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AHP Dementia Network for Wales · Rhwydwaith Dementia AHP Cymru

Allied Health Professionals Dementia Framework for Wales

Maximising the impact of Allied Health Professionals in Wales working with people living with dementia 2022–2025

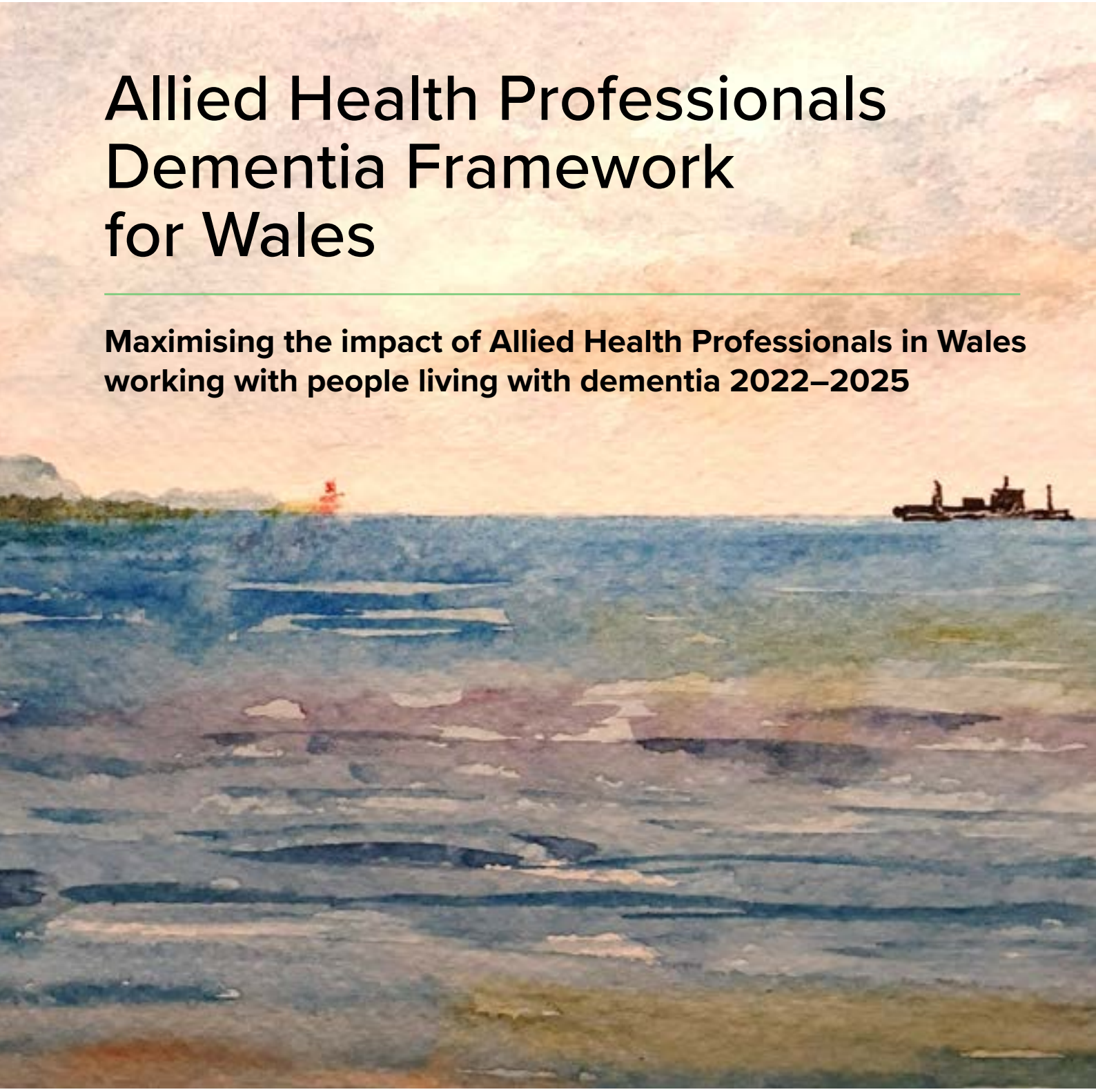

Illustration credit: 'The Sea of Uncertainty' – Frances Isaacs

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Forewords

Foreword by Andy Woodhead PhD, living with dementia and a member of the Framework Project Steering Group

A diagnosis of dementia is not something that is easy to receive. There is no miracle cure, so a fear sets in which you know everyone experiences but there is always bravery, optimism and acceptance to be found. Dementia is a condition which ultimately affects the whole family, as they join us in our journeys, which although different for everyone, will require care and expertise. It is vital that we remember that dementia is not only a condition which affects older people, and everyone with one of the over a hundred forms of this condition is different. We do not however want to carry the 'dementia' label, to define who we are on this journey with this illness; it is crucial to remember that 'I'm Still Me'!

Staying positive, happy and accepting is hard but we have to do it for our family and friends. Those who work in the caring roles are the happy faces, with the compassionate nature and constant help, which means that a life can feel comfortable, safe, secure and bearable again. We are able to believe that it is possible to live a better life than we thought possible with dementia. The sacrifices carers make is not something that immediately springs to mind as it should. The strain on families can be enormous and it is imperative that they have the advice, support and care they need too when it is requested**.**

The Allied Health Professionals (AHP) Dementia Framework for Wales most importantly will provide much needed hope and encouragement to those living with dementia, with holistic and person-centred care at its 'core'. The AHP approach to our care will ensure that we are receiving the right support post-diagnosis.

The fact that this framework has been developed through co-production, seeking out the opinions, experiences, desires, needs and challenges of those living with dementia, our families and carers, has been indispensable in putting together a strategy that we can feel confident should be fit for purpose.

It is exciting to see that we now have the opportunity to implement a framework across Wales that is going to mean so much to improve the lives of so many people. Dementia care has for a long time been fragmented and complicated in some respects for many to be able to navigate and access. This will be changed for the better by the AHP Dementia Framework. This is not something that will necessarily be easy. It is going to require structural change, resources, learning, commitment, co-operation and a change of culture if it is going to evolve well.

The opportunities for dementia care in Wales through the AHP Dementia Framework are going to be a challenge, but I know that the desire is there amongst all the stakeholders to make this initiative work. Everyone who has contributed to the development of this project are owed a special debt of gratitude. I know how much work and effort has gone into this. As a person living with dementia, with a family supporting me through my journey, I am so proud to see that Wales / Cymru are leading the way and blazing a trail in Dementia Care and ultimately, improving the quality of our lives.

Foreword by Ruth Crowder, Chief Allied Health Professions Advisor, Welsh Government

This is an important, exciting and challenging time to be an Allied Health Professional (AHP). The Allied Health Professions are 13 individual professions[1] *allied* by our belief in the importance of enabling citizens to live the lives they want to live. Yet the unique expertise of each profession has traditionally been poorly understood and under-utilised. This Dementia Framework has identified strong themes that every AHP, manager and employer needs to understand and act on if we are to ensure that our population achieve the best possible health outcomes.

The engagement work underpinning this framework has received clear messages from our colleagues and population. They tell us that we need better, easier and quicker access to our services. In particular, they need to reach us far earlier in their health journey than they do at present, to maximise brain health, to reduce risk of dementia, and to enable people to live a life of quality following a diagnosis. They tell us that we need to communicate more effectively the benefits our interventions and skills deliver, and that we need to work more co-productively and collaboratively with people with dementia and their families. This will enable us to better understand what people actually require and adapt our services to meet their needs even more effectively in future.

This framework gives us a clear set of actions to deliver the changes required to modernise and improve services across Wales. We need to innovate more and actively promote an improvement culture within our services. We need increased capacity and skills for research to enhance our evidence base and demonstrate impact, outcomes and value of AHP approaches. We need to communicate far more clearly when and how we can offer interventions that make a difference to the quality of people's lives and to help them live well with dementia. We must make access to our services less complicated and remove the hurdles to people reaching the right professional at the right time. We must be located in, and work as part of, local communities in partnership with our population.

People with dementia may have other conditions and need to access all parts of the health and social care system, so these actions need to apply to every AHP, not just those in specialist dementia services. Each and every one of us will need to embrace leadership and use our skills to change the narrative about what good dementia care should look like and champion a rights-based approach so that people with dementia can access the services and support that they are entitled to.

AHPs across Wales must transform our approach so that we are delivering more preventative interventions at times that will help people live a life of quality post-diagnosis.

[1] AHPs in Wales: • Art Therapists • Music Therapists • Drama Therapists • Dietitians • Occupational Therapists • Orthoptists • Orthotists • Paramedics • Physiotherapists • Podiatrists • Practitioner Psychologists • Prosthetists • Speech and Language Therapists

Acknowledgements and with thanks to

Many people have worked in partnership to co-produce the Allied Health Professionals Dementia Framework for Wales. We want to thank the AHP Dementia Framework Steering Group, with membership including people living with dementia, carers and supporters, health and social care professionals, third sector organisations, AHP professional bodies and higher education institutions (HEIs) (Appendix 2[2])

We would also like to extend gratitude to the partners who have supported this work:

- Age Cymru
- AHP Policy Officers
- Allied Health Professionals Dementia Network
- Alzheimer's Society Cymru
- Alzheimer's Society Dementia Voice
- Bangor University
- Cardiff University
- Carers and supporters
- Diverse Cymru
- Health and social care practitioners
- Health Education Improvement Wales
- Lleisiau Dementia
- Local NHS Health Boards
- People living with dementia
- Social Care Wales
- TEC Cymru
- Together in Dementia Everyday (tide)
- Welsh Ambulance Service
- Welsh Government
- Welsh Regional Partnership Boards

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[2] Available on request. Please email: HSS.RehabAndAHPs@gov.wales

Executive Summary

- The Allied Health Professionals (AHP) Dementia Framework for Wales defines the value of the enabling, holistic and person-centred approach to care and support that is offered by all Allied Health Professionals.

- The framework is relevant to people living with dementia, their carers/supporters, AHPs, together with AHP managers, health and social care sectors, and the third and independent sectors.

- Developed through an evidence-informed approach, the framework has been shaped by listening to people living with dementia, their carers and supporters, using an appreciative inquiry approach to understand what good care looks like, together with appraisal of research evidence and exploring opportunities, challenges and ambitions for dementia care from perspectives of AHP leaders. This work has been guided throughout by a steering group with lived and learnt experience of dementia.

- A whole system, tiered approach to care and support is offered within the framework, aligning with prudent healthcare principles, ensuring that people with dementia receive the right care, in the right place, at the right time (Welsh Government, 2019). Case studies are used throughout the framework to evidence excellent practice taking place across Wales.

- Priorities to continue the transformation of AHP practice in dementia are focused around increasing awareness of and access to AHPs, strengthening innovation and improvement approaches to continue building evidence of the value of AHP approaches, enhancing co-production and collaboration to achieve what matters most to people with dementia and developing leadership within the AHP workforce at all levels of the health and social care system to drive change in AHP practice.

- These priorities align with wider policy and strategy including the Dementia Action Plan for Wales (Welsh Government, 2018), All Wales Dementia Care Pathway of Standards (Improvement Cymru, 2021) and AHP Framework for Wales: Looking Forward Together (Welsh Government, 2019), Primary and Community Care Allied Health Professions (AHP) Workforce Guidance: Organising principles to optimise utilisation (Strategic Programme for Primary Care, Wales, 2021) and the All Wales Rehabilitation framework and guiding principles (Welsh Government, 2022).

Glossary

Allied Health Professionals	In Wales, Allied Health Professionals (AHPs) are 13 individual professions regulated by the Health and Care Professions Council (HCPC). AHPs work with people of all ages, from birth through to end of life, empowering and enabling them to manage their own wellbeing and prevent or reduce the impact of psychological and physical ill health and disability. AHPs work across health, social care, private practice and charity organisations.
Biopsychosocial approach	A theoretical framework to understanding health and wellbeing. The biopsychosocial approach takes into account the biological, psychological and social factors that may influence a person's overall participation in their everyday life.
Carer / supporter	A person who supports or cares for a person living with dementia. Other terms such as caregiver, care partner, relative, family member, friend, aid or helper may also be used in place of carer/ supporter.
Co-production	The process of working with people who use services and carers in a collaborative partnership to plan, improve and deliver care, support and services. This leads to meaningful change.
Peer support	This refers to opportunities for people with dementia and their carers/supporters to meet other people who also have dementia or care for a person with dementia. Peer support can be valuable in enabling people to share experiences, coping strategies and build new, supportive relationships in a safe space.
People affected by dementia	This may include a person living with dementia, a carer (unpaid or paid), family members, friends or health and social care professionals.
Person-centred	A person-centred care approach seeks to see the individual person, rather than concentrating on their dementia. Person-centred care recognises and respects the personhood, diversity and human rights of the person.

Rehabilitation	Rehabilitation describes support, care and interventions that help people to achieve and maintain optimal levels of functioning. This helps people to retain their independence and life roles for as long as possible, ultimately enhancing quality of life. Reablement is an enabling approach focused around supporting people to retain or regain skills within everyday life, and may form the restorative component of rehabilitation.
Strengths-based approach	A strengths-based approach recognises the strengths of a person, their family, groups and communities around the person and empowers them to achieve what matters to them. The approach recognises the abilities, interests, knowledge and resilience of the person, rather than their limits, in comparison to traditional deficit-focused models.
Stress and distress	Distress describes communication or behavioural changes in people with dementia that may be present as a response to stress, often resulting from an unmet need, such as pain, discomfort, need for connection, lack of meaningful activity or sensory needs. How a person experiences stress and presents with distress will vary person to person. This may also be described in other documents or existing research as 'Behaviour that challenges', 'Challenging behaviour' and 'BPSD (Behavioural and Psychological Symptoms of Dementia)'.
Supported self-management	This explains how someone with expert knowledge, including people living with dementia, health and social care professionals, and third sector organisations can support people with long-term conditions to develop the knowledge, skills and confidence to manage their health and wellbeing in order to continue to do what matters to them.
Team Around The Individual	The team supporting the person living with dementia. This may consist of family, friends, supporters, members of the community, in addition to a team of health, social care, third sector/charity professionals, and dementia navigators, who provide co-ordinated care, that is flexible and tailored to the needs of an individual person with dementia and their carer.

Introduction, context and vision

Vision

‘People living with dementia, their carers and families, will have enhanced access to the enabling, empowering support, care and rehabilitation that Allied Health Professionals can provide, regardless of their age or address, gender, sexuality, or ethnicity, earlier in their diagnosis, and throughout the course of their dementia.’

The Allied Health Professionals (AHP) Dementia Framework for Wales outlines how Allied Health Professionals (AHPs) in Wales can help people living with dementia, their carers and supporters to remain as physically, cognitively and socially active for as long as possible, to live a life of quality following their dementia diagnosis. The framework also details the AHP contribution to brain health of the population, reducing risk of developing dementia, in addition to supporting people to access a differential and timely diagnosis.

This framework works from the lens that ‘dementia is everybody’s business’, and for Wales to become a dementia-friendly nation as outlined the Dementia Action Plan, we need all AHPs, wherever they work, to be able to deliver person-centred, enabling and holistic care.

Audience

Though our key audience is members of the 13 AHPs across Wales, we recognise that the work of AHPs is dependent on partnership working and integration across all sectors of health and social care. Therefore, we believe that this document will be essential reading for anyone involved in delivering and planning services for people living with dementia, and specifically:

- People living with dementia, carers, family members and supporters
- AHP Leaders
- Health and social care managers
- Regional Partnership Boards
- Welsh Government
- Third sector and charity organisations
- Wider public

Whilst this framework was developed in Wales, it is realised that it may influence the work of others across the United Kingdom. Consideration of progress made in our equivalent nations has been acknowledged within this framework (Alzheimer Scotland, 2017).

Purpose

This framework provides an evidence-informed approach to demonstrate the value of AHPs in promoting brain health, and supporting people living with dementia and their carers/supporters.

The AHP Dementia Framework for Wales aims to:

- Outline the offer of AHPs in brain health, dementia risk reduction and increasing public awareness of dementia
- Define the role and contribution of AHPs in empowering people to live a life of quality after diagnosis
- Champion the voices of people with dementia and their carers/supporters, and what they tell us matters to them
- Present the most current research evidence regarding the support, interventions and rehabilitation provided by AHPs in enabling people with dementia, their carers and families
- Showcase emerging best practice taking place within AHP communities across Wales
- Serve as an evidence-based resource that can be called upon to affect change and support influencing work in Wales, from service level to policy level

National context: dementia in Wales

Dementia is one of the fastest growing causes of disability across the world and is recognised as a global public health priority (WHO, 2021).

It is estimated that there may be approximately 55,000 people living with dementia in Wales (Jones, 2018). Of course, the impact of dementia is far-reaching, with potential effects on a whole family. People living with dementia can experience a decline in their memory, thinking, perception, language, movement and other areas of functioning that have the potential to reduce participation in everyday activities. These difficulties worsen over time and can impact on a person's quality of life, and that of their family members who provide care and support.

COVID-19 and dementia

People with dementia and their carers/supporters were disproportionately affected by the COVID-19 pandemic. Research suggests that lack of social contact and change in routines, in addition to loneliness and isolation as a result of the pandemic, have led to a significant decline in cognitive and physical abilities, as well as increased mental health needs for many people with dementia and their carers (Giebel et al, 2020; Greenberg et al., 2020, Masterson-Algar, 2022). This means that there is an increased level of need in terms of rehabilitation for people with dementia to regain and maintain skills to facilitate independence and wellbeing. Increased waiting time for diagnosis following disruption to services, delays in access to support and the need for more mental health support for people with dementia and their carers/supporters (Alzheimer's Society, 2020) mean that AHPs will continue to have a vital role in facilitating rehabilitation and recovery.

“It is estimated that there are approximately 55,000 people living with dementia in Wales”

(Jones, 2018)

“The number of people living with dementia in the UK is predicted to rise to 1.1 million by 2030, 1.4 million by 2040 and 1.6 million by 2050”

(Luengo-Fernandez and Landeiro, 2022)

“82% of people affected by dementia reported an increase in dementia symptoms as a result of COVID-19 lockdown”

(Alzheimer’s Society, 2020)

Rehabilitation

The World Health Organisation global call to action highlighted dementia as a core recommendation (World Health Organisation, WHO, 2017). Rehabilitation is equally as important for people with cognitive impairment as well as physical impairments (Cations et al., 2018). Dementia rehabilitation should be centred on the principle of enabling people to function optimally in the context of their intrinsic capacity and current health status (Clare 2017). This needs to be person-centred, focused on strengths and what a person can do, maintaining focus where possible on promoting quality of life from early symptoms to later stages of a person's dementia journey (Laver et al. 2020). Despite recognition that AHPs are leaders in rehabilitation, there is currently a lack of access to AHP specialist dementia rehabilitation in dementia care (Welsh Government, 2018).

There is also a clear role for AHPs in the prevention of dementia. Livingston et al (2020) identified 12 modifiable risk factors for dementia, including obesity, diabetes, diet, reduced social contact, depression, physical inactivity, hypertension and excessive alcohol consumption, all of which can be influenced by AHPs' interventions.

Allied Health Professionals (AHPs)

AHPs work creatively and with a strengths-based approach to provide support to people across the lifespan, enabling people to do what matters to them. They use their expertise and experience, combined with research evidence in collaboration with individuals and key people in the person's life to provide tailored care and effective support. Making up approximately one third of the NHS workforce (Welsh Government, 2019), AHPs are leaders in rehabilitation, focusing on solutions to empower people to lead a good quality of life. Examples of job profiles of AHPs supporting people with dementia are available at the bottom of this page[3].

Within Wales, there are 13 AHPs working across health, social care, the charity sector and private practice, and are registered with the Health and Care Professions Council (HCPC).

Who are AHPs, and how can they help people?

Art Therapists	Art therapists provide a form of psychotherapy that uses art media as its primary mode of expression and communication to address clinical goals. Used in a therapeutic context, art is a medium to identify and address psychological, emotional and well-being issues which may be confusing and distressing.
Music Therapists	Music therapists use different elements of music to help people to achieve therapeutic goals and work with their feelings using music. This may be receptive (listening to the music) or active (making music). Neurologic Music Therapy (NMT) specifically relates to music therapy that can positively impact cognitive, sensory and motor symptoms of neurological conditions.

[3] HEIW Allied Health Professions Job Profiles

Dramatherapists	Dramatherapists are both clinicians and artists who use performance and theatre-based methods, including drama, story-making and movement, as a means to engage a person in psychological therapy. Dramatherapy is a form of psychotherapy.
Dietitians	Dietitians assess, diagnose and treat diet and nutritional problems. They also provide holistic interventions and practical advice to optimise a person's nutritional intake to improve their health and wellbeing. Dietitians work on an individual and wider public health level.
Occupational Therapists	Occupational therapists provide tailored assessment and interventions to help people to maximise their functional abilities to carry out the activities that are important to them that enhance quality of life. This could include everyday activities, like getting dressed, cooking, shopping as well as hobbies and pastimes.
Orthoptists	Orthoptists diagnose and manage any difficulties associated with eye movements and co-ordination.
Orthotists	Orthotists design and provide specialist devices (orthoses) which support the body with the aim to improve function, reduce pain, provide protection and reduce deformity.
Paramedics	Paramedics work with people who are in a health or social care crisis. They provide advanced emergency care.
Physiotherapists	Physiotherapists specialise in promoting and helping people to maintain movement, through activity and exercise. Physiotherapists can also help with management of pain that may impact on movement, independence and quality of life.
Podiatrists	Podiatrists enable people to maintain healthy feet, helping people to remain mobile, prevent falls and promote independence.
Practitioner Psychologists	Practitioner psychologists use psychological theories to understand how the brain works and to understand behaviour. They can assess, diagnose, treat and support people who have experienced changes in their mood and behaviour. Practitioner psychologists can help people to develop coping strategies and adjust to difficult life events.
Prosthetists	Prosthetists assess for, design, create and fit artificial limbs for those who those who have lost a limb through injury or disease, or were born without a limb.
Speech and Language Therapists	Speech and Language Therapists provide tailored assessment, advice and interventions to support people who have communication difficulties. They also provide support for people with eating, drinking and swallowing difficulties.

AHP Supporting Values

Although there are 13 distinct Allied Health Professions (AHPs), there are common values and approaches that unite AHPs when working with people living with dementia and their carers and supporters.

The Allied Health Professions Dementia Network for Wales explored the unique values that AHPs can bring when supporting people living with dementia and agreed on three key values. AHPs are committed to an *enabling*, *person-centred* and *holistic* approach to delivering care, support and interventions. These three values reflect the universal AHP strengths-based approach, which is underpinned by kindness and understanding.

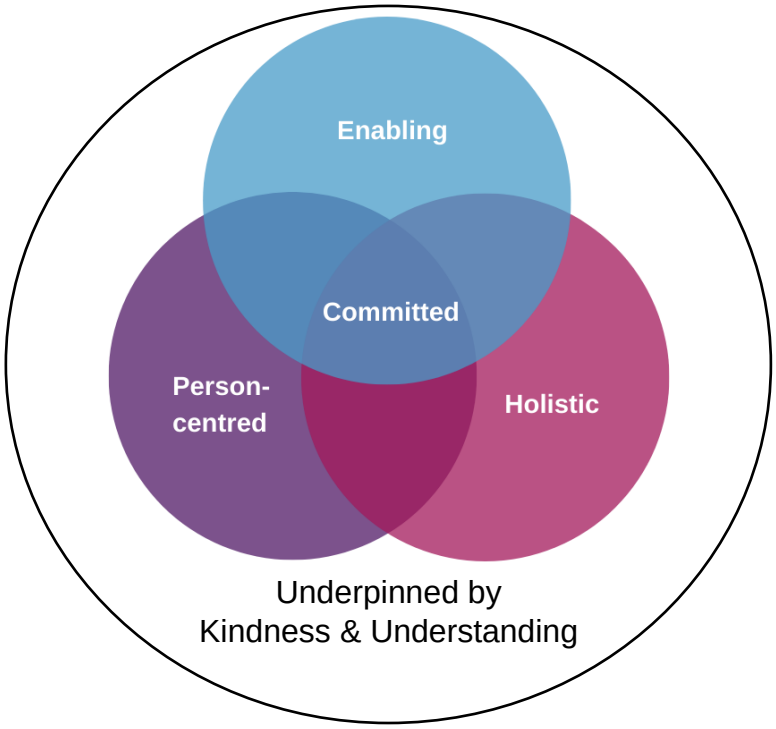

Figure 1 - Allied Health Professional Values

Enabling: Allied Health Professionals adopt an enablement approach to supporting the person with dementia, using their knowledge, skills and expertise to enable them to make informed choices about the care and support they would like to access and inspire hope. Using a strengths-based approach, AHPs use creative approaches to advocate for a person, helping to make their voice heard, facilitating participation and promoting their human rights.

Person-centred: Allied Health Professionals work in a way that is person-centred, relationship-centred and family-centred, tailoring interventions to the individual, to take into account the values, needs and identity of the person with dementia and those around them.

Holistic: Allied Health Professionals use the biopsychosocial approach to support the person with dementia, recognising the impact of the environment around the person and the need to work collaboratively across boundaries, agencies and sectors to achieve the best outcomes for the person and their carers/supporters.

Wider strategy, policy and context

The Allied Health Professionals (AHP) Dementia Framework for Wales aligns with key policy documents.

The Dementia Action Plan for Wales 2018-2022 (Welsh Government, 2018) sets out the vision for creating a dementia-friendly nation where the rights of people with dementia and their carers are recognised and they feel valued and respected. The 'Strengthening provision in response to COVID-19' (Welsh Government, 2021) document complements the Dementia Action Plan, and identifies the need for ongoing work in targeted areas. Of particular relevance to Allied Health Professionals (AHPs), it highlights the need for further development and evaluation of 'Teams around the individual' that are multi-professional and can deliver integrated, person-centred care. Additionally, the need to improve access to therapeutic interventions and rehabilitation for people living with dementia, which in turn reduces the use of antipsychotic medications, is also reinforced in the strategy.

The All Wales Dementia Care Pathway of Standards (Improvement Cymru, 2021) contains themes focused on supporting independence and self-management, concepts at the heart of AHP practice. Implementation of the AHP Dementia Framework for Wales will support the embedding of the Dementia Care Standards.

Furthermore, the 'Taking Memory Assessment Services (MAS) into the Future' (Surr, Cartwright, Platt, Robinson and Smith, 2021) improvement guide promotes the need for good quality peri- and post-diagnostic support for people living with dementia, including access to information, education, rehabilitation and peer support. AHPs have a key role here in supporting people through the assessment process, and empowering people to live a life of quality after diagnosis.

Guidelines detailed within the Wales Dementia-friendly hospital charter (Improvement Cymru, 2022) are important for AHPs working within hospital settings as key principles to improve the experience of people living with dementia and their carers in hospital.

The Good Work Framework (Care Council for Wales, 2016) defines the learning and development needs of the health and social care workforce, including AHPs, who may support people living with dementia and their carers. The framework identifies three broad groups of people: those who are at 'Informed', 'Skilled' and 'Influencer' levels, depending on the requirements of their role. The framework emphasises the importance of practice that is compassionate, competent and wise, and a toolkit has been developed to support implementation of the approach to learning and development.

The AHP Dementia Framework for Wales, its values and approach also align with the goals set out in A Healthier Wales (Welsh Government, 2018), which highlights the role of health and social care professionals in providing prudent healthcare that is preventative, out of hospital and closer to home, with a focus on wellbeing and supporting people to remain independent within their community. The quadruple aim sets out the future vision for a 'whole system approach' to health and social care in Wales:

- Improved population health and wellbeing;
- Better quality and more accessible health and social care services;
- Higher value health and social care; and

- A motivated and sustainable health and social care workforce.

The AHP Framework: Looking Forward Together (Welsh Government, 2019) outlines how AHPs will rise to the challenge to put into practice the vision of A Healthier Wales. This strategic response highlights the culture shift needed for citizens to access AHP services that facilitate rehabilitation, reablement and recovery. The framework highlights the need for AHPs to be utilised more efficiently in order to inspire the population to lead healthier lives, being directly accessible, providing evidence-based interventions working at the top of their ability, as transformational leaders.

The Primary and Community Care Allied Health Professions (AHP) Workforce Guidance: Organising principles to optimise utilisation (Strategic Programme for Primary Care, Wales, 2021) provides the organising principles and actions required for the whole health and social care system to maximise the impact of AHPs across primary and community care. The guidance promotes the need to ensure that sustainable models of delivery exist and that AHPs are deployed from a well-integrated, whole system workforce planning basis to deliver the high quality, high value services required. Ensuring effective accessibility and utilisation of AHP skillsets across primary and community care is paramount to the delivery of person-centred support, within a place-based care model of care.

A Human Rights-based approach

Dementia Statements

The Dementia Statements clearly state what matters most to people living with dementia and their carers. Founded in human rights law, the statements were created by people living with dementia and their carers to help embed a rights-based approach to care and support and are emphasised within the Dementia Action Plan for Wales (2018-2022):

- We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
- We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
- We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.
- We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
- We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

In addition to the dementia statements, it is vital to highlight that people living with dementia have a right to access rehabilitation, including specialist AHP rehabilitation. Access to rehabilitation is a human right (Low and Laver, 2020).

Welsh Language and Dementia

The Welsh language is an integral element in the care and support of many Welsh speakers, but some groups have an even greater need to receive their services in Welsh. This is especially true for people living with dementia when it can be more than a matter of choice – it is a matter of need.

People with dementia are entitled to receive health and care support services in their preferred language. Communicating in a language that is most comfortable for the person is paramount in getting the right treatment and support, accurate and timely assessment and respecting the person's culture and personhood. The Welsh Language Measure (Welsh Government, 2011) sets out the rights for people to receive services in Welsh. The active offer is particularly important for people living with dementia who speak Welsh as their first language and as dementia progresses, may only be able to use or understand Welsh. This is supported by the *More than just words* Plan 2022-27 (Welsh Government, 2022), which stresses that people should be able to access services in Welsh without needing to request them, known as the 'Active Offer'. Realising this vision is the responsibility of everyone in their respective fields so that people receive care that meets their language needs, leading to better outcomes, without having to ask for it.

Diverse communities

People from diverse groups may face more barriers in relation to accessing person-centred care. Accessing timely diagnosis and appropriate services following diagnosis may be more difficult for people from black, Asian and minority ethnic communities, lesbian, gay, bisexual or transgender (LGBT) communities, those with young-onset dementia, people with sensory impairment, people with learning disabilities, and people living in rural communities (Welsh Government, 2018). AHPs must recognise and respond pro-actively to health inequalities and appropriately meet the needs and rights of specific groups, who may also be at higher risk of developing dementia, to ensure provision of holistic, person-centred care, avoiding a 'one-size fits all' approach.

"Dementia is life-altering, not life-ending"

An evidence-informed approach

The framework has been developed using multiple methods to gather evidence and demonstrate impact

Project Steering Group

Guided by a group of people living with dementia, carers, health and social care professionals, charity sector and AHP policy officers provided guidance and expertise

Listening Events

Connecting with people living with dementia and their carers/supporters to find out what matters to them

AHP Leader Survey

Informed by professionals working with people with dementia and their families, including Dietitians, Occupational Therapists, Podiatrists, Physiotherapists, Practice Psychologists and Speech and Language Therapists

Research Review

Scoping review of the current research evidence to examine post-diagnostic AHP interventions

More detail regarding the evidence-informed approach used to develop the framework can be found in Appendix 1[4].

[4] Available on request. Please email: HSS.RehabAndAHPs@gov.wales

AHPs: A whole system tiered approach to care and support

What is the tiered approach?

A tiered approach to care means that people living with dementia and their carers/supporters can access the right support, in the right place, at the right time. A multi-level approach to AHP care, support and interventions helps to embed rehabilitation and enablement culture to all areas of dementia care.

Why is it relevant to people living with dementia and their carers/supporters?

The tiered system can be used to apply a whole system approach to dementia care, recognising the complexity of the condition. The approach reflects the need for the AHP workforce to be integrated into all areas of health, social care and third sector services for people with dementia, to ensure that work is holistic, collaborative, and cross-cutting across organisational boundaries, ultimately enhancing the experience of people with dementia, their carers and supporters.

How does the tiered approach work?

The framework provides a holistic approach by identifying all core elements needed to deliver high quality outcomes for a population; in this case, people at risk of developing dementia, or those who have a diagnosis of dementia, and their carers/ supporters. The model includes details around 'what good looks like' at *universal*, *targeted* and *specialist* levels, underpinned by a skilled workforce, strong leadership, meaningful co-production with people living with dementia and their carers, and collaboration with the wider workforce. People with dementia and their carers/supporters can access support at multiple levels at a time, depending on their needs, and can move seamlessly between each level.

Universal: Promoting independence and wellbeing, building resilience and preventing escalation of needs.

Targeted: Working collaboratively with others to improve the wellbeing of people living with dementia.

Specialist: A range of individual AHP-led interventions, delivered by both generalist and dementia-specialist clinicians to provide rehabilitation and enablement approaches.

It is important to highlight that whilst some AHPs will have specialist roles working only with people living with dementia, in the context of an ageing population and increasing multi-morbidity, a significant proportion of AHP workforce will work with people living with dementia. Here, the level of 'specialist' is defined as interventions that are AHP-led and accessed depending on the complexity of the person's needs, rather than accessing a clinician who works specifically in a dementia-specialist role. It may be that within the specialist level, there are AHPs working in enhanced or expert roles, within dementia-specialist services.

The approach provides the platform to begin conversations about how AHP services respond to people living with dementia and their carers/supporters now and in the future.

AHPs: A whole system tiered approach to care and support

Figure 2 - Tiered approach to AHP dementia care

Universal support

The universal level of support is focused around prevention, self-management and promoting independence, and is available to everyone. Here, AHPs are using their skills to empower and support people living with dementia to access information, support, and resources as early as possible that can enable them and their carers to live a life of quality. All AHPs may deliver support at a universal level.

Support at this level may include:

- Promotion of the importance of brain health and reducing risk of dementia.
- Provision of population level advice and signposting to people with memory difficulties or dementia, and their supporters.
- Awareness raising with the wider workforce, third sector and members of the public regarding the AHP offer in supporting people living with dementia.
- Promotion of a rehabilitation and rights-based approach to supporting people with dementia and their carers/supporters.
- Indirect support to all people with dementia and their carers/supporters using multiple, inclusive communication methods including websites, social media, videos, blogs and evidence-based resources.

The following sections explain key components of the universal level approach to care, with examples of practice across Wales and beyond.

Supported self-management and education

AHPs will share at population level self-management tips to enhance physical, cognitive and psychological wellbeing. Focus on using AHPs' skills to facilitate self-management can support people to maintain independence for longer before requiring more targeted, therapeutic interventions. This can help people with dementia to remain at home, avoiding unnecessary hospital admissions and potentially delay admission into a care home (Quinn et al. 2015).

Education and provision of information can support resilience in people with dementia and their carers.

The **Movement and Mobility** strategy paper, poster and resources, linked to Standard 9 of the All Wales Dementia Care Pathway of Standards (Improvement Cymru, 2021), aim to raise awareness, of the importance of physical activity following a diagnosis of dementia. The resources promote the value of movement and mobility in enhancing physical, cognitive, and emotional wellbeing, and can work as a reminder within primary care settings, GP surgeries, outpatient and rehabilitation settings, Memory Assessment Services, and community venues.

AHPs have also been central to the development of the **'Conversations about dementia'** syllabus, a national education programme which provides a range of free self-management courses to support people living with a health condition and/or their carers (Improvement Cymru, 2022).

Resources about **managing everyday 'risks'** have been developed by Occupational Therapists in ABUHB to help people living with dementia and their families to take a positive approach to everyday activities and feel more confident. These include getting out and about in the community, leaving the house and cooking. Carers and family members can also learn new techniques to support their family member.

Likewise, the **Footcare at home** leaflet, developed in partnership by podiatrists in Scotland and Alzheimer's Scotland and modified for use in Wales, provides advice to people living with dementia to promote good foot health before problems develop. The leaflet also highlights when a person with dementia should seek further support from a Podiatrist.

Making every contact count is an approach that helps people to take control of their own health and wellbeing. Health professionals can have supportive conversations with people about their diet, physical activity, smoking cessation, alcohol intake and mental wellbeing. AHPs are well-suited to conversations about making healthy lifestyle choices and can empower people to make changes to their lifestyle through short interactions as part of routine appointments. This approach to optimising brain health aligns with the 'twelve steps' to reduce the risk of dementia from the World Health Organisation (WHO, 2019), as outlined in the Dementia Action Plan companion paper (Welsh Government, 2021), as well as the commitment to ensuring that people with dementia receive advice about changes they could be supported to make to improve their overall health and wellbeing. AHPs can be involved in promoting brain health at public health level and have a fundamental role in the prevention of many lifestyle-related conditions.

Awareness and influencing

The **Dementia Action Plan** highlights that stigma and discrimination can prevent people with dementia from seeking help and support that can help them to live a life of quality (Welsh Government, 2018). Scoping and engagement work suggests that the role of AHPs is not yet fully understood by people with dementia and their families, as well as other health social care professionals, such as GPs and nurses.

The role of the **National Consultant AHP Lead for Dementia** maximises the contribution of AHPs in rehabilitation and enablement approaches in dementia care, in partnership with others, at a national level.

The **AHP Dementia Network** for Wales, a forum that provides national clinical leadership for AHPs across Wales, has begun to bring about transformational change in terms of activities to raise the profile of AHP interventions and the impact of working with people with dementia and their families. AHPs can champion the voices of people with dementia, their carers and families, in whatever setting they work, and can work alongside involvement groups, such as Lleisiau dementia, 3 Nations Dementia Working Group and Dementia Engagement and Empowerment Project (DEEP), to ensure that experts by experience are involved in shaping their care and support, and the services delivered in the future.

AHP membership within national forums such as the Welsh Government Dementia Oversight Implementation and Impact Group (DOIIG), together with Dementia Regional

Boards, can also facilitate space to advocate for the need for strengths-based approaches to dementia care.

AHPs can use creative and accessible methods to educate members of the public together with professional colleagues about the importance of rehabilitation approaches and the role of AHPs. Examples shared across Wales include videos and blogs about job roles, social media to share evidence-based advice and awareness campaigns during key events, such as AHP day and World Alzheimer's Month.

With Podiatry You Can postcards are one example of the ways that AHPs can raise awareness of the support available to people with dementia. Developed in partnership by Royal College of Podiatry in Scotland and Alzheimer's Scotland, and modified for use in Wales, and adapted and adopted for use in Wales, the postcards explain the role of podiatrists and key areas in which they can support people with dementia to enhance mobility and retain independence.

Promotion of dementia-supportive environments

AHPs have a key role in promoting dementia-supportive environments by advocating the need for a rights-based, rehabilitation approach in dementia care. AHPs' values promote personhood, participation and positive risk-taking, supporting a biopsychosocial model of care that encourages inclusivity, citizenship and a strengths-based approach (Alzheimer Scotland, 2017).

People living with dementia want to continue to access their local communities and to continue to engage in or join new community organisations that are beneficial for their wellbeing. Therefore it is important that these environments understand the needs and aspirations of people with dementia. Using their skills and creativity, AHPs can be called upon to support the development of **dementia-friendly communities** that recognise and value the contribution of people living with dementia, and to challenge stigma associated with dementia, ageing and disability, so that people can maintain social roles and feel connected to their communities.

The development of the **Dementia-friendly hospital charter** outlines the key principles of dementia-friendly hospital care. The charter promotes care that is enabling and encourages the person's strengths, skills and abilities in the support and interventions provided. It also encourages the use of positive, empowering language in place of prescribed disablement.

AHPs can also advise on the creation of enabling physical environments for people with dementia. AHPs can help to ensure that people with dementia receive healthcare in spaces that meet their sensory needs, enable people to communicate effectively and to live as independently as possible.

Case study - 'Get There Together'

'Get There Together' was a national project developed to support people living with dementia in adjusting to their surroundings due to Coronavirus (COVID-19) restrictions. Many people living with dementia and their carers expressed that they felt fearful and worried about going back into their local community when COVID-19 restrictions eased. This included going to community shops, support groups, together with going to healthcare appointments. People reported that they had lost skills and confidence due to isolating or shielding at home for a prolonged period.

The project, led by Dr Natalie Elliott, National Consultant AHP Lead for Dementia, was developed in partnership with health and social care professionals, including AHPs, people living with dementia, businesses and partners across Wales, and was supported by Digital Communities Wales. Digital stories, consisting of pictures, videos, voiceovers and text, provided advice regarding COVID-19 safety measures, and showed how key environments may look different. The films aimed to reduce anxiety and isolation as people started to go out again into their local community.

All resources are accessible, available in English and Welsh, and in printed formats alongside digital versions. The digital stories can be found on the Dewis Cymru website.

It was felt that the resources were important in helping people to re-integrate into their community and daily life.

Digital inclusion

People living with dementia want to be able to access evidence-based information that helps them to build resilience, develop coping skills to remain as independent as possible and to stay connected with their community. Digital participation is a key part of this and can have significant benefits in terms of health and wellbeing of people living with dementia and their carers.

All AHPs have a role in supporting people with dementia to access technology, where appropriate, that can help them to keep well. Digital technology can be used to assist with everyday life, aiding orientation, facilitating online shopping, serving as a memory prompt for appointments and medications, and to aid cognitive stimulation. Technologies can also facilitate social connection and interaction, through reminiscence, video-conferencing and access to social media, which can provide a platform for peer support and engaging with the community (Talbot and Briggs, 2022).

Despite misconceptions about technology, older people and dementia, we know that people with early-stage dementia may use technology to learn new skills and develop confidence, providing a sense of achievement, which in turn challenges the narrative and stigma around

dementia. Technology can provide a platform for people to engage in research, providing a sense of purpose and citizenship within society. There is an increasing community of people living with and affected by dementia forming online communities, which can help people to cope with their diagnosis, and reduces feelings of social isolation (Shu and Woo, 2021), particularly significant in areas where access to face-to-face post-diagnostic support may be variable. People with dementia should have equal access to technology, including those living in rural areas where additional challenges to receiving support may exist. It is recognised that digital exclusion and the digital divide, resulting from a range of complex factors, can create additional barriers for people living with dementia, their carers and supporters in accessing timely and effective care and support.

Community Partnerships

AHPs are ideally placed to work with people with dementia as part of a whole system, integrated approach to care.

Local meeting centres or **Dementia hubs** for people with dementia and their carers situated within the community can be a rich source information and practical support. Hubs can help to connect people with dementia to their community and services around them, signposting people to the right support at the right time, including when to seek help from AHPs. AHPs may also provide long-arm input to dementia hubs, providing information and resources about social, cognitive, and physical health interventions that can help people to live with dementia.

Links with third sector and community groups are key to encouraging people to keep active physically and socially, and enhance wellbeing. Social prescribing with a focus on what matters to the person can also lead to a variety of positive health and wellbeing outcomes, preventing further needs at a later stage. Community-based arts and health interventions, such as visual art groups, dementia choirs, dance groups and theatre groups, can provide opportunities for people to learn new skills, maintain a sense of purpose and remain socially connected within their community. AHPs will signpost people with dementia to local services that enrich people's lives through activity.

Peer support

It is vital that AHPs connect people with dementia, their carers and supporters to peer support networks. People with dementia tell us that peer support, meeting other people with dementia, who understand how dementia affects their life, is key to living a life of quality after diagnosis. Social interaction in a safe environment, opportunity to share practical coping strategies and emotional support are important to developing a support network, maintaining independence and mental wellbeing (Keyes et al. 2016).

Targeted support

Targeted support describes the role of AHPs in supporting others to care for the person with dementia. AHPs at this level may provide supervision, training, coaching or consultation with others in order to enhance the quality of life of the person with dementia. AHPs understand the inherent relationship between a person with dementia and their environment. Sharing skills and knowledge with key networks around the person with dementia is vital to supporting effective and co-ordinated joint working, improving outcomes for the person and their carers. Learning may take place in a range of settings and formats, from formal person-centred courses and accredited certifications, to more informal shadowing opportunities, critical discussions and team reflections to continually improve the experience of dementia.

Learning, training and development

AHPs work closely and collaboratively with other health and social care professionals, together with colleagues in voluntary and community services, housing and private organisations, to deliver the best outcomes for people with dementia. Working together in partnership with others to share skills and knowledge can support with embedding AHP approaches to rehabilitation and enablement. AHPs recognise that in order to deliver effective, person-centred care, there is an important role in developing the skills of others to meet the needs of people living with dementia.

AHPs may be embedded within Health Board Learning and Development teams to deliver training and learning opportunities that align with the Informed, Skilled and Influencer levels outlined in the Good Work Framework (Care Council for Wales, 2016). With examples across Wales of occupational therapists, physiotherapists, practitioner psychologists, and speech and language therapists as part of multi-disciplinary teams, AHPs can facilitate engaging and enriched learning environments that support others to make a difference in their work with people with dementia, wherever they work. Learning focused around relationship-centred care, positive communication approaches, meaningful activities, supporting carers and families, managing stress and distress, maximising physical health, and increasing independence through positive risk-taking are just some of the areas to which AHPs can apply their values in sharing skills and knowledge in supporting good dementia care.

Case study - Magic Moments from Dementia Care Training in Cwm Taf Morgannwg University Health Board

The training is developed and delivered by an Occupational Therapist and Mental Health nurse. The training consists of three levels of training, covering the 'Informed' and 'Skilled' levels of the Good Work Framework. The Level 3 training (Skilled) is recommended for anyone involved in 'hands-on' adult care, from any profession and any level of qualifications. Face-to-face sessions provide opportunities to develop knowledge and skills based largely on the work of Teepa Snow (an American Occupational Therapist). A variety of teaching methods are utilised, including PowerPoint presentations, film clips, and group discussions, with an emphasis on being as experiential as possible. Monthly virtual Support and Development sessions are also offered, with the aim of building on what people have learnt in the Level 3 five-day training package.

Magic moments - staff putting learning into practice

Community Mental Health Physiotherapist "I have used the Hand under Hand® technique to support a patient to drink. Previously, she would only take a tiny sip of juice, but now she will drink half a glass during our session. Family have also started using the technique and she is drinking with them."

A **Nursing Assistant in a General Ward** laid down under the hospital bed with a gentleman who needed to "mend the car". The gentleman was safely and meaningfully engaged for 1 ½ hours because she stopped seeing everything as 'dangerous' or 'risky' and used a person-centred approach to understand what the person needed.

Staff Nurse Mental Health Ward "There is one gentleman with whom 50% of our interactions had a negative outcome. From this course, I realised it wasn't the patient or their dementia; it was me and my approach. Since the training, our interactions have been 100% positive. The person has been in a positive place. This has made me feel I made a small difference to their day, which has made a positive difference to me also."

The AHP workforce also delivers evidence-based training and guidance regarding specific symptoms of dementia, helping to prevent escalation of needs, unnecessary pharmacological approaches and avoidable hospital admissions. Supporting the development of knowledge and skills focused on key concepts within AHP practice, such as moving and handling, nutrition and hydration, dysphagia, falls prevention, sensory accessibility, and mental capacity and decision-making can enable others to deliver enhanced care and support.

Using robust tools to aid quality assurance, monitoring and evaluation of the training are key to ensuring that learning is embedded within practice, and ultimately, to understanding the impact on the person with dementia. Magic Moments is an example of an approach that can be used by AHPs to reflect on real life experiences and support continuous improvements in dementia care (Improvement Cymru, 2021).

Case study - 'Train the trainer' approach to implementing person-centred, meaningful activities in care homes: A pilot project

Background to the project

The Alzheimer's Society reports that 70% of people in care homes have dementia or undiagnosed cognitive difficulties. It is often reported that many people living in care homes, often those living in later stages of dementia, have difficulty participating in meaningful activities. The pilot project was formulated as part of a set of action plans laid out by Wrexham Council Borough Council (WCBC) Contracts and Commissioning team, which was in response to a review of the Quality of Life and Care of People Living in Care Homes in Wales, A Place to Call Home? (Older People's Commissioner for Wales, 2014).
The Progression Service action was to pilot a project with 2-3 care homes focusing on the development of meaningful and bespoke activities on what matters to individuals and to look at a positive risk-taking culture in order to enable residents to maintain their independence and autonomy. It was envisaged that by working directly with the activity coordinator in each care home, they could then cascade learning to other staff within the care home.

Project Aims:

- To support the use of person-centred activity plans by introducing and giving relevant training to the activity coordinators on the use of the Pool Activity Level (PAL) Instrument Occupational Profiling (Pool, 2012).
- To advise and train on other strategies to support engagement in meaningful activities to include communication techniques, sensory stimulation, equipment and environmental factors.
- To develop in-house training and resources for care staff based on the "Living Well with Activity in Care Homes" toolkit, College of Occupational Therapy COT (2013), so that the activity coordinators had the resources to cascade learning to other staff within the care home.

Collaboration with Health and Social Care

During the planning stage of the pilot, meetings were held with the Lead Occupational Therapist at the local Older Person's Mental Health Unit, as it had been established that the PAL was used routinely with people admitted to the older people's wards. The PAL paperwork had been redesigned by the Occupational Therapy staff at the unit, to make it more user-friendly. It was agreed to use their PAL paperwork, with a potential of creating a unified "engagement passport"; a document that can be transferred across health and social care settings, e.g. between hospital, community and care home, to provide an immediate understanding of the person, their background and occupational needs.

The Care Homes and Residents Involved

In total three care homes were involved, with three residents from each care home. The care homes were chosen due to activity coordinators who came forward with an interest to be involved. Residents identified to be involved with the project were chosen after discussion with Activity Coordinators, Occupational Therapy, the Person-Centred Planner (PCP) coordinator, as well as the care home manager. They considered who may benefit most, particularly those who had previously experienced difficulties engaging in activities. Most of the residents on the pilot project had some degree of memory difficulties.

The Occupational Therapist Role

After gaining consent, the Occupational Therapist made regular visits to the care home (at least once a fortnight) to introduce the PAL concept, with the proposed outcome of creating a personalised activity plan based on the person's confirmed level of engagement. During visits, the Occupational Therapist observed and worked with residents and the activity coordinators during the activities they engaged in, essential for assessing the residents' ability levels and noting their interaction with their environment. This meant that the appropriate guidance and training could be given to the activity coordinator to complete the PAL. This also provided time to evaluate opportunities and barriers to engagement in meaningful activities and assess similarities and differences between the three care homes, as well as helping to identify the potential areas needed for staff training.

Project impact and outcomes

- Overall, the pilot project demonstrated that the PAL could be used as a valuable tool to identify appropriate person-centred activities that had meaning for residents as well as being used as an outcome measure.
- There was a common theme that more support is required from all care home staff to ensure a more enabling approach is used for meaningful activity provision. Supporting engagement in meaningful activity is everybody's (all care home staff) business not just the activity coordinators' and this is an approach that needs to be embedded as part of residents' daily routines. To address this, in-house training is planned to be implemented by the Occupational Therapy and PCP coordinator, initially in the care homes involved in the pilot project. This training will also provide information on other important aspects, such as communication techniques and environmental changes, which also contribute to support meaningful activity provision.
- The pilot project provided a unique opportunity to work with the health sector and it is hoped that this collaboration can be developed further to support people, especially those with dementia, to maintain their skill levels during hospital admissions.
- Involvement in the pilot project also highlighted positive initiatives that are being implemented around the local area to support people with dementia. It could be that these initiatives are linked more effectively to create a more unified approach.
- Ultimately, there is work that can be done which will benefit the well-being of vulnerable people living in care homes so that they feel that they do live in a place that they can call home.

Coaching and supervision

Supporting a workforce that is engaged is key to ensuring a whole system approach to enabling people with dementia. A key component of creating effective learning environments is to prioritise staff wellbeing (Kings Fund, 2015). When staff are treated with compassion and respect, with space to deliver creative and innovative care through collective leadership, and able to feel psychologically safe when things go wrong, people with dementia also receive care that is more compassionate and effective.

AHPs can empower colleagues to reflect on their own skills and expertise in supporting people with dementia, drawing together resources and experiences to continually improve practice. Co-producing solutions to clinical challenges can enable health and social care

professionals to take ownership of their workplace and recognise the contribution that they make to enhancing the quality of life of the person with dementia.

Case Study - Ask Us About Dementia, a pilot study

Technology Enabled Care (TEC) Cymru (2022)

'Ask Us About Dementia' pilot is a national support service for dementia, virtually connecting families and the paid workforce to advice from dementia practitioners. The pilot service was set up as a collaboration between Social Care Wales, the National Consultant AHP Lead for Dementia, and Tec Cymru. The service was available to both family carers and health and social care staff to book online video consultations with dementia practitioners from various specialities, such as dietetics, nursing and speech and language therapy. The pilot service began as a response to the pandemic and operated from September 2020 until the end of April 2022.

The aims of the service were:

- To provide timely access to advice and signposting on dementia care using telehealth
- To increase awareness of the Allied Health Professions and improve access to their expertise
- Support peer learning between health and social care practitioners
- Prevent escalation of needs and crisis where possible

The service was developed through co-production, engaging with key stakeholders including practitioners, pilot sites and people with lived experience of dementia.

Clinicians utilised a coaching model to support callers to collaboratively work through possible solutions and take ownership to commit solutions to action. Themes from calls taken included diet and nutrition, communication, mobility and exercise, advice around COVID-19, and general information about dementia.

Two independent evaluations of the pilot service were undertaken, one for the period September 2020 – April 2021, and the second for the timeframe between May 2021 and April 2022. The evaluation was undertaken by TEC Cymru, including a survey and telephone interviews.

Family and paid carers involved in the evaluation of the service had an extremely positive experience accessing it. Carers had explained that the service had enabled them to access support that would not have otherwise been easily available, and generally found the technology easy to use in terms of booking appointments and accessing the session with the practitioners.

Feedback from practitioners taking part in the project was very positive, with 100% of dementia practitioners from the survey reporting that they felt the pilot service achieved its aim of providing timely access to expert advice and signposting on dementia care through the use of video consulting, as well as supporting peer learning between health and social care practitioners. 100% of practitioners also reported that they had positive experiences of using 'Attend Anywhere' as the delivery platform for the pilot service sessions. Over 80% of practitioners felt that the pilot service had increased awareness of AHPs and enhanced access to their skills and expertise through video consultations.

Following the success of the pilot project, options for further roll out of the service will now be explored.

Consultation

The AHP workforce may be called upon to provide expert advice and consultation into local and national networks, influencing practice and policy across health, social care, third sector, and academic forums, alongside people with dementia and their carers. Opportunities for collective learning in collaboration with others, co-creating knowledge with a wide range of stakeholders can influence change in practice at a whole system level and enhance the experience of people with dementia receiving care and support (Care Council for Wales, 2016).

Reflection on case studies and stories, understanding research evidence and considering 'what matters' to individuals means that AHPs can work as part of wider, interdisciplinary, multi-organisational teams to change ways of working and build evidence of approaches.

'The Sea of Uncertainty' depicting the experience of receiving a diagnosis of dementia, by Frances Isaacs

Specialist support

The specialist level of care and support refers to AHP-led interventions that are tailored to an individual to provide person-centred rehabilitation. This care, support and rehabilitation may be delivered by generalist or dementia-specialist clinicians in enhanced services, depending on what the person and their family needs.

Within this section, examples of support provided by each of the AHPs in relation to dementia are explored. Case studies are used to illustrate the impact of these interventions, together with research evidence from the literature review (Appendix 3 - available on request. Please email: HSS.RehabAndAHPs@gov.wales).

Across the various professional groups, the research evidence together with the experiences of people with dementia, suggests that early intervention, focused on what matters to the person, delivered in people's homes and familiar environments, in collaboration with carers and family members, is most effective (Abraha, Rimland & Trotta et al., 2017; Pentland, 2015).

Arts Therapies

Arts Therapies is a collective term that describes music therapy, art therapy, dramatherapy and dance movement psychotherapy. In subsequent sections, the evidence base and

Case Report – Expanding Arts Therapies provision

(Elliott and Older Adults Arts Therapies Service (OAATS) team, 2021)

A six-month pilot project took place in an NHS Health Board in South Wales to expand access to arts therapies, in response to need for increased direct therapy for people with severe cognitive impairment and significant communication difficulties, secondary to dementia and/or complex mental health difficulties. Effectiveness of the service was measured using observer feedback forms together with feedback from colleagues. Demand for the service was also measured by recording the number of referrals received.

The team consisted of two art psychotherapists and four music therapists, providing support to people in both community and older people's mental health inpatient settings. The people living with dementia taking part were unable to complete feedback forms, and so family members observing sessions, in addition to staff members, completed evaluation forms based on their observations. Analysis of observer feedback forms taken from a snapshot of six weeks of clinical interventions showed positive improvements in communication, mood, confidence, ability to express emotions and engagement.

All therapists involved in the project reported that members of staff across mental health teams acknowledged the importance of the role of arts therapies in meeting the needs of people with dementia. The project demonstrates the value of arts therapies in enhancing wellbeing and supporting people to cope with the challenges associated with dementia and complex mental health difficulties. The team have now secured partial permanent funding for arts therapies in Older Adults services, pending further approval from Welsh Government.

outcomes relating to art therapy, music therapy and dramatherapy are outlined as recognised, registered AHP disciplines within Wales.

Art Therapy

Art therapy, or art psychotherapy, utilises visual art alongside verbal communication, to support people to work with and make sense of their own thoughts and feelings and those of others. Art psychotherapy is a form of psychological therapy and can be particularly helpful for people with dementia who may have difficulty communicating, as art therapy can provide an alternative medium for self-expression when words are not enough. Therapy may be delivered to individuals or in group settings, depending on individual need and preferences. There is promising evidence to suggest that art therapy can be beneficial for people living with dementia in promoting cognitive and emotional health (Fancourt & Finn, 2019), and reducing feelings of apathy and depression (Fancourt & Finn, 2019; Parkinson,

Case study – Therapeutic Art as part of Specialist AHP Dementia Pathway

An eight week Therapeutic Art Group formed part of a specialist pathway, developed by the Allied Health Professions (AHP) Dementia Team at Betsi Cadwaladr University Health Board, working in partnership with Wrexham Borough Council.

The group was facilitated by one qualified and one trainee Art Therapist/ community art practitioner. Sessions took place at the art studio within the Ty Pawb Community & Arts Hub, Wrexham, as an accessible, de-stigmatising local venue. Referrals to the group were co-ordinated by the group facilitators in partnership with the Occupational Therapy team at Heddfan Older People's Mental Health Unit, Wrexham Maelor Hospital.

The group aims were to ameliorate the social, functional, cognitive and psychological functioning of participants. Skilled facilitation and a carefully devised range of creative techniques were found to be significant to the overall positive outcomes. Activities focussed on engaging participants in positive experiences and the introduction of relevant themes through games, poetry, music, objects or images to stimulate imagination, positive memories and conversation. A range of qualitative, quantitative and anecdotal data was gathered to provide comprehensive outcomes information, which included reduced feelings of isolation, improved social skills, enhanced cognitive functioning, safe expression of thoughts and feelings, improved emotional regulation, confidence and motivation.

"It all seems to be coming back to me, I used to do art." (Participant)

"She was always extremely happy coming out of each class. She didn't remember them from week to week but when we helped her to remember she did have some memory. I'm convinced that it helped her mood and for me as a carer that's a big plus." (Carer).

The project demonstrated the need for sustained and long-term therapeutic engagement for people living with dementia and their carers. Community based therapeutic art groups could be well utilised as part of a pathway for people living with the early stages of dementia and would help maintain active engagement in the community.

Windle & Taylor, 2017). Some studies have found that art therapy can enhance communication, reduce symptoms of anxiety, and increase meaningful activity and connection with others (Hsai et al. 2020, Tucknott-Cohen and Ehresman, 2016). Provision of arts-based interventions are also support the need for offering 'psychosocial and environmental interventions to reduce distress in people with dementia' (NICE 2018).

Music Therapy

Music therapy is a psychological therapy that uses music as the primary means of communication for a person and facilitates processing of emotions. Music therapy may involve the person with dementia listening and responding to or making music and sounds, singing or engaging in song-writing to achieve a therapeutic goal. Engaging with music in a therapeutic setting in this way can support people with dementia to manage and process emotions such as frustration and anger which may otherwise manifest as stress and distress (D'Aniello et al., 2021).

Case study – Music therapy and dementia

The case study below demonstrates the impact of music therapy in empowering people living with dementia. *Names and personally identifiable information have been anonymised to protect confidentiality.*

Susan was 52 years old when I worked with her, and had a diagnosis of early onset dementia.

She was still in employment but having problems in several areas of her life including managing her duties at work, spiralling debt, housing and relationships. The initial goals for music therapy were improved anxiety management, improved mood, and improved self-esteem.

Susan was very uncomfortable talking about her feelings in general and was struggling to even think about her dementia diagnosis: problems were piling up unaddressed in all areas of her life.

Susan was able to use music making, and music and mindfulness techniques, as a bridge to talking about her feelings and relationship patterns, exploring how avoidance had protected her in past situations, but how she needed to find another way to face her fears about her diagnosis and approach challenges using support. She used the space to negotiate the transition from the working world and explore what living with dementia meant for her personally.

Susan gradually became open about how much she was struggling, and a team, including a social worker, was put in place. After building a supportive relationship in therapy, she was then more confident to build relationships with other professionals enabling her to articulate what was now important and meaningful to her, make the decision to resign from her job, sort out her housing and debt problems, settle on medication, and commit to attending appointments.

Robust evidence supports the use of music therapy in dementia. Benefits of music therapy include improved communication, emotional wellbeing and self-esteem. Music therapy has also been found to reduce depressive symptoms, anxiety, and stress and distress and agitation, reducing the need for anti-psychotic medication (van der Steen et al (2018). Recent research has also confirmed the effect of music therapy on reducing symptoms of pain in people living with dementia (Achterberg, 2020) and may also have benefits in terms of improving cognition, although further research is needed to confirm this (Bian et al., 2021).

Dramatherapy

Performance arts form the basis of dramatherapy, to support people to work through emotional difficulties such as depression, anxiety, bereavement and feelings connected to their dementia. Therapeutic tools such as storytelling, puppetry, improvisation, movement and embodiment are used by drama therapists, which enable the person to cope with and manage their individual life experiences that may have been challenging or upsetting. Similar to the other arts therapies, dramatherapy may provide an alternative form of communication, empowering people with dementia to express their thoughts and feelings in a way that may not be possible in their everyday life. It can be suitable for people at all stages of dementia. More research is needed to examine the effectiveness of dramatherapy using outcome measures. However, preliminary evidence suggests that dramatherapy can improve meaningful social interaction, reduce symptoms of depression and enhance quality of life overall (Lin et al., 2022).

Dietetics

Dietitians will undertake comprehensive nutritional assessments, to enable person-centred recommendations to optimise nutrition and hydration. Eating and drinking well is vital for people living with dementia, not only to maintain their physical health including maximising their cognition, but also for their general wellbeing and to help retain their independence. Eating and drinking is often the last activity of daily life that people living with dementia lose and this can have a significant impact on the person living with dementia as well as those who are caring for them (Prince, Guerchet, Albanese, & Prina, 2014).

People living with dementia are at increased risk of malnutrition and dehydration due to many of the symptoms linked to dementia, for example: taste and sensory changes, difficulty in recognising food, difficulty in cooking, forgetting to eat and drink, changes in co-ordination and swallowing difficulties. However, they can also experience weight loss or a reduced appetite due to other health co-morbidities or other factors linked with ageing. All of these factors can lead to someone being at an increased risk of unplanned weight loss, delirium, repeated infections, deterioration in dementia, falls and prolonged admissions to hospital (Martin, Barrera Ortega, Dominguez Rodriguez, Couceiro Muino, de Mateo, and del Rio (2012).

Dietitians can also provide support to help people maintain a healthy weight through a balanced diet. Changes in mood, preferences for sweeter foods, barriers to physical activity

and the ability to plan healthy meals mean that a person could experience excessive weight gain. Dietitians can advise on healthy alternatives to avoid health-related problems associated with weight gain.

Changes in eating and drinking have been identified as a significant concern for carers and families of people living with dementia (Abdelhamid, Bunn, Copley, Cowap, Dickinson, Gray, and Hooper (2016). Dietitians play a fundamental role in supporting families to manage the nutritional changes experienced with dementia (Jansen et al. 2015), but they also support other healthcare professionals to optimise nutritional care across all settings. This could be via training, information leaflets or via individual interventions and support.

‘Herewith Hedgerow Flowers’ depicting the hope of a new season
by Frances Isaacs

Case study – Dietetics and dementia

Background

Mrs P was referred to the dietetics service for support by the Admiral Nurse who was supporting her daughter, who was her main carer. Mrs P's daughter had become increasingly concerned about Mrs P's poor appetite. It was reported that Mrs P had lost 8kgs between December 2021 and February 2022 which the geriatrician had linked to her advancing dementia.

However, in the weeks leading up to the referral to dietetics Mrs P's daughter reported that her mum was now eating very little. She had previously managed 3 small meals per day but was now having no intake on some days and on other days was managing only mouthfuls of preferred sweet foods. This significant reduction in intake coincided with Mrs P experiencing loose bowel motions, leading to incontinence and so it appeared that she was restricting her intake to prevent incontinence. Mrs P was subsequently diagnosed with a bowel infection which was treated with antibiotics. The antibiotics caused oral thrush which was being treated with nystatin but initially this further impacted Mrs P's intake as her mouth was very sore.

Mrs P had previously been able to come downstairs regularly to watch television with her daughter as well as being able to mobilise independently to the bathroom situated down the corridor. Since her bowel infection and reduction in intake, she was now mainly bedbound, using a commode and spending more time sleeping during the day. Her daughter was feeling very anxious and worried about the deterioration in her mum's health.

Advice

- Provide and encourage small amounts of any preferred softer foods e.g. custards, rice puddings, yoghurts, mousses. This would prevent discomfort from oral thrush but may also encourage Mrs P to increase her intake slightly if they were foods she enjoyed rather than trying to ensure a balanced dietary intake.
- All foods/ meals should be fortified (additional calories and protein added) where possible.
- Offer home-made nourishing drinks to help with fluid intake as well as increasing nutritional intake, e.g. hot chocolate
- Oral nutritional supplement changed from a milk based one to a juice based one to try and improve compliance and prevent further weight loss while intake from diet is so poor.

Impact

2 months post initial referral Mrs P had regained 2kgs, was eating 3 small meals per day as well as snacks and fortified hot chocolates between her meals. Mrs P and her daughter reported an improvement in her mood, she was now reading the newspaper and doing puzzles again independently. She was also now able to mobilise independently to the bathroom and went downstairs on most days to spend time with her family. She was also eagerly making plans for her upcoming birthday celebrations.

Mrs P's poor intake was not actually linked to her advancing dementia. It was instead related to her physical health concerns, which once resolved with the help of nutrition support, had allowed her to return to her baseline level of functioning and wellbeing.

Occupational Therapy

Occupational therapy focuses on enabling people to take part in activities that are meaningful and important to the person (their occupations). Occupational therapists are dual-trained in both physical and mental health care, and can support people to adapt to a range of needs that may impact on everyday life. Continuing to participate in meaningful occupations of daily life such as getting washed, dressed, preparing food, maintaining hobbies and interests, and going to work are important for our mental health and wellbeing (based on what's important and meaningful to each individual). Retaining our roles within our home and community life are fundamental to upholding our identity. As many people developing dementia notice changes in their ability to carry out everyday tasks, Occupational Therapists have the unique skillset to be able to assess cognition as part of daily living 'function', and can therefore contribute towards assessment with differential diagnosis of dementia, also helping the team around the individual to understand the impact of memory changes on the person's participation.

Occupational Therapists can support people by breaking down occupations into simpler steps and/or find different ways of doing them to make it easier. They can advise on improvements or equipment for the home to make things easier and support the person to consider other adaptations such as technology, signage and memory prompts to make things easier, supporting people to practice tasks in a way that increases skills and confidence.

Personalised, tailored rehabilitation delivered by occupational therapists can support people with dementia to continue to take part in their daily life, preserving self-worth, maintaining skills and enhancing quality of life for the person with dementia and their carer. Originally developed in Ireland, Home-Based Memory Rehabilitation (HBMR) is a structured, evidence-informed programme (McGrath, 2013) that is currently offered by Occupational Therapists in some Health Boards across Wales. HBMR helps people who experience memory difficulties to develop strategies to cope with and compensate for memory problems in everyday tasks. The programme uses repetition and structure to enable people to integrate memory habits at an early stage that will be more likely to be remembered and effective as the person's memory loss continues.

Occupational therapists can also provide support in creating enabling environments (these can be in homes, work settings, leisure settings or care settings). For example, specialist assessment of the home setting can be beneficial in understanding how the environment meets the person's needs and supports wellbeing, independence and physical and mental health. Personalised equipment or adaptations may be recommended as part of a positive risk-taking approach, ranging from ramps, rails, and perching stools, to assistive technology to facilitate memory prompts, social engagement or enhance safety (Bennett et al., 2019). Joint working with physiotherapists, together with environmental modifications and telecare can also enable people living with dementia to keep safe at home and reduce the risk of falls. Recommendations regarding maximising vision, managing home hazards, and attending to sensory needs of the person with dementia can be advised by occupational therapists. Early adaptation of the home environment can be beneficial for embedding techniques and maximising function for as long as possible.

Case study – Co-producing Occupational Therapy support in Memory Assessment Service, Cwm Taf Morgannwg University Health Board

Following funding from Welsh Government, in line with the Dementia Action Plan and All Wales Dementia Care Pathway of Standards, the first Occupational Therapy service in Wales dedicated to Memory Assessment Service (MAS) has been developed through true co-production with people living with dementia. From concept, through to design and delivery of interventions, the Occupational Therapy service aims to 1) improve early diagnosis and timely interventions for people experiencing cognitive changes, 2) better inform the diagnostic process and identify occupational performance issues earlier in a person's journey, and 3) increase independence of individuals, remaining at home and accessing local community.

The team provides an assessment of individuals' occupational performance to inform diagnosis (pre-diagnostic) and deliver early Occupational Therapy intervention (pre- and post-diagnostic). They work co-productively with people living with dementia to developing intervention programmes that embed focused strategies into individual routines, including (but not exclusively) exploring the use of digital technologies.

Evaluation of service provision conducted using the Australian Occupational Therapy Outcome Measure (AusTOMs) has evidenced significant positive changes in everyday occupational performance for people living with dementia. Evaluation (at 3, 6, 12 months) indicates that despite the progressive nature of dementia, maintenance of skills in line with the person's own therapy goals has been achieved and sustained.

Feedback from people living with dementia and other Memory Assessment Team members:

"I was struggling … but after having Occupational Therapy I feel like I have turned a corner… thank you very much for all that you have done. I was misplacing items around the home & had no independence using the cooker… I felt the strategies improved my overall quality of life, & I saw the Occupational Therapist at the right time for me, Occupational Therapy went above and beyond what was expected" (Person living with dementia)

"Having occupational therapy as part of MAS has added value to our service and establishing what skills and difficulties are happening by seeing the patient at home gives an additional clinical perspective." (Clinician)

Following the success of the service, the CTMUHB MAS Occupational Therapy team is now evaluating their input and plan to share knowledge/evidence in working partnerships across Wales and beyond, creating an Occupational Therapy MAS provision blueprint and master classes to ensure a lasting impact.

Orthoptists

Orthoptists provide eye care for people with difficulties with the movement or co-ordination of the eyes. This can include double vision, misalignment of the eyes, blurred vision, or problems with the eyes that cannot be corrected by glasses. Difficulties with eye movement

can be caused by problems with the nerves that communicate between the brain and the eyes, or due to changes to the muscles around the eyes.

An orthoptist may carry out assessment of visual acuity (clarity of vision) with a person with dementia when they suspect changes in their vision. They can adapt the assessment tools, using their skills to support the person to participate in the assessment as much as possible. This helps to gain a clear picture of any visual difficulties so that the right support can be offered to help the person, enabling them to adapt to changes in their vision and maintain their independence.

Orthotics

Orthotists design and provide specialist devices (orthoses) which support the body. Orthoses can have different objectives, like improving functionality such as walking, reducing pain, providing protection, for example wearing specialist diabetic footwear and insoles, or reducing deformity, such as preventing progression of musculo-skeletal disorders. Orthotists therefore work in a range of healthcare settings, including treatment of acute injuries, managing chronic diseases, or specialist clinics such as paediatric, musculo-skeletal, or stroke and neurological disorders.

Orthotic services are often incorporated into diabetic services, where there is a higher prevalence of dementia (Tasci, Safer, Naharci, Gezer, Demir, Bozoglu and Doruk, 2018). Other specialist clinics Orthotists are involved in are also likely to have a higher prevalence of people with learning difficulties or brain damage who may show different signs of dementia which can be more difficult to spot. As Orthotists review these individuals regularly, they are well-placed to spot early signs of dementia, signpost to other services that can support people experiencing changes in their memory and refer for cognitive assessment.

Orthotists use a person-centred approach to increase the likelihood that when a person with dementia requires their support, they provide an orthosis that successfully meets their unique needs and requirements. Understanding the person, their routines, support systems, and preferences, together with supportive communication, adapted assessment of pain, and joint appointments with carers, can help a person with dementia to adapt to using new devices.

Prosthetics

Prosthetists assess for, design, create and fit artificial limbs for those with congenital loss of a limb as well as loss due to diabetes, reduced vascularity, infection and trauma.

Prosthetists empower people to regain their independence, move freely and enhance participation in everyday life.

Research suggests that people with lower limb amputation are more susceptible to developing dementia (Coffey, O'Keeffe, Gallagher, Desmond, and Lombard-Vance, 2012). Many people who access Prosthetic services have co-existing long-term conditions such as diabetes or vascular disease, which increase the risk of dementia (Tasci, Safer, Naharci,

Gezer, Demir, Bozoglu and Doruk, 2018). As prosthetists frequently support a key cohort of patients, returning for review appointments on a regular basis over decades, they are well-placed to identify changes in cognition, seek onward referral for cognitive assessment and signpost to other services that can support people experiencing changes in their memory.

Prosthetists use a person-centred approach to increase success of rehabilitation when a person with dementia requires their support. Knowing the person, their routines, support networks, interests and preferences, together with supportive communication, adapted assessment of pain, and repeated practice of exercises can help a person with dementia to adapt to using limbs. Collaborative sessions with carers/ supporters can also be helpful in embedding new exercises, techniques or strategies into everyday life.

Case study – Person-centred care in Prosthetics

Mr H was an established prosthetic user, who had been known in the service for decades. He started having problems with his prosthesis, with his GP referring for prosthetic issues. At his first appointment, no issues were identified as Mr H knew the service and his care well, and was orientated to his surroundings. However, when the GP referred again shortly after with more severe skin issues, clinicians within the service realised it may not be a simple prosthetic solution as the person was an expert user who should have been able to problem-solve himself and avoid these issues occurring. Clinicians working with Mr H started asking questions outside of his routine care, which identified some concerns about his memory. Permission was gained from Mr H to perform a cognitive screen which showed significant issues in memory, orientation and cognition. The prosthetic service contacted Mr H's GP and were able to use this information to get him access to the help he needed, within 48 hours. He now has access to the support he needs and has had no further prosthetic issues, keeping him healthy and allowing him to lead a better quality life.

Paramedicine

Paramedics play a crucial role in providing emergency care for people living in the community.

Paramedics are frequently called out to support people with dementia in an emergency due to the complex nature of dementia, and often due to co-existing health conditions that may require treatment. Therefore, regardless of their role, most ambulance clinicians will encounter people with dementia and their families, as well as people who may show changes in their cognition, but do not yet have a diagnosis. People with dementia are more likely to be admitted to hospital as an emergency than those without dementia (Buswell, Lumbard, Prothero, Lee, Martin, Fleming and Goodman, 2014). Consequently, the role of paramedics in providing person-centred, holistic assessment, that takes in account both physical and mental health, is vital.

Case study - Becoming Dementia Friendly: Welsh Ambulance Services

The Welsh Ambulance Services are working towards improving the experience for people living with dementia who use services, as well as considering the impact dementia will have on the workforce. The vision of the Welsh Ambulance Service is to be an organisation that responds to both the clinical and emotional needs of people living with dementia, their carers and families. The service aims to be more dementia aware, with a skilled workforce who deliver high quality services with improved experiences and outcomes.

It is essential that Welsh Ambulance Services support people affected by dementia by delivering person-centred care, at what can often be a frightening and distressing time, particularly in an emergency. Staff believe that developing meaningful relationships with people living with dementia is key, as well as using information that may be available to them through carers, families and resources such as Alzheimer's Society's 'This is me' document. The more we know about the person with dementia the more we can tailor our approaches, whether it involves using different communication techniques, changing pace, or providing reminiscence therapy for meaningful activity or distraction.

"If I am transporting a patient, I like to know what they like to talk about and what's important to them. It is this kind of information that makes supporting a patient easier." Emergency Medical Technician.

Within the Welsh Ambulance Services Mental Health and Dementia Plan, there is a commitment to create more optimal environments people with dementia, sensory loss and other cognitive impairments. The service receives feedback where their environments that include vehicles, processes, and staff interactions have an impact on the experiences of people receiving support and care. People have told the service that lighting, noises, lack of communication and reassurance, especially in an emergency, can cause much anxiety. Welsh Ambulance Services are exploring improvements to their environments, the skills and knowledge of the workforce and opportunities for digital technologies to support effective, person-centred care approaches.

Physiotherapy

Physiotherapists are specialists in promoting and enhancing mobility. They work with the person with dementia and their carers to encourage physical activity, to enable the person to maintain their independence and participate in their everyday life for as long as possible.

Exercise programmes tailored to an individual's needs can improve balance, co-ordination, strength or cardiovascular health. Physiotherapy may also take place in group classes, providing opportunities to socialise and have fun in a supportive environment, whilst increasing physical activity through seated exercises, balance-led exercises or stretching and strengthening exercises (Burton et al. 2015).

Physiotherapists have a crucial role in preventing and reducing falls in people with dementia. People with dementia are at increased risk of falls (Hall et al., 2017), which can have a significant impact on quality of life, reducing mobility, with potential for admission to

and prolonged stay in hospital. In collaboration with the person, their carer and family, physiotherapists advise on personalised strength and balance programmes, postural management and make recommendations to reduce the risk of potential fractures resulting from falls.

Difficulties with communicating mean that people with dementia may also find it challenging to express when they are in pain. Physiotherapists are skilled in assessing and treating pain, and can provide personalised advice to enhance posture and seating to reduce pain and increase comfort, which is particularly important in later stages of dementia (Peisah et al. 2015). This can reduce symptoms of stress and distress as a non-pharmacological approach.

Case study - Access to physiotherapy

Below is a case study example that evidences the value of physiotherapy in supporting people living with dementia and co-existing mental health difficulties. *Names and personally identifiable information have been anonymised to protect confidentiality.*

Mrs P, 65

Mrs P was admitted to the mental health ward as she was severely depressed and confused. She had additional diagnoses of osteoporosis and chronic obstructive pulmonary disease (COPD), and was dependent on oxygen for 18 hours daily. Mrs P was treated on the ward with medication and on discharge was referred to the Community Mental Health Team (CMHT) and allocated to the Clinical Specialist Physiotherapist for assessment and care coordination. Holistic assessment identified that Mrs P's depression was secondary to her dementia and additional physical health difficulties. She had severe anxiety and panic attacks, resulting in a fear of dying and not being able to breathe. She also experienced lower back pain because of her osteoporosis, which was exacerbated by her poor posture. Mrs P was constantly in forward flexed position trying to 'get her breath'. She was underweight with a body mass index (BMI) of 14 but no physical health monitoring. There was no support in place for her carer at home, and Mrs P rarely left the house due to her anxiety.

Physiotherapy intervention focused on: a) anxiety management using cognitive-behavioural therapy (CBT) principles progressing onto graded exposure work; b) supporting Mrs P to differentiate between anxiety and breathlessness due to COPD; c) pain management and back care education; d) referral to dietitian and GP for physical health management; e) referral to community matron for ongoing COPD management at home; f) referral for carer support and carer assessment; and g) integration into community groups (once she had developed coping strategies to manage her anxiety), which gave her peer support from other people with dementia and social interaction.

CBT intervention and wider support resulted in Mrs P being able to reduce and eventually come off benzodiazepine for her anxiety. Mrs P was able to enhance her quality of life and wellbeing, due to increased ability to self-manage her healthcare needs as a result of holistic, person-centred support from the multidisciplinary team, including physiotherapy.

Podiatry

Podiatrists are experts in foot health and can provide personalised advice to ensure that people with dementia can keep active and maintain healthy feet.

A high proportion of people with dementia experience problems with their feet, which can lead to increased risk of falls, reduced mobility and reduced confidence to take part in everyday activities (López-López, Grela-Fariña, Losa-Iglesias, Calvo-Lobo, Rodríguez-Sanz, Palomo-López, and Becerro-de-Bengoa-Vallejo, 2018).

Podiatrists provide tailored recommendations regarding foot care routines to improve comfort and alleviate symptoms of pain. This can include specialist advice in relation to supportive, well-fitting footwear, maintaining skin and toenails, and preventing ulcerations, infections and soreness. Comprehensive assessment provided by a podiatrist can also monitor for signs of other conditions such as circulatory problems or diabetes that can impact on the physical health of a person living with dementia.

Practitioner Psychology

Practitioner psychologists are central to ensuring that the human rights of a person with dementia are upheld and respected (British Psychological Society, 2016). Psychological therapies can enable people with dementia to understand and the emotional impact of the diagnosis and to consider how to maintain some control of their life and future, following a diagnosis of dementia.

Practitioner psychologists can contribute to pre-assessment counselling, which helps people accessing memory assessment to prepare for the possible outcome of assessment. This is important in supporting people to adjust from an early stage, taking a strengths-based approach, to explore their expectations and fears in relation to possibly receiving a diagnosis. Practitioner psychologists use neuropsychological assessment to contribute to the assessment and diagnosis of dementia. This builds a cognitive profile of the person, highlighting strengths and weaknesses in order to support differential diagnosis. This can help the MDT to distinguish between different dementia sub-types or a possible dementia from cognitive difficulties caused by other conditions, such as depression or anxiety.

Practitioner psychologists offer a range of person-centred and family-centred approaches to support people with dementia to live a life of quality after diagnosis. Talking therapies such as Cognitive Behavioural Therapy (CBT), Narrative Therapy, Acceptance and Commitment Therapy (ACT), and Compassion Focused Therapy include some of the approaches that may be offered to help people with early-stage dementia to cope with the psychological impact of diagnosis. This may often consider issues including roles, identity, relationships and loss. Recent evidence from a large-scale systematic review suggests that CBT-based psychological treatments are likely to reduce depression, enhance quality of life and improve the ability to participate in everyday activities for people living with dementia (Orgeta et al., 2022). Psychological therapies may also be offered in groups, where participants can benefit from sharing experiences and connecting together (Cheston and Howells, 2016).

Carers and family members may also benefit from talking therapies to support them in their caring role. Family therapy, another form of talking therapy, can also provide a safe environment for a person with dementia and family members to talk together about their feelings with each other and how to support each other when things are difficult.

Practitioner Psychologists are also able to work with families and staff groups to support the use of nonpharmacological approaches to stress and distress. Using psychological models to assess the distress that someone may present with and the environment in which it occurs, Practitioner Psychologists apply psychological theory to support teams and families in making sense of the possible unmet needs for the person, as well as potential triggers for stress.

Practitioner Psychologists have a role in supporting teams to work in psychologically informed ways. This might include supporting the development of psychosocial interventions in services, such as Life Story work, Cognitive Stimulation Therapy or support groups. Practitioner Psychologists frequently offer supervision, consultation and training in teams, in order to support the delivery of psychologically informed dementia care. Psychosocial interventions and formulation-led approaches are recommended as first line treatment for symptoms of stress and distress, and there have been a number of promising studies to suggest that functional analysis-based interventions may be most effective in reducing and distress in people living with dementia (Dyer et al., 2018).

'Soon the poppies will appear', by Frances Isaacs

Case study - Access to Psychological Therapy

Abigail initially accepted the suggestion of a referral for psychological therapy soon after Stephen's diagnosis with a young onset dementia. She identified that she sometimes found it hard to know how best to support Stephen. She noticed that there were times when she felt quite anxious. Her experience of her father's dementia connected with worries for her about the future. Gwenllian (Trainee Clinical Psychologist) suggested the START programme for care givers of people living with dementia, which Abigail was interested in. Strategies for Relatives of People Living with Dementia (START) is a manualised Cognitive Behavioural Therapy (CBT) intervention to help relatives develop coping resources. Abigail found this approach helpful in identifying the ways in which her thoughts and feelings shaped her responses to dementia. In particular, the opportunity to consider how to move from worrying about the future to living more in the present was helpful to Abigail in managing her stress and anxiety. Gwenllian and Abigail worked together to develop skills in Mindfulness, which Abigail continues to use several years later. At this point Abigail and Gwenllian felt that the outcomes they had discussed had been met: Abigail felt better equipped to care for herself and Stephen, and had an improvement in her experience of stress and anxiety.

Abigail requested follow-up from Psychology a year or so later to help her manage feelings of loss and grief. Abigail had noticed that she had never been able to grieve for her father, who had died around the time that Stephen developed his difficulties. She also recognised the grief and loss she felt for Stephen, their marriage and her imagined future. She feared this was impacting on her ability to care for Stephen. Using Narrative Therapy, Emily (Clinical Psychologist) has attempted to help Abigail connect with her values and her preferences for her life. For Abigail it has provided a way of being able to reflect on her relationship with Stephen and to strengthen ways of being together that are consistent with their values as a couple. It has provided a way to reflect on identity and aspects of caring that may sometimes collide with this and to think through what matters most. Abigail has been able to reflect on what has been lost but also what has been learned in her journey. When there have been significant challenges or changes that have affected the balance that Abigail and Stephen have found we have met every 2-3 weeks. Mostly this has not been needed and Abigail has simply valued a check in every couple of months. This is how she describes her experience of therapy:

'These conversations are so helpful and help me to clarify. They cleanse the mind. Life is so full on, so much time preparing /doing, no time to step back and look. I can carry on in a calmer, more knowing way. It helps to have this safe, quiet, isolated space to think through; I can become a bit more objective. If I tried to do this on my own, I would go round in circles but because you ask relevant questions it gives me a chance to question my own thoughts and motives. It would be hard to carry on living with my husband without this support. My husband gets lots of support, but this is all I get. When I talk to you, I am thinking of my own life, which I feel I have been dragged away from. I find this creative and a relief to talk about these things, knowing it is totally confidential. I can find a way forward for me.'

Speech and Language Therapy

Speech and Language Therapy (SLT) can support people living with dementia who have difficulty with their communication. This can involve difficulties with understanding conversations, using words and sentences, or changes in reading or spelling. Difficulties with taking part in conversations can have a significant impact on self-esteem, social participation and maintaining important relationships. Most people with dementia will experience some change in their ability to communicate and Speech and Language Therapists work with people with dementia throughout the stages of their condition. Difficulties with expressing needs and preferences can manifest as frustration, stress and distress, leading to reduced wellbeing.

Speech and Language Therapists may work directly with the person to explore strategies to help with talking and interacting. This may also involve exploring different forms of communication (Alternative and Augmentative Communication/AAC), including verbal and non-verbal methods, and supporting the person to plan for further communication changes in the future. Facilitating communication can also extend to assisting people living with dementia to make decisions about the care, treatment and support they receive as part of a Mental Capacity Assessment (Jayes et al., 2020). It is important that carers and supporters also know how to support the person with dementia in conversation. Carers and family members propose that difficulties communicating can be one of the most challenging aspects to deal with as a result of dementia (Egan et al., 2010). Frequently delivered by Speech and Language Therapists, communication skills training has been shown to be effective in increasing carer knowledge, skills, and resilience (Morris et al., 2018).

People with certain types of dementia, such as Primary Progressive Aphasia, may notice changes in their speech as one of the earliest symptoms. Speech and Language Therapists have a key role in assessment of cognition, communication, and speech, and are fundamental as part of differential diagnosis of dementia within the multidisciplinary memory team, enabling people to access tailored, early support for their communication needs (Enderby, 2015).

Another significant role of Speech and Language Therapy is the assessment and management of eating and drinking difficulties, and dysphagia (swallowing problems). Many people living with dementia, particularly those with more advanced dementia, experience difficulties with swallowing, leading to risks of malnutrition, chest infections, aspiration (food and drink entering the airway), choking and reduced wellbeing. Speech and Language Therapists provide advice on maximising safety of swallowing, using compensatory strategies, such as texture modification, pacing, postural techniques, and adapting the mealtime environment, whilst also balancing personal preferences, comfort and social mealtime experience. Speech and Language Therapists are core members of the multi-professional approach to managing complex eating and drinking issues, such as those arising towards the end of a person's life and decisions regarding 'eating and drinking with acknowledged risk (EDAR)', when a person continues to eat and drink despite significant risk of aspiration. Following holistic assessment, Speech and Language Therapists can advise on the safest and least restrictive options for eating and drinking to maximise quality of life and support decision-making that takes account of the risks and benefits for each individual.

Case study - Speech and Language Therapy and Memory Assessment Services

Below is a case study relating to the role of Speech and Language Therapy in supporting differential diagnosis and accessing early, evidence-based support following dementia diagnosis.

Mr B had been referred to the memory service for assessment of his cognition, following changes in his communication, attention, and executive functioning. He had previously had a stroke. Speech and Language Therapy supported differential diagnosis as part of the wider multidisciplinary team, due to consideration of a possible frontotemporal dementia, as Mr B presented with significant language difficulties and relatively spared memory. Holistic assessment confirmed that Mr B had vascular dementia. Despite his difficulties with following conversation and word-finding problems, Mr B was satisfied with his communication and did not require any direct therapy. However, Mrs B was struggling to come to terms with changes in her husband's communication, as he no longer initiated conversations, struggled to find the right words and she felt he was no longer listening to her.

Following assessment and diagnosis, the Speech and Language Therapist arranged a series of four sessions with Mrs B to offer advice, skills training and support around communication, also known as conversation partner training. Prior to therapy, Mrs B rated her confidence as a communication partner at 5/10, explaining that she didn't know how best to support Mr B when he was unable to express himself. The sessions included:

- Psychoeducation regarding typical communication changes in vascular dementia.
- Detailed explanation of Mr B's communication profile, detailing the strengths and areas of need in terms of his speech, language, communication and cognitive skills.
- Discussion regarding potential communication strategies to trial, based on assessment.
- Opportunity to trial strategies to enhance communication, with communication activities for Mr and Mrs B each week between sessions.
- A review session to draw up final list of chosen communication partner techniques and discussion around planning for communication changes in the future.

Following therapy, Mrs B expressed that she felt her knowledge about communication, and dementia more generally, had grown significantly. She expressed that the sessions had helped her to be more empathetic of her husband's needs, enabling her to take his perspective of the reality of experiencing communication difficulties as a result of his dementia. Mrs B had also shared and discussed the techniques with her adult children, and that they too had implemented the conversation partner techniques, such as writing down key words and using photos to introduce conversation topics. Mrs B rated her communication confidence at 9/10 at the end of therapy, and expressed that her anxiety had improved significantly, as she felt reassured that she was 'doing the right thing'.

This case study demonstrates the value of early Speech and Language Therapy input as an integral part of multi-disciplinary memory assessment. Early, specialist support, focused on the needs of the person and their family, can help to build carer resilience, supporting mental wellbeing of carers and family members, ultimately also improving quality of life for the person living with dementia.

Future roadmap to AHP practice in dementia

Quadruple priorities

With the introduction of national strategies and increased focus on dementia in Wales in recent times, significant progress has been made in terms of the development of AHPs' rehabilitation and enablement approaches that empower people living with dementia to live a life of quality after diagnosis. We know that there is still considerable work to do if all people living with dementia are able to access AHP approaches, regardless of their address or age. People with dementia, their carers and supporters, together with professionals and key stakeholders across Wales, highlighted four themes as key areas of focus needed to continue the transformation of AHP care in dementia.

The four key priorities are:

Priority 1: Awareness and Access to AHPs

Increasing awareness of the role and contribution of AHPs amongst the wider health and social care workforce, as well as members of the public, in optimising brain health and maximising the wellbeing of people living with dementia and their carers/ supporters

Why is this important?

During our consultation, people living with dementia and their carers told us that they really valued care and support that they had received from AHPs. People living with dementia explained that clinicians had provided tailored interventions, flexible to their needs, and involved their carers and family members which they viewed as important.

Whilst people living with dementia shared positive experiences of the support they received, they told us that they frequently met barriers in attempting to access support from AHPs. They highlighted a lack of information about what services are available post-diagnosis to support rehabilitation, and felt that they did not know what to ask for. Many people outlined frustrations with a lack of a structured pathway for support after diagnosis, following a medicalised and deficit-focused approach to assessment. People living with dementia and their carers were clear that they wanted to receive a multi-professional, holistic cognitive assessment, including AHPs as appropriate, in line with evidence and similar to approaches in other long-term conditions (Grand et al, 2011), which would enhance access to person-centred, strengths-based interventions thereafter. Furthermore, people reported that they often waited a long time to see an AHP.

People with dementia also highlighted a lack of information about future planning when newly diagnosed. Many people expressed that they would like the ability to make informed choices about their future care and support options to support self-management, agency and resilience. This included knowing when and how to request support from AHPs months and years ahead.

A recurring theme in our listening events with people living with dementia was that AHPs were often only involved at crisis point, in terms of their physical or psychological health needs. A number of carers also highlighted difficulties in accessing support when a family member moved into a care home. People living with dementia, their carers and supporters tell us that they would like involvement of AHPs at an earlier point, when they feel that they can make a bigger difference. Research evidence suggests that early psychosocial approaches offered by AHPs can help to delay the decline in cognitive and functional skills, support maintenance of key relationships and quality of life (Laver et al, 2020). Engagement in the development of the framework highlighted significant variation in access to AHPs in early stages of dementia, in terms of both generalist and dementia-specialist provision.

The AHP Leader survey (Appendix 4[5]) revealed that many AHP managers and leaders in Wales feel that other professionals, in addition to members of the public, are not aware of the role of AHPs and what they can offer in dementia care and optimising brain health. In order to increase early access to AHPs, we need to raise the profile of the impact of AHP-

[5] Available on request. Please email: HSS.RehabAndAHPs@gov.wales

led interventions from the perspective of the person living with dementia, their carers and supporters. Ensuring adequate recruitment of staff, in addition to sufficient AHP training places to meet future demand, will assist with enhancing timely access to AHPs.

Call to Action:

1. Continue to promote the value of AHP-led interventions in supporting people living with dementia, including population approaches to optimise brain health. Awareness-raising across health, social care, housing and third sector settings and within local communities, including meeting place or hubs, will align to Standards 1, 5, 6 and 11 of the All Wales Dementia Care Pathway of Standards (Improvement Cymru, 2021).
2. Develop a national communications strategy for the Allied Health Professionals (AHP) Dementia Network.
3. Increase access to multi-professional memory assessment, including AHPs, as recommended in the Dementia Action Plan (Welsh Government, 2018), to ensure that people receive timely, accurate diagnosis and tailored, evidence-based post-diagnostic rehabilitation as early as possible. This action supports Standards 6 and 13 of the All Wales Dementia Care Pathway of Standards (Improvement Cymru, 2021).
4. Develop a bank of resources to share information and practical advice at the Universal level of support, which will be co-produced with people living with dementia and their carers/supporters, and will offer advice to facilitate supported self-management and independence. There will also be a focus on supporting people living with dementia to know *how* and *when* to seek direct support from an AHP, whenever needed, in line with Standard 13 of the All Wales Dementia Care Pathway of Standards (Improvement Cymru, 2021). The resources may vary in format and include leaflets, postcards, websites, and videos to suit the accessibility needs of people living with dementia. Collaborative working with partners will ensure that resources are accessible from the most appropriate host site.
5. Explore in greater depth and define the role of AHPs in promoting and providing cognitive prehabilitation in people experiencing cognitive changes.

Outcomes to be achieved by September 2025

- AHPs will be integral as part of regional and national dementia strategies, with their offer and contribution valued and understood.
- There will be national and regional communication strategies for AHPs working within dementia care as part of an influencing plan.
- Clear pathways will exist within memory assessment services (MAS), established within each region, so that people living with dementia and their carers can access the care, support and expertise of AHPs.
- There will be a bank of AHP-led resources to support population level self-management to enhance physical, cognitive and psychological wellbeing in dementia.
- A steering group with relevant interest and expertise in exploring and contributing to cognitive prehabilitation will be established to progress work in this area.

Priority 2: Improvement and Innovation

Developing more robust evidence to demonstrate value of Allied Health Professionals' care, support, interventions and emerging practice at universal, targeted and specialist levels of support

Why is this important?

People living with dementia told us that they want to be able to receive evidence-based, effective interventions that will enable them to keep doing what matters to them. The recent literature review of AHP interventions revealed a need for larger scale, high quality research to strengthen support for approaches that people tell us are valuable to them (Appendix 3[6]).

Recent studies have provided a promising indication of the effectiveness of AHP interventions in relation to individualised rehabilitation that focuses on what is important to the person (Clare et al., 2019). There is increasing evidence regarding the value and impact of psychological therapies, including arts therapies, in supporting the wellbeing of people living with dementia and carers (Deshmukh, Holmes and Cardno, 2018, van der Steen, et al. 2018). The importance of psychosocial interventions, and therefore the potential value of AHP approaches, in the management of stress and distress in advanced dementia has also gained momentum in recent years and thus the evidence base continues to grow (Abraha, Rimland & Trotta et al., 2017).

A culture of quality improvement, spread and scale approaches where appropriate, and using meaningful and consistent outcome measures is important to develop practice-based evidence. Responses from the AHP leader survey (Appendix 4[7]) suggest a considerable diversity in outcome measures currently used across Wales. Gathering evidence of impact, from the perspective of the person living with dementia and their carers, will support future development of therapy-led services, funding for posts and a shift in culture towards rehabilitation and enablement. Resources such as the 'Magic Moments' storytelling approach can empower people living with dementia to tell us about their experiences of accessing care and support, so that we can understand what really matters and what works (Improvement Cymru, 2021). Connections with the AHP Quality Improvement (QI) Network and Q Community can support with embedding continuous improvement in practice.

Greater connections with academic institutions, protected time for research activity and infrastructure to empower clinicians to develop research skills will support with contribution to the research evidence here in Wales. Increased promotion of clinical-academic AHP careers will help to embed a culture of continuous improvement and quality.

Call to Action:

1. Continue a focus of improvement and practice development, showcasing examples of innovative practice from across the AHP community. Development of the AHP Dementia Improvement Project register will support with sharing of innovation.

[6] Available on request. Please email: HSS.RehabAndAHPs@gov.wales
[7] Available on request. Please email: HSS.RehabAndAHPs@gov.wales

2. Further scoping work in relation to the focus of improvement and engagement with research at pre-registration level of AHP training within Higher Education Institutions (HEIs).

3. Strengthen links with local, regional and national networks focused on quality improvement and research. This may include but is not exclusive to Health and Care Research Wales, the AHP QI Network, Council for Allied Health Professionals Research (CAHPR).

4. Explore the Quality Improvement skills, abilities and capabilities within the workforce and opportunities for Quality Improvement training and learning.

Outcomes to be achieved by September 2025

- A national register of AHP improvement projects in dementia care will be developed, maintained and eventually shared to aid spread and scale of approaches.
- AHPs will have the skills, knowledge and confidence to undertake improvement projects, that evidence the impact of AHP innovation and support further professional development and learning.
- AHPs will utilise tools within clinical practice to support learning and development, such as storytelling, case studies, Appreciative Inquiry (Cooperider et al, 2003), Developing Evidence-Enriched Practice (DEEP) (Andrews et al, 2015), alongside building the evidence base to demonstrate the value of AHPs.
- There will be a centralised register of emerging research and evidence undertaken by AHPs in dementia care to support dissemination of knowledge and building of the evidence base.

"AHPs can be changemakers, with their 'can do' approach to dementia"

Priority 3: Co-production and Collaboration

Working together with people living with dementia, their carers and supporters, and building relationships across boundaries to achieve integrated, effective care

Why is this important?

People living with dementia and their carers are the experts in their care. Scoping work in developing the framework has identified that there are excellent examples of co-production within Allied Health Professional (AHP) teams and services happening all over Wales, some evidenced here in this framework. Robust and meaningful co-production means that services truly meet the needs of the community that they support, based on users' experiences of 'what good care looks like' and this parallels the aspirations of Standard One of the All Wales Dementia Care Pathway of Standards (Improvement Cymru, 2021).

Many AHPs have told us that although they have been keen to engage in co-production with people with lived experience of dementia, they feel that they do not yet have the skills or resources to do this in a meaningful way. AHPs have identified that they would like to develop their skills in this area in order to be part of meaningful co-production that involves people living with dementia and their carers in equal partnerships, not at a tokenistic level. "*Nothing about us without us*" encapsulates the need for services to authentically include the voice of people living with dementia in every aspect of service design and delivery.

People living with dementia should be involved in decision-making regarding their care. People living with dementia should be central to the work that AHPs carry out, with services tailored to their individual needs at that particular time. If a person is not able to engage in making choices independently, a carer or supporter, relative or someone who knows the person well should be consulted as an expert in their care. Efforts should also be made to include people with more advanced dementia using creative methods.

In order for AHPs to deliver care and support that is holistic and effective, integrated, multi-agency working is the key foundation to building support that is tailored to the person. People living with dementia, together with clinicians, tell us that there is too often a disconnect between services across health, social care and third sector organisations. This causes delays in accessing help, breakdown in communication, and a lack of accountability and organisation in a person's care.

Call to Action:

1. All AHPs to cultivate authentic, reciprocal relationships with people living with dementia and their carers/supporters in order to learn and understand 'what good co-production looks like'. This will take place in local spaces, in addition to working with national organisations to ensure the 'dementia voice' is heard in the design, delivery and evaluation of services provided.

2. AHP Dementia Network for Wales to collate and develop resources and guides regarding the principles and practical steps needed to facilitate co-production with people living with dementia and their carers/supporters. Quarterly AHP Dementia Network meetings can be

used as forum to share examples of effective co-production in the development of interventions and services.

3. Strengthen relationships between services at local, regional and national levels, to ensure that AHP care and support are integrated and collaborative.

Outcomes to be achieved by September 2025

- People living with dementia and their carers/supporters will be involved in the design of services, big and small, from initial concept, interviewing of new staff, to evaluation post-implementation.
- People living with dementia and their carers/supporters will participate in the co-design and delivery of learning and training opportunities.
- People living with dementia and their carers/supporters will be members of service groups and strategic planning meetings, at regional and national levels, meaning that the “Nothing about us without us” value will be meaningfully practised.
- Resources to support meaningful co-production will be developed and shared by the AHP Dementia Network for Wales.

“Often we only get to see an Allied Health Professional when there’s a crisis. We want to see AHPs as early as possible, so that we can stay well, and plan for the future”

Priority 4: Leadership and Learning

Developing skilled AHP leaders who can influence and transform dementia care

Why is this important?

Dementia is every AHP's business. Whilst it is recognised that some AHPs may have more contact with people living with dementia than others, all AHPs regardless of setting should apply fundamental principles of person-centred care with an enabling and rights-based approach.

Consultation with health and social care professionals, together with the AHP Leader survey results (Appendix 4[8]), highlighted the variation in both knowledge-based and skilled-based learning opportunities available to AHPs across Wales in relation to dementia. People living with dementia and their carers also told us that whilst they had experienced high quality, person-centred care in some settings, there were also times when care they received did not align with fundamental principles in dementia care.

The Good Work Framework (Care Council for Wales, 2016) sets out principles to improve consistency in the development of knowledge and skills needed to support people with dementia and their carers to live as well as possible. AHPs need to reflect on their own learning and development needs to ensure that they have the knowledge, skills and competencies to meet the needs of people living with dementia within their area of work. It is paramount that AHPs work within robust professional leadership structures, with appropriate access to supervision and support to develop services, through AHP leadership that understands the complexity of dementia care and is well-integrated into wider Wales and UK dementia care networks, transformation and developments.

Engagement also highlighted variation in AHP involvement in learning and training delivered across the workforce. AHPs have a key role in providing high quality training regarding person-centred approaches to promoting independence, meaningful activity, communication, physical health, mobility and emotional wellbeing.

In order for AHP practice in dementia care to continue to evolve, and to demonstrate the value of the AHP contribution, transformational leadership will be needed to drive forward change. AHPs can be leaders at all levels of the health and social care system, championing the rights of people living with dementia and their carers and supporters. The AHP leader survey highlighted a significant need to further develop senior AHP leadership in dementia.

AHPs should be supported to develop their leadership skills, to influence change and bring a collective voice to change the culture of care. Leadership to support others to understand the rehabilitation and enablement approach to dementia will help to change the deficit-focused narrative around dementia, and drive transformation that will ultimately enhance quality of life for those living with dementia and their carers and supporters.

[8] Available on request. Please email: HSS.RehabAndAHPs@gov.wales

Call to Action:

1. Increase AHP leadership representation at a strategic level, including membership in Local Health Board Dementia Boards, Regional Partnership Boards, and AHP Professional Collaboratives, to build relationships across agencies with key stakeholders and maximise the impact of AHPs.

2. Develop regional AHP dementia senior leadership roles to provide clinical leadership and facilitate sharing of dementia knowledge and approaches from an AHP perspective. Working at an Influencer Level (Care Council for Wales, 2016), they will share strategic expertise within a local consultation model, which will help to mitigate regional variation in AHP service provision.

3. Increase sharing of knowledge and skills from AHPs working within enhanced dementia services with the wider AHP workforce, to implement the recommendations of the Good Work Framework. This aligns with the All Wales Dementia Care Pathway of Standards Standard 17 (Improvement Cymru, 2021).

4. Explore the current provision of learning opportunities for pre-registration AHPs in relation to brain health, ageing and dementia, to ensure that those entering the workforce are working at an Informed Level (Care Council for Wales (2016), with the fundamental skills needed to provide support for people living with dementia. This aligns with the All Wales Dementia Care Pathway of Standards Standard 17 (Improvement Cymru, 2021).

5. Ensure there are suitable, robust AHP and profession-specific leadership models supporting all AHPs in dementia care, in order to support safe, effective and best quality practice and AHP services.

Outcomes to be achieved by September 2025

- AHPs will have the skills, knowledge and capabilities needed to provide effective, safe and enabling care for people living with dementia and their carers/supporters, aligning with requirements set out in the Good Work Framework (Care Council for Wales, 2016).
- There will be regional AHP Dementia senior leadership roles, strategically placed to provide clinical leadership.
- There will be benchmarking undertaken to develop an understanding of dementia-specialist AHP staffing acuity across Wales, including Welsh language provision.
- AHPs will work within robust AHP leadership structures, across the tiered approach, integrated into multi-professional, cross-agency forums to maximise the reach and influence of AHP expertise and promotion of a rights-based, enablement approach to dementia care.

"A service should fit around the person. The person should not fit into the service"

Future directions

This framework defines how Allied Health Professionals (AHPs) in Wales can empower people living with dementia, their carers and supporters to remain as physically, cognitively and socially active for as long as possible, to live a life of quality following their dementia diagnosis. The framework also begins to explore the AHP contribution to brain health and dementia risk reduction.

It has brought together the voices of people living with dementia and their carers/supporters at the front and centre, together with health and social care professionals, and third sector organisations, to explore what best practice looks like in real terms. What is clear is that excellent work is taking place across Wales, and there is significant passion and drive within the AHP community to continue to improve standards for people living with dementia, their carers and supporters.

With the introduction of the All Wales Dementia Care Pathway of Standards, together with the All Wales Dementia Friendly Hospital Charter, and the Strengthening Provision in response to COVID-19 report, the impetus is strong for AHPs to work creatively and collaboratively to achieve the outcomes that matter most to people living with dementia and their carers and supporters.

This framework provides the evidence, momentum and actions needed to transform AHP practice in order to deliver care, support and interventions that can enhance quality of life in dementia. With oversight from the National Consultant AHP Lead for Dementia, further development will need to explore the impact of delivering the actions of the framework and a commitment from all partners involved in developing this guidance will be needed to implement the vision of this framework.

References

Abdelhamid, A., Bunn, D., Copley, M., Cowap, V., Dickinson, A., Gray, L., Hooper, L. (2016). Effectiveness of interventions to directly support food and drink intake in people with dementia: Systematic review and meta analysis. *BMC Geriatrics,* 16(1), 1. https://doi.org/10.1186/s12877-016-0196-3.

Abraha I, Rimland JM, Trotta FM*, et al*. (2017) Systematic review of systematic reviews of non-pharmacological interventions to treat behavioural disturbances in older patients with dementia. The SENATOR-OnTop series, *BMJ Open,* **7:**e012759, DOI: 10.1136/bmjopen-2016-012759

Academi Wales. (2015). *Appreciative inquiry: Using appreciative inquiry to make change happen*. Cardiff, Welsh Assembly Government. Retrieved from http://researchdevelopment.academiwales.org.uk/Content.aspx?SitePageContentID=2287&SitePageID=29&Mode=Eng.

Achterberg, W., Lauchtenbacher, S., Husebo, B., Erdal, A., and Herr, K. (2020) Pain in dementia. *Pain reports*, Jan-Feb, 5(1), e.803-e837.

Andrews, N., Gabbay, J., le May, A., Miller, E., O'Neill, M. and Petch, A. (2015) *Developing Evidence Enriched Practice in Health and Social Care with Older People*, York, Joseph Rowntree Foundation, available at: https://www.jrf.org.uk/report/developing-evidence-enriched-practice-health-and-socialcare-older-people

Alzheimer Scotland (2017) *Connecting People, Connecting Support: Transforming the allied health professionals' contribution to supporting people living with dementia in Scotland, 2017-2020*. Edinburgh: Alzheimer Scotland.

Alzheimer's Society (2020) *The impact of COVID-19 on people affected by dementia*. Available: The Impact of COVID-19 on People Affected By Dementia (alzheimers.org.uk)

Bennett, S., Laver, K., Voigt-Radloff, S., Lotts, L., Clemson, L., Graff, M., Wiseman, J. and Gitlin, L. (2019) Occupational therapy for people with dementia and their family carers provided at home: A systematic review and meta-analysis. *BMJ Open*, 9:e026308. doi:10.1136/ bmjopen-2018-026308

Bian, X., Wang, Y., Zhao, X., Zhang, Z. and Ding, C. (2021) Does music therapy affect the global cognitive function of patients with dementia? A meta-analysis. *Neurorehabilitation*, 48(4), pp. 553-562.

Burton, E., Cavalheri, V., Adams, R., Oakley Browne, C., Bovery-Spencer, P., Fenton, A.M., Campbell, B.W. and Hill, K.D. (2015) Effectiveness of exercise programs to reduce falls in older people with dementia living in the community: a systematic review and meta-analysis. *Clinical interventions in aging*, 10, pp. 421-434.

Buswell, M., Lumbard, P, Prothero, L., Lee, C., Martin, S., Fleming, J and Goodman, C. (2014) Unplanned, urgent and emergency care: what are the roles EMS provide for older people with dementia? An integrative review of policy, professional recommendations and evidence. *European Journal of recommendations and evidence*, 33(1), pp. 61-70.

Care Council for Wales (2016) *Good Work Framework: A Dementia Learning and Development Framework for Wales.* Available: Layout 1 (socialcare.wales)

Cations, M., Laver, K.E., Crotty, M. and Cameron, I.D. (2018) Rehabilitation in dementia care. *Age and Ageing*, 47(2), pp. 171-174.

Clare, L., Kudlicka, A., Oyebode, J.R., Jones, R.W., Bayer, A., Leroi, I., Kopelman., M., James, I.A., Culverwell, A., Pool, J., Brand, A., Henderson, A., Hoare, Z., Knapp, M., Woods, B. (2019) Individual goal-oriented cognitive rehabilitation to improve everyday functioning for people with early-stage dementia: A multi-centre randomised controlled trial (the GREAT trial). *International Journal of Geriatric Psychiatry*, 34(5), pp. 709-721.

Coffey, L., O'Keeffe, F., Gallagher, P., Desmond, D. and Lombard-Vance, R. (2012) Cognitive functioning in persons with lower limb amputations: a review. *Disability and Rehabilitation,* 34(23), pp. 1950-1964.

Cooperrider, D. L., Whitney, D., and Stavros, J. M. (2003) *Appreciative Inquiry Handbook*, Bedford Heights, Lakeshore Publishers.

D'Aniello et al. (2021) Effect of a Music Therapy Intervention Using Gerdner and Colleagues' Protocol for Caregivers and Elderly Patients with Dementia: A Single-Blind Randomized Controlled Study. *Journal of Personalised Medicine*, 11(6), pp. 455-464.

Deshmukh, S.R., Holmes, J. and Cardno, A. (2018) Art therapy for people with dementia. *Cochrane Database of Systematic Reviews*, 13(9), CD011073.doi: 10.1002/14651858.CD011073.pub2.

Dyer, S.M., Harrison, S.L., Laver, K., Whitehead, C. and Crotty, M. (2018) An overview of systematic reviews of pharmacological and non-pharmacological interventions for the treatment of behavioural and psychological symptoms of dementia. *International Psychogeriatrics*, 30(3), pp. 295-309.

Egan, M., Berube, D., Racine, G., Leonard, C. and Rochon, E. (2010) Methods to enhance verbal communication between individuals with Alzheimer's disease and their formal and informal caregivers: A systematic review. *International Journal of Alzheimer's Disease*. Article ID 906818. https://doi.org/10.4061/2010/906818.

Elliott, M., Older Adults Arts Therapies Service (OAATS) team (2021) Expanding arts therapies provision: a pilot project in Older Adult Mental Health Services, Aneurin Bevan University Health Board. *Public Health*, 194 pp.270-273.

Enderby, P. (2015) What is the impact on the individual with dementia and their carer, and the multidisciplinary team when an SLT is involved in early assessment and diagnosis? *Bulletin: Royal College of Speech and Language Therapists*, 763, pp.22-33.

Fancourt, D. and Finn, S. (2019) What is the evidence on the role of the arts in improving health and well-being? A Scoping Review. *Health Evidence Network synthesis report*, 67, Copenhagen: WHO Regional Office for Europe; Available from: https://www.ncbi.nlm.nih.gov/books/NBK553773/?report=classic

Improvement Cymru (2021) *All Wales Dementia Care Pathway of Standards.* Available: https://phw.nhs.wales/services-and-teams/improvement-cymru/news-and-blog/publications/dementia-standards/

Improvement Cymru (2022) *Wales Dementia-friendly hospital charter*. Available: Dementia Friendly Hospital Charter for Wales (Workstream 4) - Public Health Wales (nhs.wales)

Grand, J.H.G., Caspar, S. and MacDonald, S.W.S. (2011) Clinical features and multidisciplinary approaches to dementia care. *Journal of Multidisciplinary healthcare*, 4, pp. 125-147.

Jansen, S., Ball, L., Desbrow, B., Morgan, K., Moyle, W. and Hughes, R. (2015) Nutrition and dementia care: Informing dietetic practice. *Nutrition & Dietetics*, 72(1), pp. 36-46.

Jayes, M., Palmer, R. and Enderby, P. (2020) Giving voice to people with communication disabilities during capacity assessments. *International Journal of Language and Communication Disorders,* 56(1), pp. 90-101.

Giebel, C., Cannon, J., Hanna, K., Butchard, S., Eley, R., Gaughan, A., Komuravelli, A., Shenton, J., Callaghan, S., Tetlow, H, Limbert, S., Whittington, R., Rogers, C., Rajagopal, M., Ward, K., Shaw, L., Corcoran, R., Bennett, K. & Gabbay, M. (2020): Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study, *Aging & Mental Health*, DOI: 10.1080/13607863.2020.1822292

Greenberg, N.E., Wallick, A. and Brown, L.M. (2020) Impact of COVID-19 pandemic restrictions on community-dwelling caregivers and persons with dementia. *Psychological Trauma: Theory, Research, Practice and Policy,* 12(S1), S220-S221. https://doi.org/10.1037/tra0000793

Hall, A.J., Lang, I.A., Endacott, R., Hall, A. and Goodwin, V.A. (2017) Physiotherapy interventions for people with dementia and a hip fracture – a scoping review of the literature. *Physiotherapy*, 103(4), pp. 361-368.

Health Care Professions Council (HCPC) (2016) *Registrant snapshot – 1st December 2021.* Available at: Registrant snapshot - 1 December 2021 | (hcpc-uk.org) (Accessed 18th July 2022)

Improvement Cymru (2021) *All Wales Dementia Care Pathway of Standards: High Level Standard Descriptors*. Available at: Dementia-Standards-Pathway-document-English-Final-002.pdf (improvementcymru.net)

Improvement Cymru (2021) *Magic Moments in dementia care: A storytelling approach to learning and development*. Available at: https://phw.nhs.wales/services-and-teams/improvement-cymru/our-work/mental-health/dementia-care/resources/magic-moments-in-dementia-care-services/

Improvement Cymru (2022) *Education Programmes for Patients: Health and Well Being Courses*. Available at: Education Programmes for Patients (EPP Cymru) - Public Health Wales (nhs.wales)

Jones, C.H. (2018) *Research Briefing: A Global and National Perspective on Dementia*. National Assembly for Wales: Research Service. Cardiff: National Assembly for Wales.

Keyes, S. E., Clarke, C. L., Wilkinson, H., Alexjuk, E. K., Wilcockson, K., Robinson, L., … & Cattan, M. (2016). “We’re all thrown in the same boat…”: A qualitative analysis of peer support in dementia care. *Dementia*, 15(4), pp. 560-577.

Kings Fund (2015) *Leadership and Leadership Development in Health Care*. London, Kings Fund.

Laver, K.E, Crotty, M., Low, L., Clemson, L., Whitehead, C., McLoughlin, J., Swaffer, K. and Cations, M. (2020) Rehabilitation for people with dementia: a multi-method study examining knowledge and attitudes. *BMC Geriatrics*, 20(531), https://doi.org/10.1186/s12877-020-01940-x

Lin, L.-W., Lu, Y.-H., Chang, T.-H., & Yeh, S.-H. (2022). Effects of drama therapy on depressive symptoms, attention, and quality of life in patients with dementia. *The Journal of Nursing Research, 30*(1), Article e188. https://doi.org/10.1097/jnr.0000000000000468.

Low, L. and Laver, K. (2020) *Dementia Rehabilitation: Evidence-Based Interventions and Clinical Recommendations.* Australia: Elsevier.

López-López, D., Grela-Fariña, M., Losa-Iglesias, M.E., Calvo-Lobo, C., Rodríguez-Sanz, D., Palomo-López, P and Becerro-de-Bengoa-Vallejo, R. (2018) Clinical Aspects of Foot Health in Individuals with Alzheimer’s Disease. *International Journal of Environmental Research and Public Health*, 15(2), pp. 286-301.

Livingston et al. (2020) Dementia prevention, intervention and care: 2020 report of a Lancet Commission. *Lancet*, 396, pp. 413-446. Available: https://doi.org/10.1016/ S0140-6736(20)30367-6.

Martin, M.A., Barrera Ortega, S., Dominguez Rodriguez, L., Couceiro Muino, C., de Mateo, S.B., del Rio, M.P. R. (2012) Presence of malnutrition and risk of malnutrition in institutionalized elderly with dementia according to the type and deterioration stage. Nutr Hosp. 27, pp. 434–40.

Masteron-Algar, P., Cheshire Allen, M., Hyde, M., Keating, N. and Windle, G. (2022) Exploring the impact of Covid-19 on the care and quality of life of people with dementia and their carers: A scoping review. *Dementia*, 21(2), pp. 648-676.

McGrath, M. P. (2013) *Promoting safety in the home: The home-based Memory Rehabilitation Programme for persons with mild Alzheimer’s disease and other dementias.* London: The Health Foundation.

Morris, L., Horne, M., McEvoy, P. and Williamson, T. (2018) Communication training interventions for family and professional carers of people living with dementia: A systematic review of effectiveness, acceptability and conceptual basis. *Aging and Mental Health*, 22(7), pp. 863-880.

Orgeta V, Leung P, del-Pino-Casado R, Qazi A, Orrell M, Spector A.E, and Methley, A. M. .Psychological treatments for depression and anxiety in dementia and mild cognitive impairment. *Cochrane Database of Systematic Reviews*, Issue 4. Art. No.: CD009125. DOI: 10.1002/14651858.CD009125.pub3.

Parksinon, C., Taylor, K. and Windle, G. (2017) *Dementia and Imagination. Research Informed Approaches to Visual Arts Programmes*. UK: Dementia and Imagination.

Peisah, C., Weaver, J., Wong, L. and Strukovski, J. (2015) Silent and suffering: a pilot study exploring gaps between theory and practice in pain management for people with severe dementia in aged care facilities. *Clinical Interventions in Aging*, 9, pp. 1767-1774.

Pentland, D. (2015) *A Scoping Review of AHP Interventions for People Living with Dementia, their Families, Partners and Carers*. Prepared for Alzheimer Scotland. Division of Occupational Therapy and Arts Therapies, Queen Margaret University, Edinburgh www.alzscot.org/assets/0002/1495/A_scoping_ review_of_AHP_interventions_for_people_living_ with_dementia__their_families__partners_and_carers_2015.pdf

Prince, M., Guerchet, M., Albanese, E., & Prina, M. (2014). *Nutrition and Dementia: A review of available research*. Alzheimer's Disease International. http://www.alz.co.uk/nutrition-report

Quinn, C., Toms, G., Anderson, D. and Clare, L. (2015) A Review of Self-Management Interventions for People with Dementia and Mild Cognitive Impairment. *Journal of Applied Gerontology,* 35(11), pp. 1154-1188.

Sackett, D.L., Straus, S.E., Richardson, W.S., Rosenberg, W., and Haynes, R.B. (2000) *Evidence-based medicine: How to practice and teach EBM 2nd ed*. New York: Churchill Livingstone.

Sharp, C., Dewar, B., Barrie, K., & Meyer, J. (2017). How being appreciative creates change–theory in practice from health and social care in Scotland. *Action Research*, **16**(2), pp. 223–243. https://doi.org/10.1177/1476750316684002

Surr, C., Cartwright, V., Platt, R., Robinson, O. and Smith, S.J. (2021) *Taking Memory Assessment Services into the future: A guide to supporting continuous development, improvement and innovation in memory assessment services*. Leeds Beckett University. Leeds.

Tasci, I., Safer, U., Naharci, M.I., Gezer, M., Demir, O., Bozoglu, E. and Doruk, H. (2018) Undetected peripheral arterial disease among older adults with disease and other dementias. *American journal of Alzheimer's disease and other dementias*, 33(1), pp. 5-11.

Technology Enabled Care (TEC) Cymru (2022) *'Ask Us About Dementia' Pilot Support Service Independent Evaluation: Phase 2*.

Van der Steen, J.T., Smaling, H.J.A., van der Wouden, J.C., Bruinsma, M.S., Scholten, R.J.P.M. and Vink, A.C. (2018) Music-based therapeutic interventions for people with dementia. *Cochrane Database of Systematic Reviews,* Issue 7. Art. No.: CD003477. DOI: 10.1002/14651858.CD003477.pub4.

Watkins, J.M., Mohr, B.J. and Kelly, R. (2011) *Appreciative Inquiry: Change at the speed of light*, 2nd ed. San Francisco, CA: Pfeiffer.

Welsh Government (2011) *Welsh Language (Wales) Measure 2011.* Available: Welsh Language (Wales) Measure 2011 (legislation.gov.uk)

Welsh Government (2014) *Declaration of the rights of older people.* Available: Declaration of the Rights of Older People (olderpeoplewales.com)

Welsh Government (2016) More than just words: *Follow-on Strategic Framework for Welsh Language Services in Health, Social Services and Social Care 2016-2019*. Available at: More than just words (gov.wales)

Welsh Government (2018) *A Healthier Wales: Our plan for health and social care*. Available: A healthier Wales: long term plan for health and social care | GOV.WALES

Welsh Government (2018) *Dementia Action Plan for Wales*. Available: Dementia action plan 2018 to 2022 | GOV.WALES

Welsh Government (2019) *AHP Framework for Wales: Looking forward together*. Available: Allied Health Professions (AHP) Framework | GOV.WALES

Welsh Government (2019) *Prudent healthcare: Securing Health and Well-being for Future Generations.* securing-health-and-well-being-for-future-generations.pdf (gov.wales)

Welsh Government (2021) *Strengthening provision on response to COVID-19'*. Available at: Dementia action plan : strengthening provision in response to COVID-19 [HTML] | GOV.WALES

World Health Organisation (WHO) (2017) *Rehabilitation 2030: A Call for Action*. Geneva, Switzerland: World Health Organization. http://www.who.int/disabilities/care/rehab-2030/en/

World Health Organisation (WHO) (2019) *Risk reduction of cognitive decline and dementia: WHO guidelines*. Geneva, Switzerland: World Health Organization.

World Health Organisation (WHO) (2021) *Global status report on public response to dementia.* Geneva, Switzerland: World Health Organisation.