

# LLAIS NEATH PORT TALBOT AND SWANSEA REGION DEMENTIA SERVICES: YOUR VIEWS



**The experiences of people living with dementia  
and their carers**

# ACCESSIBLE FORMATS

**This report is also available in Welsh.**

**If you would like this publication in an alternative format and/or language, please contact us.**

**You can download it from our website or ask for a copy by contacting our office.**

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# ABOUT LLAIS



We are here to understand your views and experiences of health and social care, and to make sure your feedback is used by decision-makers to shape your services.

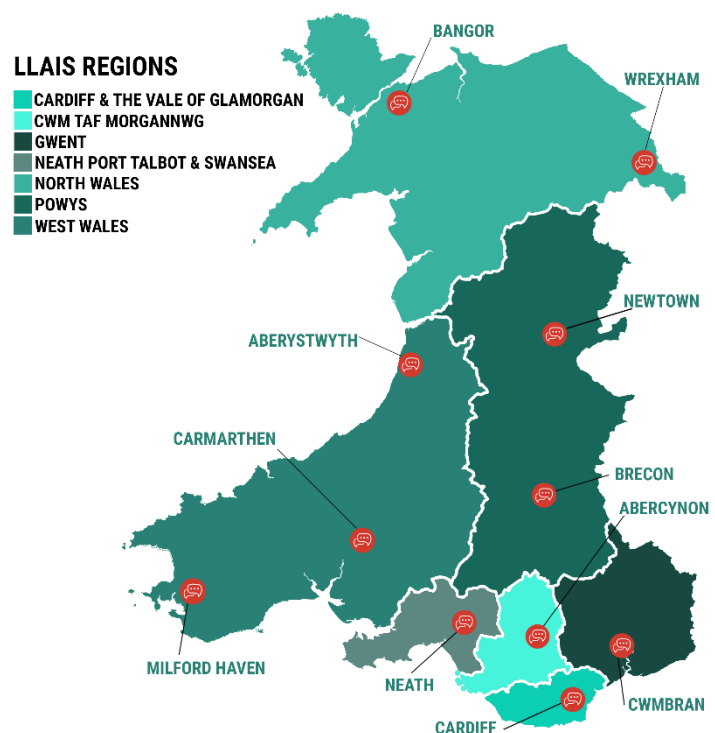
We seek out both good and bad stories so we understand what works well and how services may need to get better. And we look to particularly talk to those whose voices are not often heard.

We also talk to people about their views and experiences by holding events in your local communities or visiting you wherever you're receiving your health or social care service.

This includes working with community and interested groups to gather people's views.

And when things go wrong, we support you to make complaints.

There are 7 Llais Regions in Wales. Each one represents the "patient and public" voice in different parts of Wales.



# BACKGROUND

## DEMENTIA AS A GROWING ISSUE

Dementia is one of the fastest growing causes of disability across the world ([World Health Organisation, 2021](#)).

**We are building on some previous work by the Community Health Council which found that dementia services are important to people living in the area.**

It usually affects people over the age of 65, with 1 in 6 people over the age of 85 living with dementia. ([The Alzheimer's Society](#))

The Census data from 2021 shows that there are 79,017

people living in Neath Port Talbot and Swansea over the age of 65. The Welsh Government published its [Dementia Action Plan 2018–2022](#) because as people live longer the demand for dementia services is increasing. Local Authorities are required to identify the health and social care of their population and publish this. This is known as a Population Needs Assessment. The assessment for Swansea and Neath Port Talbot shows that there is an increase in the number of people living with dementia.

Social Care Wales predict a 65% increase in the number of people with dementia living in the West Glamorgan area by 2040. We asked the Health Board for the number of people living with a dementia diagnosis in the area currently, but this data is not yet available.

## ETHNICITY AND DEMENTIA

[A University College London study](#) found that dementia rates are 22% higher among Black people in the UK compared to those who are White and that Black and South Asian dementia patients die younger and sooner after diagnosis.

Neath Port Talbot and Swansea has a mainly White population, with Black and Asian Minority (BAME) people making up less than 3% of the population of Neath Port Talbot and 9% of the population of Swansea.

Our Project, therefore, sought to speak to people from these communities about their experiences.

We wanted to hear from as many of you as possible about what works well, what needs to change, and your ideas about new services that could be introduced to improve the lives of people living with dementia in our community.

## WHAT WE DID

Over 8 weeks, we visited 17 different settings to speak to people living with dementia, their carers, and loved ones.

We visited 1 Local Authority run day service, 2 Local authority care and nursing homes, 2 NHS services, 1 private nursing home, and 11 third sector community groups. Two of these settings were services that regularly support people from BAME communities.

**We visited 17 different settings to speak to people living with dementia. We also launched an online and paper-based survey to gather your thoughts and ideas.**

We launched a survey via our national and regional Facebook pages and shared QR codes with all the residential homes offering dementia care in the Neath Port Talbot and Swansea region. We asked care homes to direct their service users and visiting families to our survey and to contact us if people wanted to share their stories another way.

It was clear that people preferred to speak to us and tell their story rather than completing surveys.

Within the settings we visited, we met 244 people living with dementia and/or their carers. Of those people, 98 chose to share their stories with us.



We received 3 responses to our online survey, and 3 via our paper-based survey, one of which was completed in Welsh.

Given the age of people likely to be affected by dementia, who research tells us are less likely to use digital services, this was expected. When visiting larger

groups, we made sure there were extra staff or volunteers to provide as much opportunity as possible to hear stories directly from people.



We found that in visiting community groups, people spoke more broadly about their health and social care experiences, not simply about the service we were visiting. This helped us to build a fuller picture of what really matters to people living with dementia.




We also linked in with local organisations supporting people living with dementia to better understand their services and to ask that they encourage people to speak with Llais to have their say. This included: lead dementia nursing staff, care home and day centre managers, voluntary sector dementia champions, NHS service providers, Carers Centres in Neath Port Talbot and Swansea, the CVS, occupational therapists, and Local Area Coordinators.




## THE POSITIVE COMMENTS

People told us how much they appreciated Health and Social Care staff.




**"I love everybody here. I won't hear a bad word from anyone about them...they're like friends with me."**

(Comments about staff at Ty Waunarlwydd)



**"pleasant and attentive with a cheerful attitude."**




**"professional, in uniform, they honoured my mum...well trained, ready for their job, their care was exemplary."**

(Swansea Council's carers team)



**"I don't know what I'd do  
without this place."**

(St John's Day Centre)



**"Cefn Coed – absolutely  
fantastic!...wonderful  
carers, so kind, so  
relaxed with them."**



**"a lifeline for us."**

**"they keep me going."**

The most common feedback we had was the importance of community groups, some funded by the Regional Partnership Board, with all groups visited being described as a **"lifeline."**

Residents of Neath Port Talbot were particularly positive about Ospreys in the Community Sporting Memories and the Sunflower Café. They were pleased to hear about the opening of the Dementia Hwbs in the region.

There was high praise from both Swansea and Neath Port Talbot residents for the Occupational Therapy teams – **“the OTs there (Port Talbot Resource Centre) go above and beyond.”**

**“WESTFA service is excellent. Doctor, nurse, psychologist services given. Speech and language therapist. Signposted to support services.”**

A number of people praised Garngoch, saying they have found the care **“excellent”** and said they were **“very helpful.”** Somebody else described a **“really attentive service.”**

## THE NEGATIVE COMMENTS

Family member of a person receiving support from Swansea Social Care.

**“In general the support from social services is very poor...they want to do as little as possible for you. I have had to fight for everything...every phone call is a battle and you have to be at your wits end before they will do anything for**

There were several concerns raised about people's experiences of social care in Swansea. The following themes were identified by 22 of the people whom we spoke to:

- the need for consistent and stronger communication
- People not always knowing who their social worker was
- significant waits for allocation
- lack of respite
- family and next-of-kin views not being considered.
- lack of continuity of care packages following a break/ hospital stay
- People feeling that they have to fight for services
- People feeling that the support they need should be timely and flexible

## CULTURAL AWARENESS

One of the key issues raised at the start of the project was the impact of dementia upon Black and South Asian people. A lot of staff in the settings we visited commented that they had very few people of BAME heritage accessing dementia services.

The size of the group of people we spoke to is limited. The comments we did receive, suggest that for both Neath Port Talbot and Swansea arrangements need to be made for people to be able to communicate in their preferred language. There is also a need to strengthen staff's cultural competence in providing care to diverse ethnic groups.

A British/Bangladeshi family member spoke of having to attend appointments to interpret and stressed the need for more bilingual staff in care services.

We heard from a Black Jamaican person that they had sought support with communication from an external BAME organisation. They felt the social worker did not understand their culture.

It is acknowledged that this project reached very few people of Black or South Asian descent. Llais has begun to develop relationships with organisations supporting the BAME communities. Future projects will look with community groups at how we change our ways of working to make sure diverse voices are better represented.

# KEY THEMES

The stories people shared in the project mainly revolve around a few key themes:

- Communication
- Access to and lack of services
- Seeing the individual / person-led care
- Lack of / confusing information
- Lack of continuity

There are many areas of good practice identified by this report. These have been fed back to services. The main areas of concern are listed below:

## **Communication**

Many people expressed concerns about family members not being asked for their opinions or included in assessments and decisions. They also mentioned that when they complained, they didn't receive feedback on what was done about it. Additionally, people talked about having to wait a really long time for a social worker and facing difficulties in reaching the teams. People also told us about the need for professionals to have open conversations with them about their future, and end-of-life care.

## **Access to services**

Respite and sitting services were seen by a lot of people we spoke to as necessary to prevent loved ones from going into residential care. Carers talked about fighting for services, with some saying they had waited for more than a year after being told their family member would have respite.

## **Seeing the individual**

When we spoke to people living with dementia who received help from teams of carers or in residential and nursing homes, they often told us about how their individual interests and social activities were lost. Many spoke of not having a range of activities available that interested them, not being able to go on walks that they enjoyed or to a café with friends. We heard those caring for people with dementia felt strongly that their loved ones were still the same person, even though changed, and that it was important for services to remember this in the help and support they offer.

## **Information**

Lots of people told us that there should be one place for people to go to for help with all things related to dementia care. The carers we talked to said they often felt "overwhelmed," "lost," and "alone." They want a straightforward guide to know which services to reach out to and when, including in the NHS, Social Care, and the community. They also want to know the criteria for these services and who the main teams are that can give advice and guide them. Many comments were made about needing support to understand the financial aspects of care too.

## **Continuity**

We heard that care packages often stop when someone goes to hospital, on respite, or goes on holiday with family. This means having to go through the process of finding new carers again. The limited choices and the time it takes to find new carers made the people we spoke to feel like they might not be able to continue caring for their loved ones at home. This situation was causing a lot of stress for both the carers and those they care for. People told us how much they also wished that files would be read by professionals before meeting them to avoid having to repeat their story to lots of different people.

Llais Neath Port Talbot and Swansea made the following recommendations – or “representations” – on your behalf following this project. When we have a response from these services, we will make sure that we let you know via our social media channels, website and in letting the service leads know where we came to speak to you.

## **ALL PROVIDERS**

### **Representation 1: Single point of contact for information**

Please tell us if you can work together to create or develop an existing, jointly funded service that provides advice and support on all aspects of living with dementia and providing care, including emotional wellbeing for carers and financial advice. Please tell us how you will work together to provide a clear pathway from diagnosis onwards.

### **Representation 2: Promoting the individual in care and support**

Please tell us your plans to make sure that even when in temporary stays and arrangements, the individual interests of the service user will be an active part of providing activities, care and support.

### **Representation 3: Promoting language and culture in delivering services**

Please tell us how you will make sure that all staff delivering services develop their understanding of different cultures and provide translation so that everyone receives fair access to services.

## **REGIONAL PARTNERSHIP BOARD**

### **Representation 4: Funding of third sector organisations**

Please tell us the plans to ensure that there are adequate support services in the community and how the RPB can support any existing support groups.



## NEATH PORT TALBOT SOCIAL CARE

### **Representation 5: Appropriate consultation with family members**

Please tell us how social workers will make sure that family members and those receiving care will be fully kept informed, their views considered in assessments and plans and outcomes of any disagreements or complaints communicated back to families.

### **Representation 6: Increase respite provision and sitting services**

Please tell us how opportunities for respite and sitting services are being put in place quickly and how you will make sure people who need these services are receiving them.

## **SWANSEA SOCIAL CARE**

### **Representation 7: Prompt allocation of social workers**

Please tell us the existing agreed timescales for allocating a social worker, steps that will be taken to make sure this happens quickly and arrangements for alternatives where this is not possible.

### **Representation 8: Availability and continuity of care**

Please tell us the current arrangements for duty cover, and how social care will make sure that those in need of a service from social workers and care providers continue to receive the right services, even after there is a break for respite, holidays or hospital stays.

### **Representation 9: Increase respite provision and sitting services**

Please tell us how you will make sure opportunities for respite and sitting services are being put in place quickly and that those who need these services are receiving them.

### **Representation 10: Planning for residential care**

Please tell us the arrangements for planning for residential care and whether there is a need to consider how often people's needs are reassessed to make sure they are receiving the right services at the right time.

## **SWANSEA BAY UNIVERSITY HEALTH BOARD (NHS)**

### **Representation 11: Reopening of Tonna day hospital**

Please tell us if this service can be reopened and if this cannot happen, the alternatives that can be created for day care provision.

### **Representation 12: Creation of a Dementia Lead for SBUHB**

Please tell us if this role can be created to recognise the unique nature of dementia within services and the possibility of staff training and service development falling under this person's guidance.

### **Representation 13: Dementia friendly A&E services**

Please tell us if care for those with dementia can be triaged promptly in A&E and if a dementia friendly environment for waiting can be created.

### **Representation 14: Provision of diagnosis in person**

Please tell us if the NHS can make sure diagnoses are given in person to patients and if training can be provided to GPs around this.

### **Representation 15: Planning for end-of-life care**

Please tell us how the NHS will work with those with dementia and their families to plan end-of-life care in a sensitive manner at an early stage.

# THANKS

We thank everyone who took the time to share their views and experiences with us about their health and social care services and to share their ideas.

Thank you also to those who supported this project and let others know about it so we could reach as many people as possible.

We hope the feedback people have taken time to share influences services to recognise and value what they do well – and take action where they need to as quickly as they can to make things better.

## FEEDBACK

We'd love to hear what you think about this publication, and any suggestions about how we could have improved it, so we can use this to make our future work better.

## CONTACT DETAILS

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