Abstract
This article is written by someone living with Alzheimer’s disease, Ann Johnson. It considers how education about dementia can be delivered in various settings and to various audiences. It highlights the different approaches required and the feedback received.

Key words
dementia, Alzheimer’s disease, quality of life, personal experience

My name is Ann Johnson and I am 56 years old. I was diagnosed with young onset Alzheimer’s disease at the age of 52. I am a trained nurse and was a lecturer in nursing prior to taking early retirement. As a result of my condition and my previous lecturing experience, I have received many invitations to talk about living with Alzheimer’s disease. From my perspective, giving these talks has given me a sense of purpose and helps to build my self-esteem and confidence. Nathaniel Branden (1969) said that self-esteem is the ‘experience of being competent to cope with the basic challenges of life and being worthy of happiness’. As a person living with Alzheimer’s disease, it is very easy to lose one’s feeling of worth; giving talks enables me to realise that I still have a lot to offer that can benefit others.

The groups to which I have been invited to talk vary widely, and it is interesting to discuss the effects of the talks I have given. In some cases, some audience members have told me that it made them feel emotional. They describe it as having heard about dementia before, but not thinking of the condition as a person. It is possible to know all of the symptoms of the condition, but the effect created by someone, a sufferer (and that’s how I see myself), talking about how the symptoms affect him or her makes it personal and real. In such cases, the audience often becomes emotionally and personally attached to the speaker. In my talks, I find this reaction coming through regularly. Perhaps it is the listener having concerns about his or her own behaviour that provokes concern. Once the speaker is aware of the effect that their words are having on the audience, then they are more able to achieve the objective of ‘educating’.

Education can be given in a variety of settings, the same principles applied to each, but in my experience adaptations need to be made to meet the needs and values of the specific audience. An example of this can be seen in the difference between speaking to a group of people with dementia. In this situation, it is important to realise that they are experiencing the same difficulties that I experience. I handle the situation by explaining my problems and my coping strategies. Observations of their responses are interesting in the sense that their non-verbal behaviour often suggests that they are experiencing similar problems. Within this particular group it is possible to see cohesion developing and participants working together. Teaching people with dementia to use strategies to overcome their problems is vital. The strategies that I use include: a digital watch, which overcomes my problem of not being able to read a normal watch; audiobooks, which helps my difficulty in reading; and a Dictaphone, on which I can record short messages that helps my short-term memory.

I now live in a care home. When I first moved in, I was asked to explain my problems to the staff. They told me, after hearing me, that because I had spoken to them about the problems I have to live and deal with, they can understand why some of their residents are having problems and how they can help. This, to me, was a great encouragement and added to my personal sense of achievement.

It is sometimes difficult to explain the problems caused by Alzheimer’s disease, because to the listener they may appear strange. Public perceptions and understandings of Alzheimer’s disease are often related to short-term memory loss. However, some people have problems with understanding and adding up (particularly money). These are problems that I experience on a day-to-day basis and
have to learn to live with. I try to convey this to my audience with simple illustrations, such as the inability to put my coat on. It appears to help them understand the situation. Also, a specific problem that I encounter is the inability to find the word I want. The response of the listener might be to offer a suggestion that may or may not be appropriate or let me try and achieve the desired word. I, myself, would prefer to be given time to find the word. It may be possible to achieve the meaning by using other words without others being aware. Many of the symptoms of dementia are related to cognitive functioning. It could be suggested that the inability to do certain things such as counting money, telling the time on a watch and difficulty with reading occur because the skills were learned in childhood, but have now been forgotten. This would account for the inability to manage daily life.

It is important to remember that in Alzheimer’s disease, it takes the person longer to deal with even the simplest things. Time is needed to process the detail and make sense of it. A great deal can be achieved by the person being given more time and the plea is for people to be patient. Previously simple tasks become impossible situations for which a solution often cannot be found. The understanding of this by those not affected can significantly help the person with dementia. Patience on the part of the carer/supporter is needed. Often self-esteem is lost, which may lead to depression, not simply a feeling of despair. Self-worth is so very important.

The greatest encouragement can come from an understanding friend/carer/supporter, who is aware of the problems with which the person is struggling. Sympathy is not required. Trying to ‘get inside the skin and brain’ of the person with dementia and ‘being there with them’ is vital in handling what I call an accursed, unremitting disease.

Last year, I was invited to get involved in teaching on the MSc Dementia Care course at The University of Manchester and my experience has been very encouraging. The postgraduate students are also practicing health and social care professionals. I was very impressed with their presentations on how they assessed and evaluated clients, planned their care and carried it out. Overall, this has indicated to me that they have developed a thorough knowledge of approaches and ways to handle their client based on research and best practice evidence. Research-based practice is vital to good patient care. It is essential that students are able to acquire these skills to ensure better care for the person with dementia. The knowledge and experience brought to the MSc course by the different disciplines has shown that many specialties and practitioners are essential to the care of the person with dementia. All must work together to ensure the whole. Giving feedback on anonymous clients has enabled students to improve their care and helps them to understand why they are giving such care. They should be a ‘knowledgeable doer’ rather than performing actions by routine. Understanding the reasons for an action will enhance its effectiveness.

The need for education about dementia is apparent, particularly in care homes, which often provide care for residents with dementia. It is essential that the paid carer understands the needs of the person with dementia and how to care appropriately and effectively. Therefore, there is a need for an increase in education in areas such as care and residential nursing homes. It is vital to identify the appropriate people to perform this education. In my opinion, any plan (formal or informal) for teaching aspects of Alzheimer’s disease should follow a carefully designed structure. The aim should be to establish what should be achieved by the end of the session. It would be advisable to focus on the normal anatomy and physiology of the brain in order for people to understand the abnormal functioning. Individuals will thus be able to describe and understand the effects of the brain related to dementia.

It is important to educate others as to how to care emotionally, as well as physically. Many people with dementia are aware of the possible progression of the disease and therefore care staff, of whatever grade and level, should be aware of the person’s concerns at all times. If possible, involve family members, but ensure they are able to cope with the situation. Carers, themselves, often require a great deal of support and may experience grieving for the person they feel that they have lost as the disease progresses.

The person with dementia should be taught about any prescribed medication – what it is, what it does and the reason for taking it. The assessment of the person with dementia is vital to ensure that the information is given at the correct level to help their understanding. Observe their reaction to treatment and drugs and note any adverse reactions. Encourage them to share their own
thoughts and worries. Also, join them in their joys and achievements. Be realistic in educating the person with dementia in what they might expect from the disease, but tailor it to their level of ability and understanding. Do not set unachievable goals. All goals must be within their ability. Know the person and their abilities and do not push them beyond their limits.

The Mini-mental State Examination (MMSE) is often used as an assessment tool for people with dementia (Folstein et al, 1975). According to these authors, the MMSE is a practical method for grading the cognitive state of the patient. It could be suggested that the MMSE shows certain things while misjudging others. It will identify the ability to demonstrate orientation to time and place, the ability to recall three words, as well as identify and name objects. However, it will not identify the ability of the person to perform their normal day-to-day activities. In addition, it will not exhibit the demeanour of the person or display their response to the world in which they live. From the person with dementia’s point of view, it can be quite demoralising to find that one is unable to remember three simple words, spell a word forwards or backwards, or remember the day, month and year. It is important for those administrating the test to understand how the person with dementia may be feeling. In the sessions with the MSc Dementia Care students, it has become apparent to me that the students have an awareness of how their clients react to the test. They are able to share with, and appreciate their client, and show great understanding. Moreover, there is a need to see the person with dementia as a whole person, and it is the healthcare professionals’ role to listen to their views and to support them in their attempt to attain their desired lifestyle. In this way, the person, not the disability, is the prime concern (Cigno, 1995).

It is important that if anyone is worried either about themselves, a relative or a friend in relation to memory or behaviour, they should go and see their general practitioner who will advise and guide them. The earlier the diagnosis is made, the earlier treatment can begin and the person’s quality of life can be enhanced. Do not be afraid of the word dementia – it signifies a physical disorder of the brain and should not, and must not, hold any stigma. Being involved in the Department of Health’s Dementia Awareness Campaign’ (I have recently been interviewed on BBC Breakfast and on the radio and interviewed for the Alzheimer’s Society’s Living with Dementia magazine; Johnson, 2010) I would like to say that while I have dementia, I also have a life.

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References