The First 12 Months

Dementia Hwb 2022 - 2023



Dementia Friendly Swansea.org

Partneriaeth Ranbarthol Gorllewin Morgannwg | West Glamorgan Regional Partnership

Cyngor Abertawe Swansea Council

A Project by Dementia Friendly Swansea
Registered Charity Number: 1199456

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A Message from Our Trustees

“We are all extremely proud to be Trustees for Dementia Friendly Swansea. The Officers always provide us with full information, in a timely manner, on steps being taken to achieve its core purpose and the progress being made. We are constantly amazed by the commitment and drive of all Officers to seize every opportunity to ensure the Charity is a success.

Our meetings are full of good discussions. The Officers welcome any advice and guidance from us to support their hard work, where appropriate. Equally, they readily provide clarification of actions taken and new work.”



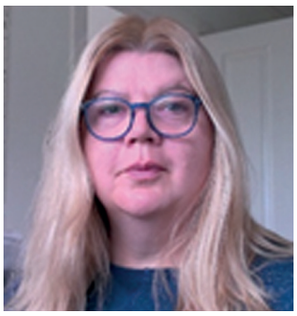
Emma Richards



Keith Harding



Lesley Abbott



Kate McCormack



Jay Crouch

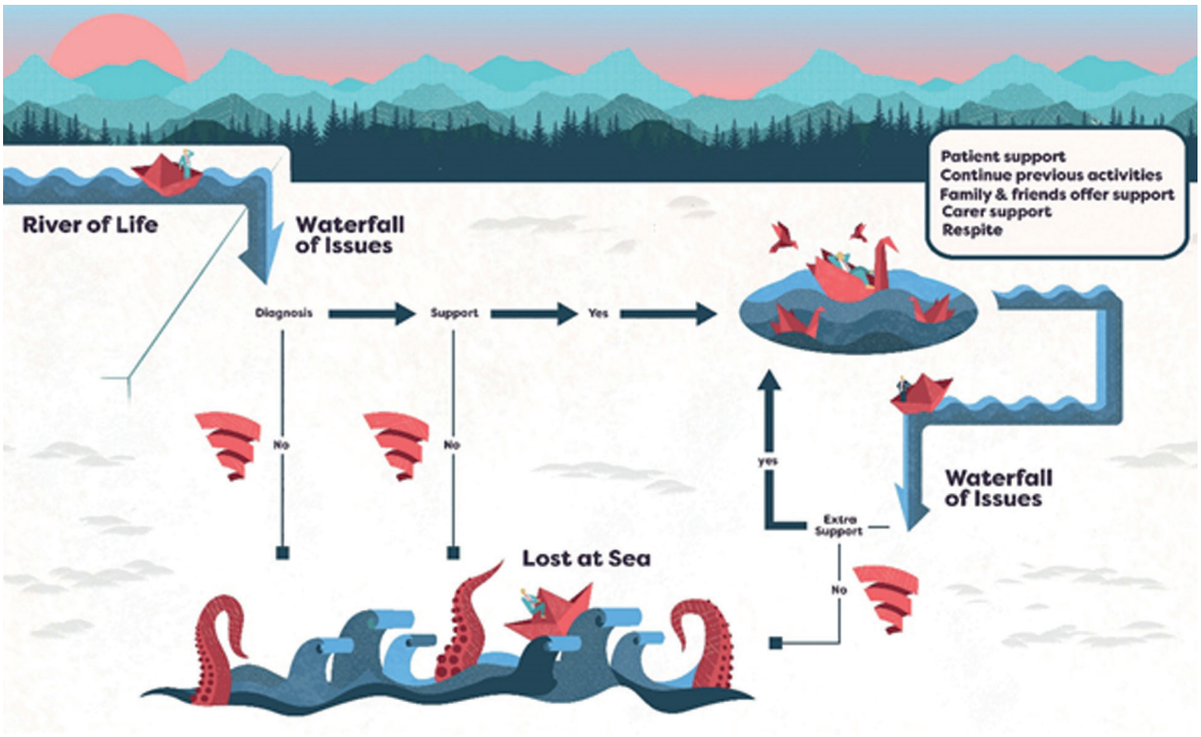
A Message from our founder

"Try to be the rainbow in someone's cloud" – Maya Angelou



10 years ago, I set up a group called the Dementia Supportive Community in Swansea as my mum had Alzheimer's and we were having an awful time getting support for her, and my disabled Dad. I knew we weren't alone in facing these issues. The first meeting was held in Morgan's Hotel with 19 attendees from a diverse background and all with a common goal to help improve things for people living with dementia - carers, health and social care professionals, private business owners, solicitors, local and national charity representatives, university staff, emergency service personnel, councillors and local authority staff. I created this diagram to show how it felt for our family at the time, tumbling down waterfalls and being thrown around in whirl pools and how we longed for Mum to be the serene swan in her pond. Many people still feel exactly that way.

For 3 years I wrote a weekly column in the South Wales Evening Post documenting the dementia journey we were on with Mum and shared the things we were learning as a family. Hopefully helping others through our research and sharing the learning from our mistakes. It was through this weekly column that other people shared their experiences with me and I realised that we truly needed to have



a voice for those of us loving someone with dementia and acknowledge that every journey is different.

One year ago, we opened the Dementia Hwb in The Quadrant Shopping Centre with help from Urban Foundry, we received funding from the Local Authority and then Regional Integration Funding and donations, and we turned the group into a registered charity (Dementia Friendly Swansea). The Dementia Hwb is a true collaboration with more than 14 organisations allowing staff to work from the Hwb at various times, offering their expertise to any visitors.

It has been a very busy year! The Dementia Hwb has helped over 2,400 people face-to-face in the first 12 months, plus even more people through our website. The launch of the Telephone Hwb and the introduction of the Safe Haven to look after visitors in a quiet environment whilst a carer gets information in the Hwb, will hopefully help even more people get the information that they need, at the time that they want it.

Thank you for supporting the Dementia Hwb and helping to be that rainbow,

Hannah x

About the Dementia Hwb

The Dementia Hwb is a one-stop information center for all things dementia related. Whether it be carers, individuals with a diagnosis, professional health workers, or those who would like to educate themselves on the topic, we are able to signpost to information and services to support each individual visitor.

Opening hours are 11:00 am – 15:00 pm 7 days a week, and we can be reached via telephone for those who are unable to visit us in person. The Hwb is predominantly staffed by volunteers, whereby we received support from 41 volunteers throughout our first year and a hand full of paid members of staff, with professional organisation representatives attending weekly.

Supporting organisations include; Age Cymru West Glamorgan, Age UK Swansea Bay, Alzheimer's Society Cymru, CADR, City & County of Swansea Local Authority, Dementia Carers Count, Mid and West Wales Fire & Rescue Service, Swansea Bay Health Board, Swansea Carers Centre, Swansea University, South Wales Police and University of Wales Trinity St David.

We have also built strong relationships within the local community, with social group and activity leaders, who support carers and those affected by dementia.

The Dementia Hwb has received a great deal of support from the public, and has also been visited by the Lord Mayor, the Lord Lieutenant, local Senedd Members, and local Councillors, who have all demonstrated their support for the cause.

Progression

The Dementia Hwb fulfilled the criteria of providing a signposting service for its visitors, and continues to do so. Throughout the year, the service has expanded to include; a telephone based Hwb, which allows individuals who are unable to physically visit the Hwb to seek support; and a safe haven, this is a short-stay private space which individuals with dementia can use, accompanied by a safe haven carer, to regroup if needed when visiting town.

The expansion of services was supported by market research conducted earlier on in the year, whereby

- **94% of visitors asked said they would find a safe haven useful**
- **86% suggesting they would find a telephone based Hwb useful.**

Through collaboration with wider services, the Dementia Hwb also offers;

- **Support with blue badge applications**
- **Herbert Protocol forms**
- **Referrals for Safe & Well checks, provided by Mid & West Wales Fire Service**
- **Referrals**

Furthermore, due to the success of the Swansea based Dementia Hwb, and demand for our service in other regions, a second Dementia Hwb opened in Bridgend.

Milestones

January	1 Month trial opening
February	Signing of the lease to extend our project until the end of March
March	A visit from the Lord Lieutenant Promoted Delirium Awareness Teamed up with the Wave radio, to promote dementia awareness week.
April	Dementia Friendly Swansea AGM Donation of Twiddle Mitts received from mid and west Wales fire service
May	Created our memory tree in aid of Dementia Awareness Month
June	Celebrating Volunteers Week Training from the Samaritans on the importance of listening and providing safe spaces. Became a registered charity.
July	Support from Bouygues to paint the Dementia Hwb Dementia Friends Session for Swansea Bid held at Social Dice for Local Businesses.
August	Swansea Aging Well Beach Festival Fundraising event hosted by Hoogah
September	Pop up Dementia Hwb in Tesco Llansamlet
October	Telephone Hwb and Safe Haven Open
November	Hosted a Dementia Friends Session in the Dementia Hwb Support from Mid and West Fire Service to decorate the safe haven.
December	Opening of Bridgend Hwb

Collaboration

An underlying message of the Dementia Hwb is that we know collaboration is key, there is a wealth of information, and incredible services available to support people affected by dementia, however accessing services may be difficult, when you don't know which direction to turn on the complicated path of a Dementia diagnosis.

Our collaborations:

On a daily basis we have organisation representatives from a range of supporting services working in the Hwb, who share knowledge among each other, with our volunteers, and with our visitors.

Additionally;

- **In March 2022 we worked alongside Swansea Bay Health board to raise awareness on Delirium. We achieved this by opening a door for conversation with visitors, and providing resources on the topic, we also took to our social media platforms to spread information, and raise overall awareness.**
- **In partnership with Swansea University, the Dementia Hwb participated in an ongoing project involving a range of focus groups, and is being used as a central model in their study, of how the third sector drives dementia care in Wales.**
- **A second ongoing project is being run by the University of Wales Trinity St David, who are conducting an evaluation of the Dementia Hwb, to review what impact it is having on the visitors.**



Samaritans Workshop

Social Media

The Dementia Hwb is active on social media. We have accounts on Facebook, Twitter and Instagram. These provide regular reminders of the information available at the Hwb. The posts also include a diary of which organisation is in the Hwb and the day they are visiting, so people are able to plan their visits more effectively. Social media provides another method of communication between people who have concerns about dementia, who may not be able to access the Dementia Hwb for many reasons including distance, work and family commitments. It also helps us develop relationships with individuals and other groups outside of the Swansea area.

Not everyone uses social media, but there will generally be someone around them who does, for example a family member, friend, support worker or health professional who can contact the Dementia Hwb online for information. The social media presence has grown organically with the message being consistent and simple: this is what the Dementia Hwb does and where you can find it.

For those online but not on social media, the Dementia Friendly Swansea website provides this information too. The website is updated regularly with content on local groups and relevant events. Whilst a lot of the information in the Dementia Hwb itself is specific for areas in and around Swansea, it is also a useful resource about the condition and its symptoms that can be accessed by anyone online, in the UK or further afield.

In local media, the Dementia Hwb partnered with The Wave to create a bespoke Dementia Awareness Week campaign to mark the opening of the Hwb and to raise awareness of the condition. The aim of the campaign was to encourage more people to talk about the condition and therefore help to reduce the stigma. The key message was to let people know that they are not alone in facing dementia and that there is support available to them. Articles were published in the Evening Post, both print and online versions, as well as on Nation Cymru.

The Dementia Hwb also produces leaflets highlighting useful telephone numbers for organisations and services that offer dementia support in Swansea. In addition, we also produced a booklet listing events and activities specifically for those affected by dementia. These sources of information are distributed from the Dementia Hwb and via other social groups in the area. This information is also available online.

Our website

Dementia Friendly Swansea - Dementia Care Help, Advice

Twitter @DementiaHwb

Facebook DementiaHwb Swansea

Instagram Dementiahwbswansea

Dementia in Wales

- Approximately 42,000 people in Wales are living with Dementia (NHS, 2016).
- On average Dementia costs the Welsh economy £1.4 billion per year, covering healthcare, social care, advocacy and research costs (Alzheimer's Society, 2015).
- Compared to the rest of the UK, Wales has the lowest diagnosis rate (53%), suggesting that many people living with Dementia are waiting for a diagnosis, or recognition of their condition (Dementia Statistic Hub, 2022).
- Over 60% of those with a diagnosis in Wales rely on friends and family members to provide care and support with daily tasks, in order to live well with Dementia (Alzheimers Society)
- Social Care Wales (2018) suggest that 12% of the Welsh population are unpaid carers, and this number is likely to increase in the coming years.
- Providing unpaid care has a lasting impact on long-term health and wellbeing, with 60% of carers reporting long-term health conditions or disability. (Carers UK analysis of GP Patient Survey 2021)

Some of our visitors



Sioned Williams MS



Cllr Mary Jones (Lord Mayor, 2022)



Mrs Louise Fleet, the Lord Lieutenant of West Glamorgan



Lord Mayor Mike Day, Lady Mayoress Chris Day, High Sheriff Stephen H Rogers, Cllr Hayley Gwilliam (2023)

Figures

Who do we support?

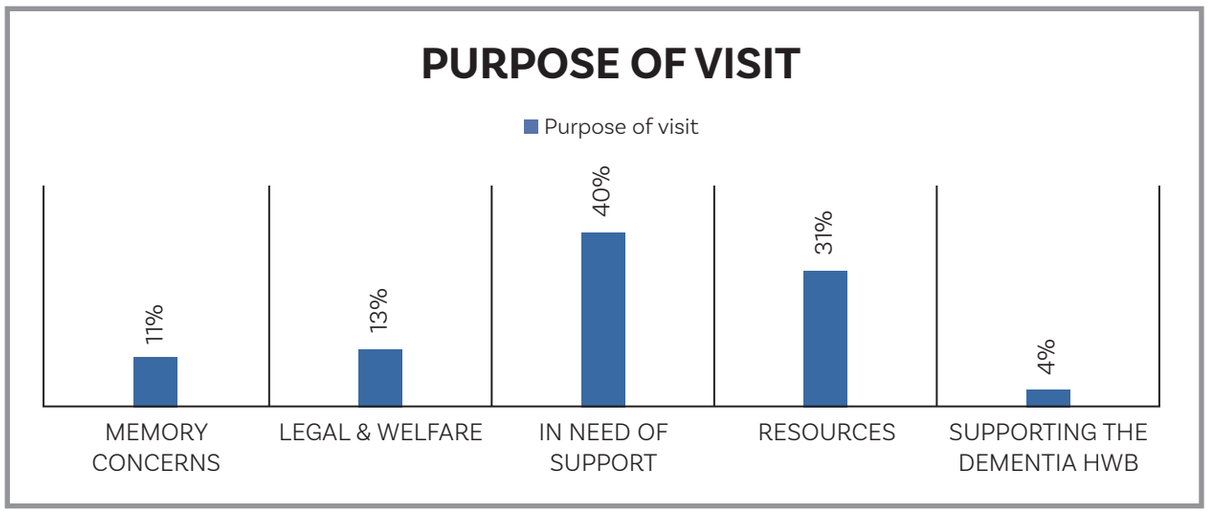
Since the opening date (29th January 2022) until January 31st 2023 the Dementia Hwb recorded 2403 visitors.

- **922 (38%) were unpaid carers of a person with dementia.**
- **404 (17%) were seeking information on behalf of someone else.**
- **282 (12%) were seeking general information regarding dementia.**
- **230 (10%) were individuals with a diagnosis of dementia.**
- **217 (9%) were individuals concerned about their own memory.**

The remaining 348 visitors included those who did not receive the support they needed, local support including offers to volunteer with us, or to make a donation, and professionals, including paid professional carers, support workers and healthcare workers.

Based on the percentage of visitors seeking general information about dementia, we have since taken action to promote prevention of dementia, with hopes of reducing the stigma, and increasing public knowledge.

The recorded purpose of visits was as follows



In terms of collating feedback, we have trialled a number of different ways throughout the year to gain meaningful feedback. Towards the end of the year, we asked our visitors whether they were pleased with their visit to the Dementia Hwb. 97% of our visitors said yes, whilst 2% said they were somewhat pleased.

Visitor feedback

As a further means of collating feedback, we provided our visitors with optional questionnaires on their visits, these could be completed in the Dementia Hwb, or online, and were completely anonymous.

"I was looking for advice to help a friend I care for and got help for her and myself. Staff were amazing"

"Staff were amazing. Took time to listen and understand what my concerns were"

"Have already recommended the Hwb. Everyone there on the day I visited were so friendly and helpful"

"Good advice and a sympathetic ear"

"Staff were friendly, knowledgeable and took time to listen. They helped me not only for my friend but for myself as a carer"

Volunteer feedback

"It's such a rewarding feeling when I'm able to help someone"

"It feels homely".

"I have nothing but praise for the support and encouragement I have received and continue to receive from the Hwb in my role as a volunteer. Thank you."

"I really enjoy working with the friendly caring staff at the Hwb who are always ready to provide advice or support to me when dealing with queries from customers that are more complex in nature."

Case Studies

1 Jane* came to the Hwb, in a distressed state, with no recollection of how she had got to town, where she lived, or who she was, including her name. She was well dressed and had been shopping prior to her visit at the Hwb.

Jane was brought into the Safe Haven, by the on duty Safe-Haven Carer, and other members of the Dementia Hwb team. They attempted to rejog Janes memory, whilst checking for any identification such as ID or credit card. The only item of ID she was carrying was a bus pass with her name printed on it. The Hwb team calmed Jane down, and offered her some tea. Whilst the Safe Haven Carer accompanied Jane, a member of staff contacted the emergency duty social service team, to see if we could find Jane on their system, and contact her significant other. No match was found. We then contacted the police to give a description of our visitor, and whether anyone matching her description had been reported missing. No report had been made.

A PCSO arrived at the Hwb, and worked with the Hwb team to narrow down where Jane lived. She was eager to get on a bus, but could not remember where too, just that she would know when she saw it. Questions about Jane's family and where she was from were asked in an attempt to jog her memory, from this we found out the name of her husband, and roughly where she lived. The PCSO was able to contact her husband, with a member of the Hwb explaining what had happened. The PSCO took Jane home, equipped with information from the Hwb for her husband, as this had never happened to Jane before.



As a follow up, a member of the Hwb tracked down Jane's GP, via the GP lead for Dementia, to make them aware of the issue, meaning they can respond appropriately at her next GP appointment.

Follow up

Jane and her husband came in to thank the Hwb team who had helped her. They notified us that the Herbert protocol form would be filled out, and that Jane was feeling better, and has not since experienced the state of confusion.

2 "The drop in Dementia Hwb ideally situated in the shopping centre near Swansea bus station is an invaluable resource for the people of Swansea. I first visited the Hwb because I had become very anxious about a friend of mine who was experiencing memory loss, issues with concentrating, decision making and the ability to take on board simple instructions. The family lived away and weren't really aware of the problems as visits were very infrequent. I just did not know what to do so came with her to seek help advice and information for both of us. The staff were very attentive and understanding and provided a wealth of useful information and tips, whilst urging my friend to seek help from her surgery. There has been continuity of care on subsequent visits to the Hwb with practical and emotional support and empathy for both of us. It is a safe haven. The situation was also starting to affect me as a friend. They helped to empower me to make sure the family became aware and involved. Many thanks. A great team."

Financial Statement

Total grants from the public sector	**£303,948**
Winter of Wellbeing Grant for the trial Dementia Hwb	**£15,535**
Regional Integrated Funding for extension of the Dementia Hwb until Match 2024 in installments of for June 2022 – March 2023	**£125,660**
followed by for April 2023 – March 2024	**£147,753**
Swansea City Council Grant	**£15,000**
Total funding from Charitable Trusts	**£2,453**
Austin Bailey for furniture	**£953**
Llysdinam Charitable Trust donation	**£1,000**
Marsh Charitable Trust donation	**£500**
Total public donations	**£1,969.33**
Hannah Davies half marathon	**£794.51**
Hoogah fundraising evening	**£784.82**
Legacy and general donations	**£390**

Thank You

The Dementia Hwb would like to send a huge thanks for all the support we have received throughout our first year. We have grown to support our local community and will strive to do so in the years to come. For those who have found comfort and support in us, we will continue to be here for you; For those who have donated to us, or returned to the Dementia Hwb to thank us for our support, we are so pleased that we could provide the support you needed, and we will be here for you when you need us. A special thank you goes to all of our volunteers, without whom we could have never opened our doors, we are extremely grateful, and hope you find meaning in volunteering with us. We would also like to send a big thank you to all members of trustees and staff, who have adapted and grown alongside the Dementia Hwb, making it what it is today. Throughout the upcoming year, we will endeavour to continue offering support to those affected by dementia, and strive to raise awareness of the risks, and preventative measures which can be taken, it is all about raising awareness, and breaking the stigma.

you are not alone

Dementia Hwb

Dementia Hwb

Contact Us:

Email: Support@dementiafriendlyswansea.org

Telephone: 01792 304519

Address: Dementia Hwb, Quadrant Shopping Centre, Swansea, SA13 QW

Dementia Friendly Swansea.org

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