



Search Newcastle

Volunteer

Training Program:
Building a Dementia
Friendly
Organisation

April 2015

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Acknowledgements

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Summary

The overall aim of the volunteer training program: *Building a Dementia Friendly Organisation* was to present the foundational aspects and basic awareness of dementia during three full day sessions and one half day workshop. The format of each session included the utilisation of a topic-related power point presentation; video clips; handout material and workbook; questions for discussion; visual and audio exercises.

Session one – Building a basic awareness of dementia

The session began with the ten attending participants exploring their pre-training knowledge of dementia. After completing an initial dementia statement questionnaire, (please see page 20), seven out of the ten participants responding stated that they had '*limited knowledge*' of dementia, whilst the remaining three stated that they had no '*knowledge at all*'.

The session continued with the inclusion of topics being addressed in relation to:

- What is dementia?
- Who can develop dementia?
- How does dementia affect people?
- What is person-centred dementia care

The session also included two hypothetical questions undertaken in a forum discussion relating to how participants would feel if: (a) *they had been given a diagnosis of dementia* and (b) *how this may affect their life*. The session also addressed a person-centred approach to dementia care in acknowledging each person living with dementia as being a unique individual.

Session two - Improving our communication skills

Building on the learning material and discussions undertaken in session one, participants were encouraged to reflexively consider how do we communicate. Six of the ten attending participants openly discussed their communication skills.

The session continued with the inclusion of topics being addressed in relation to:

- What is good communication?
- How does dementia affect our communication skills?
- What is active listening?
- How can I improve my communication with people who are living with dementia?

These topics enabled all participants to reflect on and begin to further adapt their communications skills when working with people living with dementia.

During this session participants also undertook two further exercises: (a) an analysis of a case study relating to a woman living with dementia enabling participants to identify

positive outcome approaches to working with the woman (please see page 21), (b) participants were asked to review an exercise (*'the meaning not the words'*) in which they were asked to *'look beyond the words'* and to understand that the words and actions of people with dementia ALWAYS have a meaning (please see page 22). This particular exercise required participants to re-phrase a number of statements in positive rather than in negative terms. For seven out of ten participants this particular exercise appeared to be rather challenging and it was agreed that we would review this exercise again during the workshop in week 4.

Session three – Building our understanding of living with dementia

Taking the knowledge and understanding of dementia addressed in sessions one and two, the third session explored issues in relation to the environment. Especially with regard to topics as:

- How does the environment affect a person living with dementia?
- How might it feel to care for someone with dementia?
- How may the actions of others affect a person living with dementia?

The presentation and video clip material, as well as the accompanying handouts for this session enabled participants to explore the effect of environmental features such as: lighting; time of day; medication; noise and disorientation which a person living with dementia may experience. In addition a scenario and visualisation exercise *'Lost in Amsterdam – environment Hell'* (please see page 24) was utilised to enable participants to gain an empathic understanding of the impact of external and environmental aspects on the perception and perhaps subsequent behaviour of a person living with dementia.

Session four: Workshop - Building positive approaches

The volunteer participants attending this session were given the opportunity during this half day workshop to openly discuss any questions and comments that they had relating to their learning during the programme sessions. The outcome involved returning to:

- The *'meaning not the words'* exercise from session 2 (please see page 22). On this occasion all of the participants were able demonstrate the re-phrasing of each of the sentences within a positive, rather than a negative context.
- A review of the six introductory statements, as per session one, enabled five participants who had initially offered a response of *'not sure'* to appropriately qualify their opinion with an *'agree'* or *'disagree'* comment.
- The workshop format also supported participants to review appropriate dementia-related video clips which they had sourced from social media and other health websites, as well as exchanging their recent experiences in relation to the application of their programme learning into their volunteer practice environments.

Foreward

The Dementia Training Programme for the Newcastle-based charity, **Search**, was funded by Comic Relief, under the North East and Cumbria Dementia Fund, and facilitated by an independent dementia training consultant; comprised of three full day sessions held over three consecutive weeks in April 2015. Culminating in a fourth half day workshop to enable participants to review their learning and their subsequent application into their volunteering working practice. This report highlights the training topics undertaken in each of the sessions and also offers insight into the evaluation of the programme by the participants post training.

Staff members and volunteers of the **Search** currently work with older people and their carers in the west end of the city, to increase access to services and resources and promote independence. This includes providing welfare rights advice and information and to develop a wide range of community based activities for older people, with an overall remit to promote inclusion and combat social isolation. The aims of these service activities are to support people, enabling them to: stay healthy and offer them learning opportunities in a supported environment; foster new friendships and to promote a sense of value and belonging in their communities.

Services currently provided by **Search** include:

- A week day morning 'drop in' service for advice and information.
- Advice and information outreach sessions to specific areas of high need.
- A weekly program of activities promoting physical and mental wellbeing.
- Monthly opportunities for learning and leisure.
- Regular short courses to learn new skills.
- Volunteering opportunities to build skills, confidence and social networks.
- Partnership opportunities with other local groups, so more older people in the community can access a wider variety of activities.

The **Search** acknowledges the need for user involvement and has, over 35 years, developed as an organisation by working with local people to identify unmet needs and issues of concern through various processes:

- direct everyday contact with older people accessing its centre and services, as well as outreach work in the community.
- consultation with service users and other older residents about the development of its own services and about other issues of local concern.

- commissioning independent evaluations of its services and small-scale research projects to explore particular issues in depth.
- partnership working and networking with other local organisations and with city-wide agencies working with older people.

Partnership working

Partnership activities with other voluntary sector organisations are an intrinsic part of the remit of **Search**. Our volunteers run activity groups in the community at a variety of community venues, some of which are owned by other voluntary sector organisations. These include: Cornerstone community centre; Fenham Association of Residents; St. James's Church; Pendower Good Neighbour project; St James's centre for heritage and culture and West End Befrienders.

Dementia related developments

Over the last ten years the team at **Search** have noticed that a growing number of older people who are accessing our activities and services also have cognitive difficulties in relation to memory. In contrast the understanding of what might be the causal factors of these memory problems, particularly amongst peer group members, has not grown in tandem with this perspective. Many of the older people we work with who have developed memory problems have subsequently become socially isolated. Sometimes this is because of their own feelings and reaction towards these changes; but also because they are affected by the reaction of those around them. Thus a lack of understanding in relation to the experience of living with dementia: in particular by peer group members accessing services, has often meant an inability by members in being able to adopt a supportive dementia friendly approach to others accessing services and activities.

After consultation with a small number of our service users, who were willing to share their experience of receiving a diagnosis of dementia, as well as speaking with **Search** volunteers at our annual *away day* in 2014 and a review of volunteer training needs, it was felt that dementia training was necessary for our volunteers to enable them to understand and adopt a dementia friendly approach to their voluntary work. We envisaged that our volunteers would then be able to 'cascade' their learning and understanding of a dementia friendly approach with other volunteers and colleagues post training.

The training programme

Jo Alexjuk, a former member of staff of the Alzheimer's Society North Tyneside Branch and now an independent training consultant and academic, was commissioned to write

and facilitate the training programme for **Search** volunteers who had been invited to attend the sessions. The design of the sessions and workshop included: power point presentations; a hardcopy of each power point presentation (in workbook format); subject appropriate video clips; further subject specific handouts; interactive games; audio and verbal exercises; as well as hypothetical questions to engender individual reflexivity, learning and discussion.

At the beginning of session one each student was given a dementia programme training work file and encouraged to collate copies of the power point presentation for each of the sessions, as well as other handouts circulated and to make notes in their workbook during each of the subsequent sessions and final workshop.

Evaluation of the training programme- facilitator’s feedback

Session and workshop format

Session one – Building a basic awareness of dementia

At the beginning of the session the participants introduced themselves, stating their name and volunteer role, as well as their knowledge/experience of dementia.

Participants	Responses
Seven	Stated that they had “ <i>some although limited knowledge</i> ” of dementia, gained from the media and their previous volunteering or working environments. For example one participant had undertaken mental health training and wished to pursue a nursing qualification. Two participants also shared that they had a family member who is currently living with dementia. Whilst another stated that she had a friend who had recently been diagnosed with dementia.
Three	Participants commented that they had ‘ <i>no knowledge</i> ’ of dementia at all, either professional, personally or within their volunteering roles.

They were then asked to complete an introductory questionnaire (please see page 20), which had a number of statements which participants were requested to tick as either being: ‘*agree*’, ‘*disagree*’ or ‘*not sure*’. Following the completion of the questionnaire everyone openly discuss their comments. All participants contributed. Six out of ten of the participants offered a response of ‘*not sure*’ to three or more of the questions and it was noted that there were differences of opinion relating to knowledge and understanding of dementia. Nevertheless this exercise enabled participants to begin to think about dementia and to uncover any myths and preconceptions that they may have previously held.

Participants were then informed that we would revisit the questionnaire during the week four workshop to evaluate their dementia training experience.

The aim of session one was to explore the foundational aspects of building a basic awareness of dementia with the inclusion of topics relating to:

- What is dementia?
- Who can develop dementia?
- How does dementia affect people?
- What is person centred dementia care?

As well as enabling participants to fully explore and to be empathically aware of: what the personal experience of living with dementia may be like; the practical uses of person-centred care in dementia and the acknowledgement that every person with dementia is a unique individual.

For example the content of session one included a hypothetical question for discussion:

How do you think you would feel if you had been given a diagnosis of dementia today?

- Frightened; scared; anxious; angry; agitated; depressed; sad; helpless; frustrated; denial; embarrassed or all of the above?

Followed by a second hypothetical question which asked the participants to consider and discuss:

In what way would it affect your life?

- In particular thinking in terms of: you; your family; your friends; your working commitments and your future?

These questions, as well as other memory and language exercises, video clips and an interactive memory jigsaw/board game '*Remember Me – the person*' (relating to a woman of East European origin living with dementia in the UK), were used to enable participants to effectively consider the 'experience' as to what it may be like to be living with dementia. At the end of the session nine of the ten participants, without prompting, reviewed their responses to the introductory questionnaire.

Session two - Improving our communication skills

This second session built on the learning material and discussions of session one, but addressed issues relating to communication and behaviour that we may find challenging in working with people living with dementia. The session was attended by ten volunteers; one new participant, a former nurse, replaced someone who attended session one, but who was unable to attend further sessions due to personal reasons. Topics for session two included:

- How do we communicate?
- What is good communication?
- How does dementia affect our communication skills?
- What is active listening?
- How can I improve my communication with people who have dementia?

The ten participants were encouraged to recognise that a person with dementia's verbal and non-verbal communication may alter due to their experience of dementia and that their ability to communicate can be affected not only by damage to their brain, but also by the environment.

As with session one and two the format for this session comprised of a number of video clips; a power point presentation, handout material and questions to engender reflexive discussion. This included participants being asked to reflect on the ways in which they communicate such as:

What are the differences in the way you communicate with your family and friends at home in comparison to people with whom you are working?

How would you adapt this process with different people who are living with dementia?

Three participants expressed that they felt that they were '*overly gregarious*' in the way in which they communicated with family, friends and colleagues, but felt that this would not be appropriate when working with people with dementia. They also felt that they tended to interject too quickly into conversations and appreciated that they needed to be more active in their listening approach with others. One participant particularly spoke about how she felt that her pace of conversation was often too '*fast and excitable*'. Another acknowledged that the intonation of her voice during conversations with family, friends and colleagues was often '*too loud*'. In contrast another participant recognised that she was naturally softly spoken. This exercise enabled everyone to reflect on and begin to further adapt their communications skills when working with people living with dementia.

Building on these reflexive exercises the participants were then given a case study to review and comment on relating to '*Annie McKenzie*' (please see page 21). Questions 1, 2 and 4 of the case study were easily addressed by each participant. Question 3 relating to what are the '*messages which Annie might be trying to communicate*' proved to be more challenging. However after discussing the questions the participants reached a consensus of opinion in the messages Annie was trying to convey. Following on from this exercise participants completed an exercise in which they were asked to '*look beyond the words*' and to understand that the words and actions of people with dementia ALWAYS have a meaning, (please see pages 22 and 23). This particular exercise of stating ideas in the positive rather than in negative terms proved to be

challenging for seven out of ten of the participants and it was agreed that we would review this exercise again during the workshop in week 4.

Session three – Building our understanding of living with dementia

Taking the knowledge and understanding of dementia addressed in sessions one and two, the power point presentation, accompanying video clips, exercises and handout material for this third session aided participants understanding of:

- How does the environment affect a person living with dementia?
- How might it feel to care for someone with dementia?
- How may the actions of others affect a person living with dementia?
- Living well with dementia.

The introductory exercise for this session asked the eight attending participants to spot the similarities and differences between five environments namely: prison; hospital ward; hotels; own home and residential care homes. All of the participants highlighted various similarities of each i.e. locked doors, possible time restrictions and scheduled meal times etc.; as well as differences in staff members of each establishments, (other than own home), in the wearing of uniforms. All of the participants commented that '*worryingly*' there were more similarities than there were differences; especially in relation to a prison environment. The effect of environmental features such as lighting, time of day, medication, noise and disorientation on someone living with dementia was further explored in a scenario and visualisation exercise: '*Lost in Amsterdam – environment Hell*' (please see page 24). After the completion of this visualisation exercise all of the participants remarked that this particular exercise enabled them to fully appreciate the impact of external and environmental aspects on the perception and perhaps subsequent behaviour of a person living with dementia.

Session four: Workshop - Building positive approaches

Seven volunteer participants attended this session. Unfortunately, two weren't able to attend due to work commitments, but those who did attend were given the opportunity during this half day workshop to openly discuss any queries and comments that they had relating to their learning during the programme sessions. This involved returning to:

- The '*meaning not the words*' exercise from session 2 (please see pages 22 and 23). On this occasion **all** of the participants were able demonstrate the re-phrasing of each of the sentences within a positive, rather than a negative context.
- A review of the six introductory statements, as per session one (please see page 20). The five participants who had initially offered a response of 'not sure' were able to appropriately qualify their opinion with an '*agree*' or '*disagree*' comment. However, it was noted and welcomed that with regard to question 6 - '*People*

living with dementia lose all capacity to think for themselves’; seven participants offered a more in-depth, knowledge-based and person-centred approach in the formulation of their answer.

The workshop format also supported participants to review appropriate dementia-related video clips which they had sourced from social media and other health websites; as well as exchanging their recent experiences in relation to the application of their programme learning into their volunteer practice environments.

Evaluation of the training programme – feedback from participants

In addition, during the workshop, participants were also asked to evaluate and comment on their individual learning journeys (please see pages 25 and 26). The following statements are a ‘snap shot’ of the responses received for each of the six questions in relation to prior knowledge and experience; the content and understanding of each of the sessions; what *‘they’* would take away from their training experience and any other comments they wished to make regarding the training programme. The names of the respondents have been anonymised.

Question 1: Briefly describe your experience and knowledge of dementia prior to undertaking the four training sessions?

The comments offered to this question ranged from a personal and professional perspective:

I have a grandma who has dementia and I have supported carers of people with dementia, but I didn't really know anything about it.

June

Rachael, a former nurse, spoke openly about her realisation relating to her lack of knowledge:

*Sessions were very informative. I did not realise how much I **didn't** know or understood about dementia.*

Rachael

Cathy, in contrast, spoke about ‘deepening’ her knowledge:

The course has deepened my knowledge of the various types of dementia. Prior to the course I was not aware of the perceptual experiences of the person and the fragmentation of their memory.

Cathy

Question 2 (related to Session One - Building a Basic Awareness of Dementia):
In what way has your knowledge changed in relation to: What is dementia? / Who can develop dementia? / How does dementia affect people?

Responses varied in relation to knowledge and understanding:

I have learnt that there are many different types of dementia. All have different symptoms and ways of 'presenting'. Anyone at any age can develop dementia. It can change their way of life, their relationships, and their personalities and eventually takes away their independence.

Doreen

As well as the application of knowledge into their volunteering practice:

I feel that I am now able to recognise the 'signs' of people who are perhaps living with dementia and this will enable me to assist them in my volunteering role.

Paula

Question 3. (related to Session Two - Connecting with People with Dementia):
In what way has your knowledge changed in relation to: Appropriate communication strategies and skills when working with people living with dementia?

This was question enabled the participants to reflect on their learning with some responses being particularly personal:

The course has helped me to understand that the way in which I speak, you see I am too quiet (sic), I speak very quietly and I feel that it is a 'disability', my disability and that this would have a 'knock-on' affect when working with people with dementia. I need to try and change that.

Paula

Margaret considered a practical approach in stating that:

*I need to speak slowly – listen to what is being said and give time for people (with dementia) to speak; also to look at body language and to be more person-centred in my approach. Seeing the **person**; not the dementia.*

Margaret

Question 4. (related to Session Three - Dementia and the Environment):
In what way has your knowledge changed in relation to: The physical and cognitive experiences of people living with dementia in relation to the environments; as well as identifying the ways in which different environments can be made enabling, rather than disabling for people living with dementia?

This question prompted a number of responses in relation to being aware that noise, lighting, textures and colour variations can have a substantial effect on the environmental experiences of someone living with dementia.

Margaret, who is not only a **Search** volunteer, but is also a volunteer inspector with the Newcastle Hospitals Foundation Trust, highlighted a recent example of how she was able to 'cascade' the knowledge she had gained on the dementia training programme into other aspects of her volunteering role. (This particular example related to spacial awareness and the use of prominent colours, such as blue and red being used in bathrooms for people living with dementia).

I was on an inspection visit to a hospital recently and realised that the interior building had white walls, white floors and white toilet seats in all of the bathrooms. I explained about blue and red being the last colours people with dementia are able to recognise and they have ordered blue toilet seats and are going to look at the flooring as well. I am so pleased I was able to help.

Margaret

June also commented on other environmental areas specifically related to colour:

People living with dementia may find it hard to see things, i.e. toilet seats, but this can also affect other aspects for example food on a plate. It is helpful if we provide a BOLD colour so it is easily seen. Offering a bold coloured plate for contrast, rather than a white coloured plate for example, where certain foods (potatoes, fish, and rice) would be hard to see and therefore the person (with dementia) may not eat – and then may lose weight and this could lead to other health problems etc.

June

Question 5. (asked participants to consider):
What will you take away from the dementia training programme to apply to your own volunteering / working role / life?

Many of the participants offered an overview of their learning. For example June highlighted that:

I have gained a lot of knowledge relating to dementia itself and all the different forms. I now know 'little things' (activities) to suggest to carers that they could do with their loved ones and that they could enjoy together. I now have more understanding of what people go through (sic) and how people can see 'behaviour that they may find challenging' and believe it to be just 'bad' behaviour when it isn't.

June

Cathy spoke about wanting to extending her knowledge of dementia by incorporating her learning into other aspects of her life by commenting:

I would like to develop greater awareness from undertaking this course – perhaps using my music skills, as I can see that this can perhaps be a great stimulus to a 'withdrawn' person who is living with dementia. Also I will never forget to try to 'reach' for the uniqueness of each individual.

Cathy

In contrast Rachael offered a more succinct response by stating:

I will be more person-centred in my approach when working with people with dementia. I will 'see' them, not the 'dementia'.

Rachael

Question 6. (asked participants to consider):

Any other comments regarding the training programme, (this includes delivery of sessions by trainer and resource material - presentation DVD.s and handout documentation)

This final question give the training participants the opportunity to comment on the overall aspect of the training programme. All of the participants who attended the final workshop session and therefore completed the evaluation form stated that they had '*enjoyed the programme*'. In particular being able to discuss the development of their volunteering roles in relation to working with people living with dementia.

Anne for example said:

I have enjoyed each of the sessions, they have been very good: the DVDs where great, the handout material was also good. Talking and listening to everyone – all good!

Anne

Others spoke of the appropriateness of the training material by saying:

An excellent informative and helpful programme, video material was always appropriate and memorable because of the 'appeal' to everyone's imagination.

Cathy

All of the participants spoke about wanting to receive further training for example June expressed her interest by commenting:

It was excellent, very well presented, lots of good paperwork to refer back to and easy to understand: very professional, but also a 'warm' atmosphere in the sessions. I would like to do further training on this subject, especially on disability (intellectual) and dementia.

June

Overall the training programme was well received, enabling participants to work cohesively together within a supportive environment. All the participants expressed interest in undertaking further dementia training at an advanced level.

Conclusion

The overall aim of the volunteer training program: *Building a Dementia Friendly Organisation* was to present the foundational aspects and basic awareness of dementia to ten **Search** volunteers. This was undertaken during three inter-active full day sessions and one half day workshop held in April 2015. From week one the training programme enabled participants to incrementally build on their *limited* pre-training experience and to develop an empathic person-centred care approach to working with **Search** service users who may be living with dementia. Training participants began by exploring a number of topics such as what is dementia and how does dementia affect people; before incorporating this knowledge and understanding into subsequent session topics such as: improving their own communication skills and addressing environmental issues which affect people living with dementia.

The contrasting responses to the completion in week one and then revisiting of the initial statement questionnaire in week four, highlighted the participants' overall development of dementia awareness. Enabling them to draw on and further develop their knowledge whilst working with people with dementia within their volunteer working practice. As envisaged the programme also facilitated the cascading of dementia awareness and understanding gained by participants; enabling them to act as knowledge mediators with **Search** colleagues and with other organisations through their varied volunteering environments in relation to working with people living with dementia now and in the future.

References

The format of each session included the utilisation of a topic-related power point presentation; as well as pertinent video clips; handout material and workbook; questions for discussion; visual and audio exercises. The materials which have been highlighted in this report as exemplars of training resources used are:

The Alzheimer's Dementia Care and Research in partnership with Dementia Care Matters (2003). *Make a Difference in Dementia Care Training: Resources that are effective, meaningful and fun!*

Kitwood, A., and Loveday B., (1998). *Improving Dementia Care: A Resource for Training and Professional Development*. Hawker Publications Ltd. London.

Appendices

Questionnaire 1: (given to participants at the beginning of session one and also at the end of the workshop held in week four)

Before we begin ... a review

Tick: agree or don't agree or not sure to the following statements:

1. Dementia and Alzheimer's Disease are the same:
a disease / disability / condition

Agree

Don't agree

Not sure

2. Dementia is an overall deterioration of brain cells

Agree

Don't agree

Not sure

3. Dementia only affects people over 65 years of age

Agree

Don't agree

Not sure

4. There are c.800,000+ people living with dementia
in the UK

Agree

Don't agree

Not sure

5. Dementia is hereditary

Agree

Don't agree

Not sure

6. People living with dementia lose all capacity to think
for themselves

Agree

Don't agree

Not sure

We will review these statements at the end of the training programme in week four

Session 2 HO1: Understanding Behaviour We May Find Challenging and Communicating with People Living With Dementia

Case Study: Annie McKenzie

Annie McKenzie is a 79 year old woman with dementia who has lived in the residential home for two years since the death of Alfred, her husband, who had cared for her at home. Up until the age of 74 Annie had led a very active life. She ran a newsagent shop until she was 65 and after retiring she looked after her grandchildren full time, whilst her daughter was at work. She started to have some memory problems at the age of 73 and laughed them off although she did, at times, appear to be quite worried. She started finding it difficult to cope with the two children and on one occasion the three year old went missing for half an hour in the park. Annie decided, with her daughter, that it might be best if she gave up looking after them. Annie became quite depressed after this event. Her memory rapidly declined and she became disorientated. Sometimes she thought she was still responsible for the children and a few occasions she had awakened Alfred in the middle of the night, saying that the children were lost. Alfred and their daughter became very worried about Annie. The GP diagnosed dementia. Annie herself was very worried about her failing memory.

As time went on, Annie gradually became more and more disabled. Her relationship with Alfred was solid and this helped them both. Their daughter did what she could to help, but was very busy with the demands of work and her own family. Then Alfred fell ill and was diagnosed with cancer. He did not want to worry Annie by telling her about his diagnosis. Social Services arranged for Annie to attend a day centre for five days a week to give Alfred a break and on two occasions when Alfred had to go into hospital, Annie stayed in a residential home. Annie did not settle well in the day centre or the home; she constantly asked to 'go home' and asked 'where is Alfred?'. The residential care staff struggled as they were unsure whether to tell her the truth about how ill he was – some did and some didn't.

When Alfred died, Annie went to his funeral, but became very distressed and confused and her daughter felt it had been a mistake. After this, Annie moved in with her daughter on a temporary basis, but this did not work out well. Annie's difficulties were too much for her daughter to cope with and sometimes her behaviour became quite challenging: for example, she frequently accused her daughter of hiding her things and she often forgot to go to the toilet and soiled her clothes and the furniture. Social Services helped Annie's daughter decide that Annie should move into the residential home where she had been for her respite stays. Annie was not very happy about this, but really there was no alternative as she would not have been able to cope on her own. Annie herself expressed a strong wish not to be on her own. Now Annie has been in the home for two years and her dementia is significantly worse. She is regarded as a '*challenging resident*'. She frequently accuses staff of stealing things from her room and no matter how often she is told the truth she still believes that this is happening. The GP has prescribed anti-psychotic medication, but her accusations have continued and her confusion has increased. She refuses help from staff with washing and other personal care, but is not able to care for herself independently. This combined with the fact that she wears incontinence pads, means that members of staff have to be very firm with her in order to get her washed and dressed. This can be quite a battle and Annie is frequently verbally abusive to care staff.

Annie's daughter comes to visit her once a week, sometimes bringing the grandchildren with her and Annie usually responds very positively to these visits. However, after her daughter leaves and on many other occasions during the week, Annie is very tearful. She constantly asks for both her daughter and for Alfred. Care workers have tried to distract her and cheer her up at these times, but this often makes her cry more, so now they tend to leave her alone until she falls asleep. Care workers have tried to involve Annie in activities which are run in the home, but Annie always refuses. Annie's verbal communication is quite limited; she tends to latch on to words or phrases and repeat them again and again. Care workers try their best to understand what she is trying to say, but do not usually succeed and so do not stay talking to her for long.

Questions for discussion:

1. What are your comments on Annie's care?
2. What possible needs of Annie's can you identify at each point in the case study?
3. What messages do you think Annie might be communicating through the different behaviours outlined in the case study?
4. How could the staff in the residential home meet Annie's needs and respond to the messages she is communicating?

Adapted from: *Improving dementia care*
(Loveday, Kitwood and Bowe, 1998)

Session 2 HO2: (the meaning not the words session 2 and also in reviewed during the workshop – week 4)

Improving Verbal Communication

Strategy 1: State ideas in the positive rather than negative terms.

Each of the sentences below is stated in negative terms. Restate them positive terms.

1. Don't put the ice cream in the oven
2. Don't go over there
3. You shouldn't wear that coat when it's so hot outside
4. You know that isn't yours!
5. Don't move like that when I'm trying to shave you

Strategy 2: Avoid questions by stating ideas in positive terms. Turn each of the following questions into a positive statement.

1. Don't you remember that we just went to the shops?
2. What would you like to wear today?
3. Who's the baby in the photography?
4. Do you want to wash up?
5. Do you want to visit the doctor?

Strategy 3: Do not reason or apply logic. Each of the following statements uses logic and reason. Offer an alternative response that does not confront the individual.

1. You know the toothpaste goes on your teeth not on your hair
2. Your sister died three years ago, she's not coming to visit you
3. You know if you keep hiding these bills you'll be in trouble with the electricity company
4. Of course you know May; you worked with her for 25 years
5. You just asked me that question; you already know when your wife is coming

**Adapted from: Improving dementia care
(Loveday, Kitwood and Bowe, 1998)**

Session 3: (Scenario and visualisation exercise)

Lost in Amsterdam – environment *Hell*

You are in Amsterdam, on a long weekend trip with friends. You have had a wonderful time taking in all of the tourist stops in the city centre. On Sunday evening, your final night in Amsterdam before you catch the ferry home to North Shields, you and your friends decide to go to a club that has been recommended to you on the outskirts of the city. Someone else knows the directions and is going to take you. In preparation you get all dressed up for your big night and even though you normally wear glasses, you decide to wear your new contact lens. You are taking a small bag with you which contains your wallet, money, mobile and other 'bits and bobs'. In true *Geordie-style* you don't take a coat.

The following morning, you don't remember what happened to you, but you wake up on a bench in what appears to be a park, surrounded by buildings which you don't recognise. There is no one else around. You are wearing one shoe; your bag has gone and it appears that your watch has stopped at 10 o'clock, although you can't really be sure as your eyes are very sore and you have blurred vision. You think that it must be sometime around dawn as the sun is just coming up. You have a terrible headache and are unable to think clearly. You see a man coming towards you with a big dog. As he approaches you he begins to speak in Dutch, but you can't understand him. His dog lurches at you and you step back because you are frightened of dogs. Again the man tries to speak to you. Then he touches your arm, so you quickly pull away. Next he begins to shout and then makes a grab at you. You turn and begin to walk quickly away from him; turning around occasionally you find that he is walking after you. His dog is barking and pulling at his lead. You begin to run, not knowing in which direction you are running in, but your legs are stiff and running with just one shoe on is difficult.

After a while you realise that the man and his dog have stopped following you. Trying to orient yourself you stop. Your heart is pounding and you bend over as you feel as if you are going to vomit. After a few moments you stand up straight and look around. Ahead you see what you think is a road. You quickly walk towards it thinking that maybe you will be able to find a taxi. Just as you near the road there is a loud noise and flashing lights; you just avoid being knocked down by a large van. The driver slows down and shouts in English out of the van window, but then quickly drives off. You are left by the side of the road. You are frightened, cold and you really need to go to the toilet. You know that you must get back to your hotel to pick up your suitcase and passport, but you can't remember the name of the hotel you were staying in.

The ferry for home leaves at 8.00 a.m.

What do you think?

How do you feel?

What do you do?

Adapted from: **Make a difference in dementia care training, Alzheimer's Society (Alzheimer's Society and Dementia Care Matters 2003)**

Questionnaire 2

Dementia Training Programme

Evaluation Form

Please offer your comments to the following questions

1. Briefly describe your experience and knowledge of dementia prior to undertaking the four training sessions?

2. Session One - Building a Basic Awareness of Dementia

In what way has your knowledge changed in relation to: What is dementia? / Who can develop dementia? / How does dementia affect people?

3. Session Two - Connecting with People with Dementia

In what way has your knowledge changed in relation to: Appropriate communication strategies and skills when working with people living with dementia?

4. Session Three - Dementia and the Environment

In what way has your knowledge changed in relation to:

The physical and cognitive experiences of people living with dementia in relation to the environments; as well as identifying the ways in which different environments can be made enabling, rather than disabling for people living with dementia?

5. What will you take away from the dementia training programme to apply to your own volunteering / working role / life?

6. Any other comments regarding the training programme, (this includes delivery of sessions by trainer and resource material - presentation DVD.s and handout documentation)

Thank You for participating

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