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**NORTH WALES** SOCIAL CARE AND WELL-BEING  
SERVICES IMPROVEMENT COLLABORATIVE

# North Wales Dementia Strategy

## Consultation report

### October 2019



## **Contact us**

North Wales Social Care and Well-being Improvement Collaborative

County Hall, Wynnstay Road, Ruthin, LL15 1YN

Email: [northwalescollaborative@denbighshire.gov.uk](mailto:northwalescollaborative@denbighshire.gov.uk)

Phone: 01824 712432

Website: [www.northwalescollaborative.wales](http://www.northwalescollaborative.wales)

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## Summary

The consultation for the dementia strategy involved people with dementia, carers, friends and family as well as staff who work for the health board, local councils and third sector or voluntary organisations. Around 250 people took part between May and August 2019.

The consultation found a lot of support for using the priorities from the Welsh Government Dementia Action Plan as a basis for the strategy but many people added that we should also include a theme specifically about carers.

## What works well

The areas that participants felt were working well at the moment included the following.

- Access to services in the community, including support for carers.
- An increased awareness about dementia, particularly because of ‘dementia friendly community’ schemes.
- Joint working between specific teams and with different organisations.
- Assessment and diagnosis.
- Specialist nurses to support people with young onset dementia and people with learning disabilities who have onset of dementia.
- Beginning to develop early detection screening for dementia with individuals with learning disabilities and Down’s syndrome.

Some of the comments stressed that even with good services there is room for improvement and also not everyone’s experience of these services is necessarily positive. There were also some participants who said that nothing works well at the moment or that they don’t know what’s working well at the moment.

## What needs to be improved

The areas that participants felt needed to be improved included the following.

### Support for carers

- More carer breaks, especially for carers of people in the later stages of dementia.

- Need a variety of different types of breaks and flexibility to meet the individual needs of the care and the person they care for.
- Provide emergency or crisis care, for example if the carer goes into hospital and support with planning for this.
- Carer training and advice, including someone to talk to and ask questions of particularly out of hours such as a helpline. Peer support from other carers can be very helpful.
- Improved awareness around Lasting Power of Attorney as well as concerns about the cost and the lack of a system to check everything is in place.
- Employer support for staff with caring responsibilities.
- Support for carers following bereavement.

## **Risk reduction and delaying onset**

- Raise awareness about the risks of dementia and how to reduce them, including links between hearing loss and dementia.
- The roles different agencies have in reducing risk including public health.
- More research into the causes and treatment of dementia.

## **Raising awareness and understanding**

- Suggestions about how people prefer to be treated and ideas for improving awareness and understanding in specific areas.
- The need to reduce stigma around the condition and to share positive messages about how to live well with dementia.
- Avoid labelling people, treat people as individuals and be considerate about the terms used to describe people.
- Raise awareness of the support available and help people find the information they need at the right time.
- Improve staff training and awareness of dementia and the needs of carers in hospital, care homes, home care services as well as wider public services.

## **Recognition and identification**

- Raise awareness of the symptoms of dementia and when to seek help.
- Support people with dementia to understand and accept their condition.
- Reduce waiting lists for a diagnosis.
- Rule out hearing impairment prior to referral for a dementia diagnosis.

## Assessment and diagnosis

- Simplify the process of receiving a diagnosis.
- Involve carers in conversations about assessment and diagnosis as well as the individual.
- Provide more support immediately following diagnosis for the person with dementia and for carers.
- Agencies and teams should work together improve systems and communication so that people don't have to tell their story over and over again.
- Send text reminders for appointments and include photos in letters of the people who will be at the appointment.
- Check in regularly with people who have received a diagnosis so that the right support is in place before there is a crisis.
- Improve the diagnosis of dementia in people with a learning disability.

## Living as well as possible for as long as possible with dementia

- Make sure there are a wide variety of activities for people to be involved with so that people can find those that suit them. This should include different activities for people with early stage, late stage and young onset dementia as well as support for people with different types of dementia.
- Support people to continue to be involved in their normal activities.
- Make sure communities are inclusive and dementia friendly to reduce loneliness and isolation.
- Make sure the funding and resources are in place to deliver high-quality dementia care services including for the voluntary and community sector and particularly for people with young onset dementia. This also includes the need for good pay and conditions for care staff, challenges around short-term project funding and concerns about the way dementia care is paid for by individuals.
- Make sure people with dementia and carers are listened to and involved in making decision about their care. Advocacy should be available to help with this.
- Improve access to services particularly in rural areas and for people who don't have access to transport.
- Improve coordination between different teams and agencies so that individuals receive a seamless service.

- Improve consistency of services available across North Wales.
- Improve staff continuity.
- Provide support for people with a mild cognitive impairment who don't have a diagnosis of dementia.
- Improve support for the physical health needs of people with dementia.
- Adapt the built environment to make places accessible to people with dementia and to support people to live longer at home. This included better adapted homes and purpose built homes.
- Promote the role of assistive technology and telecare.
- Look at support available for people who were diagnosed before October 2016.

## **Need for increased support**

- The importance of home care to help people remain at home. Care should be flexible, person-centred with consistency and continuity of highly-trained staff. Need support to recognise when home care is no longer appropriate and consider other options.
- Care homes should have sufficient staffing and person-centred care, including care for people in distress and in an emergency.
- Improve support in an emergency and in hospital emergency departments.
- Improve support for hospital in-patients and dementia friendly wards.
- Improve support for people when leaving hospital, including finding appropriate residential or nursing accommodation.
- Make sure Welsh language support is available.
- Improve safeguarding of people with dementia including around postal scams and using recommended tradespeople.
- Care for people in the later stages of dementia and improve planning for individuals and carers around this. This includes access to good quality residential care, emergency hospital care, palliative care, end of life care and bereavement support.

## Introduction

An Equality Impact Assessment was undertaken to identify potential inequalities arising from the development and delivery of the North Wales Dementia Strategy. The information gained through this process has been used to develop the North Wales Dementia Strategy.

This report provides details of the consultation undertaken as part of the Equality Impact Assessment and provides evidence of how we are meeting the requirements of the public sector equality duty.

## Background

Support for people with dementia is a priority in the [North Wales Regional Plan \(Area Plan\)](#) based on what people told us was important to them as part of the [population assessment](#) produced by the [Regional Partnership Board](#).

The Social Services and Well-being (Wales) Act 2014 includes a statutory duty for Regional Partnership Boards to prioritise the integration of services in relation to people with learning disabilities.

The Dementia Strategy sets out how we will work towards integrated dementia services in North Wales. It has been developed jointly by the six North Wales councils and Betsi Cadwaladr University Health Board (BCUHB) supported by Public Health Wales.

Actions and plans developed to implement the strategy will need an Equality Impact Assessment to assess their potential impact.

## Public sector equality duty

The Equality Act 2010 introduced a new public sector duty which requires all public bodies to tackle discrimination, advance equality of opportunity and promote good relations. This means public bodies must have due regard to the need to:

- Eliminate discrimination, harassment, victimisation and any other conduct that is prohibited under the Act.



- Advance equality of opportunity between people who share a protected characteristic and those who do not.
- Foster good relations between people who share a protected characteristic and those who do not.

Having due regard for advancing equality means:

- Removing or minimising discrimination, harassment or victimisation experienced by people due to their protected characteristic.
- Taking steps to meet the needs of people from protected groups where these are different from the needs of other people.
- Taking steps to build communities where people feel confident that they belong and are comfortable mixing and interacting with others.

Councils in Wales also have specific legal duties set out in the Equality Act 2010 (Wales) regulations 2011 including assessing the impact of relevant policies and plans – the Equality Impact Assessment.

In order to establish a sound basis for the strategy we have:

- reviewed the relevant sections of the [population assessment](#) including performance measurement and population indicator data along with other relevant local, regional and national data;
- consulted as widely as possible across the North Wales region including with the general public, colleagues and people with protected characteristics;
- reviewed relevant research and consultation literature including legislation, strategies, commissioning plans, needs assessments and consultation reports.

More information is available in the background information paper.

This report sets out the consultation carried out for the strategy:

- who we have consulted with;
- how we have consulted; and
- the consultation feedback.

## Consultation principles

A key part of the Equality Impact Assessment is consulting with people who may be affected by the strategy and in particular people with protected characteristics. The protected characteristics are:

- Age
- Disability
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race
- Religion and belief
- Sex
- Sexual orientation
- Welsh language

Case law has provided a set of consultation principles which describe the legal expectation on public bodies in the development of strategies, plans and services. These are known as the Gunning Principles:

1. Consultation must take place when the proposal is still at a formative stage.
2. Sufficient reasons must be put forward for the proposal to allow for intelligent consideration and response.
3. Adequate time must be given for consideration and response.
4. The product of the consultation must be conscientiously taken into account.

Local councils in North Wales have a regional citizen engagement policy. This is based on the national principles for public engagement in Wales and principles of co-production which informed our consultation plan.

# Consultation and engagement

## Consultation process

We introduced the themes from the Welsh Government Dementia Action Plan and then asked people the questions below. The themes were:

- Risk reduction and delaying onset
- Raising awareness and understanding
- Recognition and identification
- Assessment and diagnosis
- Living well for as long as possible
- Increased support

## Consultation questions

1. Do you think these are the right areas to look at?
2. What do you think works well at the moment?
3. What do you think needs to be improved? Please include your ideas for improving services and ways to make the most of the resources already in our communities, including people with living with dementia, friends and family, community groups, voluntary organisations and professionals.

The timetable for the development of the strategy was as follows.

<b>Month completed</b>	<b>Actions</b>
April 2019	Project initiation documentation approved
July 2019	Collect and update baseline data for the strategy (based on the population assessment) and map services and investment available across the region
July 2019	Engagement and co-production with people who use services, carers, providers, front-line staff and other stakeholders
September 2019	Revise the strategy, agree priorities and draft action plan.
March 2020	Consult on revised strategy and produce the final draft.

## Consultation methods

The consultation methods we used were:

- Online questionnaire and easy read questionnaire circulated widely to staff, partner organisations, the citizen's panel, people who use services and other members of the public.
- The North Wales Citizen's Panel gave people the opportunity to take part through a conversation in person, over the phone or an online chat. The panel coordinator also attended events across the region to promote the consultation and gather feedback.
- Partner organisations held consultation events.
- We asked partners to send us the reports from any related consultation events or surveys that they had already carried out in North Wales for other projects.

## Promotion plan

Details of the consultation including an online questionnaire and easy read version of the questionnaire were made available on [our website](#). We promoted the link through the strategy steering group members (representing the six local authorities, health and other partners), to people on regional collaboration teams mailing lists including members of the provider portal. Initial emails were sent out on 1 May 2019 with a reminder on 15 July 2019. A press release was sent out through the local authorities and health board.

The North Wales Citizens Panel shared the survey through Facebook, the [website](#), letters and phone calls and face to face meetings.

In addition the link to the online survey was sent to the county voluntary councils below, asking them to circulate it to their networks:

- Mantell Gwynedd (Gwynedd)
- Medrwn Mon (Anglesey)
- CVSC (Conwy)
- DVSC (Denbighshire)
- FLVC (Flintshire)
- AVOW (Wrexham)

To help reach people with protected characteristics the link was circulated by the health board to their equality networks with a request to circulate widely.

Information was sent to members of the:

- Regional Partnership Board
- North Wales Leadership Group,
- North Wales Adult Social Services Heads (NWASH),
- North Wales Heads of Children's Services (NWHoCS)
- North Wales Citizen's Panel

Presentations on the strategy were given at the following meetings:

- North Wales Carers Reference Group
- North Wales Carers Operational Group
- Community Health Council
- BCUHB HASAS 1,2,3 working group
- North Wales Adult Services Heads (NWASH)
- North Wales Leadership Group
- Regional Partnership Board

Social Care Wales circulated to the third sector representatives on the regional population assessment leads network.

## Consultation and engagement review

There were 250 responses in total to the consultation. Table 1 shows that the majority of responses were from staff and/or people with experience as a carer.

Table 1 Number of responses by type of participant

Type of response	Number
Work for an organisation	120
Carer for someone with dementia	60
Person with dementia	30
Other (relative / friend of person with dementia)	20
Other (previous caring experience)	20
Other (interest / dementia champion)	5
<b>Total number of responses</b>	<b>250</b>

Some people may have ticked more than one box. Numbers have been rounded to the nearest 5 to prevent disclosure of personal information.

We would have liked to reach more people diagnosed with dementia directly. When we realised there was a lower response rate from this group we extended the consultation period and worked with members of the steering group and partners to try to reach more people. This worked best where we were able to attend groups to discuss the strategy. We will make sure to continue to involve people living with dementia in the development of the strategy.

The consultation reached people from across North Wales as shown below.

Table 2 Number of responses by county

Type of response	Number
Anglesey	35
Gwynedd	55
Conwy	80
Denbighshire	90
Flintshire	50
Wrexham	40
<b>Total number of responses</b>	<b>250</b>

Some people may have ticked more than one box (for example if they lived and worked in different counties). Numbers have been rounded to the nearest 5 to prevent disclosure of personal information.

We also reached people in all age groups apart from those under 16, disabled people including people with a learning disability or long standing illness/health condition, carers, Welsh and English speakers. We had responses from women and men although there were not as many responses from men. We also had a small number of responses from people with different marital statuses, ethnic identity,

national identity and sexuality. We did not get any responses from trans people although we have included findings in the report from the BCUHB guide to transgender issues in dementia care that was developed with trans people. We will also make the people responsible for implementing the strategy aware of these gaps in the consultation so they can take any additional action needed to eliminate potential discrimination.

We used the equality data to monitor the responses while the consultation was open and encouraged groups representing under-represented groups to share the survey and take part. The consultation deadline was extended by three weeks to allow more time to reach under-represented groups. The full list of data tables showing the number of responses from people with protected characteristics is included in [appendix 1](#).

## Organisations represented in the online survey

Below is a list of organisations whose staff took part in the online consultation. In addition the draft strategy will be shared widely to provide a further opportunity for individuals and partner organisations to influence and shape the strategy.

### Local authorities and health

- Betsi Cadwaladr University Health Board
- Isle of Anglesey County Council
- Gwynedd Council
- Conwy County Borough Council
- Denbighshire County Council
- Flintshire County Council
- Wrexham County Borough Council

Responses from health staff included the Audiology Service, Community Dental Service, Community Learning Disability Team, Community Mental Health Team, Community Older Adults Team, Complex Disability Teams, Dementia Healthcare Assistants, Dietetics Service, hospital based staff and others.

Responses from local authority staff were mainly from within social care services.

## Other groups and organisations

- Age & Dementia Friendly Holywell
- Age connects NWC
- Allied Healthcare
- Alzheimer's Society
- Awel Homecare and Support
- Bangor University
- British Red Cross
- Bronafallen care home ltd
- Carers Trust North Wales
- Cariad Care Homes
- Clwyd Alyn Housing Association
- Communities for Work
- Community Health Council
- Connah's Quay memory café
- Conwy and Denbighshire Mental Health Advocacy Service
- Conwy Connect
- Cruse Bereavement Care North Wales
- Cycling projects - Deeside Wheels For All
- Dementia friends
- Diocese of St. Asaph, Church in Wales
- Flintshire County Council's Dementia Action Plan Steering Group
- For You Property Services Ltd.
- Haulfryn Care Limited
- Llys Elian EMI Residential home
- NEWCIS
- North Wales Housing
- Prestatyn Dementia Friendly Community
- Rhuddlan Dementia Group
- Roberts Home Care
- Royal Voluntary Service
- Sapphire Streams Ltd
- Shared Lives Plus UK
- St Kentigern Hospice



- United Reformed Church in Mold, Buckley and Ewloe Green
- The FDF Centre for Independent Living
- Venue Cymru / Theatr Colwyn
- Welsh Ambulance Services Trust (WAST)
- Ynys Mon Citizens Advice

# Consultation findings

## Introduction

The consultation was open between 1 May 2019 and 19 August 2019 and 250 people responded.

The answers to the open ended questions were coded using the Atlas.ti Cloud software. In the analysis we've tried to give a sense of how often themes were mentioned by saying whether comments were by one person, a few people or by many people. This is not to say issues raised by just one person are not important but they may need more investigation to find out more about how widespread the issue is and the impact it has.

Information that may identify people, such as people's names and organisation names, have been removed from the quotes used.

## Strategy priorities and themes

Overall 94% of participants agreed with the themes for the strategy. Comments in support of the themes include:

“All very important areas to focus on which will hopefully help people live well with dementia.”

“The above areas are absolutely correct in my view and I'm so pleased that more help is at hand.”

“These priorities are broad and far reaching and cover the whole spectrum of issues that currently face people affected by dementia.”

The most frequent suggestion people made was to include a theme specifically about supporting carers. For example:

“There is a dire and urgent need to look at support for family members or friends who are supporting people with dementia. This needs to be a holistic approach not just patient focused, the strain on families is immense, many are keeping their loved ones from having to go in to care, thus saving the

government, local and central, money. I would suggest an additional priority: supporting carers to ensure quality of life.”

“Carer and family support should be an explicit priority as they provide endless unpaid support.”

A few people mentioned the need to look specifically at care for people in the later stages of dementia and improving planning for individuals and carers around this. This included access to good quality residential care, emergency hospital care, palliative care, end of life care and bereavement support.

“The earlier stages of the process are well developed, it is the later stages where support, professional expert input and interventions are lacking. This can lead to traumatic transitions into care, often via hospital, as well as difficulties in managing behaviours that challenge [distressed responses], which can lead to additional transfers, unnecessary medication use and incidents. The end of life stages are not well prepared for, not at the start of the process via LPA [Lasting Power of Attorney] and ADs [advanced decisions (living wills)] but also later on when caring for those at the end of life. The follow up is lacking for the bereaved.”

One person mentioned that the strategy should also refer to the five priority areas in the Ageing Well in Wales Programme, which are: age friendly communities, falls prevention, dementia friendly communities, opportunities for learning and employment and loneliness and isolation. Another person mentioned that although they agreed with the themes they weren't in the order of priority that they would chose and that delaying onset and increased support should be the top priority.

There were other suggestions too about what should be included within the themes, described in the analysis below as well as the need to learn from best practice.

## What works well

This section includes the services and initiatives that participants said were working well in North Wales. Some of the comments stressed that even with good services there is room for improvement and also not everyone's experience of these services is necessarily positive. There were around ten replies where participants said nothing works well at all and another ten that said they didn't know what was working well, some because it was all new to them or their experience was from a couple of years ago.

One person mentioned that they liked the easy read version of the questionnaire as it meant their family member could follow it.

### **Access to services in the community, especially for carers**

Many people said the support they receive in the community works well. One person said they'd been more active since their diagnosis, trying new activities and going out regularly into the community with support from a care agency.

“Groups like the one in Abergele, really useful that I can meet other people with dementia.”

A lot of people particularly mentioned services for carers.

“Support groups are excellent. I was very sceptical initially, but get a lot of valuable support and knowledge from my fellow carers.”

“Attending [a group] once a week in four different venues, dementia patients enjoying the exercise to music, dining out with friends we have made. This has been a life saver.”

Other services specifically mentioned as working well include:

- Alzheimer's Society,
- Ambulance service (for dealing with a fall and referring well to other services)
- Bangor University including partnership working to provide projects such as an arts project at Rhyl library, research and working with BCUHB
- Care inspectorates
- Carers Trust

- Community agents
- Community care
- Community Psychiatric Nurse support
- Community singing sessions and coloured mats for businesses in Rhuddlan
- Daffodils
- Day Centre – Specialist support worker
- Day services – Hafod Hedd, Uned Meirion
- DEEP
- DEEP – Caban Bangor/DEEP United (South Gwynedd)
- Dementia Go
- Home Instead Conwy and Denbighshire
- Intergenerational work
- Independent housing schemes with care and support on site (well-designed, level access) such as Llys Raddington, Flint and Hafan Cefni, Llangefni.
- Local health centre and doctor
- Memory clinics
- NEWCIS
- Outreach day services – Blaenau a Tywyn
- Shared Lives
- Side by Side (Royal Voluntary Service)
- Social services
- Taith Ni
- TIDE
- Walk and talk group (BCUHB)

A few people also mentioned that there was good access to information.

“Quite a good array of information available, particularly online.”

## **Raising awareness and dementia friendly communities**

A lot of people commented that awareness about dementia is much better than it was, particularly because of ‘dementia friendly community’ schemes.

“There is an increasing awareness of dementia which has opened up the conversation about what is needed.”

“I think it seems to be working well as far as it goes - awareness of help for carers and professionals working with people with dementia is really good now.”

“Dementia friends training [awareness raising] within the community is a great initiative.”

“There are pockets of good work and groups already happening. More places becoming dementia aware and friendly.”

“Dementia Friends badges are useful so we know who knows about dementia and might be able to help us.”

“The ideas and values that are very much present within professionals and our workforce is second to none. The person centred way of thinking, and using positive risk taking by way of increasing a person's wellbeing is a vast improvement over the last few years.”

“Dementia friendly communities has made real progress and should be used as the platform to be the loudest collective voice to enact change for the strategies.”

## Working together

There were quite a few comments that mentioned that organisations and individuals were working together well or improving in specific areas.

“Improving working relationships with third sector partners and health colleagues to meet the needs of people living with dementia and their carers.”

“Good co-operation exists between members of the Adult Team and Community Psychiatric Nurses to support all those living with dementia in their homes.”

“Good joint working between social services and the health board at an operational level. Regular multi-disciplinary meetings.”

“Audiology in North Wales has made links with Memory Assessment Services, for example completing a joint audit of hearing awareness in memory assessment which flagged the need for full audiology assessment rather than

relying on patient report and pilot of direct referral to audiology by memory assessment service.”

“The introduction of the new multi-disciplinary teams in Wrexham Maelor for those living with dementia is such a fantastic idea.”

“It works well when social workers are based in the health centre. Communication, information shared more easily. Unfortunately this doesn't happen regularly.”

There was also one comment that said it was good to see a collaborative approach to developing the strategy, one that stressed the importance of a multi-disciplinary approach to the strategy and another that mentioned the importance of a strategic regional approach to the Dementia Action Plan funding through the ICF and the need for a review.

## **Assessment and diagnosis**

A few people mentioned assessment and diagnosis was working well at the moment, for example:

“Memory clinic and assessment seems to be efficient and responsive.”

“The assessment and diagnosis process has improved considerably over recent years.”

## **Young onset dementia**

A couple of people mentioned that specialist nurses to support people with young onset dementia worked well:

“The appointment of specialist nurses to work with younger people with dementia was a good initiative.”

## **Learning disability**

A couple of people also mentioned areas working well for people with a learning disability:

“Learning disability nursing input for people with a diagnosis of learning disability who have onset of dementia.”

## **New ideas and innovative projects**

Some people mentioned new projects and ideas they're developing which can help to support people with dementia. Also, one person highlighted 'the drive and passion that is out there to make difference'.

"I am in the process of bringing agencies together in South Meirionnydd to develop a programme of how to support individuals with dementia wishing to live independently."

"Blue plates, or any floral, colourful plates for patients to eat from. I've found dessert plates fantastic as they are not too small or big. Meal time together around a table - afternoon tea? A table cloth, good cup and conversation makes the world of good and difference in lifting someone's' mood."

"We have recently begun a project in the Wrexham area which provides Dementia befriending and advice services to individuals in the Wrexham area. The aim of the project is to support the individual affected by dementia, but to provide befriending and advice to those who carer for the individual and are often left feeling lonely and isolated. "

"There has been a real focus locally [in Flintshire] on dementia support, and we are working to become recognised by the Alzheimer's Society as a Local Authority working towards becoming a Dementia Friendly Council. A Dementia Friendly Council Steering Group has been established to help us towards this goal and includes representatives with lived experience."

## **New ways to support people with learning disabilities**

A few people mentioned new projects and ideas for supporting people with learning disabilities who have dementia or are at risk of developing dementia.

"Within the learning disability team that I work for we have begun to complete early detection screenings for our individuals at age of 50 and then early stages for individuals with learning disabilities and Down's syndrome. This appears to working well and is a way of monitoring individuals and picking up any concerns earlier."



“As a CLDT [Community Learning Disability Team], we have identified a group of individuals with a learning disability and Down’s syndrome and have devised a rolling system that flags up re-assessments as required.”

“We are starting to improve and develop a bespoke memory service for adults with a learning disability in Gwynedd.”

## What needs to be improved

The feedback about what needs to be improved has been split into themes below based on the Welsh Government Dementia Action Plan with the addition of a theme about support specifically for carers.

### Support for carers

Many people mentioned that more support was needed for carers:

“There is an increasing need for those who care and support individuals affected by dementia, especially for daily advice and comfort.”

“Support essential - particularly to 'elderly' carers.”

### Carer breaks

Many participants mentioned the need for carer breaks or respite. It was agreed in the North Wales Carers’ Strategy to use the term carer break rather than respite although respite is the term most often used by participants in these responses.

“Families need more respite - this gives me independence and my family a break.”

“Firstly the amount of respite given to carers should be greatly increased. At the end of my father's illness my mother was desperate, phoning me at all times of the day and night in great agitation.”

“I think that there is not enough support out there for people whose partners/family are living with dementia, who would like their loved one to stay at home as long as possible, people cannot afford to have carers coming in and giving them a break i.e. just to do a bit of shopping, a bit of me time.”

“The focus is on people living in their own homes and being cared for by their relative, this is a HUGE pressure on the carer and can lead to poor health of the carer due to the carer constantly working 24 hours a day with the person. Do you work 24 hours a day without a break! Respite places are urgently needed. “

This is particularly an issue for carers of people in the later stages of dementia.

“Respite for carers of people with more advanced dementia who may experience distress behaviours or behaviour that is challenging to manage that would probably require EMI nursing [specialist care for older people with a mental illness or disorder including dementia] if required placement.”

“There was also a problem that when my father entered stage 2 of dementia it was very difficult to find respite as his cognition by then was so poor that he required assistance to perform all tasks and could no longer feed himself.”

“My father-in-law was diagnosed with Alzheimer’s approx. 6 years ago. He has dramatically declined in the last 12 months. His wife has been struggling to cope on a daily basis to keep him safe (he wants to go back to where he lived as a young man). We managed to arrange respite care for 2 weeks while we were on annual holiday and so mum-in-law could also have a break. He was given a place in an EMI home and after 2 days they telephoned to say they couldn't cope with his behaviour and would need to return him home.”

One person commented that they were no longer able to access respite care once they were in receipt of Continuing NHS Healthcare (CHC) funding.

“A person living with dementia and their family/carers need one pathway of care not different ones dependant on whether they are health or social care responsibility. E.g. my father was receiving day care once per week and was also able to have a certain amount of respite care to enable my mum to go away for a few days. The minute he became full CHC, although he was still at home awaiting a suitable placement in a nursing home, she was no longer able to access respite care because he was now health not social services. We were also told that his current day-care (one day per week) was now not suitable and really he should not continue to attend although he was allowed

to. He never got more than one day despite funding agreement - he went from one day per week to a nursing home, no increase in support in between.”

Participants also stressed that the type of carer break was important to make sure it met the individual needs of the carer and the person they care for. The need for [person-centred care](#) came up in many other comments too.

“Please be aware that the sitting service provided locally did not suit my mother who hated the thought of a stranger having full run of the house when she was not present. I know that my mother is not alone in this matter.”

“In order for people with dementia to live better and longer in their own homes with their families, there needs to be greater investment and emphasis on providing several options of respite care that will meet the needs of the individual.”

“People with dementia could stay in their own homes for longer if there was more support for carers. **More** support for people and their carers to manage for as long as possible in their own homes, more day-care of longer length e.g. my father would be picked up between 9 and 10 and brought back between 3 and 4 once a week, this wasn't long enough for his carer to have a proper day of respite and get out of the house for the day.”

“Better roll out of shared lives and/or groups for people with dementia and/or carers.”

## **Emergency or crisis care**

A few people mentioned the need for support for people with dementia in an emergency, for example if the carer goes into hospital.

“More access to practical support for carers including short term and emergency respite.”

“Crisis care facility in case the carer goes into hospital, where will the individual go – there is a lot of pressure on carers to keep themselves well.”

“Strong campaigns to promote the need to plan for futures prior to health changes or crisis. People need to consider where they live and how they will manage should their life change suddenly Examples include: need for level

access accommodation, local amenities, supportive community provision, and local family/friends support networks.”

## **Carer training and advice**

A lot of people mentioned that training was important for carers and families as well as for staff.

“A strong support network for those living with dementia AND their loved ones - including education as to what they should expect and advice as to how to deal with the diagnosis and its presentations.”

“Better training for families, carers and individuals to be able to support.”

“Support services for informal carers understanding of the grief that is triggered following diagnosis.”

“They also need to know ASAP about planning for the future, i.e., Lasting Power of Attorney, Attendance Allowance, council tax reduction, Blue badge, etc., and more importantly to understand the diagnosis and the effects on day to day life.”

A few carers also mentioned the need for someone to talk to and ask advice of, particularly out of normal working hours, such as '24 hour access to knowledgeable support'. One carer suggested that 'a dementia line would be useful' and another person suggested the need for a variety of communication channels like live chat and email. Carers also spoke about the value of peer support and one carer suggested providing opportunities for people to speak to other carers who have been through the journey.

## **Lasting Power of Attorney**

Participants also mentioned issues around Lasting Power of Attorney (LPA), including lack of awareness of the need for one, the cost and concerns no one was checking them.

“Carers need to be involved in decisions for a 'loved one' where there is not a Power of Attorney in place. Too often the dementia sufferer does not want to admit to themselves or anyone else they have a problem early on. Once it's realised it's often too late to get the Power of Attorney in place.”

“LPA’s cost only £84 each if it is done on line but a solicitor can cost over £1,000. If in receipt of benefits it may be free. Finding someone to countersign can also cost money and not everyone has known a person on the list of signatories for the required length of time.”

“Although as a carer you should have an LPA registered for both Health and Finance nobody asked to check it.”

## **Support for carers in employment**

A few people mentioned the need for employers to better support their staff with caring responsibilities.

“Employers to consider the care needs of their staff.”

“Mae angen mwy o gymorth ar ofalwyr, yn enwedig gofalwyr sydd yn gyflogedig - angen i gyflogwyr ddeall a rhoi cefnogaeth. [Carers need more support, particularly paid carers - employers need to understand and give support.]”

“More help for carers is essential. I was juggling the care with full time work. It was exhausting and the whole experience has consequently had a detrimental effect on my own health.”

## **Bereavement**

A couple of people mentioned the need to continue to provide support for carers following bereavement.

“I also think part of the strategy should take into consideration support for people with dementia who has lost a loved one and also for people who have lost loved ones with dementia. There is also guilt due to already 'losing' the loved one to dementia before their death.”

## **Risk reduction and delaying onset**

Many participants commented on how awareness could be raised about the risks of developing dementia and how to reduce them.

“Life course approach to prevention, start with the children. Reduce health inequalities and improve lifestyles reducing or delaying onset of conditions.”

“Hearing impairment is a key modifiable factor in dementia risk reduction and delayed onset, and should be included in public health messages as such. Awareness raising in North Wales should include the interplay between hearing loss and dementia, and what actions can be taken to prevent hearing impairment from exacerbating cognitive decline and dementia.”

A responses from dietetic services highlighted how their services could do more to support this priority.

“Our service can help with the first priority through our Public Health team - training patients and others to deliver education programmes so that people are educated and empowered to consume healthy diets - they can also support patients and carers with dementia to do likewise. They could do more to support these two priorities with increased investments.”

Although one participant highlighted that this priority would be better taken forward by other agencies and the strategy should focus on the other priorities.

“The responsibility for risk reduction changes in life-style and environmental factors, which may have a minimal impact on the development of the disease and/or prognosis, are the responsibility of public health and private/public/charitable research.”

Other people mentioned the need for more research into the causes and treatment of dementia.

## **Raising awareness and understanding**

Many participants talked about the importance of raising awareness and understanding about dementia and how to support people with the condition. This was highlighted as an area [working well](#) although some people said that more needs to be done and suggested approaches. This included suggestions that it is important to work with young people and schools when raising awareness.

“Educating families when people get a diagnosis, not just give them leaflets. Some people’s families change the way they are with the person as they feel they have duty to make them safe and protect them just because they have been told they have dementia.”

“Dementia awareness of general wards. My mother was admitted into a ward in Ysbyty Gwynedd after a fall in the nursing home. She was not washed or changed or treated in any way because she did not consent to it. They did not take the dementia and the fact that she had no capacity to make her own decisions into account... A phone call to a dementia team member who could have intervened and perhaps acted as mediator might have saved a lot of stress all around.”

“Raising awareness, understanding and acceptance is vital. People who lack awareness can be unkind for others. If people have an allergy they carry and SOS type of alert. Would / could something like this help, or will this increase a person’s vulnerability?”

“...ensuring people understand the disease and the trajectory it takes, as well as how to communicate effectively with people with dementia and the impact that 'reminding' people of events can be detrimental to them - this is something we come across a lot in our work.”

“There does need to be greater awareness. People with dementia do have some memory and understanding but the links to their former cognition are broken. It mad my father very angry to be treated like an overgrown, aged toddler! At the second stage, people should be more patient as it is a question of trying to understand words substituted for others; almost like people searching for the appropriate word but using the wrong one when learning a new language.”

“More recognition that dementia affects a wide range of people including people with learning disabilities, substance misuse and mental illness. Dementia isn't just something that people develop in old age.”

“Recognition, understanding and awareness is critical. There needs to be an understanding of the fact that dementia covers an incredibly broad spectrum of people, from those with mild dementia who can still lead full vibrant lives with minimal support to those whose dementia has overtaken them and cannot live independently any more. There also needs to be more understanding that dementia does not simply mean memory loss. Many people seem to think it is just losing the ability to recall memories when in fact it is much more complicated than that. It can mean personality changes,

anger in a previously well-tempered person, different likes and dislikes, different appetite and taste. Dementia causes so many other symptoms rather than just memory loss.”

## **Reducing stigma**

Many people mentioned the need to reduce stigma around the condition and to share positive messages about how it was possible to live well and also to avoid the stigma around [seeking help](#).

“Community involvement, and national awareness on reducing stigma and illustrating repeatedly that a good life can be had with a dementia and to enjoy every day.”

“The stigma around dementia will only be better understood if people realise that it's not a diagnosis to be fearful of, and that there is a lot that can be done in terms of both medical management and support at all stages of the journey through the disease.”

## **Labelling and use of language to describe people**

A couple of people mentioned the problem with labelling people and groups and the need to treat people as individuals.

“Less labelling. A person - not an older person nor one living with dementia”

“It would also be useful to look at: Use of language in all areas of Older Adults (e.g. to removal of Elderly Mentally Infirm).”

“Terms like ‘Severe Mental Impairment’ and ‘Severe Cognitive Impairment’ are distressing for both ‘Hidden Disability’ is kinder and the details could be requested if they are needed.”

## **Finding information**

A lot of people talked about the need to raise awareness of the services available and the need to support people to find the information they needed at the right time.

“Awareness of what groups/support/day care is available. My mum has been a carer to my dad for 6 years now and has never been offered information on what community groups or day centres my dad could go to. To enable herself to have a day off she has to ask for support from her family in taking care of



him (a rarity as she doesn't want to "burden" us). If more resources were available, an email with contacts that gets circulated, leaflets or Facebook posts about what is available then more people may access resources which may very well be there already, it's just that they're not well known about."

"Getting help and advice has been very hard as my Mother has dementia and feel we have been left to get on with it."

"My main problem was that there were a myriad of groups, charities, activities etc. potentially available to us, but there was a total lack of co-ordination in North Wales. Trying to find out what was available was a complete nightmare. We eventually had a very helpful outreach worker who did a lot to help my husband. (I had had to give up teaching by this time.) Basically, I feel there should be a one-stop shop where carers of people with dementia know they can go to find out what will best suit their needs."

"There is a huge amount of information and a whole range of support organisations and activities. Navigating your way through this is very difficult, especially when you are trying to look after or support a partner. Some kind of flow chart could help."

"When my father was diagnosed got lots of information lots of telephone calls I got confused never mind my father."

Ideas to include this suggested developing dementia friendly web content and web information specific to dementia services and support as in this comment:

"One key issue that people living with dementia have told us is that there is little information for them on what support is available locally and what they are entitled to directly following their diagnosis. We are working to address this locally through working to become a Dementia Friendly Council and compiling information on our website especially for people living with dementia and their carers, but we need to work with Health Services and GPs so they are able to signpost to central sources of information."

## **Workforce development**

Many participants mentioned the need to improve staff training and awareness of dementia and the needs of carers. This included staff in hospital, care homes and home care staff as well as wider public services. Some suggestions include:

“Training on dementia needs to be embedded within the basic nurse training.”

“Need more workshops explaining and giving examples of how to deal and help those individuals with dementia, and also help staff understand people’s behaviours.”

“All government and public services should be trained and have periodic refresher courses to understand dementia and its impacts on the communities where they operate. In addition, all businesses that deal directly with the public should be taking courses to understand the disease and to know how to communicate with and if necessary assist their customers in this regard.”

“Carers don’t take the time to get to know the individual. Small schemes are appearing but it needs to become national and better quality checks. Memory boards, so staff can see what kind of person they were before dementia onset, the lives they lead, the skills they have. More money needs to put into encouraging activity, mental processing, not for them to sit for hours on end with no one to talk to them.”

“Central person/ champion within staff teams with the knowledge to support others.”

“Education of professionals in new thinking strategies such as Butterfly models, Jewels in dementia. Dementia spokespersons and societies being involved in developing services etc.”

“For staff to listen and give the... person [with dementia] choices... they are forgetful not stupid.”

“Need to have dementia specific nurses who have the knowledge and expertise on what people need and what support they can access.”

“Having the voices of the lived experience, people with the condition, involved in any/all of your learning and training and development sessions [works well]. But there is a huge gap.”

“I feel that better training and awareness of how dementia can present and how people within both primary and secondary care may need to support differently for a person with dementia e.g. communication training/ use of visuals/ use of communication passports to help people know how that individual has been affected by dementia specifically and to tailor care.”

“Need to improve attitudes to positive risk taking.”

“Training to be mandatory in public sector for dementia awareness and any commissioned services by this sector. Dementia awareness and more specialised dementia training to be mandatory for all social care and allied staff.”

Participants also talked about the need to have the right staff in place and enough staff to meet needs.

“Need to consider generic roles that can support individuals with a large number of different conditions (e.g. dementia and physical conditions).”

“Does Betsi Cadwaladr have a full time Consultant in post? This is surely one of the most essential parts of the jigsaw.”

“The procedure for employing specialist consultants needs attention. It would be possible to offer an incentive to attract doctors and to train them. There have been several locum in the Gwynedd area but none of them are willing to wait as locum pay is better than the psychiatrist's salary on the establishment.”

A few participants also talked about the need to value care staff and make sure they are paid appropriately.

“The perception that our workforce should only be paid the minimum wage, this professionalism, commitment and work ethos of this workforce should demand a greater financial reward.”

## Recognition and identification

### Raising awareness of the symptoms of dementia

Participants spoke about the need to raise awareness of the symptoms of dementia, when to seek help and de-stigmatising that help. A few people also talked about the role carers can play in identifying symptoms of dementia as well as the role of GPs.

“My friend had a family history of dementia and had been trying to hide symptoms for years without knowing where to go for help and being terrified that she was going to be 'locked up'. I had no experience of the condition or who to turn to for advice.”

“My daughter noticed [my symptoms of dementia] because she is a GP.”

“I certainly think that we need to have a higher level of campaigning, education at all levels and practical solutions as to what people can do when they first need help as in my view, too many people brush this under the carpet / go into denial and don't seek help as they feel stigmatised. We need to normalise dementia across society to send out the message that it is okay to disclose and seek help.”

“Removing fear needs to happen, we have friends in early stages who completely refuse to go for assessment; why? This needs to change.”

“Early awareness (where other family members have already got dementia). To include monitor for early onset (children) of parents who have or had.”

“Initial assessment and diagnosis early is the most important especially when it is combined with another type of neurological disease. Standard tests may not show up the problems. The carer often can spot the early signs and deterioration before the professionals.”

A couple of people also mentioned the challenges of supporting people with dementia to understand and accept their condition.

“Getting the person to understand and be aware of their condition is important. My mother never accepted that she had dementia, and thought that we were simply being nasty to her, or trying to send her into a home so that we could take her house. She did not understand risks, and at 88 was still

trying to climb on ladders, even with a broken arm. She would not accept any medication that might have helped, mainly because she didn't believe that she had dementia.”

“Many elderly people who are starting with the onset of dementia do not want to admit to it and that it's just old age. Current process of referral to memory clinic doesn't help to engage with clients at an early stage. My experience with an elderly mother is that they don't want to admit to it so there must be a better/softer approach to engage early with sufferers in a less confrontational manner.”

One person mentioned receiving a diagnosis in hospital when in for something else. A few other people mentioned people admitted to hospital for other needs with undiagnosed dementia and suggested that screening in hospitals could be improved.

### **Waiting lists**

A few people mentioned long waiting lists for a diagnosis and the difficulties this can cause. One person said they needed an earlier diagnosis rather than being treated for depression. Another person mentioned that there's not a clear pathway for diagnosis of people with [learning disabilities](#).

“Diagnosis is still taking a considerable time, delaying the provision of appropriate support and early intervention.”

“The Memory Services are not getting to diagnose people early enough, too long a waiting list and cognitive rehabilitation should be more readily available.”

“Once under the care of a Consultant and Dementia team there is info and support but getting to that point can be difficult.”

### **Links with hearing impairments**

One person highlighted that:

“NICE guidelines include that hearing impairment should be ruled out (e.g. being identified & treated) prior to referral for dementia diagnosis, and steps are needed in North Wales to identify how this may be taken forward.”

## Assessment and diagnosis

### Receiving a diagnosis

A few people mentioned the complexity around receiving a diagnosis. One person mentioned that they had a suggested diagnosis rather than an actual diagnosis.

“Diagnosis (rather than have copy of letter from neurologist suggesting diagnosis)”

“Communication of diagnosis should be more rapid and clear to families and patient. There needs to be a strategy for patients who refuse to attend clinic for assessment, as lack of insight is a common feature of dementia. If they refuse to attend, the diagnosis can be delayed or never happen which is very unhelpful.”

“I feel that diagnosis as to what type of dementia is very important as without it there is a lot of things you can't do or claim for that you are entitled to also I feel that a lot more support and help for carers is needed most carers are 24/7 unpaid workers”

“My wife was diagnosed with dementia 2013. She received a clinical diagnosis in a clinical way. Such devastating news could have been delivered much more sensitively. She was referred to the Memory Clinic... where she was supported in a much more sensitive way.”

Carers mentioned the importance of including them in conversations at assessment and diagnosis.

“Recognising the signs is vital. It took a long time to diagnose my mum as the people assessing her did not speak to the family independently enough. People with Alzheimer's do not recognise it in themselves and give positive answers to questions that family members know are not correct.”

“When the social worker comes out to do the first assessment - I think they should have a check list of questions to ask. The first social worker said my mum didn't need support - then when I queried certain areas, another assessment was done within a week and it was then decided she did need a carer going in every day. As someone new to dementia caring... I didn't know what to expect.”

“I would have found it useful to have the opportunity to talk to e.g. Consultant/Specialist Nurse at the diagnosis stage. I appreciate that it was my mother who was the patient, however, I found it very difficult to provide the full picture during hospital appointments. Communicating via side glances and surreptitious head shaking wasn't ideal.”

## **Support following diagnosis**

While some people said they had positive experiences following diagnosis, others felt that more support was needed immediately following a diagnosis both for the person with dementia and their carers.

“After diagnosis, sitting down with someone who could explain some of the likely outcomes and what support was available, would have been a great help.”

“Many people following diagnosis are shocked and isolated and need a 'service' that will help them with **acceptance** that would lead them to 'live' with the illness.”

“Currently, within BCHUB people with Dementia do not have a choice on their referral pathway and support they require. They are currently referred to one organisation who contact the individual to provide one home visit and then onward support is available through a group environment. This is not always the preferred method of support. Also, there is no formal pathway for service users who were diagnosed prior to October 2016.”

“Communication and support needs to improve as once a diagnosis is confirmed there does not appear to be the same sort of support network that is in place for those diagnosed with other life changing or terminal illnesses. Those diagnosed with dementia are often left to find the information out for themselves as to what will happen next in terms of groups, support, small changes in their environments which could make a big difference.”

## **Improving communication**

Many people mentioned the need for good communication and systems to help support run smoothly. This includes carers who found it frustrating that they weren't included in conversations and people with dementia who were frustrated when

people only spoke to their family and not with them directly. This is linked to the comments around [having a voice and being involved in making decisions](#) too.

“People talking to me and not just my family - I want to choose and have a say in what happens.”

“Reablement team stopped attending to see my mother in law without informing the family [she had mixed dementia]. They never bathed or shower her once in the 2 weeks they visited.”

Some people spoke about the frustration of having to tell their story over and over again and the need for services to communicate better to avoid that. See also [working together](#).

“One single point of contact not single point of access you have to constantly repeat the same thing to several people over and over again.”

“There are **so** many services / professionals involved that as a carer it is an absolute minefield. Goodness knows how those suffering with the illness and with no family manage to plough their way through the systems. Streamlining or having a central point of access would be a brilliant way of centralising **all** the available services / departments. The same questions are asked by **so** many services /departments - perhaps a copied response could be handed to all, so that repetition is cut. Just to ask if anything has changed since the last interview??”

“There is a lack of continuity within dementia services and you have to tell your story on more than one occasion, systems don't link. Idea for notes to be available to all about patients and for all to use the same system.”

Some suggestions for systems that need addressing to improve communication and ways to improve them follow. A few people suggested that it would be helpful if text messages were sent to individuals and their carers in addition to letters from the memory clinic with reminders about appointments.

“One other problem area is that people with dementia are not able to remember appointments, or what has been said at them, people who don't attend are often discharged from treatment which is a bit ridiculous given the nature of the condition.”



“Pictures with who is coming to see me when they send appointment letters, or when I have an appointment, I would like to see who I will see.”

“Communication of diagnosis should be more rapid and clear to families and patient. There needs to be a strategy for patients who refuse to attend clinic for assessment, as lack of insight is a common feature of dementia. If they refuse to attend, the diagnosis can be delayed or never happen which is very unhelpful.”

“Both patient and carer need a numbered identification card issued by the GP or Memory Clinic that flags and notifies all those providing Care Services and Benefits. Those departments should then be contacting the carer or patient. The strain on both at time of diagnosis is too much for many to struggle through forms.”

“Currently there is not a clearly defined system that integrating all Health Authority Departments and Government Departments (DWP) and Local Authorities (Council Tax and Blue Badge). All of these people require a copy of the letter of diagnosis (which should be confidential).”

“Information on patients is sometimes out of date and so this needs to be addressed.”

“Another suggestion is to have a system similar to that of when you pass away and they send out a message to all providers etc. to let them know not to send information, this could be done for individuals with dementia so that the carer also receives the information. Another suggestion is to ask the family and individual how they would like to receive information as sometimes emails would be easier.”

## **Memory clinics**

There was some very [positive feedback](#) about people’s experiences of memory clinics. For example:

“Encouraged to make the most of everyday as long as possible by the wonderful consultant... and being reviewed every six months by the nurse-led memory clinic.”

“From my own personal experience I had excellent support from social services, our local health centre and doctor and the memory clinic. However other people that I know have not had the same experience. Friends were invaluable.”

Some people mentioned challenges around [waiting lists](#) and others mentioned issues with the services they had received.

“The 12 month period of intervention from the memory service following diagnosis is just not enough.”

“And, after being told of diagnosis from the memory clinic, there was no follow up, no referral, just “yes, it’s dementia... there’s no medication so off you go”.”

“Memory clinic do not provide the right support for people and it feels that they ‘dump people’ with dementia.”

“The service my mum received from the memory clinic was not beneficial. I was not involved in it at all or notified of any outcomes. This was a few years ago - I hope this has now improved. The clinic just communicated with the residential home and did not include me, despite having POA. No actions followed the contact with the MC.”

Another person suggested a role for memory clinics in helping to identify earlier when someone is about to reach a crisis point.

“I see carers who have managed very well for perhaps 10 years, and then, because they have not 'accessed' any support, they go into crisis and all services are then reactive to that crisis. This could change by regular contact from the memory clinic, a phone call/review once or twice a year to notice when things are changing and to put support in place to prevent the crisis.”

## **Learning disabilities**

A couple of people mentioned improvements that were needed around the diagnosis of dementia in people with a learning disability.

“Learning disability services need to recognise the upsurge in dementia symptoms and diagnoses that will happen and plan towards this.”

“More consideration for rising numbers of people diagnosed from Learning Disability services and their individual needs.”

“In learning disabilities it is not a clear pathway on who makes diagnosis. Not many community groups specific to individuals with learning disabilities and dementia.”

People with learning disabilities said that more needed to be done to include people with dementia and that there was a need for more tests, such as at memory clinics. They also said there should be more jobs for people with dementia and gave the example of the TV show ‘The restaurant that makes mistakes’ as a good example.

They said that the things that work well are:

- “being around friends and family”
- “being looked after in their own homes”
- “incorporate music that they like”
- “things they enjoy doing to avoid boredom and loneliness”
- “respite helps!”
- “look after their carers”
- “self help groups are really helpful.”

Another learning disability self-advocacy group discussed taking part in the consultation but felt it wasn’t for them. They said that dementia wasn’t a priority for their group and they weren’t concerned it would happen to them.

## **Living as well as possible for as long as possible with dementia**

### **Service choice and person-centred services**

Many people mentioned a wide variety of activities that they were involved in in that were [working well](#) and the importance of these activities to people’s health and well-being.

“It is our observation that people with active support and good social networks manage well for longer. We’d like to see support for early interventions and innovative, flexible support in the community so people with dementia can live fulfilled and active lives.”

Many participants also mentioned the need for a choice of services so that people could find the activities that suit them, including activities for people with [young onset dementia](#).

“Activities which are suitable for all sufferers of dementia should be provided. Please be aware that not all dementia sufferers enjoy singing which seems to be another common misconception. Indeed noise can seem more intense and jarring to some people with dementia and this results in more aggressive behaviour. If the patient did not enjoy singing before dementia it is extremely unlikely that a sudden desire to sing will occur. We are all individuals with different skills and preferences. This does not change with the onset of dementia.”

“My difficulty with my husband is to find the most appropriate 'fit' for some kind of day time activity. He sleeps a good deal during the day. He is on the ball but mostly nonverbal so finds it difficult to participate in social activities even though he formerly enjoyed these activities. I was hoping that [the local] specialist dementia care establishment nearby might have some activities that he could join as a non-resident but after making several approaches I was told that they don't do that. He was on the waiting list for a project at the 'heavy workshop' doing simple woodwork but broke his hip just as he got to the top of the list! He tried 'Men's sheds' but I think they found it difficult to accommodate someone with dementia. He did an exercise class with a cup of tea at the end for both participants and their friends/carers etc. but the cup of tea was stopped and gradually the class became too hard for him. At one of the tea sessions we did a dementia friend awareness raising session. For a while I had a carer in for a couple of hours once a fortnight but there did not seem much point in paying someone to sit and watch TV whilst my husband slept. We bought an off road electric wheelchair and have enjoyed days out together but everything falls on me. One friend happily comes to help me with maintenance/ repairs but most of his former cycling friends seem to have vanished. There is a charity called Freedom Wizard who take people on the fells but unfortunately they are based in the Lake District.”

“Services need to be more person-centred and recognise that dementia affects a ranges of ages. Services should also be varied and not all about day centres and nursing homes. Community groups can play a vital role in

reducing social isolation, increasing engagement and helping individuals live at home longer.”

A few people also highlighted the need to be clear who services and activities were aimed at because the needs of people with early stage dementia were very different to those with later stage dementia.

“We went to a memory café in our town. This was disastrous. Many of the people there were well on the dementia road. My wife was in the early stages of vascular dementia and was devastated when she saw the people who were at the session because she saw what she would be like in the future.

Following that experience, whenever we were signposted to a meeting or activity, I always went first on my own to check it out. A 'health warning' could be attached to whatever is offered.”

One person recommended using the Pool Activity Level Instrument which is a set of tools used to develop a profile of an individual's likes and dislikes with a view to planning activity that best supports that individual.

## **Dementia friendly communities, day care activities and ideas for improvement**

One comment stressed the importance of continuing to involve people in their normal activities and many other participants highlighted the importance inclusion and dementia friendly communities to reduce loneliness and isolation.

“There is a need to try to ensure that people living with dementia can continue to attend social activities as they have done e.g. Merched y Wawr, Golf Club, Leisure Centre etc. for as long as they can rather than develop groups for people who are suffering with dementia e.g. Dementia Cafes.”

“Also places to enable people with dementia to volunteer, give them purpose. A way of achieving this could be within charitable organisations or dementia villages many people revert to doing what they used to do for work, evidence has shown that if they can continue with these tasks it is good for them, for example shop work, café work, carpentry etc. There is a need for much more hands on services to keep people active and their brains engaged.”

“My mum attended... [a] day centre and a bus picked her up. She did like that however she did have to be coaxed to go at times. The same person calling for them helped as they knew her so knew how to speak with her etc.”

Participants made the following suggestions for how communities could be more dementia friendly, including ideas that are already working well in some places. One comment stressed the need for follow-up actions to implement practical initiatives beyond initial awareness raising.

- Choirs
- Communication training for communities
- Dementia bus (where there was a mixed audience including professionals and carers in the same room can learn so much from each other’s perspective)
- Dementia friendly cities, towns and villages
- Dementia friendly local authorities
- Dementia friendly schools programme
- Dementia friendly swimming sessions
- Dementia friendly workplaces
- Develop social prescribing
- Horticultural therapy – giving people the opportunity to be outside with nature more in a facilitated and safe way.
- Improving awareness in shops, offices, entertainment, sports centres, churches, businesses (including cafes or pubs)
- Intergenerational work
- Involving people with dementia in the design of projects/strategies and buildings/gardens
- Livingston reminiscence [project which provides reminiscence and oral history training and loans out memory boxes].
- Local authorities to support or facilitate local communities, social enterprises and care providers to identify local community solutions by working directly with people with dementia and their carers
- Memory clinics to be used more as a welcome centre with coffee mornings provided by volunteers.
- Music therapy
- One to one support work to help people continue what they enjoy

- Open days where people can come and speak to council staff about the support available.
- Physical activity sessions
- Social events and outings such as a coach trip where everyone is either a dementia patient or a carer so there would be no need to explain people's behaviour or feel different.
- TRIO support scheme which tries to match up individual who share common interests and keep them active.
- Wear the badge! Also 'can Dementia Friend' log be added to ID cards for people who go into homes?'

There were many suggestions about how to improve day care. Some people suggested alternatives were needed for those it wasn't suitable for. There's more information about this in the [young onset dementia](#) section.

- Also places to enable people with Dementia to volunteer, give them purpose. A way of achieving this could be within charitable organisations or Dementia villages many people revert to doing what they used to do for work, evidence has shown that if they can continue with these tasks it is good for them, for example shop work, café work, carpentry etc. There is a need for much more hands on services to keep people active and their brains engaged.
- Establishing day opportunities within existing community assets/hubs.
- Services need to be more person-centred and recognise that dementia effects a ranges of ages. Services should also be varied and not all about day centres and nursing homes. Community groups can play a vital role in reducing social isolation, increasing engagement and helping individuals live at home longer.
- Others said how much they valued the current services and would like to see them extended to be more accessible.
- More awareness of Welsh language day care (Waen Gofal Dydd) and how people can access this.
- Day care facilities for all, not just for carers respite. Individuals living on their own with no family/friend support need access to day care services.

## **Funding and resources**

Many participants mentioned the need for funding and resources to deliver high-quality dementia care services including for the voluntary and community sector

and particularly for people with young onset dementia. This also included the need for good pay and conditions for care staff and challenges around short-term project funding.

“There seems to be a plethora of organisations offering places for people with dementia to get together for social activities, or more targeted interventions. Not sure that there is any evaluation of these services happening? Often initiatives last for a short period and then funding stops.”

“The 'living as well as possible' is key as socialising and enjoying a range of activities is key to helping keep the disease at bay for longer and helping battle the likelihood of associated depression. However, the services we accessed, particularly the fabulous 'Lost in Art' at the Ruthin Craft Centre, were faced with constant financial cut-backs.”

“For me I think that the support of community groups and voluntary groups needs to be properly valued, it needs to be consistently available and not dependent upon where a person lives. Things like befriending to reduce loneliness, respite care for carers, transport, are crucial to maintaining people's independence as long as possible.”

One comment highlighted the need to review what is currently being funded.

“Review of spend on dementia beyond that which is funded via the Dementia Action Plan and consideration of new ways to meet the needs through joint commissioning with less restrictive criteria.”

A few people also mentioned challenges around the cost of care and how it is paid for, including comments about the difference between the cost of dementia care and other conditions.

“The cost of private care is prohibitive and plans must be put in place to develop nursing homes to care for the rising number of people who need specialised care but cannot afford to pay for care in privately owned establishments.”



## **Being involved and being heard**

There were many comments about the need for people with dementia and carers to be listened to and be involved in making decisions about their care. There's also more feedback about this in the [improving communication](#) section.

“There has been an increase in professional peer groups for people affected by dementia where they have the opportunity to express opinions on how to improve services. People from all areas of North Wales and further afield are linking to share experiences, this is helping raise awareness about dementia, break down barriers and reduce stigma.”

“It is crucial that service users are involved in the decision making for improving services across North Wales and should be involved in every aspect.”

There were a few comments about the need for advocacy and to support people to be involved in decision making.

“I have attended a number of interdisciplinary continuing health care meetings. Fortunately I had researched the criteria and prepared a paper with my observations against the criteria. Had I not done that I might well have been overwhelmed by the comments of social services, the care home, the district psychiatric nurse and the district nurse. Carers and relatives should be advised of these meetings and the implications well before the meetings take place.”

“Brother had dementia – people need to share information so that others know what is happening, especially to the family. Advocacy needed to be involved and were not due to the lack of service provision.”

“More support: key workers appointed carers that act as supervisors/project managers for individuals, including advocacy. So that families have one person to go to and one person that oversees all aspects of care and support. Otherwise people are forced to arrange/find/sort out a plethora of things whilst trying to support someone and continue having a semblance of life.”

## **Access to services, rural issues and transport**

Access to services was a challenge for some people, particularly those who did not have access to transport and it was also highlighted as a problem later in the evening.

“As soon as got dementia, my driving license was taken away. You can’t drive. My husband drives and my friends take me places, but there aren’t many buses. If I didn’t have a support network, I couldn’t go anywhere. Transport to attend appointments, support and activity groups, as always, is an issue in rural Wales and seems to be a topic that is constantly raise with no solutions offered.”

“Community Navigator was very helpful in suggesting things for my mum - but lots of things not in the vicinity for her without me having to take time off work to take her.”

“I had several visits to assess my need and ended up with a carer’s card and a newsletter. The workshops etc. were all based in Ruthin or Mold. Accessing them was very difficult.”

“Transport co-ordination desperately needs work on - taxis have been cancelled last minute, and have been as much as an hour late or an hour early!! It takes hours to get someone with dementia ready for the day - simple tasks like washing and getting dressed can take up to an hour and a half - and for the taxi to be cancelled at the last minute is heart breaking.”

“They accessed some groups in Flintshire but these don’t offer lifts to and from the centres, so rely on family to take them and he wouldn’t be able to go in a taxi alone.”

“Patients can easily go under the radar of services, resulting in detrimental effect on health and well-being and increased risk to health, carers breakdown etc.”

This was particularly a challenge for those living in rural areas, including the lack of service provision in rural areas.

“If a service is advertised as being Gwynedd wide there is an expectation that it would also cover South Meirionnydd (which is in Gwynedd). There has been

a tendency for this area to be neglected in the past and agencies... haven't been able to fulfil their role in this area due to lack of workers / volunteers. There is a need for this to be enforced in order for this to be carried out.”

“We need to better target rural areas, find ways that we can take services out to them. Services are a bit of a postcode lottery.”

A few people mentioned challenges of losing their cars and concerns that people were driving past the point where they should and better systems needed to be in place.

“Those living with dementia try to hide their problems for as long as possible to avoid the probability that they might lose the use of their cars and their independence.”

“I do feel the GPs should have the responsibility to inform DVLA about driving, as some people we know have not readily given up their vehicles. So assessment and diagnosis should be as rapid as possible.”

One group response asked the question about whether bus drivers know what to do if someone goes missing and said that dementia friendly taxi companies and drivers are needed. Another group mentioned about confusion around Blue Badges and the need to renew these regularly. It was felt that there needed to be an easier mechanism to get these for people living with dementia.

Participants also highlighted are other barriers to people too being able to access activities including good communication and [continuity of staff](#).

“...good events organised for people with Dementia but as I explained to one of the workers - unless someone physically calls for my father at his flat and tell him to get involved he would not know or remember to do so.”

## **Working together**

Although different organisations and individuals working together was mentioned as an area that were working well there were a lot of other comments saying that they'd found services disjointed and that they need to be better coordinated.

“Poor communication between health and social care mean the journey is not smooth for the person, carer/members of the family in accessing formal

support. It's a very lonely place to be when no-one is there to help or support and you're at breaking point."

"Currently third sector, including voluntary organisations, appear to work as an independent and separate entity to the NHS; this means the support from these sector is limited and not always as recommended by healthcare professionals. Social services need to be closely linked with memory clinics and dementia care; home adaptations or placement need to be addressed when the need is identified, and not having to wait for so long."

"There is a pressing need to ensure that the support is led by those with personal experience in partnership with providers. I am concerned that a lack of collaboration is likely to arise if a comprehensive structure is not supported because of the way money is currently distributed."

Some participants described the difficulties they'd had getting the right support.

"When my parents moved into the area my mother already had a dementia diagnosis; I have tried to achieve a referral to Social Services but have not been able to get beyond the Single Point of Access. This is apparently because we have arranged a package of care through private means and, it would appear, their needs have been met. However, I feel that they are very vulnerable and I am not confident that what has been arranged is the best for them. I think that an assessment and some specialist advice is not too much to ask, and can inform us as to how to keep Mum and Dad safe and well at home for longer. The GP has referred to local EMI services, but no appointment has come through. Given the severity of Mum's dementia I am surprised that they are still waiting for their first appointment 3 months after referral. They have had a letter from continence services saying that they will be contacted in about 10-12 weeks to discuss Mum's double incontinence. Again, this would appear to be a very long time to wait given the risks associated with double incontinence and my Dad, the main carer, is in his mid-80s and physically frail. It doesn't appear that the referral pathways allow for a response that matches the need."

"Having a hub for dementia patients, so that we can drop in anytime if we have any worries as it is so hard to get a doctor's appointment, and A&E are so busy and a safe haven if we need to leave them for a short period."

One of the main challenges people mentioned to the current system was the difficulty of [finding information](#) about what's available due to the complexity. There were also similar issues highlighted in the [improving communication](#) section.

## **Working together: how to improve services**

Suggestions for improving the way organisations work together include:

- Integrating services that support people with dementia, perhaps into a specific dementia team or local hub. Professions that were mentioned specifically included those involved with vascular, hearing, eyes, infections, exercise and education, carers services, third sector services. Also, improving the way GPs refer people on for early help, advice and support in the community.
- Joint commissioning, where organisations plan and commission services together rather than separately. Suggestions included meeting regularly to share suggestions, improve understanding of services and referral pathways and agree shared approaches, pooled budgets to include community groups and third sector providers with expertise in working with people with dementia.
- People with dementia and carers working in partnership with the community, councils and other organisations to put the strategy into action together. Some people called this co-production, which is where different groups share the power and responsibility for making changes.
- Home treatment team for people with dementia. Making better links with specific organisations and professions including mental health services, transport providers, house and equipment designers, the planning department, between day care and local community mental health services, faith communities, fire and rescue services (conduct fire safety checks so could help identify individuals with memory loss or carers in need of support).
- Improving communication and co-ordination between health, local authorities and the voluntary and community sector.
- Finding ways to help prevent people from having to tell their story multiple times to different professionals and organisations.
- Collaborating with other initiatives such as Ageing Well and work to support people with other conditions such as Autism or the Brain Injury Trust.
- Looking at the model at Queens Hospital, Nottingham, which works well for both staff and patients. They have an integrated team around the families with a loved one with dementia and so access support (single point of access) –

systems need to be more reactive and have specialist nurses who have the interest in dementia and the right skills and knowledge about dementia (Dementia Support Workers).

- Looking at the Dementia Care Matters work by David Sheard.
- Services for LGBT+ with dementia and improve communication with LGBT+ organisations.

One comment summarised suggested changes for learning disability services and another stressed the need for services for people with learning disabilities who are LGBT+.

“Within learning disabilities we need to develop better links with local old age services - primarily in relation to managing behavioural presentations in the later stages of dementia. Optimise the non-medical interventions and involvement of therapies. Increase in the availability of nursing placements for adults with learning disabilities and dementia.”

Participants also mentioned the need for more consistent services across the region and including in rural areas.

“There is certainly a need to work on harmonizing the support services for individuals living with dementia across the whole of Wales.”

“We need to better target rural areas, find ways that we can take services out to them. Services are a bit of a postcode lottery.”

## **Continuity of staff**

A lot of people mentioned the need for staff continuity.

“Sufficient time to undertake the tasks with people who work at a very slow pace, and can't understand or cope with numerous changes of staff and community/agency carers. There has been a significant shift towards "recovery" and "independent living" and short/fixed term services. Dementia and old age are terminal conditions, you don't "recover" from either condition. Continually re-assessing and re-configuring services is costly to the service provider and disruptive and detrimental to patient and family.”

“Continuity of social workers is badly needed.”

“When they live alone having someone regular to drop in for a chat helps them however, different people calling all the time didn't help her. She had carers but when an agency was employed they were bringing someone new then showing them what to do and mum wasn't having that one to one chat so it wasn't good for her.”

“My husband was diagnosed in 2015 and it was very difficult to get help. The OT was ill herself and there was no one to take her place. When help was at hand after a year, the social people were very kind and helpful but it was frustrating that they kept changing. There was no continuity.”

### **Mild cognitive impairments**

A few people mentioned the need to support people with mild cognitive impairment who don't have a diagnosis of dementia.

“The strategy needs to focus not just on individuals with a diagnosis, but should include people living with cognitive impairment/memory loss also and their carers.”

### **Support in the early stages**

Some participants also mentioned the need for more support in the earlier stages of dementia although others said there were plenty of services in this area and the need was for people more advanced dementia, which suggests the need for a variety of services to suit different people.

“Also I believe a new type of day centre for people with milder dementia or other conditions not affecting their mental capacity could be incredibly beneficial. My dad's dementia is mild and his mental capacity is still moderate, despite loss of most speech. If we were to try and encourage him to go to a typical day centre he would refuse, he believe that most people who attend have more advanced cases of dementia so the activities are not stimulating enough. Having been a community carer as well I am aware of many other people who have the same problem of being 'lumped in' with people with advanced dementia despite having other limiting factors, e.g. stroke, instead of any cognitive impairment.”

“The raising awareness and understanding of everyone in the community is vitally important in order to get rid of the stigma associated with the disease.

My sister is living well on her medication at the moment as she is only at the end of her first year. Being able to mix with others at her level would have been good, as she knows what will come, having been a nurse, so isn't keen on being involved with too many others who are further along the journey."

## **Young onset dementia**

Many people mentioned the need for services for people with young onset dementia and a range of services that address what matters to each individual.

"Especially with young onset Dementia there is much more of a need for one to one support workers, who can support people to continue engaging within their communities, carry on doing what they enjoy i.e. person interests, shopping etc. Not all people want to attend day centres!"

"Home care seemed to focus on physical needs such as washing showering, for a younger person fully mobile no set time for this, had to be opportunistic."

"Increased support for younger people living with dementia in the community and increased age appropriate day centres/support."

"My mother had to wait quite a bit for a CPN [Community Psychiatric Nurse] as she was under the age of 65. There was currently only 1 CPN for under 65's and this person was off work sick. This didn't seem fair to me."

"The services for people diagnosed with younger onset dementia need far more specialist resources as their needs are very different to dementia in older age."

## **Physical health and sensory impairment**

There were a few response that mentioned the importance of addressing people's physical health needs.

"Better provision for people with dementia in primary and secondary care health services and a recognition that people with dementia can have other complex health problems that left untreated can exacerbate the difficulties of dementia."

There were responses from audiology and dietetic teams that highlighted the support their services could provide.



“Our clinical Dietetic team see many people with dementia - either because of deteriorating nutritional status associated with the condition or for other diseases. With funding the service could build dedicated Dietetic services to these patients and their carers to support them more effectively to improve quality of life and function.”

“Awareness and support of sensory impairment during diagnostic pathways is key to appropriate assessment and diagnosis. With high prevalence of hearing impairment amongst those living with dementia, it is essential that living well includes appropriate hearing well information and support. Those support services being both aware and supportive of hearing and hearing aids.”

### **The built environment and accommodation**

A few people mentioned the importance of adapting the built environment to make places accessible to people with dementia and to support people to live longer at home. This included better adapted homes and purpose built homes. One suggestion included reviewing public facing premises to see if they are dementia friendly.

“Wider consideration by non-health and social care services in public sector to the needs of people living with dementia including planning department. Potentially leading to appropriate accommodations being built such as properties with annexes to house dependants.”

“Increased awareness of things that help people living with dementia especially in public places so I’m thinking of things such as dementia friendly toilets and dementia friendly signage.”

“Use dementia aware designers for building design, interior decorating and external hard-landscaping, see the ‘housing LIN’ websites for design guidance.”

“Including those living with dementia in the design of projects/strategies and buildings/gardens.”

“Provision of safe and appropriate accommodation for people living with dementia.”

“Need to add the development of independent supported housing with care.”

### **Assistive technology and telecare**

A couple of people mentioned the need to consider the role of assistive technology and telecare.

“More needs to be done to inform carers about the facilities available with telecare ... although my mum has this - no one mentioned it - apart from the Dementia Connect lady.”

“Promote telecare - what is available now and what will be available in the future.”

“Digital technology review, think about the challenges to assistive technology including the infrastructure changes pending with the ending of analogue phone lines by 2025. How can we be innovative and future proof?”

### **Gaps in services**

One person highlighted a gap in support in services provided by Carer’s Trust.

“At the moment only people diagnosed since October 2016 can access services provided by Carer's Trust, anybody diagnosed prior to October 2016 is not able to access the services they offer. If they have been diagnosed after October 2016, but missed or chose not to take up the services at point of diagnosis, they cannot be referred directly into Carer's Trust Services by another organisation. They have to be referred back to GP or Memory Clinic in order to access these services, time consuming and additional work, to get access to Carer's Trust services, especially if the person has a diagnosis of vascular dementia and has been closed to the clinic.”

There also seemed to be gaps in services for people with different types of dementia, such as the vascular dementia mentioned in the quote above and another participant said:

“Frontotemporal Dementia support is non-existent.”

## The need for increased support

### Home care

Some participants praised the care at home that they were receiving and stressed how important it was to them to have the right support to be able to continue living at home.

“We are receiving excellent care from [the care provider]. They seem to really care for my Mum and are helping my Dad to understand his wife's changing needs and helping him to care for her in a positive way.”

Other people mentioned how important it was to have [flexible, person-centred support](#) as well as [consistency and continuity of care staff](#).

One person mentioned the need for specialist training for home carers and there's more information in the [workforce development](#) section.

“Specialist care training for home carers as many have no formal dementia training and refuse to provide care when patients are aggressive or have significant cognitive impairment making it impossible for patients to remain at home living with dementia. Some patients are only distressed on intervention and are settled otherwise but end up in placement as no community care available.”

Another mentioned the need to recognise when home care was no longer appropriate and a care home should be considered.

“There needs to be a clear boundary for people living alone with dementia. It is unacceptable that some people live alone in their homes, with no understanding that it is their home when they become a danger to themselves. Some comfort is derived from being in one's home setting and may slow down the progress of dementia, but once that recognition of their home has evaporated and they are incapable of supporting themselves there is no comfort of being at home and instead only a heightened danger remains.”

People also spoke of the financial pressure on organisations providing home care and the need to pay staff well. One person suggested:

“Developing alternative models of care across the region could include setting up user and workers co-operatives by utilising direct payments and personal financial assets.”

## Care homes

Some participants mentioned examples of care homes that are [working well](#).

“The care in some nursing homes is excellent, and they know how to handle people with dementia.”

“The increased confidence in residential homes to care for a person at end of life, stopping unnecessary admissions at an already stressful and highly emotional period works really well.”

Carers mentioned challenges of finding suitable placements for [carer breaks](#), including care that could cope with challenging behaviour as well as [emergency residential care](#).

A few people mentioned the need to have sufficient staffing and person-focussed care within care homes.

“Services [need to be improved], how they are looked after in care homes, the lack of activity they are engaged in, the lack of staffing to make it more person centred. Not making everyone go to bed at 7pm because that's when there shifts finish, not having time to sit and just chat, make the person feel someone is there for them.”

“Small, local residential care.”

One person made a suggestion for how to improve care for people with dementia in distress.

“We need specialist support for people living with dementia who are distressed. In other parts of the UK there are specialist teams, with psychologists and nurses who can work with care homes and family carers to assess the reasons for the distress and develop an action plan to address them. This would make a big difference in North Wales - distress (sometimes known as 'behaviour that challenges') is the biggest factor in reducing quality of life for people with dementia and for carers, and can lead to unnecessary

and disturbing hospital admissions. We need more availability of evidence-based post-diagnostic support e.g. cognitive stimulation therapy, cognitive rehabilitation and arts-based approaches, with staff trained and resourced to deliver to all who would benefit, in accordance with NICE guidance. Research has shown that people with dementia and carers give priority to having continuing contact with a knowledgeable, skilled professional, who can guide them and stay with them along the dementia journey. They do not want to be discharged from services and then re-referred and re-assessed every time the situation changes, they want continuity. We need a genuine multi-agency approach committed to delivering a seamless, continuous service, as promised in the Wales Action Plan on dementia.”

### **Support in an emergency / hospital emergency departments**

A few people commented about the difficulties faced when people with dementia need to access emergency care.

“Should the person with dementia require urgent hospital care, the worst place for them is to be in emergency unit at a hospital, for all sorts of reasons that it would take an essay to outline. Perhaps there needs to be crisis beds available in specialist geriatric units with specialist consultants available. During visits to the emergency departments I have seen a number of patients with dementia, this is an entirely inappropriate place for them to be, with busy staff, who can't provide the specialist nursing they require, it also places a strain on a very overworked department which could be alleviated by more appropriate treatment.”

“A greater focus on care in the community could be explored as when a person with dementia comes into accident and emergency this can cause great distress and can be resource intensive.”

“Attending A&E with a person with dementia is an absolute nightmare! They are so confused anyway about being taken out of their reasonably familiar environment, and to then have to wait (up to 28 hours was a recent experience!) is not really a great thing to experience. A separate room would be amazing where you could calm the person down and they don't have to witness the 'goings on' of other patients. I realise that this is a difficult task but it certainly adds to the stress levels for all concerned.”

## Support for hospital in-patients

Many participants talked about the need for better support for people with dementia when they are in hospital and dementia friendly wards. Some also gave examples of what's currently [working well](#). This is linked to the themes about [raising awareness](#), [improving communication](#) and [working together](#).

“The strategy should ensure that the care and support needed as the disease progresses to the advanced stages is included. For example, if admission to a dementia inpatient assessment unit is indicated, this care needs to be provided by specialist, highly skilled trained staff. It should include the services of psychologists, speech and language therapists, occupational therapists, physiotherapists, pharmacists etc.”

“Concerned that a hospital ward is not always the right environment for people with dementia as it can be noisy and very disorientating, stressed that people shouldn't be segregated but need correct support.”

“...what concerns me is that the wards in the General Hospitals are not dementia friendly and although some of the wards employ Activity Coordinators, one per ward is not enough and also that they can be used as Health Care Support Workers, which takes them away from supporting those patients who are confused and disorientated. Some the challenging behaviours are caused by lack of understanding and activities, none of the wards have any reality orientation aids to try and help keep people orientated. More training on dementia care and managing challenging behaviour should be made available and mandatory...Dementia Friendly wards, a Day Centre away from the wards to help try and keep dementia suffers active to help manage challenging behaviours that may occur due to boredom and agitation. As mentioned there are no visible reality orientation aids on the wards and better training around dementia care and managing challenging behaviours and DOLS [Deprivation of Liberty Safeguards].”

“My mum was in hospital for 6 months and was passed around different wards and bays which did not help her.”

“Length of stay is difficult for both patients, family and staff as the person can get very disorientated and can be 'difficult' for staff to handle – the right staff

need to also be put in place, need those who have specialist knowledge of people with dementia.”

“Recognition and identification within a hospital environment is paramount and of EXTREME importance to the patient and their family.”

One person highlighted that there was good support for patients in their hospital and suggested improvements to the systems:

“I think on diagnosis we should have a flagging up system (with consent) in order to be able to prioritise appointments/ suitable area to assess if admitted..... We are working on this but IT infrastructure difficult to work around.”

Another person mentioned that the improvements made so far have been funded through staff volunteering and local organisations donating and it would be good to have more funding to support these changes.

There was also a comment about the role volunteers can play within hospitals, such as BCUHBs Robin Volunteers to enhance the work of clinical staff. However another comment cautioned about being too reliant on volunteers because of the difficulties in finding enough people who are sufficiently trained and experience.

### **Support when leaving hospital**

A few people mentioned issues around finding nursing home accommodation for people when they leave hospital.

### **Welsh language support**

A few people mentioned the importance of Welsh language support.

“Mae hwn yn ddechrau da ond gellir gwella llawer ar yr ystyriaeth o bwysigrwydd iaith Gymraeg mewn gofal a hefyd anghenion unigolion wrth i ddementia ddwysau. [This is a good start but much can be improved on the consideration of the importance of the Welsh language in care and also the needs of individuals as dementia intensifies]”

### **Safeguarding**

There a couple of concerns raised about safeguarding including issues with people being targeted with postal scams. There was also a suggestion that we could provide

a list of recommended tradespeople for those who are vulnerable in the community. A few people also mentioned that while keeping people at home as long as possible was important it can reach a point where that is no longer safe and alternative arrangements need to be quickly put in place.

## Other consultation and engagement activities

### Tide response to ‘Together for a dementia friendly Wales’

In 2017 in response to the Welsh Government consultation about the dementia action plan Tide organised three events for carers in North Wales in Anglesey, Gwynedd and Conwy, in partnership with Carers Outreach and Bangor University’s North Wales Dementia Network. Some carers who were unable to attend the events sent individual responses.

The report said that carers were unanimous that carers should be included as an additional theme in the dementia action plan. It highlighted the unique challenges of caring for someone with dementia and the need for services that meet each individuals’ needs. Some also said the co-ordination of care should be a specific theme as fragmented and dis-jointed services have major impacts on their lives.

Other points related to the North Wales strategy include the following.

- Use ‘networks’ rather than ‘pathways’ to meet the needs of people with dementia due to many different types of dementia and different ways people experience it.
- Communities are only ever working towards being dementia friendly as one bad experience will undermine the claim.
- Dementia friendly awareness raising is a good start but there’s a lot more that can be done to improve people’s understanding and ability to respond to the needs of people with dementia and their carers.
- Challenges with GPs include the need for GPs to talk to carers directly as equal partners in care, acknowledge concerns, and recognise the value of a dementia diagnosis.
- Need for a single point of access or named person for information and advice. Many carers found being handed a ‘dossier’ of leaflets unhelpful. Need help to find a way through the system and find out what you’re eligible for.



- Post-diagnosis support needs to be offered at the point of diagnosis. There is some excellent support available in North Wales but not everyone is able to access it and few carers had been offered a carers assessment.
- Challenges of trying to organise help when their needs changed and of finding a good care home when needed.
- Lack of support for younger people with dementia who were often expected to use services set up for much older people and the time taken to get a diagnosis.
- The value of activities to stay active, meet with other people and provide peer support although these were often 'stumbled on by chance' and need transport to access.
- The difference between life story work (like 'Book of you') and personal profiles (like a 'This is me' fact sheet) with key information about individuals to be shared with care staff.
- Challenges of inflexible services, such as transport timed to arrive before carer workers are able to support someone to get up and ready.
- Concerns about the low pay and training that home care workers receive, although many are well-meaning and do a good job.
- Importance of involving people with dementia in the design and planning of services and avoiding tokenism. This can include: training staff, recruiting staff, speaking at conferences, meeting with health board and social services managers on specific issues, having a seat at the table in planning forums/project groups, focus groups in specific service settings to give feedback.
- Examples of professional paid staff, including those working in specialist dementia services, being unable to manage people with dementia in the services but expecting family members to come and rescue them. This raises serious concerns about training.
- Mixed experiences of hospital care – some very positive experiences and some not so good. Need to highlight schemes like 'This is me', the Butterfly Scheme and John's Campaign as well as guidance for diagnosis, prevention and management of delirium in hospital settings.
- Challenges of accessing respite care that meets their needs. Care homes are not appropriate for everyone and overnight and evening care at home was almost impossible to access.
- Need to reference the learning from *In Search of Accountability: A review of the neglect of older people living in care homes investigated as Operation Jasmine*'

(Flynn 2015), in particular the importance of listening to family carers and involving them in the care of their relatives should they wish to continue this role.

- Difficulties of accessing continuing health care funding.
- Importance of including end of life care, reference to resuscitation policies and approaches and the impact of bereavement on carers and the need for continued support.

Overall what would make it easier for carers to look after the person they care for includes the following.

- A single point of contact or a named person to go to for advice and information
- A structured programme of post diagnostic support for you and the person you care for
- Opportunities to meet with other carers (peer support)
- Respite care that gives more choices than admission to a residential care home
- Overnight and evening care
- Staff working in hospitals, GP surgeries and social services who understand about dementia and what it means
- Being treated by these staff as an equal partner in care
- Recognition of your role as a carer and your expert knowledge of the person you look after
- Information about local services and what options you can consider, for example, different sorts of housing
- Staff who speak Welsh

## **Transgender issues in dementia care**

BCUHB have written a guide to understanding, reflecting and responding to transgender issues in dementia care in partnership with activists within the transgender community of North Wales. The guide includes people's stories of their transgender lived experience and the protections transgender people have in law.

The guide looks at the psychological needs of people with dementia – Love at the centre, which 'is an unconditional acceptance of the other person, an expectation that we provide what the person needs in a truly accepting way with no expectation of reward'. Then the other needs attachment, comfort, identity, occupation and inclusion which are different in every person and are key to maintaining the

personhood of the individual with dementia and the guide highlights issues for health care staff caring for transgender people in relation to each of these.

The guide emphasises that ‘support me to be the person I want to be’ sits at the heart of dementia care and concludes:

“If we are unable to promote these things [sense of self and self-identity] for ourselves then we are at risk of being assigned a different self-identity by others than we would otherwise wish for.

It is the greatest fear that people newly diagnosed with dementia have and for transgender people affected by dementia it is made worse by the potential loss of a preferred gender identity, denial of gender expression or an imposition of a gender identity that others think is more socially acceptable.”

## Conclusion and recommendations

The consultation findings are supportive of using the themes from the Welsh Government Action Plan as the basis for the North Wales Dementia Strategy. Based on these findings it's recommended that a specific priority is added to the strategy about the needs of carers. The other themes should also include additional priorities raised in the consultation, such as end of life care and bereavement.

To make sure that the views of participants are fully included in the strategy it's recommended that further consultation is carried out on the draft strategy, particularly with people with dementia.

# Appendix 1: Equality monitoring data

Please note, the tables below only reflect around 150 participants who gave answers to the equality questionnaire rather than all 250 participants. For a full picture of the engagement with people with protected characteristics these figures should be considered alongside the list of organisations who responded to the consultation.

Table 1 Number of responses by type of participant

Type of response	Number
Work for an organisation	120
Carer for someone with dementia	60
Person with dementia	30
Other (relative / friend of someone with dementia)	20
Other (previous caring experience)	20
Other (interest / dementia champion)	5
<b>Total</b>	<b>250</b>

Some people may have ticked more than one box. Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not add up due to rounding.

Table 2 Age

Age	Number
16 to 24	<5
25 to 34	10
35 to 44	20
45 to 54	50
55 to 64	45
65 to 74	20
75 and over	10
<b>Total</b>	<b>150</b>

Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not add up due to rounding.

Table 3 Sex

Sex	Number
Female	115
Male	30
<b>Total</b>	<b>150</b>

Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not add up due to rounding.

Table 4 Ethnic identity

Ethnic identity	Number
White	140
Indian	<5
Black	<5
Mixed heritage	<5
<b>Total</b>	<b>150</b>

Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not add up due to rounding.

Table 5 National identity

National identity	Number
British	140
Other	5
Irish	<5
Other European	<5
<b>Total</b>	<b>150</b>

Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not add up due to rounding.

Table 6 Preferred language (spoken)

Preferred language	Number
English	100
Welsh	30
English and Welsh	25
<b>Total</b>	<b>150</b>

Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not add up due to rounding.

Table 7 Preferred language (written)

Preferred language	Number
English	110
Welsh	20
English and Welsh	20
<b>Total</b>	<b>150</b>

Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not add up due to rounding.

Table 8 Disability

Disability	Number
Learning disability	12
Long standing illness or health condition	10
Physical impairment	5
Mental health condition	<5
Sensory impairment	<5
<b>Total</b>	<b>30</b>

Some people may have ticked more than one box. Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not add up due to rounding.

Table 9 Religion

Religion	Number
Christian	80
None	60
Buddhist	<5
Hindu	<5
<b>Total</b>	<b>150</b>

Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not add up due to rounding.

Table 10 Sexuality

Sexuality	Number
Heterosexual / straight	130
Lesbian, gay or bisexual	5
<b>Total</b>	<b>150</b>

Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not add up due to rounding.

Table 11 Carers

Carers	Number
Yes	65
No	75
<b>Total</b>	<b>150</b>

Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not add up due to rounding.

Table 12 Number of hours of care provided each week

Number of hours	Number
1 to 19 hours	45
20 to 49 hours	10
50 hours or more	10

Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not add up due to rounding.

Table 13 Marital status

Number of hours	Number
Married	95
Single	30
Divorced	5
Widowed	5
<b>Total</b>	<b>150</b>

Numbers have been rounded to the nearest 5 to prevent disclosure of personal information and may not add up due to rounding.