

STORY OF CHANGE TEMPLATE

Reporting Period	End of Year Report – Financial Year 2023 - 2024
Strategic Partnership	West Glamorgan Regional Partnership
Programme Name	Dementia Programme

Programme Overview

The West Glamorgan Dementia Programme forms part of the wider Emotional Wellbeing and Mental Health programme, which was re-launched in April 2022.

The vision for the programme is that people with dementia and their carers can access the services and support when, where and how they need it across health, social care and voluntary services.

A predominant focus for this year continues to be the implementation of the all-Wales Dementia Standards and Action Plan. An initial engagement event was held at the end of the last financial year, feedback from which has confirmed that whilst partners across the region have achieved a large amount, there is still more to do, especially in relation to early diagnosis and supporting people to live at home for as long as possible. The region continues to develop its Regional Dementia Strategy, progress with this has been slower than anticipated, but developments are now progressing at pace.

The Regional Dementia Steering Group reports directly into the Emotional Wellbeing & Mental Health Programme Board and oversees the following 5 interconnected workstreams.

1. **Community Engagement** – raising community awareness and support of dementia as well as improving social value and building supportive, resilient communities.
2. **Assessment & Diagnosis (Memory Assessment Service & Learning Disability)** – improving access to assessments to reduce waiting times and provide timely diagnosis and immediate support if required.
3. **Community Care & Support (including Dementia Connects)** – ensuring the correct level of seamless wraparound support is available at home or as close to home as possible.
4. **Hospital Settings (including the Hospital Charter)** – Improving the experience of people in hospital settings and facilitating their discharge in a safe and timely manner, back into their home, with the correct level of support in place for them and their carers.
5. **Workforce Development & Measurement** - focussed on improving knowledge and skills across the workforce (paid and voluntary) and ensuring we achieve Strategic outcomes and improve people's lives across the region.

The Dementia Programme is responsible for ensuring that the recurrent RIF (Regional Integrated Funding) funding is aligned to meet the needs of people living with Dementia and their carers across the region and dovetails with other RIF funded schemes across the Partnership.

A considerable amount of work is currently being undertaken in mapping service provision for those living with dementia and their carers across the region, and constructing a report which demonstrates where all services (funded and statutory commissioned) are available. This will assist the region in developing its regional strategic approach. It is anticipated therefore that the current governance arrangements for the Dementia Programme may evolve as the Regional Dementia Strategy comes to fruition.

The population group this programme supports is predominately older people living with dementia, adults with early onset dementia, and those who care for them (including young carers). Additionally, people with learning disabilities are at a higher risk of developing dementia which is sitting within the Wellbeing and Learning Disability Programme.

Delivery Partners

Across the region there are 15 different projects supporting the delivery of the Dementia programme in a variety of ways. 10 of these projects are regional, with 5 being local – 2 in Swansea and 3 in NPT. 11 out of the 15 are third sector organisations, with the remaining 4 delivered by Statutory partners.

Theme 1: Building Dementia Friendly Communities

- **Me, Myself & I Neath Port Talbot (MMI)**

MMI is a community hub that is attractive to people of all ages, they aim to support people on their dementia journey, provide opportunity for people to maintain their independence, remain in the community for longer and help to prevent social isolation and loneliness. Through this hub, based in the Briton Ferry, they use existing assets, organisations, and partnerships to actively encourage involvement, engagement, and participation.

- **SCVS (Swansea Council for Voluntary Service) – Swansea Dementia & Carer Project**

Aim 1 - To establish a co-ordinated programme of support across Swansea for individuals with Dementia and their Carers that will enhance their wellbeing. There will be three strands to this support:

- Befriending Support for individuals with Dementia via the Community Dementia Support Volunteers.
- Peer Support through the establishment of Dementia Cafes
- One to One Support through the Dementia Clinic

Aim 2 - To provide development support and robust training for third sector organisations and community groups, to enable them to support individuals to live well with Dementia. This will be underpinned by harnessing the power of lived experience through the production of local digital stories.

- **Ospreys in the Community – Sporting Memories**

Sporting Memories harnesses the collective power of sport to engage people in a conversation, and then use this initial engagement as a vehicle to encourage participants to take part in appropriate and relevant physical activity.

The project has created a framework that includes the following activities:

- Sporting Conversation gatherings including those conducted in Welsh
- Volunteer Development pathway and training sessions
- Volunteer opportunities to run the gatherings as well as support the wider programme.
- In addition, they hold regular knowledge transfer seminars to share best practice with other sports, third sector organisations and public agencies.

- **Red Community Project – Musical Memories Choir (Swansea)**

The Red Community Project delivers choirs at two venues each week. In addition, they offer 'Musical Memories Choir on the Road' sessions where they visit different communities across the city to demonstrate the many benefits of singing and where possible support them to start their own regular singing groups. With funding for extra staff time and an extra easily portable keyboard, speaker, projector and screen set up, they proactively offer the Musical Memories Choir across the city to areas and people. A pack of resources has been developed including backing tracks, lyrics, and music to leave with the groups to keep the singing going.

Theme 2: Providing Community Care & Support

- **Age Cymru - West Glamorgan Regional Dementia Partnership project**

This project consists of the formation of a new, voluntary sector-led Dementia Partnership, following an identified need to provide a new, long-term, wrap-around community support service for people with dementia and their carers in the region. Our partnership consortium comprises of:

- Age Cymru West Glamorgan
- Carers Centre Swansea
- Carers Centre Neath Port Talbot
- Citizen's Advice Swansea Neath Port Talbot
- Care & Repair Western Bay

The project is a two-year pilot, which will utilise the strengths, expertise, networks and client engagement levels that each of the five partner organisations can offer.

- **Dementia Friendly Swansea – Dementia Hwb**

In March 2024, a second Dementia Hwb opened in Port Talbot, Aberfan Shopping Centre that quickly grew to seeing the same footfall as the Dementia Hwb in Swansea Quadrant within a few weeks. Both Hwb's are open to the public 7 days a week, from 11:00-15:00. There are also 5 mobile Hwbs that visit different locations across the region one day a week. The Dementia Hwbs provide vital support and information to enable people to find out what could help them and their loved ones, with information available for every stage of the Dementia journey.

- **Age Connects NPT – Dementia Care Connects**

This project consists of Dementia Development Officers experienced in promoting effective practices for people recently diagnosed with dementia. These key workers will maintain an ability not only to recognise the needs of those with dementia but will also incorporate the support needs of care givers and provide preventative support services/activities. The approach will focus upon the unique needs of each service user, where project team members will provide a bespoke service tailored to the individual needs over an agreed timescale.

- **Age Cymru – Dementia Pathway Service**

This project supports newly diagnosed patients to:

- Have a person-centred support plan that will provide a pathway to local services that the client and their unpaid carers need to live well and independently for as long as possible, whilst delaying the need for statutory intervention
- Have advance planning in place and adhere to it when patients lose cognitive ability i.e. Lasting Power of Attorneys
- Avoid unnecessary hospital/nursing home admissions and/or being 'lost in the system' following dementia diagnosis
- Delay the need to access statutory services by ensuring clients have a Person-Centred Support Plan
- To address late diagnosis of dementia among older people in West Glamorgan. Our new Dementia Pathfinder Service will work collaboratively with local NHS services, GP surgeries, local voluntary services, and the older generation in communities, to raise awareness of dementia, memory clinics and to support timely diagnosis.

- **Alzheimer's Society – Dementia Connect**

This project supports those people waiting to be seen by the Memory Assessment Service through an established pathways that those worried about their memory and those needing guidance through the diagnosis process have the information, advice, and navigation they need. Dementia Support Service is a simple, single point of access which works hand in hand with clinical care. It connects service users, including carers with vital practical support to empower them to independently manage their condition and remain active within their community. Anyone affected by dementia can be referred pre- or post-diagnosis into the service by their GP, Social Services, carer, family, or they can refer themselves.

- **SBUHB (Swansea Bay University Health Board) (NPT area only) – Pre-Memory Assessment Support Project**

The project consists of Dementia Support Workers that:

- Help people whilst they wait for a diagnosis of dementia, by developing an integrated support plan, and coordinating practical and emotional support as required to support people to maintain their independence and improve their sense of well-being and take control of their own lives.
- Liaise and escalate concerns with individuals waiting a diagnosis via the GP and Virtual Wards.
- Work closely with the Cantab Champions, Third sector, Local Area Coordinators, and wider early intervention and prevention services.

Theme 3: Assessment & Diagnosis

- **SBUHB – Advanced Nurse Practitioners**

The establishment of Advanced Nurse Practitioner / Non-Medical Prescriber supports improvement in diagnostic capacity within the Memory Assessment Services. The Advanced Nurse Practitioner manages and provides clinical practice within the Memory Assessment Service in line with local, strategic, and NICE guidance. As an autonomous clinical practitioner working in this service, they can differentiate and formulate diagnosis for people with suspected dementia, identifying suitable medical and psychosocial treatment pathways.

- **SBUHB – Speech & Language Therapy**

There were no Speech and Language Therapists employed as part of Memory Assessment Services for the general population across Swansea Bay University Health Board to provide specialist communication and dysphagia (i.e. swallowing difficulties) assessment, advice and support for people presenting with early cognitive and linguistic changes. This includes young onset dementia services as well as services for older adults.

Establishing a Speech and Language Therapy service as part of the Memory Assessment Service has ensured a robust and holistic delivery of key drivers and standards e.g. Dementia Action Plan 2018-2022, All Wales Dementia Care Pathway of Standards, 2021, NICE guidelines 2018 and the Health Board's Dementia Pathway which will in turn lead to improved patient, family, and carer outcomes.

Theme 4: Post Diagnosis

- **Marie Curie - Dementia Care and Respite Service**

The Marie Curie Dementia Care and Respite Service provides care and respite support for the growing number of people in West Glamorgan who are living with dementia to enable them to remain at home, and to provide support for their carers to help prevent escalation of

need and crisis. The service works as part of the Swansea Bay multidisciplinary team (MDT) to support the Virtual Wards, Community Resource Teams, and existing dementia support services to prevent hospital admissions and enable safe discharge from hospital.

- **Advocacy Support Cymru - Home from Hospital Dementia Advocacy Service**

This project provides a non-statutory advocate to ensure that discharge planning is person-centred, and that advocacy support is available to patients with dementia discharged from hospital in SBUHB, to ensure an effective transition between hospital and home.

Similar to the IMHA role, the advocate spends time getting to know the patient and what matters to them. Learning about their likes, dislikes, preferences, wishes and concerns. Advocacy input ensured that the correct processes are followed, that patients are safeguarded, and that patients' rights are upheld.

- **Ty Waunarlwydd Care Home – Complex Dementia Beds**

Westfield house offers 8 step-down beds from acute hospital settings, for people that are medically fit for discharge, live with complex dementia related needs, and require a settlement & assessment period to establish their future plan and move on. This project sits in the Communities and Older Peoples Programme.

Assessment of Delivery

The projects above have been themed into the four following areas:

Theme 1: Building Dementia Friendly Communities

4 RIF projects provide a suite of face-to-face activities giving people opportunities to socialise around themes such as sports, music, crafts, drinks, food and chats. Progress is going well with increased over prescribed membership of some of the projects. Demonstrating the need to expand the number and range of such activities.

Theme 2: Providing Community Care and Support

There are currently 6 RIF projects who work in partnership to bring wrap around services available to citizens. There are a number of face-to-face dementia connector type services enabling citizens to access services and support matched to their needs. The Dementia Connector roles are supported by advice & practical support working closely with Citizen Advice Bureau, Care & Repair services. The Dementia Hwb projects brings all the available information, services, and support to 7 key accessible venues in areas across the region.

Theme 3: Assessment and Diagnosis

There are 2 projects that work within the Memory Assessment Service, one is pre-diagnosis support and increasing diagnosis rates and the speech and language team assessing people for disorders such as swallowing difficulties. Both projects are having a positive impact on early diagnosis.

Theme 4: Post Diagnosis

There are 3 projects supporting people post diagnosis and assisting home from hospital transfers. The projects involve person-centred care & support plans which result in less readmissions to hospital than would otherwise be seen.

Update on Programme Delivery

Theme 1	Quantitative Measures	Qualitative Indicators
<p>Theme 1: Building Dementia Friendly Communities</p> <p>Primary Model of Care: Prevention and Community Co-ordination</p>	<p>Theme 1: Building Dementia Friendly Communities</p> <p>A key priority for the region is to support people living with dementia to live independently at home for as long as possible.</p> <p>To achieve this, there needs to be options available to those living with dementia and their carers, and they need to be fully aware of the support available to them and empowered to make decisions about their lives at every stage of their dementia journey.</p> <p>There are 4 projects aligned to this theme. The 4 RIF projects provide a suite of face-to-face activities giving people opportunities to socialise around themes such as sports, music, crafts, drinks, food and chats.</p> <p>Theme 1: Building Dementia Friendly Communities</p> <ul style="list-style-type: none"> • 2182 people have accessed the services with 137 of those being new people • There has been a total of 9696 contacts through the year • 1665 people have attended wellbeing activities • 739 people were signposted to other services • 99% reported they were satisfied with the early help received • 92% reported feeling less isolated 	<p>The focus on building dementia friendly communities is the establishment of group activities that support people living with dementia. The impact of these different opportunities includes reducing loneliness and isolation, improving social skills and a general improvement of wellbeing. They also provide opportunities to maintain physical and cognitive function. The groups are well attended demonstrating how much enjoyment people with dementia have through participating.</p> <p>Examples of qualitative evidence include the following quotes:</p> <p><i>“I wanted to feedback and recognise the benefits that Musical Memories Choir is having on my wife. She responds to the music and the socialising. The spontaneity of her comments in social situations is noticeable in recent weeks. It is a great credit to you, as the opportunity arises, feedback our thanks and recognition for the energy and compassion you bring and the impact it has for both of us” Musical Memories Choir provided by the Red Café (third sector)</i></p> <p><i>“The main benefit of being supported is knowing that there is someone there that has the knowledge and experience to support me through my problems” Swansea Dementia Carer Project, SCVS</i></p> <p><i>“I can’t remember days, names, what I did, where I am, but for some reason I can remember this. I have friends here; they are my family and you girls make me feel safe. I just wish I knew what it was that helped me remember this club, because I can’t remember anything else” Sporting Memories Project, Ospreys</i></p> <p><i>“When we came, I would be reminded of why I do this, the man I knew and loved came to life when he came here. This was the only time there would be a glimmer of the man he was. I know he’s not here anymore, but I still come, because I have fond memories of bringing him here, this was the light in that</i></p>

		<p><i>dark time. He may not be here anymore, but I still have family here. This project gave me that, it was his safe place and a chance for him to be him. But now it's my safe place and my time to remember him and be me" Carer, Sporting Memories, Ospreys</i></p> <p>The activities available also provide support to unpaid carers through signposting to appropriate services, advice on what support is available on how to keep the person they are caring for at home for longer, or even being able to speak to other unpaid carers on their experiences and not feeling so alone.</p> <p>Having a number of different types of groups gives opportunities for choice, from a choir to having a group discussing rugby. The early intervention provided is stigma free and provides positive modelling that there is a life to be lived with dementia.</p> <p>Living well with Dementia within local communities provides the required support to avoid escalation to statutory services along with crisis intervention.</p>
	<p>Programme Contribution to Model of Care and exploration of what is different</p>	<p>What have we learned about things that went well? What have we learned from any challenges that occurred?</p>
	<p>The four projects address the outcomes of the 'Prevention and Community Coordination' Model of Care.</p> <p>All projects under 'Theme 1, building dementia friendly communities', work in partnership with regional services and support available for people living with dementia. These services compliment primary and secondary care services by empowering people to have opportunities to actively make choices to prevent and/or delay the requirement of more intensive, intrusive interventions.</p> <p>The nature of dementia cafes, sporting groups, singing groups etc. brings people together to experience peer support in a social setting and promotes good emotional health and well-being.</p>	<p>Challenges</p> <p>A number of projects have commented that transport is a challenge – whilst the projects are hyper local, there continues to be barriers where previously people with Dementia used to be able to drive, but now have to rely on public transport which don't provide options to travel where people want to go.</p> <p>Successes</p> <p>Successes include having an opportunity for stigma free early intervention and support, signposting and simply providing an opportunity to discuss what it is like to have dementia or care for a person with dementia, reducing loneliness and isolation for people with dementia and their unpaid carers.</p> <p>The local projects are also making links with each other and</p>

		have started to develop multi-agency working. This will avoid duplication of the support provided and will support groups in signposting to other community groups across the region.
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Theme 2	Quantitative Measures	Qualitative Indicators
<p>Theme 2 – Providing Community Care & Support</p> <p>Model of Care – Prevention & Community Co-ordination</p>	<p>The theme supports ensuring that the correct level of seamless wraparound support is available at home or as close to home as possible. There are 6 projects aligned to this theme.</p> <p>Theme 2: Providing Community Care & Support</p> <ul style="list-style-type: none"> • 3,456 people have received support across these projects • 1163 were new people • 7696 contacts through the year • 2537 people were signposted to additional/ more appropriate services 	<p>Projects within this theme and Model of Care have been set up to ensure information, advice, care and support is provided to enable individuals to continue to live at home for as long as possible after a dementia diagnosis. The type of support being provided includes rapid response in critical moments, delivering information sessions from benefits team and local care providers etc. along with providing advice on dealing with Dementia through one-to-one discussions and sign posting to more appropriate services.</p> <p>Support for unpaid carers is also an intrinsic part of the work carried out by these organisations. Through having access to support that can unpick behaviours, finding out about financial support and benefits, unpaid carers have reported feeling empowered and informed, and ultimately have confidence in what they are providing to their family members.</p> <p>Examples of these projects include the Dementia Hwb which are one-stop information centres - one located in Swansea and one in NPT shopping centres along with 7 outreach mobile hwbs, set up specifically for all things related to dementia. It serves carers, individuals with and without a dementia diagnosis, professionals, and those who want to educate themselves on the topic. The Hwb offers signposting to information and services to support each visitor, emphasising that they are not alone on their dementia journey.</p> <p><i>“You just really have no idea on what support is out there, thank you for all your help.” [Female, 30s, both parents with a dementia diagnosis on her follow up contact after initially approaching the Dementia Hwb for a Blue Badge and finding out they could access finance/benefits assistance].</i></p>

		<p><i>“I wanted to volunteer at the Dementia Hwb as my Bampa has Dementia. My Nana who cares for my Bampa used these services before and had said the people were lovely and helpful. I thought I wanted to be a part of something like that too. After doing my volunteering for college, 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.” [Female, 16, placement student at the Dementia Hwb] - View feedback from *redacted*s’ Nana here https://vimeo.com/912882714?share=copy</i></p> <p>The Dementia Pathfinder Project supports individuals through the provision of a Dementia Support Plan providing support to people living with Dementia and their carers and the pathways to navigate on where to get the right support at the right time. Feedback from one user who received support to access the correct benefits resulted in an increase in attendance allowance, pension credit and housing benefit, as well as eligibility to cold weather payments and free TV license.</p> <p><i>“I couldn’t have felt more relaxed and able to talk through my problems. Without Dawn talking through everything I would have been oblivious to what I was entitled to. Dawn has been so helpful, and I am so aware of what is available as a carer. This is wonderful service, all I can say is a massive thank you for all you have done” Dementia Pathfinder Project, Age Cymru West Glamorgan</i></p> <p>Within another project, practical help is provided through the provision of ‘handyman interventions’ including such things as walk in shower installations, grab rails and other minor adaptations that support individuals to live at home for longer.</p>
	<p>Programme Contribution to Model of Care and exploration of what is different</p>	<p>What have we learned about things that went well? What have we learned from any challenges that occurred?</p>

	<p>The six projects support primary and secondary care services by providing pre-diagnosis and post diagnosis, with community based support.</p> <p>These services address the key themes contained in the Model of Care, 'Prevention & Community Co-ordination': by supporting independence through an emphasis on preventative services and early intervention.</p> <p>This subsequently delays the need for more intensive support such as the need for Social Worker intervention which could lead to statutory services being put in place earlier than would be required if the above support services were not in place.</p>	<p>Successes</p> <p>Through the piloting of the schemes, the referral pathways have been enhanced by having the opportunity to test what is required by the population across the region.</p> <p>The different organisations are also working together to ensure the provision is not being duplicated and that different methods of support are being provided. Knowledge of the other organisations also gives signposting opportunities on what else is available.</p> <p>Challenges</p> <p>Lack of volunteers – there are fewer people able to become volunteers across the sector through increasing volunteering opportunities; alongside this the cost-of-living crisis having an impact with those previously volunteering now needing to work more days than previously.</p> <p>Consideration needs to be given on how services can become better known to ensure people are accessing them earlier in their dementia journey, to support reducing the number of times an organisation is only contacted when in crisis. Through the implementation of the All-Wales Dementia Standards, work on engagement and publicising services is a priority area.</p>
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Theme 3	Quantitative Measures	Qualitative Indicators
<p>Theme 3 – Assessment & Diagnosis</p> <p>Model of Care – Promoting Good Emotional Health and</p>	<p>Theme 3: Assessment & Diagnosis</p> <p>There are 2 projects aligned to this theme. The 2 projects are based within the Memory Assessment Service, one is pre-diagnosis support and increasing diagnosis rates and the speech and language team assessing people for disorders such as swallowing difficulties. Both projects are having a positive impact on early diagnosis.</p>	<p>Providing the right support at the right time is the main priority under this theme. Through early intervention and diagnosis, a number of support services are identified including third sector organisations as well as statutory services such as secondary mental health services. Early diagnosis also prevents crisis, avoids unplanned hospital admissions, and admissions into long term care facilities and is an important part of a person's dementia journey.</p>

Wellbeing	<p>Theme 3: Assessment & Diagnosis</p> <p>Theme 3: Assessment & Diagnosis</p> <p>Theme 3: Assessment & Diagnosis</p> <p>Theme 3: Assessment & Diagnosis</p> <p>Theme 3: Assessment & Diagnosis</p> <p>Theme 3: Assessment & Diagnosis</p> <ul style="list-style-type: none"> • 555 referrals Received this financial year • 484 assessments completed • 516 of the referrals accepted 	<p>As a result of discussions, the Memory Assessment Service have been invited to work as part of a small UK wide group, developing a UK Primary Progressive Aphasia Resource Bank, led by UCL. Feedback from local patients on different resources and will feed into this theme, ensuring that our patients are at the forefront of national work in this area.</p> <p><i>‘Having things explained to me like this... there are pennies dropping everywhere... the way my dad’s been... I can really see why this might have been now. I hadn’t realised how much the way I was talking to him might have been adding to his confusion and frustration. This session has given me a lot of practical advice and tips to try.’ Speech and Language Therapy in Memory Assessment Service, SBUHB</i></p> <p><i>I’ve been really struggling recently, coming to terms with the fact that my husband has needed emergency respite care because of my own ill health. Having the communication passport ready when he went in at short notice was a real comfort as it meant I had all the quality-of-life things that are important to know about him were all in one place ... things he likes to talk about, things that he enjoys, things that make him smile.’ Speech and Language Therapy in Memory Assessment Service, SBUHB</i></p> <p><i>“my mother stopped eating in the first week she moved to [the care home]. You were able to explain her communication needs to the staff, who were strangers to my mum, which really helped.’ Speech and Language Therapy in Memory Assessment Service, SBUHB</i></p> <p><i>‘to be honest, we didn’t quite know what to expect from a Speech and Language Therapy session... what a difference an hour made! You helped me understand the difficulties I’m having when I’m talking... my word finding difficulties are so frustrating and have been really getting me down. You gave</i></p>
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		<i>me and my wife ideas of things to try and I feel really good about this. I really liked the 'toolkit' idea where I try different pieces of communication advice and see what is helping me as we go along. I feel good leaving this session'. Speech and Language Therapy in Memory Assessment Service, SBUHB</i>
	Programme Contribution to Model of Care and exploration of what is different	What have we learned about things that went well? What have we learned from any challenges that occurred?
	The projects meet this model of care through improved diagnostic capacity within the Memory Assessment Services. Earlier diagnosis improves people's opportunity to engage in preventative measures, identifying suitable medical and psychosocial treatment pathways, slowing down decline and improving people's emotional health as well as physical. Both projects lead to improved patient, family, and carer outcomes.	<p>Successes</p> <p>The main success from these projects is reducing the time it is taking for people to receive a diagnosis that can then be supported by several organisations that are set up throughout the region.</p> <p>Challenges</p> <p>There are challenges in collecting data as it takes away from the clinical time that is required to deliver the service. Difficulties in recruitment, retainment and absence of medical cover has also continued to be a challenge.</p>

Theme	Quantitative Measures	Qualitative Indicators
<p>Theme 4 – Post Diagnosis</p> <p>Model of Care: Complex Care Closer to Home</p>	<p>Theme 4: Post Diagnosis</p> <p>There are 3 projects aligned to this theme. The 3 projects support people post diagnosis and assist home from hospital transfers. The projects involve person-centred care & support plans which result in less readmissions to hospital than would otherwise be seen.</p> <p>The projects have:</p> <ul style="list-style-type: none"> Supported 401 people (133 of which are new). Completed 194 assessments 	<p>Whilst it is the ambition of the region to provide support which prevents and delay the onset of dementia, and support people living with dementia to remain as independent for as long as possible; it is recognised that once an individual's illness progresses, it is possible to remain living at home and in the community with the right level of support available to them and their carers.</p> <p>Support provided post diagnosis varies from respite care, advocacy and dementia beds. Each have their place in supporting people post diagnosis, however they provide very different services. The main aim within each project is to support individuals with a dementia diagnosis in having a</p>

- Received contacts from **1204** people.
- **145** of those surveyed achieved their intended personal outcomes.

choice of where they live, being listened to, and supported in making decisions appropriate for themselves. This includes giving unpaid carers the correct level of support to enable those who want to live at home to be able to do that safely.

The Dementia Respite Service provided by Marie Curie, through interviews have demonstrated the value as an option for carers, respite also supports individuals to continue with their caring responsibilities alongside being able to keep on working. The impact of the dedicated senior nurse joining the team in summer 2023 was visible in the data in an increase of inter-service referrals within Marie Curie in response to the needs of the service users at the time. Unfortunately, the senior nurse has left the role, so they are currently recruiting a replacement. In the interim, the role is being covered by other staff from across the wider Marie Curie service.

“It’s a great help when someone from Marie Curie is there, I can focus on myself for a short time, I have had to cancel hospital appointments for myself in the past, as had no one to care for mother, but since input from Marie Curie, I have now been able to attend appointments therefore my own wellbeing has improved Mum’s dementia is very unpredictable, and any help is greatly appreciated. I have been able to meet up with a close friend that lives in Port Talbot which was lovely.” Marie Curie, Dementia Care and Respite Service

“The service relieves the pressure – weight is taken off my shoulders when someone is there with wife. I can have some time to myself to get some shopping done or just take out dog for a walk. It’s good to have some time to clear my head.” Marie Curie Dementia Care and Respite Service

“I have been able to have my hair done, get chores completed, either general shopping or going to the chemist, it gives me the time and opportunity to meet up with friends for a catch up. I have also just been able to have a much-needed nap without the worry of how my partner is, as being cared for by MC staff”. Marie Curie Dementia Care and Respite Service

		<p>Identification of the correct level of ongoing support as soon as possible, keeps people healthier for longer. Reducing hospital admissions also reduces the number of people that need to go to long term care, as individuals stay more active if they are living at home.</p> <p>The step-down beds have provided opportunities for reablement to support going home:</p> <p><i>“To all the carers that have looked after Maureen during the time she has been with you. I would like to say a big thank you, the improvement from this time has been remarkable. All due to your care and concern for her welfare. The work you all do is commendable, once again, thank you all” thank you card sent to Westfield House, step-down beds</i></p> <p><i>“I cannot thank you for all the amazing care you have shown me over the last 6 weeks. You have helped me through a difficult time and have made my stay as easy as it could be” thank you card sent to Westfield House, step-down beds</i></p>
<p>Programme Contribution to Model of Care and exploration of what is different</p>		<p>What have we learned about things that went well? What have we learned from any challenges that occurred?</p>
	<p>There are three project that fit under the Model of Care, ‘Complex Care Closer to Home’ and support avoidance of admissions/readmissions by providing services closer to home. These services prevent escalation of need and crisis. Providing this type of support is imperative to ensure people with complex needs can remain either at home with a comprehensive package of support or into a step-down facility away from an acute setting where people have an opportunity to resettle and gain their strength back before going home. Supporting carers is an important part of the going home option.</p> <p>Without these projects there is a risk of individuals going into care home placements, and with deconditioning due to being in acute settings longer than necessary; dementia</p>	<p>Successes</p> <p>People with dementia are given the opportunity to be involved in the decisions that affect them, ensuring they are provided with the correct level of support to enable their choices to be met. Where it has not been possible to achieve their wishes, clear explanations are being provided.</p> <p>Links are also being made by projects across the region with other RIF projects to ensure collaborative working is taking place, reducing duplication in services.</p> <p>The benefit for carers allows them to have personal time to get on with things and not worry about their family members.</p> <p>Challenges</p>

	<p>nursing beds may be the only option. Due to the deficit of dementia nursing beds across the region, this would then result in out of area placements, which would not be cost effective.</p>	<p>Staffing issues in relation to social workers and nursing staff. These types of roles are continually challenging to recruit to.</p> <p>A particular challenge for the respite service is ensuring there is enough support provided as part of the project. Initially set up for Monday to Friday 8am to 10pm, feedback has been that overnight and weekend support is also required and this is now being delivered and continually monitored as it is a more expensive provision due to the need to pay staff enhancements.</p> <p>The projects have reported that there is a higher request for support than is deliverable, demonstrating how valuable the services provided are, and how invaluable the funding is to ensure they can continue to provide the services currently being delivered. Engagement work will be carried out as part of the implementation of the All-Wales Dementia Standards to find out the priority areas for the region to see where the biggest needs lie.</p>
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System Constraints

There is an issue around data collection especially for dementia diagnosis. Currently statistics are gathered from the GPs, however there is a lack of confidence that the GP registers have all dementia cases recorded. Currently there is a review of pathways into the four Memory Assessment Services across the region and a system will be introduced to record all dementia diagnosis.

It is possible to estimate the dementia rates in the region through rates of diagnosis across Wales. The population aged 65 and over in the West Glamorgan region is 78,100 (Census 2021) and the diagnosis rate in Wales is **53.9%**. The estimate for diagnosis of dementia in the region therefore equates to **42,096** people. It is estimated that by 2040 the diagnosis rate will increase to 70% of over 65's.

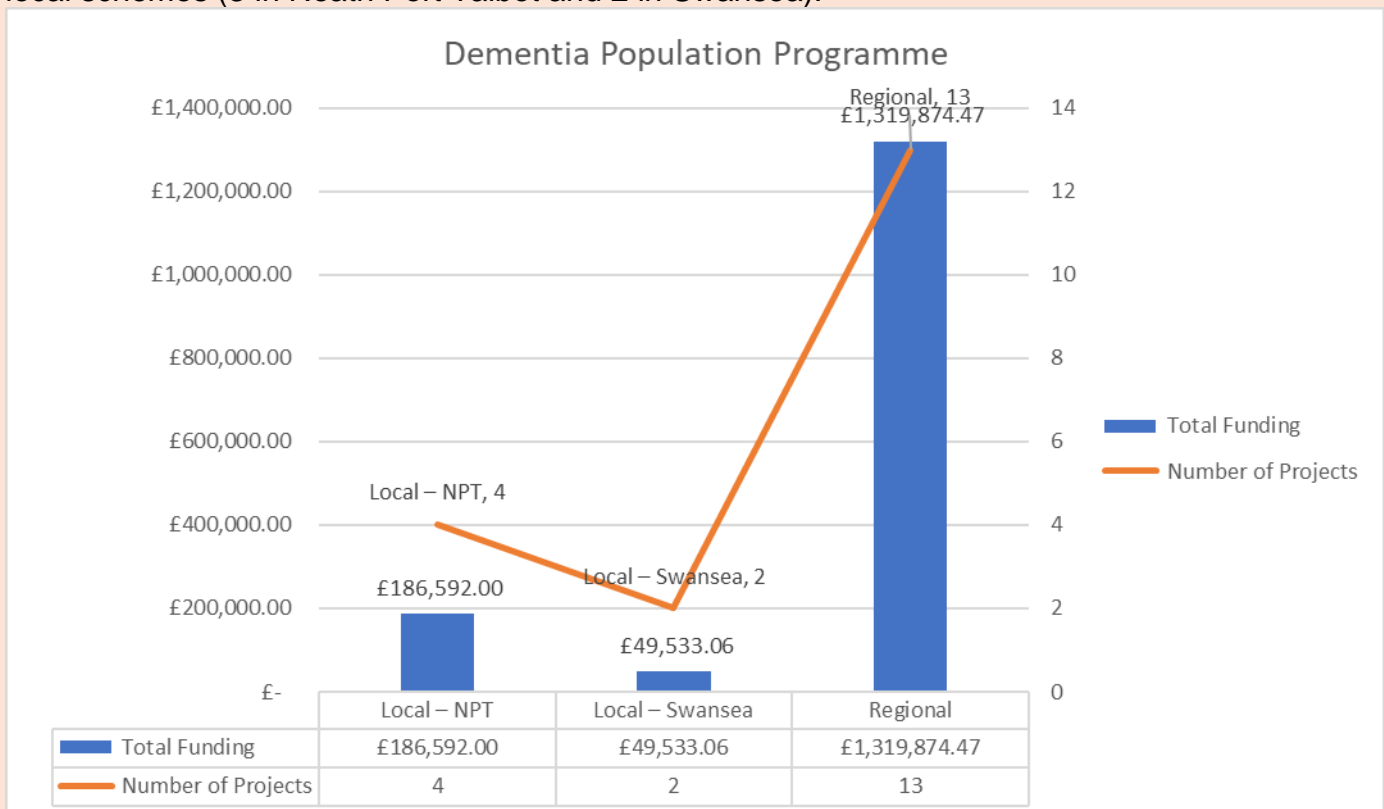
Lessons Learned

The Me, Myself & I (MMI) project for younger people did not have the attendance that was hoped for, and the project has closed. Although the MMI format works well for older people, greater thought needs to go into working with young people to find out what support they need and create projects to suit their needs.

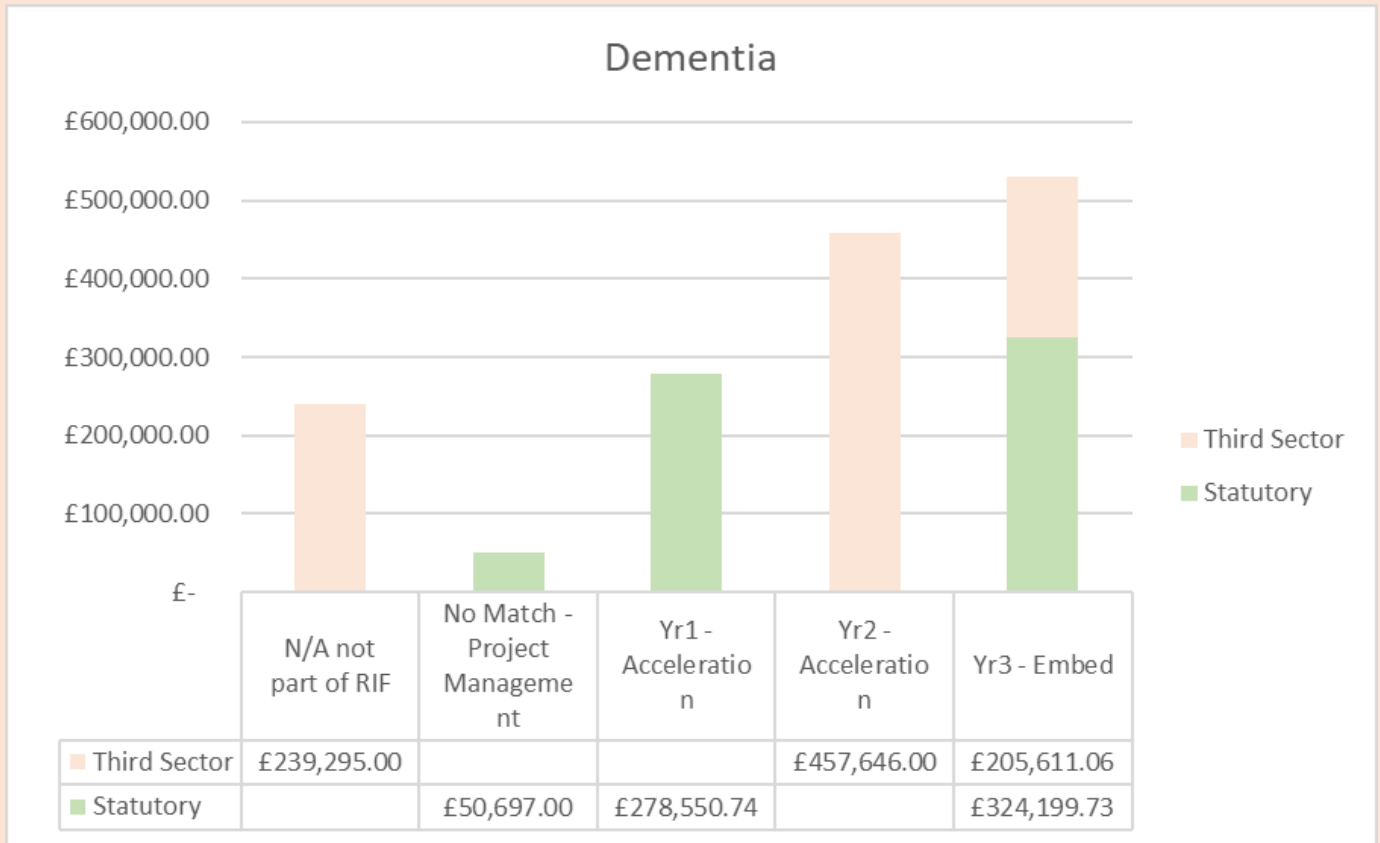
There was an issue with the Hospital Advocacy Support (Advocacy Support Cymru), who were initially only supporting one person. We supported the project to make contact with the social work teams, hospital discharge team and advertised the service through regional networks etc. The project now supports 21 people.

Funding Utilisation

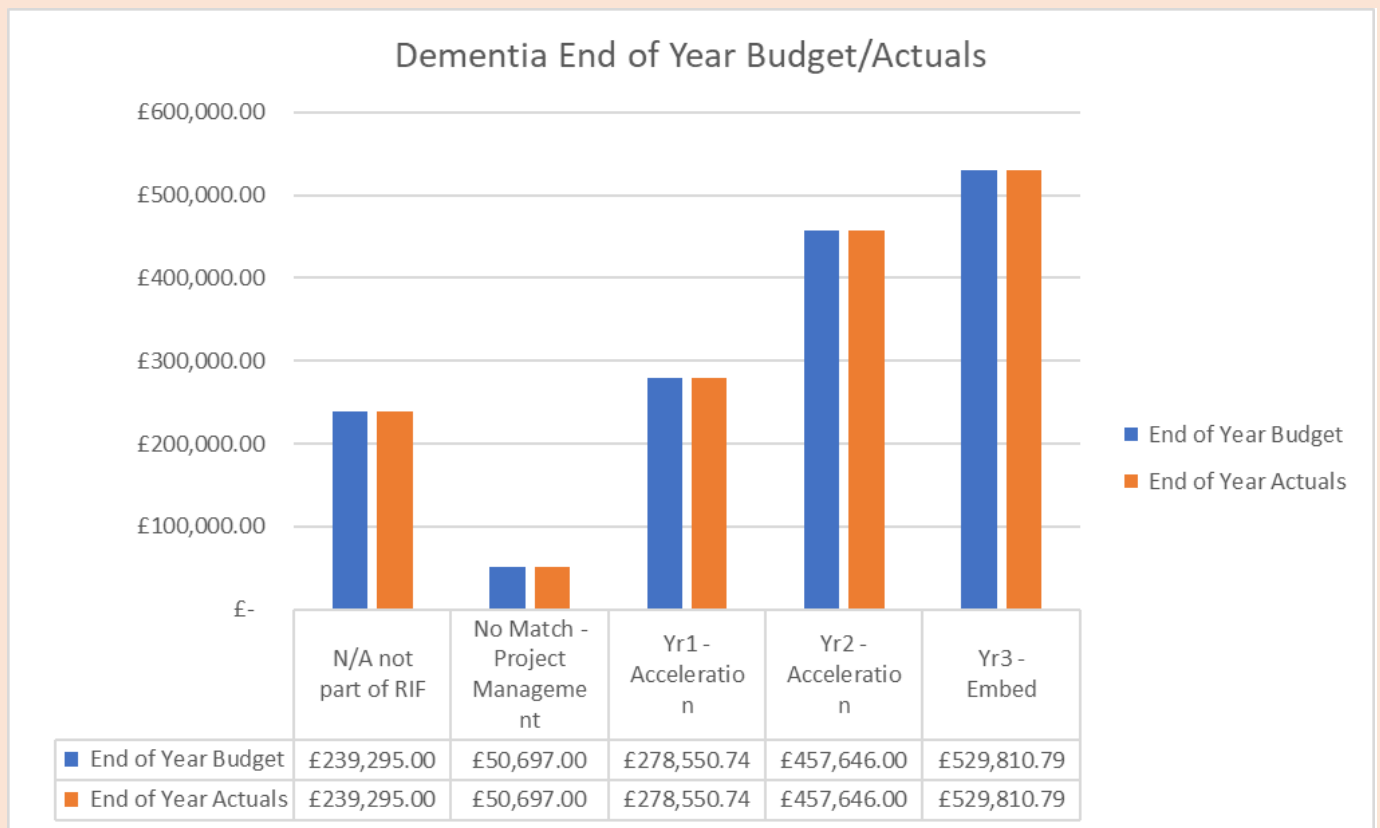
The total allocation for the Dementia Programme for 23/24 is £1,556,000. 12 different organisations were provided with RIF Funding in 2023-24. There are 10 regional schemes and 5 local schemes (3 in Neath Port Talbot and 2 in Swansea).



Dementia RIF Allocations 23-24



RIF Budget/Spend Position at end of year



Financial and Economic Data

There are a total of 15 projects funded via RIF within the Dementia Programme. 11 of which are third sector projects, and the remaining four with statutory partners.

The mentioned projects are positively impacting people's lives through community groups, enhancing well-being, and providing support for unpaid carers. Across Wales, there are approximately **310,000 unpaid carers**, with an estimated **38,000** in the West Glamorgan region. While not all of these carers support people with dementia, the community groups offer essential assistance that makes it easier for them to fulfil their caring responsibilities.

Supporting individuals with dementia not only benefits the person directly affected but also their unpaid carers. The wellbeing of both are impacted on positively through the work carried out. Community groups offer support and connection to people with dementia and their unpaid carers, participants have an opportunity to share stories, challenges and coping strategies, fostering a sense of belonging and reducing feelings of loneliness. This also offer opportunities for peer support to learn practical advice, tips, and information.

'**Osprey's in the Community Sporting Memories**' is an extremely popular project which has been running since 2019. The project utilises Wales's passion for sport and rich history, to help tackle some of the biggest issues in the local area namely dementia, isolation and loneliness. The project has grown rapidly from six people in Dunvant RFC in 2019 to over 664 people supported, this financial year across seven local rugby clubs with an estimated social return of circa. £3million.

Programme Case Studies

Dementia Hwb Project Visit & Case Studies

[Dementia Hwb - Regional Integration Fund on Vimeo](#)



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Sporting Memories Case Study



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Westfield House Project Visit Digital Story & Cast Study

[Westfield House - Regional Integration Fund on Vimeo](#)



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Me, Myself & I Case Study



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Dementia Pathway Finder Case Study



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Alzheimer's Society Case Study



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