

REPORT

Introducing Mindfulness to caregivers and people living with dementia in residential care homes and creating guidelines for teaching mindfulness to this population



*Mindfulness Teacher Jonathan Barker
jbjonathanbarker@gmail.com*

*Dementia Specialist Catharine Arakelian
catharine@arakelian.co.uk*

Acknowledgments

With grateful thanks to the Oxford Mindfulness Centre for the award of an Access Grant in 2016 to carry out this work.

With many thanks to Mark Whittle and the Directors of Shaw Healthcare in introducing us to one of their care homes.

We thank Nadine, Doreen and all the staff at the Mill River Lodge Care Home, Horsham, for their enthusiastic participation in the project and their invaluable insights and feedback.

We acknowledge the help given by the Oxfordshire Dementia Advisers in setting up the Taster sessions in Oxfordshire.

Contents

Summary	page 3
Background	page 7
Appendices	page 21

Summary

The original aim was to deliver a large number of single Mindfulness Taster sessions to reach 160 caregivers and 64 people living with dementia in eight settings, to develop eight Mindfulness Champions in those homes, and to create guidelines for teaching mindfulness to this population. In September at a meeting with our partner Shaw Healthcare it became clear that they would prefer a single 6 week course in one care home to a series of tasters in 8 homes.

This change in the plan had a positive effect in that we could focus on and pilot the guidelines and what was lost in quantity has been gained in quality. However, it was not possible to follow up the Dementia Mindfulness Champion idea with Mark Whittle as he was unable to find eight homes for us to work with. There was a small amount of grant remaining after the care home phase at Mill River Lodge so Jonathan also taught three Taster sessions to different groups of carers and people with dementia living in the community in Oxfordshire, facilitated by the Oxfordshire Dementia Advisors.

There was clear evidence from the evaluations of both the longer course in the home and the Taster sessions that Mindfulness was perceived to have benefits for the caregivers and by implication for their care of the people living with dementia.

The Guidelines for Teachers of Mindfulness to People Living with Dementia are comprehensive and we hope will be of lasting value. The Guidelines are attached and may be shared with acknowledgment to OMC and Jonathan Barker and Cath Arakelian.

There was mixed evidence from observations as to the value for people living with severe dementia in a care home, not because the mindfulness sessions were not enjoyed but because for some residents this resulted in them being over stimulated – in the words of one senior staff member “unsettled”. This stimulation might be worth researching as a route to partial rehabilitation of the mind, but this apparent “waking up the mind” may not be seen as desirable in a care home where a level of passivity is expected. However, there was clear evidence for the value of mindfulness to people living with less severe cognitive impairment in the community.

Jonathan will attend a conference in July 2017 to describe the project and the guidelines. We hope to be able to follow up this work with further groups and find other places willing to work with us on developing the full course.

What we delivered

With the two qualified mindfulness teachers and a dementia care specialist we developed a set of draft guidelines to run help teachers run mindfulness sessions with people with dementia. Researching previous attempts to introduce mindfulness to people living with dementia we discovered a report that indicated that the cognitive input was the hardest part of the classic courses for people living with dementia to engage with. We decided to create a course outline based on sensory experience rather than cognitive engagement.

We were introduced by OMC to Shaw Healthcare who wanted us to run a six week course in one of their nursing homes. With the support of the home management we were enabled to do this over five days in successive weeks in December 2016 where we taught one session of mindfulness for the staff and followed this with a session with the residents. We had planned to run a sixth day but we were prevented by illness in the home. In March and April 2017 we ran three Taster Sessions with people living with dementia in the community.

Outcomes

The project was able to reach 15 people living with severe dementia in the care home and 11 care staff and a further 15 people living with mild dementia and 15 carers in the community.

Benefit to those living with dementia – Outcomes

The problem with measuring these desired outcomes is obtaining sufficient valid and reliable evidence and methods to evaluate them. The stated aims and evidenced outcomes are summarised below. (See page for more detail on evaluation methods and findings)

- Awareness of mindfulness as a way to alleviate one's own stress and anxiety - NO IN CARE HOME / YES, PARTIALLY IN COMMUNITY
- (Immediate) Left with a feeling of an enjoyable activity – YES, OBSERVED IN BOTH
- (Immediate) A sense of calm in daily activities after the session – MIXED – SOME STIMULATION (see Dementia Specialist observations)
- (Immediate) Enhanced communication about feelings/thoughts between the person and their caregiver – YES – PARTIALLY OBSERVED IN CARE HOME
- (>24hrs) Retained awareness of mindfulness strategies – NO IN CARE HOME / YES - PARTIALLY In COMMUNITY
- (>24hrs) Expressed desire to continue mindfulness – NO IN CARE HOME / YES IN COMMUNITY

Benefit to care givers – Outcomes

There was clear evidence from the evaluations that both the longer course in the home and the Taster sessions had benefits for the caregivers and by implication for their care of the people living with dementia.

The stated aims and evidenced outcomes are summarised below.

- Awareness of mindfulness as a way to alleviate one's own stress and anxiety - YES
- Improved confidence in managing the psychological needs of clients - YES
- Enhanced sensitivity to client's feelings seeing kindness as a resource - YES
- Desire to continue to develop mindfulness professionally or personally – YES – 50%

Reflection and Learning on the Mindfulness Course in the Care Home



The staff sessions were welcomed and we were pleased with the range of staff who attended from administrators, support and care staff and managers. The Home Manager was a powerful promoter of the project although she was only able to attend one staff session herself. The Deputy Manager attended a number of staff and resident sessions and was positive in encouraging other staff to take part. In a care home the backing of these two managers, which were responsible for staff rotas was critical for the success of the project. If the home had not

been under varying staff pressures each week we feel sure more members would have attended more sessions.

It is hard to gain any objective assessment of the lasting impact of the sessions on the residents as we were unable to complete our final teaching session and follow up session due to illness closing the home to visitors for six weeks in January. In the couple of months while the sessions were in progress (November – December) there was a clear sense that they were welcomed and seen as valuable at the time, which is reflected in the session evaluations and the phone interview feedback

We would have liked to have built into our programme a structure to promote regular staff practice for themselves and for the residents. There was some evidence that some staff attempted a daily practice. We could perhaps have linked individual staff members with individual residents to encourage practice between the taught sessions.

Residents had little active choice in whether to participate because the activity was held in the lounge which is where most of them are sat after lunch and which hosts a variety of afternoon activities take place. Those who liked to walk about were permitted to do so. Some people did choose not to participate and were in their rooms. The content and conduct of the resident sessions was seen as beneficial by the Team Leader and Activity Organiser. We had a wide range of cognitive capacity in the session but they seemed to hold attention and be generally welcomed each week.

BACKGROUND

Care Staff Course

Participation

Twelve individual staff members took part. Three staff were able to complete all the sessions. Not all staff were released to take part in every session depending on staff numbers, and two people came in on their day off to take part. In total 33 out of a potential 60 staff/sessions were completed.

Delivery of 5 sessions to 3 people	15
Delivery of 4 sessions to 0 people	0
Delivery of 3 sessions to 3 people	9
Delivery of 2 sessions to 2 people	4
Delivery of 1 session to 4 people	4

This group included the Senior Home Manager and Deputy Home Manager, one team leader, two activity coordinators, four care staff, one administrator, one member of support staff and two Shaw managers.

Course Delivery

All staff in the care home were invited to attend a six x one hour per week course which would support their wellbeing and prepare them to enable the residents on the residents' course.

Gender mix: 10F, 1M

Age range: no response = 1

under 19 = 1	20 – 29 = 2	30 – 39 = 1
40 – 49 = 2	50 – 59 = 2	60 – 69 = 2

Analysis of Breathworks Questionnaire

Each member of staff was asked to complete a Breathworks Questionnaire which comprised different sections including: demographics, course details, employment, sleep patterns, perceived stress scale, satisfaction with life, quality of life, HADS (depression scale) and the Five Facet Mindfulness Questionnaire. They also completed a consent form. 11 forms were completed by staff who participated in the Mindfulness staff sessions at the start of the course. When it became difficult to revisit the home in January because it was closed due to infection, the planned second questionnaire (end of course) was abandoned as being too far removed in time from the course – more than two months.

Overall, the crude analysis of the questionnaires gives an impression of a quite emotionally balanced and personally insightful staff group. The sample size of 11 staff is small and the group is to some extent self-selecting as these were the people who wanted to try mindfulness and therefore are maybe more attuned to their emotional life than others. The group included nursing and care staff

as well as auxiliary and management staff and the range of ages from 19 to 68 illustrates how the staff of a care home straddle the generational divide.

Findings

Job satisfaction: 64% said they were satisfied or very satisfied with their jobs and 82% said they felt productive or very productive on a typical working day. 64% felt very tired or fatigued and most rated their fatigue right now as between 4 and 7 on the 10 point scale. Less than half the respondents said that fatigue partly (6 and above) interfered with their general activity, mood, walking ability or normal work, and fewer that it interfered with their relationships with other people.

Sleep patterns: there was no pattern to the sleep patterns of this group, perhaps because the sample size is so small. 82% of respondents typically slept between 6 and 8 hours each night although there was slight decrease in the number of hours actually slept in the past two weeks – 64% between 5 and 7 hours with two people reporting they had had under 4 hours sleep per night.

Perceived stress scale and quality of life: There were no patterns here.

HADS: 54% reported feeling tense or wound up occasionally. 36% reported these feelings were most of the time or a lot of the time for them. 73% reported that they got “a sort of frightened feeling that something awful is about to happen”, however, the same number felt they could “see the funny side of things.” Most of the staff group reported feeling cheerful sometimes or most of the time. 73% reported that when they “feel inadequate” they remind themselves that “feelings of inadequacy are shared by most people.” And most of the staff group reported that they were “intolerant and impatient towards those aspects of my personality that I don’t like.”

Five Facet Mindfulness Questionnaire: All the staff felt they were pretty “good at finding words to describe my feelings” 54% sometimes true, 45% often true. Similarly, the clusters of answers are mostly around the “sometimes true” and “often true” for the remaining questions. Only one member of staff seemed to feel very negative about him or herself, while two expressed very positive views.

Resident course

Together with the care home deputy manager and ward team leader individuals who were thought might benefit from the course were selected and consent obtained for their involvement by the ward team leader. Their case notes were investigated to check for any other safety considerations. Cath, as the Dementia Specialist looked at the person-centred care plans to note any background which might be salient. Before each session we checked with the staff on the current emotional wellbeing of the group and went through the planned activities to determine the level of risk, such as choking on a raisin, allergy to the smell of vanilla, swallowing of objects.

To create a baseline profile of each member of the residents group a Wellbeing Interview (based on the Warwick-Edinburgh Mental Well Being Scale 2006) conducted with the Dementia Specialist

Each week on the Tuesday of the course they were encouraged to participate by the care staff and were given a Named Invitation to the "Feel Good" session in the morning. When they joined the group each week they were given Name Badges so the teacher and enablers could use their names.

Total number of participants: 15

Gender: M 2 F 13

Age Range:

70 – 74 = 3

75 – 79 = 1

80 – 84 = 3

85 – 89 = 6

90 – 94 = 1

95 – 99 = 1

Condition from case notes (verbatim)

Alzheimers: 7

Vascular Dementia: 1

Mixed/"dementia" or other: 7

Participation:

11 attended 5 out of 5

2 attended 4 out of 5

0 attended 3 out of 5

2 attended 2 out of 5

Evaluation of outcomes

We had originally intended to use a Well-Being Survey as before and after measures to determine how people felt after the course. However, they were not the right tool for this group who live with significant cognitive impairment and we were unable to administer them twice. We felt we gathered more useful data about the impact of the course from staff observations.

The Well Being Surveys revealed a wide range of emotional states and are a snapshot of how that person was feeling at the time of the interview. A respondent was asked if they wanted to do the questionnaire as an interview with Cath, whom they already had met in the sessions. The interviewer read out the questions, and the five point scale, and recorded the responses verbatim. Most respondents could not use the scale easily and preferred to respond to the statements directly in their own way; in others, their responses seemed unconnected to the statements. Most respondents were able to complete the interview and found it a positive experience. In four cases

the care staff considered that the person was not well enough to be interviewed. One respondent seemed tired and another became distressed, and in both cases the interview was stopped. We did not carry out a second interview.

Gender	Age	Nature of disability (as verbatim recorded in case notes)	Participation (max 5 sessions)	Wellbeing Survey 14 items on 5 point scale Selected comments as intelligible – WB statements are in italics. Interviews conducted during the programme in November 2016
F	99	Mixed dementia Depression Anxiety Diabetes Type 2	4	Being optimistic about the future is not easy. I've got lots of things to think about. I've felt useless We had a weekend. I felt I was getting somewhere I'm not terribly good at being bossy. I can handle things I think I've improved At times I've felt much better about myself
F	74	Alzheimers	2	Not interviewed
F	88	Alzheimers COPD Complex needs	5	I've not been at my best recently. <i>I've been feeling close to other people</i> - at the moment. [generally very positive outlook 8 out of 14 items – all the time/often]
F	87	Alzheimers	5	We never lose track of what's going on <i>I've been feeling interested in other people</i> - up to a point We all get together here – most evenings I've been feeling better than when I first came We sings and laugh and that's what I call loving <i>I've been feeling cheerful</i> when my son's around [generally positive outlook 7 out of 14 often]
F	80	Mixed And anxiety	5	I am happy. I just like it – it's my life.

				<p><i>I've been feeling confident – pretty fair</i></p> <p>This is me. That is my life. This is the world.</p> <p>[We finished interview early as she seemed a little distressed]</p>
M	73	Multi-infract dementia	2	<p><i>Optimistic – all of the time</i></p> <p><i>Feeling useful - often</i></p> <p>I'm not bothered about other people</p> <p><i>I've been feeling good about myself</i></p> <p>I don't know if I've been feeling anything at all really?</p> <p>I haven't got any problems.</p> <p>No response to many questions and long pauses.</p> <p>Perked up when discussing sea-fishing</p>
F	89	Dementia Diabetes Type 2	5	Not interviewed
M	87	Alzheimers	5	<p><i>I've been feelings optimistic about the future</i></p> <p><i>I've been able to make up my own mind about things</i></p> <p>Shook head - <i>I've been dealing with problems well</i></p> <p>[Generally positive outlook – 6 out of 14 often or all the time]</p>
F	90	Vascular Dementia	5	<p>I don't know much about it</p> <p>No, I've just gone along with everything</p> <p>I like everybody</p> <p><i>I've been able to make up my own mind about things –</i> I wouldn't like to say that</p> <p><i>I've been feeling loved – I'm a long way away really</i></p> <p><i>I'm interested in new things – I like it all</i></p> <p>[Watching the PAT dog eating his food] – I love to see it – makes me laugh</p>

F	77	Dementia	5	<p>I'm getting out of here</p> <p><i>I've been thinking clearly</i> – my bleeding head's going round</p> <p><i>I've been feelings interested in other people</i> - I like my friends</p> <p><i>I've been feeling close to be people</i> – I wanted to see my mum</p> <p><i>I've been feeling loved</i> – by mum</p> <p><i>I've been feeling cheerful</i> – when I'm doing (sewing) for the staff</p> <p>[Happy respondent very articulate but possible to say that the respondent lacks capacity to understand the statements. However, the statements trigger responses which have validity on their own terms]</p>
F	84	Dementia diabetes	4	<p><i>I've been feeling useful</i> - I haven't been doing what I want to do</p> <p><i>I've been feeling good about myself</i> – I try not to think about myself at all</p> <p>[generally in low spirits – 8 of 14 some of the time/rarely]</p>
F	81	Dementia (advanced)	5	Staff did not consider it appropriate to interview her
F	73	Alzheimers (late stages)	5	Not interviewed – not able to speak – [although this respondent has plenty of other ways of communicating through her gestures and eyes]
F	87	Dementia - Alzheimers (late stages)	5	Not interviewed
F	79	Alzheimers	5	Not interviewed

Staff feedback through structured interviews

As there was a lapse in time of nearly six weeks between the end of the taught sessions and being able to ask for feedback, due to Christmas holidays and then illness in the home, we simplified our phone interviews to three questions: what was the impact of participating in the mindfulness programme on oneself, what was the impact on the residents and what was the impact on the institution (if any).

Administrator - who participated in the staff sessions)

Impact on her: Helped her to step back from her life. At the time of the course she had lost someone dear to her and was going through a lot of grief. It helped her take a step back and count down from that. She still felt the strong feelings with her but they weren't coming up in her mind all the time. She feels it has had a lasting impact and she does the breathing meditation which she prefers to the body scan.

Impact on residents: she doesn't work directly with them and didn't hear anything.

Impact on the institution: she feels the staff that did the course learnt how to be in the moment and be calm. She feels its important lesson in how to be with residents in the moment.

Deputy Manager - who participated in the staff sessions and some resident sessions)

Impact on her: taught her how to relax and at work do breathing exercises when she felt stressed. She felt she could use it at home and at work.

Impact on residents: Residents commented on the meditation teacher's voice which they felt was calm and soothing and helped them relax. Staff did the hand/finger meditation with residents afterwards and this particularly helped when residents were cross or unhappy. A Senior Care staff member and an Activity Coordinator used the hand massage a lot. Since the listening to music session (Moonlight sonata). The Activities Coordinator uses music a lot in group sessions when residents are sitting in a circle.

Impact on institution: She had lots of feedback from staff who found the course very beneficial. One of the activity staff members said it was brilliant. Social workers, GPs and carers from outside the home who heard about it were very impressed. The staff looked forward to the weekly sessions and some said it helped them calm down and unwind before going home.

Senior Nurse and Team Leader - who participated in staff sessions and most of the resident sessions)

Impact on her: it was helpful and made her more aware when she was stressed. She has learnt to take a few moments out to calm down, sit and focus on her breathing and body and it helped her block out anything else which was going on.

Impact on residents: it definitely helped, it was surprising how much they could focus on cerebral things and it helped bring them out of themselves. Normally after lunch we would see people talking about wanting to go home, this gave them something else to focus on. They enjoyed the sessions at the time but were restless afterwards because they had something to do – but this is the same with

any activity. One resident did the hand/finger meditations after we had gone. He also read a poem (Owl and the Pussy cat) to the whole group.

Impact on institution: couple of members of staff have talked about it since and the things they found useful for their own development. One staff member who only came to a few classes said how useful she had found those and wished she had signed up earlier. She was one of the staff members who involved residents in some of the techniques.

Session Evaluations Analysis – Care Home Staff

All sessions took place in a room on the first floor used for activities. Each person had a comfortable chair and a soft blanket. We asked staff to wear a name tag so they could be addressed personally. Cath took the register and distributed the evaluations, and took notes during the sessions. Jonathan taught the session for around one hour and answered questions afterwards.

After each staff session a written evaluation was completed asking the following questions: *What will you take away from today? How might participating in this course benefit you?; and Do you have any queries or comments?*

Numbers of evaluations returned: Session 1 = 7 , Session 2 = 7, Session 3 = 0 (possibly not collected), Session 4 = 5, Session 5 = 8 .

This is some selected feedback.

Staff Session 1

What will you take away from today?

I all way enjoy (sic)

Learnt that when a feeling begins to overcome – take a step back from it and think about the situation

To pay attention to something in the present

Take more time to experience and stay in the moment

Must remember to meditate

How might participating in this course benefit you?

To help with stress

It might make me more relaxed and focussed

To remind me to relax and to use these skills with people I support as well

To try and find 10 minutes a week (sic) to relax

Help me with my anger and my grief

Do you have any queries or comments?

Very relaxing

Staff Session 2

What will you take away from today?

It was very interesting to hear the thoughts and feelings experienced by the participants on the course and will definitely practice/develop the skill of meditation

Learnt about breathing exercises

How to use breathing to focus

I felt really relaxed

More (comfortable?) on (sic) my body – feeling very good

Being in the moment (try)

How might participating in this course benefit you?

To enable me to share my experience with friends and colleague because I did feel the benefits of the breathing meditation

To help me deal with my stress and depression

All way more relaxed on (sic) my body make me feel good and calm

Help me de-stress. Take note of how I'm feeling

Do you have any queries or comments?

Happy with the progression

Getting more relaxing as the sessions progress

Staff Session 4

What will you take away from today?

To accept things and let them in

To be kinder to myself

Take time to feel how my (minor irritations) thoughts affect my body – stomach, chest, breathing

Evidence that Shaw healthcare staff are receiving mindfulness workshops to enhance well-being of themselves and others (Visiting Shaw officer)

How might participating in this course benefit you?

Another tool to assist with dementia patients

By bringing it to the workplace and using it to communicate with residents

Make me more mindful not just for myself but for our residents

Do you have any queries or comments?

I really enjoyed the meditation. Must do more. I know it works.

Staff Session 5

What will you take away from today?

Calmness – trying to remember techniques to assist in everyday scenarios where stress takes over a situation

Facts about the difference in how the mind intakes negativity and positivity

Improvement on depth of meditation

Negative thoughts stick

Think more positive – take time to enjoy things

Looking at things a different way

How might participating in this course benefit you?

Help me reduce my stress and depression

Learning to be less reactionary, more able to balance difficult situations

Taking time out to be kinder to one self could assist in lowering blood pressure – less stress, more contentment

It will help me in my work

Helps me think more in the moment and relaxes me

Better level of focus

Do you have any queries or comments

Courses/ tapes/CDs/books would be beneficial to carry this further

(In fact, at the start, we supplied a copy of the book which accompanies the courses to the home, and each person was given a flash stick with the meditations.)

Very interesting. Wish I had been able to have attended previous sessions but due to six week absence was unaware of the course – perhaps next time

Session Evaluations Analysis – Taster Sessions

Three taster sessions were held with different groups in Oxfordshire in March, April and May. These consisted of a mix of paid carers and family carers and people living with dementia. It is not possible to distinguish the writers in these anonymous evaluations.

Unlike the group of residents in the care home, these participants are living with dementia in the community and are therefore not as unwell or disabled by their cognitive impairment.

Number of taster session evaluations returned: 32 (selected responses)

1. *What will take away from the taster session today?*

Peace and friendship

It's been could to try it out today – thanks for the opportunity

I still don't know what it's about

This is something that could work for me and my husband – make sense

Not sure – I can see the benefits but not sure it is for me

Very useful to experience some relaxation and being the moment

Something to think about

Interesting, helpful, useful, restful

Determination to join a class soon

Hopefully, to practice clearing my mind

2. *How might participating in an 8 week mindfulness course benefit you?*

It would help ease personal worries and deal with them

To learn how to relax and deal with stressful situations

I could return to the person I used to be

To stop going over and over a distressing incident

At this time very little

Greatly

To have some peace and quiet time where I might be able to focus on myself

I would enjoy a course

The course would probably make me more confident in order to lead similar sessions myself

For anxiety

Not at the moment thank you – too many appointments

Very much if I could manage to attend all 8 sessions

To help me focus on the here and now

3. *Could you pay a fee of £4 per session?* Yes = 9 No = 1

4. *Do you have any questions or comments on today's sessions?*

It would be good but wouldn't fit in with our lives at the moment

I think the sessions have to be held for people who "get it". It can feel uncomfortable when people are not taking it seriously

Some of these ideas are new to the group but I think everyone tried hard to enjoy the experience

Nice to have a coffee and a chat, although not totally necessary

A quiet sunny room and comfortable surroundings

I really enjoyed (sic)

5. *Would you like to be contacted about a mindfulness course?* YES – name and address supplied x 5 NO – 4

LIST OF APPENDICES

Appendix 1	Draft Guidelines for Teaching Mindfulness to People Living with Dementia
Appendix 2	Jonathon Barker Interim Report 14 December 2016
Appendix 3	Financial Report
Appendix 4	Outline of Taster Session
Appendix 5	Taster session Report
Appendix 6	Summary of mindfulness sessions for Staff Course in Care Home

Appendix 1

Draft Guidelines for Mindfulness Teachers wanting to work with people living with dementia

These guidelines assume that the teacher is adapting the Breathworks Mindfulness Course for Stress or equivalent.

1. Reduce or omit cognitive explanations of why mindfulness works
2. Work for only about 35/45 minutes in any one session
3. Always focus on the body and the senses as a way to calm the mind
4. Focus on sensual activities – such as taste and texture, nice smells on tissues, objects to look at and hold, finger meditation
5. Don't expect quiet in the room
6. Repeat and recycle exercises in subsequent sessions
7. Always speak slowly and loudly, using few words and short sentences
8. Pay special attention to getting everyone's focus, especially in a big group.
9. Consider repeating the exact words of information or instruction with pared down simplicity – for example, repeat four times – once to each "side" of the circle
10. Use the bell to signal the start of a mindfulness input – focus and peaceful
11. Use a sung welcome greetings and "prayerful" farewell - the same ritual each session
12. Add non-verbal input - whiteboard picture of "train of thoughts"
13. Invite recognition and participation in reciting common phrases, poems (Daffodils/Owl and the Pussycat)
14. Vary activities but contain within a predictable sequence each session
15. Create opportunities for group participation - such as singing
16. Use attractively designed name badges and eye-contact to greet people by name
17. Recycle activities from session to session
18. Build on an activity in a future session
19. Run separate cognitively based Mindfulness training for staff to act as enablers
20. Create incentives within the staff group to maintain daily practice for themselves and the people they care for

During the session staff remarked on how well residents gave attention to Jonathan and how much residents enjoyed his voice and the choice of activities. Some participants appeared to feel energised during the session and joined in by moving around, clapping or calling out. After a session several participants remained stimulated and more vocal. This could be a positive thing but in a care home may have other implications. One senior staff member remarked that it was harder to settle the residents after a mindfulness session. This reflects the fact that alert residents may be more demanding than passive residents and there may not be enough staff to support the demands of such residents.

Daily practice is an important idea in the mindfulness teaching. Staff understood this for themselves. However, it proved difficult to encourage staff to enable residents to do a daily practice but one member of staff reported using the finger meditation in her work after seeing it in the session. Staff did not recognise the mindfulness teaching as a something to incorporate into the resident's daily life, but as a separate weekly activity for the residents. It would need a policy decision to incorporate mindfulness into the culture of the home and to add it to care plans to enable regular daily practice for the residents.

This short mindfulness course began a process of "waking up" the mind for some participants, and this process could be the start of intensive rehabilitation of a type rarely attempted with people living with dementia. It seems that for some participants being trained to use their bodily sensations to access their minds and influence their own well-being could bring positive outcomes. However, this would require any institution to support continued weekly classes, staff willing to enable daily practice and a numerous staff trained to be able to manage the resulting more alert and demanding patients. Our experience suggests the potential value of a research project into the impact of intensive mindfulness training on rehabilitating the mind of someone living with dementia.

Appendix 2

Jonathan Barker Interim Report: 14th Dec 2016

Mindfulness for Carers and Residents at Mill River Care Home, Horsham.

Prior to starting the course Cath spent 3x2 hour sessions introducing me and another teacher Kate Moberly to the field of dementia and what might arise when teaching. She outlined some of the key issues when working with this client group, such as how people with dementia stop being cognitive beings and become more feeling beings - so it's our job is to get alongside them emotionally. She outlined some salient academic research such as Tom Kitwood's "Daisy" theory and the Sonas programme developed in a Dublin care home run by nuns. The latter is a multi-sensory programme for older people using smell, singing, music, taste, clapping and familiar proverbs. We discussed the similarities with mindfulness and decided to create a course where working with the senses was a key component, using touch (stroking the body, soft blankets & cushions), sound (music), smells (essential oils, foods) and taste (raisin) and overall creating a 'bubble of beauty in the space'.

Cath outlined appropriate ways to behave when visiting a care home such as giving the impression you are only passing by, arriving gently and leaving gently. Three golden rules from Contented Dementia: 1) Don't ask questions, make statements instead i.e. what you are going to do and whether they'd like to join you. 2) The person with dementia is the expert: listen to what the person is trying to say and what is important to them and find out what they want. 3) Don't contradict or argue and avoid conflict. And come with the attitude that you (the observer) is often confused not the person with dementia; often people only get upset when the observer doesn't understand. Ultimately the purpose is to protect their sense of self and wellbeing.

We discussed how people with dementia like things around them that are familiar and in the same place – such as things they would have had in their own home. So it's helpful to recreate the past in the present, and for people to feel at home and to be needed. I have very little experience of working with this client group so found these three sessions immensely helpful.

Kate and I then met to discuss the syllabus of the 6 week course. At the outset we decided we should do two distinctive courses: one for people with dementia and the other for carers, especially staff. I had recently taught mindfulness in a homeless hostel and found that when I ran a course for staff first, and then did a residents course, it was far more effective because staff encouraged residents. The residents' course was a combination of mindfulness and other activities taken from Sonas and elsewhere (*for more info see attach syllabuses for each week?*). We decided each session of the course would be focussed on a different sensory experience starting with taste, though we would work with other senses in each session too. We incorporated several elements of the BW stress course such as breath mediation, body scan and some concepts such as working with thoughts.

For the staff course we decided to teach the first 6 (of 8) weeks of the Breathworks Stress course. I

considered amalgamating weeks 6, 7 and 8 but after advice from my supervisor decided to finish on week 6, which usefully ends on an important theme for this group – being in the green circle. The purpose of the staff course would be to not only teach them mindfulness but also enable them to use mindfulness techniques with the residents. We decided to encourage and support them in this by giving them daily practice sheets where they could note any mindfulness work they did with residents.

Following the OMC suggestion we teamed up with Shaw Health Care and its representative Mark Whittle found us a care home at Mill River Care Home, Horsham, Surrey. Unfortunately the distance and length of journey meant Kate's therapy work and her care of an elderly relative meant she was unable to teach the course. We visited the home a couple of times before starting the course and were able to talk through our plans with managers Nadeen and Doreen. The initial plan was to teach people in the early stages of dementia, their enablers, volunteers and staff but the layout and daily routine of the home made it difficult to teach all of these people. We finalised on an hour session with the staff followed by a short break and then an hour session with residents on the 2nd floor.

Evaluation is a key component of this work so we asked staff to fill out a BW evaluation forms after each session and asked them to put a coloured sticker on each resident's mindfulness sheet when they did any mindfulness with them. And especially encourage each residents key worker to do mindfulness with their resident. We started the course in October and completed 5 sessions before Xmas.

Week 1: for the staff session 8 people turned up including team leader Gemma, activity worker, Alyson and caretaker Graham. Mark Whittle attended this and the residents' session. The group were fairly reserved to begin with. Alyson said she had done TA and others said knew very little about Mindfulness. Cath provided everyone with soft blankets which everyone wrapped themselves in – one course member hid her head under the blanket during a meditation session. After the first meditation people seemed to relax and talked more about their experience. At the end I encouraged group to work with residents.

The residents' session lasted approx. 40 mins. There was a mixed group of about 15 people (*check*) with about 4 carers including Gemma. We began with music. The plan is to use the same music each week and repeat several of the meditation techniques to help embed the practice. Then Cath began by welcoming everyone individually by standing in front of each person in turn and singing a song: "Welcome, Doris, we welcome you..." I felt this transformed the atmosphere in the room and gathered people's attention.

At the start of each mindfulness practice I rang a chime to draw people's attention and encouraged them to listen to the sound of the bell. This seemed to resonate with this group, perhaps reminding them of a school bell, and many said how they liked the actual sound too. We then handed round sultanas to each resident. Some people ate them straight away others didn't like them, some followed my instructions. Generally I didn't feel this worked well with this group. Similarly when I moved on to more formal meditative practices it became apparent, given the cognitive abilities of the group, that asking people to close their eyes (or lower their gaze) and do breathing or body scan meditation was going to be problematic. Some people would be able to bring their attention to this but for many this would not be possible and might possibly disrupt those who could.

Previously I had talked to my previous supervisor about meditation techniques that might be helpful with different groups and he suggested using some MiSP (.b) meditation techniques such as FOFBOC and finger breathing so I decided to try this instead. I starting with FOFBOC but residents found it hard to engage with this too so instead I asked them to gently rub their feet on floor, stroke their hands on thighs and rub their hands together. This seemed to focus participants attention and they enjoyed it.

Cath asked people to complete short proverbs (i.e. a bird in the hand is worth two ...) and read some poetry which worked well too. I did a finger breathing mediation (MiSP), but focussing more on the finger sensations rather than the breathing which also seemed to focus residents' attention too. Some residents could do this on their own, some liked staff members or Cath moving our finger up and down their fingers. There was a strong sense of people being in the green zone and attentive to the physical sensations. Where appropriate I encouraged residents to do this on their own. At the end of each session I asked everyone to close their eyes as I said: "may you be well, may you be happy, may you be free of pain and worry." Some people put their hands together in a prayer posture. We played music at the end. We had intended this session to last about 1 hour, but after dropping the meditation practices it lasted about 35 mins. Cath read Wordsworth's Host of golden daffodils poem.

Week 2:

This week the staff course was attended by x people (*check*). Some people had done some home practice, but not a lot. A few, particularly the activity workers had used some mindfulness techniques with residents but to a limited degree. At the end of the session I showed people practice sheet and encouraged staff members to put a coloured sticker on each residents practice sheet when they did any mindfulness with them too.

In the residents course I used the same basic structure as the previous week though this time with a theme of 'touch'. I felt the touch meditations had worked well in the previous week and wanted to consolidate this. This emphasis on repetition was prompted by the importance Cath gives to this when working with this client group. At the beginning she welcomed each person by song in the same way she had last week. I feel this approach not only makes each resident feel part of the group and makes them feel good but also re-enforces what happened in previous week which they may remember on some level. This week we handed round small objects such as soft toys, smooth stones for residents to touch and enjoy. Cath encouraged a male resident to read a poem which he seemed to enjoy and certainly did very well. Again people's attention was drawn to me by the sound of the bell and as a signal for meditation.

Week 3:

The staff course was attended by 15 people. This week the theme was thoughts. This week one of the managers attended for the first time. The activity workers were more engaged in the group discussions than others. There was not much evidence of staff using mindfulness techniques with residents or at least putting stickers on residents charts. At the end I again emphasised the importance of doing this. Cath and I discussed how else we might be able to encourage staff. At the end of the session Cath talked to the group about the psychology of people with dementia, they may

have a brain disease but they still have a mind.

During the residents session I decided to try introducing week 3's concept – 'train of thoughts'. In previous groups I have led participants often cite the train diagram as one of the key concepts they remember. I spoke to my supervisor about this and he encouraged to give it a go, as did Cath, though I was not confident cognitive work would sit well with this group. In the eventuality I'm not sure many people took it in. I also repeated the touch meditations we had done in previous weeks such as finger touching. During this week as I began to reflect more on the impact the teaching may or may not be having. A key element of the BW course is about understanding the mind on a deeper level and learning techniques that might be helpful in alleviating stress or chronic health issues. This cognitive element of mindfulness doesn't apply to the same degree when teaching this group but what does work is giving residents and staff techniques they can use to bring their attention into the present moment, here and now, and also find pleasure and enjoyment through the senses. This week Cath read the owl and the pussy cat poem.

Week 4

Each week both the care home activity workers have attended and one in particular has shared her experience and thoughts of doing mindfulness during the sessions. Other staff members seem reticent and I have discussed this with Cath. It's hard to know but workplace courses are not always environments where people feel most at ease. During the first session, for example, the maintenance worker shared his experience but has not spoken since, although he has come each week. Each week we hand out evaluation forms and participants say very little about themselves, generally they just repeat the contents of the course.

This week in the residents' course we explored listening to sounds as well as repeated the touch meditations. I played 6 minutes of Beethoven's Moonlight Sonata and asked people to bring their attention to actually listening to the sounds it as much as they were able. To begin with some of the group were quite restless but as the music continued everybody fell into a deep silence as if transfixed by the sound. I tried repeating the train of thoughts concept so whether it would make a deeper impression a week later but again I felt it want right for this group.

I also tried some new meditations. Firstly, I asked residents to hold up the palm of one of their hands against someone else's palm, either their neighbour sitting next to them or one of the care workers. They very much enjoyed this exercise and seemed very attentive to the sensations of the other person's palm. I then encouraged some residents to lead the hand movement and for their partner to follow and then try it the other way round. Some people were very engaged with this too. One of the residents I did it with had previously not allowed anyone to touch her hands during the finger meditations.

Week 5

The staff group still doesn't feel entirely relaxed and engaged as a group. One of the activity teachers talked about her experience again. Another person said they thought looking at objects in silence was weird and then quickly back tracked on what she was saying, as if she might be being assessed. This

off the cuff remark made me think again that maybe staff members feel inhibited in the workplace and so don't say much at all.

This week with the residents we explored, along with several mediations we had done in previous weeks, the sense of smell. We spread droplets of lavender and then vanilla on tissue paper and handed it around. The residents seemed to enjoy this experience though some found it harder to identify vanilla and get a sense of its smell. I repeated the touch meditations, which again work very well as did the chime. Cath welcomed everyone by song which people enjoy a lot and did the proverbs too. She also read the Lewis Carroll's Jabberwocky poem.

As a pilot project these first five sessions have been a useful way of gauging the effectiveness of mindfulness in a care home. I don't think we fully understand the staff dynamic yet and why members are more reserved than other groups I have taught. The residents' sessions have gone well although we have had to adapt them according to the cognitive abilities of the group we are teaching. Generally it has gone extremely well and I think this group of residents have found it fulfilling and nurturing.

Appendix 3

Financial Statement (not including matched funding from Shaw Healthcare)

Financial Report

Grant of £3937

	ACTUAL
Teacher 1	1912
Teacher 2	108
Support Worker at sessions	312
Project Management	675
Dementia Training	360
Total Mileage (see notes)	370
Contingency (see notes)	200
<hr/>	
Total expenditure	3937
<hr/> <hr/>	

Notes on the financial statement

- Contingency was spent on the July 2017 conference accommodation for Teacher 1 and a one night overnight for the Dementia Specialist in December 2016.
- The budgeted mileage was not adequate for a project based in Horsham, rather than Oxford. This budgeted figure was divided pro rata between the drivers.
- Both the Dementia Specialist and Teacher 1 contributed many hours in preparation and evaluation which were not budgeted for.

Appendix 4

Outline of Taster Sessions March - May 2017

Mindfulness Course for People Living with Dementia - Taster session (Living with memory loss: Medium-Severe)

Furniture/props

- Music player & music – ASK staff WHICH MUSIC
- Name badges
- Meditation bell
- Chairs (close circle with staff included, CA in circle too)
- CD/ipod of moonlight sonata or other track?
- List of proverbs
- Poem: owl and pussy cat
- Evaluation form

Remember (from previous work with PLWD)

- Break down what I ask people to do into steps (bring your attention to your feet / pause / now rub your feet, repeat several times, speak slowly and lengthen vowels.

Taster session (40 mins)

- Participants arrive to **MUSIC – *Moonlight sonata or something else?* (5/5mins)**
- Signal session is **STARTING**: turn off music and ring bell 3 times
- INTRODUCTION: JB introduces himself + course: sometimes life can be difficult and overwhelming. This mindfulness course is about finding joy, fun and pleasure through bringing our attention to our **senses** and its about help us deal with unpleasant thoughts and feelings too
- Mindfulness is about bringing our attention to our senses: particularly our sense of touch, but sometimes sounds, smell, sight and tastes too. Each week we work a different sense.
- This is a taster session to give you an idea of what mindfulness is all about and whether it might be helpful for you
- This week we'll be exploring our sense of touch and looking at compassion: being kind to ourselves and others. (7/12mins). *Please take part in silence if you can and I'll ring a bell at end of each section.*
- **MOVEMENT EXERCISE**: Sitting down
 - Shake arms, soft hands
 - Sitting: stretch legs: heel and foot (or slide foot if shoes off)
 - Open/close hands to breath
 - Put hands together in prayer position and move side to side
Give yourself a big hug.
- **MEDITATION**: Start with bringing attention to FOFBOC. Gently rub hands on thighs and hands together. **Ring bell & enquiry -TBC?** (10/17mins)

- **PROVERBS** –ask participants to complete: A woman’s work ..., When the tough gets going ... , Love makes the ... (5/23mins)
- **FINGER MEDITATION**: run index finger over fingers on other hand (NOTE: MAY NEED HELPERS) OR OPENING/CLOSING HANDS **Ring bell & enquiry -TBC?** (10/33mins)
- **READ POEM** – THE OWL AND THE PUSSY CAT. (5/38mins)
- **KINDNESS** mediation - start with breathing meditation if there’s time. Feel warmth in heart area, say to yourself: may I be well, may I be happy may I be well and happy. **Ring bell & enquiry -TBC?** (10/48mins)
- **WRAP**: hope you had a nice time, remember if your mind starts drifting off or your feel anxious bring your attention to your senses: do a FOFBOC.
- **MUSIC**: *Moonlight sonata* (2/50mins)

Evaluation: After session hand out evaluation forms

APPENDIX 5

Taster Group Report

Report on 3 Tasters

Shotover View Care Home.

Before the session started I played music in the background. The room was large, warm and bright in a recently built care home. 9 people attended: some residents, others visiting the home as well as 2 organisers from Oxon Dementia and a volunteer care worker. The volunteer began the session with some simple movement exercises to music whilst the participants were sitting down: sliding their feet on the ground, raising their hands above their heads etc. I then began the Taster session. I explained a little about mindfulness and moved through the taster session outline.

At the end of the session the 2 care workers said they had found it helpful and thought some of the residents had too. One of them said they were surprised how well the session worked for such a diverse group and that a 4-week session might be better than 8 weeks. She said she enjoyed the Owl and the pussy cat poem. The volunteer suggested I should add how much a course would cost of the questionnaire. Another person said I needed to speak louder. 4 out of 9 people said they would like to do the course.

Kidlington Methodist Hall

This session was organised at a place and time where people living with dementia and their carers drop in once a week, about 10 people came. My session was due to start at a particular time but 3 couples arrived late as well as during a breathing meditation which disrupted the session. As this was a taster I felt I had to start again for each arrival but this effected the flow and attention of the group. I moved on to the proverbs and then the finger meditation. Two of the group members got the giggles and left the room after a while, apologising. I then read the owl and the pussy cat and they got the giggles again and had to leave again.

Afterwards one of them apologised again and someone else said she had been very stressed recently and this had been the first time she had seen her laugh in months. I felt the late arrivals and giggles didn't give participants a good impression of what mindfulness is about though several people approached me afterwards and said they had enjoyed it. I emailed the organisers afterwards about doing a longer session and they said this would be possible.

Witney Methodist Chapel

This was organised at a time and place where people living with dementia and their carers drop in once a week. About 15 people came with two people from Oxon Dementia and a Care Assistant from Life carers. I talked to the organiser beforehand and she described the group. She asked me to speak loudly and I invited her to add comments if she felt anything wasn't clear or I wasn't loud enough. After talking to my supervisor earlier in the week I added some simple movement exercises whilst

sitting down to the programme (see course outline). One woman said it was painful because of her arthritis and I emphasised that she didn't have to do this and that if it was painful do it very mildly or not at all. Generally everyone was attentive and quiet and after the meditation practices said they felt relaxed. The session lasted for about 35 mins.

From the feedback sheets 3/10 said they'd like to do an 8 week course. I spoke to a few people about this they said they couldn't commit to 8 weeks on a regular basis. Others said it wasn't for them. One couple said they were interested so long as it was based on facts, it turned out they were x-Oxford University teaching staff, but now living with dementia. Staff members told me that there was a problem for carers (often a spouse) leaving their partners and this centre didn't have a facility to care for them whilst the carer did the course. Several carers said some of the practices I had done, such as the finger meditation, were useful and something they could do at home on their own or with the person living with dementia. They said a joint course for both would be better than one for just carers, though again only a few wanted to do this. The organiser suggested I come for a one-off session every few months.

The conclusion I'm drawing from this and the other tasters is that there is no demand for an 8 week mindfulness course. Some individuals have wanted it but not enough to sustain the costs, which is a pity since those who would like it – particularly carers would benefit. I discussed other options and the organiser suggested I contact training organisations that run courses for carers, mostly (I think) for professional staff rather than spouses. The advantage of this would be to give carers mindfulness practices and skills they could use in their work and for themselves. She also suggested contacting care homes and suggested some local ones. Generally running these tasters has given me a good impression of what works and doesn't and how to take mindfulness with this client group forward.

Appendix 6

Summary of 6 week course for staff at care home (Stress)

Flipchart

Week 1: What We Resist Persists.

Welcome and house keeping

Introductions

Intro to course, mindfulness & autopilot

Raisin

Key Concept: Primary & Secondary Experience

Meditation: Body Scan Practice & debrief

Closing & home practice

Flipchart Primary & secondary

Week 2: Coming to Our Senses.

Body Scan

Home Practice review

Recap and intro to Session 2

Breath enquiries

Doing and Being Modes

Posture workshop

Mindfulness of Breathing and debrief

Closing & home practice

Flipchart Coming to senses triangles

Week 3: A Penny for Your Thoughts.

Mindful Movement

Home Practice review

Recap and Introduction to Session 3

3 Minute Breathing space & debrief

Mindfulness of thoughts

Mindfulness of Breathing & debrief

Closing & home practice

Flipchart

Train with bridge

Week 4: When Your Buttons are Pressed.

Mindfulness of Breathing

Home Practice review

Recap and Introduction to Session 4

Key Concept: Acceptance

Acceptance meditation & debrief

Mindful Movement

Closing & home practice

Week 5: The Pleasure of Small Things.

Body Scan meditation

Home Practice review

Recap and Introduction to Session 5

Key Concept: Negativity Bias

Seeking out the pleasant & exercise

Letting in the good meditation and debrief

Movement meditation

Closing and Next Steps

Week 6: The Tender Gravity of Kindness: combine sessions 6, 7 and 8 into one session?

Mindful Movement into Breathing

Home Practice review

Recap and Introduction to Session 6

Key Concept: Criticism v Kindness to self and others

Kindness exercise

Meditation: kindness to others & self. Debrief

Closing and Next Steps