



*Connecting people through
conversation and inquiry*

Appreciative Conversations: “what is important to YOU?”

Alzheimer Scotland was commissioned by Scottish Government to develop a model of practice for allied health professionals, also known as commitment 4, Scotland’s Dementia Strategy (2013). It was important the model was informed by the experiences, hopes and aspirations of as many people as possible who are living with dementia and family members.

To help us do this we invited people living with dementia and their families to come along for a “chat” and share their thoughts with allied health professionals so that together we could shape the future work of allied health professionals in Scotland’s dementia care. We were interested to understand what is important to people now and in the future and we wanted to listen to their stories their perspective.

We were interested in whatever people wished to bring to us and therefore the approach to the conversation was based on appreciative inquiry to explore what was important to people when living with dementia and their families. The conversations used appreciative language, allowing us to hear the rich detail on peoples experience and we did this using photos and powerful questions. This offered us a flexible resource that could be used in groups or with individuals where people pick a card and say why they like it and then chose to respond to one of the questions on the other side.

On the 30th January 2015 a group of Allied Health Professionals that work with people with dementia attended a workshop focussing on powerful questions and inquiry. As a result of the workshop a set of 12 questions were selected to form the basis of conversations over the following two months.

During March and April 2015, the 10 allied health professionals hosted 20 conversations with 50 people living with dementia and/or family members. The conversations took place where ever the people naturally came together. This ranged from dementia cafes, care homes, coffee shops, art galleries, NHS ward, Alzheimer Scotland resource centre and a day centre. The locations ranged from Aberdeen, Galashields , Perth, Ayrshire, Edinburgh, Stirling, Callander, Falkirk, Aboyne and Glasgow.

To help us carry the conversation forward we will summarised the themes that came from the conversation, the themes noted were agreed prior to the conversation ending and the reflections are from the therapists only and no-one was personally quoted.

This document summarises these conversations, surfacing significant themes and learning reflections for us to consider when developing the allied health professions evidence based policy document and the recommendations to be included.

Themes from themes

Conversations always surface themes; there are universal themes that connect us as humans in the context of this set of conversations the themes are as follows:

Importance of family and relationships

The majority of conversations identified the importance of family as a theme. The narrative that underpinned this ranged from simply keeping in touch with family and staying connected, to looking after grandchildren to taking part in shared activities and being able to reminisce. Also the value placed on the relationships with significant others.

Independence and a sense of freedom

Quite a number of people talked about maintaining their independence. The narrative that underpinned this was around being able to travel, to continue driving to enable them to access activities and just have freedom to do what they wanted. Travel was important and the need to access local community and groups. People also want to be able to take risks.

Engaging in activities valued as important

A number of people identified the need to continue with their social activities and these were varied – cooking, baking, eating out, dancing, gardening, growing flowers, table tennis, swimming, singing, and music and just having a laugh! The narrative that underpinned this was around doing things that they enjoyed, learning new things, being with others, getting out, importance of keeping up with current activities and also trying out new activities.

Positive elements of the conversations that emerged as significant were:

- Peer support makes a difference; reduces isolation and loneliness and creates a space for reminiscence, learning, activity and fun. People want to feel useful and valued. This was important for both the family and the person living with dementia
- AHPs and other healthcare professionals do make a difference in a number of ways from ‘medical’ knowledge to signposting to listening.
- People do have hope for the future and are determined to live as full a life as possible.
- The real story wasn’t about dementia; it was about people trying to feel good about life, themselves and their contribution.

What stood out to the person hosting the conversation and felt important was:

- Many the reflections touched on the importance of family in some way. Dementia doesn’t only affect the person but also the family.
- Many of the reflections touched on the importance of support, people want to be supported as a whole person and not just as an illness or diagnosis. For some there was the importance of working and the sense of loss when this stopped.
- Many of the reflections touched on the concept of independence. Whether this was about being at home for as long as possible, doing things for themselves and others, maintaining community connections or undertaking new activities. The importance of good transport connections for this to be maintained was also highlighted.
- Many of the reflections touched on the commitment of people with dementia to have a ‘new normal’ and how this in turn felt humbling to those hosting the conversations.

What do the stories tell us about what really matters?

Listening

Perhaps unsurprisingly being listened to in itself had a huge positive impact on the people with dementia, they have stories to tell. There was also something about the quality of listening, really seeking to understand what matters to people and hear the whole story, which is different from some listening in a diagnostic process. Dementia and memory loss were not the big issues from the conversations, people were more concerned with being valued and their physical health and well-being.

Connectedness

Group conversations support friendships and connections and that feeling of connectedness is central to the desire to be valued as an individual. People want to connect with people, not a faceless service. AHPs have a lot to offer and do facilitate positive change. People who had been diagnosed for several years remained well and say being connected and valued as a significant part of this.

Ownership

People still want to feel useful and are able to take on new roles. People with dementia want to be part of the solution and have involvement rather than having things done for or to them. The environment is an important part of that and a relaxed informal setting was favoured. People with dementia favour services that respond in a can do/let me help way rather than a fitting in to the system approach.

Learning and thoughts for the future

1. All the groups that took part; people living with dementia in a care home, people with dementia in their own home and carers agreed that the format of the conversations was useful and would like to repeat the process. Appreciative conversations allowed people to join in rather than look to others to speak for them.
2. The conversational approach sits comfortably with person centred care and the desire for more relationship based care for people living with dementia and their carers.
3. AHPs do make a difference and people with dementia want to speak to people who have the knowledge to support them but also the skills and behaviours to treat them as individuals.
4. It is clear that if you don't ask or get a referral that the role of AHPs may still not be getting to the right people. Both people with dementia and their families/carers still found it hard in some instances to identify which services they got the support from.

What next

The reflections of the key messages from this work will be embedded and included into the development, writing and actions of the AHP evidence based document. (Commitment 4).

The policy document will highlight the importance of involving people living with dementia and their families in all aspects of AHP contact from designing services, being involved in interview panels, feedback invited when rehabilitation has been provided and then services responding to the feedback data.

The use of appreciative inquiry and powerful questions has been valuable to assist the allied health professionals understand the needs and priorities of people living with dementia and their families, and that by asking the right question and actively listening to the conversation we can have rich and meaningful engagement.



*Can you tell us a
story about what
enables you to live
your life the way
you want to?*

The table below shows the original 12 questions and the frequency of use during the conversations.

Question	Frequency
What matters to you in your life right now and in the future?	2
What things are important to you, or do you value in your life?	0
What do you value most in your life?	5
Can you tell me about the things in your life that you look forward to the most?	1
When you reflect on a good day, what is it that has made you feel happy/satisfied/confident/pleased/proud?	2
When thinking about positive health and well-being what things do you value?	2
Can you tell us a story about what and who enables you to live your life the way you want to?	0
What's your best story of engaging with services in your local community?	3
Can you tell us a story about the times/activities that you enjoy sharing with your friends or family?	6
Can you tell us a story about a pastime that meant or means a lot to you?	5
Can you tell me about a time when the dementia cafe/dementia support services have helped you live well with your dementia?	5
Can you tell us a story about what enables you to live your life the way you want to?	6

A framework for reflection

To enable the themes of the conversations to be drawn out and themes captured it would be helpful to complete these four questions, in no more than 2 pages and send it back to Elaine at ehunter@alzscot.org. We will also follow up when we meet again on the 22nd April.

Who took part in in this consultation (number of people and their relationship to dementia?)

Consultation conducted by:

Location:

Date:

Questions selected:

What were the themes of the conversations?

What were the positive elements of the conversations?

What bits stand out for you or struck you? Why was this?

What does the story tell you about what matters?

Thank you

Thank you to:

The people who shared their stories, honesty and humour to enable us to learn and think with you

Fiona MacNeil who shared her skills, expertise and guided us to reflect on the power of inquiry

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