

“The doctor has said he shouldn’t go out alone but that isn’t helpful because he can still go to the shops to get a pint of milk. It feels like he’s lost his independence too soon.” (Carer)

People have the right to be treated with dignity and respect and to ensure that appropriate safeguards are put in place to protect them from abuse and neglect. As dementia progresses, support needs become more complex and the person with dementia may lose capacity to make certain decisions. Capacity can fluctuate and always needs to be assessed in relation to a particular decision at the time it needs to be made, taking into account people’s communication abilities, which may be compromised<sup>77</sup>.

When undertaking risk assessments<sup>78</sup>, it is important to remember that all activity involves an element of risk-taking, and that restricting activity may detrimentally affect a person’s wellbeing. This has implications for carers, providers and the community, as well as policy makers and legislation. A risk averse approach can have significant implications for respite, how it is delivered and the options that are made available to people.

Throughout the Rethinking Respite engagement activity, people living with dementia said they wanted respite opportunities that gave them the opportunity to carry on doing things they enjoyed - such as walking outside, cooking, using public transport and making things using tools– all things that might be deemed ‘too risky’ for them at some point. ‘Risk enablement’ recognises the current strengths and abilities of a person with dementia and how to support them and there is a range of guidance to help practitioners work in this way<sup>79</sup>.

**‘Developing systems for enabling and managing risk is one of the most important ways of allowing people with dementia to retain as much control over their lives as possible.’<sup>80</sup>**

A particular feature of the lives of many people living with dementia is that their lives can become somewhat ‘internal’, where fears about people getting lost or falling contribute to them being restricted from going outside. As previously highlighted, many of the people living with dementia (and carers) said that respite opportunities

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77 Social Care Institute for Excellence (SCIE) Safeguarding people with dementia resources <https://www.scie.org.uk/dementia/after-diagnosis/support/safeguarding.asp> (accessed 26/03/2018)

78 Older People’s Commissioner for Wales (2011) Protection of Older People in Wales; A Guide to the Law

79 Blood, Imogen (2016) Enablement in dementia Research in Practice for Adults

80 Department of Health (2010) Nothing Ventured, Nothing Gained; Risk Guidance for people with dementia

in the wider environment were particularly important to them.

Some people had found solutions through technology, even for the short term:

**“For Dad it’s really important to get out. Mum’s not able to do this with him anymore. Going for fresh air really, it’s good for you and Dad loves it. We had a tracker for a start but that’s not enough now.”** (Carer)

Tracking technology can play an important role in enabling people living with dementia to go outside in relative safety. Whilst there are ethical issues associated with the use of technology that need to be taken into account<sup>81</sup>, used sensitively it has the potential to work well. A care home in Australia has developed a range of activities to enable people living with dementia to enjoy being ‘outside’ in safety, and options for people are developed in partnership with family carers:

### **Practice example: Elizabeth Lodge, Sydney, Australia**

Elizabeth Lodge has developed a range of ways of enabling residents living with dementia to enjoy the outside – either enabling them to go out or devising ways of bringing the ‘outside in’. This includes:

The Club – for residents living with dementia the conversation is all about ‘going out’ and ‘going to The Club’, which includes a balcony area, and people are encouraged to socialise and select an activity of their choice.

This is highly ritualised (through, for example, dressing for the weather) to promote the idea of ‘going out’ and of it being special.

Walk N Talk runs seven days a week, for seven hours a day. A staff member is assigned to accompany residents outside for a walk. Sometimes residents go alone, sometimes they go in small groups of up to three people. The staff member wears a bright orange t-shirt and is clearly identifiable.

GPS watch/phone - Elizabeth Lodge owns three GPS watches which are regularly used by several residents, all with a diagnosis of dementia. Residents who use the watches must still have good road sense and the ability to understand the simple instruction of answering the phone.

**For further information: Taking the risk: strategies to support getting out and about (2017) <http://journalofdementiacare.com/taking-the-risk-dementia/>**

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81 Bartlett, Ruth (2015) Realising disability-rights in dementia care: Using location technologies as an example, University of Southampton

## Risk of abuse

Another dimension of safeguarding includes abuse or potential abuse, as highlighted in ‘Crimes against and abuse of older people in Wales’<sup>82</sup>. This cuts across every level of society; it can take place within statutory and independent providers and within familial and extended household relationships.

Research indicates that having multiple caring roles, stress, isolation and living in the same household is amongst a range of factors that increases the risk of abuse<sup>83</sup>. Furthermore, if a carer does not know how to meet the needs of a person with dementia, or where risk arises from a lack of coping skills or unmet needs, unintentional harm can be caused:

**‘Perpetrators might therefore be family members, paid or unpaid carers, practitioners, or neighbours or friends. However, we do appreciate that sometimes abuse is not intentional. Often it can be ‘passive’ because someone lacks the skills or support they need to adequately care for another person.’<sup>84</sup>**

These risks have been recognised by the Welsh Government in their Information and guidance on domestic abuse (2017), which was produced in partnership with the Older People’s Commissioner for Wales<sup>85</sup>. This guidance also draws attention to carers who may be at risk of harm, where the person living with dementia may lack understanding of the negative impact of certain behaviours and actions, and/or may react with force if they are in a distressing situation<sup>86</sup>.

The Centre for the Study of Ageing, Abuse and Neglect within Aberystwyth Law School is currently undertaking a research project – ‘Choices’ - looking into different aspects of ageing, family relationships, elder abuse and justice<sup>87</sup> and this is providing people with a range of support, knowledge and skills to explore and act on these issues.

Whilst abuse takes many forms and can be precipitated in many ways, research suggests<sup>88,89</sup> that respite can be an important intervention to alleviate stress and reduce the risk of abuse, as part of a planned approach to dementia support.

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82 Wydall, S, Zerk R and Newman J (2015) Crimes against and abuse of older people in Wales; Access to support and justice: working together Older People’s Commissioner for Wales

83 Kohn, R and Wendy Verhoek-Oftedahl, Caregiving and Elder Abuse Med Health R I. 2011 Feb; 94(2): 47–49.

84 Dementia Services Development Centre Elder abuse and dementia (2016)

85 Welsh Government (2016) Information and guidance on domestic abuse: Safeguarding older people in Wales

86 Alzheimers Research UK (2015) Dementia in the Family; The impact on carers

87 Choices programme (The Centre for the Study of Ageing, Abuse and Neglect, Aberystwyth Law School) <http://choice.aber.ac.uk/about/> (accessed 20/04/2018)

88 Kohn, R and Wendy Verhoek-Oftedahl, Caregiving and Elder Abuse Med Health R I. 2011 Feb; 94(2): 47–49

89 Dementia Services Development Centre (2016) Elder abuse and dementia



## Diversity issues

This report has already raised issues related to complex needs and other health conditions (page 49). Further to this, respite support needs to serve the broad diversity of people. Policy makers, commissioners and providers need to recognise the barriers people may face associated with this, related to age, gender, disability, sexual orientation, ethnicity and culture (including language preference), and these issues were raised by engagement participants:

**“No two people are the same.”** (Person living with dementia)

**“They’re unable to speak people’s own language. It’s important that this is available.”** (Person living with dementia)

A report by the National Care Forum<sup>90</sup> outlines the prejudice and lack of support still experienced by lesbian, gay, bisexual and transgender (LGBT) people with dementia. The authors note that a positive change in social attitudes (and the law) mean that today’s older LGBT people, who will be more open about their sexual orientation and gender identity compared to previous generations, will require ‘a fundamental, leading role for the social care, health and voluntary sectors’ in developing stronger dementia care strategies and support, underpinned by robust training for professionals.

A global research review on women and dementia<sup>91</sup> describes how dementia impacts women more than men, not only because women make up over 60 per cent of the global ageing population, but because they are the main caregivers, both paid and unpaid. Evidence also suggests that female carers are the most exposed to social isolation and may experience the greatest benefit from having respite from caring<sup>92</sup>.

An All Party Group on Dementia report concerning the experiences of black, Asian and minority ethnic communities<sup>93</sup>, published in 2013, set out the language, cultural and religious barriers that people may face, and the lack of culturally appropriate support available. It highlights that local areas need to properly understand the needs and assets of their local communities in order to put the right support in place.

Language preference is a particular issue for Wales, covered in law through the Welsh Language Measure and associated Regulations<sup>94</sup>. It is also a particular

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90 National Care Forum (2017) Foundations for the future: dementia care for LGBT communities

91 Erol, P, Brooker, D and Peel, E. (2015) Women and Dementia; A global research review Alzheimer’s Disease International, London

92 Romero-Moreno, et al (2014). Leisure, Gender, and Kinship in Dementia Caregiving: Psychological Vulnerability of Caregiving Daughters With Feelings of Guilt. Journals of Gerontology Series B: Psychological Sciences & Social Sciences, 69(4), 502–513.

93 All Party Parliamentary Group on Dementia (2013) Dementia Does Not Discriminate; the experiences of black, Asian and minority ethnic communities

94 Welsh Language Measure (Wales) 2011 and Welsh Language Standards (No. 6) Regulations 2017

issue for dementia, because people are often more confident communicating in their first language as dementia progresses, even if they have been fluent in a second language. The implications of this were recently set out in a report by Bangor University, 'Access to dementia services for bilingual (Welsh and English) residents'<sup>95</sup>, which puts forward a range of recommendations including the promotion of bilingual support and the establishment of 'hubs' where people can access a range of information and support. The report makes reference to a successful example of bilingual community support:

### **Practice example: Day Service, Waengoleугоed Independent Chapel St Asaph, Denbighshire**

Waengoleугоed Independent Chapel hosts a bilingual day service that is open to anyone who is 'not in health' including people with dementia. There is transport with Dial-a-ride from door to door for people living in Denbighshire, and transport support is possible for people who live in Conwy and Flintshire.

A wide range of activities are available, such as craft activities, mild exercise, singing and entertainers, days out, creative writing and guest speakers. The centre also operates as a 'hub' for wider services, such as advice, help to fill in a form, 'benefit advisers' who come on a regular basis and information on where to go if you need more help.

There is a small library of Welsh and English books available, and an opportunity to read the newspapers and Papurau Bro (a Welsh-language local community newsletter).

The service is self-funding, reliant on donations and volunteers.

**For more information: <http://www.capelywaen.btck.co.uk/>**

There is evidence that this kind of 'hub' model (which can provide respite alongside a range of other services) can also offer sustainable solutions for people affected by dementia who live in rural areas<sup>96, 97</sup>. Furthermore, smaller scale services, such as Homeshare day support, have the potential to offer flexible alternatives in rural environments:

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95 Hedd Jones, Catrin (2018) Access to dementia services for bilingual (Welsh and English) residents Bangor University for National Assembly for Wales Research Service

96 Clark A, Bradford L and Robertson J (2010) Dementia care at home in rural and remote areas; Summary findings of literature review Centre for Rural Health; Research and Policy; UHI Millennium Institute and University of Aberdeen

97 Innes et al (2006) Service provision for people with dementia in rural Scotland – difficulties and innovations. Dementia, Sage Publications Vol 5(2) pp249-270

## **Practice example: Homeshare (day support), North Wales Crossroads, Wales**

The Homeshare scheme, based in Anglesey, is provided by North Wales Crossroads (Carers Trust). It involves Carer Support Workers taking up to three people living with dementia into their own home for the day for 5-6 hours.

The people involved can enjoy taking part in a homely setting, have lunch and socialise, and a range of activities can be supported. This service is offered weekly for up to 12 weeks and is free.

**For more information:** <http://www.nwcrossroads.org.uk/homeshare>

Although the prevalence of dementia increases with age, the age range covered is actually very wide. A person living with young onset dementia may have very different requirements than someone who is 30-40 years older, and the Welsh Government has provided funding to Local Authorities to support the development of related support services.

Amongst the people with early onset dementia who participated in the engagement activity, there appeared to be variation in terms of the level and quality of support available to them:

**“We need respite that’s appropriate for the person – age and stage appropriate.”** (Carer)

**“There’s nothing out there for under 65s.”** (Carer)

**“He was offered a part day in our local day centre. He’s late 60s and he doesn’t feel old. When we went in they were all just sitting there... I really didn’t want to leave him, just sitting there like that. He can do that at home. I wanted stimulation for him.”** (Carer)

**“I felt safe. My angel turned up....You have a person like that and one door opens and then others open.”** (Person living with dementia, commenting on support from the early onset dementia nurse)

A service for younger people with dementia has been established in Flintshire, which makes efforts to promote community engagement:

## **Practice example: SYD - Service for Younger People with Dementia, Flintshire County Council, Wales**

In Flintshire, a range of support is offered to people with early onset dementia. A terraced house is available to the SYD Club, which provides a homely domestic

environment. Lunch is cooked together every day and people are involved in going out to get the shopping. This can also provide an opportunity for people to do their own personal shopping if they wish.

The house can support up to seven people at a time. Activities are agreed by members, who have a meeting every six weeks to consider what they would like to do; this includes a range of outings and everyday activities in the local community as well as activities within the house.

‘Dine with SYD’ is another strand of the service, which provides regular opportunities for members to meet and go out in the evening to a local pub or restaurant. There is an ‘open door’ policy for carers, who can join in activities if they wish. Referrals are through social services, and the service is available to people under 65 but may also support people up to the age of 70.

**For more information on SYD and other support for people with early onset dementia in Wales: <https://www.youngdementiauk.org/wales>**

# Maintaining and building relationships

## Relationships with family, friends and neighbours

Participants involved in the engagement activity lived in a range of different circumstances and caring relationships – people living alone, couples in spouse or partner/co-habiting relationships, people living with wider family members or friends, and carers providing support at a distance. Sustaining relationships with friends, neighbours and wider family members – and securing their help and support - was an important feature of respite for many people:

**“Our next door neighbours have helped. They fitted a gate on top of the stairs and sensors to keep [Jim] safe. They’ve put a gadget on the phone to stop cold calls.”** (Carer)

**“I go and stay with my sister. My daughter picks me up. It helps [my husband] too, having a break from me.”** (Carer, with husband nodding)

**“Old friends can be of huge value. One of them is playing bridge with my father today. He is my respite.”** (Carer)

However, some people expressed concerns about the sustainability of this.

**“My family can’t take me out all the time.”** (Person living with dementia)

**“[My father] goes to stay with my brother for respite, but the worse he gets that respite is more difficult. But he won’t go with anyone else.”** (Carer)

**“You get to a certain age when it’s a big pressure on your friends.”** (Person living with dementia)

As highlighted in ‘Dementia: More Than Just Memory Loss’, there were frustrations that family and friends could sometimes fail to appreciate the caring situation, the impacts of dementia or the ways in which people can be positively supported.

**“Everyone had been giving me a wide berth – ‘Don’t talk to her, her husband’s got dementia’ – same as my family. It’s the lack of understanding.”** (Carer)

The impact on wider relationships and recognising and supporting ‘caring networks’ is also something that may require further attention from policy makers and providers. This is something that has been recognised by Alzheimer’s Scotland, which has produced a booklet targeted at friends who may not know how best to support people: “I’ll get by with a little help from my friends; Information for friends of people with dementia.”<sup>98</sup>

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98 Alzheimers Scotland (2015) I’ll get by with a little help from my friends; Information for friends of people with dementia

It has already been highlighted that a diagnosis of dementia can put particular strain on relationships and some people involved in the engagement activity suggested that family mediation support could be of value here. The ‘adaptive-coping’ model<sup>99</sup> was developed in recognition of the strain on relationships that a diagnosis of a severe illness or a chronic condition can bring, and there are many changes to which the person and their family have to adjust. This model has been adopted by ‘Meeting Centres’ for people with dementia, which were developed and established in the Netherlands and are now being piloted in the UK:

### **Practice Example: Meeting Centres – Brecon Friendship Circle, Wales**

The Brecon Friendship Circle, which began in March 2017, meets twice weekly and encourages well-being and quality of life, particularly for those living with dementia and memory loss who may be isolated in the community. The Friendship Circle is based on the principles of the Meeting Centres Support Programme, which was originally developed in the Netherlands 25 years ago, based on the ‘adaptation-coping’ model. There are now 144 Dutch centres with a national infrastructure that local groups can utilise to establish new centres.

Practical information, personal advice and support is available, responding to the needs of the local members, and includes recreational and social activities. It is facilitated by a small team of staff and volunteers trained in the ethos of person-centred dementia care. The carer support is provided under the same roof and by the same people as the support of the person living with dementia.

Research has demonstrated that participating in Meeting Centres has positive outcomes for people with dementia and for carers. The model is currently being established in Italy and Poland, and UK Meeting Centres linked to this programme have also been established in Droitwich, Leominster, Ross on Wye and Lutterworth. The Meeting Centres model is being evaluated as part of an EU-funded research project called MeetingDEM.

**For further information see: <http://dementiamatterspowys.org.uk/dementia-meeting-centres>**

**[https://www.worcester.ac.uk/documents/Meeting\\_Centres\\_Support\\_Programme\\_Overview\\_evidence\\_and\\_getting\\_started\\_Conference\\_booklet.pdf](https://www.worcester.ac.uk/documents/Meeting_Centres_Support_Programme_Overview_evidence_and_getting_started_Conference_booklet.pdf)**

**<https://www.meetingdem.eu/>**

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99 Brooker, D., Dröes, R. & Evans, S. (2017). Framing outcomes of post-diagnostic psychosocial interventions in dementia: the Adaptation-Coping Model and adjusting to change. *Working with Older People*, 21(1), 13-21

Questions about the option of ‘foster families’ or ‘live in’ support were raised by a couple of engagement participants as providing possible solutions for respite. This kind of support is available in some areas, with schemes such as ‘Shared Lives’ providing respite of variable duration within a host family’s home:

### **Practice example: Shared Lives**

In Shared Lives, an adult who needs support and/or accommodation becomes a regular visitor to, or moves in with, a registered carer. It is a regulated service where a family includes an individual in their family and community life. The service aims to match the person needing care with those providing it based on compatibility, so they can form a meaningful relationship. A disabled or older person can become a permanent part of a supportive family, visit for short-breaks or get day support. Short-break support can involve the person staying with a Shared Lives carer from one night to several weeks. This form of support has predominantly been targeted at people with a learning disability but is increasingly includes people affected by dementia. An example of this support, where Shared Lives carers opened-up their home to an older person with dementia, can be found in a recent report *The state of Shared Lives in Wales* (see below).

Shared Lives Plus is being supported in Wales to develop more services for older people, including people living with dementia.

**For more information:** <https://sharedlivesplus.org.uk/home/nations-and-regions/wales>

An independent evaluation of Shared Lives<sup>100</sup> has shown that the Shared Lives model can enhance wellbeing, reduce feelings of social isolation, and reduce the likelihood of carer breakdown. It can also reduce confusion caused by multiple environments for different forms of care. The evaluation demonstrated that Local Authority-run Shared Lives respite schemes are cheaper compared to more ‘traditional’ forms of respite. Most schemes have some experience of dementia support and the suitability of the service has been evaluated and shown to provide positive outcomes<sup>101,102</sup>.

This kind of support can also be delivered through a person needing accommodation coming to live in a household, in return for providing a set number of hours of support. For example:

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100 Shared Live Plus (2018) *The state of Shared Lives in Wales* (2018)

101 Shared Lives Plus (2017) *An independent review of Shared Lives for older people and people living with dementia* PPL with Cordis Bright and Social Finance

102 Shared Lives Plus (2013) *National Dementia Project Final Report*

## **Practice example: Homeshare (accommodation), UK wide with a branch in Wales**

Homeshare brings together people with spare rooms with people who are happy to chat and lend a hand around the house in return for affordable, sociable accommodation. Participants are carefully vetted, matched and supported. The scheme can support people living alone and older couples who feel they might benefit. There is ongoing support from the scheme to ensure the placement runs smoothly.

There are more than 20 different HomeShare schemes across the UK and Republic of Ireland and they are brought together under one umbrella organisation - Homeshare UK. The website provides a map of local schemes and an application process for people seeking accommodation.

**For more information: <https://homeshareuk.org/>**

## **Social support and peer support**

Several examples provided through the good practice call provide respite opportunities where one of the primary objectives is social support, either for people living with dementia and/or for carers. Within the engagement, some people had used such groups, including 'Memory Cafes', and enjoyed the contact with people in a similar situation that this provided.

It was notable that several people who were attending activity-based groups said this was a crucial 'stepping stone' in gaining social support. In many cases the social support was a 'by-product' of the activity, but it became one of the most important outcomes for them, significant to both people living with dementia and to carers:

**“My Mum wasn’t a group type person before and it took a lot for her to come along [to Dementia Go]. But she enjoys it now and coming here has given her more confidence. It’s not about the exercise really, it’s the social side.”** (Carer)

**“It keeps people in the world... He might not have joined a group - this sort of thing - but he really gets so much out of it.”** (Carer)

**“He used to try to go home [from the day service], but now he’s very involved and engaged... You need to know someone to know what they’ll enjoy.”** (Carer)

A couple of people commented that men in particular may find activity-based groups helpful, building on the idea of 'Men's Sheds', which are local groups or enterprises that are set up in communities for the benefit of men and can take many forms depending on the interests of those involved (for example, wood work or gardening).



There is growing recognition of the benefits of this form of support for men living with dementia<sup>103</sup>.

The value of peer support was highlighted in ‘Dementia: More Than Just Memory Loss’ in relation to carers, but the value of this for people living with dementia was very clear in the Rethinking Respite engagement activity. Many people were gaining this kind of support through quality respite activities, such as the one described below:

### **Practice example: Me Myself & I Community Friendship Club, Briton Ferry, Wales**

The Me Myself & I club provides a range of support to people living with dementia, and carers can join in activities if they wish. There are options of a ‘Day Break’ service (charged, including meal and transport, where people can self-fund or be referred through Social Services) plus a drop-in Community Friendship Club, which is free and open to all. There is a wide range of activities available, including games, crafts, quizzes, music, sports and exercise, and there is a Wednesday Walking Group. People can choose to join in activities or undertake solitary activities if and when they prefer. There is a kitchen where people are enabled to cater, safely, and the environment is decorated and organised in a homely manner with lots of different spaces to use.

Me Myself & I is funded through donations and fund-raising, and is almost entirely supported on a volunteer basis. A dementia academy (established and run by the Me Myself & I organiser) is attached to the service, and this helps to ensure volunteers are trained with an enabling ethos. As well as enjoying the range of activities, people with dementia placed particular value on the friendship and peer support that the service made possible:

**“The first time I came here people were talking to me and not at me.”**

**“I come here and people understand.”**

**“When they’re crying I know how to talk to them. I know what they’re going through ... every week [another member] cried. She had to hold my hand but she’s laughing now.”**

**“Everyone’s friendly. No-one looks down on me ’cos I can’t remember. It doesn’t matter.”**

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103 Milligan C, Payne S, Bingley, A and Cockshott (2012) Evaluation of the men in sheds pilot programme Age UK

Carers are also welcome to attend and they also valued the peer support:

**“I come here for support and the circle of unity and the banter, as a relative it is very lonely and I feel isolated, caring for someone with dementia. It also gives me insight into understanding dementia.”**

As well as talking about the emotional support and opportunity for information sharing, being able to laugh and joke together was really significant to people living with dementia:

**“We laugh a lot. A lot!”** (Person living with dementia)

**“We have a laugh – I love it, you can talk to all the people around us in confidence.”** (Person living with dementia)

**“My life changed going to these meetings and exercise classes. It’s got to be one of the best places...I couldn’t be better looked after. We all have a good laugh and pull each other’s leg.”** (Person living with dementia)

It is also important to listen to people living with dementia when they do not wish to join in with group activities, as stressed by a couple of people living with dementia during the engagement activity:

**“I mainly like to read.”** (Person living with dementia)

**“I can also sit here by myself. There’s no pressure.”** (Person living with dementia attending Me, Myself & I)

## Social inclusion and having an 'ordinary' life

**"It's about going out, being a part of the world."** (Person living with dementia)

Social isolation is a major challenge for people living with dementia. A 2014 Alzheimer's Society survey of 1,000 people found that less than half felt a part of their community, 40% felt lonely recently and almost 1 in 10 only leave the house once a month. This sense of isolation was highlighted in 'Dementia: More Than Just Memory Loss' and was evident through our Rethinking Respite engagement work:

**"I do my own housework. It's company to do things I need."** (Person living with dementia)

**"It's the isolation. We came here [to Me Myself & I] to have a social life because we didn't have a social life for about five years."** (Carer)

The factors contributing to isolation were not only associated with the barriers to respite that have been highlighted in previous sections - for some people it was the attitudes of others:

**"People got up and left me."** (Person living with dementia)

**"People crossed the road."** (Person living with dementia)

**"People are ignorant, they stop speaking to you."** (Person living with dementia)

**"Since my Mum was diagnosed it's surprising how many people you know are affected – friends and colleagues. There's still a stigma. People hide it and don't talk about it."** (Carer)

Concerningly, the impact of this could be potentially life threatening and three people involved in the engagement work said they had previously self harmed or considered suicide linked to this sense of rejection - a feeling that had been transformed since their experience of quality respite and peer support.

The establishment of dementia friendly communities<sup>104</sup> was greatly appreciated amongst engagement participants as an important element in raising public awareness, and reducing social isolation. When working well this can enable people to have opportunities for respite through accessing 'everyday' activities and facilities, rather than having to rely on separate service provision:

**"I like bus trips, it's nice to go out and about. Unless I have company I don't go out. We went on a mothers' day trip for £99 to Liverpool - the trip was easier because we met a lady who was a Dementia Friend. She helped me when I got a little lost in the hotel. It was really helpful to have people who**

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104 Morgan, S and Williamson, T (2014) How Can 'Positive Risk-Taking' Help Build Dementia-Friendly Communities? Joseph Rowntree Foundation

**understood dementia.”** (Person living with dementia)

**“If I see someone with the Dementia Friends badge it makes me feel like I can talk to them and ask them for help.”** (Person living with dementia)

People were keen for this to go further, with added support if needed:

**“The dementia friendly ethos needs to go to all different groups. Walking groups, craft groups, dementia friendly shops.”** (Carer)

**“It would be good to go into colleges to have your hair done - [the students] will also get to know about how to work with people with dementia.”** (Carer)

**“Someone to enable you to do the things you always used to do, shopping trips, things like that.”** (Person living with dementia)

**“I’d like to feel able to go and visit my daughter for a few days without having to rely on family to take me. It would be good to have a Dementia Friend to help me travel.”** (Person living with dementia)

### **Practice example: Solva Care, Solva, Pembrokeshire, Wales**

Solva is a small coastal community in Pembrokeshire which is striving to become a dementia friendly community. Solva Care was set up in 2015 in response to community need, and is designed, set up and run by the community. It aims to maintain and improve the health and wellbeing of individuals and families, including people living with dementia and carers. Care and support is provided by a voluntary service run by one part time paid co-ordinator; volunteers are vetted and have been trained by the Alzheimer’s Society.

A range of individualised support is available to help people get out and about, including offering respite support, and people are enabled to join in community activities as much as possible. People are also signposted to other sources of help and information.

Solva Care is funded by a number of sources, including the Sustainable Development fund, Welsh Government, Police, Hywel Dda Health Board, donations. There is no charge for services but contributions towards fuel used in transport are welcomed.

Research and evaluation has been undertaken internally and in partnership with Cardiff and Swansea Universities. This has found that social enterprises such as Solva Care can be of real benefit to communities and offer a great deal in terms of social value.

**For more information: <https://solvacare.co.uk/>**

# Rethinking Respite: Conclusions and Next Steps

This exploration of respite has provided important evidence concerning the experiences of people living with dementia and carers. It has shown that not all 'routes to respite' are clear to the public, the infrastructure for delivery is not always sufficiently enabling and there is uneven access across the country.

With some notable exceptions, many people said that current options are not delivering the quality, flexibility or accessibility they need and there was concern that money is being spent on respite services that do not deliver meaningful outcomes.

This is not an effective use of public monies, especially in times of restricted resources. The business case for supporting carers is clear: carers are estimated to save the Welsh economy the equivalent of £8.1bn of care every year in care costs<sup>105</sup>, and commissioning for carers could equate to a saving of almost £4 for every £1 invested<sup>106</sup>. It is difficult to quantify the financial impact of respite support in delivering outcomes for people living with dementia, as there are no studies that have specifically addressed the economic outcomes of respite from the perspective of people living with dementia; however, evidence from the research and the range of practice examples provided have demonstrated that positive ways of addressing these issues are possible, often at similar or far less cost compared to the more traditional forms of service delivery, and with better outcomes. Respite also needs to be available throughout the dementia care pathway - not driven by crises - with an 'invest to save' preventive approach that helps to sustain caring relationships, build resilience and promote quality of life.

We need to **rethink respite** in order to support delivery of positive outcomes – both for carers **and** people living with dementia in Wales.

On this basis, we must Rethink Respite in the following ways:

## Rethinking Language and Terminology

The language and terminology we use is an important step in reframing how people understand the issues related to respite.

As set out in the 'Exploring Respite' section of this report, various alternatives to the word 'respite' have been put forward, such as 'short break', 'alternative care'

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105 Carers Trust Wales (2016) Investing in Carers, Investing to Save Key Principles for Health and Social Care Commissioners

106 Conochie, G (2011), Supporting Carers: The Case for Change The Princess Royal Trust for Carers and Cross-roads Care

and ‘replacement care’, but some of these terms fail to take into account the perspectives of people living with dementia.

The term ‘respite’ has also been used to describe both an **outcome** and a **service**, which can cause confusion in aligning with the fundamental principles of the Social Services and Well-being (Wales) Act 2014, which has a focus on outcomes. It will therefore be helpful to make a distinction here, as follows:

**Respite** relates to the outcomes (or benefit) experienced

**Short Break** relates to the support or service delivered.

Making this distinction matters because language and terminology drives thinking and practice. According to the Carers Learning and Improvement Network (Wales), current usage can hinder professionals’ understanding of what can be offered and does little to unpack the potential possibilities of a range of diverse, creative and innovative solutions.

Changing language will help to:

- Promote ‘short breaks’ as a distinct form of service delivery that can be counted in terms of ‘throughputs’, which can in turn be measured against a clear set of outcomes.
- Make clear that delivery of a break is only really meaningful if it delivers positive outcomes for carers and people living with dementia.
- Make clear that opportunities for families and individuals to talk about personalised solutions to meet their ‘wellbeing outcomes’ in relation to current and future ‘respite needs’ are part of the ‘what matters’ approach and essential to making the National Outcomes Framework real for people affected by dementia.

Based on the evidence of what people affected by dementia have said respite means to them, I propose the outcomes framework outlined in the table below, that **relates both to carers and people living with dementia**.

## Rethinking Outcomes

These respite outcomes correlate to the National Outcomes Framework and have the potential to be a useful tool for practitioners, regulators, policy makers, providers and people who use services, to promote the development of more meaningful respite alternatives and measure their impact.



The Carers Learning and Improvement Network (Wales) have already expressed an interest in rethinking terminology and practice in relation to respite and are keen to work in partnership to develop this. I will also continue to work alongside the Alzheimer's Society, DEEP network and through my engagement roadshow to ensure that the experiences of people living with dementia are used to consider this and shape practice delivery.

## Rethinking Monitoring and Measuring

This report has made clear that the current systems for monitoring and measuring levels of ‘respite’ are not fit for purpose – for example, the Welsh Government respite performance indicator only relates to overnight stays. Further to this, the evidence base for ‘quality’ respite is unclear because the research and evaluation measures employed often relate only to carer experiences and frame the caring role as a ‘burden’.

What is needed is:

- A revised performance indicator that relates to short break service inputs and respite outcomes (as indicated above)
- Transparent reporting of the delivery of short breaks and related outcomes
- Effective engagement with people living with dementia and carers to ensure measurement and monitoring tools and systems are person-centred.
- The further development and promotion of evaluation and research tools and measures that are based on meaningful respite outcomes for carers AND people living with dementia.

## Next steps

To improve respite support for people in Wales affected by dementia, I have begun discussions with the Welsh Government, Social Care Wales, Carers Learning and Improvement Network and people affected by dementia to outline how I expect learning from this report to be used to ensure that outcomes-based, meaningful respite options are made available to all people affected by dementia. These discussions are based around the Rethinking Respite themes set out in my key messages.

## Sustaining the physical, mental and psychosocial wellbeing of people affected by dementia

My report has shown the difference that can be made to the physical, mental and psychosocial wellbeing of people affected by dementia when meaningful respite support is available. It has also demonstrated the personal anguish and distress, alongside loss of physical, mental and social functioning, when respite is ‘done to’ people living with dementia rather than worked out ‘with them’ based on the outcomes that matter to them. To ensure a future where people living with dementia are offered respite based on the outcomes that matter to them, the following actions must be considered.



## What is needed:

- All partners should work together creatively and in partnership with people affected by dementia and local communities to make different routes to respite a reality. This requires collaboration with a wider range of partners – including the hospitality, sports, arts and leisure sectors – as well as further development of social prescribing initiatives, peer support opportunities, and dementia friendly and supportive communities.
- Respite is dependent on Local Authorities and Health Boards effectively implementing the Social Services and Well-being (Wales) Act 2014. ‘What Matters’ conversations need to take account of respite outcomes, enable different routes to respite and understand why people may refuse respite, and work in partnership to deliver meaningful alternatives.
- The roll out of ‘Good work: A Dementia Learning and Development Framework for Wales’ across public and commissioned services is vital to enabling the workforce to understand the rights, and implement the views, wishes and feelings, of people affected by dementia.

## Information and Empowerment

This report has made clear that there is a lack of targeted and timely information for people affected by dementia, to ensure that they are aware of different routes to respite and have a clear understanding about issues such as direct payments as an important vehicle to enable flexibility, choice and control. People’s voices must be listened to and acted upon when they make efforts to shape respite support creatively and meaningfully.

## What is needed:

- Public Bodies should be providing accessible up to date information about ‘routes to respite’ available in their area and ensuring that this is widely available to all people affected by dementia in their region.
- Effective engagement with people living with dementia and carers is essential, at both an individual and strategic level, in order to deliver effective respite and meaningful outcomes.
- Direct Payments should be widely offered as a route to respite that people are encouraged to explore and empowered to use. A targeted awareness campaign is required through efforts of all relevant partners to convey the benefits of Direct Payments to specific populations such as people affected by dementia.

- I will be playing my part by producing a national pocket guide about routes to respite for people affected by dementia.

## The central importance of respite to restoring and sustaining individual resilience and personal relationships

This report has shown the importance of meaningful respite in facilitating individual wellbeing and resilience, as well as in sustaining positive caring relationships. It is essential that this is understood by the Welsh Government and other partners in taking forward the Dementia Action Plan for Wales 2018-2022 and the Ministerial priorities for carers announced in 2017.

### What is needed:

- The development of the 'dementia care pathway' and Team around the Individual (as stated within the Dementia Action Plan for Wales 2018-2022) must consider the respite needs of all people affected by dementia as their condition and situation changes. This must include consideration of people who are not deemed to be primary carers, such as children in a multigenerational home, as well as critical social networks for single people living with dementia.
- Spending on respite is an essential investment, given the importance of positive caring relationships to all people affected by dementia, and the wellbeing of unpaid carers to the Welsh health and social care economy. Allocation of the additional £10m funding stream under the Dementia Action Plan over the next 3 years must be open and transparent in relation to spending on respite as a driver for improved wellbeing. This must be shared with the Dementia Delivery Assurance and Implementation Group. Allocation of budget on the Ministerial priorities for Carers (see Appendix 1) should be subject to the same transparency and shared with the Ministerial Advisory Group on Carers.
- Meaningful respite is dependent on quality commissioning for outcomes. This demands that the more traditional forms of respite are considered in terms of the issues raised in this report and providers are enabled to work creatively towards positive change. It demands collaboration with a wider range of partners (such as the hospitality, sports, arts and leisure sectors), as well as further development of existing initiatives such as social prescribing and dementia friendly and supportive communities. It is essential that co-production sits at the heart of the approaches adopted by commissioners.

The National Outcomes Framework is an important basis for change, but in order to **rethink respite** this has to be underpinned by changes to language and terminology, through understanding the respite outcomes that are meaningful to people, and by effectively measuring and monitoring changes to practice and delivery. Crucially, this can only be achieved through listening to both people living with dementia and carers of people living with dementia in terms of what respite means to them.

# Appendix 1: Welsh policy related to respite

## Dementia Action Plan for Wales 2018-2022

The Welsh Government's Dementia Action Plan for Wales 2018-2022<sup>107</sup> was published in February 2018.

Within the section 'Support for families and carers including personalised respite' it is stated:

**'... we need to ensure there are different options for respite care which can be provided within the home or outside the home and be relevant to different age groups as well as providing opportunities for people living with dementia to sustain and maintain their physical, intellectual, emotional and social abilities. Additional funding has been awarded to local authorities across Wales in order to develop new approaches to respite care which are based on the needs of carers and those being cared for<sup>108</sup>. We will also ensure that we learn from the Older People's Commissioner's Rethinking Respite research following its publication in 2018.'** (p24)

There is a commitment to:

- Ensure that the new 'teams around the individual' enable families and carers to access respite care that is able to meet the needs of the carer as well as those of the person living with dementia.
- Monitor the use of funding provided to local authorities for respite provision to identify best practice in supporting the needs of the carer and the person who is cared for and ensure this practice is shared.

The Welsh Government's Dementia Action Plan for Wales 2018-2022 states that there is 'an additional £10 million a year from 2018/19' to support delivery of key actions in the document (p5), and progress against delivery of the plan will be overseen by a Dementia Delivery Assurance and Implementation Group (p6). Membership of this group will include people living with dementia and their carers and families. Progress against this plan will 'be a key vehicle for demonstrating achievements and areas for improvement outlined within the Health and Care Standards for Wales'.

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<sup>107</sup> Welsh Government (2018) Dementia Action Plan for Wales

<sup>108</sup> See details of this under Carers Strategy, below

## Carers Strategy and related priorities

The Carers Strategy for Wales was published in June 2013<sup>109</sup>, building upon the 2000 strategy and 2007 update. In the 2013 strategy it is stated:

‘No carer can be expected to care 24/7 for 365 days a year. All carers must have reasonable breaks from their caring role. These breaks enable them both to maintain their capacity to care, and to have a life beyond caring. Carers will have different needs, expectations and preferences which will need to be taken into account when determining a reasonable pattern of caring.’

Whilst respite is defined very specifically in relation to carers in this strategy, it is stated that ‘the emphasis has to be on finding solutions and approaches which meet individual need and the preferences of carers and those they care for.’

Subsequent to the Carers Strategy, in May 2017 £3m was provided to Local Authorities to support respite for carers<sup>110</sup>. On Carers’ Rights Day in November 2017, the Welsh Government announced three **National Priorities for Carers**<sup>111</sup>, the first of which relates to respite:

- Supporting life alongside caring - All carers must have reasonable breaks from their caring role to enable them to maintain their capacity to care, and to have a life beyond caring.
- Identifying and recognising carers - Fundamental to the success of delivering improved outcomes for carers is the need to improve carer’s recognition of their role and to ensure they can access the necessary support.
- Providing information, advice and assistance - It is important that carers receive the appropriate information and advice where and when they need it.

This was accompanied by £1m in 2018/19 for health boards to work collaboratively with all partners to enhance the lives of carers in line with the priorities identified, plus £95,000 in 2018/19 to fund projects to drive forward a national approach to delivering against the priorities, which will be overseen by a new Ministerial Advisory Group.

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109 Welsh Government (2013) The Carers Strategy for Wales

110 Welsh Government (2017) Written Statement - Update: Social Care Funding 2017-18

111 Welsh Government (2017) Written Statement - A Carer Friendly Wales

# Appendix 2: Approach to the research

## Literature review

The literature review was undertaken by the University of Worcester, Association for Dementia Studies.

**Stage 1:** A broad-brush search was conducted within the Open University and the University of Worcester libraries and Google/Google Scholar to assess the lay of the land in terms of academic literature relating to respite. The starting point for the literature review was a range of systematic reviews from the last five years, as these reviews reflected the literature over a period of around 20 years. This was followed up with a wider search outside of the reviews for literature over the last five years that might not have been part of those systematic reviews. The following terms were included in the literature search: respite care, dementia, person with dementia, carer, learning disabilities, replacement care, autism, paediatrics, frailer older people.

**Stage 2:** During Stage 1 it became apparent that a number of countries are pioneering in the area of respite in terms of their approaches to policy and practice. These international areas of good practice were identified and, consequently, Stage 2 of the literature review focused on policy, reports and examples of practice within these countries. This included literature relating to both dementia and other disabilities and conditions, such as learning disabilities, autism and frailty. The search was carried out in the databases as described above and using the same search terms but with the addition of a specific country.

References were collated using the Mendeley reference management software package. The references are included as a separate Annex on the Older People's Commissioner for Wales website and were used to inform the writing of this report.

## Good Practice Call

This was undertaken as a partnership between the University of Worcester Association for Dementia Studies and the Older People's Commissioner for Wales.

There was a two-pronged approach to collecting examples of practice, namely a call out to organisations and an internet search. For the call, anyone could submit examples that they thought represented good practice. The accompanying information requested that people consider respite in broad terms, including examples that:

- might be a break of a few days, a few hours, or a way to enable people to experience even shorter moments of quality time

- might be provided to the person living with dementia, to the person caring for them - or to both together
- may or may not be 'building based'
- might take place in someone's own home, somewhere local or be a holiday opportunity elsewhere
- may or may not be part of a group

A letter/email was cascaded in November 2017 through both the Older People's Commissioners for Wales' office and the University of Worcester. A short form was designed to capture key information about examples of practice, focusing on what the service or project is, who its target audience is, a short description of it, why it is considered to be good practice, and how the respondent knows about it. Contact details for the service and the respondent were also captured to enable further information to be obtained if necessary, either by visiting relevant websites or contacting people as appropriate.

Initially designed as a Microsoft Word document, an online version of the form was also created on Survey Monkey. This was sent out with a covering email and information sheet to potential respondents as a package, in both Welsh and English. As part of the package, respondents were offered the opportunity to complete the form online, as a soft copy to be returned by email, or as a hard copy that could be posted back to the research team. All three options were used by respondents.

Dissemination of the form within Wales was overseen and disseminated by the Older People's Commissioner for Wales. The call was also advertised through social media on Facebook and Twitter. Reminder emails and social media posts were sent over a three month period that the survey was open.

In total, 37 responses were received, comprising 26 online forms (26 English, 1 Welsh), 9 via email, and 2 postal responses. Three quarters of respondents were examples of practice from Wales covering a range of services. These projects and services are included in an Annex on the Older People's Commissioner for Wales website. However, some responses to the practice call included services which were indirectly related to respite or included limited details about the service, and on this basis were excluded. The call for practice was supplemented by an internet search for examples of practice, through a systematic search on Google by country, respite, services for people with dementia and carers. Those that have been used in the report for illustrative purposes are also included in the attached Annex.

The term 'good practice' will mean different things to different people and is likely to be a continuum along which providers and individuals operate. As not all of the services and projects have been subject to evaluation, the term 'examples of

practice' is used in this report.

## Engagement with people living with dementia and carers

This was undertaken as a partnership between My Home Life Cymru, based within Swansea University, and the Older People's Commissioner for Wales.

People were invited to attend focus groups in each of the seven Health Board areas during January and February 2018. Invitations were circulated to networks known to the Older People's Commissioner for Wales via email, including DEEP, the Alzheimer's Society and Ageing Well in Wales networks. There were regular tweets and events were advertised through local radio in some areas. Four events were hosted with the assistance of existing groups, including Dementia Go in Porthmadog, Me, Myself & I in Briton Ferry, Dementia Matters Powys, and the singing group linked to Chepstow Methodist Church.

42 people living with dementia and 81 people caring for someone living with dementia contributed to the engagement events (total 123).

The groups included large and small group guided discussions. To enable people to feel comfortable to share their views, there were also opportunities for participants to mingle informally with the staff who were guiding the sessions and talk on a one-to-one basis if they wished. A simple feedback form was also provided for people to write down and share their views anonymously. Scribes were in attendance to take notes and quotes. Up to six staff were in a support role at each of the events (depending on the numbers attending). The format of each event was tailored and adjusted in an effort to respond to local circumstances and ensure that people's voices could be heard.

An information pack was provided to all of those who attended, and included information related to the project, confidentiality and data protection, direct payments, and national and local information sources.



# Appendix 3 Definitions of respite in relation to dementia

Below are definitions of respite care from systematic reviews in relation to dementia:

**Mayan et al. (2014)<sup>112</sup>:** ‘Respite services’ generally are provided with a view to ‘providing a temporary break in caregiving for the carer’, in order to reduce ‘stress’ and ‘burden’ for carers of people living with dementia.

**Phillipson et al. (2014)<sup>113</sup>:** The provision of temporary relief of care giving responsibilities to the primary carer, usually via the provision of supervision to the care recipient in the absence of the carer.

**Neville et al. (2015)<sup>114</sup>:** The burden and stress experienced by family carers place them at greater risk of physical and psychological health problems. Respite is intended to mitigate this risk of physical and psychological health problems so that carers can continue in their role.

**Vandepitte et al. (2016)<sup>115</sup>:** Respite care - which can be defined as a supportive service provided in or outside the home to give the informal caregiver a temporary relief or break from caregiving duties.

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112 Maayan, N., Soares-Weiser, K. & Lee, H. (2014). Respite care for people with dementia and their carers. Cochrane Database of Systematic Reviews, Issue 1, Art. No. CD004396

113 Phillipson, L., Jones, S. & Magee, C. (2014). A review of the factors associated with the non-use of respite services by carers of people with dementia: implications for policy and practice. *Health & Social Care in the Community*, 22(1), 1-12

114 Neville, C., Beattie, E., Fielding, E. & MacAndrew, M. (2015). Literature review: use of respite by carers of people with dementia. *Health & Social Care in the Community*, 23(1), 51-63.

115 Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Faes, K. & Annemans, L. (2016). Effectiveness of Supporting Informal Caregivers of People with Dementia: A Systematic Review of Randomized and Non-Randomized Controlled Trials. *Journal of Alzheimer’s Disease*, 52(3), 929-965.

# Appendix 4: Routes to respite

The routes available to access respite in Wales are summarised below:

## Social Services assessment:

Under the Social Services and Well-being (Wales) Act 2014, a needs assessment is available to anyone if it appears that they may have care and support needs. Carers can have a carer assessment regardless of whether the person they care for has had their own assessment or whether the person has had an assessment, but the local council has decided that they are not eligible for support or whether the person they care for has refused support. Further information is available through:

**Older People's Commissioner for Wales - Navigating Social Services Toolkit:**  
<http://www.olderpeoplewales.com/en/publications/sswb.aspx>

**Carers Wales - Assessments; A guide to getting an assessment in Wales from April 2016 (March 2016)** <https://www.carersuk.org/files/section/5424/factsheet-w1020-assessments-a-guide-to-getting-an-assessment-in-wales-from-april-2016.pdf>

## Social Services organised respite provision:

Respite support can be provided through Social Services as a result of a needs assessment of the person living with dementia and/or after a carer assessment. Social services are likely to charge the respite care recipient for any respite care services provided, on a means tested basis. They may also charge for any services provided to the carer. Respite organised by social services is generally funded through mainstream social services care budgets. Guidance on charging is provided in Age Cymru factsheets:

**Age Cymru - Paying for care and support at home in Wales Factsheet 46w May 2017** <https://www.ageuk.org.uk/Global/Age-Cymru/Factsheets%20and%20information%20guides/FS46w.pdf?dtrk=true>

**Age Cymru - Paying for temporary care in a care home in Wales Factsheet 58w August 2017** <https://www.ageuk.org.uk/Global/Age-Cymru/Factsheets%20and%20information%20guides/FS58w.pdf?dtrk=true>

## Respite through NHS Funding:

Continuing Health Care funding NHS Continuing Healthcare funding is a package of care arranged and funded solely by the NHS to meet physical and/or mental health needs that have arisen because of disability, accident or illness. It can be provided in any setting including, but not limited to, a care home, a hospice or people's own home. Eligibility is decided via a full assessment.

NHS-funded nursing care The NHS is responsible for meeting the registered nursing costs of all residents in care homes that provide nursing care. This is known as the NHS funded nursing care contribution; people can receive it if they are not eligible for fully funded NHS Continuing Healthcare funding, but have still been assessed as requiring certain services from a registered nurse in providing, planning or supervising elements of care, including respite care.

A factsheet on NHS continuing healthcare and NHS-funded nursing care in Wales is produced by Age Cymru:

**NHS continuing healthcare and NHS-funded nursing care in Wales Factsheet 20w September 2017** <https://www.ageuk.org.uk/Global/Age-Cymru/Factsheets%20and%20information%20guides/FS20w.pdf?dtrk=true>

## Direct Payments:

These are an alternative form of provision to people deemed eligible for services (with certain provisos) following a Social Services assessment. They can offer more choice and control for people in what kind of respite they want. Means tested charges will still apply. A description of direct payments and how to access them is included in Appendix 5 and Age Cymru have produced a direct payments factsheet:

**Direct payments for social care services in Wales Factsheet 24w August 2017:** <http://bit.ly/2n6Nkdg>

## Hospice provision:

Some hospice provision is now specifically tailored to the needs of people affected by dementia and may provide outreach support, day support or overnight stays.

## Social prescribing:

Social prescribing is a way of linking individuals to sources of non-clinical, community-based support. There is no agreed definition encompassing what is prescribed or to whom, but the kinds of things that have been prescribed include exercise, horticulture programmes and community arts. A list of social prescribing projects by area has been produced by Primary Care One, where a search can be

undertaken by theme or by area: <http://www.primarycareone.wales.nhs.uk/social-prescribing>

## Organising your own break:

Many people self-fund their own breaks. This could be for a whole range of different things that help people to get a break. For those wanting to organise their own 'holiday' type break there are some organisations who specialise in advising people on accessible and dementia friendly accommodation. Paying for your own break can sometimes be supported or subsidised by bursaries, grants and leisure discounts.

Further information is provided by Carers Trust: <https://carers.org/article/how-pay-respite>

# Appendix 5: Direct Payment information

Direct payments are a cash payment instead of receiving a directly provided service organised by Social Services. The level of payment is agreed following a needs assessment from Social Services.

A direct payment could be a one-off payment or a regular payment, depending on the type of need. There is a lot of flexibility about how the money can be used though this has to relate to identified needs.

Carers who have been assessed as requiring support services from the Local Authority can also opt for direct payments.

Where someone with care needs lacks capacity, direct payments can still be available, provided a suitable, trusted person can manage the payments on their behalf.

Local Authorities must ensure that they develop local support services for direct payment recipients and/or the person representing them.

Direct payments can offer more choice and control. There are examples of people using their direct payment very creatively, for example:

- paying for a football season ticket for a volunteer to regularly accompany the person living with dementia to matches
- paying for driving lessons if this will enable the carer to manage their caring role more effectively

However, arrangements for how flexibly direct payments can be used vary significantly across Local Authorities.

**More information is available through an Age Cymru factsheet: 'Direct payments for social care services in Wales' (Factsheet 24w).**

**The factsheet is available from <http://bit.ly/2n6Nkdg> or by calling the Age Cymru Advice Line on 08000 223 444.**

