Mindfulness and Dementia:

Report of a pilot study

Introduction
This project set out to test the proposal that mindfulness has the potential to improve the quality of life for people with dementia.

The hypothesis was that mindfulness’s focus on being in the ‘here and now’ could alleviate some of the suffering that people with dementia experience in adjusting to the challenges of living with their condition. Potential benefits were thought to include:

• being able to ‘stand back’ a little from the distress of the illness. Mindfulness helps people to develop a way of acknowledging the experience; but having more choice about how they respond to it.

• The cultural support that mindfulness philosophy gives to ‘being here now’. This could counter some of the distress experienced by people with dementia when confronted with difficulty in accessing past memories or possible confusion about the future.

• Mindfulness is effective in reducing stress and this could be of direct benefit to carers. They might gain new skills in how to deal with their own thoughts and feelings in relation to the person with dementia

• The enhanced experience of intentionally being ‘in the moment’ – should be valuable to someone who might spend a lot of time in various degrees of confusion

Mindfulness involves learning to notice what is occurring in one’s present moment experience, with an attitude of openness and non-judgmental acceptance.

“Mindfulness is the awareness that emerges through paying attention in a particular way, on purpose, in the present moment, and non-judgementally, to the unfolding of experience moment by moment” [1]

Research Questions
Mindfulness skills may therefore provide people, particularly in the early stages of dementia with some tools with which to manage their negative feelings.

This small pilot study funded by the Sir Halley Stewart Trust sought to explore two questions:-

• Is it possible to teach mindfulness to people with dementia

• Can mindfulness improve the quality of life for people with dementia
Results
Results were collected from 12 people with dementia and 8 carers. The headline messages were:-

- It is possible to teach mindfulness meditation to some people with dementia, particularly those in the earlier stages of the illness
- The teaching of mindfulness to people with dementia is likely to be more effective with a course which is adapted to convey the ‘cognitive elements’ in more dementia friendly ways
- Those people with dementia who are able to understand and practice mindfulness meditation can derive a wide range of quality of life benefits
- It is difficult for people with dementia to continue to practice without support

Ability to learn mindfulness
It is clear that some people with dementia were able to learn about mindfulness, as is evident from the following quotes from people with dementia themselves:-

Sitting down concentrating: it’s amazing what goes through your mind! It’s been fascinating to see how you can transform your experience with meditation. I can feel a lot better.

It didn’t come immediately, but there’s been a progression. The more I do the more I get from it, the more I get ‘within myself’. It’s good. But you must do it at home. When I’m at home my meditation is my time. It’s calming. Otherwise my mind is racing all the time with all the mistakes I make. It helps with stress - forgetfulness is very stressful. I can step out of worries or anger and go to my little stream*. (leaves floating down a stream was one of the images offered during meditations to help with the idea that thoughts are only thoughts.)

He does it at home and I’m amazed really because he listens to every word. He really does it and I think it helps him

It was also clear however that a number of people, particularly those who were more disabled by their dementia, had greater difficulty and were unable to learn about mindfulness:-

A carer talking about their mother with dementia said...I don’t think there was a clear understanding of what we were doing or why we were doing it. There was no lasting memory although sometimes there was a sense of calm in the moment.

A carer talking about their husband with dementia said...Not sure C... understood some of the things – didn’t quite sink in what he was supposed to do.

Impact on Quality of Life
The reported improvements in the quality of life for people with dementia were many and various:-

- Reduction in anxiety
  I can say that it has been good for B... (person with dementia). He is a worrier – but when we sit down and meditate and have a quiet moment, he forgets that he is worried.
• **Help with pain control**  
  I’ve noticed him doing the physical exercises that we did in the class (mindful movement) ... and he hasn’t complained so much of pain in his legs (which he usually suffers with)

• **Help with coping with dementia**  
  When you’re first diagnosed it can cause problems in the family - the repetitions of things you say, things you do wrong... I’ve learned to relax, and to feel what’s going on within me - which is a great thing for people with Alzheimers. My stream and my leaf is my little refuge. I can let things go, know that they’re gone, that the next hour is the next hour.

  So many conceptual aspects of my personality have changed very radically and increasingly I’m finding it very difficult to operate in a conceptual way. So more and more I’m operating in an emotional way and “being here now” is to a large extent emotional and has a very positive effect.

• **Help with regulation of emotions**  
  There are all sorts of dark areas of the mind, dark thoughts on the surface–particularly when you try to meditate. I’ve found this approach very useful in helping me to notice and stay away from places. With this meditation you can do that much more quickly, so I found it much easier to cope with. This has given me something I can handle. With dementia you have little control over things, but this I can handle, and this allows me to go into myself. I sit down of an evening, watch TV, or whatever, without going into those dark areas.

  What has helped him the most is when he has tantrums like a little kid. When he gets frustrated I say “Come on, breathe. It’s not that bad” and he is much better at that now

  My problem is anger and frustration and the course has made a massive difference, massive, just massive.

• **Improved sense of self**  
  I’m more comfortable in myself ... I can relax. I can be by myself – which I didn’t like before.

• **Improved cognitive functioning**  
  It’s making me think more constructively in day-to-day situations. I’m taking more time over things.

• **Restoring previous functional abilities**  
  After mindfulness he has started riding his bike with our youngest daughter again, he has started cooking again, he has started singing again. That for me is a massive difference.

• **Improved awareness and sense of appreciation**  
  Experiencing that it’s a beautiful wonderful world and when I’m being here now I realize how beautiful it is and what an amazing gift it is to have life here in this beautiful way.

• **Improved interpersonal relationships**  
  It’s helped to make me more aware of other people and other things. There’s been some developments in my life recently and it’s helped me understand more.
Outcomes for Carers
The impact of mindfulness on carers was not a principal focus of the project. That having been said it was clear throughout the project that most carers were understanding the teaching of mindfulness and getting a huge amount out of the practice. A few examples:-

• It’s been brilliant. I wish it could have gone on longer. I cant thank you enough because it has really been an eye opener. I found it relaxing and refreshing and it has given me a sense of being able to cope more with difficulties.
• Last week I found it hard to get out of the meditation. It was a bit spooky! But it was really, really nice: a comfortable place I’ve never been in before
• I am absolutely aware when I get stressed and I always now remove myself from the situation, breathe through it and I realize it is not so bad...it helps you to cope with the situation easier.
• I’ve already started getting up earlier and doing something in the morning. But also when I’m dealing with R…. I have more awareness with him

Although not measured, one could conjecture that the reported quality of life benefits could have an important beneficial impact on how carers relate to people they are caring for.

With the data from the follow up interviews it was clear that most of the carers were continuing to practice and were finding it of benefit in helping them to cope with their lives. The pressure of caring responsibilities is clearly an issue for many of them, but by the same token, most of them reported how mindfulness helped them directly to cope better with these stresses.

Conclusion
This was a very small scale study, nevertheless it has provided some very interesting data on the feasibility of teaching mindfulness to people with dementia. It also indicates that there are potentially significant benefits over a range of quality of life domains. There are also significant benefits for carers of people with dementia, some of which may have a knock on benefit for the people being cared for.

A further more rigorous study is planned.

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• Copies of the full report can be accessed here
  http://positiveageingassociates.com/mindfulness-and-dementia/