

What's important to people with lived experience of dementia in Scotland

An Allied Health Professional Resource



People who have lived experience have always been recognised in our work as important, valued and as a key stakeholder in all our work as Allied Health Professionals.

Embedding this experience is also fundamental to taking a human rights-based approach in our practice, ensuring that contributions by people with lived experience are recognised, on an equal footing with professional expertise and that it is embodied in the PANEL human rights principles.

In developing this work, we recognise the need to take a flexible approach so everyone who wants to, has the opportunity to engage in a way that works for them.

By engaging regularly with people with lived experience, we develop a greater understanding of issues and challenges as they emerge, giving more

opportunity to identify and deliver flexible solutions. For example, earlier consultation with people with lived experience could identify obstacles experienced in getting access to relevant and timely rehabilitation and enable small changes and interventions to happen incrementally and workable solutions to be reached more quickly.

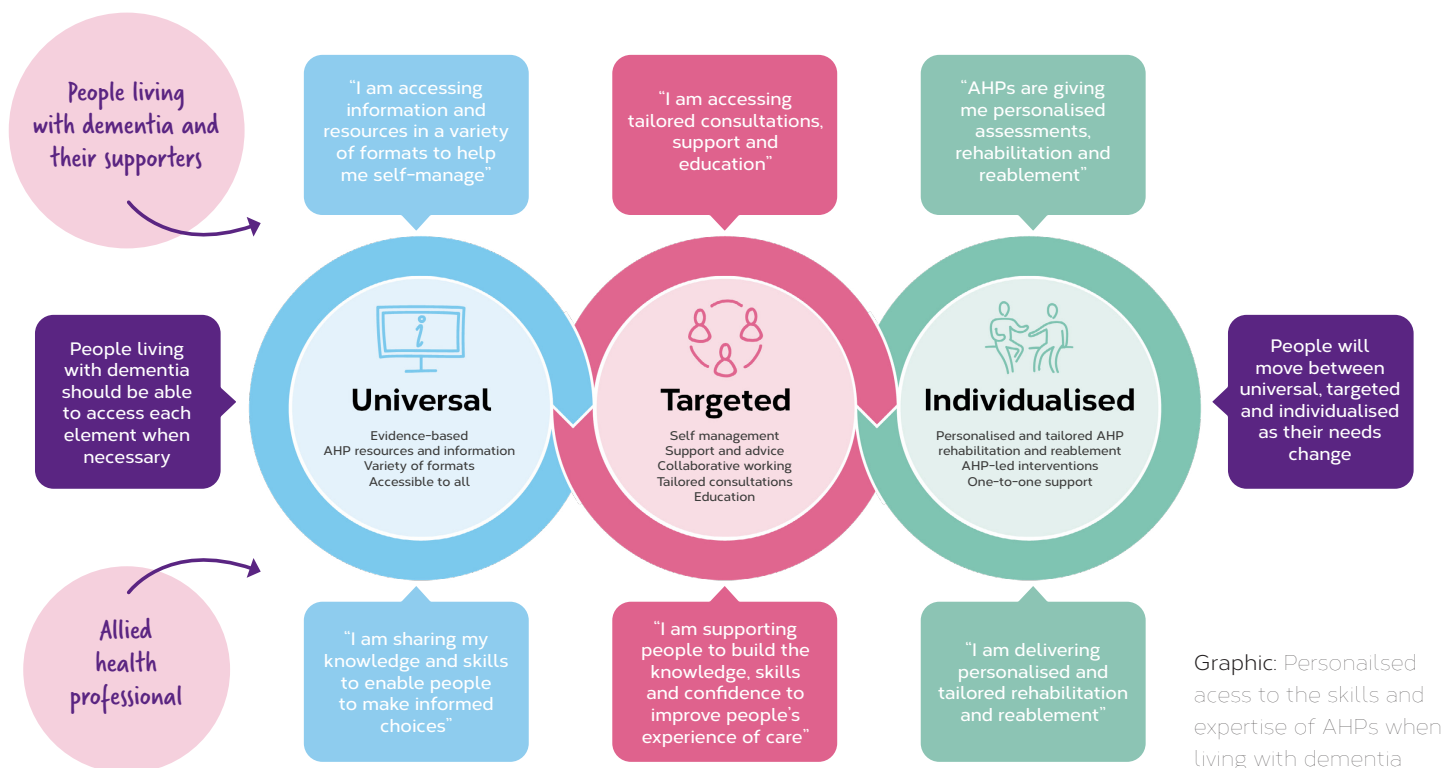
This toolkit has been designed to support you, as Allied Health Professionals, to capture everyday conversations to ensure that the voices of people with dementia and dementia carers inform and shape our national and local AHP programmes.

It is important that we remain aware of the current issues and recurring concerns that people with dementia, their families and carers are facing on a daily basis. And then, it's even more important to respond to what we hear.

You are already hearing about what is important to the people and communities you work with. This resource is designed to provide the tools to help us build on that, developing a national approach with a local delivery, to ultimately achieve the changes that people tell us they need. Often the most powerful voices to call for change are those of people living with dementia and carers themselves.

This resource is intended to support you with information to:

- 1 } Provide opportunities for people living with dementia and carers to talk about what is important to them, and come together to begin to create a collective voice in partnership with Allied Health Professionals.
- 2 } Talk with people with dementia and carers about how we can support them more effectively.
- 3 } Maintain contact with people with dementia and carers and keep them informed of the progress we are making as Allied Health Professionals.
- 4 } Speak to people with dementia and carers about issues affecting them locally in relation to accessing support and information about dementia and Allied Health Professionals.
- 5 } Facilitate opportunities for people with dementia and carers to meet together and with you to identify and discuss local priorities in relation to dementia.
- 6 } Collate and summarise the information gathered from the discussions and use it to plan and prepare for engagement with local services.



We want to inquire through everyday conversations what's important to the person, what's working, and what's problematic in their lives. Capturing the recurring issues and emerging themes from these conversations means that we can ensure our offer as AHPs is well informed when deciding our collective offer and implementing our AHP approach and our personalised approach to services. This pack contains the tools to help you capture these everyday conversations, and support us to deliver a personalised approach to AHP Services as outlined above.

There are a number of approaches that you and your teams may wish to take to capture the voice of people living with dementia and their supporters:

**Set up a 'listen and learn' event
and invite people to attend**

**Approach local existing groups and ask
to attend one of their regular sessions***

**Offer opportunities to share feedback
and ideas via posters and postcards in
local community focal points, e.g. libraries,
Alzheimer Scotland Brain Health and Dementia
Centres, Meeting Centres, Carers Hubs**

**Gather feedback and
ideas before, during or
after a regular
interaction in the clinic
or on a home visit**

**In each case it is vital to empower people to know their voices are
important and valuable and will be heard and responded to.**

*Using the principle of 'going to the communities and where people meet'

This principle emphasises the importance of engaging with people in their own environments. Key aspects include:

Accessibility	By meeting people where they are, services and initiatives become more accessible to those who might not otherwise engage.
Inclusivity	This approach helps to include voices that are often marginalised or overlooked in traditional settings.
Relevance	Understanding the specific needs and contexts of different communities ensures that interventions are tailored and relevant.
Trust Building	Engaging with communities in their own spaces helps build trust and rapport, which is crucial for effective collaboration.
Empowerment	It empowers communities by involving them directly in the decision-making processes that affect their lives.

Adapted from: National Standards for Community Engagement developed by the Scottish Community Development Centre (SCDC)

A great starting point is to look at information from people living with dementia about how to get this right:

The Scottish Dementia Working Group has created comprehensive guidelines to help make meetings more accessible for people with dementia. **Dementia-Friendly Meeting Guidelines Dementia** (alzscot.org).

Timing: Schedule meetings mid-morning to mid-afternoon to accommodate energy levels.

Presentations: Keep them short (max 10 minutes) and use clear, simple slides.

Workshops: Provide written instructions and allow plenty of time for responses.

The DEEP Network's guide offers practical tips for gathering feedback from people with dementia. **DEEP Network Guide to Collecting Views**

Simple Language: Keep questions clear and straightforward.

Patience: Allow ample time for responses.

Encouragement: Make participants feel valued and heard.



Ideas to get you started...



Publicising the Opportunity

Utilise Contacts: Reach out to all your contacts and locality colleagues to identify potential participants.

Expand Invitations: Consider inviting local dementia support groups. Bringing treats and sending your outline and questions ahead of time can help make the session more welcoming. Alternatively, ask to attend a regular meeting of an existing group.

Keeping participants updated

It is important to keep your participants updated on progress following your group/ one-to-one discussion. An initial thank-you email/ letter should be sent within seven working days; this can reiterate the key issues discussed.

Structure of the Event – 1.5 hours (including breaks and refreshments)

Introductions and Setting the Scene (15 minutes)

- Facilitator Introduction: Provide context for the discussion, explaining the purpose of the meeting (e.g., to listen to their experiences with AHP services and prioritize their needs).
- Purpose Explanation: Inform participants about the intention to follow up on the discussion.

Themed Discussion (30 minutes)

- Introduce Questions: Start with the questions and let the discussion flow naturally, ensuring it remains focused on the theme.

Comfort Break (15 minutes)

Themed Discussion (15 minutes)

- Continuation: Continue the discussion, maintaining focus on the theme.

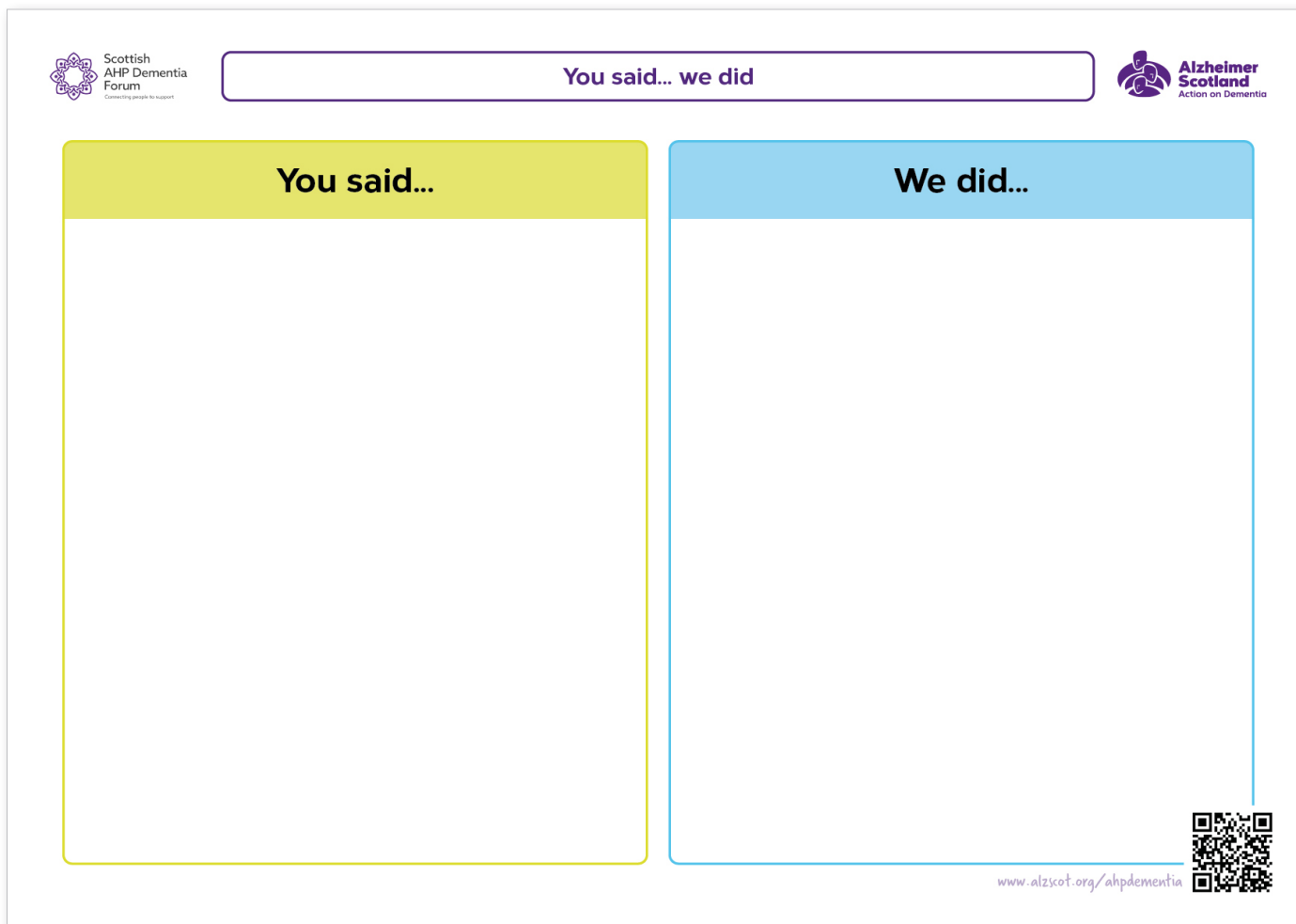
Closing Themed Discussion (15 minutes)

- Share Initial Themes: Summarize the key points from the discussion.
- Explain Next Steps: Inform participants about how and when the outcomes will be shared.
- Thank Participants and explain how their input will help improve services.

You said / we did posters

A you said / we did type approach allows you to reach the original participants and encourage other people to share their voice and opinions

- **Transparency & Trust:** Shows we listened and acted on your feedback.
- **Wider Participation:** Sharing results encourages more people to share their thoughts.
- **Easy Feedback:** QR codes make it simple to give more feedback.
- **Keeping You Updated:** We'll follow up with what we did based on your input.



The poster template features a header with the Scottish AHP Dementia Forum logo on the left and the Alzheimer Scotland logo on the right. The title 'You said... we did' is centered in a rounded rectangle. Below the title are two large rectangular boxes: a yellow one on the left labeled 'You said...' and a light blue one on the right labeled 'We did...'. At the bottom right of the poster is a QR code and the website address www.alzscot.org/ahpdementia.

Note: Print or digital template on the following page – click and type directly into the boxes

You said...

We did...



Postcards

Give out or sit with someone at the end of a treatment session.


‘Sharing your story with Allied Health Professionals – for better outcomes for you’

People living with dementia, their families and carers tell us valuable things all the time. Use this to capture a quote or some details of an issue the person has spoken about. Ask if they are happy for their story to be shared – this can be done either anonymously or with their name and contact details to allow us to follow up with them if appropriate.


Share your story with Allied Health Professionals – for better outcomes for you

What helps?

What could make things even better?

 Scottish
AHP Dementia
Forum
Connecting people to support

Please return to:

 Alzheimer
Scotland
Action on Dementia

Note: Print the template on the following page

Share your story with Allied Health Professionals – for better outcomes for you

What helps?

What could make things even better?

4 - Questions for participants

**What can I help you
with today?**

**What makes your day
better or easier?**

**What helps you have
a good day?**

**What are the barriers to
having a good day?**

**What would you like
to tell us?**

**What would you like
to see happen?**

**Is there anything that
would make it easier for you
to use our service?**

What went well?

**What would make things
even better?**

**What have we got
right for you?**

**What could we have
done differently?**

**Have we achieved your
goal today?**

Please tell us about your experience

What have we got right for you?

What could we have done differently?

**Is there anything that would make it
easier for you to use our service?**

Is there anything else you'd like to tell us?

Let's talk about dementia and Allied Health Professionals

Are you, or someone you care for, living with dementia?

Have you had contact with any Allied Health Professionals to help you live well with dementia?

Do you have a story to tell about accessing these services whilst living with dementia?

Or have you had difficulty accessing these services and would you like to share your opinions about how this could be made easier?

If you have any personal experience of dementia and would like to share your views about Allied Health Professional services, **please contact:**

Allied Health Professions:

Art Therapy
Diagnostic radiograph
Dietician
Drama Therapy
Music Therapy
Occupational Therapy
Orthoptics
Orthotics
Paramedic
Physiotherapy
Podiatry
Prosthetics
Speech and Language Therapy
Therapeutic radiography

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Allied Health Professions:

Art Therapy
Diagnostic radiograph
Dietician
Drama Therapy
Music Therapy
Occupational Therapy
Orthoptics
Orthotics
Paramedic
Physiotherapy
Podiatry
Prosthetics
Speech and Language Therapy
Therapeutic radiography

We hope you found this resource helpful.

For further information or to share your story please contact:

AHPDementia@alzscot.org

Stay connected on social media **[@AHPDementia](#)**

You can access further FREE information online at
www.cpcs.online and **www.alzscot.org/ahpresources**

You may also find the following Age Scotland Storytelling resource useful:
https://www.agescotland.org.uk/assets/000/001/149/Storytelling_user-guide_DPS_original.pdf?1726657368

Resource created by Fran Hamilton, Elaine Hunter and Helen Fisher.

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