

# **Curing the NHS by removing the glass wall (silo) between Patient and Public Involvement rhetoric and practice in research**

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## **1 Recommendation for a culture shift**

To comply with Sussex Partnership Foundation Trust (SPFT) admirable rhetoric about welcoming patient and public involvement (PPI, its leaders should change the staff culture from **ignoring** to **welcoming** suggestions from patients and the public for research and improvements to services, by following this procedure:

- 1 Acknowledge every suggestion with a 'thank you'.
- 2 Ensure that all points are considered seriously by the appropriate manager.

3 Reply stating when the suggestion is to be implemented, or if not, why not.

Manifest the above procedure regarding the suggestions that I have made by:

- a) Recreating the Mindfulness Interest Network initiated and run by Brenda Roberts and Fergal Jones from about 2004-7, and maintained by me and others until 2011, when it folded for lack of a SPFT chairman.
- b) Initiate a trial of Osho dynamic meditation with a view to getting it NICE-recommended.
- c) Initiate a trial of Hellinger Family Constellation group therapy with a view to getting it NICE-recommended.
- d)** Initiate a trial to test my hypothesis that the 'glass wall' between staff and patients is part of the cause of the NHS crisis of low staff morale and low patient confidence.

## **2 My experience of PPI generally**

My mother and sister were psychiatrists, and my daughter is a clinical psychologist. I followed my father into consulting engineering. I have been a community activist and campaigner in Brighton and Hove since I moved here 43 years ago. I was elected a councillor from 1995-99, and was involved in making nominations to the Community Health Council. Since my first wife died in 2000, I have been a full time patient representative. From 2000-06 I was in the Sussex Cancer Patients Forum. From 06-08 I was on the PPI Forum. From 08-11 I was on the Local Involvement Network (LINK). From 09-11 I was on the National Association of LINK Members (NALM) representing Sussex. From 2007-11 I was the secretary of the Sussex Mindfulness Interest Network (MIN, for which the minutes are shown in appendix 2)

The Conservative election manifesto leading up to the 2010 election promised to open up the market to Any Willing Provider, so in 2010 I founded the Social Enterprise Complementary Therapy Company (SECTCo) see [www.sectco.org.uk](http://www.sectco.org.uk). We bid unsuccessfully for public sector contracts to run mindfulness courses, so that GPs can prescribe them as easily as Prozac, as they can in Avon and Wiltshire, as described in paragraph 10 below.

I suffered arthritic breakdowns in my health since 1992, and was greatly helped by complementary therapy. I was much inspired by Prince Charles' charity, the Foundation for Integrated Health (1993-2010). Since 2005 I have written over 50 papers for the NHS, showing how his vision of integrating the best of complementary therapy into the NHS could be implemented. They are published on my websites: [www.reginaldkapp.org](http://www.reginaldkapp.org) section 9, and [www.sectco.org.uk](http://www.sectco.org.uk).)

However, my experience was that very few of my communications were even acknowledged, let alone replied to (except Freedom of Information ones, which had to be replied to within 20 working days by law) I was never thanked for my efforts. I conclude that the public service culture is to ignore all communications from members of the public. Staff take their jobs for

granted, and forget that the public pay their salaries from the taxes they pay, and 'he who pays the piper should call the tune.'

### **3 Glass wall (silo) mentality**

This culture of ignoring suggestions from patients and the public creates a 'glass wall' (or iron curtain, or silo) between staff and the public they are supposed to serve. This has an apparent benefit to staff, who cannot be held accountable for the consequential outcome, as they can pretend that they never received the communication. However, without this feedback, the system deteriorates to the detriment of both staff and patients.

Eventually, as has now happened after 65 years, the NHS has become a monster, which everyone (even the previous government) were powerless to control or change. The only beneficiary is the drug companies, to whom taxpayers continue to pay more than £15 bn pa. They have used their wealth to buy influence in all the corridors of power, including the medical profession, the health regulatory authorities, academia, and now the Advertising Standards Authority (ASA) The following petition addressed to Health Secretary, Jeremy Hunt, has just (23.8.13) been issued by Avaaz Community on behalf of complementary therapists:

'The ASA is stopping complimentary therapists from advertising. They have censored us from even mentioning any medical condition on our websites and will not acknowledge benefit for more than a handful of conditions ignoring NHS, NICE and World Health Organisation Evidence. They have also 'banned' patient testimonials. This is unacceptable censorship and a serious threat to natural medicine which has helped millions worldwide.'

This monstrous Big Pharma centred system imprisons both staff and patients in silos, isolating them. The demoralising effect of this mentality is the main cause of the crisis in the NHS and Social Care, and low public confidence, as manifest by long waits at A&E.

The symptoms of this NHS disease were exposed in damning reports, such as the LSE report (June 2012) on 750,000 depressed patients untreated, Winterbourne View, Care Quality Commission (CQC) report on abuse in care homes, Francis report (Feb 2013) on premature deaths at Mid Staffs Hospital, and the Geogh report, (July 2013) which took 11 hospitals into emergency measures.

What is the cause of the NHS disease? Drugs, for which a billion monthly prescriptions were issued last year in England. Half the population are on 3 drugs continuously. The side effects of this massive overprescribing cause more harm than good to public health. However, it is not politically correct to say so, because Big Pharma have become so powerful that they can end the careers of anyone who blows the whistle on them. I am in the fortunate position of not needing any patronage.

#### **4 The health regulators are at last being held to account**

The good news is that the crisis in the NHS has already resulted in a much needed tightening up of health regulation. The Care Quality Commission (CQC) are responsible for inspections: A recent (Aug 2013) consultation document says: 'We are on the side of the people who use services, making sure they are respected and listened to.' (p6) They also say: 'We make sure that directors or leaders of organisations have made legal commitments to provide safe and high quality care, and are personally held to account for it.' About time too. ([enquiries@cqc.org.uk](mailto:enquiries@cqc.org.uk))

Previously, all the health regulators seemed to be on the side of the providers. This perpetuated the *provider* centred service we have had for 65 years, rather than bringing in the long promised *patient* centred service. When the CQC inspect providers, their 5 main questions will be: 1. Is it safe? 2 Are they doing what they should? 3 Are they caring? 4 Do they change to meet peoples' needs? 5 Is it well led? (p14)

If inspections by CQC are conducted with integrity, I believe that most providers will fail most of these questions, because: 1. All drugs have potentially harmful side effects, so are inherently *unsafe*. 2 Patients go to the NHS to be *cured* of their condition. This rarely happens, because most drugs do not even *claim* to cure, and are often worse than the disease. 3 'Callous disregard' would be a more appropriate description than 'caring' in the above mentioned reports. 4 I know of no providers to date who have changed as a result of any campaigning efforts, even by the government. 5 No. Most leaders would not last long in the market place, and only remain as they are protected by their monopoly status.

Monitor is also being held to account. It's duty is to promote: 1 An efficient, effective and economic health service, 2 Integrated care, 3 Ensure that choice and competition are operating in the best interests of patients. They have recently issued a consultation (1.7.13-1.8.13) calling for evidence to determine the extent to which commissioning and provision of GP services is operating in the best interests of patients. ([gpservices@monitor.gov.uk](mailto:gpservices@monitor.gov.uk)) (0207 340.2400)

I have responded saying that the NHS that I see is none of those things. Their questionnaire seems to be only about trivial matters, such as 'seeing the same GP', while ignoring the reason why patients go to the doctor, namely for safe effective *treatment*. This means drug-free treatment, but in Sussex the waiting time for talking therapy is *years* (unless you are suicidal) whereas for a service worthy of the name, it should be *weeks*, as it is in Avon and Wiltshire (as described in paragraph 10 below).

## **5 My experience of PPI in SPFT research**

I have been a member of SPFT (together with thousands of others) for at least 5 years. I attended every AGM since, and many other public meetings, including many staged by the research department. As SPFT is the main provider of mental health services throughout Sussex, I copied many of my papers to SPFT staff (such as CEO Lisa Rodrigues, clinical director Kay Macdonald, and managing director Richard Ford ) I have never had any acknowledgement or reply from them.

I was therefore very pleased to receive notice last autumn (2012) that the research network had been formed, and that members of the public could join it, which I promptly did. On the front cover of issue 1 of the Research magazine was a notice: 'Find out how we are involving people with lived experience.' The message from Lisa Rodrigues was: 'We all have a duty to provide the best possible services, whether we provide front line care, or support others who do.' This is what I have always tried to do, hence my papers, including this one.

Inside on p12 was the welcoming statement: 'The Research Network is a new and exciting initiative for service users to find out more about research, and how they can get involved.' There was an account of many exciting research projects, together with the contact details of the researchers. I therefore have been trying to get involved with them.

Jean Southey welcomed me, and I had a meeting with her in April, when she told me to meet Ruth Chandler. I have been e mailing her, and trying to meet with her unsuccessfully for the 4 months since then.

In May, I e mailed 6 of the researchers mentioned in issue 1. I received cursory replies from them, but was surprised that all were negative, without giving any reason why they couldn't take up my suggestions. On 2.8.13 Ruth told me on the phone that they were upset because I should

have contacted them through her. However, as mentioned above, I have been trying unsuccessfully to meet with Ruth.

They all seem to regard me as an alien to be shunned. When I approach them in coffee breaks at public meetings, I sense that they are afraid of me. This applies even to people like Robert Marx, who I have known since 2006, as we were both on the Mindfulness Interest Network, (MIN) of which I was secretary from 2007-11, and gave him a platform to address us, which he did in 2010.

My experience shows that the SPFT policy of welcoming service user involvement (implied as in the Research magazine) is not working as intended by the management. They are simply trying to comply with government policy, which made PPI a legal requirement under the Health Act, 2007. I conclude that the glass wall syndrome also applies to SPFT research staff.

In making this observation, I am not singling out any individual, or even the whole of SPFT, as I have I have found the same glass wall reaction in all the public sector staff with whom I have tried to engage, including council, and NHS commissioners.

I therefore believe that this glass wall syndrome is the normal staff culture throughout the whole public sector (totalling over 10 million nationally). This may be the reason why David Cameron, Jeremy Hunt and other ministers are calling for a culture shift.

Part of the job of PPI is feedback to management on how their policies are practiced. I have written this as a basis for discussion at a meeting with Mark Hayward, who has kindly agreed to meet me from 4-5pm on 3.9.13. However, I have postponed it, to enable me to attend an open day at Swindon, see paragraph 10. I set out an agenda in paragraph 8.

## **6 My experience of SPFT's mental health service**

I have not been a service user of SPFT myself, but I have attended many meetings organised by MIND to get feedback from service users. From about 2006-9, these were held under the Improving Access to Psychological Therapies (IAPT) programme, and since then, called: 'Listen to

the Voice of Experience' (LIVE) They were held quarterly until the end of 2011, and perhaps 2 per year since. They used to be attended by NHS commissioners Margaret Rooney, Anne Foster etc, and were organised by Julie Wright.

My impressions of those meetings were that the service was very poor, as few service users had a good word to say about it. The main complaint was the excessive waiting times to be seen, assessed, and treated. When they were eventually treated (sometimes years later) they tended to be over-medicalised, as waiting time for CBT were sometimes years. This was reduced when 40 new CBT therapists were recruited in 2010, but it is still much too long. My requests for more mindfulness courses seemed to fall on deaf ears.

When these services are inspected to the CQC's new 5 main questions (from paragraph 4) I believe that it would fail, for the following reasons:

1. Is it safe? No, it is over-medicalised with drugs with harmful side effects.
2. Are they doing what they should? No, they are not providing enough talking therapies.
3. Are they caring? No
4. Do they change to meet peoples' needs? Yes, they have trained about 20 more mindfulness facilitators, but this is not nearly enough for all Sussex.
5. Is it well led? Maybe. The leadership seems to be doing their best according to the old provider centred NHS, but in no way could it be called a patient centred service.

I have recently come across the Scottish Recovery Indicator **SRI 2**, and have copied the following off their website, [www.scottishrecovery.net](http://www.scottishrecovery.net), as it looks like a good way to improve the service

'SRI 2 enables mental health practitioners to provide ever more recovery focused services. We know that people working in mental health services want to demonstrate their commitment to recovery. We know that the people using services want to experience the benefits of that commitment; and we know that the Scottish Government wants to support services to embed the principles and values of recovery in all that they do.

SRI 2 is the tool of choice that enables all of that to happen, through a clear, evidence based and effective process. SRI 2 provides the opportunity for people who provide the service, and people who use the service along with their carers, to rate aspects of the service against ten recovery indicators. This results in stimulating and reflective conversations, leading to an action plan which is then fed into the web based tool. The resulting service improvements can be recorded and celebrated, and the next SRI 2 scheduled, thus ensuring continuous improvement and service development.'

## **7 The crisis in the NHS**

This is being aired daily in the media. Staff morale is said to be at an all time low, and A&E departments are overwhelmed. As said above, I believe that part of the reason for this is this 'glass wall' between the public and staff.

I raised this idea in paragraph 12 of a 9 page report that I have recently (9.8.13) written for the Brighton and Hove Health and Wellbeing Board called: 'Curing the NHS crisis and depressed patients by mass-commissioning mindfulness courses.' I hope it will be discussed at their next meeting on 11.9.13.

I have also written to the Clinical Commissioning Group (CCG) asking for it to be discussed by their board. I have received an acknowledgement (22.8.13) from Emma Snowden that I will get a written answer from the CCG by 24.9.13. (This implies that it is seen as a Freedom of Information question, which has to be answered within 20 working days.)

## **8 My suggestion to revive the Mindfulness Interest Network (MIN) within the new Sussex Mindfulness Centre**

I am thrilled by the news that Sussex has become the fifth Mindfulness Centre in the country, after Bangor, Oxford, Exeter, and Aberdeen. I have written to Clara Strauss, Fergal Jones and Robert Marx suggesting that the Mindfulness Interest Network be revived, but have had no response to date. They may be subject to the glass wall syndrome, and be missing the opportunity this offers to put Sussex on the map, so I will describe the history as I remember it.

The Sussex Mindfulness Interest Network (MIN) was formed about 10 years ago by clinical psychologists Brenda Roberts (chairman) and Fergal Jones (secretary). They held bi-monthly meetings at Hove Polyclinic, and any member of the public who was interested in mindfulness was welcome to attend. This was true community involvement, and I couldn't believe my luck in being able to participate in it.

I first heard about MIN in 2005, from Rory Singer, the founder of the Centre for Mindfulness Based Education, (CMBE) 28, New Rd, Brighton. He got published in the local paper (Argus) that

the MBCT course had achieved NICE-recommendation in Dec 2004. I went to see him, and he told me that anyone could join MIN, and attend their meetings. I became a regular attender, together with about 15 others, including Taravajra and Karunavira, who even then had been teaching mindfulness in the third sector for many years, and still are.

When Brenda and Fergal retired in 2007, they asked for volunteers to take over the administration of MIN. I was elected secretary. Rory became the first chairman, followed by Brenda Davis, followed by Carolyn Pollack. When she resigned on 14.12.10, no member of SPFT staff could be found to be chairman. MIN could no longer book meeting rooms in Trust premises, which proved a fatal blow.

We held 2 meetings in my home. The second, on 27.3.11, was attended by 6 people, and Lotus Nguyen (organiser of a Brighton Sangha) was elected chairman. She was asked, and agreed to speak of her vision at the subsequent meeting on 23.5.11, but only she and I attended, so MIN has been sleeping ever since. I took the minutes of the 18 meetings held over 4 years 2007-11, and they are reproduced for the record of what we achieved in appendix 2 below.

## **9 What other mindfulness centres provide for the community**

The first mindfulness centre was founded by Dr Jon Kabat Zinn in 1979 at the Masssetusetts Medical Centre . [www.umassmed.edu](http://www.umassmed.edu). It is now called the Centre for Mindfulness in Medicine, Health Care and Society, and hosts a 5 day annual conference attended by thousands of people. It has created programs for mindfulness in schools, prisons etc, and a world wide movement has grown from it.

Dr Mark Williams introduced it to UK in 1995, and while at Bangor university, founded the Centre for Mindfulness Research and Practice, (CMRP) whose mission statement is to 'advance physical and mental well being, and alleviate the effects of ill health and stress by promoting good practice in the teaching and researching of approaches based on mindfulness practice, within health and social care and a range of contemporary settings. It is a self-funding organisation based in [School of Psychology](#) which is part of [Bangor University](#).

The CMRP is committed to the promotion of wellbeing through the application of mindfulness-based approaches. This is achieved by training professionals in the application of mindfulness based approaches and researching applications of mindfulness. We also offer classes in mindfulness based stress reductions (MBSR) and mindfulness based cognitive therapy (MBCT) to specific populations and the general public both locally and further afield.'

Mark moved to Oxford University about 10 years ago, where he founded the Oxford Mindfulness Centre, (OMC) for 'preventing depression, and enhancing human potential by combining modern science with ancient wisdom.' It is based at Warneford Hospital , Oxford.

[www.oxfordmindfulness.org](http://www.oxfordmindfulness.org)

I hope that the management of SPFT will support the new Sussex Mindfulness Centre to emulate these centres by welcoming members of the public to promote mindfulness for the public good. I suggest that we revive the MIN by calling a meeting. I still have 60 people on the MIN database.

### **10 News. Shortest waiting time (a few weeks) for mindfulness courses in Swindon**

Channel 4 news on Tuesday 20.8.13, featured that Swindon NHS has the highest access rate, and shortest waiting time in the country (a few weeks) for talking therapies if you are depressed or anxious. This made my day, as I have been complaining about the waiting time for talking therapy in Sussex, which is over a year for CBT (unless you are suicidal) and over 20 years for a MBCT course. This is evidence of a post code lottery a hundred miles away, which was not supposed to happen under the old regime of PCTs and SHAs.

A report by Barack O'Brian showed a mindfulness course in progress, and interviewed manager Barbara Stapleford, and Mary, a patient. Mary said that she can get counselling support whenever she needs it, by phoning. Barbara said that this service cost *less* than in other places. Health minister, Norman Lamb was interviewed and said that mental health is his highest priority, and

that commissioners should apply for £400 million, which is available to improve services in the way portrayed.

I telephoned NHS Swindon, and spoke to CCG communications officer Carol Sales (01793 444687, [communications@swindonccg.co.uk](mailto:communications@swindonccg.co.uk)) and therapist Geoff Windle (01793 600405) He told me that the service is called Least Intervention First Time (LIFT) Psychology, which is part of the Improving Access to Psychological Therapies (IAPT) programme throughout Avon and Wiltshire NHS. Their strapline is 'Lift anxiety, Lift mood, Lift depression.'

This service started 18 years ago, and is part of the local in house, mental health service, directly employing NHS clinicians. It is not contracted out, although it has its own website which is [www.lift.awp.nhs.uk](http://www.lift.awp.nhs.uk). They provide hundreds of different courses (including an introduction to mindfulness) for thousands of patients, who are referred through GPs, but patients can also self-refer.

They seem to be doing what I am proposing for Brighton and Hove, so I intend to write a report about them for the Health and Wellbeing Board. I have asked Geoff for links to annual reports, and am trying to arrange to visit them Swindon. If anyone from the research department wants to accompany me, I would be delighted. This is certainly 'research for patient benefit.' They have an open day on Tues 3.9.13, for which I have booked.

## **11 Proposed research trials for patient benefit**

At a SPFT research meeting in May I was given a call for bids 2013 form for 'R&D own account research funding', and have been trying unsuccessfully to engage with research department staff to make an application before the deadline closes on 30.8.13.

I was told to write to Clara Strauss, which I did on 22.5.13 (see appendix 1) saying: 'I have ideas for further research projects for patient benefit, which I would like to share'. I got no reply.

In June, I wrote to Ruth Chandler, expanding this proposal. saying that I want to propose trials to test Osho dynamic meditation, and Hellinger family constellation group therapy with the objective of getting them NICE-recommended, so that they can be publicly funded for patient benefit. The correspondence is reproduced in appendix 1. I am waiting for an answer when Ruth gets back from leave, but I am disappointed that we have missed the deadline.

However, I have just (22.8.13) received notification by e mail of another funding stream, with a deadline in 3 months time (19.11.13). I hope that Ruth will help me to find a researcher who will make an application with me for the same proposals, from the following programme:

'The NIHR Public Health Research Programme is accepting applications to its researcher-led workstream. More information on how to apply can be found on [http://www.phr.nihr.ac.uk/fundingopportunities/researcher\\_led.asp?src=0813\\_RL6](http://www.phr.nihr.ac.uk/fundingopportunities/researcher_led.asp?src=0813_RL6)  
Closing Date: 19/11/2013.'

## **12 Principles of welcoming PPI in research**

I hope that when I meet with Ruth and other researchers, they will apply the principles of welcoming PPI, as set out in the booklet titled: '**Involve. Promoting public involvement in NHS, public health and social care research. Good practice in active public involvement in research**' It is published by the National Institute for Health Research (NIHR) and dated Feb 2009, see [www.invo.org.uk](http://www.invo.org.uk). It says: 'Active involvement in research is different from simply taking part in a research study. For example, it can mean:

- Helping researchers to identify and ask the right questions in the right way.
- Making sure that health and social care research is relevant to patients, people using services, and the public.
- Getting involved in the research process itself, whether designing, managing, undertaking, or disseminating research.

It goes on to advocate building respect and mutual understanding, as I recommend in paragraph 1 above.

However, Ruth's response dated 31.7.13 (see appendix 1 below) does not welcome my suggestions, but seems to invent reasons to reject them without even meeting me to discuss them. For example she says:

'However, at present your research question is not formed and does not sufficiently identify the gap in NICE guidelines it seeks to fill. One of the criteria for own account funding is that the research proposal should show how it would lead to NIHR portfolio research on the future and NIHR research rules out evaluation as a fundable activity.'

That is the job of research staff (like Clara) who later emailed me that she did not have time to meet me. I am therefore in a catch 22 situation, hitting brick walls whatever I do.

Like all the others, Ruth and Clara are nice people, but seem to be subject to the same glass wall syndrome. Deep down they seem to automatically see me as an alien to be feared, rejected and dismissed. If they could drop their fear, relax, and make time to have a cup of tea with me, we could work together with mutual benefit.



f) Other reason.....

Q5 If you did not take positive action (namely b) to g) in Q3) why not?

- a) It is not my job to take any of these positive actions.
- b) It is my job to consider suggestions, but I did not have time, as I am overloaded.
- c) I don't get involved with suggestions because I fear that I will be persecuted as a whistle blower.
- d) Other reason.....

Q6 Do you believe that any of the suggestions could improve the service? Yes No

Q7 If yes to Q 6, please recall what they were? (continuing on another sheet if necessary)

.....

Q8 If you list any suggestions in your answer to Q7, should any of them be properly considered now? Yes No

Q9 If yes to Q8, can you now take appropriate action to deal with them? Yes No

Q10 If yes to Q10, what action have you taken?

.....

Q11 I have the following suggestions of my own on how the services should be improved

.....

Q12 How would you rate your present job satisfaction and morale:

Very low, Low, Moderate, High, Very high.

Q13 If the suggestions made in answers to Q7-Q11 were implemented, would your job satisfaction and morale be improved? Yes No

Q14 Please give your opinion on the statement: 'The staff culture is to ignore suggestions on how the services could be improved.'

Agree strongly, agree, disagree, disagree strongly.

Q15 Have you any other suggestions as to how your job satisfaction and morale could be improved? .....

Thank you for filling in this questionnaire. Please submit it to ..... by .....

Name.....(optional)

Department.....(optional) Date.....

#### **14 Hypothesis about the cause of the glass wall – paternalism**

To cure the NHS of its disease, we have to discover the underlying cause. I say elsewhere that the part of the cause is the over-prescribing of drugs, but this begs the question, why are they over-prescribed? I answer elsewhere that this is because GPs have nothing else to offer patients, as the waiting time for talking therapies is too long.

I believe that the cause of the glass wall is paternalism, which is an ego trip of feeling superior because of your job. This is most obvious in doctors, who are seen as on a pedestal, playing God, and telling patients on their knees to 'keep taking the pills.' There is a joke which illustrates this truth. 'Why is it that doctors have a decade less life expectancy than average, and pharmacists have a decade longer life expectancy than average? Answer: because living on a pedestal is not healthy, and pharmacists read the patient information leaflets, and never take what they dispense.'

Doctors have the disease of paternalism worst, and pay the price with their lives, and by suffering long term conditions 18 years early, as do the poor. However, they are not the only ones to suffer from it. All NHS staff do, and there is a 'pecking order' of superiority, with hospital porters at the bottom of the pile.

However, even hospital porters feel superior to patients, who are the lowest of the low, equivalent to the 'sudras' (untouchables) in Hindu tradition. The NHS paradigm (underlying, unconscious belief system) about patients is that they are by definition ill, and therefore lack mental capacity. You cannot believe a word they say, (which is condemned as 'anecdotal') which is why their bodies are subjected to so many tests.

The paternalistic feeling of stigmatising superiority is the cause of the glass wall (silo) mentality. It prevents people from communicating from their hearts, which requires a humble attitude of seeing others as equal human beings. But it is only a habit, and can be cured by the local leadership, who should set a good example, as Nelson Mandela did.

Furthermore, leaders should recognise that patient and public involvement (PPI) is the antidote to paternalism, as it requires a **role reversal**. The patient is on top of the pedestal, telling the doctors and managers on their knees where they get off. Their morale right to this 'superior' position (as mentioned above) is that patients collectively pay for the NHS in their taxes, so should 'call the tune' in determining the service provided at their expense.

This is a hard pill to swallow for everyone, staff and patients alike. However, healing the NHS, like everything else, requires letting go of our egos, and accepting the interdependence of everybody as equal partners, working as a team in our community. That is where meditation comes in.

SECTCo's mission statement is: 'medication to meditation' and its strapline is: 'Give a man a pill, and you mask his symptoms for a day. Teach him meditation, and he can heal his life.'

### **15 Proposed agenda for my meeting with Mark Hayward**

This was arranged for 3.9.13, but I postponed it, so that I can attend the open day at Swindon.

1 Introductions

2 My recommendation for a culture shift to remove the glass wall (see paragraph 1)

3 My suggestion for reviving the Mindfulness Interest Network as part of the new Sussex Mindfulness Centre. (see paragraphs 1a) and 5,6, and 7)

3 My suggestion of a research trial of Osho dynamic meditation. (see paragraphs 1b) and 8)

4 My suggestion of a research trial of Hellinger family constellation group therapy. (see paragraphs 1b) and 8)

5 My suggestion of a research trial of the glass wall syndrome (see paragraphs 1b) and 8)

6 Action plan

## **Appendix 1 Correspondence with members of SPFT staff**

### **1 Re my involvement in research projects listed in issue 2 of the Research magazine.**

2.8.13 Dear Researcher (No response received to date)

I am a member of the Research Network, and receive and read the Research Magazine. I see on p 20 of the latest version (2013) that Dr Jessica Eccles is exploring the link between double jointedness and anxiety, and Prof Gillian Bendelow is investigating section 136 detention rates in Sussex, and the need for more appropriate crisis interventions within OOH services, and a review of the therapeutic interventions of BPD. I would like to engage with them.

On p 22, I note that Lizzie Clark is a PHD student assessing the feasibility of delivering mindfulness-based therapies in a self-help form in the NHS. Geoff Davie is studying neurocognition and schizophrenia.

Sarah Fielding Smith is studying voice- hearing experiences, and personal triggers.

Lucy Nelson is studying blood pressure and Alzheimers disease

I offer my time for interview. I have always been interested in mental health. My mother was a psychiatrist, as is my sister, and daughter. On a drop in basis, I have been leading the following complementary interventions: dynamic meditation for 11 years, family constellations for 5 years and Mindfulness courses for nearly 4 years. I have 'treated' more than 1,000 people, and have learned much from them, which I would like to share with researchers.

I live at 22, Saxon Rd Hove BN3 4LE, and am available to meet any time. My phone no is 01273 417997. Please forward this to them, and anyone who may be interested. Thanks in anticipation. Please acknowledge this e mail, so that I know that it has been received.

Yours john Kapp

### **2 With Ruth Chandler re my involvement in research projects**

2.8.13 on phone, Ruth said that she would meet me in Sept. I complained that I have been trying to meet with her for 3.5 months (since 17.4.13) She said that she had been off sick with a nervous breakdown. She complained that I had copied in Mark and Lisa. I said I was fed up with the rhetoric of the Trust involving service users, but when I try, nobody will engage with me, or even acknowledge my e mails. She said that the 6 people I contacted directly were upset, because I should have done so through her.

2.8.13 Dear John

I am sorry to hear you are disappointed. I will telephone you tomorrow to explain my decision not to take on your project myself. As Clara has explained, only Trust employees are able to apply for own account funding and the key priority of my role is facilitating involvement in research design with clinicians. I can sometimes do service user led research but my research activity has to be carefully assessed against capacity to deliver on the design remit. Neither myself nor my colleague currently have the capacity to take on the development work your project would need to meet the own account criteria this year.

Best Wishes

Ruth

1.8.13 Dear Ruth

Thanks for this. I have been asking for a meeting with you for months, and I am very disappointed that you seem to be rejecting my ideas for an application for this year's funding simply because you happen to be going on annual leave for the whole of August. We still have a month to get the outline proposal in by 30.8.13, and 4 month for the full proposal by 29.11.13. Jean is your deputy, and as I said on the phone, I am willing to meet her while you are away. You say:

'Your research question is not formed'. and

'I would need to see the project defined through the lens of your lived experience as a service user and a rationale for why that enhances the scientific quality of the research and why that would lead to greater therapeutic benefits for service users than a clinically led study or the same benefits at lower cost'.

In the outline I sent you, I tried to say briefly why I think dynamic meditation and family constellation should be trialled to see if it can get NICE recommendation (as mindfulness did in 2004) I believe that these techniques have much potential for patient benefit.

I do not know what is meant by 'NIHR funding' or what the 'in house Trust portfolio' is. I have e mailed more than 6 trust staff who say in the magazine that they want public involvement, and all have cursorily rejected my overtures.

I therefore have the general impression that none of the Trust staff really want any involvement, or any ideas for applications from members of the public. This flies in the face of the rhetoric that Mark, Lisa and the government keep saying publicly. I am therefore copying this to Mark and Lisa for their information.

I repeat my request to meet with you or Jean to discuss my ideas for an outline application, and am available to make an appointment on 417997. Best wishes Yours john

----- Original Message -----

**From:** [ruthchandler@yahoo.com](mailto:ruthchandler@yahoo.com)

**To:** [John kapp](#)

**Cc:** [Strauss Clara](#)

**Sent:** Wednesday, July 31, 2013 1:19 PM

**Subject:** Re: reseach proposals

Dear John

You have conducted a really interesting evaluation which could potentially contain a rationale for a research project in the future. However, at present your research question is not formed and does

not sufficiently identify the gap in NICE guidelines it seeks to fill. One of the criteria for own account funding is that the research proposal should show how it would lead to NIHR portfolio research on the future and NIHR research rules out evaluation as a fundable activity.

There is also the question of where the project would sit on the in house Trust portfolio. I believe Clara Strauss has already indicated that she is not willing to support through the MARS theme as you are not a member of staff and therefore not eligible to apply. For me to support the proposal as Involvement Coordinator, I would need to see the project defined through the lens of your lived experience as a service user and a rationale for why that enhances the scientific quality of the research and why that would lead to greater therapeutic benefits for service users than a clinically led study or the same benefits at lower cost. We would still need Clara's support for that as involvement is not a research theme.

There is a lot of work needed to get it to this place which would not be achievable in the time scale even if I were not going on annual leave. This means that my answer is no to supporting your application this year. However, I am willing to meet with you in September on my return to discuss next steps and how LEAF could support you to develop a feasible proposal that would be acceptable to Clara too.

With regards to your invitation to sample your group, I must decline as mindfulness is not a technique that is always helpful to me regarding my own established meditational practices and fluctuating relationship with what is happening in my body. In my consultations with service users, I have heard a similar story. For the people for whom mindfulness works it is great but for some people it is really scary so I would like to see some scientific analysis about for whom mindfulness is helpful and for whom it is not as part of your proposal. If I can identify a limit with your research as it stands it is your slightly evangelical approach to the self evidence of therapeutic benefit around mindfulness. To be scientific, research has to be undertaken from a position of equipoise, that is being curious about results for and against the research hypothesis without favouring one over the other. This is often hard when one has a commitment to a practice but absolutely necessary for good quality research.

I hope my review is not too disappointing. I would be happy in September to work with you on an action plan to make your project eligible for own account funding in the next round and provide any support that is in my remit to do that.

best wishes

Ruth Chandler Sent from my iPad

On 31 Jul 2013, at 10:45, "John kapp" <[johnkapp@btinternet.com](mailto:johnkapp@btinternet.com)> wrote:

Dear Ruth

Here is what I sent last week

26.7 Dear Ruth

Further to my phone call, I am an engineer and scientist by background, and keen to do some legwork. For example in 2012 I conducted a research project on 22 participants of my MBCT courses which was initiated by Kate Spiegelhalter (doing a PHD on mindfulness in Sussex) which I wrote up in a 19 page report (attached) The average increase in positivity was 20%, and the best half (11) increased by 30%.

I would like to do the same sort of research project with other forms of meditation, with the object of getting them NICE recommended (like the MBCT course) namely dynamic (1 hour to a CD) and family constellation.

I have been leading dynamic mediation on a drop in basis 3 times per week for over 10 years I have been facilitating family constellations at least once per month on a drop in basis for more than 5 years.

Rather than trying to explain these meditations, I invite you to come and experience them. I happen to have 2 clients who are doing dynamic every day, and you are welcome to join us. I do it at Revitalise, 86 Church Rd Hove (opposite Hove town hall)

Weekends (Sat and Sun) it is from 8-9am, and weekdays (Mon-Fri) half an hour earlier, so that people can get to work, ie from 730-830am. Access by back door, as front door is locked until 9am.

If you would like to try family constellations, I do them on the 4th Sunday of each month, which happens to be this Sun 28th, at 3, Boundary Rd Hove BN3 4EH, (near Kingsway coast road) from 10-4pm. Please come at 10 to hear the explanation

I am open to suggestions as to how we recruit to these studies.

I am available to meet you at the Sussex Education Centre any time next week by appointment.

Please ring me on 417997.

Best wishes Yours John

<Questionnaire results report 15.12.12.doc>

### **3 With Robert Marx re my involvement in the new Sussex Mindfulness Centre**

16.6.13 Dear Robert

It was nice to see you at the research day on Thursday (13.6.13). I am so pleased about Sussex getting the Sussex Mindfulness Centre, which is a great tribute to Brenda Robert's work. I hope that the Mindfulness Interest Network (MIN) that she started a decade ago, but which has been dormant for 3 years, can be revived. As I said, I am willing to be secretary, if a chairman can be found from the Trust, so that meetings can again be held with the authority of the Trust in its buildings.

As you know I am active politically, and my campaign to reduce the waiting time for MBCT courses now has the support of my MP, Mike Weatherley. He recently asked 4 questions of the Health minister (Norman Lamb) about mindfulness. I attach these questions and his answers (which are disappointing) and my 6 supplementary questions which I hope he will ask soon. I would be pleased to receive comments. My phone number is 417997.

Best wishes Yours John

14.6.13 Thanks Robert (Nemeth). How about the following supplementaries: Is the minister aware that:

1 The Mindfulness Based Cognitive Therapy course is NICE-recommended, so, under the NHS constitution patients have the statutory right to it if their doctor says it is clinically appropriate?

2 The chairman of NICE (Sir Michael Rawling) said publicly (on 2.8.12) that commissioners who fail to commission NICE-recommended treatments are breaking the law?

3 One in three patients in primary care present with depression, for which the Mindfulness course should be considered by GPs?

4 That there are 160,000 depressed patients in Sussex, for whom only about 8,000 patient places are commissioned, so if the course were considered clinically appropriate for all for them, the waiting time would be 20 years?

5 That one way to reduce waiting times in A&E departments would be for GPs to prescribe courses such as Mindfulness, which give patients self-help tools to better manage their conditions without going to hospital?

6 That health inequalities could be reduced by GPs prescribing vouchers by which poor patients could pay for private sector provided Mindfulness courses, as if they are rich? (the going rate in Sussex is £150-370)

----- Original Message -----

#### **4 With Clara Strauss and Fergal Jones re my involvement in the new Sussex Mindfulness Centre**

22.5.13 Dear Clara Strauss and Fergal Jones

It was nice to meet you at the research lectures. Congratulations on becoming the Sussex Mindfulness Centre, along with Bangor, Oxford, Exeter, Aberdeen. As I said, it would be good to revive Brenda Robert's MIN, so that the clinical side and the mindfulness in schools side could work together. I took over from Fergal as secretary about 6 years ago, but it fizzled out 3 years ago. I am willing to resume that role if someone will be chairman.

I have run 6 MBCT courses for about 60 people over the last 3 years. I ran a study with a before/after questionnaire last year, getting 22 participants, who increased their positivity 20% on average, as the attached report shows. Eleanor Hope (SPFT) has the source data.

I did a .b teacher training in March, and am offering to run mindfulness courses for school teachers on Sat mornings and in the holidays. However, I have never had a supervisor, and would like to find one, or a group who would offer supervision.

I started a company to bid for contracts, see [www.sectco.org.uk](http://www.sectco.org.uk), and papers on section 9 of [www.reginaldkapp.org](http://www.reginaldkapp.org). I would like to hear your reactions to this.  
I have ideas for further research projects for patient benefit, which I would like to share.  
Best wishes Yours john

# **Appendix 2 Minutes of 18 meetings of Sussex Mindfulness Interest Network (MIN) from 2007-11**

**1 Minutes of a meeting of the Mindfulness Interest Network (MIN)** Held on Tues 27<sup>th</sup> Nov 2007 at Hove Polyclinic

**Present** Brenda Roberts (chairman) Brenda Davis, Lynn Kupfermann, Richard Gilpin, Rory Singer, Judy Lewis, Caroline Ratnada Kini, Nicky Boella, Carolyn Pollack, Graham Molyneaux, Geoff Mothersole, Rebecca Groom, Catherine Cameron, Cruij Terman, John Kapp (secretary) (15 in total)

## **Discussion of the ‘Inquiry Process’ in MBCT**

Brenda described the use of the inquiry process within the MBCT programme. After each practice session in the class, participants are asked “What did you notice during that practice?”

She usually gives them about 5 minutes in pairs to reflect what each noticed within the body and the mind by telling the other. Then the bell is rung to indicate a change from the pair discussion to a group discussion.

The aim of this is to develop the participant’s ability to be *aware of and describe* what came up for them in the moment, whether that experience was pleasant, unpleasant or neutral. Inquiry encourages participants to observe all their experiences, to accept and welcome them without judgement, with less of the ‘attachment’ and ‘avoidant’ reactions that often dominate awareness.

John described the allied technique of ‘appreciative enquiry’ which had been researched in the USA, as taught in the ‘Values in Healthcare’ course ([www.jankifoundation.org](http://www.jankifoundation.org)). The questioner adopts an attitude of appreciation which relaxes the other to release endorphins and co-operate. Questioning can otherwise produce adrenaline from fear, resulting in a defensive reaction and withdrawal.

It was said that Jon Kabat-Zinn gives his mobile phone number to all the members of his groups, telling them to ring him whenever they want, after imagining what he would say to them. This makes them feel that he is always there for them, and gives them confidence that they have a safety net. While this was thought to be incredibly brave of him, he had apparently been called only once.

## **The future of the Group**

Brenda said that Hove Polyclinic would no longer be available as a venue, but that the Allen Centre, 60, Sackville Gardens, Hove, has a room available for future meetings from 230-4pm on Tuesdays. Neither she nor Fergal Jones can lead the group, and she asked for volunteers to take over.

John said that meditation is an important method of getting the body to produce endorphins, without which it cannot heal. He thought of the group as a support group for meditation leaders, which is badly needed and should continue.

Rory Singer was elected as chairman. John Kapp was elected as secretary. It was agreed that we should meet about 6 times per year, as before, and everybody with an interest in the clinical applications of mindfulness is welcome to attend.

## **Next meeting**

The next meeting will be held on Tues 12<sup>th</sup> Feb at the Allen centre from 230-4pm. Rory Singer will lead a discussion on ethics and boundaries.

For the meeting following this (date and time to be decided on Feb 12), Brenda Davis will lead a discussion of the possible applications of mindfulness-based approaches to work with children and adolescents.

Participants were asked to volunteer to lead future discussions to the secretary, John Kapp, tel 417997, [johnkapp@btinternet.com](mailto:johnkapp@btinternet.com)

## **2 Minutes of Mindfulness Interest Network 12 Feb 2008**

**Present** Rory Singer (chairman) Carolyn Ruiterman, Judy Lewis, Lucia Swanepoel, Brenda Davis, Kirsty Ralston, Kate Charlton, Lynne Kupferman, Nicola Sheriff  
Kate Gooch (minute taker) Deresh Turnbull, John Kapp (secretary)

**Theme of meeting** **Ethics** What is MBCT? Is it a clinical application or not, or both? Who do we allow to run MBCT courses? Ethical tension of offering MBCT courses at the Centre for Mindful Education for example, where none of the tutors are cognitive therapists.

1. **Evaluation** Importance of NICE guidelines, but how far can we deviate from the model? As long as you are evaluating its efficiency that's OK. Practice-based evidence as important as evidence-based practice.
- 2 What is mindfulness? How do we convey that it's something that can be done off the cushion? Do participants realise it's an introduction to meditation?
- 3 As a meditator, is it OK to charge for the course, rather than doing it for donations?
- 4 How ethical is it to offer it to some people and not others? Should there be selection criteria? People running courses at Buddhist Centre don't have the access to medical records that NHS professionals have
- 5 How much of a mindfulness practice is needed to enable someone to lead a course? Is the course a closed therapy group, or a class in which to learn skills? Are some groups more interpersonally oriented? The course is always experiential but perhaps intra-personal rather than interpersonal  
Participants' expectations may differ.
- 6 Should not doing homework be made a shame-based experience?. How essential is it to do the homework?
- 7 How much do participants need the interactional space? For people with depression one of the most pressing needs is for community
- 8 **Follow up**-the ethical issue of leaving people in a vacuum after the course ends. Can we have regular follow ups? Can participants from courses use the follow up drop ins at other Centres?

### **Secretary's note.**

I apologise for being late, and am grateful to Kate for taking these minutes. I would have liked to say the following:

We all seemed to agree that to practice meditation in groups is important follow up for progress for both therapist/teachers and patients. To make this easier for us all to access, I suggest that the group produces a

flier stating the availability of drop-in meditation in Brighton and Hove, which we can all give to our classes and patients.

If you agree and know of drop-in meditations in Brighton and Hove, please e mail the details to me on [johnkapp@btinternet.com](mailto:johnkapp@btinternet.com) and I will produce a draft flier for approval at the next meeting.

**Interviews wanted.** Nicola Sheriff is a third year counselling psychologist at Roehampton University doing research on the perceptions of psychotherapists who practice mindfulness, and needs people to interview. If you can help, please contact her on [nicolasheriff@hotmail.com](mailto:nicolasheriff@hotmail.com)

**Next meeting: Tues 15<sup>th</sup> April 2.30-3.50** The Allen Centre, 60 Sackville Gardens, Hove

**Theme:** Storytime-people's first encounter with mindfulness and what brought us here. Spontaneous chair. All with an interest in mindfulness welcome.

**Registration/de-registration** Please contact me on [johnkapp@btinternet.com](mailto:johnkapp@btinternet.com), or phone 01273 417997

### **3 MINDFULNESS INTEREST NETWORK**

**Minutes** of the meeting held on Tues 15<sup>th</sup> April 2008 at the Allen Centre

#### **Present**

Brenda Davis (deputy chairman, in the chair) Catherine Cameron, Robert Marsh, Rosy Roberts, Catherine Ruijterman, Richard Gilpin, Carolyn Pollack, Sally Caritt, Karunavira, John Kapp (secretary)

#### **Apologies for absence**

Rory Singer, (chairman) Lyn Kupfermann, Taravajra, Graham Molyneux, Medhina, Nicky Boella, Brigitte ONeil, Fergal Jones, Kate Gooch, Anna Barnard

#### **Meeting**

Everyone introduced themselves. A short meditation was led. It was agreed that every meeting should include a short meditation at the beginning and the end.

Everyone said what they wanted the group to be. It was agreed that written terms of reference are not required, and that the name of the group is the Mindfulness Interest Network. It is not a Meditation Interest Network, because there is an evidence base for mindfulness- based therapies, not meditation. However, it is acknowledged that meditation is an essential part of the therapy to promote lifestyle behavioural change.

Members want a network where they can meet with colleagues who are using or teaching mindfulness as therapy eg Mindfulness Based Cognitive Therapy (MBCT), Mindfulness Based Stress Reduction (MBSR),

Acceptance & Commitment Therapy (ACT) & Dialectical Behaviour Therapy (DBT). Key features are acceptance of yourself as you are, and contacting the wisdom within yourself. Anyone interested in these is welcome to attend.

### **Future meetings**

It was agreed to continue to meet every 2 months at the Allen Centre, on Tuesdays from 2.30-3.55pm.

The next meeting will be held on **Tues 1<sup>st</sup> July**. The agreed topic was sharing the language we use/how we communicate in the meditations & therapy.

### **Papers tabled for collection**

Flier 'Mindfulness in Clinical Practice' Sat 14<sup>th</sup> June 10-1230 £25, at Centre for Mindfulness Based Education, tel 01273 681333, [Jackie@ontopofthemountain.com](mailto:Jackie@ontopofthemountain.com)

Flier 'Places to Meditate in Brighton and Hove'

Paper 'Cathartic Meditation as Prevention and Therapy' available from [johnkapp@btinternet.com](mailto:johnkapp@btinternet.com)

## **5 MINDFULNESS INTEREST NETWORK**

Notes of a meeting on Tues 9<sup>th</sup> Sept 2008

at the Allen Centre from 2-345pm

**1 Present** Rory Singer (chairman), Carolyn Ruijerman, Lynne Ley (formerly Kupfermann) Brenda Davis, Jenny Connolly, Rebecca Groome, , Sally Caritt, Judy Lewis, John Kapp (secretary)

**2 Apologies** Ratnadatini, , Jiva, Brenda Roberts, Carolyn Pollack, Catherine Cameron Brigitte O’Neile, Richard Gilpin, Rosy Roberts, Taravajra., Geoff Mothersole, Julia Counsellor, Ann Stracher, Kate Charlton, Kirsty Ralston.

**3 Minutes of the last meeting 1.7.08.**

It was proposed and agreed that there is no need of formal minutes, but notes should be taken and circulated for the information of those not able to be present. Action secretary.

**4 Dialectical Behaviour Therapy (DBT) led by Rebecca Groome**

Rebecca has run 3 DBT courses in Worthing for patients with traits of Borderline Personality Disorder (BPD) The courses run for 2 hours per week for 16 weeks, (but according to the protocol should run for a year)

The first 2 courses started with 12 participants and finished with 8, and they gelled as a group. The third course was hampered by being held on a split site. It started with 7 and finished with 3, and the participants did not gel. This made it difficult to deliver this course as intended.

Many of her patients exhibit habitual high risk behaviours, which are often their only known coping strategies. They live in a nightmarish world, struggle to sit still, find it hard to accept themselves, and put themselves down as stupid.

She enjoys running these courses because she feels that the DBT is a skills training which provides participants with coping strategies which serve them better than their habitual ones. The tools they learn in DBT enable them to deal more positively with their distress, and overcome their painful emotions. Evaluation shows that many benefited from the course. A few also benefited from repeating it. (Secretary’s note: this implies that 16 weeks is not long enough for some participants)

The discussion included the problematic use of antidepressants, and the fear of the therapist saying something that might provoke a patient to self-harm. Therapists have to make risk assessments to try to avoid this possibility. However, these assessments rely on patients disclosing their problems, which they do not always do.

**5 Next meeting Tues 11<sup>th</sup> Nov** at 3-5pm at Hove Polyclinic, off Neville Avenue, Hove Topic Mindfulness Based Pain Reduction (MBPR) led by Ratnadatini

**6 Programme for 2009** It was agreed that we wish to continue to meet every 2 months in 2009, preferably on Tuesday afternoons from about 3-5pm, in Hove Polyclinic. Action. Secretary to contact Catherine Cameron to arrange venue.

**7 Any Other Business** John Kapp said that he had drafted a paper for Brighton and Hove PCT promoting MBCT courses for staff and patients entitled ‘Improving Health by ending the Prozac Nation’ The paper can be seen and downloaded from section 9.28 of his website [www.reginaldkapp.org](http://www.reginaldkapp.org).

# 6 MINDFULNESS INTEREST NETWORK

Notes of a meeting on Tues 11<sup>th</sup> Nov 2008

at Hove Polyclinic from 3-5pm

**1 Present** Brenda Roberts (chairman), Ratnadakini, Carolyn Ruijerman, Rosie Roberts, Brenda Davis, Catherine Cameron, Sally Caritt, Deeresh Turnbull, Jiva Masheder, Michelle Hughes, Lucia Swanpoet, Jez Morris, John Kapp (secretary) 13 in total.

**2 Apologies for absence:** Marion Martin, Catherine Pollack, Kate

## **3 Mindfulness Based Pain Reduction (MBPR)**

Ratnadakini (Kay Tremayne) is an ordained Buddhist, and has been practicing meditation since 1978 and teaching it since 1985. She was inspired by the work of Vidyamala, who helped to set up 'Breathworks' in Manchester, and whose book 'Living Well with Pain and Illness' has just been published. Breathworks is a not-for-profit company running courses on Mindfulness.

Ratnadakini qualified as a Breathworks teacher in 2006. She has been running Breathworks courses in the MS centre in Southwick, and working with Karunavira to run Mindfulness Based Cognitive Therapy (MBCT) courses at the Buddhist centre in Brighton,. It has not been easy to get clients. She is investigating whether to seek work in the government's initiative to get the long-term unemployed back to work. Under payment by results, she might not get paid unless and until her clients are able to hold down a job for over 12 weeks.

The Breathworks pain reduction course content is similar to the MBCT course. It is a 5 step process of becoming aware of your body, your pain, your self as container of pain, and your choice of blocking, drowning, resisting, or accepting it. She emphasises the 'kindly awareness' of yourself and others as being 'just like me'.

Recommended reading included:

'Get out of your mind and into your life' by Stephen Hayes,

'Leave your mind behind' by .

'Teach yourself Acceptance and Commitment Therapy' (1999)

'Full Catastrophe Living' by Jon Kabat-Zinn

'Mindfulness Based Cognitive Therapy' by Rebecca Crane' (just published)

The following issues were discussed:

### **1 The client/patient's wish to know how the therapy is going to work?**

The patient/client's wish to control is the *problem*, not the *solution*.

MBCT is not a skills-based approach. The therapeutic effect of *being* over *doing* has to be accepted as a *paradox*, like a Zen koan. Not going for the change is the biggest change.

## **2 Client/patient's habitual need to talk (tell stories).**

It was agreed that talking is not helpful, because you 'miss the bus'. The facilitator should be a mirror (example) leading the class in the discipline of practicing meditation instead of talking, so that they can experience the benefit of letting go of this habit.

## **3 Client/patients who do not do the homework practice.**

They notice the beneficial changes in others who do their homework, and want those benefits for themselves. Some are so disturbed and isolated that just getting themselves to the class is a big achievement and benefit in itself.

Ratnadakini led us in a 20 minute guided meditation which beautifully illustrated the healing effect of her approach.

## **4 Annual General Meeting**

The following officers were elected for next year:

Chairman Brenda Davis, secretary John Kapp.

Meetings in 2009 will be held at Hove Polyclinic on the second Tuesday of every second month from 3-430 pm, to include one hour discussion on a mindfulness-related topic led by a nominated speaker, with optional socialising and networking afterwards until 5pm.

20<sup>th</sup> Jan, (exceptionally the 3<sup>rd</sup> Tues) 10<sup>th</sup> March, 12<sup>th</sup> May, 14<sup>th</sup> July, 8<sup>th</sup> Sept, 10<sup>th</sup> Nov 2009. Action secretary to arrange venue with Catherine Cameron.

**Topic for 20<sup>th</sup> Jan** Acceptance Commitment Therapy, speaker Sally Carritt.

Those who would like to speak at future meetings please contact the secretary.

## **5 Other meetings**

Rosie Roberts mentioned a conference 'Mindfulness and Beyond 15-16 April in Holloway Rd, London.

Deeresh Turnbull mentioned a mindfulness course that he is running at the acupuncture clinic in Hove on Tues evenings from 6-730pm.

# 7 MINDFULNESS INTEREST NETWORK

Notes of a meeting on Tues 20<sup>th</sup> Jan 2009

at Hove Polyclinic from 3.15-4.45pm

**1 Present** Brenda Davis (chairman), Catherine Cameron (minutes), Sally Caritt, Anita Franchi, Lynn Ley, Kirtsy Ralston Carolyn Ruijerman,

**2 Apologies for absence:** Fergal Jones, Rosie Roberts, Swanepoel Lucia , Taravajra, Dhereesh Turnbull.

## **3 Acceptance & Commitment Therapy (ACT)**

Sally Carrit works as a private psychotherapist. She outlined her background and how she became interested in ACT,

She presented her overview of ACT initially in terms of her expectations and experiences and we were encouraged to reflect on our expectations & experiences about the presentation as we were listening to it.

This approach was used as an illustration of the focus of ACT, before outlining the theory briefly. ACT has behavioural roots (arising out of 'functional contextualism'), but differs from other behavioural approaches (the importance of context) and focusing on context and language in understanding people's suffering.

It takes the view that we all suffer as a result of experiential avoidance and cognitive fusion (see below).

Language can cause difficulty when applied as a means of 'internal problem solving', as it leads to being 'fused' with one's thinking (i.e. because we think it , we see it as true). To avoid the suffering this causes, we then avoid being aware of our experiences. ACT then sees language as part of our problems, but also a partial means to changing them.

Some of the techniques ACT uses were discussed. Sally noted the role of mindfulness in ACT and the emphasis on being in touch with ones experience without being 'fused' with one's thoughts. However, mindfulness is seen as a means of being fully present **with a view to engaging people in goals** which serve their personal values (committed action) making their lives 'about' more than avoidance. As such it was one part of the approach and a tool rather than the central focus.

She then talked about an individual case to illustrate how she has found it helpful, which pulled together the theory and highlighted aspects of how it is used.

Books:

Learning ACT.: An Acceptance and Commitment Therapy Skills Training Manual  
by [Jason B. Luoma](#), [Steven C. Hayes](#) & [Robyn D. Walser](#)

Talking ACT: Notes and Conversations on Acceptance and Commitment Therapy by [David Chantry](#) & [Steven C. Hayes](#) (transcripts of sessions)

A Practical Guide to Acceptance and Commitment Therapy by Steven C. Hayes and Kirk D. Strosahl

#### **4 Any Other Business**

The topic of the core business of MIN was revisited. Concerns were expressed about the use of the mailing list to advertise events, where these are not about the empirically supported use of Mindfulness.

It was agreed that the group's focus will be on topics directly related to therapeutic practice of mindfulness within empirically validated approaches such as MBSR/MBCT.

The mailing list itself should be used to advertise events **only** by first sending such events through the chair, and other than this used directly **only** for apologies and practical arrangements.

#### **5 Future meetings**

Meetings in 2009 will be held at Hove Polyclinic, unless otherwise specified.

The dates agreed are 10<sup>th</sup> March, 12<sup>th</sup> May; 14<sup>th</sup> July, 10<sup>th</sup> September and 10<sup>th</sup> November. Times are 3.15-4.45pm

PLEASE NOTE THE CHANGE OF START TIME

On the 10<sup>th</sup> of March : Taravajra will be talking about a Buddhist understanding of mindfulness

# 8 MINDFULNESS INTEREST NETWORK

Notes from Tues 10<sup>th</sup> March 2009 at Hove Polyclinic from 3.15-4.45pm

**1 Present** Brenda Davis (chairman), Catherine Cameron (minutes), Sally Caritt, Kate Gooch, Lynn Ley, Kirsty Ralston, Taravajra,

**2 Apologies for absence:** John Kapp; Judy Lewis.

## **3 Mindfulness & Buddhism**

Taravajra, who leads MBCT groups in a number of settings and is also a practising Buddhist, lead an interesting discussion on the relationship between mindfulness as used within MBSR/MBCT approaches, Buddhist understandings of mindfulness and Buddhism.

## **4 Any Other Business**

It was reiterated that the mailing list itself should be used to advertise events **only** by first sending such events through the chair, and other than this used directly **only** for apologies and practical arrangements.

## **5 Future meetings**

Meetings in 2009 will be held at Hove Polyclinic, unless otherwise specified.

The dates agreed are 12<sup>th</sup> May; 14<sup>th</sup> July, 10<sup>th</sup> September and 10<sup>th</sup> November. Times are 3.15-4.45pm

PLEASE NOTE THE CHANGE OF START TIME

# 11 MINDFULNESS INTEREST NETWORK

Notes of a meeting on Tues 8<sup>th</sup> Sept 2009 at Millview Hospital.

**1 Present** Sally Carritt, John Kapp (secretary)

**2 Apologies for absence:** Brenda Davis (chairman), Rosie Roberts, Taravajra, Dhereesh Turnbull.

### 3. Discussion

John and Sally shared their personal experiences of Mindfulness and how it had benefited them. Sally talked about the value of Mindfulness based interventions in her work as a therapist and how it is an important component of ACT. John spoke about his wish to see MBCT courses more widely available for NHS patients and staff. Sally agreed. John produced copies of papers he had written to this effect. (**Error! Hyperlink reference not valid.** section 9.28 and 9.34)

It was agreed that the future of MIN was a priority for discussion at next meeting

### 4. Future meetings

Tuesday 17<sup>th</sup> November 3.15 – 4.45 pm Hove Polyclinic. AGM

MIN seems to hold little interest for most people on the mailing list (64) as attendance has slipped to 2 or 3 for the last 3 meetings, with few apologies. It would be a pity to let MIN fade away if it could be of benefit. A few questions for you to ponder:

1 Is people's interest in mindfulness being catered for elsewhere?

2 Do we need MIN? If so, what would you like our meetings to be about?

Do you want speakers, discussions, experiential work, time to get to know each other?

3 Can MIN help us to be more useful, present, empathic with our clients/patients?

4 Can we encourage an interest in mindfulness in more people in the medical and caring professions and beyond? Or shall we give MIN a decent burial?

What do you think? If you want it to continue please be prepared to nominate somebody for chairman and secretary for next year, with ideas for convenient days, frequency and venue.

**Please come with your ideas/views to the next meeting or email them to Brenda Davis and mailing list.**

# 12 MINDFULNESS INTEREST NETWORK

Notes of a meeting (AGM) on Tues 17<sup>th</sup> Nov 2009 at Hove Polyclinic.

**1 Present** Catherine Cameron, (CC) who is running MBCT courses in the NHS pain clinic, Caroline Ruijterman (CR) who is running MBCT courses in the private sector in Littlehampton, Carolyn Pollak (CP) second year student at Bangor, Jiva (J) third year student at Bangor, Brenda Davis (BD) (chairman) who has done the 8 week course but not yet the teacher training, Sally Carritt (SC) who is using mindfulness in her private counselling, John Kapp (JK) (secretary) who has just done the teacher training 5 day Oxford course and wants to start running courses as a helper. Most people present were experienced meditators going on regular retreats in various places.

**2 Apologies for absence:** Dhereesh Turnbull, Harriet Heal, Robert Marsh, Anna Stratford, Sally Sedgewick, Richard Gilpin, Jenny Connoly (resigned).

## 3. Questions raised in discussion

Q1 Is NHS and Sussex Partnership Trust (SPT) serious about MBCT? Yes. The SPT is wanting to make MBCT courses available to staff and patients.

Q2 Who was the lead or figurehead in SPT for MBCT? Brenda Roberts, who had introduced MBCT to SPT and run many MBCT courses for staff and patients until she retired a year ago.

Q3 Who is the lead or figurehead in SPT for MBCT now? Nobody knew for sure, but it was said that Robert Marsh may have asked Jodi Mardel of Bangor to run training courses in Sussex, and that Lynne Ley is hoping to run further MBCT courses in 2010.

Q4 When can the MIN members who are doing the MBCT teacher training run courses?. The 6 SPT clinical governance requirements had been circulated to MIN members, and will be circulated again, **action BD/JK**. It was agreed that one of the roles of MIN is to support newly qualified facilitators.

Q5 What precautions can be taken against Serious Untoward Incidents?

Q6 Is MBCT a therapy? J suggested that MBCT is a different species of treatment.

Q7 How long is the waiting list now for talking therapies in Sussex? Opinions varied from 4 weeks (BD) to over a year (JK), which was the opinion of the IAPT committee.

Q8 Is MIN a lobbying group? No. A supervision group? No, although it can help find supervisors. A support group? Yes.

Q9 What is MIN's mission statement? How about: 'A local resource of support for the promotion of mindfulness in the community in Sussex.'

Q10 Do we want notes of MIN meetings? Yes, to inform those who are not present what was decided. It was reported that Taravajra is running Mindfulness courses in Dorothy Stringer and Varndean schools, and that Varndean is calling itself a 'mindful' school with the support of the new head.

Q11. Do we want MIN to continue? Yes.

Q12 Who is going to take responsibility for arranging meetings? CP and J volunteered to book the room and facilitate or chair occasional meetings, (perhaps alternately on a rotating basis). John volunteered to continue as secretary. These officers were duly elected to hold office for 2010. BD was thanked for being chairman in 2009.

## 4. Future meetings

It was agreed to continue meeting 6 times per year on the 4<sup>th</sup> Tues of each odd month at Hove Polyclinic if the room is available **action CP**. Next meeting is on Tuesday **26<sup>th</sup> January** 3.15 – 4.45 pm Hove Polyclinic. The topic will be the compassionate mind, and the discussion will be led by CP and SC. The

following meetings will be on Tues 23<sup>rd</sup> March, and 25<sup>th</sup> May, and the suggested discussion leader is Rory Singer, **action CP**.

## **13 MINDFULNESS INTEREST NETWORK**

Minutes of a MIN meeting on Tues 26<sup>th</sup> Jan 2010 at Millview hospital room 6.

### **1 Present**

**Carolyn Pollak** (CP) chairman, (who worked 20 years in the prison service) **Judy Lewis**, (JL) who has run 3 MBCT/ MBSR courses for 8-12 HIV patients at the Beacon Centre, Bevendean for the Elton John Foundation, with another 2 courses in the pipeline.

**John Kapp** (JK) (secretary) (qualified MBCT facilitator and campaigner for commissioning and providing of MBCT courses in large numbers on the NHS)

### **2 Apologies for absence:**

Carolyn Ruitermann, who attended at 315pm and was turned away by the receptionist saying that the room had been booked by somebody else. (JK had to get someone to turn the others out of the room)

Jiva, Brenda Davis, Richard Gilpin, Robert Marsh, Sally Carritt.

### **3. Minutes of the AGM held on 17.11.09**

These were accepted as a correct record as circulated.

#### **4 Matters arising**

Q1 Is NHS and Sussex Partnership Foundation Trust (SPFT) serious about providing MBCT courses? A1 We still don't know. Robert Marsh is concerned to maintain authorisation of facilitators to run MBCT courses, and is in touch with Bangor University re accreditation. He told JK to ask Dr Jon Willows, who is in touch with the commissioners. JK has e mailed him twice, with no response to date. JK met Richard Ford (commercial director) on 27.1.10, and asked him to raise this with Dr Kay Macdonald, clinical director, without response to date, despite an e mail reminder to both.

Q2 Who is the lead in SPFT for MBCT? A2 We still don't know, see A1

Q3 When can the MIN members who are doing the MBCT teacher training run courses?. A3 We still don't know. The SPT clinical governance requirements do not require clinical qualifications, but Karen Firtle was not allowed to take JK on as a helper in Hastings because he does not have the right qualifications.

Q4 How long is the waiting list now for talking therapies in Sussex? A4 Don't know.

Q5 What is MIN? A5 A support group for those interested in the therapeutic use of mindfulness, including MBCT, MBSR, ACT, DBT.

Q6 What is MIN's mission statement? A6 A local resource of support for the promotion of the therapeutic use of mindfulness in the community of Sussex.

Q7 Do we want minutes of MIN meetings? A7 Yes, to inform those who are not present what was decided, and a summary of the discussion.

Q8 Who is going to take responsibility for arranging meetings? A8 CP has booked the room and will facilitate or chair occasional meetings, perhaps on a rotating basis with Jiva, and perhaps on a rotating day if required.

#### **5 Mindfulness in the news**

a) CP reported a Guardian article saying that mindfulness is the new way to treat depression which is better than drugs, but there is a shortage of courses and facilitators.

#### **b) Commissioning MBCT courses in the NHS**

JK reported that he has been lobbying the PCT and SPFT for years to commission and provide MBCT courses which were NICE-approved in 2004. He spoke on local radio on 25.1.10, and has written many papers for the NHS and SPFT on this subject, which can be seen on section 9 of [www.reginaldkapp.com](http://www.reginaldkapp.com). The NHS constitution became law on 20.1.10, which gives all citizens the statutory right to all NICE-approved treatments free at the point of use provided that their doctor says that it is appropriate, so the NHS risks being taken to judicial review if they do not commission them in sufficient numbers to meet the demand.

#### **c) How many MBCT/MBSR courses are being run in Sussex?**

It was agreed that MIN should research this, and list the facilitators. **Action All facilitators to report this information to the secretary. ([johnkapp@btinternet.com](mailto:johnkapp@btinternet.com) 01273 417997.)**

#### **6 Reflections on compassion training at Samye Ling**

CP lead a discussion on this subject as she is doing a compassion module there. Compassion is defined by the Dalai Lama as 'sensitivity to the suffering of self and others with the strong wish to relieve it'. It was noted that an article on compassion in the Nursing Times did not include self-compassion for nurses, but focussed exclusively on helping others. It was agreed that if we do not have compassion for ourselves, we cannot have full compassion for others. Lack of compassion for ourselves can lead to an increase of suffering and burnout.

Prof Paul Gilbert's book 'Compassionate Mind' promotes the idea that emotions (such as anger, hate) arise in the 'old brain' system, and are there to scan for threats as a survival

response/reaction. However, thoughts and reasoning arise in the new brain, which tends to judge emotions, and can lead to feelings such as guilt and shame. We therefore continually beat ourselves up, letting our mind be hijacked by our emotions, which is the cause of dis-ease and eventually sickness. Mindfulness teaches us to accept everything as it is without judgement, and live at ease with our emotions and thoughts, whatever they are. To do this we have to allow ourselves to feel the impact of pain.

Research with Buddhist monks shows that with mindful practice every day the brain changes. It eventually becomes hard wired for self-compassion and compassion for others. CP had been on a retreat at Gaia house with Christine Feldman and John Teesdale, at which the acronym 'RAIN' was presented, meaning: Recognise, Allow, Investigate, Non-Self. It was agreed that this message runs directly counter to the blame and shame culture in which we live, including much of our conditioning.

In discussion, JK mentioned the family constellation work of Bert Hellinger, who demonstrates compassion in action with a wide variety of clients. A video of his last workshop in London in 2008 is available on loan from JK who facilitates family constellations in Hove on the 4<sup>th</sup> Sunday of each month, contact details above, see [www.hellinger.com](http://www.hellinger.com))

## **7 Future meetings**

**a) Tues 23<sup>rd</sup> March**, 3pm for 3.15 start – 5 pm at room 6 of Millview hospital. Rory Singer will present the theme for discussion: **'What do participants gain from an MBCT course'?**

### **b) Tues 25<sup>th</sup> May**

Room 6 of Millview hospital has been booked from 3-5pm. JK volunteered to speak about his campaign to get MBCT courses commissioned and provided free on the NHS in large numbers, as described in item 5b) above.

c) It was agreed at the AGM that we should continue to meet on the 4<sup>th</sup> Tues of each odd month, but we may be able to change the date of the July meeting (Tues 27.7.10) if members make alternative proposals to the secretary for consideration by the officers, and if a room is available.

# 14 MINDFULNESS INTEREST NETWORK

## Minutes of a MIN meeting on Tues 23rd March 2010 at Millview hospital room 6.

### 1 Present

Carolyn Pollak (CP) chairman, Robert Marx, John Mitchell, Liz Stead, Terry Rixon, Michael Hoy, Catherine Cameron, Ratnadakini, Naomi Citssceido, Lotus Nguyen, Anne Pether, Nell, John Kapp (JK) (secretary)

**2 Apologies for absence:** Brenda Davis, Jiva Masheder.

### 4 Matters arising from the minutes

Questions asked:

#### **a) Is NHS and Sussex Partnership Foundation Trust (SPFT) serious about providing MBCT courses?**

We still don't know. The official position of SPFT was stated by John Rosser (Director Working Age Adults) in a written answer dated 9.11.09 to a question posed by the Local Involvement Network (LINK) , quoted below:

*'The MBCT course is delivered by Clinical Psychologists accredited in MBCT (currently only one routinely involved in service delivery) At present 4 new groups (of 10-20 clients per group) run over the course of any one year and so the maximum capacity is 80 clients treated per year. The typical wait is currently 4 months – clients may well have had another brief intervention in the interim.'*

The 'one' was thought to be Robert Marx (formerly Marsh) who may be regarded as the lead in SPFT for MBCT, as he is still trying to arrange trainings from Bangor. (secretary's note: in a paper (1) presented to Brighton and Hove commissioners and providers (SPFT) on 19.8.08 the demand for MBCT courses in Sussex was estimated to be 1 in 20 of the 1.5 million population, ie 70,000 places pa, which is a thousand times more than the current provision capacity)

**b) When can the MIN members who have done, or are doing the MBCT teacher training run courses?. Possibly Robert Marx is able to clarify. Action secretary to ask Robert.**

#### **c) How many MBCT/MBSR courses are being run in Sussex?**

It was reported that:

**Catherine Cameron** is doing them for BSUH under the name of pain control.  
**Bridgit O'Neil** is doing them as a locum in the NHS (recovery) in W. Sussex.

**Hannah Ball** is doing them in the NHS in W.Sussex

**Carolyn Ruiterman** is doing them in the private sector in Littlehampton.

**Rory Singer, Rosie Roberts**, and others in the Centre for Mindfulness Based Education (CMBE) is doing many courses pa in the private sector.

**Taravajra** is doing them in the private sector.

**Judy Lewis** is doing them for the Elton John Foundation for HIV patients at the Beacon Centre, Bevendean

**Karen Firtle** is doing them in the NHS in Hastings.

If anybody knows of other MBCT facilitators doing courses in the NHS or private sector, please inform the secretary, together with the number of courses they run pa.

**d) Do NICE-approved MBCT courses have to be provided to honour the rights of patients under the NHS constitution?**

Yes, (see appendix 1) but as the NHS constitution only became law 2 months ago, it has not yet been tested by judicial review.

**e) Can the MBCT course deliver the Boorman requirements to cut NHS staff sickness rate by 1%?**

MBCT courses for NHS staff is possibly one way to help the NHS meet the Boorman target of reducing staff sickness by 1% (reproduced in appendix 2) Carolyn Pollack is going to a meeting of SPFT staff in April. It was agreed to produce a flier for her to table. **Action All to send material by the end of March to the secretary to compile into a draft flier.**

**f) Can the government do another IAPT, and recruit 10,000 MBCT facilitators?**

If the government wanted to support recruitment of MBCT/MBSR tutor and there is no specific indication that they do, it would need to be acknowledge that the basic requirement of at least a two year mindfulness meditation practice is necessary, and not just a few weeks of learning techniques.

**5 Mindfulness in the news**

It was reported that Aberdeen University has just accredited a MSC in Mindfulness studies.

**6 What do participants get out of a MBCT course?**

Rory lead a discussion on how to help participants grow by developing a new attitude of mind to meditation practice as pleasurable, even joyous, (rather than onerous) To do this we need a supportive structure on 3 legs, like a tripod, as follows:

**Community** (Sanga)

The MBCT course is a group community for 8 weeks. People are naturally gregarious so it is easier to meditate in a group rather than in solitary confinement. We feel nourished by the presence of others, and enriched by others' expressions. We discover that others have the same resistance as we do to making time for meditation, and the same difficulties in quietening our restlessness and anger.

**Container** (Dharma)

The MBCT course is a weekly 'container' of stillness for us to learn how to pay attention to what is going on inside us. We learn that we don't have to follow our own thoughts, or believe the idea: 'there's nothing I can do.' We learn to take responsibility for ourselves in an easy going (rather than a religious) way, not shouting at the children (or ourselves) when we are distracted. By the end of the 8 weeks, the aim is to set up our own 'container' of place, time, and group, so that continued meditation practice becomes embodied into our life.

**Mentor** (Buddha)

The MBCT facilitator and group members mentor each other in a supportive (non judgemental) way. We learn how to give space and receive from whoever we happen to be with (rather than longing for someone else) We learn to ask ourselves: "What am I up to"? "Is this a subtle wish to harm myself, or others?" Mindfulness helps the attention to be brought into the present moment, non-judgementally no matter what is present. It can help to ease suffering and by the end of the course it may be possible to bring more mindfulness into everyday life and have a more accepting attitude towards self and others.

In discussion, the following were found to be effective:

Encouraging a lot of dialogue. Having a break with hot drinks and chocolate biscuits. Asking: 'what causes harm?' Stating: 'Thoughts are not facts.' Asking: is that thought: True? Helpful? Compassionate? Remembering the process takes patience.

## **7 Future meetings**

**a) Tues 25 May** 3pm for 3.15 start – 5 pm at room 6 of Millview hospital. **Action Taravajra** to ask Karunavira to present the theme for discussion: '**What is the mechanism of change in MBCT?**'

## **b) Tues 27<sup>th</sup> July or another day of the week?**

Please notify the chairman or secretary if you want to suggest another day of the week, which would be subject to the availability of a room and the officers. Taravajra is willing to speak on 'Turning towards difficulty.'

## **Secretary's notes, clarifying the above points made.**

### **Appendix 1 Extract from Section 2a of the NHS Constitution**

(which became law on 21.1.10)

" You have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate for you." NICE (the National Institute for Health and Clinical Excellence) is an independent NHS organisation producing guidance on drugs and treatments. 'Recommended' means recommended by a NICE technology appraisal. Primary care trusts are normally obliged to fund NICE technology appraisals from a date no later than three months from the publication of the appraisal.

The Handbook of the NHS Constitution states:

'All NHS organisations work to improve the quality of the services they provide or commission, including by assessing clinical and service innovations relevant to their clinical responsibilities. In 2008, the Department of Health and the NHS agreed a more ambitious vision for making quality improvement the organising principle of everything the NHS does. *High Quality Care For All* defined quality as having three dimensions: ensuring that care is safe, that it is effective, and that it provides patients with the most positive experience possible. These three dimensions of quality are being placed at the core of everything the NHS does – both as ends in themselves, but also because delivering the best quality of care will ultimately ensure that the system as a whole gives best value.'

### **Appendix 2 The Boorman requirements to improve the health of NHS staff**

This report was accepted by the government in Nov 2009, since when the NHS has an additional target to reduce its sickness rate by 1% (from about 5% at present, which is 50% worse than the national average of 3.3%) saving 3.5 million days lost pa. The following is an abbreviated list of requirements taken from the DH website:

'1 Provide staff with health and wellbeing services centred on prevention.

- 3 Develop and implement strategies for improving the health and wellbeing of their workforce.
- 4 Implement the guidance from NICE on the promotion of mental health.
- 5 Put staff health at the heart of their work.
- 6 Training in health and wellbeing should be managed training and built into annual performance and personal development planning.
- 7 Managers have skills and tools to support staff with mental health problems.
- 8 Draw up a staff health and wellbeing strategy.
- 9 Provide access to early and effective interventions for common muscular-skeletal and mental health problems as these are the major cause of ill health among NHS staff.'

Asking the NHS to prevent illness is like asking car mechanics to prevent accidents. Neither car mechanics nor NHS clinicians know how to do this, because they have not been trained in it. Prevention of accidents (and illnesses) requires a totally different set of skills to fixing crashed cars (and crashed people) Prevention requires us to take better care of ourselves, which requires us to be more aware of what we are doing to ourselves, which requires us to learn how to meditate.

The Darzi / Boorman requirements of preventing sickness in patients and staff can only be delivered by the NHS if it outsources prevention services to the experts in prevention who have been professionally trained and qualified to deliver them, namely complementary and alternative medicine (CAM) therapists. I have written a business plan on how the NHS can do this (2)

The 'active ingredient' for healing in CAM is meditation. Participants are taught how to meditate in yoga classes, Buddhist and other centres. However, the only NICE-approved course which teaches meditation is the Mindfulness Based Cognitive Therapy (MBCT) course. To comply with the above targets, the MBCT course should be commissioned and provided in large numbers. (3,500 course pa in Sussex, for 70,000 participants pa) The MBCT course was found to halve the rate of relapse in depression, and was approved by NICE in 2004 as an alternative to antidepressant medication. Dr Mark Williams told us in the teacher training in Sept 09 that it has since been found effective for almost everybody, with hardly any contra-indications.

## **References**

- 1 Paper 'Improving Health by Ending the Prozac Nation' 19.8.08 by John Kapp, section 9.28 of [www.reginaldkapp.org](http://www.reginaldkapp.org).
- 2 Business Plan of a Proposal for Free CAM on the NHS, 18.11.09 by John Kapp section 9.39 of [www.reginaldkapp.org](http://www.reginaldkapp.org)

# **15 MINDFULNESS INTEREST NETWORK**

## **Minutes of a MIN meeting to discuss the mass provision of the MBCT course, held on Tues 28<sup>th</sup> Sept 2010 at Millview hospital meeting room.**

### **1 Present**

Carolyn Pollak (SPFT) chairman, Robert Marx (SPFT), John Mitchell, Liz Stead, Terry Rixon, Michael Hoy, Catherine Cameron (SPFT), Ratnadakini, Naomi Escudeiro, Lotus Nguyen, Anne Pether, Nell, John Kapp (secretary)

**2 Apologies for absence:** Brenda Davis, Jiva Mashedder, Sally Carritt.

### **3 Minutes of the last meeting on 23.3.10**

These were not taken for accuracy, but had been checked and approved by the chairman. They had been circulated to the mailing list, and no amendments had been received.

The next meeting on 25.5.10 was attended only by Sally Carritt and John Kapp, who agreed that no minutes should be recorded. The scheduled meeting on 27.7.10 was cancelled by the chairman.

### **4 Training of approximately 8 new MBCT facilitators by Sussex Partnership Foundation Trust (SPFT)**

Robert Marx said that senior management of SPFT are keen to expand MBCT course provision, recognising the need to bring staff who are interested in delivering mindfulness groups up to the clinical governance standards that the Trust has set for all staff who want to run such groups. This should ensure a minimum standard of quality which the Trust is keen to demonstrate. Accordingly they have allocated funding for the training of approximately 8 new MBCT facilitators in 2011. Selection for these places has not yet happened. Robert has been asked to organise this training with support from staff who are also employed by Bangor University Centre for mindfulness research and practice.

#### **a) Prospectus for this training**

In answer to a question about demand, he said that he knew of interest from 30-40 colleagues, who will be invited to apply in December, and be interviewed in January 2011. The training will start in March, and consist of a total of 8 days, in 4 modules of 2 days, at approximately 2

monthly intervals. It will also include supervision, co-facilitation of a group, monthly reflective practice seminars, and a week of personal retreat alongside regular personal mindfulness practice. The entry requirements will include that candidates have done an 8 week course, have an established personal mindfulness meditation practice, have experience of working with groups and be in a position to offer groups within the services in which they work. Cognitive Behavioural Therapy (CBT) experience is helpful but not essential.

### **b) Supervision**

In answer to a question, he said that supervision is absolutely essential. Supervision is planned into the provision of the proposed mindfulness training and the Trust is looking at how it can support ongoing supervision beyond graduation.

### **c) Accreditation**

In answer to a question, he said that he is not aware of any plans nationally to accredit facilitators, and that it is up to each Trust to set their own standards. SPFT have a series of requirements, including that their facilitators have done the 8 week course, the 2 day introduction, the equivalent of the 5 day intensive teacher training course provided by Bangor and Oxford, that supervision is in place, that facilitators have had their own mindfulness practice for at least 2 years, and that they attend regular CPD events. Bangor have published good practice guidelines on their website. [www.bangor.ac.uk](http://www.bangor.ac.uk) and the guidelines suggested by the UK Network of Mindfulness-based teacher trainers are available on <http://www.mindfulness.ie/wp-content/uploads/Mindfulness-teaching-good-practice-guidelines.pdf>. He said that interest in the MBCT course is mushrooming quickly, and Carolyn said that Aberdeen was the latest university to join Bangor, Oxford, and Exeter in having a course.

## **5 What is the purpose of the Mindfulness Interest Network, (MIN) and how should its meetings be organised?**

There was a round table discussion to which everyone contributed. It was generally agreed that the Network is a forum for those interested in therapeutic aspects of mindfulness meditation to share their ideas and experiences, and hear about other approaches and gatherings. There was a wide variety of preferences expressed which broadly fell into three themes: those who wanted to promote MBCT in the private sector and NHS; those who wished the meeting to be an information sharing and networking forum at the same frequency as at present; and those who wanted the meeting to move to a less frequent but longer meeting involving workshops on selected topics. Some people wanted MIN to be a combination of these three.

### **a) NHS Clinicians views**

The NHS clinicians present said that they have to justify their time in coming to MIN meetings to their managers as part of their Continuous Professional Development (CPD). MIN meetings are similar to peer group meetings but can only be justified within NHS time and on NHS property if they support the practice of those clinicians' NHS work.

### **b) Non-NHS staff views**

The non-NHS staff said that they found it remarkable and exciting to be allowed into a hospital to talk to clinicians about treatments provided in a free and open manner as a bridge between the NHS and the public. (Known as Public and Patient Involvement (PPI) which has been a legal requirement in the redesign of services since the Local Authority Act of 2007) One asked: 'Could MIN promote the MBCT course?' Robert said that having NICE recommendation for this course is a monumental step for the NHS, and the commitment of the trust to train what might seem like a small number of teachers is a huge step in terms of mental health provision. Robert also said that MBCT is currently only recommended by NICE for people who have experienced three or more episodes of depression and who are currently in remission although there is growing evidence for its effectiveness with other clinical populations.

### **c)The relationship of MIN to the NHS**

Clinical psychologist Brenda Roberts introduced mindfulness to SPFT around 2004, and retired in 2008. She founded MIN around 2005, which has since held bi-monthly meetings on NHS premises. Brenda encouraged attendance by non-NHS staff, such as Buddhists offering mindfulness groups. In her day attendance averaged about 10-15. The mailing list is 65, mostly SPFT staff.

The chairman said that we have a lot of autonomy, and do not have to stick to this traditional regime. We can choose another venue, frequency and format. She said that she has sometimes found it difficult to book a room in Millview hospital, and that we had been particularly fortunate on this occasion in getting the meeting room. Previous meetings had been held in meeting room 6 upstairs which is small and without a window, and is stuffy in summer.

### **d)Frequency of meetings**

Robert proposed that MIN holds occasional whole day and half day workshops where visiting speakers are invited to present on a topic, or led a period of shared practice. The secretary agreed that these are desirable, but require organising. He will support proposals by anyone who offers to arrange speakers and promotion. The meeting agreed to maintain the tradition of holding bi-monthly meetings from 3-5pm on Tuesday afternoons.

## **6 Opening up the publicly funded MBCT course market to the third sector**

John Kapp said that he had been campaigning for several years for the MBCT course to be mass-provided free to patients on GP referral. He has been meeting with commissioners, and has been told that they are proposing to open up the market to the third sector.

He has founded a company called Social Enterprise Complementary Therapy Company (SECTCo) to contract a Service Level Agreement to mass-provide the MBCT course in a 5 hours per week 'enhanced sandwich' version. He is training facilitators in the hope that SECTCo will be able to offer 150 courses pa to 3,000 patients in 2011. He tabled his 'Enhanced sandwich MBCT course text book', which will be published on the company website [www.sectco.org](http://www.sectco.org)

SECTCo offer GPs the ability to prescribe this course for clinically appropriate patients. We assume that clinical responsibility for the patient's safety is deemed to remain with the prescribing GP, so we do not vet or refuse any patient, however challenging. Robert and Catherine said that they interview all patients, and sometimes refuse to take those for whom they think the course would be clinically inappropriate or for whom it would pose a potential hazard – for instance those who might be at risk of suicide or para-suicidal behaviour.

## **7 Date of next meeting Tues 23<sup>rd</sup> Nov subsequently changed to 14<sup>th</sup> Dec)**

According to the agreed formula of the 4<sup>th</sup> Tues of each odd month, the next meeting will be on Tues 23<sup>rd</sup> Nov, at 3-5pm. As it is the last meeting of the year, it will be the Annual General Meeting (AGM) The present officers (Carolyn Pollack and Jiva Mashedar, co-chairmen, and John Kapp, secretary) will stand down, and new officers will be elected from those nominating themselves.

Secretary's note: As this meeting had the biggest attendance (13) for years, I propose that the topic for discussion at the AGM continues as: **the mass-provision of the MBCT course.**

# **16 MINDFULNESS INTEREST NETWORK**

## **Minutes of MIN Annual General Meeting held on Tues 14<sup>th</sup> Dec 2010 at Sussex Education Centre, Neville Av, Hove.**

### **1 Present**

Carolyn Pollak (SPFT) chairman, Robert Marx (SPFT), Jiva Masheder (private sector), Catherine Cameron (SPFT), Heather Ball (SPFT), John Kapp (private sector) (secretary)

### **2 Apologies for absence:** Ratnadakini,

### **3 Minutes of the last meeting on 28.9.10**

These were agreed as a correct record.

### **4 Matters arising**

#### **a) Training of new MBCT facilitators by Sussex Partnership Foundation Trust (SPFT)**

Robert Marx said that he had had 36 applicants for 12-14 places. This shows that mindfulness is of great interest among the staff.

#### **b) Mindfulness courses for stressed staff**

Carolyn is planning to offer a weekly drop in 'introduction to mindfulness' for the nursing staff of the hospital.

Jiva is running courses for staff of Royal Sussex County Hospital, but the staff have to pay £100. The venue is the chapel, which is free.

John has run a training course on behalf of SECTCo for 9 new facilitators. He has offered to run MBCT courses for stressed council and PCT staff for 2.5 hours per week for 10 weeks at a tariff price of £400 per participant.

### **c) Vetting of participants**

John said that he had been converted to the view that vetting is appropriate by Jon Kabat-Zinn's answer to his public question in Oxford on 12.11.10. Jiva said that individual vetting is alright for her small groups of 6, but would become very time consuming with big groups, when group vetting might have to be used.

### **5 Election of officers**

The retiring officers were thanked for keeping MIN going, and nominations were requested. John was the only nomination for secretary, so was duly elected. There were no nominations for chairman/facilitator. It was therefore agreed to advertise the vacancy in an e mail to the database (66) for election at the next meeting. Also to check that recipients still wish to be on the data base. **Action John to ask, and nominees for chairman/facilitator to contact John.**

### **6 Future of MIN**

It was agreed that ***the Mindfulness Interest Network is a forum for those interested in therapeutic aspects of mindfulness meditation to share their ideas and experiences, and hear about other approaches and gatherings.***

Interest in mindfulness is mushrooming, as witnessed by the huge response to the offer of training in SPFT, which was triply oversubscribed. Supervision and peer support of practicing facilitators is needed to meet SPFT's clinical governance requirements, but is not sufficiently available at present. **Could MIN help with this, or with anything else? Please contact the secretary with your answer. Action All**

### **7 Date of next meeting Mon 25<sup>th</sup> Jan (note change of day)**

While seeking a leader, it was agreed to continue to hold MIN meetings as before, but not on NHS premises. The next meeting will be held on **Monday 25.1.11 from 3-5pm** at Revitalise, 86 Church Rd Hove BN3 2EB (opposite Hove town hall). The room hire cost of about £32 will require donations of about £5 from those that attend. Robert agreed to update us on the progress of the training of new MBCT facilitators. **Action John to book the room.**

# 17 MINDFULNESS INTEREST NETWORK

## Minutes of MIN meeting held on Mon 24<sup>th</sup> Jan 2011 at Revitalise, 86, Church Rd Hove.

### 1 Present

Lotus Nguyen, Terry Rixon, John Kapp (secretary)

**2 Apologies for absence:** Robert Marx (SPFT), Jiva Masheder, Heather Ball (SPFT),

### 3 Minutes of the last meeting (AGM) on 14.12.10

No amendments had been notified, so these were agreed as a correct record.

### 4 Matters arising from the AGM

#### a) Training of new MBCT facilitators

Robert Marx reported that he had just completed interviews for 18 places on Sussex Partnership Foundation Trust MBCT training, and hopes to start the training in March.

#### b) Election of a chairman

Lotus Nguyen was nominated. In the absence of any other nomination, she was duly elected.

### 5 Constitution of MIN

It was agreed that it would be advantageous to have a written constitution. **Action Lotus and John to draft.**

### 6 Website of MIN

It was proposed and agreed that MIN should have a website. **Action Lotus and Terry**

### 7 Costs of room hire for meetings, and website set-up costs

John had paid £27 for the room, which he agreed to lend to MIN. It was proposed and agreed that he would continue to hire and pay for a room. Those who pay expenses on behalf of MIN should keep receipts and account for what they have lent. **Action John**

### 8 Date of next meeting

It was agreed that we should continue the tradition of meeting 6 times pa, for 2 hours, on the 4<sup>th</sup> day of the odd months. For the convenience of those working fixed hours, it was agreed that we should offer choice of meeting on Mondays or Tuesdays, namely either on **Mon 21<sup>st</sup> March or Tues 22<sup>nd</sup> March.**

We should give choice of time, either from **3-5pm, or 4-6 pm** at Revitalise, 86 Church Rd Hove BN3 2EB (opposite Hove town hall).

Or **530-730pm, at 22, Saxon Rd, Hove** BN3 4LE (near the lagoon), as Revitalise is not available then. Members should be asked to state their preferences to the secretary ([johnkapp@btinternet.com](mailto:johnkapp@btinternet.com)) who will notify the membership the date, time and venue, 10 days before the meeting.

## **18 MINDFULNESS INTEREST NETWORK (MIN)**

### **Minutes of MIN meeting held on Tues 22nd Mar 2011 at 22, Saxon Rd, Hove.**

#### **1 Present**

Lotus Nguyen (chairman, Buddhist meditation leader and Mindfulness Based Cognitive Therapy (MBCT) course facilitator), Adam Tearle (Aurora CBT, until end 2010 CBT therapist with SPFT), Tim Hockin (mental health therapist, formerly in Lewes, now in Guildford) Kate Gooch (speech therapist, 3/5 years training in MBCT at Bangor University), Terry Rixon (attended a MBCT course in 2010), John Kapp (secretary, founder Social Enterprise Complementary Therapy Company [www.sectco.org](http://www.sectco.org), seeking to provide MBCT courses under contract to public sector organisations)

**2 Apologies for absence:** Ratnadatini, Jiva Masheder, Sally Sedgewick, Ann Barnard, Nick Boella, Rosie Roberts, Nick the Dharmahouse, Astrid Furmeister, Robert Marx (SPFT), Lynn Ley (SPFT), Heather Ball (SPFT) Deeresh Turnbull (Aurora CBT)

### **3 Minutes of the last meeting on 24.1.11**

No amendments had been notified, so these were agreed as a correct record.

### **4 Questions discussed**

#### **a) Why is no one here from SPFT?**

John said that the mailing list has nearly 70 on it, mainly from SPFT clinical psychologists staff. He thought that now is a difficult time for the NHS, as commissioners are changing from PCT to GP Consortia, creating job insecurity. He said that the MBCT course is an anomaly in the NHS because it is not an intervention that is done to patients, but teaches them how to be. Adam said that SPFT therapists cannot attend meetings because they are too busy seeing patients in working hours, and are too tired after work.

#### **b) What is the objective of MIN?**

It was agreed that MIN is a support group for practitioners (people practicing mindfulness meditation) who want to share their experience by teaching it to others, such as by facilitating MBCT, MBSR, and mindfulness courses. The clinical governance of publicly funded MBCT courses requires supervision and continuous professional development (CPD) which MIN could help provide. Lotus said that she had found websites for some 200 on line mindfulness groups. It was agreed that MIN should continue to hold meetings in person, perhaps backed up by a website. Presentations by speakers on topical subjects should be held to make meetings attractive.

### **5 Dates of next meetings**

It was proposed and agreed that we should continue the tradition of meeting 6 times pa, for 2 hours, on the 4<sup>th</sup> Tuesday of the odd months, from 530-730pm. However, on Tues 24<sup>th</sup> May there is a reunion for MBCT course facilitators at Ammerdown organised by OCTU, for which John is booked, so the next meeting will be held on **Mon 23rd May. It will include a chairman's address, on Lotus's vision and proposed structure for MIN from 530-730pm, at 22, Saxon Rd, Hove BN3 4LE** (near the lagoon) Further meetings will be held on Tues 26<sup>th</sup> July, 27<sup>th</sup> Sept, and 22<sup>nd</sup> Nov.

**Secretary's note:** A meeting was held on 23.5.11 as agreed, but only Lotus and John were present. They concluded that to be viable, MIN meetings had to take place on SPFT premises. As this is not possible, they decided to discontinue MIN's activities. John notified the data base of that decision, and no meetings have taken place since.