



# Connecting People, Connecting Support: looking back, looking ahead

An update report on transforming the allied health professions' contribution to supporting people living with dementia, their families and carers in Scotland



Elaine Hunter, Alzheimer Scotland National Allied Health Professional Consultant



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#### **Audience**

This report will be of interest not only to people living with dementia, their families and carers and practising allied health professionals (AHPs), but also integration joint boards, NHS boards, health and social care managers and practitioners, AHP leaders, social services and the third and independent sectors.

#### **Purpose**

This third report from Connecting People, Connecting Support (CPCS) is about how AHPs in Scotland can support people living with dementia, their families and carers to live positive, fulfilling and independent lives for as long as possible. Covering the period March 2020 to April 2024, it presents an update on the work of CPCS aligned to Scotland's new dementia strategy, Everyone's Story, published in 2023. It continues to advocate for an evidence-informed approach to practice for AHPs working with people living with dementia, their families and carers – what is called the AHP approach – with the intention of promoting local integration and implementation.

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The previous two Connecting People, Connecting Support (CPCS) reports of 2017 and 2020 were developed collaboratively and were informed by the views, ideas and aspirations of many key stakeholders. The integration of CPCS into local practice has also been a collaborative effort. Alzheimer Scotland would like to thank everyone who supports CPCS, in particular:

- the Scottish Dementia Working Group and the National Dementia Carer Action Network, who give up their time generously to guide our work and support the AHP workforce to be at the 'Informed' and 'Skilled' levels in dementia care;
- people living with dementia, their families and carers, who continue to share their stories and narratives, reminding us that they are the real experts in their own experiences, needs and aspirations;
- Alzheimer Scotland AHP Dementia Forum members, who are CPCS agents of change and collaborate wholeheartedly in making the four ambitions for change of CPCS a reality locally and nationally; and
- all AHPs who are testing, piloting and spreading new creative AHP interventions for the benefit of people living with dementia, their families and carers, then sharing their work on film, blogs, webinars and so much more.

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## **Abbreviations**

**AHP** allied health profession(s)/professional(s)

**AHPFS** Allied Health Professions Federation (Scotland)

**CPCS** Connecting People, Connecting Support

**GIRFE** Getting it Right for Everyone **HEIS** higher education institutions

**MS** Microsoft

NDCAN National Dementia Carers Action Network

**NES** NHS Education for Scotland

**PANEL** Participation, Accountability, Non-discrimination and equality,

Empowerment, Legality (principles)

**RCOT** Royal College of Occupational Therapists

**SDWG** Scottish Dementia Working Group

**SIGN** Scottish Intercollegiate Guidelines Network

WHO World Health OrganizationWTEs whole-time equivalents

## Foreword by the Chief Executive of Alzheimer Scotland



Connecting People, Connecting Support (CPCS), the allied health professional (AHP) national strategic dementia programme, is commissioned by the Scottish Government and hosted by Alzheimer Scotland. At Alzheimer Scotland, we ensure that community connections, engagement and integration of the programme are driven and informed by people living with dementia, their families and carers.

At the heart of CPCS is partnership working. We know communities work best when they work together. At the beginning of the CPCS journey in 2017, we said

that no single service, profession or group of professions can transform dementia care in Scotland on their own. Change is more effective when people work collaboratively and in tandem with people with lived experience, and this remains true in 2024.

The input of AHPs to that collaborative endeavour is vital. Over the last seven years, CPCS has built a strong foundation to ensure that people living with dementia, their families and carers have the right AHP care, at the right time and in the right place. Our aim is to enable people living with dementia, their families and carers to have access to AHPs in all settings and throughout their dementia journey, and that AHP services are underpinned by a rights-based approach to public health, self-management and rehabilitation.

Despite the evident successes inspired by CPCS, many of which were recorded in the second CPCS report in 2020, some people continue to face challenging issues in accessing AHP services. This third CPCS report describes how AHPs will address this by building on the achievements gained so far through CPCS to ensure that people living with dementia, their families and carers have fast access to the wide range of AHP expertise and support available to them in Scotland.

In pursuit of this aim, we will of course continue to work very closely with our partners in the Alzheimer Scotland AHP Dementia Forum, whose formation I warmly welcomed in my foreword to the first CPCS report. The forum's leadership has been, and will continue to be, instrumental in driving CPCS forward locally.

I would like to thank the Scottish Government for its continued support of, and funding for, this transformative programme. My grateful thanks also go to our National AHP Consultant Elaine Hunter, who has led on CPCS on behalf of Alzheimer Scotland, the AHP Dementia Forum, our partners in the Scottish Dementia Working Group and the National Dementia Carers Action Network, and Scotland's AHP workforce and people with lived experience for their inspiring work in delivering this progressive and innovative programme. Their efforts have brought tangible, and very welcome, benefits to people living with dementia, their families and carers in Scotland. The work now continues, and I very much look forward to seeing the CPCS programme develop in the months and years to come.

#### **Henry Simmons**

# Foreword by the Chief Allied Health Professions Officer, Scottish Government



I am delighted to welcome this third report of the allied health professions (AHPs) dementia workforce framework, Connecting People, Connecting Support (CPCS), and to see within it the continued progress towards achieving the ambitions for change to our AHP services for people living with dementia, their families and carers in Scotland.

At the launch of CPCS in 2017, we declared that 'dementia is every AHPs' business'. CPCS plays an important role in fulfilling our commitments to people living with dementia, their families and carers in Scotland. The breadth

of work showcased in this report demonstrates exactly this, with AHPs across the 14 professions in both specialist and generalist roles building awareness and relationships, and continuously developing skills and services to enable better care and support for people living with dementia, their families and carers.

The work celebrated in this report contributes to the delivery of many Scottish Government initiatives.

Scotland's Dementia Strategy, Dementia in Scotland: Everyone's Story, and its associated Dementia Strategy: initial 2-year delivery plan – 2024 to 2026 were co-produced by people with lived experience and with significant input from AHPs. The strategy and delivery plan set our direction. They have four key elements: the upholding of human rights; the delivery of equity of access; the creation of dementia-inclusive environments; and the development of a skilled and knowledgeable workforce who work to the principles of co-production and collaboration. These four key elements are also central to CPCS.

AHPs are experts in rehabilitation and have the skillset when they leave their undergraduate courses to support prevention, early intervention and healthy and active living for people living with dementia, their families and carers. At the heart of this approach is the desire to support individuals to live well with long-term conditions. It supports individuals to access meaningful rehabilitation that is based on their individual needs and is outcomes-focused.

Getting it Right for Everyone (GIRFE) is the proposed Scottish Government multi-agency approach of support and services from young adulthood to end-of-life care. It will place the person at the centre of all decision-making that affects them, with a joined-up consistent approach regardless of the support needed at any stage of life. GIRFE will form the future practice model of all health, social care and public sector professionals and shape the design and delivery of services, ensuring that people's needs are met.

The Scottish Allied Health Professions Public Health Strategic Framework Implementation Plan 2022 to 2027 sets out a plan for how AHPs can be supported and empowered to expand upon their leadership roles in public health improvement. We want AHPs to be leaders in public health, driving progress on promoting good brain health and supporting lifestyle changes.

We know that to achieve our goals in an ever-shifting and challenging context requires flexibility and collaboration. That is why it is so uplifting to see examples in this report of how AHPs have placed a spirit of collaborative working at the heart of CPCS, working across systems to put people at the centre of their own care and provide person-centred services closer to home.

I am proud of all of our AHPs and support workers, our AHP leaders, managers, teachers, researchers and students across the sectors. They all play a vital role in providing the skills, passion, creativity, innovation and commitment necessary to meet the ambitions of CPCS.

I commend this new report and urge AHPs across Scotland to continue to build upon this good practice to improve the experiences of people living with dementia, their families and carers.

#### Professor Carolyn McDonald

## The voice of lived experience

#### Reflections from the Scottish Dementia Working Group and the National Dementia Carers Action Network

The Scottish Dementia Working Group (SDWG) is a national, member-led campaigning and awareness-raising group for people living with a diagnosis of dementia in Scotland. The National Dementia Carers Action Network (NDCAN) is also a national, member-led campaigning and awareness-raising group of current and former dementia carers in Scotland.

Priorities and focus areas for both SDWG and NDCAN are set by the members, informed by their own personal experiences and by the experiences they hear about through their engagement with people living with dementia, their families and carers across Scotland. By connecting with people who are living with dementia, their families and carers, hearing what is important to them and building connections, colleagues based in our localities can ensure that the voices of people affected by dementia are heard.

The voice of lived experience has been central to the work of Connecting People, Connecting Support (CPCS) and we have been proud to support a number of the allied health professions (AHP) work programmes, from supporting AHP student placements, co-presenting at international conferences, developing self-management resources and teaching on continuing professional development modules, to being co-authors of a textbook. All of this has given us invaluable insight into how and in what ways AHPs can support people living with dementia, their families and carers.

As described in this report, the AHPs span 14 professions, working across sectors in hospitals, communities, care homes and people's homes. AHPs can play an incredibly important role in helping to improve the quality of life for people living with dementia, their families and carers, and we have long enjoyed a close working relationship with AHP colleagues. Working with AHPs allows us to share the reality of living with dementia, relating our personal experiences and providing insights that can support the transformation in AHP services that CPCS aspires to, while also respecting the rights of people living with dementia, their families and carers.

A number of us have had direct access to AHPs. Their support, guidance and rehabilitation interventions have been invaluable to us, and we want to ensure that other people living with dementia, their families and carers also have access to their expert clinical experience. However, lived experience shows there is still much to be done to ensure access to AHPs for those who need it. We know all too well that people are still unaware of who the AHP professions are and how to access them from their local communities. Many are unaware of all the rich AHP evidence-based self-management information that is available.

Throughout the next 24 months, in partnership with the National AHP Consultant, we will continue our long-established relationships with AHP colleagues working in health and social care to develop new programmes and opportunities, including informing the AHP workforce of what's important to us when we have contact with services in the community, primary care, hospital and care homes.

We will continue to build and develop our work with AHPs by promoting the role of AHPs in prevention and early intervention to support good brain health, advocate for and support more visible and direct access to AHP expertise, develop research priorities, and ensure that people living with dementia, their families and carers are integral to the transformation of AHP services in Scotland. All this work will be informed by lived experience.

Much has been delivered through CPCS, but an implementation gap in delivery of the ambitions remains. We welcome the renewed strong commitment to address these, as outlined in this updated report.

The way forward set out in this report resonates with SDWG's and NDCAN's priorities, which are underpinned by human rights and ensuring the voices of people living with dementia, their families and carers inform and are integral to the ambitions of CPCS and the transformation of AHP services in Scotland. We now look forward to continued work with AHPs and others to deliver on the ambitions of CPCS.

# Part 1. Context and history

#### Introduction

## Allied health professionals in Scotland

Allied health professionals (AHPs) apply their specific expertise to improve health, prevent illness, and diagnose, treat and rehabilitate people of all ages and conditions. They work across the spectrum of health and care, education (including early years), academia, research, and the voluntary and private sectors. AHPs are often first-contact practitioners and, together with a range of technical and support staff, deliver direct care, emergency and anticipatory care, rehabilitation and public health interventions (Figure 1).

Figure 1. AHPs in Scotland

Art therapist	Dietitian	
Diagnostic rac		
Occupational therapist	Music therapist	
Drama th	· · · · · · · · · · · · · · · · · · ·	
Orthoptist	Paramedic	
Orthotist		
Physiotherapist	Prosthetist	
Podia	trist	
Speech and language therapist	Therapeutic radiographer	

AHPs are key members of all multidisciplinary teams and are the third largest clinical workforce in the NHS. NHS workforce configurations are assessed in whole-time equivalents (WTEs). Official workforce statistics from the Scottish Government's TURAS data intelligence system for 31 March 2024 show a WTE number of 14,029 AHPs working in NHS Scotland, including 252 physiotherapists and 29 occupational therapists in primary care (Scottish Government 2024a). In a response to the consultation on the National Care Service (Scotland) Bill (Stage 2) (Scottish Parliament 2024), the Royal College of Occupational Therapists (RCOT) quoted official statistics stating that around 600 occupational therapists are employed by local authorities in Scotland. Of these, 501 WTEs are in social work services.

All AHPs will most probably meet someone living with dementia at some point in their professional or personal lives. Projected estimates show a 50% increase in the number of people living with dementia over 65 over the next 20 years. Alzheimer's disease and other dementia conditions continue to be among the leading causes of death in Scotland (National Records of Scotland 2024).

According to Scottish Government figures (2023), one in three people born today will go on to develop dementia. The Government also estimates that approximately one third of people living with dementia in Scotland are in residential care, and those residents make up at least 65% of the overall care-home population. People living with dementia are frequently admitted to hospitals, often with illnesses that could be managed at home (Health Improvement Scotland 2023). Those living with dementia who are over 65 years have, on average, four comorbidities (Health Improvement Scotland 2023).

"I am proud to represent the British Association of Prosthetists and Orthotists on the national AHP Dementia Forum and raise awareness of dementia within the profession, as it is every AHP's business to consider the needs of those whose lives are touched by dementia."

Susie Fraser, AHP

For some AHPs, such as occupational therapists, physiotherapists, dietitians, music therapists and speech and language therapists, working with people living with dementia, their families and carers (hereafter shortened to people living with dementia and their families) will be their prime focus. Others, including podiatrists and paramedics, will have a key role in supporting people living with dementia and their families in the community. Examples of good practice presented in the previous Connecting People, Connecting Support (CPCS) publications (Alzheimer Scotland 2017, 2020a), in Part 2 of this report and in a range of impact infographics provide a solid foundation for AHPs' work with people living with dementia and their families (Appendix 1).

Dementia remains a priority for the AHP community, which is supported by Scotland's AHP directors, the national AHP mental health leads, the Allied Health Professions Federation (Scotland) (AHPFS) and the academic heads of the seven higher education institutions (HEIs) in Scotland that offer pre-registration AHP courses. All have worked collaboratively with members of the Alzheimer Scotland AHP Dementia Forum on projects that deliver improvements to the quality and experience of care, support wellbeing, and provide tailored, personalised self-management and rehabilitation approaches.

"We are delighted to support the third Connecting People, Connecting Support framework. Scotland's Directors of AHPs view dementia and brain health as an ongoing priority for all our AHPs in Scotland and we will work collectively to support integration of this programme of work into our national and local priorities."

Heather Cameron, Chair of Scotland's Directors of Allied Health Professionals

#### **CPCS**

CPCS, commissioned by the Scottish Government and launched in 2017, was the first strategic AHP dementia workforce framework in Scotland. It is designed to maximise the impact of AHPs in response to the complex care needs of people living with dementia and their families.

CPCS seeks to ensure that people living with dementia and their families have better access to AHPs regardless of age or place of residence. It sets out how AHP services in Scotland can be remodelled to meet the needs of people living with dementia and their families before diagnosis and throughout the illness.

Since its launch, the CPCS framework has been promoting and developing collaborative and integrated ways of working. It provides a strategic foundation for the AHP workforce to secure better outcomes for people living with dementia and their families.

#### AHP approach, underpinning principles of practice and ambitions for change

The CPCS framework defined **the AHP approach** to guide AHPs' practice in all care settings with people of all ages who are worried about their memory or have a diagnosis of dementia of any type. The AHP approach is evidence-based and is underpinned by human-rights principles.

Each element of the AHP approach is presented separately, but must be considered collectively within overall universal, targeted and individualised interventions. Together, they call for AHPs to adopt an early intervention, rehabilitation and reablement process through a personal-outcomes approach (Figure 2).

Figure 2. The AHP approach

 Families and carers as equal partners in care Maximising families' and carers' physical health and psychological wellbeing Joint working with health and social care practitioners Supporting families & carers as equal partners Keeping physically active Valuing everyday activities Falls reduction and Enhancing vocational and **Enhancing** fracture prevention **Maximising** educational opportunities physical daily living Eating well AHP-led targeted wellbeing rehabilitation The AHP interventions approach #dementia **Maximising** psychological Adapting everyday wellbeing environments Maintain and maximise Enabling environments communication Using everyday technology Psychological interventions · Equipment and adaptations to Psychological therapies the home

The effectiveness of the AHP approach relies on active contributions from, and collaboration with, people living with dementia and their families.

**Four underpinning principles** were outlined in CPCS to support the integration of the AHP approach in practice. These state that AHPs should:

- adopt a human rights-based approach to practice using the PANEL principles (Participation, Accountability, Non-discrimination and equality, Empowerment, Legality) (Alzheimer Scotland 2024a);
- follow the biopsychosocial approach to rehabilitation;
- · adapt and tailor rehabilitation interventions to the needs of individuals; and
- · accept that dementia will be at the core of most AHPs' roles.

AHPs were invited to offer services in dementia-aware environments, with people living with dementia and their families being active contributors to the AHP early intervention, rehabilitation and reablement process through a personal-outcomes approach.

CPCS also defined **four ambitions for change** that set out what people living with dementia and their families can expect from the services they access from AHPs. The ambitions focus on:

- enhancing access;
- promoting partnership and integration;
- supporting an AHP workforce practising at the 'Informed' and 'Skilled' levels defined in the Scottish Government's Promoting Excellence framework for all health and social services staff working with people living with dementia, their families and carers (Scottish Government 2021), with a commitment to clinical leadership; and
- · driving innovation, improvement and research within everyday AHP practice.

The ambitions are described in detail in Appendix 2.

The key elements of the AHP approach, the four underpinning principles and the four ambitions for change are now well recognised by AHPs in Scotland. Their adoption has led to many successes as AHPs engage with people living with dementia and their families.

#### A person-centred approach

Inspired by CPCS, a growing number of AHPs are now developing universal, targeted and individualised approaches that enable people living with dementia and their families to access AHPs' skills and expertise within integrated health and social care services. Figure 3 shows how the tiered approach adopted by AHPs to implement CPCS in 2020 has evolved into a seamless approach that reflects a whole-system tailored-delivery model. What this means is that people living with dementia and their families can access support from AHPs at multiple levels at the same time, depending on their needs, and can move seamlessly between each level.

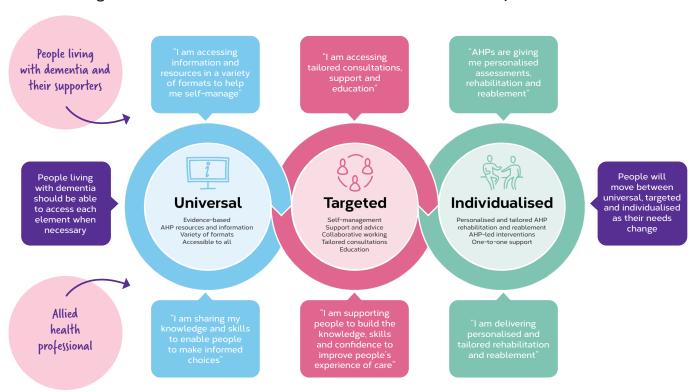


Figure 3. Personalised and tailored access to the skills and expertise of AHPs

This whole-system, seamless approach provides the platform from which AHP services can respond to what people living with dementia and their families are asking for, now and in the future. It also offers a framework through which AHPs in local services can measure their impacts on the personal outcomes that are important to individuals and local populations.

#### **Alzheimer Scotland AHP Dementia Forum**

The AHP Dementia Forum, which is hosted and supported by Alzheimer Scotland, works collaboratively with the Alzheimer Scotland National AHP Consultant to provide local clinical leadership. The forum facilitates the translation of policy into local practice, using CPCS as a driver for working inter-professionally and with people with lived experience, and embedding appreciative inquiry¹ when working with others to transform practice.

Forum members are quietly and confidently driving innovation through quality improvement initiatives that make a positive impact on people's personal outcomes. The forum's membership at the time of this report is shown in Appendix 3.

<sup>&</sup>lt;sup>1</sup> Appreciative inquiry is a strengths-based approach to creating change. Rather than identify a problem and look at how to solve it, appreciative inquiry involves exploring what is already working and how to build on it (Scottish Social Services Council 2016).

## **Emerging evidence base**

The first CPCS report, published in 2017, was informed by three sources of evidence:

- conversations with people living with dementia and their families;
- collaboration with health and social care practitioners; and
- · research and scoping evaluations.

Each of these evidence sources can still be viewed on the Alzheimer Scotland website (Alzheimer Scotland 2024b).

The sources were then reviewed for the subsequent 2020 CPCS impact report and again for this report. The original research commissioned for CPCS (Pentland 2015) was updated in 2022 (Braithwaite 2022; Braithwaite et al 2024).

AHP interventions must continue to be informed by the developing international evidence base, which highlights the benefits of lifestyle modification towards supporting good brain health, early intervention for prevention, supported self-management and rehabilitation as ways in which AHPs can continue to support people living with dementia and their families to do things that are important to them. The following provides some examples of emerging evidence in key areas that provides a solid foundation on which to inform and enhance AHP interventions.

#### Lived experience

People with lived experience continue to inform our understanding of dementia and its impact on their everyday lives. The ways in which they do this include challenging assumptions around user-led research and untold stories (Ashworth et al 2023), sharing their unique experiences of living with dementia, giving insights into the value and importance of creativity and occupation (Scharg et al 2023), writing blogs (Alzheimer Scotland 2024c), leading AHP dementia webinars (Alzheimer Scotland 2023a), presenting at conferences (Alzheimer Scotland 2023b) and creating animations (Alzheimer Scotland 2023c).

#### Dementia prevention and brain health

A new and emerging approach to dementia prevention and brain health highlights the impact of several modifiable factors, including some that are linked to lifestyles. A recent Lancet Standing Commission report (Livingston et al 2024) concluded that up to 45% of dementia could be prevented or delayed by addressing 14 risk factors, with further detail provided by Alzheimer's Disease International (2023).

National policies underpin the work of AHPs in supporting population health (Scottish Government 2022a), with all AHPs required to understand the role of their profession in health promotion, health education and preventing ill health (Health and Care Professions Council 2023). Work on defining the specific role of AHPs in leading interventions on lifelong brain health (Alzheimer Scotland 2024d; Braithwaite 2022; Fullerton et al 2023) and being key members of staff in brain health clinics (Alzheimer Scotland 2021a) is underway.

#### Rehabilitation

Emerging evidence supports the effectiveness for people living with dementia and their families of rehabilitation interventions (Lawler et al 2024; Lindelof et al 2023) that are person-centred and apply a biopsychosocial approach.

Work by the World Health Organization (WHO) recognises that all people living with dementia and their families can benefit from rehabilitation interventions delivered by a range of professionals, including AHPs – typically occupational therapists, speech and language therapists, physiotherapists and dietitians (WHO 2023). Alongside this, there is evidence of the need for rehabilitation, including for people with neurodegenerative disease, to be everyone's business (British Geriatrics Society 2024).

All interventions need to focus on building rapport in rehabilitation programmes (Hall et al 2023), working with families (Raj et al 2021), and providing continuous and tailor-made support at home (University of Stirling 2023).

Evidence continues to demonstrate that early psychosocial approaches offered by AHPs can help delay decline in cognitive and functional skills and support the maintenance of key relationships and quality of life (Laver et al 2020). The effectiveness of home-based occupational therapy interventions (Griffen et al 2022; McKean et al 2023) and peer-support self-management groups facilitated by occupational therapists (Craig et al 2023) is also backed by evidence. At the same time, AHPs are leading new and emerging areas of research, including supporting communication (Braithwaite et al 2022) and assistive technology (Curnow et al 2024).

#### SIGN dementia guideline

The most recent Scottish Intercollegiate Guidelines Network (SIGN) dementia guideline (Health Improvement Scotland 2023) offers opportunities for AHPs to lead and support the integration of the guideline in practice. They can do this through, for example, inputting to the diagnosis of dementia (including the provision of functional assessment by occupational therapists and speech and language therapists), providing post-diagnostic support, employing non-pharmacological approaches for distressed behaviours and supporting access to rehabilitation after the person has been diagnosed.

CPCS can be seen in the sections of the SIGN guideline that relate to education and training resources for professionals and people living with dementia and their families, with all the AHP evidence-based self-management resources being cited in the section on resources for people living with dementia and their families.

## **CPCS** – the story so far

This report provides an update on how CPCS is transforming the contribution of AHPs in supporting people living with dementia and their families in Scotland and highlights areas of action for the future. But before describing what's been delivered, and where transformation has occurred and progress made in the context of changes in health and social care, it is important to reflect on how we got to this point, which means rewinding to 2010.

#### 2010–2011: getting underway

This was when the Scottish Government published Realising Potential (Scottish Government 2010a), a three-year action plan for AHPs in mental health. It was a first for Scotland in that it brought together AHPs and people with lived experience, families, carers, professional organisations and NHS boards to define and refine the AHP contribution to delivering mental health services to the population. It marked the first mention of dementia in an AHP policy document, recommending that early interventions should form part of a care pathway for people with complex needs such as dementia. The action plan made the case for appointing AHP mental health leads in health boards to drive and enable transformational change.

The same year – 2010 – saw publication of the first national dementia strategy for Scotland (Scottish Government 2010b). It was launched at an occupational therapy community-led group, with AHPs being defined as integral to the strategy's implementation and monitoring group. Concurrently, three local AHP consultants were appointed in NHS boards, funded by the Scottish Government.

#### 2012-2013: building the foundations

Over the next couple of years, AHP mental health national engagement events were held with the aim of applying evidence to practice, while Scottish Government policy confirmed the central role that AHPs could play in dementia care and support. Realising Potential: Our Own and Others (Scottish Government 2012), a follow-up to the 2010 action plan, showcased, for the first time, examples of AHP best practice in dementia care.

Reflecting the need for Scotland-wide strategic leadership, a national AHP consultant role in dementia was established in 2012, forged from a partnership between the Scotlish Government and Alzheimer Scotland.

The following year, the second national dementia strategy (Scottish Government 2013) confirmed that AHPs were very clearly aligned to the government's strategic vision. The strategy included a commission for Alzheimer Scotland to produce an evidence-based policy document that outlined the contribution of AHPs to ensuring implementation of the 8 Pillars Model of Community Support for people living with dementia and their families living at home. This document was to become CPCS (Alzheimer Scotland 2017).

A national AHP dementia forum was established, bringing together AHPs, people with lived experience, and representatives from health boards and AHP professional bodies. The forum co-designed and informed the commissioned evidence-based AHP dementia policy document (CPCS).

The pace of progress was picking up. AHP engagement events continued around the country, including a three-day workshop with colleagues from the United States on non-pharmacological interventions. In October 2013, more than 200 occupational therapy students came together to learn about dementia. The same month saw the beginning of the Building Bridges academic internship and AHP practice placement programme at Alzheimer Scotland.

#### 2014: collecting evidence, identifying good practice

Let's Talk About Dementia (Alzheimer Scotland 2024e), a WordPress blog, was launched in 2014. It continues to this day, with weekly posts demonstrating creative, innovative ways to connect with people living with dementia and their families. What began as a way of sharing hints and tips on dementia self-management has, a decade on, built into an invaluable resource.

Three books were published (Alzheimer Scotland 2014a, 2014b, 2014c), providing an evidence base for the unique contribution of AHPs in acute hospital care for people living with dementia and their families, post-diagnostic support and care co-ordination. Forty case studies were included. The books commenced the process of collecting evidence that is informed by the voice of lived experience, identifying real-life examples of the contributions AHPs were making to supporting people living with dementia and their families. This process was to underpin the development of CPCS.

Two more national engagement events took place in 2014, supported by people with lived experience and promoting the message that dementia was becoming everybody's business among AHPs – in hospitals and especially in the community.

#### 2015: increasing engagement, evaluating impacts, building alliances

By 2015, efforts were intensifying to ensure the voices of people living with dementia and their families were central in conversations about AHP services and informed the content of the commissioned evidence-based policy document. Collaborative work between the AHP Dementia Forum and the Scottish Dementia Working Group (SDWG) gathered the views of SDWG members living with dementia.

The year was spent listening to the voices of people living with dementia and their families, using appreciative inquiry to identify what they felt was most important to help them stay connected to their local communities (Alzheimer Scotland 2015a).

Also in 2015, an evaluation report of the AHP dementia consultant role was published (Gordon & Griesbach 2015). Its findings were encouraging. At the time there were four such consultants, three working in NHS boards and one in Alzheimer Scotland. The evaluation looked at their impact and found that feedback from local and national stakeholders was overwhelmingly positive.

Alzheimer Scotland commissioned a scoping review of the contribution of AHPs to post-diagnostic support in dementia (Alzheimer Scotland 2015b) and a scoping review of AHP interventions for people living with dementia and their families (Pentland 2015).

All the evidence collected helped to shape the CPCS framework and promote best practice.

It was not just in clinical settings that advances were being made. Strategic partnerships were built with higher education too, and 2015 saw Alzheimer Scotland and Queen Margaret University in Edinburgh working together to develop an MSc module, Developing Rights-based Practice for AHPs Working with People Living with Dementia, their Families and Carers (Alzheimer Scotland 2021b). The two organisations signed a strategic agreement for their continued partnership.

### 2016: campaigning for change

The Ask an AHP campaign was launched In Dementia Awareness Week in 2016 and was so successful that it is still running today. Its aim is to connect people through conversations and inquiry while raising awareness of the role of AHPs by sharing AHP-led selfmanagement leaflets and postcards. Stands are hosted at national conferences, blogs are written and questions are answered.

The same year saw the start of an occupational therapy home-based memory rehabilitation improvement project in post-diagnostic support. And more national engagement events took place with all key stakeholders on the content and ambition to be included in CPCS to gain guidance on, and endorsement for, the final report.

#### 2017: CPCS launched

CPCS – which presented an evidence-informed case to support an approach to practice for all AHPs when working with people living with dementia and their families – was launched in 2017 at an event hosted by Alzheimer Scotland and the Scottish Government. People with lived experience of dementia were keynote speakers, challenging AHPs to deliver on the four ambitions for change the framework outlined. A local group from Fife, led by a person living with dementia, provided the music.

The third national dementia strategy (Scottish Government 2017), published the same year, included a commitment from the Scottish Government to support the implementation of CPCS.

A new dementia forum for AHPs (the Alzheimer Scotland AHP Dementia Forum) was formed by Alzheimer Scotland and was tasked with integrating CPCS nationally and locally, with the support of the National AHP Consultant.

#### 2018–2019: developing the digital offer

Every means possible was employed to promote the AHP role in dementia, and 2018 brought the launch of the @AHPDementia Twitter (now X) handle. The National AHP Consultant coordinates a group of experienced and committed AHPs who share tips and hints on living well with dementia from an AHP perspective. Posting every day, the account has to date managed to attract more than 6,000 followers.

Alzheimer Scotland developed and shared five short films on the role of AHPs in people's dementia journey and funded new Alzheimer Scotland AHP self-management awards, supporting the delivery of six self-management projects (Alzheimer Scotland 2024f).

The national occupational therapy Journeying through Dementia improvement project, a peer-to-peer post-diagnostic support group for applying evidence to practice, began in 2018. And a national AHP dementia webinar series was launched, sharing the work and practice of AHPs and partners across Scotland.

In 2019, an online leadership learning space called The Blue Wave of Change began. The platform enables the sharing of high-quality online practical leadership tools to support AHP dementia clinical leaders on their change-maker journeys and supports the transformation that CPCS invites the AHP community to make.

## 2020: evaluating CPCS impacts

In February 2020, Connecting People, Connecting Support in Action (Alzheimer Scotland 2020a) revisited the original CPCS report to assess its impact. Through 40 practice examples and 10 vignettes of change, it showed what was working well and how CPCS was being integrated into local practice to make things better for people living with dementia and their families. The AHP community had a celebratory launch with the Scottish Government, Alzheimer Scotland and national partners and, importantly, with the voice of lived experience at its heart.

In March, COVID-19 interrupted the integration of CPCS ambitions for change that had been published the month before. However, the Scottish Government COVID-19 action plan laid out measures to support the recovery from coronavirus for people living with dementia (Scottish Government 2020) and continued to support the work through the recovery phase.

With much face-to-face contact being forced online, AHPs, like many others working in health and social care, were challenged to innovate and responded by making information as accessible as possible. This included the launch of an interactive website (Alzheimer Scotland 2024g), development of online AHP advice lines, hybrid AHP practice placements and more online AHP-led self-management resources.

#### 2021-2023: renewal following COVID-19

As COVID-19 receded, AHPs launched various tools and resources, including videos and animations co-designed with SDWG and NDCAN. AHP live streams in the Alzheimer Scotland Virtual Resource Centre were deployed to drive home key messages about AHPs' value in leading and supporting rehabilitation in dementia.

The Alzheimer Scotland AHP Dementia Forum set new priorities that reflected recovery and renewal of the transformation CPCS offered and asked for an updated CPCS report.

The Scottish Government funded a new and innovative 12-month CPCS AHP leadership scheme, supporting local leadership and change driven by local priorities. Testing of The Balanced System® suite of tools (The Balanced System® 2024), also funded by the Scottish Government, was started in two health and social care partnerships.

A scoping project began to assess progress on an agreement with academic heads in HEIs in Scotland that all AHPs leaving their universities would be 'Informed' and 'Skilled' on graduation. A new AHP CPD module with an emphasis on human rights, brain health and rehabilitation was developed in partnership with Edinburgh Napier University.

And early in 2023, Occupational Therapy and Dementia was published (Maclean et al 2023), a book that critically analyses traditional thinking and challenges readers to reflect on and develop their work, with the voice of lived experience embedded in the text.

Scotland's fourth dementia strategy, Dementia in Scotland: Everyone's Story, was published (Scottish Government 2023), with continued support for AHPs and CPCS and with a new vision for change that supports rehabilitation in dementia.

#### 2024: looking to the future

AHPs were integral to the series of multi-agency and multi-sectoral working groups to develop the dementia delivery plan for 2024–2026 (Scottish Government 2024b) and are central to the dementia strategy subgroups on workforce and community resilience. Recognition is growing of the foundation good AHP practice provides and that we are at the beginning of a longer-term process.

This document, the third in the CPCS series, sets out to identify where CPCS is working well, where adjustments are required, where there are implementation gaps and where the future focus should be placed. It uses the voices of AHPs and people with lived experience to map out a plan to further enhance the AHP contribution to supporting people living with dementia and their families.

## 2025 onwards: the journey continues

So it has been a long journey that has led to this point. And the journey continues, with lessons and achievements from the past informing the future.

Since 2010, AHP practice has made great strides in improving the lives of people living with dementia and their families, informed at all times by lived experience. AHPs are actively re-engaging with local communities, having everyday conversations and asking 'What's important to you?' and 'How can we help?'

The ask for AHPs in Scotland was never to do more, but to do differently, to meet changing population needs.

# Part 2. Progress to date

# Realising the CPCS four ambitions for change to transform AHP practice

This part of the report describes what has happened since CPCS was published in 2020. It follows the four ambitions for change of CPCS, providing examples of how they are being integrated locally.

Alzheimer Scotland launched a series of weekly blogs in June 2014 and the content presented here is drawn from those blogs (Alzheimer Scotland 2024e). With a reach much wider than just Scotland, the blogs provide a new way of connecting colleagues to people living with dementia and their families, creating a whole new kind of community that lets people share their work in dementia. As well as presenting practical hints and tips for people with lived experience, the blog content also offers an opportunity to describe some of the transformation and impact stories that emerged between April 2020 and December 2023. In doing so, they offer an insight into the real and critical value of AHP interventions in improving people's experiences of care and support.

Eight blogs by authors from around Scotland are shared here to illustrate how AHPs are moving forward with the four ambitions of CPCS, delivered during the pandemic. A brief introduction to each ambition is provided, summarizing progress nationally ('Where we are now'), and links to additional impact stories highlighting the delivery of the ambitions are listed after the blogs. More detail on the progress of the actions for change can be found on the Alzheimer Scotland website (Alzheimer Scotland 2024h) and by linking locally with the AHPs in the Alzheimer Scotland AHP Dementia Forum (Appendix 3).

An additional 24 links to other blogs that share the range and reach of CPCS in local practice are provided. In all these examples, the voice of lived experience is shared alongside the work of our partners, who include dementia nurse consultants, Alzheimer Scotland link workers and AHP students on practice placements with Alzheimer Scotland. The AHP contribution to research is also highlighted, with examples of change and innovation.

The AHP approach, the four underpinning principles for practice and the four ambitions for change to support and drive the transformation of AHP services to meet the needs of people living with dementia and their families, as described in the first CPCS document, remain unchanged. The four ambitions for change have now been mapped to Scotland's national dementia strategy two-year delivery plan and the nine National Health and Wellbeing Outcomes (Appendix 2).



#### **Ambition 1. Enhanced access**

As a result of action on this ambition, people living with dementia and their families can expect that:

- I am supported to look after my own health and wellbeing; and
- I feel I get the support I need to keep on with my caring role for as long as I want to do that.

#### Ambition for change

People living with dementia and their families will experience visible and easy access to AHP expertise and services at the earliest time to derive maximum benefit to modify lifestyle changes or address the symptoms of the illness, now and in the future. This will include the availability of, and access to, AHP-led lifestyle information, AHP-led self-management information and supported self-management advice. It will also feature evidence-informed AHP-led targeted interventions from integrated and co-ordinated AHP services that integrate the five key elements of the AHP approach.

#### Where we are now

Dementia in Scotland: Everyone's Story (Scottish Government 2023) describes a national drive to make the experience of living with or caring for someone with dementia better than it is currently, delivering equity of access to information, treatment, care and support. We have therefore continued to work collaboratively to update and integrate a national personalised approach to service delivery (see Figure 3) and to be proactive in universal, targeted and individualised service delivery. This approach has ensured that we can begin to deliver on what people asked for, raising understanding and expectations of what an AHP can do and supporting the integration of specialist AHP knowledge into everyday practice.

The overall aim is to increase visibility of AHPs and promote early intervention for prevention and for AHP-led interventions. We want people living with dementia and their families to be able to access support at multiple levels at the same time, depending on their needs, and to move seamlessly between each level. This well-recognised AHP approach to service delivery is applicable across the full spectrum of AHP practice, from primary care, to hospital, to home.

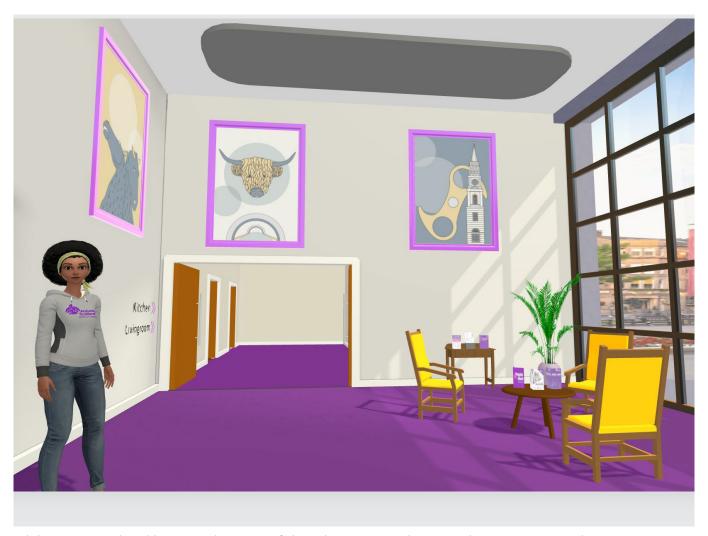
AHPs make a huge contribution to supporting lifestyle changes involving, for instance, diet, physical exercise and social engagement that potentially can reduce the risk of developing dementia, delay progression of the illness and enhance quality of life. A strategic and co-ordinated approach to developing accessible self-management resources is being pursued.

Universal and targeted interventions have been further developed, exploring technological and digital opportunities for innovations to increase access to evidence-based AHP-led self-management resources, while also evaluating outcomes and impacts, with over 100 resources available on one website (Appendix 1). This work has been recognised nationally through inclusion in the most recent SIGN guideline (Healthcare Improvement Scotland 2023b), in a range of profession-specific publications (RCOT 2024; Nutrition and Diet Resources UK 2023) and in local communities, including Meeting Centres Scotland and Alzheimer Scotland brain health and dementia resource centres.

The AHP offer is also integral to the Alzheimer Scotland Virtual Resource Centre (Alzheimer Scotland 2024i), an online space from which people can benefit in the comfort of their own home. This accessible resource is available where and when people living with dementia and their families need it.

While the digital offer has been expanded, print-out versions of AHP-led resources for families, link workers, care homes, dementia advisors and people living with dementia have also been developed. We continue to support Dementia Awareness Week, National AHPs' Day and local awareness events, using these as springboards to share Once for Scotland AHP-led self-management information.

Developing specialist interventions has included successfully engaging with AHPs in NHS boards to implement and integrate post-diagnostic occupational therapy home-based memory rehabilitation (McKean et al 2023) and a peer-to-peer support group, Journey through Dementia (Craig et al 2023). Some new roles, including for speech and language therapists in post-diagnostic support in Oban and occupational therapists in memory assessment in Edinburgh, have also been developed.



Alzheimer Scotland has a wide array of digital resources that people can access online.

## **AHP information day in Aberdeen**

#### Posted 2 March 2023 by Claire Clark, speech and language therapist, NHS Grampian

In mid-2022, Aberdeen City community adult AHPs met to consider how we could enhance access locally in a way that was manageable for professionals and accessible for those who needed to access that information.

With the support of the local Alzheimer Scotland Dementia Resource Centre, we decided to run a pilot event aiming to provide people with a range of self-management information. We decided to use the resource centre as it is a central location and had accessible space and facilities. We settled on 10am-1pm as a good timeslot as this allowed setting-up time and meant we were available for people coming by public transport or working around carers' visits.

We recognise that many people do not know about the wide range of AHPs and the scope of our roles, so we developed a booklet for distribution to all attendees describing the roles of all the AHPs attending and local ways to self-refer or get referred.

We promoted the event via multiple routes including the NHS staff bulletin, local Alzheimer Scotland newsletters, link workers (who provide some post-diagnostic support), community nurses and community psychiatric nurses.

On the day there was a buzz of excitement as the AHPs set up their stalls. We had no idea how many people to expect and what they would want to know. We were lucky enough to have representation from speech and language therapy, dietetics, physiotherapy, occupational therapy and podiatry. We also benefitted from having an occupational therapy student who was able to act as a welcomer, take numbers and distribute feedback forms. The Alzheimer Scotland Dementia Advisor was also on hand to provide support and information about their services.

Just before 10am there were people waiting at the door and we were then busy for the next two hours; in fact, at times there was a queue, particularly for the occupational therapists who were much in demand. The speech and language therapists were also busy with people who hadn't realised how language is impacted and how their loved ones could be supported.

We had 38 attendees, mostly in couples or small groups. To our surprise, many had not previously accessed the dementia resource centre so the Alzheimer Scotland Dementia Advisor was also very busy.

Our feedback forms, from both attendees and staff, provided useful information. Everyone enjoyed the day and attendees found it really useful to have face-to-face meetings with a range of AHPs.

We hadn't anticipated that people would want in-depth chats and that will be taken into consideration next time. The wide range of places where the day had been promoted was beneficial, as many people had seen it advertised. Some professionals from caring agencies and charities also attended. Each of the professions took some new referrals or provided self-referral forms. The referrals were all appropriate and hopefully the self-management information provides people with some ideas while they wait to be seen; it may also have prevented some unnecessary referrals.

Are we going to do it again? Yes – there were a couple of issues that needed to be ironed out (for example, the need for privacy for some conversations). However, it was enjoyed by and beneficial to all.

Some comments suggested that it might be helpful for other agencies to attend: dentistry, carers' organisations and advice on benefits and financial support were suggested. On reflection, we decided that we wanted to keep this as an AHP activity, partly due to the size of the space but also because of the impact that planning and organisation has on our clinical caseloads. However, we may consider having leaflets for other services at the event.

We all found it very beneficial and enjoyable and look forward to repeating the experience.

#### Update since posting the blog

The AHP information day has now taken place on four occasions and feedback continues to be positive, with many able to access relevant information for the first time, and appropriate signposting and referrals made. Carers, representatives of voluntary agencies and NHS staff have attended each one, reflecting a need for further information, and a review of the best way to support staff learning needs (Ambitions 2 and 3) in this less formal way is being considered.

## Connect You to Support. Practical advice developed for you by AHPs

# Posted 10 February 2022 by Gillian McMillan, Advanced Diabetic Practitioner (Mental Health Services), NHS Lanarkshire

The Lanarkshire Allied Health Professional Dementia Group is a collaboration of AHPs working in health and social care who have a passion to support people living with dementia and their families in our communities to live well. We know that as AHPs we have a wealth of knowledge, skills and experience which, when shared, can have a positive impact on people's lives.

A few years ago, we produced a range of simple hints-and-tips leaflets on topics that people living with dementia and their families had often asked us about. At the end of 2019 we were successful in securing a grant from Alzheimer Scotland to help us to refresh and develop this work. Unfortunately, soon after, the COVID-19 pandemic hit so it took a bit longer than originally planned. However, we are pleased that we can now share the results with you – Connecting You to Support: Living Well with Dementia.<sup>2</sup>

Connecting You to Support is intended as a practical advice resource for people receiving post-diagnostic support. When you look through it, you will see that it includes advice on a range of topics to help support both health and wellbeing. We understand that not everyone's experiences of dementia are the same. We also know that not everyone receives their diagnosis at the same point in their dementia. As a result, not all the information included will be relevant to each individual. Some may also find the amount of information is overwhelming or at times may even appear frightening.

For that reason, we would suggest that the best way to make good use of Connecting You to Support is to use it as a self-help directory. You can encourage people to dip in and out of the various sections if and when they need them and consider whether they may wish to share the advice with people close to them who support them.

If the full booklet is overwhelming, the relevant sections can be printed off to support the person in the way they find most useful. Topics include communication, swallowing, eating and drinking well, physical activity, mobility, foot care, falls reduction, memory management and home safety.

During the redesign, we took the opportunity to add more information on topics such as delirium, employment, driving, attending appointments, X-rays and scans, and using ambulance services, as well as advice from other health professionals on hearing and eye care.

Although some aspects of the information will be specific to living in Scotland, please feel free to share it with anyone you know who is living with dementia if you feel it would be useful to them. We value and welcome any feedback you may have and in particular from people who are using the resource. Please send this to me on behalf of the group: AHPDementia@alzscot.org

## Update since posting the blog

This resource has been well received by people with lived experience, with copies shared at conferences and downloaded from the Alzheimer Scotland AHP webpage (Alzheimer Scotland 2024f). It is a resource that is integral to the Carers Academy facilitated by the University of the West of Scotland and Alzheimer Scotland Centre for Policy and Practice in Hamilton and Dumfries and Galloway.

## Additional impact stories highlighting the delivery of this ambition

Listening, being and connecting [music therapy] <a href="https://tinyurl.com/uut2bp5y">https://tinyurl.com/uut2bp5y</a>	Practical Tips to Help My Memory booklet [occupational therapy] https://tinyurl.com/2uf9e2jp
Bringing flavour back! [dietitian] <a href="https://tinyurl.com/5ee3hdru">https://tinyurl.com/5ee3hdru</a>	Footcare at home [podiatry] <a href="https://tinyurl.com/2s3rf6dj">https://tinyurl.com/2s3rf6dj</a>
Exercise programmes for people living with dementia [physiotherapy] <a href="https://tinyurl.com/muvp5pxb">https://tinyurl.com/muvp5pxb</a>	Communicating Well with Dementia. A supported conversation group [speech and language therapy] https://tinyurl.com/2t5jc5vk

<sup>&</sup>lt;sup>2</sup> https://tinyurl.com/2wppwfa3.

## **Ambition 2. Partnership working**

As a result of action on this ambition, people living with dementia and their families can expect that:

• I feel that I am treated as a person by the people doing the work – we develop a relationship that helps us to work well together.

#### Ambition for change

People living with dementia and their families are the experts on the impact of the disease on their daily lives and will experience AHP services delivered in a partnership approach across teams, voluntary agencies, community resources, and the third and independent sectors (including housing associations), providing the right support for individuals in the right place and at the right time.

#### Where we are now

Partnerships and integrated working involving AHPs, people living with dementia and their families, services, partner organisations, health and social care practitioners and the third sector remain key to the success of the integration of the CPCS ambitions into local practice and services. We have continued to work collaboratively with health and social care partnerships and NHS boards to support local integration of the AHP offer to people living with dementia and their families and to redesign dementia services, with a particular focus on integrated and coordinated AHP service provision.

This ambition was always about people living with dementia and their families being central to leading and advising on ways of supporting them (Alzheimer Scotland 2017). As AHPs, we continue to advocate for a personal-outcomes approach for people living with dementia and their families, recognising people as experts in their own lives with strengths, hopes and aspirations.

The SDWG and NDCAN have been key supporters and influencers of CPCS nationally. Their participation is supporting this ambition and Ambition 3, ensuring the voice of lived experience is at the forefront of, and driving, our national work as AHPs in Scotland.

Locally, the AHP dementia clinical leads in the Alzheimer Scotland AHP Dementia Forum are taking the time to review and understand their local areas, develop insight into local services, influence local strategies, establish local AHP dementia forums and connect with colleagues and people living with dementia and their families locally.

We have worked with many partners and key stakeholders since the launch of CPCS, which potentially represents one of the greatest strengths and outcomes of this national AHP dementia programme. We continue to undertake strong partnership working with Focus on Dementia and NHS Education for Scotland (NES), both important partners for the ambitions of CPCS to be realised and sustained.

We also have strong partnership working with the AHPFS, HEIs, NHS board dementia nurse consultants and Health Improvement Scotland. Strategic support from Scotland's AHP directors and AHPFS has continued, ensuring collaborative working and delivery of national and strategic objectives in areas such as frailty, with a developing strategic public health approach to the AHP contribution to brain health.

AHPs have been integral to Health Improvement Scotland's dementia improvement programmes (such as those focusing on dementia in hospitals, improving care co-ordination for people living with dementia and their families in Inverclyde and post-diagnostic support in primary care), some of which were AHP-led, and CPCS was a key resource in the Quality Improvement Framework for Dementia Post-diagnostic Support in Scotland (Health Improvement Scotland 2021).

## Stuart's story in animation: a partnership project

Posted 9 November 2023 by Megan Roberts, MSc physiotherapy student, Edinburgh Napier University; Stuart Dougall, Scottish Dementia Working Group; and Alison McKean, National AHP Post-Diagnostic Support Lead

'Dementia is just one thing about me, not everything!'

The Animation Working Group was originally established to test animation as a new way of sharing rehabilitation advice for and with people living with dementia and their families. The remit expanded to include a focus on brain health, with the information shared being relevant to all. Some of the original work can be found online.<sup>3</sup>

Members of the SDWG and NDCAN have been working in partnership with AHPs and AHP students for over 10 years. The animations bring together the expertise of lived experience along with that of the AHPs in a co-design process, with everyone learning together. Different animation styles have been tested with the voice of lived experience narrating and bringing the animation to life, while also delivering our shared goal of using animation to promote brain health and rehabilitation, led by people with lived experience.

A key benefit of this work is the opportunity for AHP students to learn from, and work in partnership with, people with lived experience. Below, Stuart Dougall from the SDWG and Megan Roberts, an MSc physiotherapy student from Edinburgh Napier University, share their experience.

#### Stuart

When I was first approached regarding working with a physiotherapy student, my first thoughts were what a great idea, what an interesting concept. I was sure it would be an interesting experience for both of us, but in reality it was an absolutely fantastic experience for me.

I first met Megan via MS [Microsoft] Teams where I shared my journey, the highs and lows, and to Megan's credit, she wanted to learn all about me and my journey. I was taken aback at her enthusiasm and thirst for learning. So, after our first meeting, I was gobsmacked when she sent me 'homework', a really interesting in-depth questionnaire to complete regarding our future animation project. Megan really has a real talent and desire to learn.

Then we met for the first and only occasion face to face and this time Megan had completed all the groundwork, so from student, she was now director and producer. However, we were in a small office with no equipment other than what was already there and her mobile phone.

I was conscious we did not have any expertise in the animation field, but I feel this also makes it more real and meaningful, as we own it.

So now that the animation is complete, would I do it all again? Absolutely. For me, working with a physiotherapy student on a project like this certainly has benefits with great potential going forward, not only in something like this, but in many more aspects of their work.

Working with Megan was an absolute pleasure. She has a great manner, makes you feel totally at ease and I'm sure she will make a great physiotherapist and have a great future ahead of her. Well done, Megan!

<sup>&</sup>lt;sup>3</sup> https://tinyurl.com/y56cb5tu; https://tinyurl.com/26kcy4vf.

#### Megan

Having the opportunity to work alongside Stuart in a collaborative animation has been inspiring and eyeopening. Getting to know Stuart and listen to his story in depth was something I personally wanted to do, to really hear his thoughts and feelings towards his diagnosis and how he lives his life.

Stuart had a great attitude towards the project and showed a lot of enthusiasm towards me being a student. I was really intrigued to hear his thoughts on my plans for the project as I wanted to make sure this story was 'heard as him'. I felt we worked together effortlessly and had a good plan of action going forward with the project.

Even though we only met once on MS Teams and once in person, we managed to have laughs when making the animation – videoing, reorganising the room and holding all the pieces of paper up for his 'story board'.

I thoroughly enjoyed my time getting to know Stuart, which allowed me to reflect on the way the animation was presented. I felt Stuart was owning his story and that it was very important to see his face when presenting in the animation. Everything within the project was thoroughly discussed, down to the details of what Stuart listens to in the gym, which was important to him.

I think this is a great opportunity for students to collaborate with someone living with dementia as there is learning and deeper one-to-one understanding of the person.

I am proud to say it was a pleasure to meet Stuart and I am grateful for the patience, attention to detail and awareness that has been brought through this animation. Like Stuart said in the animation, 'Dementia is just one thing about me, not everything!' Thank you, Stuart!

We are delighted to share our animation with you and hope that many more AHP students can benefit from such a rewarding partnership experience.

#### Update since posting the blog

The project has evolved to focus on animation to support rehabilitation and brain health and involved people with lived experience working in partnership with AHPs and AHP students. Stuart presented this work at the Alzheimer Europe conference in 2023 and the presentation can be viewed on YouTube (Alzheimer Europe 2023). Stuart also shared his story about driving and dementia at an AHP webinar using a digital platform to demonstrate partnership working, and you can also view this presentation on YouTube (Alzheimer Scotland 2023a).

The animation group has developed into a strategic consultation forum which, along with NDCAN, aims to guide and inform the national AHP dementia programme with the Alzheimer Scotland National AHP Consultant.

## Changing ideas, hearts and minds - and then came the crockery

# Posted 31 March 2022 by Wendy Chambers, Alzheimer Scotland Dementia Consultant, NHS Dumfries and Galloway

In summer 2021, an interested group of folk in NHS Dumfries and Galloway's acute general hospital got together to discuss what could be done to support people living with dementia in the hospital to eat and drink well. The catering department were curious as to what else they could do to entice people to eat and drink. They invited AHP colleagues (dietitians, occupational therapists, speech and language therapists, and physiotherapists), as well as nurses, ward volunteers and the Alzheimer Scotland Dementia Advisor, and I was delighted to also be asked to join the conversation as the Alzheimer Scotland Dementia Consultant.

We discussed many familiar topics, such as use of picture menus, having a choice of snacks available, social opportunities to eat (these are limited in our new-build hospital with single rooms), developing a finger-food menu and how frequently we request contrasting crockery.

As a clinician, and now a leader in dementia care, I tend to adopt an aspirational approach. So I broached the idea with nursing ward management – how would they feel if we were to change ALL the crockery in one of their elderly care wards so everyone got their meals on contrasting crockery? Staff wouldn't have to take time to think about and request the contrasting crockery. Patients who might benefit would have ready access to crockery, which the research shows enhances nutritional intake for older people with visual impairment as well as dementia.

They agreed, so I broached the idea with the group, adding a quote I'd heard from a colleague from another NHS board area: 'We don't diagnose by crockery.'

Unfortunately, as great an idea as it might have been, the catering department said it wasn't possible for technical reasons.

Never underestimate the impact and power of the words you choose to use. A couple of months later an email arrived – the catering department manager, inspired by the inclusive idea of providing crockery which met the needs of all, rather than different crockery for a few, had had a change of heart and mind. He wanted to change the crockery, ALL of it. But not just for one ward. He needed to replace some crockery in two acute sites, due to breakages and wear and tear. So he decided he wanted to replace all the crockery, for everyone, across three hospital sites. Crockery, inclusive for all, which would support everyone to eat and drink well and contribute to reducing harm from dehydration, malnutrition and delirium.

While the pandemic brought and continues to bring challenges, it has also afforded opportunities for different thinking, conversations and solutions. Contrasting crockery, with a clearly defined blue rim, was not a new idea but somehow in NHS Dumfries and Galloway the time was right. The catering manager convinced budget-holding hospital managers that this was something we could do to support staff to deliver safe and effective patient care. It was the right thing to do, at the right time. It was kind and brave, it was possible. By December 2021, we had new crockery that was inclusive of the needs of people living with dementia.

We shared what we were doing on social media and received such warm and positive responses from across our board region and communities. We inspired some other areas across the UK to also change the crockery – all of it.

#### Update since posting the blog

Wendy reached out to a number of stakeholders, including the Excellence in Care lead, nursing management and the catering department, to ask what difference the crockery continues to make. The responses reflect a change in approach and culture. The contrasting crockery has become part of the normal fabric of mealtimes in the hospitals. The wards and ward staff are busier in 2024 than they were in 2021, so the decision to adopt an inclusive rather than targeted approach to use of the crockery has removed one extra job from the workload, freeing up time to provide essential care.

## Additional impact stories highlighting the delivery of this ambition

Lorna's Story [lived experience] https://tinyurl.com/yckum2z4	Willy's story – a very personal journey learning and adapting to living with dementia [lived experience] <a href="https://tinyurl.com/ymkkv6xt">https://tinyurl.com/ymkkv6xt</a>
The Carers' Academy: Supporting Family Carers Affected by Dementia [dementia nurse consultant] <a href="https://tinyurl.com/yhzjpjv8">https://tinyurl.com/yhzjpjv8</a>	Programme for Falls and Frailty [paramedics] <a href="https://tinyurl.com/5dpx5y3b">https://tinyurl.com/5dpx5y3b</a>
A collaborative approach to the Allied Health Professions offer in Scotland & Wales [partnership working] https://tinyurl.com/22akcy7w	The Life of an Alzheimer Scotland Dementia Link Worker [partnership working] https://tinyurl.com/278t9k37

## **Ambition 3. Skilled AHP workforce**

As a result of action on this ambition, AHPs can expect that:

• I feel I get the support and resources I need to do my job well.

#### Ambition for change

People living with dementia and their families will experience services that are led by AHPs who are 'Skilled' in dementia care (as defined by the Promoting Excellence framework (Scottish Government 2021)) and committed to a leadership and quality-improvement approach that drives innovation, shares best practice and delivers high-quality, personal outcome-focused and AHP-led therapies.

#### Where we are now

The Promoting Excellence framework for all health and social services staff working with people living with dementia and their families (Scottish Government 2021) was updated in 2021. We continue to implement the framework strategically, offering a range of rich learning opportunities in partnership with HEIs in Scotland and health and social care practitioners.

We have published a number of evaluation reports, including a review of occupational postgraduate MSc education (Alzheimer Scotland 2021b) and an impact report on an academic internship with the third sector (Alzheimer Scotland 2023d; Maclean et al 2023). Alzheimer Scotland also led on a scoping report with the AHP Dementia Forum and the seven HEIs in Scotland that offer AHP preregistration programmes (Alzheimer Scotland 2024j) on how they have supported an 'Informed' and 'Skilled' AHP workforce on graduation, concluding with an agreed strategic way forward.

For AHP practice placements, we have creatively and innovatively integrated the use of a range of digital platforms, including Near Me, GoTo and MS Teams, to support this ambition – with huge success. AHP national dementia webinars, which began in 2018, continue to offer a creative way to support health and social care staff, particularly so during the pandemic, when digital technology allowed practitioners to offer specialist AHP triage for people in their homes.

As we emerged from the pandemic and began renewing CPCS, Scottish Government funding enabled us to support local AHP dementia leadership for approximately 12 months. NHS boards were able to enhance the pace of transformational change in the AHP offer, with a focus on engaging with people with lived experience, defining the education requirements of the local AHP workforce and capturing current good practice in boards. These dedicated temporary AHP CPCS leadership roles were introduced in small integrated island NHS boards, such as NHS Shetland, and also the largest NHS board of NHS Greater Glasgow and Clyde. An impact summary report is being developed and will be shared by the end of 2024.

Members of the AHP workforce in dementia have been recognised for their leadership through receiving merit awards from their professional bodies (NHS Dumfries and Galloway) and NHS board innovation awards (Inverclyde Health and Social Care Partnership), the Constance Owens Early Researcher Award (NHS Tayside) and through involvement in the NES digital leaders programme (NHS Lothian), with staff in NHS Fife achieving national recognition for their roles as dementia champions.

The Alzheimer Scotland AHP Dementia Forum has continued to be the strategic clinical group that leads the local delivery of CPCS ambitions, with ongoing strategic leadership provided by the Alzheimer Scotland National AHP Consultant. This national forum meets monthly and was an important peer group at the height of the pandemic. While the forum's priorities are informed by national strategy, it also works collaboratively on developing shared priorities. Members of the forum were involved in the Scottish Government subgroups to develop the dementia delivery plan, which then informed Part 3 of this report, 'Looking ahead'.

The need for evidence-based innovations in AHP practice remains a priority, with the goal of sharing and spreading the learning and supporting local implementation based on population needs and cost-effective AHP-led interventions.

# Occupational therapy students deliver a digital gardening group at @alzscot

## Posted 29 July 2021 by Gill Wilkie and Claire O'Shaugnessy, former occupational therapy students at Queen Margaret University, Edinburgh

We were asked to develop an occupation-based group for Alzheimer Scotland to support the current online activities on offer in the Highlands. After attending some of the different activity groups and getting to know their members, we found that gardening was of interest, but wasn't currently being offered as an online group. We had never facilitated or planned a group before, let alone done any gardening, so we had definitely set ourselves a challenge. Here's what we did.

We created a proposal to justify the rationale for the virtual gardening group. We created group goals, looked at the group structure and materials required, and considered the environment and adapted as necessary. We then prepared a session plan for the first week, and a similar structure was followed for future sessions. This group was facilitated every Thursday for one hour over three weeks.

#### Sessions one and two

We planned our first activity, which involved potting plants (lavender, nasturtiums and cress). We had no prior knowledge of the members' skills and abilities so had to plan for every eventuality. We bought and sent group members the resources ahead of the sessions, created a step-by-step guide and a welcome letter, and sent an email with the MS Teams meeting link.

We started the second week by sharing our plant progress. We also shared pictures showing what our plants will eventually look like. We then went on to make a birdfeeder 'kebab'.

#### Session three

We needed some inspiration for the third week and decided to explore the Queen Margaret University garden and allotment to get some ideas and a quick selfie.

## Summary

We created a sensory activity in the form of a PowerPoint presentation. We explored all of the five senses, offering four different images to stimulate conversation. We encouraged members to bring something from their own garden to share. They engaged really well with this activity and there was lots of storytelling, laughter and reminiscing.

Despite the fact we were not expert gardeners (in the slightest), we managed to make this group successful. Everyone enjoyed each session, and we watched friendships form and grow, which was really rewarding as first-time group facilitators. We gave members the opportunity to continue a meaningful occupation by bringing the outdoors indoors. The feedback we received from group members was extremely positive and we were happy to hear they would like to continue a gardening group if there was an opportunity to do so.

## Update since posting the blog

Alzheimer Scotland has continued to offer a range of successful AHP student placements, including for students of art therapy, music therapy, occupational therapy and physiotherapy. A range of learning opportunities has also been developed, including speech and language therapy first-year visits, academic internships, MSc modules and continuing professional development courses.

## Journeying through Dementia: reflections of the past year

Posted 23 December 2021 by Ashleigh Gray, former occupational therapist, NHS Fife, now Practice Education Lead, Occupational Therapy, Edinburgh Napier University

I am sharing with you today the last blog for now in my role as project lead with Journeying through Dementia, a partnership project involving Alzheimer Scotland, Sheffield Hallam University and eight test sites across Scotland.

Over the past 15 months we have come together through the most challenging and testing times, committed to our aim of supporting people living with dementia and their families in Scotland to access occupational therapy and to continue to live as independently as possible. In response to COVID-19, much work has taken place to adapt and reconsider how to deliver this intervention while adhering to safe practices.

All the test sites are working hard with their efforts and plans to deliver Journeying through Dementia, with a number of groups already underway. I would like to share my top three reflections from my role as project lead.

#### Trying something new

It can often be daunting undertaking something new – for the majority of our test sites, this was their first experience of delivering Journeying through Dementia. However, add a pandemic to this and it would be natural to expect apprehension and an increased fear of the unknown. Despite this, all involved have done a great job and showed a real determination, as is evident in the achievements to date. Hearing the facilitators speak so passionately about the work they have done and the benefits the intervention has had for people living with dementia and their families has been so inspiring and encourages us all to face our fears – and do it anyway!

#### Communication

This was key throughout all stages of development and delivery. A large part of my role has been to maintain communication with each of the sites and connect them through a number of ways. A further key factor in communication has been to share news and developments of the work more widely, which has included creating a project Twitter [now X] account, @ScotJtDementia, and writing blogs such as this. I even did my first ever vlog, sharing a poem to provide an update on our work!

#### **Teamwork**

This project has taken on a true partnership approach, with all parties working collaboratively to support, motivate and encourage one another. From the early development meetings to a more recent get-together to celebrate the achievements of the past year, the team involved have embraced the opportunity to integrate Journeying through Dementia into their practice to support people living with dementia and their families in Scotland. This role has been a fantastic opportunity and experience and I would like to finish with a very big thank you to all involved.

### Update since posting the blog

This improvement project was completed in November 2023 and demonstrated benefits to people with lived experience, captured by using qualitative and quantitative data, including a film. In 2024, the intervention is being extended to a further 10 test sites in health and social care partnerships in Scotland and will be integral to local post-diagnostic support. More about the work can be seen on the Alzheimer Scotland website (Alzheimer Scotland 2024k) and Craig et al (2023), and via the @ScotjtDementia Twitter/X handle.

## Additional impact stories highlighting the delivery of this ambition

Brain Health: a new frontier in public health [occupational therapy] https://tinyurl.com/vn358y45	Connecting People Connecting Support: partnership working in action. In conversation with Scottish Dementia Working Group and National Dementia Carers Action Network [speech and language therapy students] https://tinyurl.com/yfw6z49t
#MusicTherapy Takeover at @AHPDementia [music therapy student] https://tinyurl.com/3yumyy4f	Let's talk about stairlifts & cognitive impairment. AHP dementia webinar [occupational therapy] <a href="https://tinyurl.com/8v7s6b2n">https://tinyurl.com/8v7s6b2n</a>
Public Health and Brain Health in Action – AHP dementia webinar [partnership working] <a href="https://tinyurl.com/3p78ewuc">https://tinyurl.com/3p78ewuc</a>	'Taking care to the patient' – AHP dementia webinar [paramedics] https://tinyurl.com/2yhard66

## Ambition 4. Innovation, improvement and research

As a result of action on this ambition, people living with dementia and their families can expect that:

• the right care for me is delivered at the right time.

#### Ambition for change

People living with dementia and their families will experience AHP services delivered by therapists who are committed to an approach that drives improvement, innovation and research in the delivery of high-quality, responsive, rights-based and person-centred AHP rehabilitation.

#### Where we are now

In transforming AHP practice, the need to measure whether the change has led to improvement, as defined by the experience of people living with dementia and their families, has remained a priority. Implementation and integration of CPCS within local practice continues to be underpinned by an improvement approach that aims to fully realise the impact of the ambitions across health, social care and partner organisations.

We have continued to support innovation and improvement, using both qualitative and quantitative data, and to respond helpfully for services locally. We have completed the evaluation of evidence of the impact of occupational therapy home-based memory rehabilitation in one health and social care partnership, creating a video in partnership with the SDWG to demonstrate the value of rehabilitation in dementia. The video can be viewed via YouTube (Alzheimer Scotland 2022).

AHPs were integral to the development of the new dementia SIGN guidelines as members of the Guideline Development Group and as specialist reviewers. AHPs were also integral in their leadership roles to the evolving international work of Davos Alzheimer's Collaborative generally in Scotland and specifically in NHS Dumfries and Galloway

We have worked with two health and social care partnerships to test The Balanced System® (2024) in AHP services delivered by occupational therapy. The Balanced System® is a framework and suite of tools and templates that can be used to improve the commissioning and delivery of services that benefit from an integrated approach to delivering outcomes. The model is theoretically driven and practically tested and is now in the final stages of testing in AHP dementia care with positive learning and outcomes.

Research is a continuing priority for us going forward as an AHP dementia community and we are re-establishing connections with the wider research community in Scotland, including the Scottish Dementia Research Consortium and Brain Health Arc. We will be working with research colleagues to roll out the education in 'confident conversations' in research to both the AHP workforce and AHP student population.

In 2025, we will be embarking on an innovative research project in partnership with Edinburgh Napier University, Heriot Watt University, SDWG and NDCAN that is funded by the RCOT. The project, 'Cocreating the future: the use of multifunctional robots in occupational therapy and dementia', will aim to co-create and explore with people living with dementia and their families the feasibility and potential use of robots in dementia practice and explore with occupational therapists if the use of robots can promote meaningful person-centred participation in occupations.

## Talking Mats, footcare and podiatry

#### Posted 4 May 2021 by Karen Mellon, Lead Podiatrist for Learning Disabilities, NHS Fife

I was initially introduced to Talking Mats by my learning disability speech and language therapy colleagues who were using the resource to support patient engagement.

The Talking Mats social enterprise aims to improve the lives of people with communication difficulties by increasing their capacity to think about, and communicate effectively about, things that matter to them. The award-winning Talking Mats communication tool uses specially designed communication symbols that were developed by speech and language therapists in partnership with a visual artist and people with communication difficulties (University of Stirling 2024).

I could see the real benefits of how Talking Mats could support our interactions with patients with a learning disability or those living with dementia and empower people to be more involved with decisions around their care.

Our speech and language therapy colleagues had undertaken the Talking Mats train-the-trainer programme and were then able to train our podiatrists in using the resource. Having used the existing resources, we found that we weren't able to discuss/explore people's views deeply enough; for example, when they developed foot ulceration or were at risk of ulceration. This was the spark that ignited the idea to look at developing a specific podiatry resource to enable these conversations.

The aim was to promote patients' engagement in their care – both in preventive care and when specialised input is required. By creating the resource, we aimed to explore what really mattered to the person and what, for them, were acceptable goals and outcomes. By developing a specific Talking Mats resource, we were able to explore treatment options and the impact of conditions and actively engage the person in expressing their views, thereby creating a person-centred care plan. Evidence shows that when people are involved in decision-making they are more satisfied with their care, which in turn improves their quality of life.

Having consulted with the Talking Mats social enterprise, we jointly created a resource which we piloted within NHS Fife over a six-week period. People living in care homes and people with a learning disability were the target audience for the pilot. Using the resource, we were able to understand more about the impact that foot ulceration was having on people and their views on treatment options.

One example of this positive impact involved a 60-year-old woman with learning disabilities and dementia. She lives independently with one hour of support each day to assist with personal care. She has been known to podiatry for some time due to repeated ulceration. Specialist footwear has been supplied and regular input is in place to reduce the risk of re-occurrence. However, at times the foot does break down.

In May, she experienced a break-down on her foot. She is a very pleasant lady who always comes across as if nothing bothers her and everything is fine; she doesn't like to 'cause a fuss'. It was felt the use of a Talking Mat might give us greater insight into the impact the wound was having.

By completing the Talking Mat, we were able to discover she was in fact having difficulties with the type of dressing and was experiencing pain. We were able to address this and change to an adhesive dressing, which took up less room in her shoe. We started her on paracetamol four times a day to address her pain. Follow-up discussions revealed she was much more satisfied with the dressing; it was more comfortable and easier to keep dry when showering. She also reported that she was experiencing much less pain.

As a result of using the mat, we were able to identify concerns she had but didn't share as she didn't want to be a burden. We were able to address this and create a plan that was acceptable to the patient and improved her wellbeing.

Moving forward, I hope this resource will benefit people living with dementia by enabling them to have their views heard and be an active participant in their care planning. By using this resource, we can help explore people's views and wishes, thereby enabling co-production in care. The resource promotes preventive care as well as specialist intervention; however, there are many other areas of foot health that could potentially be explored by developing further resources.

# Update since posting the blog

In collaboration with Talking Mats, podiatry-specific training is now available to enable other service providers to learn how to use the resource and give access to the tool. From training delivered so far, five NHS boards in Scotland now have podiatrists training with access to the resource. It has also been presented at the Royal College of Podiatry annual conference and highlighted in The Podiatrist journal as an example of how to support communication for people living with dementia.

# Occupation Matters: CPCS online digital platform

Posted 14 June 2020 by Dr Claire Craig, Professor of Design and Creative Practice in Health, and Co-Director of Lab4Living, Art & Design Research Centre, Sheffield Hallam University

Everyone has a story to tell about how COVID-19 has impacted their life. Stories of loss and loneliness will sit alongside tales of hope and generosity as people have come together in the face of challenge and adversity. I wanted to use this blog to reflect on my experiences and what COVID-19 has taught me about the value of friendship and community.

A few days after lockdown was announced, I was on a Zoom call with Elaine Hunter (Alzheimer Scotland National AHP Consultant), Alison McKean (Alzheimer Scotland) and my colleague Helen Fisher (Design Researcher, Lab4Living). Over the last three years, we had been implementing a research-based post-diagnostic support programme with occupational therapy colleagues in Fife and Aberdeenshire. The occupation-based programme, Journeying through Dementia, focuses on enabling people living with dementia and their families to continue to engage in the activities that bring meaning and promote quality of life.

We were due to begin a second wave of implementation of the research. However, as we shared experiences of colleagues on the front line and of the people living with dementia and their families we worked alongside, we realised that the most pressing issue was to find a way of creating a mechanism to bring people together to meet them where they were. Within four days of the call, we had designed and created an online digital platform.

CPCS is the name of the policy document under which our post-diagnostic support programme was being delivered. It seemed natural to take the name <a href="https://www.cpcs.online">www.cpcs.online</a>, recognising that while the policy document embraces the role of all AHPs working with people living with dementia and their families, our focus was on occupational therapy. Our strapline therefore read: Occupation Matters.

The plan was to release two topics a week. On Tuesdays the topic would be focused on the research and relate to ways of maximising meaningful activity and daily living (such as daily routines, sleep and mealtimes) and the Thursday topic would be focused on creative activities, hobbies and pastimes (like music, art, creative writing and gardening). We provided links to the Alzheimer Scotland helpline, which Alison and Elaine were closely involved with. By releasing two topics a week we were able to respond to feedback from people living with dementia and their families, who could then shape the focus of the materials. A paper-based version of the materials was also created so that when the time was right it could also be downloaded or sent out to families who could not access the site.

Since that day in March the four of us have met twice a week online to plan and share feedback. In the beginning, the calls offered a rhythm to the week. We focused on the materials but we also found time to share, to talk of family and of the challenges we faced, and through this to offer much-needed space and support. Very quickly I found the calls becoming the highlight of my week. CPCS took on a whole new meaning for as we came together online. I found myself not simply connecting with colleagues, but also drawing support from valued friends.

Amid all that COVID-19 is, I feel incredibly fortunate to have had the opportunity to get to know these three strong, generous, caring and compassionate women. I come away from our weekly meetings uplifted, supported and ready to face whatever challenges come my way. I have learnt that in the face of huge trials (even in the midst of a global pandemic) that good things can happen and friendships can blossom. Thank you Elaine, Alison and Helen – this experience has meant more to me than you can possibly imagine!

## Update since posting the blog

This interactive website (Alzheimer Scotland 2024g) has had a huge impact and an international reach, with 33,000 visitors between March 2020 and August 2024. Most visitors (72%) are UK based; 28% are from outside the UK, including visitors from the United States, New Zealand, Canada and Singapore.

The website was updated in November 2023 to reflect the developing evidence base with the inclusion of brain health, described as Lifestyle Matters. Further topic additions are culture, sport and planning for the future. A supporting webinar can be viewed on YouTube (Alzheimer Scotland 2020b).

# Additional impact stories highlighting the delivery of this ambition

Activities and relationships: providing meaning in the everyday lives of people with advanced dementia living in a care home [PhD student] <a href="https://tinyurl.com/yc6zhmuw">https://tinyurl.com/yc6zhmuw</a>	Supporting Good Communication in Care Homes [local evaluation] https://tinyurl.com/ywat3pw8
Can Watching Music Videos Reduce Stress and Distress Within an Acute Dementia Ward? [local evaluation] <a href="https://tinyurl.com/bdfyf5er">https://tinyurl.com/bdfyf5er</a>	Shifting our focus in acute settings: function to occupation [innovation] https://tinyurl.com/2vp4zhcm
A Rights Based Approach to Driving & Dementia [research project] https://tinyurl.com/yc84uwns	Healthcare System Preparedness for the Early Detection of Alzheimer's Disease – A Global Project [innovation] https://tinyurl.com/4mjf57ur

# Part 3. Looking back, looking ahead

# What have we learned?

CPCS sets out an ambitious and co-designed national AHP vision, with the ultimate goal of achieving better access to AHPs for people living with dementia and their families, regardless of age or place of residence, from pre-diagnosis to diagnosis and throughout their illness.

The four underpinning principles and ambitions for change in CPCS, which support and drive the transformation of AHP services, have brought huge progress through a number of key enablers for change. These include:

- being guided by the voice of people living with dementia and their families, both in national groups such as the SDWG and NDCAN and local lived experience groups;
- delivering a personalised and tailored approach of universal, targeted and individualised access to people living with dementia and their families;
- · leading the design of a rights-based approach to an evidence-informed AHP offer;
- maintaining a national network of local AHP leaders via the AHP Dementia Forum, who can respond to local population need with delivery support, and with oversight nationally from a strategic AHP dementia consultant post hosted in Alzheimer Scotland; and
- integrating improvement methodology into all local and national projects, enabling them to 'start small, think big and measure the impact'.

Despite the progress made, key areas of change outlined in CPCS have not been fully delivered in relation to the integration of the AHP offer. This part of the report looks at some of what we have learned through CPCS implementation and what issues remain to be addressed. This chapter discusses learning in some broad areas of AHP activity and the next sets out specific themes in which further action is now needed.



Members of the SDWG and NDCAN.

# **Learning from CPCS**

## We still have an implementation gap

An **implementation gap** between the AHP national dementia framework and lived experience outcomes and impact remains in place. Scotland's dementia strategy, Everyone's Story (Scottish Government 2023), signals a new approach to addressing the challenges that people with lived experience are facing. It sets out a fundamental change in approach in dementia policy, one that is focused on ways of addressing the gap between policy, practice and experience. AHPs are integral to this national change of approach.

#### Access remains a problem

Historically, people living with dementia and their families have experienced inequitable **access** to AHPs due to a multitude of factors relating to geography, variable service provision, differences in funding and staffing levels, and stigma, all of which create barriers to accessing AHP support (Braithwaite et al 2024). In Scotland, we know from people with lived experience that access to AHP expertise remains fragmented and complicated to navigate, which brings undue pressures on people who need AHP expertise. In one health and social care partnership, people indicated they felt unable to seek out or ask for AHP services or help – but when they were able to access AHPs, it made a significant difference.

#### We need to enhance work in local communities

While we have made great progress in our universal offer of AHP access in relation to the provision of AHP advice and self-management information, there is still a need to enhance our offer in **local communities**. We must continue to better understand what people actually require and adapt our services to meet their needs even more effectively. We need to communicate far more clearly when and how AHPs can offer interventions that make a difference to the quality of people's lives.

## The rehabilitation gap must be filled

Despite wide recognition that AHPs are key professions in **rehabilitation**, the emerging evidence base and the inclusion of rehabilitation in Scotland's dementia strategy, there is currently a lack of access to AHP specialist dementia rehabilitation. We need to increase awareness of what dementia rehabilitation is and how it can add value to the lived experience and services, and apply the evidence of dementia rehabilitation in practice.

# More needs to be done to recognise the role of AHPs in prevention

Modifying risk factors in people's lifestyles that may contribute to the development and progress of dementia calls on many interventions that are core skills of the AHP workforce, such as combining nutritional guidance, physical exercise, social stimulation and management of vascular and metabolic factors in working with people at high risk of developing dementia. Yet AHP skills in enhancing the public health and prevention agenda and in brain health services nationally are often **underutilised or unrecognised**. AHPs have a key role in prevention and early intervention that must be enhanced and developed.

# Is 'dementia every AHP's business'?

The aspiration that 'dementia is every AHP's business' has not been fully achieved, and the idea that anyone living with dementia has 'no rehabilitation potential' remains a concern. We need to prioritise the integration of our AHP-led self-management resources in practice to all 14,760 AHPs in Scotland, including those in areas of practice such as hospital at home and primary care.

# Promoting education means promoting excellence

We need to align our AHP dementia framework to other AHP policy and priority areas, while also continuing to work with our seven HEIs to support them in the ambition that **all AHP graduates leave university 'Informed' and 'Skilled' in dementia** in line with the national Promoting Excellence framework. The voice of lived experience must be embedded in programmes to exercise the right of people living with dementia to rehabilitation through education.

## AHPs lack workforce equity and need stronger leadership

AHPs working in, or contributing to, dementia care are not always **visible and equal partners** in the health and social care workforce. This restricts their ability to maximise their impact to improve health outcomes for people with lived experience in Scotland. AHP dementia **leadership** in services is variable and there is a need for AHPs to be integral to local dementia strategies, with their offer and contribution valued, understood and included. Developing leadership within the AHP dementia workforce at all levels of the health and social care system will drive change in AHP practice and ensure local strategic support for any changes made, enhancing their sustainability.

## The evidence demands change

CPCS outlined an AHP dementia approach informed by evidence, but there is an **emerging evidence base** that requires the AHP approach in dementia to be updated and then shared. The need to promote evidence-based innovations in AHP practice and for knowledge translation remains a priority, and we must expand our use of data, both qualitative and quantitative, to identify opportunities for improvement and increase opportunities for research.

"Please consider how you can uphold the rights of people living with dementia in your working life by listening to carers who have a clear understanding and agreement of the 'wishes' or 'rights' of the person they support."

Thea, NDCAN member

"I want to see systems and processes that recognise need, person-centred public policy, and people treated with dignity."

Margaret, SDWG member

# Where do we go next?

AHPs are in a strong position in Scotland to be key stakeholders and partners for change, and to improve, add value and contribute to realising the thematic priorities identified in the new dementia strategy for Scotland, Everyone's Story (Scotlish Government 2023).

The way forward has a focus on the contribution of AHPs informed by lived experience, evidence, practice and policy, with AHPs being integral to the transformation of dementia services in Scotland. But they cannot do it alone. Delivering better experiences for people will always require a collaborative approach with senior leadership teams in health and social care partnerships. AHPs have a strong record of partnership working that will be as critical now as it was when CPCS was first published.

# Thematic priorities and the role of AHPs in Scotland going forward

## Digital offer

Digital solutions will continue to be integral to the work of the AHP dementia programme, facilitating access to AHP-led support and interventions, enhancing lifestyle changes and supported self-management, and reviewing access to AHP services delivered in community settings, including care homes and people's homes.

AHP digital resources will be informed by themes identified by people living with dementia and their families while also taking account of local and national drivers and strategies. The principles of human rights and person-centred care will be embedded in this work. The digital resources will be informed by the AHP approach and will be tested and evaluated.

#### Workforce

AHPs will be key members of the Short-life Workforce Working Group established by the Scottish Government that aims to further develop current understanding of the workforces supporting people living with dementia and their families, identify any gaps, and establish a profile of the known learning and development needs of these workforces, building on the Promoting Excellence framework (Scottish Government 2021). This will ensure AHPs are supported to strategically implement the Promoting Excellence framework in local AHP services in partnership with the seven HEIs in Scotland that lead our AHP programmes (Alzheimer Scotland 2024j) and AHP practice education leads in NHS boards.

The Alzheimer Scotland AHP Dementia Forum will continue to provide national clinical leadership, with ongoing strategic leadership provided by the National AHP Consultant. This group will be pivotal in developing local infrastructure for clinical engagement, developing a strong foundation for collaboration and building relationships.

# Stigma

Support for heightening the awareness of, and understanding about, brain health and dementia among the AHP workforce and strategic AHP leaders will continue, ensuring that those who provide services understand and respect the rights of people living with dementia and their families.

Evidence-based, accessible and quality-assured AHP self-management information will continue to be developed and shared. Defining and leading on what rehabilitation can offer people living with dementia and their families will also be core.

#### Brain health

We will continue to promote the AHP role in promoting good brain health and supporting lifestyle modifications, including diet, physical exercise and social engagement, all of which can potentially reduce the risk of developing dementia, delay progression of the illness and enhance quality of life.

The principles of positive brain health, including management of known risk factors, will be promoted across the AHP workforce. We will also support the AHP contribution to the integration of the SIGN guideline (Healthcare Improvement Scotland 2023b) in practice.

#### Diagnosis and post-diagnosis support

AHPs, in partnership with relevant stakeholders, will integrate the whole-system, personalised AHP model of service delivery (Figure 3). They will be proactive in universal, targeted and individualised interventions, promoting brain health and early intervention for prevention and rehabilitation, while also exploring technological and digital opportunities for innovation to transform service delivery.

Work will be undertaken with data specialists to ensure AHP data is considered in published data collections on diagnosis and post-diagnosis support.

#### Resilient communities

AHPs will be members of the Resilient Communities Programme Board, which is tasked with identifying and promoting existing good practice in community initiatives and promoting consistency in access to those initiatives, highlighting opportunities and gaps.

We will continue to develop our understanding of what is important to people with lived experience in our local communities to inform AHP priorities and transformation. Universal and targeted AHP dementia resources will be available in a range of community settings, including Alzheimer Scotland brain health and dementia resource centres, Meeting Centres Scotland and Dementia Friendly Communities Scotland.

## The hospital experience

AHPs will be key partners in any wider system improvement and reform at both NHS board and health and social care partnership level to improve the hospital experience.

This will include contributing to the identification of ways to ensure that people living with dementia do not remain in hospital when not clinically necessary, recognising both the complexity of current pressures on the whole health and care system, and developments in areas such as the Getting it Right for Everyone (GIRFE) initiative (Scottish Government 2024c) and the My Health, My Care, My Home healthcare framework (Scottish Government 2022b). We will work in partnership with Scotland's directors of AHPs and local AHPs in health and social care on this priority.

## Care partners/unpaid carers

We will continue to work towards families and carers being integral and fully involved in the AHP offer of personalised and tailored access. We will also continue to develop our understanding of the priorities of care partners and unpaid carers and the role of AHPs in sustaining that caring role, particularly as individuals face the pre-death grief often associated with caring for someone with dementia.

We will promote good practice and evidence-based AHP interventions through care co-ordination and other approaches that support care partners/unpaid carers, with the support of their communities.

## Measuring progress and success

AHPs are key partners in supporting the delivery of Scotland's dementia strategy and the current two-year delivery plan. There is an ongoing commitment to maximise the role of AHPs in supporting people with lived experience and improve access to the specialist support and treatment offered by AHPs, delivered by a confident workforce that is 'Informed' and 'Skilled' in dementia.

Reporting on progress on the impact of CPCS will be integrated within the national governance structures for monitoring Scotland's dementia strategy. This will be led by the National AHP Consultant, who will work in partnership with the AHP Dementia Forum, the Scotlish Government, Alzheimer Scotland and Scotland's directors of AHPs. A detailed workplan will be developed with a clear reporting framework to enable all stakeholders to know and understand what is being delivered, and to identify progress and barriers.

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# **Appendices**

# Appendix 1. AHPs deliver digitally

AHP resources for people living with dementia and their families that are FREE to access include:



**6** AHP dementia <u>postcards</u>



**6** AHP information <u>sheets</u>



**10** AHP selfmanagement <u>resources</u>



**2** AHP exercise <u>videos</u>



1 AHP <u>interactive</u> <u>website</u> with a focus on occupation and activity



1 AHP <u>leaflet</u> on how to refer to an AHP



1 weekly <u>blog posting</u>, now with 570 blogs



**2** X (formerly known as Twitter) <u>accounts</u> offering daily hints and tips to 7,344 followers



1 email address to contact us at AHPDementia@ alzscot.org



**35** AHP dementia webinars sharing the work and practice of AHPs



**27** AHP dementia academic posters



**5** AHP dementia <u>podcasts</u>



**1** AHP <u>booklet</u> to support AHPs in practice



1 AHP <u>leadership</u> <u>learning space</u> website to support local AHP dementia clinical leaders



**5** AHP sessions in Alzheimer Scotland Virtual Resource Centre



**1** AHP <u>policy in a postcard</u>



**2** national <u>AHP</u> dementia policies



1 national Alzheimer Scotland AHP Dementia Forum that makes things happen

# Appendix 2. CPCS four ambitions for change mapped to National Health and Wellbeing Outcomes and national dementia strategy

The four ambitions for change
outlined in CPCS

#### AHP contribution to thematic priorities in Scotland's national dementia strategy two-year delivery plan

# The nine National Health and Wellbeing Outcomes that apply to integrated health and social care

#### 1. Enhanced access

People living with dementia and their families will experience visible and easy access to AHP expertise and services at the earliest time to derive maximum benefit to address the symptoms of the illness, now and in the future. This will include the availability of, and access to, AHP-led self-management information and supported self-management advice. It will also feature evidenceinformed AHP-led targeted interventions from integrated and co-ordinated AHP services that integrate the five key elements of the AHP approach.

#### Digital offer

Digital solutions will continue to be integral to the work of the AHP dementia programme, facilitating access to AHP-led support and interventions, enhancing lifestyle changes, supported self-management, and reviewing access to AHP services

# Diagnosis and post-diagnostic support

AHPs will integrate the wholesystem, personalised AHP model of service delivery and be proactive in universal, targeted and individualised interventions.

#### Care partners/unpaid carers

Families and carers will continue to be integral and fully involved in the AHP offer to personalised access. We will continue to develop our understanding of the priorities for care partners and unpaid carers and the role of AHPs in sustaining their caring role.

People are able to look after and improve their own health and wellbeing and live in good health for longer

People, including those with disabilities or long-term conditions or who are frail, are able to live, as far as is reasonably practicable, independently at home or in a homely setting in their community

Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services

People who provide unpaid care are supported to look after their own health and wellbeing, including measures to reduce any negative impact of their caring role on their own health and wellbeing

#### 2. Partnership and integration

People living with dementia and their families are the experts on the impact of the disease on their daily lives and will experience AHP services delivered in a partnership approach across teams, voluntary agencies, community resources, and the third and independent sectors (including housing associations), providing the right support for individuals in the right place and at the right time.

#### **Resilient communities**

AHPs will be part of the Resilient Communities Programme Board. We will continue to develop our understanding of what is important to people with lived experience in our local communities to inform AHP priorities and connections

#### The hospital experience

AHPs will be a key partner in any wider system improvement and reform, at both NHS board and health and social care partnership level, to establish how to improve the hospital experience. People who use health and social care services have positive experiences of those services and have their dignity respected

Health and social care services contribute to reducing health inequalities

People using health and social care services are safe from harm

The four ambitions for change outlined in CPCS	AHP contribution to thematic priorities in Scotland's national dementia strategy two-year delivery plan	The nine National Health and Wellbeing Outcomes that apply to integrated health and social care
3. AHP workforce 'Informed' and 'Skilled' in dementia care People living with dementia and their families will experience services that are led by AHPs who are skilled in dementia care (as defined by the Promoting excellence framework) and committed to a leadership and quality-improvement approach that drives innovation, shares best	Workforce AHPs will be key partners in the short-life working group established by the Scottish Government. This will ensure AHPs are supported to strategically implement the Promoting Excellence framework.  Challenging stigma There will be continued support for awareness of,	People who work in health and social care services are supported to continuously improve the information, support, care and treatment they provide and feel engaged with the work they do.
focused and AHP-led therapies.  brain amor Defin rehabliving	and understanding about, brain health and dementia among the AHP workforce. Defining and leading on what rehabilitation can offer people living with dementia and their families will also be core	
4. Innovation, improvement and research People living with dementia and their families will experience AHP services delivered by therapists who are committed to an approach that drives improvement, innovation and research in the delivery of high-quality, responsive, rights-based and person-centred AHP rehabilitation.	Brain health We will promote the AHP role in supporting good brain health and lifestyle changes. We will also support the AHP contribution to the integration of the SIGN guidelines in practice	Resources are used effectively in the provision of health and social care services, without waste

# Appendix 3. Alzheimer Scotland AHP Dementia Forum membership

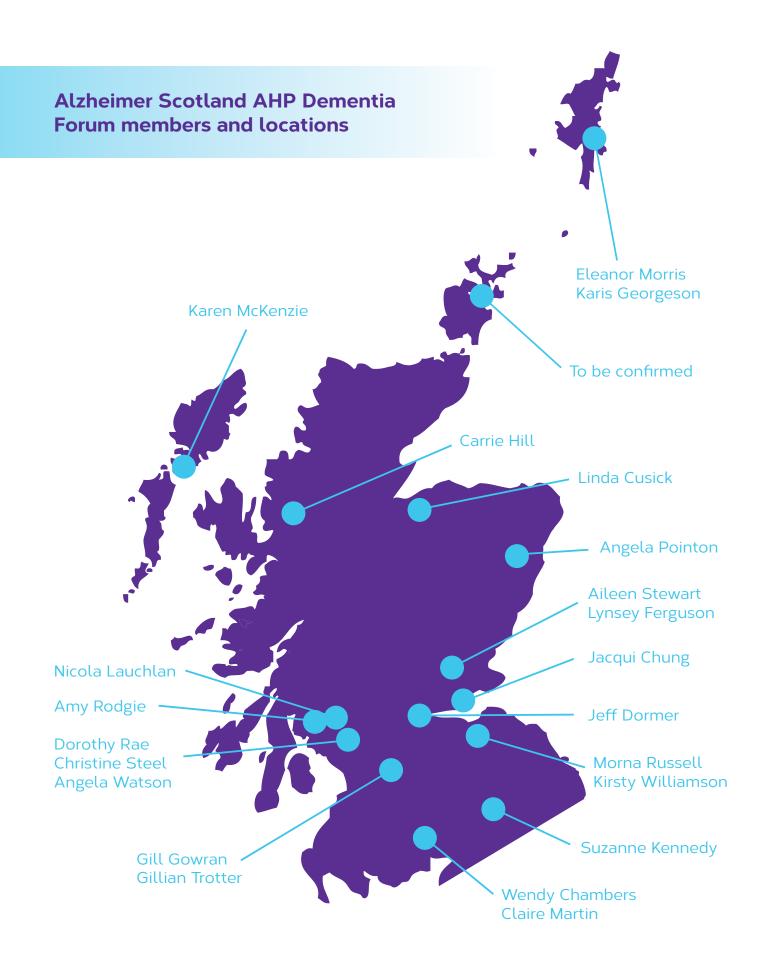
# **Meet the team**: Alzheimer Scotland AHP Dementia Forum

- · Professor Maggie Nicol, Chair
- Professor Elaine Hunter, Co chair, National AHP Consultant, Alzheimer Scotland

# Integral to the role and remit of the Alzheimer Scotland AHP Dementia Forum, we are supported by:

- British Association of Art Therapists (unconfirmed)
- Peter McCrossan, Scotland Director of AHPs
- Laura Bolton and Kassandra Esilva, British Association of Music Therapy
- Susie Fraser, British Association of Prosthetics and Orthotics
- Karen Thom, Fiona Maclean. External Partners
- Gillian McMillan and Jill MacRae, British Dietetic Association
- Claire Craig, Chartered Society of Physiotherapy
- Audrey Taylor, NHS Education Scotland
- Gaby Stewart, Royal College of Occupational Therapy
- Rebecca Kellett, Royal College of Speech and Language Therapy
- Jackie Rayner, NHS 24
- Vicky Burnham and Iona Crawford, Scottish Ambulance Service
- Karen Mellon, Liz Oakley, Kyle Coates and Dorothy Hathaway, Royal College of Podiatry

Accurate as of June 2024.





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