

# Connecting People, Connecting Support

Transforming the allied health professionals' contribution to supporting people living with dementia in Scotland, 2017-2020



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## Foreword by the Minister for Mental Health

The integration of health and social care is providing an opportunity to create a structured, coordinated and strategic approach to community support for people living with dementia. Connecting People, Connecting Support provides health and social care partnerships with a framework for restructuring and integrating the contribution of allied health professionals (AHPs) to dementia care so that these professionals are working to greatest effect.

Dementia has been a priority for the Scottish Government since 2007, and very much remains so. Scotland's third national dementia strategy was published in June 2017 and builds on the significant progress in many aspects of dementia care and support we have seen in Scotland.

In 2011, we introduced the human rights-based Standards of Care for Dementia in Scotland and the national dementia workforce training and education framework, Promoting Excellence to support services across the country to meet the dementia standards.

In 2013, we set out our distinctive national commitment to provide dedicated post-diagnostic support to those newly diagnosed. While we have made progress in meeting that commitment, we have much more to do over the course of the new dementia strategy.

We have in place a network of nurse and AHP dementia consultants, dementia champions and dementia ambassadors helping drive improvements for people living with dementia across a range of service settings. These professionals have a vital role in supporting front-line staff working as real agents of change and transforming services for people with dementia, their families and carers (whom I shall refer to collectively as people living with dementia).

Direct engagement with people living with dementia has been, and will continue to be, at the heart of this national action. While data is important in helping us to support the planning and redesign of dementia services, direct testimony on experience of services is also vital.

That is why we place so much value on our relationship with the Scottish Dementia Working Group and the National Dementia Carers Action Network – and why there is so much value in people living with dementia being involved in influencing and guiding dementia policy and practice.

That is also why Connecting People, Connecting Support is such an important document for people living with dementia. First and foremost, it sets out how AHP services in Scotland will be re-modelled to meet the needs of people living with dementia as they define them, using the best evidence from formal research to help people achieve what they say is most important to them.

I'm proud of the continuing priority placed on dementia by the Scottish Government and gratified to see how individuals and services on the ground are taking action every day to care for, enable and support people living with dementia. AHPs have a major role in providing support and making a positive difference to people's lives, enabling them to live well and live confidently in their own homes for as long as possible.

Connecting People, Connecting Support will play a big part in helping us meet the hopes, wishes and needs of people living with dementia by increasing their awareness of, and access to, the vital skills and interventions of our AHP workforce in health and social care.



**Maureen Watt, MSP**

Minister for Mental Health  
Scottish Government

## Foreword by the Chief Health Professions Officer

An estimated 90,000 people have dementia in Scotland in 2017, around 3,200 of whom are under the age of 65. By 2020, it is estimated that there will be around 20,000 new cases diagnosed each year.

People with dementia over 65 years are currently using up to one quarter of hospital beds at any one time. They are more likely to be admitted to hospital and generally have a longer length of hospital stay, but we know that most people with dementia live in the community.

A significant body of experience in providing individualised services for people living with dementia, their families and carers (people living with dementia) is building in Scotland. There are many examples of allied health professionals (AHPs) delivering exceptional practice: people living with dementia bear testimony to the positive impact AHPs have on their lives.

But no service, profession or group of professions can do it alone. Services are much more effective when they are coordinated, integrated and working in tandem with people living with dementia. Alzheimer Scotland plays a key role in this, providing advice, support, services, education and advocacy for individuals, the public, policy-makers and professionals.

AHPs' help, support and interventions are critical throughout the period, from pre-diagnosis to end of life. AHPs support people living with dementia to live well, ensure improved hospital and discharge outcomes and enable people to remain safely and confidently in their own homes and communities for as long as possible. Improvements such as these not only correspond with the National Health and Wellbeing Outcomes, but are also consistent with the expressed wishes of people living with dementia.

Scotland has in place a coordinated policy response to meeting the needs of the whole population, including the National Clinical Strategy, Realistic Medicine, the National Health and Social Care Workforce Plan, and the Active and Independent Living Programme (AILP).

AILP was developed following a parliamentary debate and public engagement exercise. Its vision is that:  
*Allied health professionals will work in partnership with the people of Scotland to enable them to live healthy, active and independent lives by supporting personal outcomes for health and wellbeing.*

Dementia care is one of the six identified national priority workstreams for ALIP.

The policy agenda in Scotland recognises that in a challenging financial situation, and with a population that is not only ageing, but may be doing so with a wide range of health and social problems, we need to think and do things differently. The aim is to ensure that health and social care interventions are appropriate to people's needs, that people can access services in their homes and communities when appropriate, and that they can see the right professional at the right time. That is the vision.

Connecting People, Connecting Support will play a big part in realising that vision. It presents an evidence-informed case to support an enabling approach to practice for AHPs working with people living with dementia – what we call the AHP approach. Evidence tells us what should be included in the AHP approach: it reflects what people with dementia want, and what their families tell us works best for them.

In addition to fulfilling a specific commitment from Scotland's National Dementia Strategy 2013–2016, Connecting People, Connecting Support will also play a key part in implementation of commitment 10 from the National Dementia Strategy 2017–2020, AILP and other ongoing dementia-focused policy initiatives in Scotland.

Connecting People, Connecting Support is the first policy of its kind for Scotland and, indeed, the UK. AHPs in Scotland are leading the way in outlining what they can do to help people to live well with dementia.

We have worked closely with Alzheimer Scotland in developing Connecting People, Connecting Support, drawing on the extensive evidence base it has been able to pull together. I strongly support this partnership approach: combining the strengths of government, AHPs, AHP directors and associate directors, the Allied Health Professions Federation Scotland, health and social care services, the third sector and people living with dementia enables us to develop and deliver policy that is relevant, realistic and realisable.

We will provide support for national delivery of Connecting People, Connecting Support through the National Alzheimer Scotland AHP Consultant, AILP and the Dementia Strategy as we move to the next stage of implementation. It is now time for teams to embrace and implement the AHP approach within local integrated structures, building on the innovative and exciting projects that have already been taken forward.

AHPs are the only professions who, as they leave their undergraduate programmes, are experts in rehabilitation and equipped to work in both health and social care settings. Connecting People, Connecting Support presents all AHPs, regardless of profession or service setting, with a great opportunity to realise their full skill-sets and work in new ways to deliver support and enablement for people with dementia. It sets out a path that will enable AHPs to come together to deliver tailored personalised interventions within a biopsychosocial approach.

My call to action is that AHPs can no longer think dementia is a specialist topic, and that the rehabilitation and enablement needs of people with dementia are the sole provision of our AHP dementia specialists. All AHPs need to have an enabling approach to support prevention, early intervention and healthy and active living for people living with dementia. Dementia is therefore every AHP's business.



**Jacqui Lunday-Johnstone, OBE**  
Chief Health Professions Officer  
Scottish Government

## Foreword by the Chief Executive of Alzheimer Scotland

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We have been fortunate and very pleased in recent years to support the connectivity between people living with dementia, their families and our AHP community. Our work has been funded by the Scottish Government, led by our National Alzheimer Scotland allied health professional (AHP) Consultant, Elaine Hunter, and supported by many dedicated, insightful and highly committed AHPs. Connecting People, Connecting Support is a culmination of this work and reflects a new synergy between the world of AHPs and the lives of people with dementia.

When we set out on this work, our aim was to help people with dementia, their families and carers to learn about the skills, strengths and expertise that exist within the AHP community in Scotland. We wanted to help people understand the value and potential support an AHP could offer to each person at all stages of their dementia. We also wanted to help the broad AHP community embrace the issues facing people with dementia and demonstrate to them how many of their skills and values could and should be used to support people with dementia from the point of diagnosis through to the advanced stages of the illness.

I believe we have made great progress towards this goal, and Connecting People, Connecting Support and its ambitions provide a further roadmap that can continue to guide us. The value of individually tailored, person-centred AHP practice in improving the experience and lives of people with dementia is unquestionable, and the truth is, we want and need more of it.

Connecting People, Connecting Support uses the important platform we have developed through our 5 Pillar, 8 Pillar and Advanced Care models as entry points for AHPs. These not only provide clear opportunities for AHPs to be part of the team, but also represent a strong conceptual framework and focus to which AHPs can relate and to which they can weld their practice.

We have been so pleased to see the response from our AHP community to this work and we very much would like to maintain the momentum by supporting the implementation of Connecting People, Connecting Support. That is why we warmly welcome the action to establish an Alzheimer Scotland AHP Dementia Forum, which we hope will work with us alongside people with dementia, their families and carers to support the integration and implementation of all Connecting People, Connecting Support's ambitions.

Alzheimer Scotland recognises that we have some way to go to ensure that the right level of access to the right AHP support at the right time is available for every person living with dementia, but we firmly believe that the ambitions in Connecting People, Connecting Support will help us achieve this and we look forward to working together to deliver on its ambitions.



**Henry Simmons**

Chief Executive  
Alzheimer Scotland

## Acknowledgements

Connecting People, Connecting Support was developed collaboratively and informed by the views, ideas and aspirations of many key stakeholders.

Alzheimer Scotland and the Scottish Government would like to thank everyone who contributed to and supported its development, in particular:

- Professor Maggie Nicol, chair of the Alzheimer Scotland AHP Dementia Expert Group, 2013–2016
- members of the Alzheimer Scotland AHP Dementia Expert Group who met from 2013–2016, helping to gather the evidence for the document
- allied health professional bodies and health and social care practitioners, who supported many of the engagement and collaborative events
- people living with dementia, their families and carers, for sharing their stories and narratives and reminding us they are the real experts in their own experiences, needs and aspirations.

Design and graphics by Andy Palfreyman and Hannah Johnston, Alzheimer Scotland.

Special thanks are due to artist Andy Peutherer, who gave permission for his painting 'Isle of Tiree, summer storm, Hebrides, Scotland', to be used on the cover of this publication ([www.scottishlandscapepainting.co.uk](http://www.scottishlandscapepainting.co.uk), original Scottish painting, prints and commissions).

Grateful thanks to all those who provided images for use in this report.

## What is Connecting People, Connecting Support?

Connecting People, Connecting Support is about how allied health professionals (AHPs) in Scotland can improve their support for people with dementia, their families and carers (people living with dementia) to enable them to have positive, fulfilling and independent lives for as long as possible.

### Evidence for action

As well as evidence developed through research, Connecting People, Connecting Support draws heavily on evidence collected by Alzheimer Scotland from people living with dementia, a scoping exercise on post-diagnostic support and research on AHP consultants. The evidence for action therefore reflects three sources:

- **conversations** with people living with dementia using appreciative inquiry approaches to support participants to effect self-determined change by identifying what works best for them
- **collaboration** with health and social care practitioners, higher education institutions and AHP professional bodies through engagement events and publications
- **evidence** from research, literature reviews and scoping evaluations.

### The AHP approach

The approach aims to maximise the AHP contribution to high-quality, cost-effective dementia services that are tailored to the needs of individuals, reflect the best available evidence and are delivered by a skilled AHP workforce.

The AHP approach focuses primarily, but not exclusively, on five key elements.



The elements are presented separately, but must be considered collectively within the overall AHP assessment and rehabilitation approach for individuals.

## Who is Connecting People, Connecting Support for?

Connecting People, Connecting Support will be of interest not only to people living with dementia and practising AHPs, but also integration joint boards, health boards, health and social care managers and practitioners, AHP leaders, social services and the third and independent sector.

## The vision

Connecting People, Connecting Support will ensure the rehabilitation skills and expertise of the workforce have an even greater positive impact on the lives, experiences and outcomes of people living with dementia than is currently the case. The aspiration is that people living with dementia have better access to a range of AHPs regardless of age or place of residence, early in their diagnosis and throughout their illness.

# Visual executive summary

## Connecting People, Connecting Support

### What will Connecting People, Connecting Support deliver?

The aim is to ensure that AHP practice and AHP-led interventions for people living with dementia is underpinned by four principles.

- **A human rights-based approach** will be at the forefront of each and every AHP interaction, with an emphasis on participation and empowerment, and recognition of personhood, identity and value.
- AHPs will deliver services to people living with dementia using the **biopsychosocial approach to rehabilitation**, integrating the five key elements of the AHP approach, best clinical practice and what people say is important to them.
- **Dementia is every AHP's business**, offering services in dementia-aware environments, with people living with dementia being active contributors to the AHP rehabilitation process.
- AHPs will **adapt and tailor their rehabilitation interventions**, taking into account the individual and at times changing needs of people living with dementia.

### What will Connecting People, Connecting Support achieve?

Local implementation of the AHP approach will result in:

1. **enhanced access** for people living with dementia to AHP-led information, supported self-management and targeted interventions to tackle the symptoms of dementia
2. **partnership and integration**, contributing to a personal-outcomes approach, multiagency pathways and integrated models of care
3. **skilled AHP workforce in dementia care**, with a commitment to leadership for transforming AHP practice
4. **innovation, improvement and research**, utilising and generating research and integrating improvement science within everyday AHP practice.

# Section 1.

## Introduction and context

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# Background

An estimated 90,000 people in Scotland have dementia in 2017, around 3,200 of whom are under the age of 65 (Alzheimer Scotland, 2017). Dementia can have a considerable impact on the quality of life of people with the disease, as well as on their families and other carers. People with dementia experience declining cognitive function that, over time, affects their ability to live independently and can shorten life expectancy. Those providing most of the care, usually spouses or adult children, experience often quite heavy demands on their time and energy, which can have a long-lasting impact on their own health, employment and wellbeing.

## This document

### Purpose

Connecting People, Connecting Support is about how allied health professionals (AHPs) in Scotland can support people with dementia, their families and carers (referred to collectively as people living with dementia) to live positive, fulfilling and independent lives for as long as possible.

The document presents an evidence-informed case to support an approach to practice for AHPs working with people living with dementia – what we call the AHP approach – with the intention of promoting local integration and implementation.

In addition to defining AHPs' contribution to promoting the key messages from Scotland's National Dementia Strategy 2013–2016 (Scottish Government, 2013), it also delivers on a specific strategy commitment:

#### **Commitment 4**

*We will commission Alzheimer Scotland to produce an evidence-based policy document outlining the contributions of AHPs to ensuring implementation of the 8 Pillars model.*

Commitment 10 from Scotland's National Dementia Strategy 2017–2020 (Scottish Government, 2017a) confirms support for the implementation of Connecting People, Connecting Support.

The outcome of these commitments is to ensure that people living with dementia are provided with AHP information appropriate to their needs and that AHPs are in a position to provide advice, education and information to people living with dementia when they need it.

Going forward, implementation of Connecting People, Connecting Support's ambitions and actions for change will also support implementation of the National Dementia Strategy 2017–2020, the Active and Independent Living Programme (AILP) (Scottish Government, 2017b) and other ongoing dementia-focused policy initiatives in Scotland. The human rights-based approach that informs all aspects of the National Dementia Strategy is reflected in the Standards of Care for Dementia in Scotland (Scottish Government, 2011) and has provided a strong foundation for Connecting People, Connecting Support.

### The vision

Connecting People, Connecting Support will ensure the rehabilitation and enablement skills and expertise of the AHP workforce have an even greater positive impact on the lives, experiences and outcomes of people living with dementia than is currently the case. The aspiration is that people living with dementia have better access to a range of AHPs regardless of age or place of residence, early in their diagnosis and throughout their illness.

Connecting People, Connecting Support informs people living with dementia about the AHP-led support available to them, offering them informed choice on potential beneficial interventions. It promotes an integrated and co-ordinated AHP approach of multifactorial interventions through improved understanding of AHP roles across all professional groups and making AHP-led interventions more accessible to the public.

## Audience

Connecting People, Connecting Support will be of interest not only to people living with dementia and practising AHPs, but also integration joint boards, health boards, health and social care managers and practitioners, AHP leaders, social services and the third and independent sector.

## Dementia is every AHP's business

The allied health professions are a distinct group of health professionals who apply their specific expertise to improve health, prevent illness, diagnose, treat and rehabilitate people of all ages and conditions working across all sectors and specialties.

AHPs often work as first point of contact practitioners and, together with a range of technical and support staff, deliver direct care, emergency and anticipatory care, rehabilitation and public health

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### Arts therapist

The term arts therapies incorporates the four separate professions of: art therapy; dance movement psychotherapy; drama therapy and music therapy. Arts therapists use the specialisms of art, dance, drama and music as a therapeutic intervention to help people with physical, mental, social and emotional difficulties.

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### Diagnostic radiographer

Diagnostic radiographers produce high-quality images using mainly digital recording media, ionising and non-ionising sources of radiation and ultrasound. With advanced education image reports are provided by some radiographers. Radiographers also provide care across a wide spectrum of health services.

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### Dietitian

Dietitians are qualified health professionals who assess, diagnose and treat diet and nutrition problems at an individual and wider public health level. Uniquely, dietitians use the most up-to-date public health and scientific research on food, health and disease, which they translate into practical guidance to enable people to make appropriate lifestyle and food choices.

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### Occupational therapist

Occupational therapists work with people and their families to develop and maintain a routine of everyday activities that creates a sense of purpose and supports a good quality of life. Typically, they look at a person's self-care, leisure and work activities and their hopes and aspirations. They also advise on changes to the home, and on technology and equipment to aid people's memory or help keep them safe.

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### Orthoptist

Orthoptists assess and manage a range of eye problems, mainly those affecting the way the eyes move, such as squint (strabismus) and lazy eye (amblyopia).

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*As of June 2017, 11,492.6 AHPs were working in health care in Scotland (ISD, 2017a), with approximately 500 occupational therapists in social services (ISD, 2017b).*

interventions, and enabling services across social care and housing services. The professions and their roles are outlined in Table 1.

All AHPs will most probably meet someone living with dementia at some point in their professional or personal lives, but for some, such as occupational therapists, physiotherapists, dietitians, and speech and language therapists, working with people living with dementia will be the prime focus of their role.

Dementia is increasingly becoming part of the core remit for AHPs in acute settings as people with dementia over 65 years of age are currently using up to one quarter of hospital beds at any one time (Alzheimer Society, 2009). They are more likely to be admitted to hospital than people without dementia due to co-existing conditions and/or secondary complications of dementia, such as falls, fractures and infections (Health Improvement Scotland, 2017). An estimated two thirds of people living with dementia live in the community, and one third in care-home settings (Alzheimer Society, 2013).

*Table 1. The allied health professions*

<b>Orthotist</b>	Orthotists assess, diagnose and treat conditions which lead to functional problems and that can be helped with the use of body-worn devices known as orthoses (splints, braces etc.). These provide support to parts of a patient's body to compensate for muscle weakness, provide relief from pain or prevent physical deformities from progressing.
<b>Paramedic</b>	Paramedics attend people suffering traumatic, health or social care crisis, carrying out full assessments and initiating a wide range of treatments. These can include transfer to secondary care but can also include referral to other services or home discharge with robust safety-netting. Specialist paramedics also work in ambulance control centres, primary care and as part of specialist critical care teams.
<b>Physiotherapist</b>	Physiotherapy helps restore movement and function when someone is affected by injury, illness or disability through movement and exercise, manual therapy, education and advice. Physiotherapy uses physical approaches to promote, maintain and restore physical, psychological and social well-being.
<b>Podiatrist</b>	Podiatrists, sometimes known as chiropodists, specialise in keeping feet in a healthy condition. They play a particularly important role in helping older people to stay mobile and, therefore, independent.
<b>Prosthetist</b>	Prosthetists assess and provide care and advice on rehabilitation for service users who have lost or who were born without a limb, fitting the best possible artificial replacement
<b>Speech and language therapist</b>	Speech and language therapists assess, diagnose and manage a range of communication and swallowing needs. The role also encompasses the training of others and making environmental adaptations to support communication, eating and drinking.
<b>Therapeutic radiographer</b>	Therapeutic radiographers treat mainly cancer patients using ionising radiation and, occasionally, drugs. They provide care across the entire spectrum of cancer services.

While dementia is often viewed as an isolated illness, people living with dementia have a high prevalence of comorbid medical conditions (Scrutton & Brancati, 2016). AHPs in community settings will therefore be working with people with dementia in their day-to-day practice. There is huge motivation among the AHP workforce to do their best for people living with dementia, whether they consider this as their area of specialty or not.

For the benefits of AHP-led contributions to be realised for all people living with dementia, and for the AHP contribution to be integrated and co-ordinated, AHPs require new ways of thinking and working that increase their visibility and access to the people who will benefit from their involvement.. People need person-centred services from a skilled AHP workforce who see treating the symptoms of dementia as very much "their business". Connecting People, Connecting Support sets out to make this happen in Scotland.

## National direction of travel

Any practical approach developed to enable AHPs to more appropriately and effectively meet the needs of people living with dementia cannot occur in isolation. It needs to reflect, complement and support implementation of the wider policy context – national and international – that influences and affects the lives of people living with dementia.



Connecting People, Connecting Support aligns to A Plan for Scotland (Scottish Government, 2016) and has resonance with the four underpinning priorities within the plan that will help bring about long-term improvements to the health of the population:

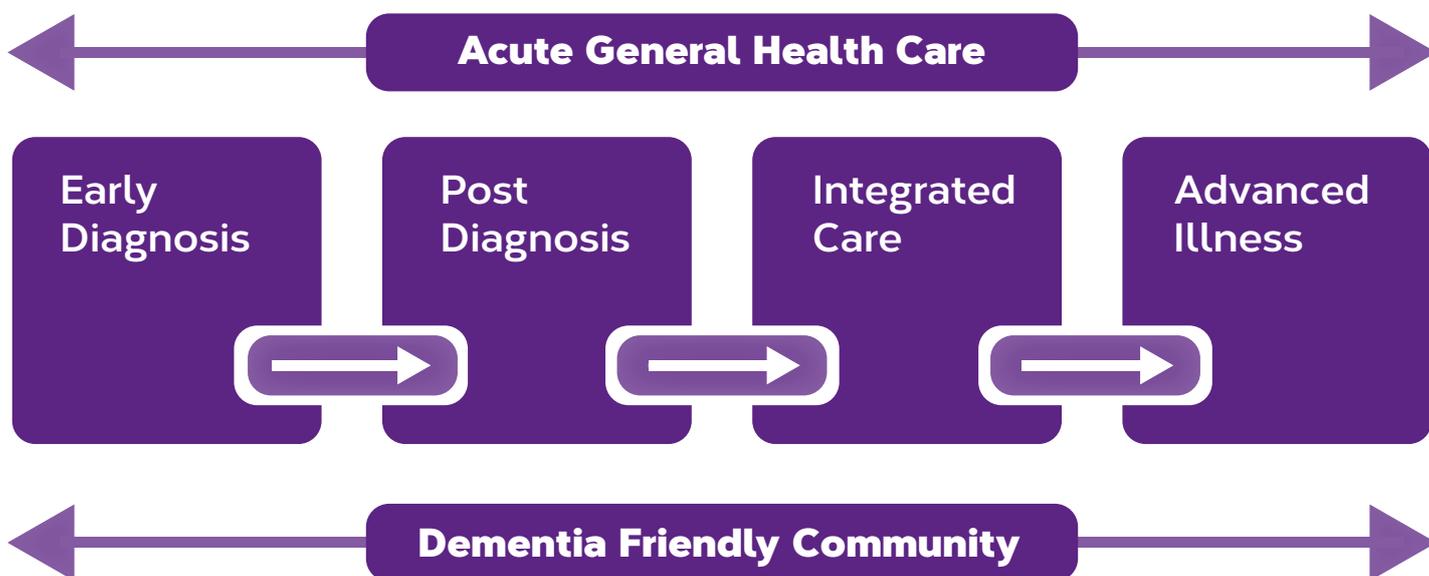
- empowering a truly community health service
- enhancing mental health
- improving population health
- supporting clinical leadership of transformation.

Significant policy initiatives in Scotland include the integration of health and social care, the National Health and Wellbeing Outcomes, shifting the balance of care from hospitals to communities, measures to improve experiences and outcomes for older people, the roll out of self-directed support, the National Clinical Strategy, the Health and Social Care Delivery Plan, and dementia-specific initiatives, spearheaded by Scotland's national dementia strategies and the post-diagnostic commitment for everyone newly diagnosed. These drivers are focused on enhancing people's self-management capacities, promoting independent living, providing services in or close to people's homes, and delivering truly person-centred care.

Also significant to the work of AHPs is the AILP. This will support AHPs, working in partnership with fellow health and social care staff, to deliver key elements of the Health and Social Care Delivery Plan and other national policies. It sets out six overarching ambitions to drive significant culture change in how people can access and receive AHP support for prevention, early intervention, self-management, rehabilitation and enablement services. An improvement programme within AILP will drive this agenda by delivering improvements in support for people to manage their wellbeing, live active and independent lives, become or remain economically active and participate in their local communities (Scottish Government, 2017b).

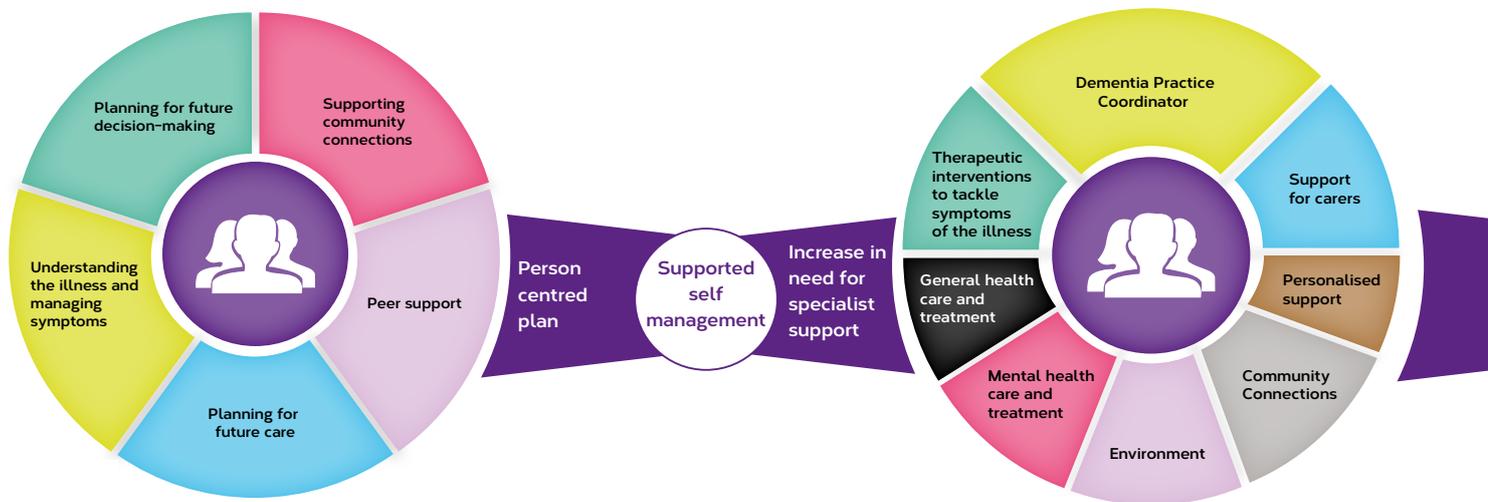
Alzheimer Scotland has a clear vision for change, prioritising six key areas of focus if people living with dementia are to be properly supported and their human rights respected from diagnosis to end of life and in every setting. (Figure 1).

*Figure 1. Transforming the system: improving lives*



## 5 Pillars Model

## 8 Pillars Model



© Alzheimer Scotland 2012, 2014, 2015

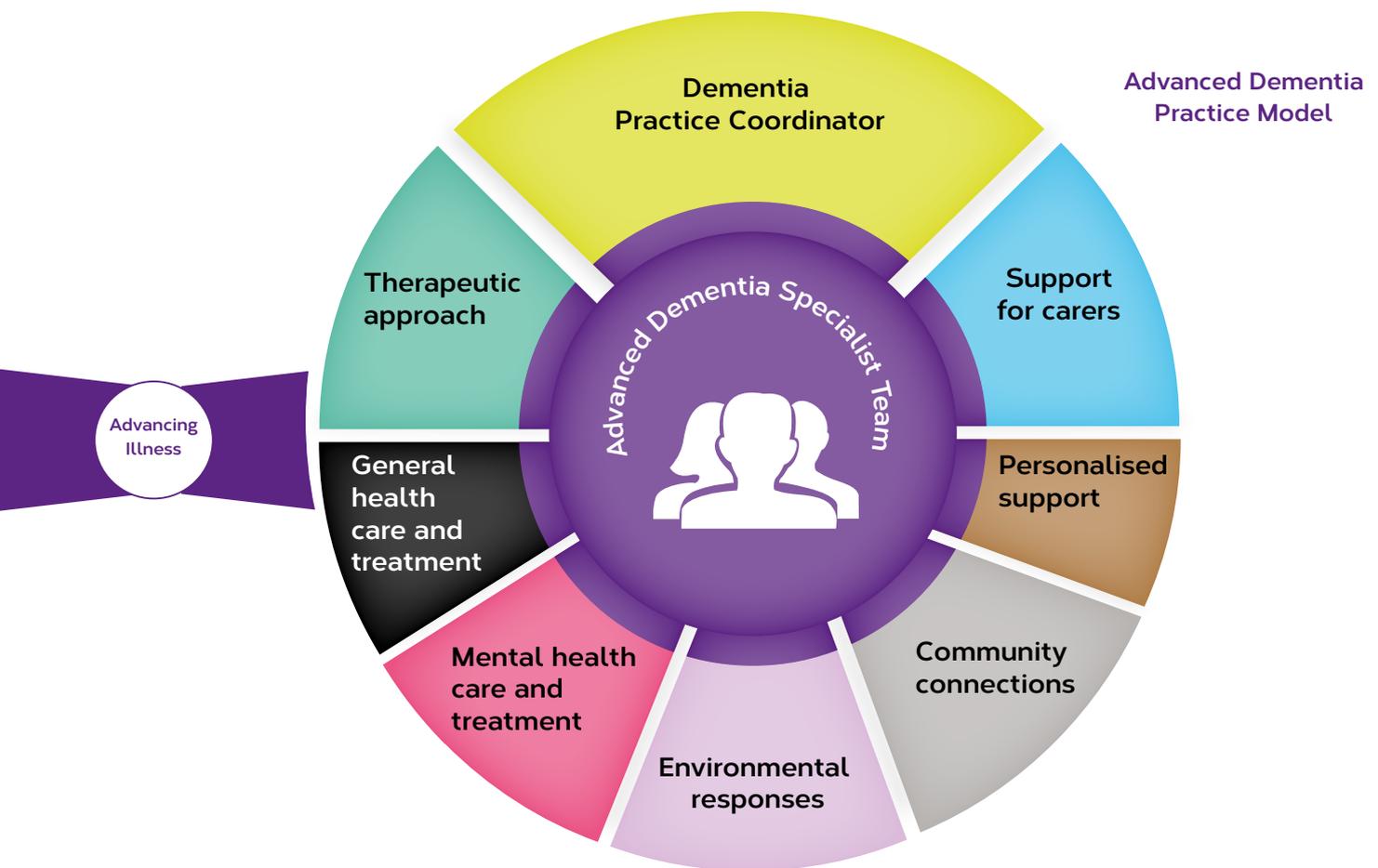
Alzheimer Scotland has developed three evidence-based models to support transformational change for people living with dementia in Scotland from diagnosis (the 5 Pillars Model of Post-diagnostic Support) (2011), through a period of self-management to an integrated model of community support (the 8 Pillars Model of Community Support) (2012), on to a model to better understand and transform advanced dementia through more intensive support (the Advanced Dementia Practice Model) (2015) (Figure 2). Together, these evidence-based models of practice provide a human rights-based approach to the care, support and treatment of people living with dementia throughout their illness, beginning at post-diagnostic support (5 Pillars Model), through to community-based support (8 Pillars), and then end of life support (Advanced Dementia Model).

Care co-ordination through case management provided by an enhanced practitioner (either a link worker or dementia practice co-ordinator) who is a named contact to support the person and family forms a key component of all the three models, while also incorporating community assets.

The Scottish Government has adopted the 5 Pillars Model and has tested the 8 Pillars Model (Scottish Government, 2017c). These are central to the Scottish Government's commitments to supporting people living with dementia from diagnosis throughout the illness. The National Dementia Strategy 2017–2020 commits to testing the Advanced Dementia Practice Model.

The AHP approach to people living with dementia we describe in *Connecting People, Connecting Support* reflects and specifically responds to the current policy environment and takes account of wider transformational change occurring in health and social care in Scotland. It demonstrates clearly how the policy drive of enabling self-management, promoting independent living, changing the service focus from institutions to people's homes and communities, and promoting a human rights-based and person-centred approach in service delivery is an exact match with the aims, aspirations and capabilities of AHPs.

Figure 2. Support through the 5 Pillars, 8 Pillars and Advanced Dementia Practice models



## Evidence for Action

AHP interventions need to be supported by evidence. The evidence base for embedding the AHP approach in dementia care and support in Scotland is growing, and must be recognised and integrated.

Work was therefore taken forward with a wide range of stakeholders to identify the evidence base that would underpin the AHP approach. As well as evidence developed through research, the work also drew heavily on the lived experience of people with dementia collected by Alzheimer Scotland. A national scoping exercise of the contribution of AHPs to post-diagnostic support was undertaken and Alzheimer Scotland commissioned research on the impact of AHP consultants' leadership role.

Following over two years of extensive consultation and information-gathering, the evidence for action therefore reflects three sources:

- **conversations** with people living with dementia using appreciative inquiry approaches to support participants to effect self-determined change by identifying what works best for them
- **collaboration** with health and social care practitioners, higher education institutions and AHP professional bodies through national and local engagement events and publications
- **evidence** from research, literature reviews and scoping evaluations exploring in depth the available evidence to support AHP-led interventions in dementia care (Figure 3).

All of the work undertaken, including resources developed to support and inform Connecting People, Connecting Support outlined in Figure 3, can be found on the Alzheimer Scotland website [[www.alzscot.org/ahp](http://www.alzscot.org/ahp)].

The wide range of evidence explored provides a rich foundation from which to build and enhance AHP interventions. While the formal evidence base is relatively new and is still emerging, it is beginning to identify specific AHP interventions that bring benefits. Our understanding of what works will continue to grow as the evidence base develops. The key themes identified from the evidence underpin, and are embedded in, the AHP approach described in Section 2.

# 1. Conversations with people with dementia and their families

## Social media

Blog: "Let's Talk about Dementia" [www.alzscot.org/talking\\_dementia](http://www.alzscot.org/talking_dementia)

At the time of publication (September 2017), the blog's reach was:



In June 2014, we launched our blog site "Let's Talk about Dementia", hosted and supported by Alzheimer Scotland and led by AHPs. The blog has offered us a new way to connect to people living with dementia and has provided a platform for individuals to voice their views and share ideas.

## Connecting people through conversations and inquiry

During March and April 2015:

10 AHPs hosted 20 engagement conversations with over 50 people living with dementia.

The conversations took place wherever the people naturally came together across Scotland.



## Ask an AHP Blethers

Three years of participating in Scotland's dementia awareness week around Scotland from Inverness to Dumfries and Ayrshire to Edinburgh resulted in:



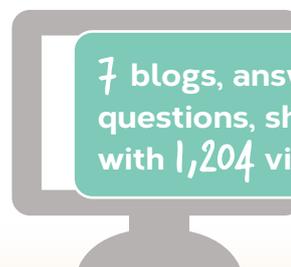
over 2,000 AHP leaflets and postcards being shared



52 AHPs took part in over 200 conversations



7 stands being hosted at national conferences - over 3,000 participants



7 blogs, answering 22 questions, sharing 56 photos with 1,204 views

## 2. Collaboration with health and social practitioners

7 national engagement events with over 1,000 health and social care staff

Three publications written and shared at conferences, AHP stands and online sharing:



### Building Bridges, an AHP practice education programme

Over three years, 100 plus AHP students, AHP interns and AHP volunteers from 6 of the AHP professions:



## 3. Evidence from research, literature reviews and scoping evaluations

### Impact of the AHP dementia consultants in Scotland

- National survey of 383 AHPs in NHS and local authority settings
- Interviews with sample of 14 survey respondents
- Interviews with 16 national and local strategic stakeholders
- Interviews with 4 AHP consultants

### National scope of AHP contribution to post-diagnostic support

- National survey completed by 147 AHPs from dietetics, occupational therapy, physiotherapy, podiatry and speech and language therapy
- National survey completed by 49 Alzheimer Scotland post-diagnostic link workers
- Semi-structured interviews with 9 Alzheimer Scotland post-diagnostic link workers and 7 AHPs
- Resulted in 5 areas for action identified and 2 improvement programmes developed

### Systematic review

215 papers included in a review of AHP interviews for people living with dementia, including

- 172 primary research reports
- 34 systematic reviews of 543 studies
- 22 literature reviews of 489 papers

## Section 2. The AHP approach

## The AHP approach

The AHP approach is applicable for all people with a diagnosis of dementia and in all care settings, including younger people living with dementia, people with rarer types of dementia and those who may also be living with another long-term condition. It is underpinned by principles of human rights, using the PANEL (Participation, Accountability, Non-discrimination and equality, Empowerment and Legality) approach as a framework (see boxed text) (Alzheimer Scotland, 2017), person-centeredness, and collaborative and partnership working, and is informed by models of good practice.

### The PANEL approach to human rights

The PANEL principles provide a strong framework for ensuring that a human rights-based approach is adopted in practice. The approach promotes:

- Participation – everyone has the right to participate in decisions that affect them in a way which is accessible and meaningful to them
- Accountability – effective monitoring of human rights standards as well as effective remedies for human rights breaches
- Non-discrimination and equality – all forms of discrimination in the realisation of rights are unacceptable
- Empowerment – individuals and communities should understand their rights and be fully supported to participate in the development of policy and practices that affect their lives
- Legality – recognising that rights are legally enforceable entities and are linked to national and international law.

These principles underpin the Standards of Care for Dementia in Scotland (Scottish Government, 2011a) and the Promoting Excellence framework (Scottish Government, 2011b). The elements of Participation and Empowerment have particular relevance to the day-to-day work of AHPs.

The approach aims to maximise the AHP contribution to high-quality, cost-effective dementia services that are tailored to the needs of individuals, reflect the best available evidence and are delivered by a skilled AHP workforce.

The fundamental understanding driving the approach is that people living with dementia **can** benefit from AHP-led interventions. Early intervention and support to maintain independence are critical: they can help minimise the impact of the symptoms of dementia and improve quality of life. The aim is to build on the strengths of the AHP professions collectively not by doing more, but by supporting them to work in integrated and innovative new ways.

People living with dementia benefit greatly from a biopsychosocial approach of care that acknowledges the interactions of neurological, psychological, physical, social and emotional elements. The AHP approach therefore combines the biopsychosocial approach with an integrated and co-ordinated approach to providing AHP interventions to people living with dementia.

While AHP specialists in dementia are relatively few, many more AHPs will meet and work with people living with dementia as part of their roles: the approach therefore aims to bring meaning and purpose to the work of all AHPs in relation to dementia, identifying the contribution AHPs can make to both universal and targeted AHP-led interventions.

To achieve this, the AHP biopsychosocial approach to understanding the experience of dementia and delivering AHP-led interventions – what we're calling the AHP approach – focuses on five key elements (Figure 4).

For each element we offer a definition, provide some key facts, explain why it is important when working with people living with dementia, and briefly define what will be delivered. The elements are described separately, but must be considered collectively within overall universal and targeted AHP-led rehabilitation and support for individuals.



**Figure 4. The AHP approach – five key elements**

The AHP approach reflects the fact that dementia affects people in very individual ways, and that people require tailored responses to best meet their needs, aspirations and wishes. It provides a foundational underpinning from which AHPs will be able to build, using their own skills, experience and understanding of the person to provide a service truly tailored to individual needs.

The five key elements are now described in more detail.



## Supporting families and carers



### *What*

This is about families and carers being fully involved in the AHP approach. They are equal partners in areas such as education and skills training as potential co-therapists, and are potential recipients of AHP-led interventions to meet their own health and wellbeing needs (developing coping strategies and accessing support to maintain their own hobbies and interests, for example).

### **Key facts**

Living with a carer has been shown to have a protective effect in delaying a person with dementia entering institutional care (cited in Alzheimer Scotland, 2012).

Key recurring interventions that have proved beneficial in experimental studies that involve carer interventions include problem-solving and coping strategies (Pentland, 2015).

There is evidence that caregiver psychosocial interventions, particularly those that include multiple interactive components, can be beneficial in improving caregiver mood and quality of life (Alzheimer Disease International, 2011).

### *Why*

People with dementia living in the community are frequently supported by informal carers, including spouses/partners, other family members, friends and neighbours. Family carers of people with dementia have higher rates of depression and anxiety, and experience high levels of stress and distress (Petriwskyj et al., 2015). The process of taking on a caregiving role is often experienced as an unexpected and unplanned event and transition; there is a growing realisation of the need to ensure family carers have access to services that can support them (Ógáin & Mountain, 2015).

Family involvement is often the key to the success of home-based interventions and many AHP-led interventions (Pentland, 2015); individual family members are experts about the person and his or her care needs.

Family carers have the right to have their own needs met, to maintain quality of life, to have fun, and to have their hopes and dreams fulfilled. This can be supported through assessing carers' needs, developing care plans, and promoting the social support of being connected to their local community.

Families' and carers' expertise and knowledge and the quality of the care they provide for the person must be acknowledged. The adverse impacts of caring can be reduced with appropriate and timely AHP support to prevent crises. It is everyone's job to identify and support carers, and their physical and emotional needs should be considered independently of the person with dementia.

### *How*

#### **Families and carers as equal partners in care**

AHPs develop effective strategies and involve family members in AHP-led interventions, identifying methods of working with families and carers so that the voice of the person with dementia is heard and his or her needs are balanced with those of carers in ways that do not compromise the caring relationship.

Family members can provide essential knowledge about the person with dementia to inform the therapeutic process and provide feedback about the degree of therapeutic success. Their engagement is crucial in providing continuity of AHP-led therapeutic strategies within daily routines at home and in the community. Partnership-working between AHPs and families also enables skills and routines to be maintained during episodes of general hospital admission and at discharge.

## **Maximising families' and carers' physical health and psychological wellbeing**

AHPs support family members and carers to maintain their existing relationships, hobbies, interests, vocational roles and informal support networks. This helps to maintain resilience, prevent social isolation and protect their physical and psychological wellbeing. Support is offered in a range of formats and topics, including personalised support on communication strategies, advice on stress management, access to up-to-date information and advice, appropriate training on equipment and access to adaptation services. Evidence suggests that positive feedback from professionals has an enormous effect in keeping people feeling positive about their caring role (Dewar & MacBride, 2015).

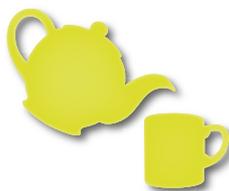
## **Joint working with health and social care practitioners**

AHPs have always worked with other health and social care practitioners to support people's rehabilitation. This continues to be a priority for people living with dementia. Assessment, interventions and family-carer support are more effective when the health and social care team works in collaborative, inter-professional ways with people living with dementia. The approach is therefore designed to be implemented within multidisciplinary, multi-professional teams working collaboratively across agency lines.

AHPs work directly with health and social care practitioners, including dementia link workers, dementia advisors, and people from the third and independent sectors, providing creative and innovative opportunities for skills-sharing, skills development, joint working and training. AHPs will signpost people living with dementia to other services, such as care and repair, leisure, established community groups and voluntary services, to enhance independent living. There is also a significant opportunity for the AHP contribution to be incorporated and co-ordinated within the care home sector.



## Enhancing daily living



### *What*

The ability to wash and dress, prepare food, use transport, engage in everyday life, do things around the house, have fun, work, study, and take part in family and leisure activities is important for overall health wellbeing and integral to good-quality dementia care.

People with dementia can be supported to continue to engage in the life of their community, whether that be a city, town, village, neighbourhood or care home, extracting value from their everyday participation in activities and enhancing their wellbeing. A range of evidence-informed, home-based AHP rehabilitation interventions exists to support people in their activities of daily living, with developing evidence on the role of vocational rehabilitation for those of working age.

### *Key facts*

Therapeutic interventions to engage people with dementia and carers that include meaningful occupation, daily living activities and environmental adaptations are associated with significant positive effects on people's ability to participate in daily life activities (Laver et al., 2016).

Maintaining a work or volunteering role may help to preserve the dignity and sense of self of people living with dementia and, at the same time, enable carers and family members to continue to work and support the person (Roach & Drummond, 2014).

An assessment in the home followed by environmental and compensatory strategies appears to improve health and quality of life for people living with dementia and their caregivers (Letts et al., 2011).

### *Why*

There is increasing evidence about the importance of occupation and activity for people with dementia (Harmer & Orrell, 2008; Travers et al., 2015), with research evaluations acknowledging that interventions individually tailored to meet people's interests, preferences and abilities are more effective. Providing opportunities and choice in activities should be an integral aspect of dementia care and treatment in communities, people's homes and hospital and care-home settings (Phinney et al., 2007; Smit et al., 2016).

Having a purpose in life is a fundamental human need and is important to maintaining health and wellbeing. Occupation, which is defined as being "involved in the process of life in a way that is personally significant and which draws on a person's abilities and powers" (Kitwood, 1997), is one of the five main psychological needs of people with dementia.

Recreational activities provide an opportunity for people with dementia to engage in meaningful activity and meet their needs for communication, self-esteem, sense of identity and relaxation, and help to promote physical wellbeing. The recommendation or decision to cease driving, for example, is a significant milestone in the lived experience of dementia (Berndt et al., 2015): there is therefore a requirement for people to be supported to consider how recreational activities are maintained by using alternative transport (Hawley, 2015).

Evidence is emerging of the positive impacts of adapting complex AHP interventions in home and community settings (particularly by occupational therapists and physiotherapists) in maintaining people's function in the community, supporting families and carers, and increasing feelings of competence and self-efficacy, all of which can result in improved quality of life for people living with dementia. The key components are that the interventions are tailored, individualised, delivered by AHPs (Pitkälä et al., 2013; Wesson et al., 2013; Pentland, 2015; Hynes et al., 2015) and build on developing and current literature on early intervention (Graff et al., 2006; Wenborn et al., 2016), supported self-management (Mountain, 2006; Mountain & Craig, 2012; Sprange et al., 2015; Quinn et al., 2016; Craig, 2017) and rehabilitation (Gitlin et al., 2009; Marshall, 2005).

Both the evidence base for, and interest in, people living with dementia remaining at work are increasing (Chaplin & Davidson, 2016; McCulloch et al., 2016). People with early onset dementia who are in employment can continue working with the correct support. Initial evaluations of work-based projects have demonstrated successful programmes designed to support people with dementia in supported or open employment (Kinney et al., 2011; Robertson et al., 2013; Robertson & Evans, 2015). Explorations of the experience of people with dementia in employment highlights that vocational rehabilitation is primarily carried out by AHPs (Ritchie et al., 2015) and that continued employment post-diagnosis can be beneficial for people with dementia (Ritchie et al., 2017).

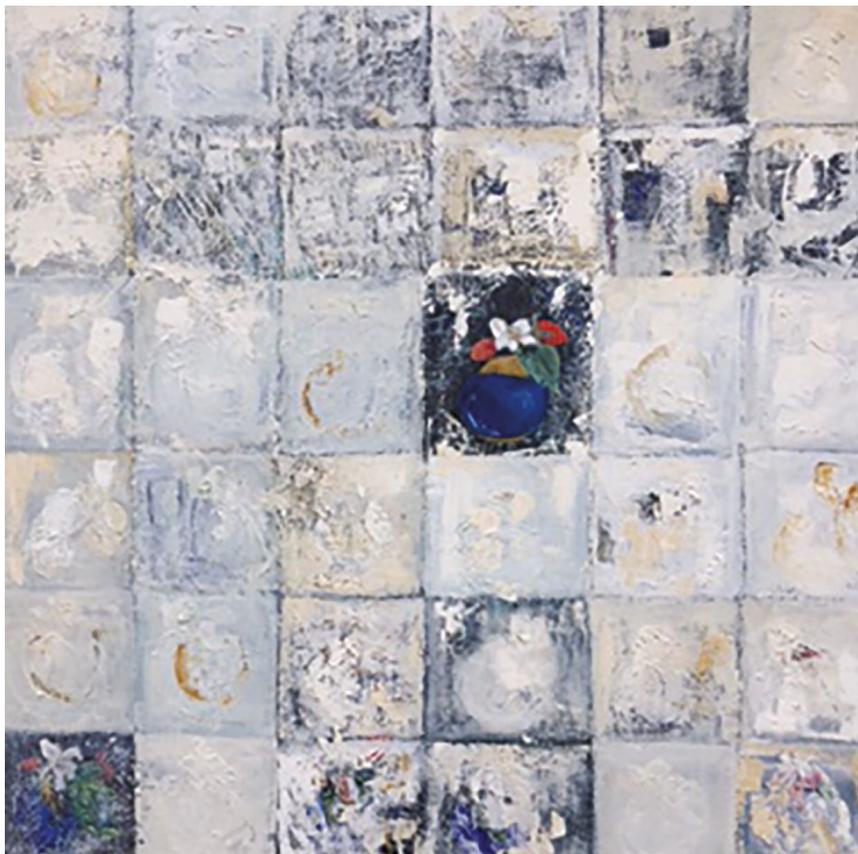
Dementia and work will also be a potential issue for organisations and employers as the workforce ages, the retirement age rises and the number of people with dementia increases (Centre for Economics and Business Research, 2014). There is also a need to support family members who may wish to continue to work while in the caring role.

## ***How***

### **Valuing everyday activities**

Therapeutic activities are delivered by a range of health and social care staff, third sector practitioners and volunteers with appropriate training and supervision, which is vital for the benefits of engagement in activities to be realised. AHPs, particularly occupational therapists, can play an important and collaborative role as experts in understanding the intrinsic relationship between person, environment and occupation, using assessment tools and models of practice to identify personalised meaningful activities. They can break down activities into fundamental components, develop compensatory techniques, adjust activities to individual preferences and strengths, and offer activity strategies to encourage maximum engagement.

AHPs support people to remain engaged in everyday activities through a risk-enablement approach that enhances the person's ability to retain identity and a sense of purpose. AHPs work directly with health and social care practitioners, including dementia link workers and those in the third and independent sectors, providing creative and innovative opportunities for skills-sharing, skills development and training.



## Enhancing vocational and educational opportunities

AHPs play a central role in helping people to remain and/or return to work and manage their health and wellbeing, with many examples of vocational rehabilitation initiatives led by AHPs in partnership with job centres or employment agencies creating employment pathways. They assess functional abilities in clinical settings and workplaces to provide the most appropriate solutions to deliver long-term benefits, with many having completed extended training courses specialising in vocational rehabilitation.

AHPs, particularly occupational therapists and physiotherapists, can help keep people at work by advising employees on their fitness for work and successful return, and offering recommendations to employers on modifications and reasonable adjustments to help the person with dementia remain in work (Allied Health Professions Federation, 2012). Speech and language therapists can offer advice to employees and employers on communication modifications and workplace support strategies. Post-employment support will be integral to AHPs' roles, allowing people to consider alternative work opportunities if appropriate.

## AHP-led targeted rehabilitation interventions

AHPs are delivering successful AHP-led targeted interventions in people's homes and in the community that focus on the symptoms of dementia. The starting point for AHP-led interventions is a dynamic and specialist skilled assessment. From individual assessments, often in the person's own environmental context, personalised and tailored personal outcome plans are developed to best meet the person's needs, aspiration and wishes, focusing on assets and strengths. The use of personalised and tailored outcome plans align with key Scottish Government policy areas, including the national post-diagnostic commitment.

The rehabilitation strategies will incorporate modifying environments, simplifying tasks, establishing routines and repetitive practising of tasks, with a strong emphasis on quality of life.



## Adapting everyday environments



### **What**

Adapting everyday environments relates to where the person is staying, whether in his or her own home, a care home or in hospital, and to community settings and outside spaces. Changes can be small, such as improving lighting in a room or enhancing environments by using everyday technology, or making things easier for people through installing equipment or other adaptations.

### **Key facts**

Environmental assessment and modification significantly reduces not only the number of falls people experience, but also the number of people who fall (Pighills et al., 2015).

All home adaptations should be considered as early as possible to ensure the needs of people with dementia are person-centred, well planned and promote living well at home for as long as possible (Brown et al., 2017).

Telecare can provide a high-quality, cost-effective service to support a significant proportion of people with dementia to live in the community. The key resource saving is likely to be avoidance of care-home admission (Craig & Sanderson, 2012).

### **Why**

Most people with dementia live in the community and their quality of life can be significantly improved by ensuring their home environment is well designed. There is a good research base demonstrating how small changes can make a big difference in enabling people to live at home for longer (Allen et al., 2017), stay independent, remain physically active, reduce falls and enhance psychological wellbeing. Suitable seating and postural management can enhance people's ability to engage with those around them, eat and drink independently, and take part in activities.

Specific attention needs to be paid to the environment for people with dementia, whether at home, in a care home or during a stay in hospital (Dementia Services Development Centre, 2013), with specific consideration given to lighting, contrasting colours, noise levels, access to outside spaces and creation of a relaxing environment. Solutions can be integrated in the design of, or modifications to, a person's home or by selecting suitable everyday items, such as transparent kettles to enable people to see when the water is boiling (Scottish Dementia Working Group, 2015).

Current, new and developing technology can improve quality of life and support people to stay in their own home for as long as possible, helping people to feel confident, maintain routines, connect to families and friends, go out and share interests and hobbies. Evaluations of the use of technology suggest the need for it to be tailored, individually integrated into everyday lives, discrete and devised to support completion of the practical activities viewed as most important by the person (Pentland, 2015).

### **How**

#### **Enabling environments**

AHPs understand the potential impact of environment and how it affects health and wellbeing. They can demonstrate this in their day-to-day practice by completing assessments that focus on how the person interacts with the environment, offering advice on small modifications, and suggesting simple changes to the physical environment in four priority areas: improving lighting; ensuring flooring/paving is consistent in tone; ensuring the toilet is easy to find; and ensuring good contrast in the toilet/bathroom (Dementia Services Development Centre, 2013).

Many AHPs currently offer advice on these issues as they relate to a home environment, hospital (Parkinson & Bushrod, 2012), care environment or as an aspect of routine AHP practice. The purpose is to enable the person with dementia to stay engaged at meal times (thereby enhancing nutritional intake).

walk safely and minimise falls, promote engagement in meaningful activities and maximise orientation (Marquardt et al., 2011).

### **Using everyday technology**

AHPs working with other specialists can support and offer advice on the use of assistive technology to support independence, enable people to manage their own health, safely fulfil personal aspirations, and stay connected with family and the wider community.

AHPs currently integrate everyday technology use in practice, including extending service reach in rural areas using smart screens that link people in health and social care settings and connecting arts and health interventions in remote and rural communities. Digital storytelling supports communication through a low-tech communication framework, and people are being supported to use touch-screen technology to connect with others, from making contact through social media and iPad use, to conducting environmental home assessments using video conferencing. Visual memory-prompts to support daily activities can be supported by technology, and telecare is becoming integral to supporting older people at home who have experienced a fall.

### **Equipment and adaptations to the home**

AHPs, particularly occupational therapists, assess how people interact with the environment and recommend specialist daily living equipment (and the space required to use it) (Walker, 2017). They identify potential adaptations to the home and suggest equipment that can contribute to promoting occupational engagement, independence, health and wellbeing (Boniface et al., 2013).

Advice on adaptations and equipment will reflect current and future needs, what is feasible for the person to remain in his or her own home, how someone may feel about using equipment or having their home changed, how equipment or adaptations may be installed, ongoing maintenance and associated regulations. Occupational therapists who specialise in housing may also contribute to broader housing agendas, advising on adaptations and design that will optimise people's independence in day-to-day living activities.

Equipment will range from small to large pieces, such as toilet seats, bathing equipment, ramps, wet-floor showers and stair lifts. AHPs can provide assessments of suitable seating and specialised chairs, postural management advice to optimise health and wellbeing, and advice and interventions with others to ensure the suitable and accurate provision of any equipment and adaptations to the home.



# Maximising psychological wellbeing



## *What*

The central importance of finding ways to communicate (verbal and non-verbal) that work for each individual and which make meaningful connections that may have wide-ranging benefits in relation to overall wellbeing and quality of life is recognised. Psychological interventions of different intensities are reflected to promote emotional health and psychological wellbeing, with the provision of psychological interventions for depression, anxiety, and expressions of stress and distress. This element builds on established AHP psychological interventions and therapies.

## *Key facts*

There is evidence to support training for communication partners in conversation skills and cuing strategies. Communication-skills training in dementia care significantly improves the quality of life and wellbeing of people with dementia and increases positive interactions in various care settings (Eggenberger et al., 2013).

Psychological interventions can play a key role in improving the wellbeing of people with dementia and their families and carers (British Psychological Society, 2016).

Music therapy can significantly improve and support mood, alertness and engagement, reduce use of medication, and help manage and reduce agitation, isolation, depression and anxiety (Ridder et al., 2013).

## *Why*

People with most types of dementia will at times struggle to find the right words or follow a conversation. Language impairment affecting speech and/or understanding may be an initial presenting feature for some people, and sensory impairment (such as visual and hearing loss) can further affect their ability to communicate effectively.

Communication difficulty can be exhausting for the person, families and carers and affects his or her identity, relationships and social functioning. Frustration can lead to distressed behaviour as the person attempts to make sense of the environment or communicate an unmet need.

The psychological needs of people living with dementia is well documented. We know that people can often find it difficult to talk about dementia, with three quarters of people with dementia and two thirds of caregivers saying that others perceive those with dementia negatively. Many people living with dementia experience social isolation due to withdrawal from friends and other important people in their lives (World Health Organization, 2012).

Dementia can have a profound psychological impact and may be linked to feelings of anxiety and depression. A non-pharmacological therapeutic approach is advocated for the treatment of psychological symptoms and a person-centred stepped-care model of support.

## *How*

### **Maintain and maximise communication**

AHPs are aware that optimum communication occurs in environments that are comfortable, where a person can feel relaxed and safe, and when the AHP-led intervention is tailored and individualised. AHPs have experience in training others in conversation skills and cuing strategies, identifying key elements for effective everyday communication and supporting opportunities to practice communication strategies in a social context, helping the person to gain confidence in the interaction.

Speech and language therapists can provide personalised communication advice (aimed at, for example, developing communication passports, assessing communication networks and maximising communication opportunities) that is shared with family members to facilitate their communication

skills. Where language difficulties present as a primary feature of the dementia, as in primary progressive aphasia, speech and language therapists will carry out assessments to identify specific communication impairments and abilities. Their findings will contribute to the diagnosis and be used to plan therapy and strategies.

### **Psychological approaches**

AHP core psychological skills are unique to each profession and vary according to their undergraduate education and postgraduate development activity. AHP interventions to maximise psychological wellbeing require excellent communication skills and the ability to integrate psychological interventions and psychological therapies into core AHP practice.

A number of approaches based on the psychological understanding of dementia and its effects, including reminiscence approaches, life-story work, anxiety management, and engaging in everyday occupations and activities, will be core to AHPs' day-to-day practice.

With additional enhanced training opportunities, **psychological interventions** can also become core to AHP roles and integral to a team approach to a stepped-care model of assessment and intervention. Psychological interventions include motivational interviewing, behavioural activation, mindfulness-based cognitive therapy, cognitive stimulation therapy, cognitive rehabilitation and cognitive behavioural therapy. Specific psychological interventions providing individualised, formulation-led interventions in response to stress and distress in dementia, ranging from low-intensity to specialist interventions, can also be within AHP remits.

**Psychological therapies** are highly specialised psychological interventions that include the established AHP disciplines of art psychotherapy and music therapy.

Art psychotherapy creates opportunities for verbal and non-verbal communication by using art to enable people to feel connected to a sense of self, other people and the environment around them. It can support people living with dementia by reducing anxiety and increasing coping skills (Safer & Press, 2011), depending on how interested the person is in art activities, art materials and how they feel about one-to-one or group activities. Art psychotherapy can be particularly helpful for people who find it hard to express their thoughts and feelings verbally, enabling self-expression and enhancing sense of self and personhood.

Music therapy builds on people's ability to respond to music to develop a therapeutic relationship and facilitate positive changes in emotional wellbeing and communication through engagement in live musical interactions. It has a robust evidence base as an effective, non-pharmacological intervention that can significantly improve and support the mood, alertness and engagement of people with dementia, reduce the use of medication, and help to manage and reduce agitation, isolation, depression and anxiety (Ridder et al., 2013).

These art-based therapies are particularly helpful when people find their emotions are too confusing to express verbally, when verbal communication is difficult or when words are not enough. Supervision for the AHP professions is integral to all of the interventions.

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“ Art psychotherapy can be particularly helpful for people who find it hard to express their thoughts and feelings verbally, enabling self-expression and enhancing sense of self and personhood. ”

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## Maximising physical wellbeing



### *What*

This is about encouraging people to be more active, with the aim of preventing the potential negative outcomes of dementia. The primary focus is factors such as mobility, physical activity and fitness, falls reduction, foot care, identification of previously undetected pain or discomfort, management of pain, diet, nutrition and hydration, and swallowing, and inclusion in physical rehabilitation approaches delivered by AHPs.

### *Key facts*

There is promising evidence that exercise programmes may improve the ability to perform activities of daily living in people with dementia (Forbes et al., 2015).

Evidence that small changes to the eating environment may be associated with increased calorie consumption and increases in weight is strong (Alzheimer Disease International, 2014).

People in hospital who have dementia show improvements in activities of daily living as a result of rehabilitation from occupational therapy and physiotherapy and are then more likely to be discharged home (Vassallo et al., 2016).

### *Why*

Physical activity benefits people with dementia in many ways, including positively influencing cognition (Groot et al., 2016), enhancing activities of daily living, independence, functional ability and psychological wellbeing, promoting socialisation (if individuals are active outdoors or in groups) and reducing feelings of loneliness and isolation. A positive connection has been shown between physical activity and improvements in balance and muscle strength (Telenius et al., 2015) and in activities of daily living, and falls reduction (Burton et al., 2015). It is therefore essential that people with dementia remain as active as they can and engage in physical activity.

People with dementia are at increased risk of falls, and the personal consequence of a fall can be significant. Increased risk is related to problems with muscle strength, balance, environmental factors and vision, and preventing falls is an important area to develop using risk-enabling principles.

Diet, nutrition and hydration play an important role in maintaining health and wellbeing. What we eat and drink can also be used to celebrate life events and demonstrate our religious, cultural or ethical beliefs. It helps define who we are and is an important part of our daily lives; it should therefore be optimised, normalised and adopted as a core aspect of dementia care.

Sensitive and inclusive design of dining rooms, kitchens, furniture, lighting and tableware can all make important contributions.

### *How*

#### **Keeping physically active**

AHPs have the knowledge, skills and expertise to promote physical activity for people with dementia through providing advice, signposting, referring on and delivering specific interventions. They can advise on how physical activity can be incorporated into people's routines, realising benefits such as prevention of muscle wasting and mobility problems, and improving sleeping routines, mood and social participation.

Exercise is a more structured form of physical activity, often with a specific goal such as increasing strength, flexibility, balance, co-ordination or cardiovascular fitness. AHPs, primarily physiotherapists, have the relevant expertise to give general advice to people living with dementia and design personalised exercise programmes to best meet needs.

Physiotherapists and occupational therapists play a crucial role in maintaining and improving people's mobility through interventions such as assessing function and activities of daily living, providing equipment and walking aids and offering gait re-education. AHPs, primarily specialist physiotherapists, have the knowledge and skills to use manipulation, acupuncture, mobilisation and electrotherapies to combat pain. Other non-pharmacological interventions used by AHPs in advanced dementia (usually physiotherapists and occupational therapists and often in partnership with families and carers) include passive movements, positioning, splinting of contractures and pressure care.

### Falls reduction and fracture prevention

AHPs play a crucial role at all stages of falls reduction and management pathways by supporting self-management of falls and fracture risk, identifying people at risk and delivering prevention interventions, such as strength and balance programmes.

Multifactorial programmes based on individual risk assessment are key evidence-based interventions to prevent and reduce falls. While these programmes can be delivered by a range of health and social care professionals, physiotherapists and occupational therapists are key to implementation. Effective interventions include individualised strength and balance exercise programmes, environmental assessments and home modifications, and use of telecare.

Good foot care can impact positively on a person's ability to self-manage and can reduce falls, lessen the risk of infection, increase independence and participation in social activities and boost psychological wellbeing. Podiatrists have the skills and knowledge to help prevent and treat foot ulceration, but can also provide evidence-based self-care advice on foot health and support people with dementia to maintain their mobility and independence. Podiatrists will also provide support to others who may be providing foot-care services.

### Eating well

AHPs, particularly dietitians and speech and language therapists, use their expertise to help people maintain adequate nutrition and hydration. Dietitians can identify, assess and, where appropriate, provide practical advice to maintain nutritional health (Molyneux, 2016) and address issues arising as a result of the dementia, including taste changes, weight gain (weight-management advice) or loss (nutritional support), hydration issues, constipation and making the eating environment more suitable.

Dietitians offer nutritional assessments, support and therapeutic dietary advice, translating evidence into practical advice. Speech and language therapists assess changes in swallowing function and, with dietitians, advise on compensatory strategies, including alternative ways to support nutrition when needed. The aim is always to balance risk against quality of life and the continued enjoyment of the social activity of eating. Appropriate specialist advice increases independence, helps to maintain eating skills and can reduce the risk of undernutrition, dehydration, chest infections and aspiration.



## **Section 3.**

# **Principles, ambitions and actions to transform AHP practice**

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This section outlines principles, ambitions and actions for change to support local integration and delivery of the AHP biopsychosocial approach to understanding dementia and delivering AHP-led interventions in every area of Scotland – **the AHP approach** – as outlined in Section 2.

Implementation will be supported nationally by the National Alzheimer Scotland AHP Consultant, Alzheimer Scotland (which will have a strategic leadership role to oversee and support implementation) in partnership with the Scottish Government, NHS Education for Scotland and Healthcare Improvement Scotland (HIS). More crucially, however, AHPs will lead the development and strengthening of partnerships for delivery and co-design of local solutions. All of this activity will contribute directly to the delivery of the commitments set out in Scotland's National Dementia Strategy 2017–2020 (Scottish Government, 2017a) and achievement of the ambitions of AILP (Scottish Government, 2017b).

AHPs in Scotland have made great progress in their practice in dementia care, treatment and support, and can now build on these achievements. There is still much to be done, however, to improve the way people can access AHPs' rehabilitation and enablement skills and "get the right care, in the right place, at the right time" (Scottish Government, 2015).

## Support to implement the AHP approach

Four underpinning principles and four ambitions for all AHPs and AHP services have been developed, with actions for change. The four ambitions have been mapped against the nine National Health and Wellbeing Outcomes (Appendix 1).

The underpinning principles are the foundations for AHP practice and the ambitions outline the vision for transformational change in the way AHPs work with people living with dementia, now and over the next three years. The actions for change describe how these changes will be integrated and implemented, with the expectation the actions will evolve over time depending on the context of local delivery plans and service redesign.

The measure of success will be how well the four underpinning principles and ambitions are implemented in practice according to local need and service demands. A logic model and measurement framework will be developed and shared by December 2017 to guide understanding of whether the changes have resulted in an improvement to the quality of care provided by AHPs as reported by people living with dementia and other key stakeholders.

## Four underpinning principles

The four underpinning principles for supporting people living with dementia for **all** AHPs are as follows.

- A **human rights-based approach** (see page 21) will be at the heart of person-centred AHP services and will be integrated into everyday AHP practice. Human rights will be at the forefront of each and every interaction, with an emphasis on participation and empowerment, and recognition of personhood, identity and value.
- AHPs will deliver services to people living with dementia using the **biopsychosocial approach to rehabilitation**, as outlined in the AHP approach, which is informed by best available evidence. They will integrate the five key elements of the approach (see page 22), best clinical practice and what people say is important to them.
- **Dementia is every AHP's business**, offering services in dementia-aware environments with people living with dementia being active contributors to the AHP rehabilitation process through a personal-outcomes approach.
- AHPs will **adapt and tailor their rehabilitation interventions**, taking into account the individual and developing needs of people living with dementia, ensuring maximum participation while supporting individual ambition and enacting a risk-enablement approach to maximise outcomes in independence.

## Four ambitions

The four ambitions supporting local implementation of the AHP approach relate to:

1. **enhanced access** to AHP-led information, supported self-management and targeted interventions to tackle the symptoms of dementia
2. **partnership and integration**, contributing to a personal-outcomes approach, multiagency pathways and integrated models of care
3. **skilled AHP workforce in dementia care**, with a commitment to clinical leadership for transforming AHP practice
4. **innovation, improvement and research**, utilising and generating research and integrating improvement science within everyday AHP practice.

Why it matters, where we are now, and ambitions and actions for change are now described for each ambition with indications of what people living with dementia can expect by 2020 as a result of actions across the ambitions that have been adapted from the guide to support the local implementation of health and social care intergration (Scottish Government, 2015).



“ We are delighted to see AHPs’ forward-looking vision for families and carers as equal partners in care. It is a vision that goes beyond appreciating our understanding of the cared-for person to a recognition of the potential value of collaboration, support for education and skills development and carers’ potential as co-therapists and recipients of AHP interventions. ”

*National Dementia Carers Action Network*

# 1. Enhanced access

*What people living with dementia can expect by 2020 as a result of action in this area:*

- *I am supported to look after my own health and wellbeing.*
- *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 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 evidence-informed AHP-led targeted interventions from integrated and co-ordinated AHP services that integrate the five key elements of the AHP approach.

## Why this matters

Transformational change in health and social care has a focus on prevention, early intervention, supported self-management and community-based treatment to help people remain as independent as possible and connected to their families and community for as long as they can. The developing evidence on the benefits of AHP early interventions, supported self-management and rehabilitation on helping people to live well with dementia is overwhelming. It is therefore imperative that AHPs develop and/or adopt models of practice based on the evidence and which reflect greater use of self-management, technology-based, co-created and partnership approaches.

The public and people living with dementia are looking for information to help them stay well at home and build their resilience. They also want to understand how AHPs can help them and how they can access their services, levels of each of which are currently inconsistent. People are looking for good-quality, dignified, respectful and therapeutic treatment in all care settings – at home, in a care home or in acute and specialist NHS facilities.

The evidence base informing this work defines how successful rehabilitation relies to a great extent on how AHPs adopt an enabling approach that promotes resilience for people living with dementia. The evidence supports therapy being individualised, personalised, focused on people's strengths, inclusive of families and delivered across multiple sessions (Pentland, 2015).

## Where we are now

A key outcome of Scotland's National Dementia Strategy 2017–2020 (Scottish Government, 2017a) is that more people with dementia should be enabled to live safely with as good quality of life as possible at home or in a homely setting for as long as they and their family wish. The critical input of families and carers is acknowledged, while also recognising and addressing their own needs. The three Alzheimer Scotland dementia models support services to meet this aspiration (Alzheimer Scotland, 2011; 2012; 2015).

The national AHP post-diagnostic scoping exercise and conversations with people living with dementia<sup>1</sup> nevertheless show that access to AHPs in Scotland is variable and at times inconsistent. AHPs are developing innovative work locally and nationally to address this situation: in addition, Alzheimer Scotland and partners have developed paper-based, online and social media materials to promote awareness of what AHPs do and can offer.

Work is under way with all AHPs focusing on wellness campaigns to "Eat Well", "Move and Improve" and "Make Every Communication Count". This programme of work (Scottish Government, 2017b) will link and integrate the needs of people living with dementia in Scotland.

Small test-of-change programmes are being developed to evaluate the practical application and implementation of the AHP approach in practice. For example, a strategic partnership involving Alzheimer Scotland, Queen Margaret University and practising occupational therapists has been developing delivery of a post-diagnostic occupational therapy evidence-based intervention called the

<sup>1</sup> Available at: [www.alzscot.org/AHP](http://www.alzscot.org/AHP)

Home-based Memory Rehabilitation Programme (HBMR) in 12 areas of Scotland since May 2016. In addition, AHPs are embracing a self-management approach to deliver interventions and a pilot of work by Craig (2017) is being developed in partnership with the Alzheimer Scotland AHP Consultant and therapists in some parts of Scotland. The Tailored Activity Programme (TAP) has been developed in a number of board areas to support implementation of the 8 Pillars model (Alzheimer Scotland, 2012); this is the focus of an Alzheimer Scotland AHP PhD studentship.

These interventions, each of which has a built-in evaluation and improvement component, are examples that highlight how work to support the delivery of this ambition is already under way. It is known from research that other AHP-led programmes could be implemented using the national roll-out model for HBMR and the TAP, each supporting the ambition to reduce variation in AHP access and practice.

AHPs must prioritise prevention and early interventions for people living with dementia, underpinned by a rights-based, personal-outcomes approach and supported by inclusive, accessible information. Relevant technology should be used to facilitate access to AHP-led interventions, enhancing supported self-management and reviewing access to AHP services delivered in community settings and people's homes. This approach will support people to remain in their own homes and help avoid unnecessary hospital admissions.

The AHP approach should now be shared: AHPs will need to work with others to test and evaluate applicability and usefulness in practice in the context of local integrated services. They should also consider what can only be delivered by AHPs and what contribution can be made to support family carers, other health and social care practitioners and third sector and community services. This will offer clarity on the AHP role and what should be expected.

## Actions for change

1. Alzheimer Scotland and partners will raise awareness of the AHP role, informing people who AHPs are and how they can help throughout the illness, and ensure people are clear on how to access the AHP workforce. This work will extend to raising awareness of the role of rehabilitation and dementia to the AHP workforce and health and social care services.
2. AHP-led, evidence-based self-management resources for people living with dementia will be developed as standard across Scotland to support self-management before targeted intervention is required. AHP resources available locally will be reviewed and, if appropriate, made available to the public. The national resources will be co-produced and designed in a partnership involving Alzheimer Scotland, people living with dementia, AHP leads and other stakeholders.
3. Focused work to support and strengthen early access and post-diagnostic AHP-led interventions, as outlined in Section 2, will continue to be undertaken. AHP post-diagnostic improvement support will continue to be developed and integrated within the transformation of primary care.
4. Work will be developed in partnership to support and strengthen the integration of the AHP approach to integrated care co-ordination in the community for people living with dementia and the Advanced Dementia Practice Model to understand and transform advanced dementia and end-of-life care. This will focus on rehabilitation and targeted and tailored AHP interventions in a range of health and social care settings.

## 2. Partnership and integration

*What people living with dementia can expect by 2020 as a result of action in this area:*

- *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 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.

### Why this matters

Partnerships and integrated working involving AHPs, people living with dementia, services, partner organisations and local planning structures will be key to the success of integration of the AHP approach in practice.

People living with dementia are central to leading and advising on ways of supporting them. They want to feel useful, be part of the solution and be involved in their treatment and care, rather than having things done for or to them.

Many AHPs will currently be working with people living with dementia in their day-to-day practice, as people living with dementia will often have other long-term or chronic conditions. AHPs are also key contributors to specific dementia care and treatment, but are a small specialist part of provision in health and social care. They therefore need to be willing to share their expertise with others, working collaboratively across organisational and professional boundaries to integrate the AHP approach within dementia and other care pathways designed and developed locally.

The partnership and integration ambition will focus on co-ordinating how AHPs connect with each other to create efficient pathways across acute, community and third sector settings. The aim is to simplify processes for inter-AHP referrals across services and AHP-led national programmes. AHPs will need to develop new partnerships as integration progresses locally and nationally to support key integration objectives in areas such as delayed discharge and unplanned admissions.

### Where we are now

AHPs take an asset-based and personal-outcomes approach to working with people living with dementia, enabling people to be at the centre of AHP-led interventions and integrating their care needs into current AHP rehabilitation programmes based on need, not diagnosis. AHPs have practice examples of integrating Emotional Touchpoints and experience of asking what matters most to people living with dementia. There are many practice examples of AHPs working in creative and innovative partnerships with other health and social care practitioners, and the third and independent sector (Alzheimer Scotland 2014a; 2014b; 2014c).

AHPs' contributions to vocational rehabilitation and the national falls programme are examples of how their input has been transformed in Scotland over the last few years. Work to integrate the needs of people living with dementia in national workstreams, such as vocational rehabilitation, falls reduction (including the national collaborative ambulance pathway) and frailty is under way. Integration of AHP services in response to national changes in health and social care is also happening, providing the opportunity to integrate the AHP approach in practice. The AHP approach needs to be used locally to inform conversations among integration joint boards, AHP acute hospital services, GP hubs and people living with dementia to review current AHP service delivery and meet the needs of the local population.

## Actions for change

1. A personal-outcomes approach for people with dementia, recognising people as experts in their own lives with strengths, hopes and aspirations, will be promoted across all AHP services.
2. AHPs will work collaboratively with new integration joint boards and NHS boards to support local planning and redesign of dementia services, with a particular focus on integrated and coordinated AHP service provision.
3. AHPs will connect with each other to create efficient pathways across acute, community and third sector settings, with the overall aim of simplifying processes for inter-AHP referrals across services.
4. AHPs will collaborate to ensure the inclusion of the needs of people living with dementia in AHP-led national programmes, as outlined in AILP.



### 3. AHP workforce skilled in dementia care

*What AHPs can expect by 2020 as a result of action in this area:*

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

#### Ambition for change

People living with dementia will experience services that are led by AHPs who are skilled in dementia care (as defined by the Promoting Excellence framework (Scottish Government, 2011a)) 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.

#### Why this matters

Training and education of the current and future health and social care workforce is key to the transformational changes required to improve the experience and outcomes of care and treatment for people living with dementia.

On graduation from their programmes, AHPs moving into health and social care posts should have as a minimum the skills, knowledge and confidence defined at the “Skilled level” of the Promoting Excellence framework. This will enable them to understand dementia and its impact and the ability to tailor and target their rehabilitation interventions appropriately.

Often, the most important interventions for people with dementia are human interventions delivered via access to tailored, person-centred, skilled and therapeutic specialist care and support. There are opportunities for AHPs to lead in key posts in dementia models, including enhanced practitioner link worker in post-diagnostic support, dementia practice co-ordinator in community settings and the advanced model of dementia care, as these models are rolled out and/or adapted over the next three years.

Education cannot transform AHP practice on its own, however. AHP clinical leadership locally and nationally will need to drive the delivery of all four ambitions to ensure they are realised. A skilled AHP workforce with strong clinical leadership is needed to promote innovation and deliver high-quality, responsive services developed around people’s needs. We need AHPs to be actively engaged dementia advocates who view supporting people living with dementia as a core part of their role regardless of grade or practice setting and have a focus on strengthening AHP clinical leadership in dementia.

#### Where we are now

This ambition is supported by Promoting Excellence and the Standards of Care for Dementia in Scotland (Scottish Government, 2011b). Promoting Excellence describes four levels of knowledge and skills staff require, depending on their role and level of contact with the person living with dementia – Informed, Skilled, Enhanced and Expert.

Levels of knowledge about dementia and the skills necessary for effective practice vary across the AHP professions and their pre- and post-registration preparation. Alzheimer Scotland and AHPs in health boards have been working with higher education institutions in Scotland to support dementia education at undergraduate and postgraduate levels to ensure all AHPs are functioning at Skilled level on graduation, and a range of national learning resources and local initiatives have been developed to embed Promoting Excellence in everyday practice.

Actions already taken to support this ambition include:

- the creation of over 90 AHP dementia champions in health and social care, providing an enhanced workforce in dementia care
- a national network of AHPs and established uni-professional networks with a special interest in dementia care, offering a distributed model of professional leadership
- a network of AHP practice education leads in health boards supporting AHPs to access internal

training opportunities and leading on dementia training locally

- a developing Alzheimer Scotland AHP practice education programme called “Building Bridges”, developed in partnership with the four higher education institutions in Scotland offering AHP programmes
- a network of Alzheimer Scotland nurse consultants and AHP consultants and the national strategic mental health AHP leads group, enhancing interdisciplinary collaboration.

An opportunity now exists to strategically embed dementia skills into the work of the AHP workforce, enhancing the engagement and reach of each of the AHP groups and aligning their knowledge and skills against the Promoting Excellence framework. The aim is for all AHPs in Scotland to practice at a minimum of Skilled level, but this would need to be agreed and decided by each AHP service.

Research highlights the crucial role of bringing AHPs with an interest in dementia together to exchange information, ideas and expertise and establish an infrastructure to ensure the spread and sustainability of AHP-led innovations and practice. The research also highlights the impact of AHP dementia consultants’ clinical leadership in improving AHP knowledge and strengthening relationships between third sector organisations and higher education institutions involved in AHP education (Gordon & Griesbach, 2015).

## Actions for change

1. Work will continue with a range of stakeholders, including higher education institutions, NHS Education for Scotland and local practice development teams, to implement the Promoting Excellence framework to support the development of a Skilled AHP workforce as a minimum, and further support the development of an Enhanced- and Expert-level AHP workforce.
2. An Alzheimer Scotland AHP Dementia Forum (Appendix 2) has been developed to provide national clinical leadership and an infrastructure of leadership for integrating Connecting People, Connecting Support principles and ambitions, and transforming current and future AHP practice. This newly established Forum will have a pivotal role in planning and supporting implementation nationally and locally.
3. Each member of the Forum will have strong links with their AHP director/associate director or their professional body and will develop local AHP dementia networks with a range of stakeholders. The networks will include AHP representatives from, for example, practice education, acute, primary and social care, and the third sector, and will engage meaningfully with people living with dementia.
4. The Alzheimer Scotland AHP Dementia Forum will work collaboratively to ensure a national approach to the implementation of evidence, sharing of best practice and use of outcome measures, developing a shared understanding of priority areas for development.



## 4. Innovation, improvement and research

*What people living with dementia can expect by 2020 as a result of action in this area:*

- *the right care for me is delivered at the right time.*

### Ambitions for change

People living with dementia 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.

### Why this matters

AHPs need to demonstrate their impact through robust evaluation and research, creating and promoting evidence to support the transformation of their contribution to dementia care. A focus on collecting rigorous outcome data over a significant time period will help build knowledge of what works and enable AHPs to target support most effectively.

Good examples of evidence-informed AHP interventions exist, but good practice needs to be further amplified and spread. The requirement is to implement the evidence that is available, evaluate the impact of changes, disseminate findings and support local implementation.

The AHP approach is based on the best current available evidence. There is now a need to evaluate practice across the five key elements of the approach. For this, improvement methodology will be required to collect, understand and use data, question practice and, most important, improve AHP interventions in dementia care.

Reviews of AHP studies show promising examples, but more research and evaluations are required to develop the evidence base.

### Where we are now

The two commissioned literature reviews informing Connecting People, Connecting Support (Shenton et al., 2011; Pentland, 2015) provided important insights into effective AHP-led interventions. They showed that the most successful include carers, which appears to deliver added value. This finding is supported by observations from practice.

Strong examples of innovative service improvements and evaluations exist in Scotland, demonstrating the effect of standardised outcomes and assessments. AHP students and PhD candidates are evaluating current AHP practice and developing new practice models. Service redesign is happening already, some being integrated into current workstreams and others adopting a dementia-specific rehabilitation approach. Examples can be accessed on the AILP community of practice website.<sup>2</sup> This work is being supported by improvement support from the Scottish Government, HIS and local services.

Support exists to develop the quality-improvement capacity and capability of the AHP workforce. Many AHPs are skilled in improvement methodology, having successfully completed or commenced the Scottish Improvement Leader programme locally or nationally or the Scottish Quality and Safety fellowship led by NHS Education for Scotland. The AHP dementia programme locally or nationally also has dedicated improvement support from an improvement advisor from the AILP programme and will support Alzheimer Scotland AHP Dementia Forum members and their improvement teams in local areas.

AHPs are also working currently in partnership with the HIS Focus on Dementia programme. Focus on Dementia is a national improvement portfolio led by HIS, who work in partnership with national organisations, health and social care partnerships and people living with dementia to reduce variation and improve quality of care.

<sup>2</sup> Available at: [www.knowledge.scot.nhs.uk/ahpcommunity/ailip-priority-workstreams/dementia.aspx](http://www.knowledge.scot.nhs.uk/ahpcommunity/ailip-priority-workstreams/dementia.aspx)

Occupational therapists are integral to the Scottish pilot of the International Consortium for Health Outcomes Measurement (ICHOM) standard set for dementia and testing its applicability to practice. This work is currently being led by HIS on behalf of the Scottish Government and is measuring outcomes to better understand how to improve the lives of people with dementia.

The task now is to spread and sustain effective practice examples in Scotland, developing local demonstrator sites for enhanced access and support and new models of evidence-informed, targeted AHP dementia practice. We will need to measure and monitor the successes and learn from practice.

## **Actions for change**

1. The Alzheimer Scotland Dementia Forum will work in partnership to define research and evaluation priorities, including:
  - evaluating the impact of the current awareness-raising campaign led by Alzheimer Scotland in partnership with AHP professional bodies
  - evaluating the impact of AHP-led self-management information in enabling earlier access to AHP services
  - evaluating the contribution of AHPs to supporting people with dementia to remain at work
  - analysing feedback from people living with dementia on their experiences of AHP services.
2. A clear national evaluation framework will be developed to support local implementation and enable measurement and evidence of change. The evaluation framework will be based on improvement methodology and will include metrics, targets and timescales as appropriate. This will start by collecting baseline data on all four ambitions, which will then be repeated in 2020 to measure any changes or improvements.
3. New, innovative, evidence-informed AHP models of practice, underpinned by a national measurement framework, will be tested and rolled out. These new models of practice will enhance the AHP contribution to meeting broader national priorities, so work will be aligned to, and integrated with, relevant national and local programmes. Local or profession-specific issues will be identified and addressed.
4. Progress and opportunities arising from the Connecting People, Connecting Support AHP dementia programme will be shared as three-monthly flash reports and formal annual updates linked to the Dementia Strategy and AILP. The work will also be shared creatively through social media, presentations and newsletters.



## Next steps

We have been developing the work to support this document over the past three years, building awareness of the AHP role. Connecting People, Connecting Support brings this work together, and we now have to begin to deliver.

Great progress has been made in AHP practice in recent years. While much remains to be done to improve the way people can access AHPs' rehabilitation and enablement skills, we are fortunate to have such a solid foundation of excellence on which to build.

Our main focus now has to be on how to sustain and extend good practice in the new and developing culture of integration, with integration joint boards and primary care hubs based on local population health needs being the focus of delivery. Aligned to Scotland's National Dementia Strategy 2017-2020 (Scottish Government, 2017), national support will be supplied through a strategic partnership between Alzheimer Scotland and the Scottish Government, but a co-designed partnership approach to delivery will be required.

Governance and monitoring of the four ambitions will be led by the National Alzheimer Scotland AHP Consultant. Reporting of progress on the impact of Connecting People, Connecting Support will be integrated with national governance structures for the implementation of Scotland's National Dementia Strategy and AILP.

The Alzheimer Scotland AHP Dementia Forum will provide an infrastructure of leadership to ensure clarity of responsibility and provide practical support. Each member of the Forum will have strong links with their AHP director/associate director or their professional body .

We have developed a shared vision for change, outlining the AHP approach to people living with dementia. At each and every stage of dementia, AHPs could – and should – have a role in prevention and early interventions in primary, acute and community settings, and also in secondary prevention and self-management through dementia rehabilitation. This will make a significant contribution to the nine National Health and Wellbeing Outcomes and support delivery of local integrated structures and integration joint board priorities.

AHPs must work differently and collaboratively with people and the communities in which they live and work. Above all else, implementation of the AHP approach needs to focus on what matters most to people living with dementia.

## Invited comments

### Comment by the Scottish Dementia Working Group

The Scottish Dementia Working Group is the national independent voice of people with dementia within Alzheimer Scotland. It campaigns to improve services for people with dementia and improve attitudes towards them.

We are delighted to write this comment on Connecting People, Connecting Support. For too long, people living with dementia in Scotland have lived with stigma and have received services that while well-meaning and much appreciated, don't fully respond to our wants and needs – the things we see as being important to us.

That's why we welcome the AHP approach and the ambitions set out in Connecting People, Connecting Support. We see it as a firm statement of AHPs' determination to deliver evidence-based services underpinned by specialist skilled assessment that is individualised.

We're glad that AHPs want to reach out to people living with dementia, to provide them with the skills, information and access we need to continue to live well in our communities. We welcome AHPs' aspiration to look at our situations in the round and not just focus on one element of the approach. And perhaps most of all, we're delighted that they recognise our need to be part of the solution. As people with dementia, we have unique knowledge and understanding of our needs. We want to work in equal partnerships with AHPs and other professionals, building our resilience and enhancing our self-management capabilities.

But we need to see action. In particular, action to increase access to AHPs when we want or need them and to get the information and services we require. It doesn't mean we want to see an AHP each time we have a problem – if they can signpost us to the right information and provide the right advice, in all likelihood we'll be able deal with many problems ourselves.

This reflects what we feel is a very important message from Connecting People, Connecting Support – that it is not about asking AHPs to do more, but to do differently. We're very struck by the potential benefits this could bring not only to people living with dementia, but also to health and social care services in Scotland.

How will we know Connecting People, Connecting Support is working? We'll know when we understand who AHPs are, what they can do, how we can get to them, and what they can do for us and with us. When it's working, our resolve to ensure we can access wider support to help us live as well and as independently as possible will be strengthened, realising our human right to get the services to which we are entitled. Connecting People, Connecting Support gives us a lever to gain maximum benefits not just from AHPs, but from the whole health and social care system.

We now look forward to working with the Alzheimer Scotland AHP Consultant and the Alzheimer Scotland AHP Dementia Forum to make the AHP approach and ambitions of Connecting People, Connecting Support a reality.

## Comment by the National Dementia Carer Action Network

The National Dementia Carers Action Network (NDCAN), which campaigns on issues faced by carers of people with dementia, was set up to ensure that their experience influences the national dementia policy landscape in Scotland. NDCAN is highly appreciative of the unique contribution made by AHPs to supporting the needs of people living with dementia. We are therefore delighted to be invited to comment on this ground-breaking document.

NDCAN strongly approves of AHPs' evidence-based approach, which inputs the perspective of people living with dementia into service design. We particularly welcome how this approach contributes to the third National Dementia Strategy by a combination of ambitious vision for the future and a practical, realistic, action plan. This approach is framed by Alzheimer Scotland's platform of the 5 Pillars, 8 Pillars and Advanced Care models, emphasising flexible and person-centred interventions based on human rights and delivered by dementia-skilled AHPs throughout the progression of the condition and in all health and care settings.

Particularly welcome is the focus on a much-needed enhancement of the everyday life of people living with dementia at home through diversity of support, including promotion of self-management, preventative and rehabilitative interventions in the context of personal outcomes. For people living with dementia, this approach adds a meaningful depth to the 8 Pillars model and an interface between policy and practice. We also applaud how the AHP approach is underpinned by a call for multidisciplinary and multi-sectoral practice, an essential response to tackling the complex diversity of needs, especially as the dementia progresses.

We are delighted to see AHPs' forward-looking vision for families and carers as equal partners in care. It is a vision that goes beyond appreciating our understanding of the cared-for person to a recognition of the potential value of collaboration, support for education and skills development and carers' potential as co-therapists and recipients of AHP interventions.

Finally, Connecting People, Connecting Support demonstrates a strong commitment to addressing the unequal and inconsistent availability of AHP services within Scotland. Additionally, there is a determination to tackle the lack of knowledge and understanding of the rich offerings of support provided by the professions. This resonates with NDCAN's priorities, which are underpinned by an aim to connect more effectively with localities to improve access to services and information and strengthen communication.

We now look forward to continued work with AHPs and others to deliver on the ambitions of Connecting People, Connecting Support.

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## Section 2

### *The AHP approach*

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## **Section 3**

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## **Next steps**

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“I have dementia but  
it does not define  
me, my actions, my  
hopes and dreams  
define me”

*Henry Rankin,  
Scottish Dementia Working Group*



# Appendix 1.

## Ambitions mapped to National Health and Wellbeing Outcomes

<p><i>The four ambitions for change outlined in Connecting People, Connecting Support</i></p>	<p><i>The nine National Health and Wellbeing Outcomes that apply to integrated health and social care</i></p>
<p><b>1. Enhanced Access</b></p> <p>People living with dementia 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 evidence-informed AHP-led targeted interventions from integrated and co-ordinated AHP services that integrate the five key elements of the AHP approach.</p>	<p>People are able to look after and improve their own health and wellbeing and live in good health for longer</p> <p>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</p> <p>Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services</p> <p>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</p>
<p><b>2. Partnership and Integration</b></p> <p>People living with dementia 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.</p>	<p>People who use health and social care services have positive experiences of those services and have their dignity respected</p> <p>Health and social care services contribute to reducing health inequalities</p> <p>People using health and social care services are safe from harm</p>
<p><b>3. AHP workforce skilled in dementia care</b></p> <p>People living with dementia 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 practice, and delivers high-quality, personal outcome-focused and AHP-led therapies.</p>	<p>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.</p>
<p><b>4. Innovation, improvement and research</b></p> <p>People living with dementia 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.</p>	<p>Resources are used effectively in the provision of health and social care services, without waste</p>

## Appendix 2.

# Alzheimer Scotland AHP Dementia Forum

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**Maggie Nicol**

Chair

**Elaine Hunter**

National Alzheimer Scotland AHP Consultant/  
AILP Dementia Lead (co-chair)

**Alison McKean**

Alzheimer Scotland AHP Post-diagnostic Lead

**Mark Hamilton**

AILP Improvement Advisor (Dementia)

**Lynn Flannigan**

Improvement Advisor, Focus on Dementia

**Audrey Taylor**

NHS Education for Scotland

**Joanne Payne**

**Jacqueline McComish**

NHS Ayrshire & Arran

**Katie Masterson**

NHS Borders

**Wendy Chambers**

NHS Dumfries & Galloway

**Jacqui Chung**

NHS Fife

**Ruth Gardner**

**Sheila Munro**

NHS Forth Valley

**Samantha Flower**

**Christine Steel**

NHS Greater Glasgow & Clyde

**Katie Lyon**

Golden Jubilee National Hospital

**Iona Parkinson**

NHS Grampian

**Carrie Hill (Argyll & Bute)**

**Fiona Mclean (North Highland)**

NHS Highland

**Lesley Bodin**

NHS Lanarkshire

**Rebecca Kellett**

NHS Lothian

**Moraig Rollo**

NHS Orkney

**Vicky Burnham**

Scottish Ambulance Service

**Elaine Brown**

**Amanda Manson**

NHS Shetland

**Gordon Thomas**

NHS Tayside

**Christine Lapsley**

**Karen Mackenzie**

NHS Western Isles

**Alison Wren**

British Association of Art Therapists

**Gillian McMillan**

**Lynne Stevenson**

British Dietetic Association

**Claire Craig**

**Anna Paul**

Chartered Society of Physiotherapy

**Michelle Dunne**

Royal College of Occupational Therapists

**Rory Campbell**

**Emma Maclean**

British Association for Music Therapy

**Dorothy Hathaway**

**Karen Mellon**

Society of Chiropractors & Podiatrists

**Caroline Handley**

Society and College of Radiographers

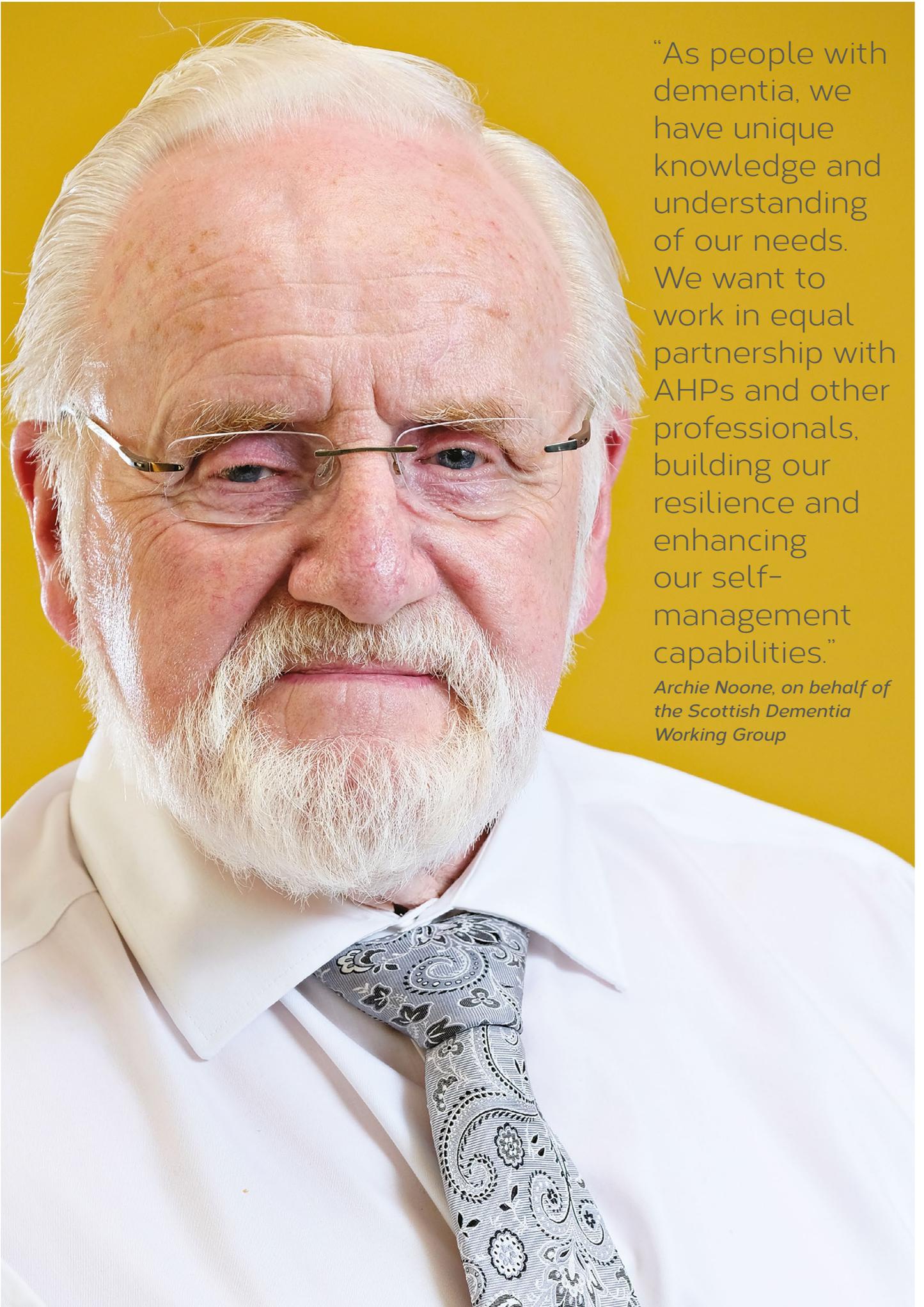
**Rebecca Kellett**

**Jenny Keir**

Royal College of Speech & Language Therapists

*Membership accurate at time of publication.*

*Members nominated by AHP director/associate director or policy officers.*



“As people with dementia, we have unique knowledge and understanding of our needs. We want to work in equal partnership with AHPs and other professionals, building our resilience and enhancing our self-management capabilities.”

*Archie Noone, on behalf of the Scottish Dementia Working Group*





Alzheimer Scotland, 160 Dundee Street, Edinburgh, EH11 1DQ  
Phone: **0131 243 1453** | Email: [info@alzscot.org](mailto:info@alzscot.org) | Web: [www.alzscot.org](http://www.alzscot.org)  
Twitter: [@alzscot](https://twitter.com/alzscot) | Facebook: **Alzheimer Scotland**

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*Making sure nobody faces dementia alone.*