LLAIS
Eich llais chi mewn iechyd a gofal | Your voice in health and social care

HOLDING IT TOGETHER: CARERS SPEAK ABOUT THEIR JOURNEY

What we did

Llais visited community groups to speak with people living with dementia, their carers, and families. We wanted to listen and understand what care and support looks and feels like for them – and what better care and support would mean in their lives.

This included attending groups in the community, such as those run by the Royal Voluntary Service, to hear first-hand experiences of health and social care services.

These conversations gave us valuable insight into the challenges people face and the support that makes a real difference.

What people told us

It was clear from our conversations that more support is needed, many near breaking point. Carers shared they often feel invisible, lonely and lost and unsure about what help is available. Many don't want to burden others, even when they're finding things difficult.

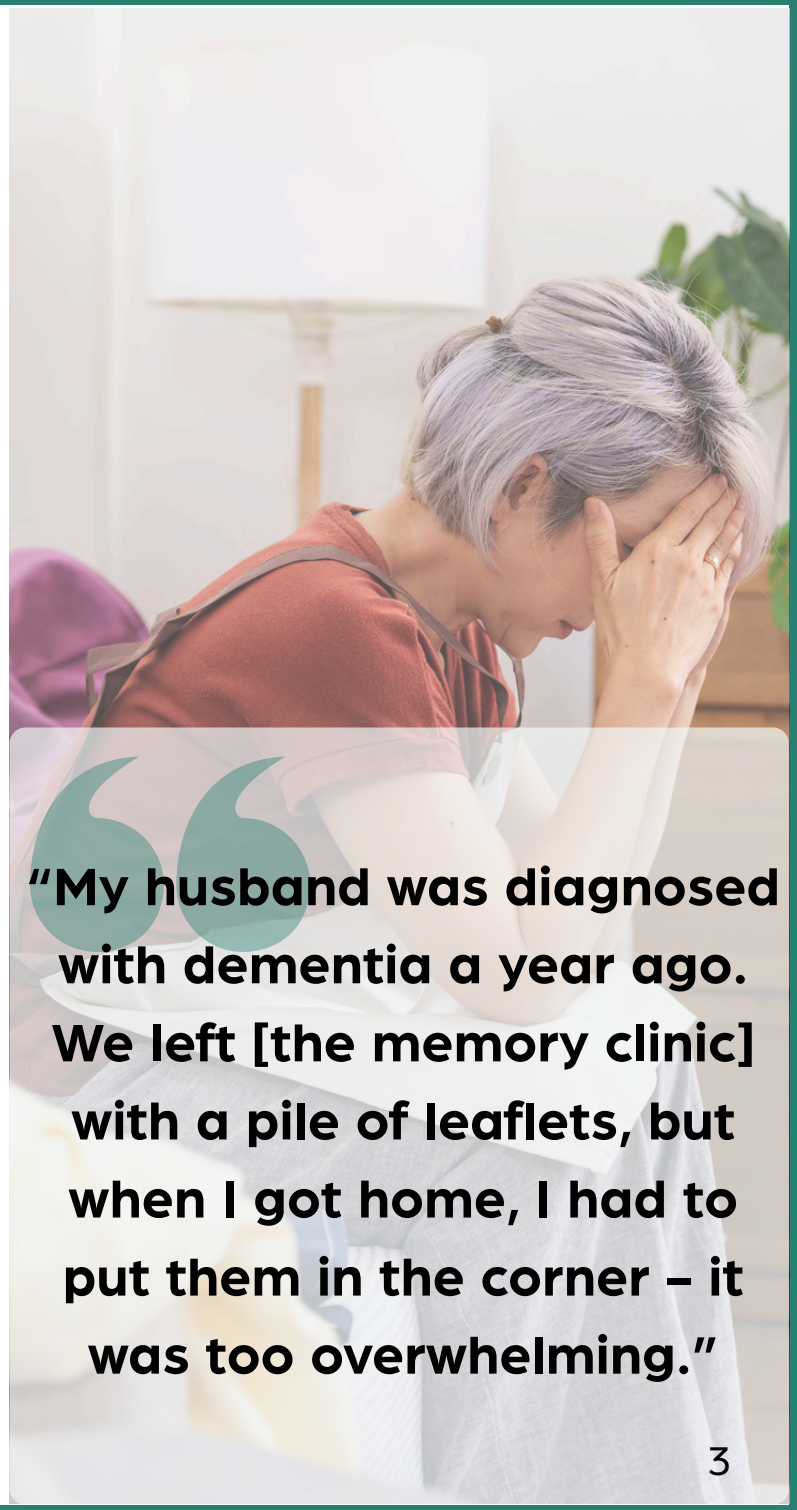
Memory Clinic

After appointments at the memory clinic, people told us they felt overwhelmed when they received their diagnosis. Although they were given a few leaflets for support, this often felt like too much, too soon.

People shared that they would value having time to process the news first, and then receiving clear, supportive information when they feel ready – rather than at the point of diagnosis.

Carers also shared that during appointments, their voices were not always heard. They told us they would value the chance to speak with clinicians to confirm details or share observations that could help provide a fuller picture of their loved one's needs.

Many suggested that regular check-in calls, perhaps every three months, would make a big difference in supporting both the person with dementia and those who care for them.



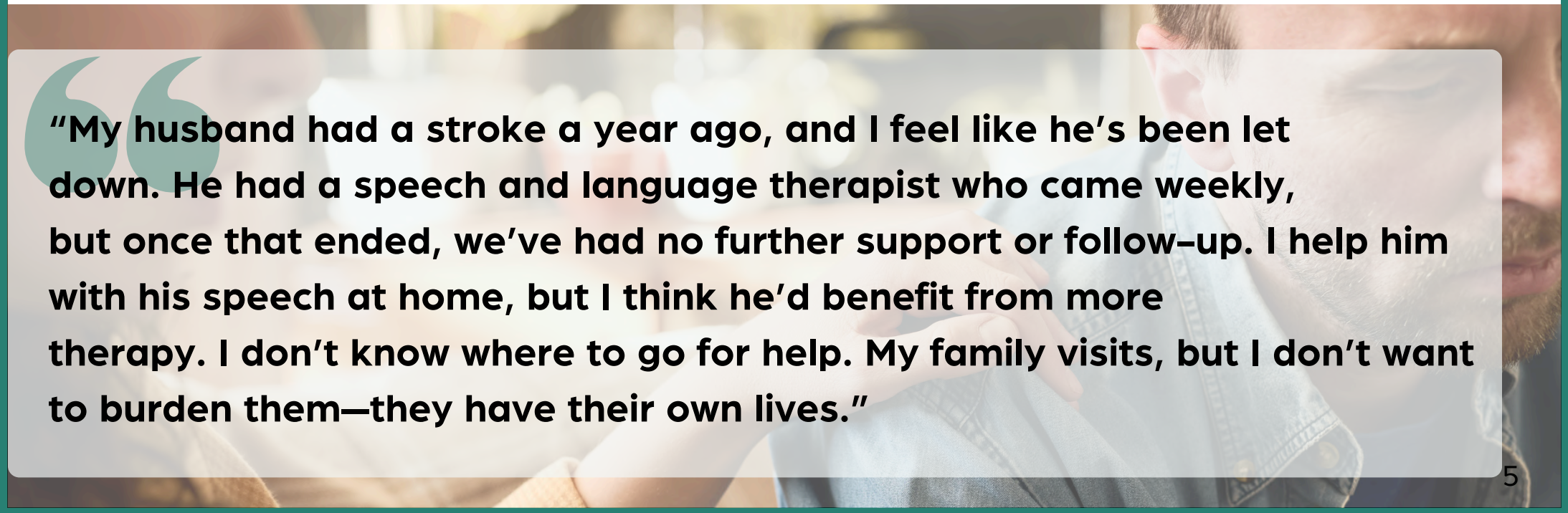
"My husband was diagnosed with dementia a year ago. We left [the memory clinic] with a pile of leaflets, but when I got home, I had to put them in the corner – it was too overwhelming."

"My husband was diagnosed with dementia. **For two years, I felt angry – not at him, but at the diagnosis.** I'm still trying to come to terms with it. **I don't want his life to stop because of dementia.** If you seem to be coping, services assume you don't need help."

Follow–up care and support

Follow–up appointments at the memory clinic often felt too far apart – typically every six months or even once a year. They felt that more regular contact would help them build a stronger relationship with the memory clinic team, so the team could really get to know the person behind the diagnosis.

This isn't just about dementia – one carer shared her experience of supporting her husband after a stroke. She told us that when his speech therapy ended, the follow–up stopped too, leaving her feeling alone and unsure where to turn for help. She didn't want to burden her family – they had their own lives to manage.



"My husband had a stroke a year ago, and I feel like he's been let down. He had a speech and language therapist who came weekly, but once that ended, we've had no further support or follow–up. I help him with his speech at home, but I think he'd benefit from more therapy. I don't know where to go for help. My family visits, but I don't want to burden them—they have their own lives."

Support Services

Carers told us that finding support and respite for their loved ones is hard – most information is online, services differ across boroughs, and with the demands of caring, they often don't have the time or energy to search for what's out there.

Carers sometimes sacrifice their own health because support services are limited or inaccessible. One carer told us she desperately needs respite but couldn't find a day centre in Newport. She's delaying two knee replacements because leaving her husband in a care home would feel like the end for him.

This shows how vital it is to provide flexible, local support that meets carers' needs without forcing impossible choices

Our recent engagement with carers and individuals aligns closely with the national picture highlighted in Carers UK's State of Caring report. The voices we've gathered locally in Gwent reflect many of the same concerns raised nationally.

Our Response to the Senedd Inquiry: Supporting Unpaid Carers

Our recent response to the Senedd inquiry into improving access to support for unpaid carers echoes many of the report's key themes:

- Financial strain: Carers cutting back on essentials like food and heating, with many falling into debt or poverty.
- Mental health and wellbeing: Carers report high levels of stress, anxiety, and isolation. Llais has heard from carers who feel "invisible" and "at breaking point."
- Access to support: Long waits for assessments, inconsistent respite care, and poor communication from services are common barriers.
- Recognition and voice: Carers want to be seen as partners in care, involved in decisions, and supported in ways that reflect their real needs.

Turning Voices into Action

To make sure carers get the right help at the right time, we're starting conversations with our partners. These questions come from what carers told us and aim to shape more responsive, compassionate support. We will continue to amplify voices, work with partners to address the gaps identified, and push for more accessible, compassionate, and coordinated support for carers across Gwent. Below is a summary of responses we received from partners.

Aneurin Bevan University Health Board:

The Memory Clinic

1. **Post-Diagnosis Support**

   Can you provide a structured follow-up after diagnosis (e.g., at 3 months) to prevent families feeling abandoned?

   Response:

   Yes, we provide post diagnostic appointments 3-4 months after diagnosis

2. **Carer Involvement**

   How do you ensure carers are included in discussions about care and medication, especially when the person with dementia cannot advocate for themselves?

   Response:

   Carers are encouraged to take part in all appointments, except where patients have expressed a wish not to involve them. Capacity and Lasting Power of Attorney (LPA) would also be taken into account.

3 Accessibility & Communication

What is your current response time for calls and messages, and how do you make sure carers can easily reach someone for advice?

Response:

This depends on locality areas, vacancies, sickness, clinic commitments etc – however we do aim to get back to messages/calls as soon as possible. There is a duty desk for any urgent queries which is manned Mon–Fri 9–5 by a clinician.

4 Information & Guidance

Do you offer a clear, accessible guide for families post-diagnosis that includes local support services and contact details?

Response:

We signpost to Alzheimer's Society, Dementia Hubs, diagnostic leaflets are awaiting printing, which also helps. We have the Memory Assessment Service (MAS) Website which is in use and also has links to local support services along with contact details.

5 Practical Help

Are there recommended activities or resources to help slow deterioration (e.g., cognitive exercises, speech and language activities)?

Response:

The MAS website details activities to aid cognitive stimulation, referrals to other services such as SaLT/OT would be considered on an individual basis.

6 Continuity of Care

How do you ensure carers know who their assigned nurse or point of contact is?

Response:

MAS would provide contact details for their team at the point of diagnosis. Dedicated nurses are not always possible, due to sickness/vacancies etc however we strive to ensure there is continuity, where possible.

Stroke Services

1 Access to Ongoing Support

After initial post-stroke therapy ends, can carers or patients contact your team for further support or advice? If so, how?

Response:

All patients are sent information about the 'Living Well After Stroke Service' which provides support and signposting to local services and opportunities. This service is closely linked with the Community Neuro Rehab Service and the Neurostute Neuro Recovery College which provides opportunity to access some longer-term support in the community including Neuro sessions at local gyms, Aphasia groups, a Stroke choir, and Stroke Support Groups.

To speak with one of our Living Well After Stroke practitioners, please call us on 01495 363461 (8:00am – 4:30pm, Monday to Friday. Answerphone available outside these hours).

If patients require ongoing support when the Early Stroke Discharge team complete their intervention, people are referred to or linked with appropriate services in their area - these may or may not be stroke specific as people can benefit from general access groups that are in their local neighbourhood.

2 Follow-up Care

Is there a structured follow-up process after therapy finishes to check progress and identify ongoing needs?

Response:

For people completing support with the Early Supported Discharge Service there is a review at the end of intervention to check progress against goals and identify plans for continued recovery. There is not a review further down the line due to current resource limitations. All patients discharged from the service are given the details of the 'Living Well After Stroke Service' and can access signposting and information through that.

3 Referral Pathways

If additional therapy is needed, what is the process for re-referral? Can carers initiate this, or does it require a GP?

Response:

Following completion of the Early Supported Stroke Discharge programme, there is a reciprocal agreement in place with the Neurophysiotherapy service for people to self re-refer for stroke specific issues without the requirement of going through the GP. The Adult Speech and Language Service has a request for helpline that does not require GP referral.

4 Information for Carers

Do you provide clear guidance for carers on what to do if they feel their loved one needs more support?

Response:

Whilst people are inpatients, carers have access to information supplied by the Stroke Association, there are regularly maintained information points on the Stroke Hyper Acute Stroke Unit (HASU) and rehabilitation wards. Since the beginning of February, there are Carers Clinics that run on a twice weekly basis in Ysbyty Ystrad Fawr and further information is provided there as required. The Early Supported Discharge service provides a Stroke Information Guide to all which includes national and locality specific contact details for further support. People are also signposted to a network of nine Stroke Clubs in the Aneurin Bevan University Health Board area. There are opportunities for people to become Peer Partners through the volunteer service.

5 Signposting

Are carers given contact details for relevant charities or community services (e.g., Stroke Association) as part of discharge information?

Response:

Carers have access to information supplied by the Stroke Association, there are regularly maintained information points on the Stroke HASU and rehabilitation wards. Additional information: the newly appointed Allied Health Professions Consultant in Stroke is working on a Stroke Carers Pathway in partnership with the Regional Carers Transformation Lead. A video series is in production to provide bite sized education to carers of people with stroke and brain Injury about fatigue management. There is a monthly community based Stroke Carers meeting. Website link: Community Neurological Rehabilitation Service – Aneurin Bevan University Health Board – which contains information about the Early Supported Discharge in Stroke team and the Living Well After Stroke Service

Local Authorities in Gwent

1 Respite and Day Centres

What options for day centres or respite care are currently available in each borough, and how are carers informed about them?

Response:

Across Gwent, respite and day opportunities are provided through a combination of in-house local authority provision, externally commissioned services, and community-based alternatives. Availability and delivery models differ by local authority area to reflect local need.

While not all partners directly deliver day or respite services, carers are supported to access clear and accurate information about what is available in their local area. Outreach Workers maintain up-to-date knowledge of local services, including:

- Day centres and community-based day opportunities
- Short-break and respite provision
- Specialist dementia and disability day support
- Alternative options such as sitting services and community activities
- Eligibility criteria and referral routes

Information is tailored to the carer's borough and individual circumstances to ensure relevance and clarity

How carers are informed

Carers are made aware of respite and day opportunities through multiple routes, including:

- Direct conversations with Outreach Workers
- Community groups, outreach sessions and events
- Telephone support offering personalised guidance
- Printed information and leaflets where available
- Carers' groups, which also provide peer support and informal information-sharing

Partners ensure carers understand not only what services exist, but also how to access them, whether referrals are required, and where support can be provided to assist with the referral process.

Carers' groups

Carers' groups are open to carers and the people they care for. This inclusive approach recognises that carers may be unable to attend if they cannot leave their loved one at home. Opening groups to both carers and cared-for individuals helps remove barriers, supports inclusion, and reflects the realities of caring roles.

2 Accessible Information

Can information about carers' support be provided in formats beyond online (e.g., printed guides, community hubs), given many carers struggle to find help digitally?

Response:

Partners recognise that not all carers are able to access or feel confident using online information. To address this, information about carers' support is provided in a range of formats, including:

- Printed guides, leaflets and easy-read materials
- Information available through community venues
- Postal information on request
- Telephone support and face-to-face conversations in community settings

These approaches ensure carers who are not digitally connected, or who prefer personal contact, can still receive clear, personalised advice, guidance and emotional support.

3 Carers' Assessments

How are carers made aware of their right to a carers' assessment, and what practical support can they expect from it?

Response:

Although partner organisations do not undertake Carers' Assessments directly, they actively ensure carers are aware of their legal right to request one from their local authority.

During contact with carers—whether through appointments, telephone calls or community events —partners explain:

- What a Carers' Assessment is
- Why it is important
- How it can support carers' well being
- The types of support that may result

Carers are also supported to understand what to expect from the assessment process, including the types of questions that may be asked and how the assessment considers both wellbeing and the caring role. This helps reduce anxiety and makes the process feel more manageable.

Referrals

Where appropriate, referrals to the local authority can be completed and submitted on behalf of the carer. This reduces the burden of navigating forms and processes and ensures referrals are made accurately. Ongoing contact is maintained while carers await outcomes.

Post–Diagnosis Support and Mental Health Services

Following a diagnosis of dementia, post–diagnostic appointments are offered approximately three to four months after diagnosis to help prevent families feeling unsupported.

Carers are encouraged to be involved in discussions about care and medication, unless the individual has expressed a wish not to involve them. Consideration is given to capacity and Lasting Power of Attorney arrangements.

Response times to calls and messages vary depending on locality pressures, staffing and clinic commitments; however, teams aim to respond as promptly as possible. A duty desk is available for urgent queries Monday to Friday, 9am–5pm, staffed by a clinician.
Families are signposted to relevant support services, including Alzheimer's Society and Dementia Hubs. Information is also available via the MAS website, which includes links to local support services and contact details. Diagnostic leaflets are awaiting printing.

Practical support, including cognitive stimulation activities, is outlined on the MAS website. Referrals to other services such as Speech and Language Therapy or Occupational Therapy are considered on an individual basis.

At the point of diagnosis, contact details for the relevant team are provided. While dedicated nurses are not always possible due to staffing pressures, continuity of care is prioritised wherever feasible.

Local Authority Day Centre and Respite Provision

Each local authority across Gwent provides a range of in-house and commissioned services for older adults, people with dementia, individuals with learning disabilities, and children and families with neurodiversity.

Provision includes building-based day services, community-based support, respite houses, outreach services and supported employment opportunities. Access is typically via social services needs assessments and internal referral routes.

Partners across Gwent remain committed to ensuring carers and people living with dementia receive clear, accessible and person-centred support. By offering information in multiple formats, supporting access to respite and day opportunities, promoting awareness of Carers' Assessments, and providing post-diagnostic follow-up, services aim to reduce pressure on carers and support them to access the help and recognition they deserve.

We trust this response addresses the issues raised and welcome continued dialogue with you to support ongoing improvement.

Next steps

Carers across Gwent have shared honest insights that highlight the need for clearer information, timely support and stronger recognition of their vital role. Llais will continue to share these experiences with partners, monitor the actions outlined in their responses, and ensure carers' voices remain at the centre of improvement