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# CARING FOR SOMEONE WITH DEMENTIA

**FINDINGS FROM THREE ROUNDTABLE SESSIONS,  
COVERING WALES NATIONALLY, AND THE SWANSEA AND  
NORTH WALES REGIONS**

## EXECUTIVE SUMMARY

Over the course of three sessions, Carers Trust Wales have identified several challenges and recommendations to supporting carers of people living with dementia in Wales. Whilst discussions were held separately, several reoccurring themes have been identified and discussed, including the need for:

- increased collaboration between third sector, local government and service providers;
- prioritising respite and care support post-pandemic; and
- the need for more sustainable funding to meet the growing demand for services

## INTRODUCTION

The objective of these three roundtable sessions was to proactively engage with professionals working within or connected to dementia care. Intended as an opportunity for discussion around carer support, the sessions also allowed professionals to engage with one another's work, identify challenges and solutions surrounding dementia carer support, and understand the work of Carers Trust Wales in this area. Attendees were connected to our recently published guide for carers of people with dementia and encouraged to use this resource within their own practice.

The discussion questions focused on four key areas:

- Challenges around support for carers of people with dementia that have been created or highlighted by the ongoing COVID-19 pandemic, and how services have adapted to these challenges
- What information and support might be available to carers of people with dementia, both locally and nationally
- The specific challenges faced by older carers who are providing care to someone living with dementia
- Feedback and recommendations for future amendments and use of Carers Trust Wales' guide for carers of people with dementia

Each session was attended by approximately 5-10 participants, representing a broad range of relevant professional backgrounds including researchers, social workers, dementia advocates, and third-sector professionals. Each group provided thorough and comprehensive discussion around each discussion topic and presented solutions and recommendations to the given challenges.

Attendees for the sessions represented such organisations as: NHS Wales, the Shaw Foundation, Swansea University, Bangor University, Shared Lives Plus, Social Care Wales, and Alzheimer's Cymru, as well as local authorities and network partners relevant to the regions. For the regional sessions, attendees were asked to self-identify whether they felt their organisation worked within the local authority, or one of the local authorities representing that region.

## DISCUSSION

### NATIONAL ROUNDTABLE

This session included attendees from across Wales, and discussion was focused around how each topic applied to Wales as a nation, rather than to its separate regions.

**Challenges presented** in this session were particularly focused around knowledge and communication- both for the carer and those providing services and support to carers. In particular, conversation revolved around the lack of shared information and learning between third sector, social care providers and local authorities, especially around individual carers. Often carers had to repeat their experiences for each new case worker or involved person.

Communication issues also concerned the idea of personhood, and how the person with dementia's own personhood was not communicated or otherwise ignored. Engaging with an individual's memories, interests and hobbies can allow carers or service providers to offer more personalised and effective care, and can bring a sense of personhood to even individuals with severe cognitive decline. Similarly, the effect of cognitive decline on relationships was discussed, and how this can be ameliorated by an increased sense of personhood.

**Discussion around COVID-19** was present throughout the session, but notably was included particularly around digital communications and respite services.

Service providers noted they received mixed reviews from carers about the use of digital technologies to communicate with peers, loved ones and their wider community- some found it easily manageable, to others it was simply another point of stress. It was evident that despite pushback from some carers, use of digital communication and the internet was fairly necessary to maintain the links between the carer and the world outside of caring. Points were raised about how the internet can allow a sense of escapism and offer something else for the carer to focus on- whether that was running a small online business, or connecting with online communities around hobbies or interests. This can also build confidence for carers, as they may have been isolated for a long time and may otherwise struggle to reconnect with their interests.

For those providing respite opportunities for carers, digital communication is likely to continue even post-pandemic, allowing them to reach an audience of carers who may be housebound or unable to attend events physically. In this way the ongoing pandemic has compelled respite service providers to be even more innovative and flexible in their offerings.

**Research identified** in this session included Damien Murphy's 'Getting Along', which studies and supports couples who have been affected by dementia, to help them understand how dementia has affected their relationship.

The group also suggested that research should be conducted on the effects of PPE on how well an individual with dementia is able to recognise those providing care. There was concern surrounding how 'alien' full PPE may look to someone experiencing cognitive decline due to dementia, and how this may cause distress or anxiety. In turn, the carer must then manage this increase of stress and may find it more difficult to carry out caring responsibilities.

**Solutions and recommendations** were identified by the attendees, including:

- Continuing the use of digital communication methods post-pandemic to improve reach and engagement with services
- Improve communication between third sector, service providers, and local authorities to ease the responsibility of communication for the carer
- Consider what kind of language may be insensitive to carers and find new ways to communicate sensitive topics
- Create a resource of terminology a dementia carer may come across, such as medical and legal terms

## NORTH WALES REGIONAL ROUNDTABLE

**Challenges presented** during this session focused mainly on the capacity of service providers, and how an increase in those seeking services and support has left providers stretched and unable to cope with demand. Services in North Wales have seen a large increase in safeguarding reports to their local authorities, and ability to deliver services have varied wildly.

**Discussion around COVID-19** was again predominantly focused on respite and digital communications, and how difficult it has been to increase uptake of digital communication platforms amongst older carers particularly. Services have been providing guides on how to use platforms such as Zoom to carers, and dementia advocates have been trained on safeguarding and managing crises during online events.

**Research identified** during this session was very extensive. Bangor University attendees highlighted their own research, including an online tool developed alongside the World Health Organisation to help carers provide good care, and work conducted with their Asian dementia carers research group that enabled individuals to become Dementia educators. There was also considerable discussion around exploration groups, such as Creative Conversations and the Cabin Group.

**Solutions and recommendations** from this session tended to focus on the large amount of collaborative efforts in North Wales, and how these could be utilised. These groups include the Cabin Group, North Wales Dementia Network, Digital Wales, and Creative Conversations.

Some solutions and recommendations suggested were:

- Recognising how each case of dementia can present unique challenges, and should be approached with a sense of individuality
- Utilising collaborative software, such as Docuflow, to easily share information within the sector
- Using self-care and hobby parcels to engage both carers and people living with dementia during quarantine periods
- Disseminate the Dementia Guide further, into smaller booklets or resources

## SWANSEA REGIONAL ROUNDTABLE

**Challenges presented** by attendees were invariably linked to the increased uptake of their services (in part due to the ongoing pandemic), and the lack of funding to deal with this increase. Services are having to prioritise carers in crisis, leaving many carers unsupported.

**Discussion around COVID-19** during this session focused on innovation brought about by necessity- including increased online and phone services. Care workers have also found new ways to care for clients without needing to enter the home. For example, instead of entering one client's house four times a day to prompt her to take her medication, they have set an alarm system to prompt instead. Attendees were concerned about how the ongoing pandemic has disrupted the routines of both people living with dementia and their carers, which could lead to faster cognitive decline. It was suggested that we should be considering the potential trauma a carer may experience thanks to months of isolation and lack of respite, and make proper arrangements post-pandemic for specific respite and support. Discussion was also centred around how we may continue to innovate post-pandemic, to make caring easier to navigate for the carer themselves. Suggestions are included below.

**Research identified** during this session included some research conducted by one of the attendees, surrounding dementia care and managing incontinence. This research highlights the difficulties in communicating and managing taboo subjects, which often make carers feel they are not up to the task of caring.

Several advocacy projects were also mentioned, including the Dementia Advocacy Project, and the Hope Project.

**Solutions and recommendations** from this session included:

- Mapping the available services and provisions for carers within the region
- Hold multi-disciplinary meetings to allow greater collaboration between third sector, service providers and local authorities
- A re-emphasis on the social model presented by the SCWB Act (2014)
- Funding in-house advocated, such as the Admiral Nurses

# RECOMMENDATIONS

The most consistently discussed concern during these three sessions was the lack of communication between third-sector, local authority and service provision organisations. Attendees highlighted the fact that this makes the bureaucracy of caring much more difficult to navigate for carers of people living with dementia. Therefore, they recommended greater collaboration efforts between these groups to ease pressure on carers decrease the time carers must spend explaining their personal situations and seeking the correct support. This could be achieved via an online resource or toolkit that maps available services in the local area, accessible by service providers and carers alike.

Another concern shared by attendees was the lack of respite for carers during the pandemic. Some solutions to this issue were at-home activity

parcels sent to carers, digital events and informal phone calls. Whilst these are all excellent solutions, none can compete with physical interaction and leaving the home. Thus, post-quarantine, they advised that service providers focus on offering as much out-of-home respite as possible. Carers Trust Wales is currently working with Swansea and Bangor University through a Welsh Government funded project to explore effective models of respite and to create a roadmap for respite provision post pandemic.

Finally, the groups emphasised the need for further funding to carer support services, such as the Admiral Nurses or home-visit care workers. This may allow for prevention of crises, and ease pressure on service providers so that the increased number of carers they are supporting can be supported effectively.

## NEXT STEPS

Considering the above recommendations, Carers Trust Wales will consider the following options, as part of our commitment to ensure more professionals can identify and support carers of people living with dementia.

These options are:

- Create a 'carer profile' template, so that carers don't have to explain themselves to every professional they come across within their caring role. These profiles could be shared between organisations.
- Create a 'positive conversations' document for professionals working within the dementia care sector, including tips and tricks on appropriate language, and layman's definitions on terms that carers may struggle to understand.
- Establish information sharing sessions for anyone working within the field of dementia.

