

Annual Report 2023/2024

Dementia Hwb

www.dementiafriendlyswansea.org
A Project by Dementia Friendly Swansea
Registered Charity Number: 1199456

Partneriaeth Ranbarthol Gorllewin Morgannwg | West Glamorgan Regional Partnership

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A Message from our Chair of Trustees

Once again, we are all extremely proud to support Demenita Friendly Swansea and celebrate a very successful second year.

This success has been due to a combination of work and dedication from all staff, volunteers and co-production organisations to achieve the objectives of the Charity. The large number of visitors to the Hwb has enabled the information obtained to be used by themselves as individuals, as well as informing friends and family to benefit the wider community.

We want to thank all involved for the success achieved this year. We eagerly look forward to the third year and supporting the Charity to go from strength to strength.

Message from Hannah - General oversight of the year.

"Be the change you want to see in the world"
Mahatma Ghandi

Our second year of helping people affected by Dementia across West Glamorgan has seen what we do in Swansea's Quadrant shopping centre be consolidated with another 2,300 visitors. The work has been shared between the 14 co-production organisations sending staff to work from the Hwb or providing referrals to each other. We've built up the volunteer team to around 40 voluntary hours each week, wonderful people who listen empathetically and provide signposting along with the professional staff. As an example of true coproduction between the third sector, Swansea and NPT local authorities, Swansea Bay Health board and the private sector, we have been visited by professionals from the Swedish city of Helsingborg, amongst others.

We are finding more younger people and those living with a diagnosis are reaching out to us, so to meet this public need we have recruited Dawn into the role of Buddy to provide peer support for those living with early onset dementia or going through a diagnosis, and this aspect of our work is growing in popularity as the awareness spreads of the support.

Our little team has grown to 12 employees along with our 5 Trustees and everyone is committed to deliver beyond any job description with their truly caring natures and perseverance to find novel solutions to un-solved problems. As we move into our third year, we are looking to expand with a Dementia Hwb in Aberafan shopping centre and also create mobile Hwbs to be held at regular intervals in more rural venues to support people who can't reach the city and town centres. We look forward to welcoming as many people as we can to all of our Hwbs to show how a simple volunteer-led model can really make a massive improvement to the quality of life of others. We want to see a change in the stigma and quality of life for those affected by Dementia, and we believe we all have a chance to make it.

Thanks for supporting the Dementia Hwbs, Hannah xx

Our services

Dementia Hwb, Swansea

The Dementia Hwb is a one-stop information centre anchored in the heart of the community for all things dementia related. Whether it be carers, individuals with a diagnosis, professional health workers, or those who want to educate themselves on the topic, we can signpost to information and services to support each visitor.

Opening hours are 11am – 3pm 7 days a week, and we can be reached via telephone or email for those who are unable to visit us in person to ensure that anyone can access our service.

Safe Haven, Swansea

A short-stay private space which individuals with Dementia can use, accompanied by a safe haven carer, to regroup if needed when visiting town.

Dementia Hwb, Aberafon

A replica of the Swansea Hwb has opened in Aberafon Shopping Center, open weekdays from 11am – 3pm.

Mobile Hwbs (Swansea & NPT)

We are aware that access to services can be difficult, especially for those with accessibility barriers, including living rurally. To rule out the postcode lottery effect, the Dementia Hwb launched its mobile Hwbs. The Hwbs appear in regular locations each week, with a regular member of staff. Our mobile hwb support workers are working hard to cover each GP cluster by being situated in community bedded areas, such as cafes, libraries, and community halls.

Currently, our mobile Hwbs cover 16 locations across Swansea and Neath Port Talbot.



Buddy Project

The Buddy Project is an opportunity to have one on one conversations with someone who is on the same journey as you are. Whether you already have a diagnosis or are on the way to gettng one, you can speak to your buddy, even if it's not about dementa.

Memory assessments at the Hwb

In May we began memory assessments with the SBUHB Community Memory Support Team. These are bookable appointments which take place in the Dementia Hwb, with a member of the team who can go through memory assessments with an individual who has concerns about their memory. Since the implementation of the assessments, we have had 18 assesments take place at the Hwb as well as a further 28 individuals directly signposted to the Community Memory Support Team.

Bookable meeting room

We are glad to offer our meettng room space to co-production staff, where they may book in appointments to see clients privately. This space can also be utilised to provide training sessions if needed. For enquiries about using this space, please contact support@dementiafriendlyswansea.org.

Dementia Friendly Swansea Forum

We organise a bi-monthly open forum for professionals from statutory organisations, third sector and private businesses as well as carers, people living with dementia and anyone who is interested. The forum is used to share news, hear good ideas and discuss issues that people are facing. It is intended to be a group for finding Best Practice and improving networking amongst those offering support.

Media

The Dementia Hwb is active across a range of social media including Facebook, Twitter, Instagram and LinkedIn. We regularly update our pages with information about the Hwbs, and other social events going on in and around Swansea. Our audience has organically grown over the past couple of years to reach over 2000 people. We also keep our website updated with local, and general information regarding Dementia, and national services which can support, with the aim to cater for those living further afield. We started uploading regular blogs to share updates about the Hwbs, information on how to live well with Dementia, support for carers, among other interesting topics which you can view by visiting our website or scanning the QR code.

Throughout the year we teamed up with The Wave Radio, to support Alzheimer's Society Dementia Awareness week, with our main message being spread 'You are not alone'. As our Buddy Project launched this year, run by our very own Dawn Davies, who herself received a diagnosis of early-onset Dementia, and sought support from the Dementia Hwb. We were very fortunate that she chose to share her story, and the impact the Dementia Hwb has had on her, and her family's lives. Interviews aired with Dawn, and other members of the Dementia Hwb team across several channels, including; BBC Wales, ITV Wales, and S4C. Additionally, we were mentioned in the Evening Post, Wales Online, and the Chief Executives Blog for Swansea Council, among others.



Figures

Who do we support?

Between January 31st, 2023 – January 31st, 2024, the Dementia Hwb recorded **2,307 new visitors,** and 2440 contacts. 'Contacts' refer to the initial visit, and a follow-up, suggesting **5%** of visitors have used our service on more than one occasion. Since our initial opening in January 2022, we have now reached **4850 visitors supported.**

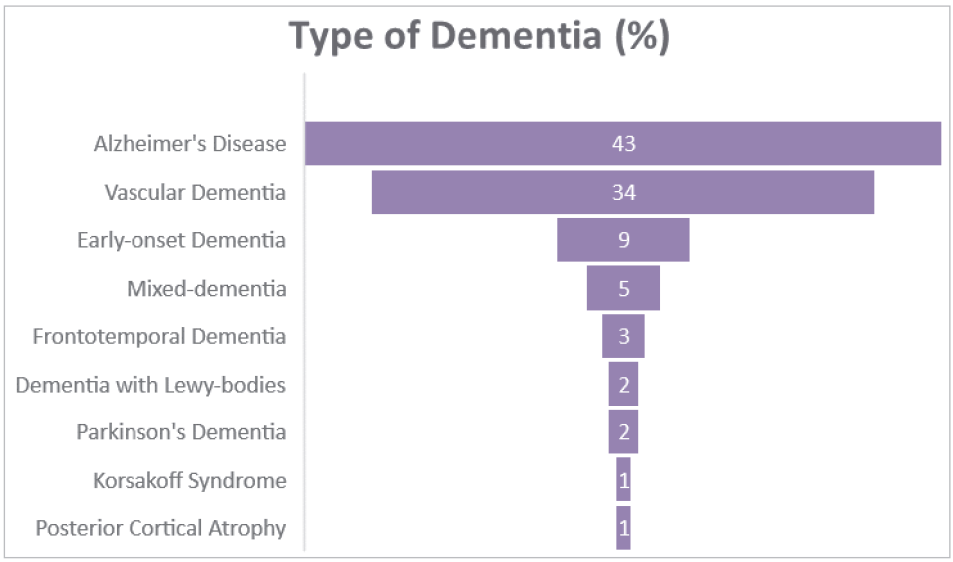
68% of our visitors were female, and 32% male, with 55% being under the age of 65.

Among others, our new visitors included: 727 unpaid carers; 107 people looking for a diagnosis of Dementia for themselves, or a friend/ family member; 75 had a diagnosis of Dementia; 115 professionals, including healthcare and social care workers.

In partnership with Swansea University Bay Health Board Community Memory Support Team, we were able to deliver 18 memory assessments, and plan to continue this service.



Of those diagnosed with Dementia, we found that Alzheimer's Disease and Vascular Dementia were most reported, followed by Early-onset Dementia.



Over 1/3 of support provided through the Dementia Hwb is delivered by our volunteers and co-production staff, highlighting the communal effort needed to drive an initative like ours.

Financial statement January 2023 – December 2023

Public Sector

Total amount £227,724.66

- West Glamorgan Regional Partnership Regional Integrated Fund (RIF) - Dementia Hwb Swansea £152,701.42
- Regional Integrated Fund (RIF) Cwm Taff Morgannwg Projects Dementia - Bridgend Hwb £12,765.31
- UK Shared Prosperity Fund - Swansea Mobile Hwb £30,150
- UK Shared Prosperity Fund - Neath Port Talbot Mobile Hwb £32,107.93

Charitable Trusts and Company

Total amount £20,544

- Community Foundation Wales £9896
- Charles Hayward £6700
- Llysdinam £1000
- Pobl Trust £948
- Oakdale Trust £750
- Capgemini £500
- Blakemore Foundation £150

Donations

Total amount £3201

Swansea City Match collection £356.19

Welcome Inn £1500

Public Donations £1344.81

Milestones

The past year has been an amazing rollercoaster, filled with networking, and new opportunities to deliver better Dementia support. Alongside our new Hwbs and new projects we also...

Turned the town purple...

With the support from Purple Angels World Rocks Against Dementia, The Wave, Swansea Council, and the Quadrant Shopping Center we turned the town purple! Our main goals were to raise awareness of the importance of music in Dementia care for the Purple Angels campaign and raise awareness for World Alzheimer's month. We took over the Quadrant Shopping Center for three days, alongside co-production staff, and a musical performance. The Hwb saw a 205% increase in visitors needing Dementia support in South Wales following this campaign.



Welcomed new friends to the Hwb . . .

Following a meeting with Carmarthenshire Therapy Dogs, two of our staff took their pawesome pets to train to become therapy dogs. Sully and Stanley are now official members of the Dementia Hwb team and can provide comfort for those who need it on their visits.



Got involved in research . . .

In collaboration with Swansea University, the Dementia Hwb supported research investgating the role of social enterprise organisations in supporting family carers of older people living with Dementia. Our volunteers and staff took part in focus groups, alongside Swansea Carers Center, and the LGBTQ+ Dementia Advisory group to contribute to the research. The research findings were discussed between the Hwb's Abi Davies, and Swansea Universities Dr Maria Cheshire-Allen on a podcast, shared at a dissemination event and later presented by Maria in Florida for the Gereontology Society of America. With a published article: Cheshire-Allen, M., & Davies, A. (2023). The Role of Social Enterprise Organizations in Supporting Family Carers of Older People Living with Dementia. ***Innovation in Aging,*** 7(Suppl 1), 105.



Dr Ceri Phelps, and Kyra Quarterly, from University of Wales Trinity Saint David performed a service evaluation of the Dementia Hwb to identify the extent to which the Hwb was meeting the psychological support needs of its visitors. Participants reported higher levels of satisfaction with the help they received. The full evaluation poster can be viewed on the next page.

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Y Drindod Dewi Sant
University of Wales
Trinity Saint David

A Service Evaluation of The

Kyra Quarterly, Ceri Ph
Abigail Davies I Dem

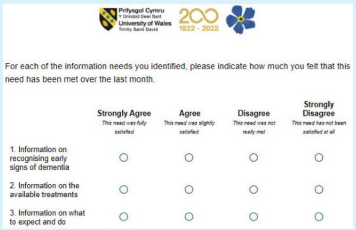
Background

- The psychosocial challenges of caring for a loved one with dementia are well documented in the literature (Cross, Garip & Sheffield, 2018; Hazzan et al., 2022).
- In January 2022 Dementia Friendly Swansea received grant funding to set up an easily accessible one stop hub for people seeking information and support related to Dementia, called The Dementia Hwb.

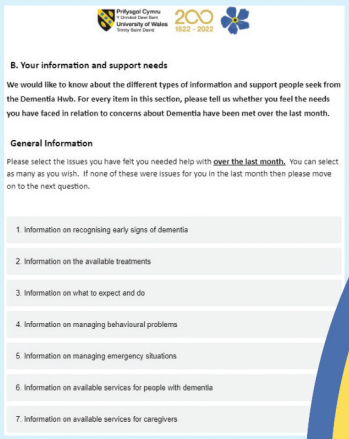
'Has loads of great advice and information and the volunteers have experience and knowledge'

Design

A pragmatic mixed methods approach incorporated a longitudinal questionnaire to capture changes over time in unmet information and support needs, the demographic profile, and free text of Hwb visitors (*see figure 1*).


For each of the information needs you identified, please indicate how much you felt that this need has been met over the last month.

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. Information on recognising early signs of dementia	○	○	○	○
2. Information on the available treatments	○	○	○	○
3. Information on what to expect and do	○	○	○	○


B. Your information and support needs

We would like to know about the different types of information and support people seek from the Dementia Hwb. For every item in this section, please tell us whether you feel the needs you have faced in relation to concerns about Dementia have been met over the last month.

General Information

Please select the issues you have felt you needed help with over the last month. You can select as many as you wish. If none of these were issues for you in the last month then please move on to the next question.

1. Information on recognising early signs of dementia
2. Information on the available treatments
3. Information on what to expect and do
4. Information on managing behavioural problems
5. Information on managing emergency situations
6. Information on available services for people with dementia
7. Information on available services for caregivers

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Findings

33 participants have completed baseline questionnaires (Q1 & Brief questionnaire).

- Over 40% had visited the Hwb more than once (**n=14**), with most respondents having heard about the Hwb by walking through the Quadrant Shopping Centre, where it is located.
- The main reasons respondents attended the Hwb was being a carer for a loved one with dementia and seeking general information about dementia.
- **Information & Support Needs:** The most endorsed need when visiting the Hwb was to find information about available services for dementia patients (**n=25, 76%**), followed by seeking information on the location of professional services (**n= 18, 55%**) what to expect and do (**n=16, 49%**), available services for caregivers (**n=16, 49%**), and information on recognising early signs of dementia (**n=14, 42%**).
  - All but one respondents stated that these needs had been met during their visit to the Hwb.
- The least endorsed needs of visitors was availability of hospitals (**n=2**), counselling for caregivers' anger/frustration/guilt (**n=2**), and support from caregivers' employer (**n=2**).

References: Cross, A. J., Garip, G., & Sheffield, D. (2018). The psychosocial impact of caregiving in dementia and quality of life: a systematic review and meta-synthesis of qualitative research. Psychology & Health, 33(11), 1321-1342.
Hazzan, A. A., Dauenhauer, J., Follansbee, P., Hazzan, J. O., Allen, K., & Omobepade, I. (2022). Family caregiver quality of life and the care provided to older people living with dementia: Qualitative analyses of caregiver interviews. BMC geriatrics, 22(1), 1-11.
Vaingankar, J. A., Subramaniam, M., Picco, L., Eng, G. K., Shafie, S., Sambasivam, R., ... & Chong, S. A. (2013). Perceived unmet needs of informal caregivers of people with dementia in Singapore. International Psychogeriatrics, 25(10), 1605-1619.

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Evaluation

- Over a six-month period Hwb visitors were asked to complete a questionnaire (online or paper copy).
- The questionnaire included an adapted version of 'The Caregivers' Needs Checklist for Dementia' to record unmet information and support needs, basic demographic data and optional free text comments (Vaingankar et al., 2013).

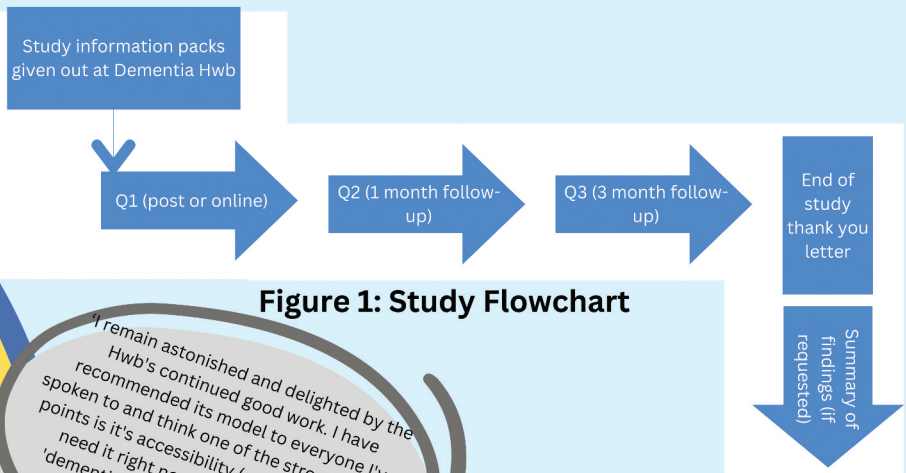


Figure 1: Study Flowchart

a Hwb Swansea

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f Evaluation

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jectives

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ached groups.

'I remain astonished and delighted by the Hwb's continued good work. I have recommended its model to everyone I've spoken to and think one of the strongest selling points is it's accessibility (even if people don't need it right now, it's far better to have 'dementia' in the heart of the community, spoken about and shared rather than another empty shop)'

Conclusions & Recommendations



- Overall participants reported high levels of satisfaction and that their needs had been met.
- Free text comments suggest that the Hwb offers a unique and valued volunteer-led signposting service that is seen as accessible and community-based.
- Only a small proportion of Hwb visitors completed questionnaires and this may partly reflect the challenges of evaluating a community-based dementia signposting service. Unfortunately, the low number of respondents to the follow-up surveys means that it was not possible to statistically analyse changes in unmet information and support needs over time, or the extent to which the positive outcomes reported from the initial or multiple Hwb visits were sustained.
- Overall, the Dementia Hwb is meeting its overall objective through helping to ensure that for every person who requires support, guidance and information, based in Swansea and surrounding areas, they have assistance to be able to access the services they require, as and when they need them.

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y keen appreciation for
the time and energy
devoted by so many'

Acknowledgements
Special thanks to Hannah Davies, Jude Dale, Dementia Hwb Swansea; and all of the Hwb visitors who agreed to take part in this evaluation.

Contact Details:
Dr Ceri Phelps - ceri.phelps@uwtsd.ac.uk
Kyra Quarterly - k.quarterly@uwtsd.ac.uk
Abigail Davies- abi.davies@dementiafriendlyswansea.org

Feedback

The Dementia Hwb has proven to not only support its intended visitors, but also its volunteers and staff.

100% of volunteers asked agreed that:

1. They find volunteering at the Hwb rewarding.
2. They feel valued as a member of the Hwb team.
3. They have opportunities to develop their skills.

Here is what one of our student volunteers had to say about the Hwb "I wanted to volunteer at the Dementia Hwb as my Bampa has Dementia. My Nana (Janette) who cares for my Bampa used the Hwbs services before and said that the people were lovely and helpful. I thought I wanted to be a part of something like that too. After doing my 5 hours of volunteering for my collage project, I knew that I didn't want to stop coming here. I want to help people with Dementia, and the people surrounding them, in whichever way I can, especially in a place like this". To hear what Janette had to say about her visit, follow the QR code below.

Dementia is a topic which has affected many of our staff and volunteers, meaning that the information spread at the Hwb supports more than just our visitors. Dawn, a member of staff was informed about the Fire Service Safe & Well Check referrals by another member of staff Donna. Dawn said "Without their visit and advice I wouldn't have found out about this information anywhere else. I didn't have to wait long from the point of referral to the point of visit."

The Dementia Hwb will continue to work alongside local organisations, and emergency services to aid crisis prevention. We do this by informing visitors and volunteers about the Police Herbert Protocol, the Fire Service Safe and Well Checks, and providing free Lions Message in a Bottle, which provide first responders with vital information.

Thank You

Since opening in 2022, the Dementia Hwb has supported 4850 visitors. We have accomplished this with the commitment of 63 volunteers, six of who are now paid members of staff at the Dementia Hwb. Currently, we have 16 active volunteers who support the running of the Hwbs, alongside frequent professional representation from our co-production partners including: Age Cymru West Glamorgan, Alzheimer's Society Cymru, Care & Repair Western Bay, CADR, City & County of Swansea Local Authority, Dementia Carers Count, Mid and West Wales Fire & Rescue Service, Swansea Bay University Health Board, Swansea Carers Centre, Swansea University, South Wales Police and University of Wales Trinity St David, Marie Currie among others.

The Hwb has yet again received so much support, from the Lord Lieutenant of West Glamorgan, the Lord Mayor of Swansea, Senedd members, local councillors, our emergency services, co-production organisations, and the public.



We cannot thank everyone enough for the ongoing support, and trust to continue responding to community needs. We will endeavour to continue breaking down the stigma and barriers faced by those affected by Dementia and show that for those who feel lost, **you are not alone.**

Notes



Dementia Hwb

Contact us

Phone: 01792 304519

Email: Support@dementiafriendlyswansea.org

Follow us on our socials

Facebook: Dementiahwb Swansea

Instagram: Dementiahwbswansea

Twitter: DementiaHwb

LinkedIn: Dementia Friendly Swansea

Find our website and sign up for our newsletter

www.dementiafriendlyswansea.org