



THE BRITISH PAIN SOCIETY

**Special Interest Group for Philosophy and Ethics**

**Living Well Right to the End**

**Rydal Hall, June 26<sup>th</sup> to 29<sup>th</sup>, 2017**



## Contents

### Living Well Right to the End

Introduction <i>Peter Wemyss-Gorman</i>	4
Living with the uncertainty of Cancer <i>Karol Sikora</i>	6
Taking Care of the person in chronic illness <i>Sara Booth</i>	20
Creative approaches to palliative care <i>Kate Binnie</i>	35
Living to die <i>Andy Graydon</i>	43
Coming alive at last <i>Jeremy Swayne</i>	52
To let the patient live and die with dignity <i>Sophie-Freda Borge</i>	57
Contemplative care <i>Narapa Steve Johnson</i>	65
Healing while dying <i>Emmylou Rahtz</i>	77
My recent training in hypnosis <i>Tim Johnson</i>	87
Valuing end of life care <i>Peter Bennett</i>	90
Homeward bound <i>Gillian Bartram</i>	96

## Editor

Peter Wemyss-Gorman Retired Consultant in Pain Medicine

## Contributors

Karol Sikora,	Consultant Oncologist and Dean, University of Buckingham Medical School
Sara Booth	Honorary Consultant in Palliative Care, Cambridge University Hospitals NHS Trust and Associate Lecturer, Cambridge University
Kate Binnie	Music therapist and teacher of yoga and mindfulness in palliative care
Father Andy Graydon	Catholic Priest and hospital chaplain, working in palliative care, mental health and chronic pain
Jeremy Swayne	Retired GP, homoeopathist and Anglican priest
Sophie-Freda Borge	Nurse Specialist in Anaesthetics and Palliative Care, Norway
Narapa Steve Johnson	Buddhist Chaplain and Mindfulness Teacher
Emmylou Rahtz	Associate Research Fellow, Exeter University
Tim Johnson	Consultant in Pain Medicine, Salford
Peter Bennett	Retired senior civil servant, Department of Health. Associate Faculty Member. Science Policy Research Unit, Sussex University
Gillian Bartlam	Hypnotherapist and Psychotherapist. Professional singer

## Introduction

Peter Wemyss-Gorman

I first suggested the theme of this meeting to our steering committee last year after I read the wonderful book *Being Mortal* by Atul Gawande. He addresses the potential conflict between the successes of modern biomedicine in prolonging life in old age and terminal disease with the need to avoid unnecessary suffering. This led us into the general area of wellbeing and its promotion throughout life, not only at its end.

Gawande's book is written from an American perspective, a country where prolongation of life has sometimes been pursued to a degree that is not only ridiculous but frankly cruel. But I think we do face similar challenges and I have the impression that we are sometimes precariously poised on the brink of the same slippery slope.

In his introduction Gawande writes:

Modern scientific capability has profoundly altered the course of human life. People live longer and better than at any time in history. But scientific advances have turned the process of aging and dying into medical experiences, matters to be managed by health care professionals. And we in the medical world have proved alarmingly unprepared for it.

The waning days of our lives are given over to treatments that addle our brains and sap our bodies for a sliver's chance of benefit. They are spent in institutions where regimented routines cut us off from all the things that matter to us. Lacking a coherent view of how people might live successfully all the way to their very end we have allowed our fates to be controlled by the imperatives of medicine, technology and strangers.

He contrasts the old age of his grandfather in India who continued to live with his family and remained its undisputed head and that of the family business, and was physically and mentally active until his death at 110, with the last days of people in the affluent West, living in nursing homes where only their physical needs are met. Although medicine increasingly keeps us alive until we are no longer able to care for ourselves, the *potential* for maintaining independence with mutual advantages to both old people and their families has in fact never been better.

Historically, he observes, medicine and public health has transformed the trajectory of our lives. Until relatively recently you stayed healthy until illness hit and then you fell off the cliff.. This could occur at any age from childhood, and for a long time few people survived beyond 40. Then medical progress delayed this until later and later. But the curve for most acute illnesses stayed much the same shape until the last 100 years or so. Even now people with cancer often stay quite well until late in the illness and then deterioration and death are rapid. But for many chronic diseases such as COPD and heart failure, the pattern of decline has changed and looks less like a cliff than a bumpy road down a mountain. Frequent hospital admissions for acute exacerbations are followed by partial recovery, but there is never a return to the previous baseline, less and less capacity to withstand minor problems like a simple cold, until the time comes when there is no recovery.

But many of us now get to live out a full life span without following either of these two patterns, and the trajectory becomes a long slow fade to death.

As Gawande says:

There is no single disease that leads to the end - just the accumulated crumbling of one's body systems. Medicine carries out maintenance on our joints and hearts etc to keep them functioning as long as possible, but the process is inexorable. We do not fully understand how the aging process works but it is apparent that everything wears out in the long run and there is nothing at the moment that medicine can do about this.

Gawande again:

No-one ever really has control. Physics, biology and accident ultimately have their way in our lives. But we are not helpless either. Courage is the strength to recognise *both* realities. We have room to act, to shape our stories, though as time goes on it is within narrower and narrower confines. ... Our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions and our culture in ways that transform the possibilities for the last chapters of everyone's lives.

There is indeed a universal human need for meaning and purpose. This may be as simple and practical as maintaining independence and self-caring or as complex as a religious faith. It may even include the struggle for survival and length of life, though this may become meaningless as it becomes more futile.

Where do our responsibilities lie? Our main preoccupation as clinicians is the relief of physical pain and suffering, so far as it lies within our powers. But is this our only priority? The last word from Gawande:

We in the medical professions tend only to be interested in the downhill stretches of these trajectories and fixing discrete problems. We think our job is to ensure health and survival. But is it much more than that? *Is it also to enable well-being? - the reasons one wishes to be alive, which matter not just at the end of life or when debility comes, but all along the way?*

## Living with the Uncertainty of Cancer

Karol Sikora

Let's look at you – average age in the room: 30, 31? Haven't got my glasses on! Let's say 40. The average age for death in the UK is 81.5. That means that you've got 41.5 years before you're going to die. That's inevitable – not for individuals because there is a big spread. One or two of you are going to get cancer if you haven't got it already. Many fewer people are dying of cardiac problems now. The healthcare trajectory is changing dramatically. I've been in the NHS for 38 years, and you can see that things have changed in one generation of doctors. The fundamental change (and I shall want to point out some of the societal changes as well as the technological changes) is that people have access to information and you can't hide it. I remember going on ward rounds where you bypassed the patient with metastatic cancer – you talked about mitotic activity, NG for new growth, neoplastic disease - all words to ensure the patient didn't know what was going on - and the grand team would just walk on to the next bed. There was an old boy at the Middlesex who would just grunt – he wouldn't even say good morning to the patient who was dying of cancer. Those were different days. We have seen a complete transition in practice.

### Uncertainty

So we'll take it that you have 41.5 years to go now and we say "you've got cancer and you're going to die within six months because it's metastatic". We're very good at telling people they have cancer but not so good at telling them what it really means; unless they actually ask and surprisingly few people actually ask. Giving someone a cancer diagnosis is easy. What is much more difficult is that if you've got metastatic breast cancer your average survival is less than 24 months. Prostate cancer is a bit longer because of the different growth pattern of the disease. But these are of course *averages* and they reflect a huge uncertainty. I've had breast cancer patients who have died within a month of having a lump, with infiltration of bone marrow, vertebral collapse: metastatic disease unresponsive to therapy. In contrast I have a delightful lady who is 87, who is retired to Tenby. We have treated her at the Hammersmith for the metastatic cancer she has had for more than 30 years. And all that's happened is that we flick around with the hormones and she seems to respond again. The disease is stable although she has well documented, biopsy positive cancer. So the problem we have got is that there is such variation in outcome, and the patient has to live with that uncertainty. The title of this talk is 'living with the uncertainty of cancer' in an age when there is information everywhere. You can't read a Sunday paper without finding something about cancer in it, and our patients and their relatives are reading it too.

### Valuing life – accepting death

This leads to another question: I tell you you've got cancer and six months to live ... how much would you pay me to give you another six months? How much is *your* life worth? – not my life, not a group of cancer patients, not people working for NICE, adjudicating on the best value for money for the drug industry - but say I can give *you* another six months of life. If I were to say: if you give me a pound I can do it – would you give me the pound? – of course you would. If I say give me ten million pounds for six months most people would say that's ridiculous - that's not possible. When you're trying to make rational judgements the extremes are easy. The trouble is that the reality is in the middle. And that's where we have the crisis

now. One of my pet hates at the moment is crowdfunding sites for patients who are essentially dying with metastatic cancer; well-meaning people giving money for a specific patient – not necessarily a charity - to get drugs not available on the NHS or to travel to America. It's very difficult to assess what is going on. And very difficult to see this change. It is increasingly difficult for patients faced with the situation that they may only have six months to know what to do. Should they believe the onslaught from the media and the internet about what is available? Or do they say "enough's enough, this is not worth it, I'm going on a cruise, going up a mountain, visiting relatives I haven't seen for years... to be at peace with myself and then let go. And that's where palliative care is so good in Britain: it balances the aggression in the USA which is based on immortality which as we all know is completely unachievable at any cost, even ten million pounds. This approach may delay things a little bit but it creates total uncertainty in a patient's mind. There have been several surveys of doctors asking how they would behave if they had metastatic cancer, and the answers are very realistic. The worst kind of cancer is probably pancreatic with a five-year survival of less than 3%; if it has metastasised you're probably going to die within 12 to 14 months. It usually goes to the liver. I vividly remember a patient I had about a decade ago, a very wealthy industrialist and head of a big international corporation, who came to me for a second opinion. He said: "They tell me there is nothing more they can do at the Marsden and I've come to you as there must be *something...*?" The CT scan showed that his liver was full of metastases, he had had all the chemotherapy, and I told him that there was nothing I could offer. He said: "I want to go to the States; which centre should I go to?" I told him that it was a complete waste of time but if he was determined to go I suggested the Sloane Kettering Institute in New York - the largest cancer centre in the USA - so he flew out on Concorde. He came back to see me the next day and admitted that I had been right – there really was nothing to be done. So that was his way of making acceptance.

The problem we are facing today is that it's increasingly difficult with all this information available for people to accept that death is not something to be frightened of. It's something that we've got to get through and it's inevitable. This is creating huge amounts of tension. Of course it is fuelled by all sorts of things such as the pharmaceutical industry. The most expensive cancer drug now costs £165,000 a year. That's unachievable - even Americans can't afford that on their insurance schemes. This creates stress, as do the media, and cancer charities. The latter mean well but if you look at the Cancer Research UK or the Macmillan websites you'd think cancer had been cured several times over. So if I read that and I don't know anything about cancer, and I or my wife has cancer, I think – what's this? Why hasn't it been used to cure my cancer? Why can't I get things that seem to be going to other people like the ones in the little anecdotes that are used in advertising for charitable donations? So we are in a very strange place.

## The future of cancer care in four boxes

So what I'd like us to do now is to think about where the future is going. In cancer there are four boxes. The first is the technology box, which is really easy as all you have to do is draw a line from the last thirty years forward for the next thirty years. What you can't predict in technology is step change - someone coming up with an idea that you couldn't have anticipated even five years ago. The first step change that I saw in cancer is the CT scan. I saw my first CT scan in 1975 as a registrar in Cambridge. I thought – my goodness this is going to change the world. And indeed it did; it changed the whole way we assess and stage cancer and determine its likely outcome and how best to treat that patient. The second step change is one you probably won't have heard of, the polymerase chain reaction, which is a technique to amplify tiny amounts of DNA to allow whole molecular analysis of body tissues, and in every emergency room there are PCR systems in operation to determine various

genetic and molecular markers. In cancer we use them all the time and the pathology report today bears no resemblance to that of even a decade ago. It is used in all sorts of ways to determine the likely outcome of the cancer and the optimal treatment for that patient. These are step changes, but we have also seen changes in surgical techniques, less invasive, with fewer days in hospital. This has a profound psychological impact because if you're going for day breast surgery there's not much time to chat to anybody about the fact that you've got cancer: you don't have the same experience as when you were in for a week for mastectomy, for example. It's great because you spare normal tissue and it's much less destructive, there is no need for rehabilitation and you're back home and back at work in a few days, but doesn't help your uncertainty and anxiety about the future. Radiotherapy is much more precise, thanks to computerised imaging and planning, with much more selective delivery of radiation dose at to the cancer but not to normal tissues. Chemotherapy really began in 1944 during the second world war in the National Cancer Institute in Washington. It was a chance observation in Bari harbour where the allied fleet was based. One night in 1942 the Germans bombed it and some of the American ships contained canisters of nitrogen mustard. This was all kept secret, but it was observed that a lot of the sailors who survived dropped their white blood counts about ten days later. It was realised that they had been exposed to an agent that had suppressed their bone marrows. So a haematologist in Washington decided to give it to patients with certain types of leukaemia and lymphoma and indeed dramatic responses were seen. The patients all died because of drug resistance, but that led to the whole concept of giving drugs that would actually control cancer. And now we are in an era of being able to use the polymerase chain reaction to actually assess what is going on in individual patients.

We are entering an era of what is called personalised medicine and the results are gradually improving. When I became a consultant the survival rate for cancer was about 35% overall. Now it's about 52%, and slowly improving every year. That information and positivity is in everyone's head when they or someone they care for gets cancer. Technology is moving dramatically, diagnosis is better; the ability to know what is likely to happen – the predictive signature of the cancer – is getting much better. So the technology box is exciting, and dramatic. It's where the money is, it's in the newspapers and on the TV. It's where all the young doctors want to be, in that technology box.

The second box is much more challenging: that is the changing societal box. The first societal change is that we are living longer. There is more loneliness in the world than there was 40 or 50 years ago. Village structures have generally gone, family structures are imperilled by high divorce rates, transgenerational mixing, second marriages and so on. So there isn't the core stability in society when crisis hits. If you look at church attendances they are right down. It's very difficult to assess the depth of faith in society. There was a great article in the Telegraph looking at communion uptake across the different Christian churches over the years and there was a fascinating table. I was brought up a Catholic (my father was Polish) and the Catholics maintained their communion rate. The Methodists were down and the Church of England was right down the bottom. And that challenges what you see in the countryside: churches with one service a month or being closed down and used as restaurants. It's not the church attendance that matters, it's more the depth of faith. If you have a crisis on your life – you're told you have metastatic cancer – what are you going to turn to? In the past you could turn to whatever it was in your faith – it didn't have to be Christian. So for many people there is now nothing. We have created a whole structure of counselling, complementary therapies and all sorts of things to help fill the gap where there isn't the strength of faith that there was in the past.

There are other factors such as international mobility. I have three children and at one point last year they were all working abroad. That wouldn't have happened a generation ago. The other thing that has changed in society is the role of women. I hesitate to say this as I could get into trouble touching such a politically sensitive area, but women work. I accept this – my

daughters love to work. Many women have families and then go back to work, and that's totally changed from two or three generations ago when the woman's place would be in the home. So if Granny had cancer there would be instant support to take her to hospital or nursed or whatever was needed. That's all gone. But society has created this expectation that everything is the same. But it's not; it's changing and is going to change even more. I have a theory (which you may disagree with) that this thing (a smartphone) is changing society as well: changing the way in which we communicate with each other. I take the early commuter train every morning and it's full of financial guys. (In suits but no ties as no-one wears ties in the city nowadays) and they are on their laptops or phones or both. Nobody says hello or good morning to anyone. So there is an alternative culture which is changing the way people communicate. But of course if you are suddenly faced with a life-changing situation such as cancer how are people in modern society – how are my grandchildren – going to react to it. They will be totally internet aware, even when they reach the age when cancer is more likely to strike, and are going to use it as a way to access information about all sorts of things: how can they get the best care possible. Sometimes they may be right but sometimes they may be misled.

The third box for the future is how we deliver cancer care, including psychological support. When I started working in oncology there was almost no psychological support for patients. Sometimes you were given the diagnosis and sometimes you weren't, but there was no support whatsoever – no-one you could turn to. As a young registrar I was obsessed with the blood counts and the X-ray findings. I didn't want to talk; I was polite, but I was more concerned with the response to treatment than with about how the patient felt. Now we - indeed all professions within healthcare - are much better at talking to people, and trying to assess the amount of information they want. That has got better but we still deliver cancer care in the cathedrals of medicine which is the wrong way forward. The cathedrals of medicine are the big city centre teaching hospitals. If you are referred to Guy's or the Hammersmith or the Royal Marsden it's a struggle for many people to get there. Many people with cancer are elderly. Driving around London, even if you're rich and can afford a taxi, is slow and unpredictable and can create huge tensions. If you are a woman with breast cancer today it's likely that in the first year you will receive a lot of diagnostic, chemotherapy, radiotherapy and removal of the lump and of course lots of follow-up with more X-rays and blood counts. That can take up to eighty visits in the first year. Now imagine you have to struggle to get to a major city cancer centre more or less every week. You've got your family to look after, perhaps a job to go back to. So it's a struggle, but it's not necessary. There are ways of getting round this, and I predict that what we are going to see is a much more user-friendly system: in part driven by the smartphone and online information, so that so that people's lives are less disrupted. The NHS and to some extent the private sector don't value people's time. Every other consumer service values your time. Look how easy it is to book an EasyJet ticket with two or three clicks; but if you try to get anything out of the NHS with two or three clicks you don't get very far. There is no incentive to make it adaptable to the modern world. So I can see chemotherapy and radiotherapy being distributed to smaller and smaller centres so that you avoid having to go to the metropolis for your cancer care. This will allow you to get to know people and see the same receptionist every time. This has a huge impact on people. A free cup of tea can have more benefit than the most expensive drugs. So we need to redistribute the way in which we give care, but make sure that the quality of that care is excellent. You can do that with a computer; everything you do can be quality assured and monitored centrally. So there is no reason why you can't have the same quality of care in Ambleside as you do in Manchester or Preston. That will transform care for little cost..

The fourth box is the most difficult: how are we going to pay for care? How are we going to decide how much to spend on you if you have metastatic cancer? Should it be different if you

are 80 or 30? Does it matter if you have children? Does it matter what type of cancer it is? If you have lung cancer and you are a heavy smoker, do we really want to give you £250,000 worth of drugs? If you look at any equitable solution you've got to take everybody in the same box. Do you allow people to say: OK, you give me the drugs you can give me and I'll buy my own: I'll go crowdfunding for the expensive ones and you can give me those as well? Is that fair? Obviously it's not. In the last decade we have had a very complex and politically sensitive scheme called the Cancer Drug Fund. It became clear that the NHS couldn't afford all the drugs that were coming onto the market, so about eight years ago, when Cameron was first elected, the Conservative manifesto promised that every cancer patient could get any drug recommended by their consultant. £300 million was put into the Cancer Drug Fund every year, top-sliced from the NHS, to give people high cost drugs. The average duration of benefit from these drugs was less than three months, and for many patients there was no benefit. Despite huge cost with little benefit, politically it was very difficult to stop. We were in the ridiculous situation of filling in five-page forms on the NHS computers which were sent off for central ratification and decision making. You were allowed to enter information about 'social value'— it was a crazy time. I remember attending a meeting of the London Drugs Commissioners; we had a little workshop and I queried this stuff about social value. How do you put social value on someone with lots of kids: do you give them a higher social value? If you are a prisoner do you have any social value at all? There was a great example of a doctor who had managed to get a drug for his patient because he was looking after his invalid wife. He wanted to have a few more months of survival so he could continue to care for her (she had Alzheimer's and never left the house) But one of my smart colleagues said "say it was a cat. Would a lady with a cat have a higher social value than someone without a cat?" So we get ourselves into all sorts of tangles. Now the idea is that NICE are going to make the adjudication and you either get or don't get the drug. But you can imagine that all this creates untold uncertainty for patients. They don't know – they think that maybe there is something going on out there. Two months ago the Times restaurant critic A.A.Gill died. He had lung cancer and he wanted a drug called Nivolumab which is an immunotherapy agent and costs about £100,000 a year. He didn't actually get it as he had very rapidly advancing cancer and died within a week of the story coming out. But it created a lot of noise, fuelled by the drug companies who thought – this is great, we can sell more of this expensive drug. But if you actually look at the data, despite what you read about it, the actual prolongation of survival is pretty minimal. It's true that the side effects are not that heavy but there is no doubt that you have to make a choice. If you ignore the cost, would you still give the drug? There have been very few studies of patients and how they actually feel at the end of life: if you offer something they will always take it. In one study from about twenty years ago 91% patients with metastatic cancer would try something with only a 2% chance of any benefit.

### Living with uncertainty

And that is the difficulty we as health professionals have when facing cancer patients. Living with uncertainty is the most difficult thing to do, and predicting what is going to happen to any individual is almost impossible. That is the other weakness. With metastatic cancers you know roughly the averages but with an individual patient you really have no idea. Our most famous prediction (which I like to think wasn't as wrong as people thought) was the Lockerbie bomber. He was in gaol in Greenock, imprisoned for life for murdering 270 people on Pan Am 103 in 1988. The Scottish Government and the Ambassador said we have to come up with an answer: is he going to live three months? If it's less, we can release him, but we can't if it's more. So we got a team of doctors together and we all went up to the gaol and spent the afternoon there. We concluded that if he was treated properly he would probably live more than three months, but if he was kept in prison where he couldn't get chemotherapy there was no chance that he could. So we signed some papers and about a

week later on television there he was back in Libya being greeted by Gaddafi's son. We got it wrong because when he got back to Libya they got some German and Italian doctors to prescribe all sorts of chemotherapy. He survived for three years although he lived in complete misery. I think if we had been able to go back and play his life again he would have stayed in that Scottish gaol. I went to see him about a year before he died and he had no quality of life.. And that is the problem with modern technology. There was one amusing incident: as we were going back to the airport the Libyan ambassador said " would you join me for dinner? (The plane was going in an hour!) Thank God it's Friday! So we sat down in a restaurant near the airport. He asked me what I would like to drink so I thought I had better just have a diet Coke, and then he ordered a double Scotch for himself! So I was able to change my order and it was great to have a pint of beer after such a stressful day.

So the difficulty for the future is that the technology box is going to go on generating more excitement, but the societal box will continue to provide challenges which the health professions are going to have to engage with. You can see how general practice has been transformed over the last thirty years (my wife is a practice nurse). GPs don't know their patients, patients can't get appointments with the same doctor; if you're on the bottom part of the trajectory with multiple problems you're stuck. We are still treating disease as if it was a series of episodes rather than a continual line. My mother-in-law died last year at the age of 93 in a care home. Every three or four weeks we would get a call to say that an ambulance had been called because she had been taken unwell and was in the medical admissions unit at the hospital. After a few days she would be discharged having cost the NHS about five or six thousand pounds worth of tests. And on the whole at 93 you're not going to get much better by going through the emergency room. On one occasion in the nursing home she had an oxygen saturation thing on and it was a bit low – about 92% which is not that bad – and she was eating her lunch! – and they dialled 999 for an ambulance! – and of course she was fine, but spent two days in hospital.

### The challenge: a better end of life

So the challenge of trying to make the end of life better is that we've got to work out how we can allow people to let go, how we can help them to plan their dying.. We must separate the money and the dreadful crowdfunding business from it, and accept that everyone has to die, and that they need the time to come to terms with this. That is the most difficult thing. Telling people they have cancer is very easy because they don't necessarily see it as a death sentence. But when you say the cancer has spread and they ask "can you cure it?" we have to say "we can't cure it but we can control it, but the time for which we can control it is going to be hugely variable. It's going to depend on how the drugs work on the cancer, what side-effects they cause you and are these going to limit the dose we can give"; all these things have to come into that discussion. So what in the past would have been a ten-minute discussion before starting chemotherapy now takes at least 30 minutes and maybe even an hour. And it depends on good rapport between the doctor and the patient. Increasingly cancer specialist nurses are getting involved in the counselling and discussion afterwards. Dealing with acute cancer is very separate from palliative care. It seems to me that the term palliative is not quite right; shouldn't it be supportive care? I think we want to move away from the term palliative – I've referred patients to a palliative care colleague but avoid the use of the word; then they find out and come back and say "you didn't tell me that was palliative care - that's the death doctor!" But it's not – it's dealing with symptoms rather than disease. And that's what we have got to try to do. There was a phase when Macmillan tried to introduce palliative care very early in the management of cancer patients but it is separate. Working together is probably the best way forward. Palliative, or rather supportive care in its broadest sense should include complementary therapies, integrative medicine; allowing

people to choose what *they* want as opposed to the oncologist telling the patient what he or she recommends and the patient has to take it or leave it. We can look forward to a much broader future involving integrating all sorts of things in medicine, and *putting the patient in the centre*. That is the most difficult thing to do, especially at the end of life.

## Discussion

*I am a music therapist ...working in palliative care. I am neither a doctor or a nurse, nor a chaplain.. I'm just a woman with my piano and my violin. So the questions people ask me are very different from those they would ask a doctor. Once I brought a friend to one of my groups and she introduced herself as an oncologist from Germany. They sat up a bit straighter and when they introduced themselves they said something like "I'm John and I have pancreatic cancer" – which was quite different from the way they would have spoken if she hadn't been in the room. They wouldn't have talked about their cancer; they might have talked about the way they felt, perhaps about dying, spiritual issues or whatever.*

*So often I see patients who seem not to know they are dying. I think, hold on – I'm just a music therapist ... but they don't seem to have grasped the fact or they haven't been told, even though as I can see they are clearly on their last legs. They are still talking about new trials ...*

People don't feel empowered. You obviously do because you're in a hospital or care environment - you can cop out and say you'll have to ask the doctor or the nurse - but it's a very different conversation. Even within the hierarchy of medicine, nurses are afraid sometimes - they feel they can't say ... Most cancer patients have no idea they are going to die within the average time frame that people do. But it takes time to sit down and talk to patients - and in the current system time is not on our side – and find out what it is that they are afraid of, what do they want to do, what are their aspirations.. Perhaps, (especially in a working-class area), instead of offering someone a drug at £10,000 a shot couldn't we just say "don't bother about the drug; I'll keep £5000 for the hospital and you can have £5000 to take your wife on a cruise." Half of them would probably take it. Talking like this is difficult ... young student nurses on night duty often get asked things like "am I dying?" because they don't want to go higher than a nurse. It's unfair on the nurse who hasn't been trained to have that conversation. Some people are good at this sort of thing and some are not good.

*It's often the person giving you a bath - the cleaner – people who are not at the top of the hierarchy but just there, just listening – they don't have any information to give but it's that listening which is so precious. My own father died last year and I went with him to the oncologist and watched with horror each time the subject was avoided. Instead there was this continuous barrage of information which left him none the wiser. I had to explain to my own father that he was dying...*

And the leaflets ... One thing that always amuses me is that we have the word CANCER on the door of the cancer centre so people must know they have it but a little old lady with a basal cell cancer which can be cured with a single shot of radiotherapy is obviously not going to die from it is going to have leaflets about cancer and websites and so on. So there is an overload of information but none of it is specific.

*I think sometimes people have been told but they don't hear it. I have an elderly lady who called me to the house one day with a classic shingles rash - but she said had it on the other side as well. So she showed me the other side and she had a fungating tumour bursting through the skin of her breast and she said "it's not cancer, is it doc?" ! "Er well, it could*

*be...” ! She completely refused to have any treatment but I put her on some Tamoxifen and it shrunk it back. She perked up a bit, but she has died - but there was this brick wall ...*

Just as there is variation in the way cancer behaves there is even more variation in the way people behave when they are told of a cancer diagnosis. The most extreme was an intelligent woman who ran a travel agency who agreed to a biopsy of a breast lump which was positive but she didn't want it treated. This didn't seem a very good strategy but I encouraged her to come back in a couple of months by which time it had got bigger. She came back every two months for a year and each time it had grown until it was three times the size and I said – you've got to have it treated, radiotherapy or whatever. She would only accept Tamoxifen but it was metastatic and she died. She had a 95% chance of cure the first time I saw her, but the last time I saw her it was inevitable. I don't know why she refused although I spent quite a lot of time trying to understand.

*Can I ask you about the drugs? You mentioned the Lockerbie bomber and you said he lived a shocking life because of the treatment. Now all the rhetoric about the drugs is about how long people might live; it's not about how miserable you will be. How do you as oncologists deal with this balance between the misery of the side effects and prolongation of life? – because all the quality of life measures are pretty crackers – they don't work because of individualism and different values that people have. How do we deal with this balance?*

With great difficulty. Chemotherapy is mainly an outpatient business: you see a snapshot of that person's life. You don't see how they live; you don't see if they can get up to use the toilet on their own – things like that. We follow protocols and algorithms now, and you can't really deviate for a variety of reasons; people can sue you if you don't. But it's a very important question. The cost is high but the benefit may not be as much as the overall survival. The gold standard for assessment of drugs is how much longer will it prolong life. but that may not be the important aspect. For example the Lockerbie bomber was on three drugs sequentially. He did get a response but he never really got out of bed for the last two years of his life. So that, two years of prolonged suffering, was a pretty poor way to go. It's very difficult to assess as it is impossible to put a metric on to it. You can measure overall survival and that is the one that is used. And of course the pharmaceutical industry ... the drugs have got more expensive and they do create an impression through their media supporters ... About a month ago at the American Society of Clinical Oncology annual meeting - I tend to go every other year; there are about 30,000 people there - and so I was in London this year; everyone else has gone, and I got phoned by Sky News and the BBC about some press releases and asked to comment. My son said they're only asking you because you're the only oncologist left in London!

Success means different things to different people. Those that really know are the family close to the patient.

*But it's the family who get into this business of we must do everything as much as the patient. Often the drive for crowdfunding comes from the family. It seems to be a complete misunderstanding of the value of the drugs. They're not looking at the patient - they're looking at this spurious concept of prolonging life at all costs.*

*It's also about you feeling that if you're refused the drug your life isn't valued. As well as crowdfunding there is Change.org – you get these petitions all the time... [inaudible] ... actually changed the law on second stem cell transplants ...it had been slipped in again without any discussion. And then people were faced with saying to this young woman you can't have it because it is not available. And yet you can feel that if it is available in other countries why can't I have it, and that means society doesn't value you. And then this way of*

*doing it with petitions and crowdfunding puts us as clinicians in a very difficult position if you feel by not signing it you are condemning someone. It's a very strange psychology.*

It generates a lot of anger. I've sat with families who have directed a lot of anger at me. The patient has probably got about two months to survive, and in the face of all this anger she is sitting there miserably not wanting to get involved in a great argument when the family are threatening to sue you or the hospital, write to their MP, to the Prime Minister etc. "You're just saying that because you want to save money." – and so on.

*There is also fear – the family's fear. That brings out a huge amount of feeling. Perhaps the way that is dealt with ...*

*It's like taking the nipple out of the baby's mouth. They're angry with you because the breast has been removed. You're being demonised because you represent the withdrawal of love and you happen to be there. Understanding that is perhaps a useful thought process when working with the family ...*

The trouble is if you go to an oncology clinic the nurses don't really behave as cancer specialists; they're kind of floating around on the outside. You've got ten minutes – fifteen at the most for follow-up appointments and you've had this conversation perhaps you're saying you've come to the end so you'd better go and see Dr X in palliative care. You're right it's removing the breast of the oncology team who are their only hope of avoiding mortality. We all know that if you've got metastatic cancer it's inevitable sooner or later but the patient isn't aware of that.

*Does anyone ever actually sit down with the patient and say "you're going to die very soon". When my sister was dying – I'm her prime carer - I kept saying to the doctor "so what is going to happen?" - because my fear ... It took a doctor friend of mine whose brother was an oncologist to say "Gillian, you do realise that your sister is going to die." As soon as that was actually said to me I was able to deal with things so much better as it was clear. We skirt around those things, and that's not a good idea.*

I have an example at the moment of a medical journalist whose niece at the age of only 33 is dying of metastatic colon cancer in France. She is married to a Frenchman and has two small children. He went out there and on return asked to talk to me about it. He said that she is obviously dying but they say the disease is stable after a few cycles of chemotherapy which are achieving absolutely nothing. She is going to die within the next six months and getting dreadful toxicity from one of the drugs. Quite frankly they should call it a day ... but I'm not her doctor ...

*The night that my sister died I drove all the way down and they said "it's all right, you don't need to come in till the morning; she's sleeping at the moment - it's just to discuss a possible change..." – and I got a phone call in the middle of the night ... and I missed being with her when she died. That was partly my fear but if someone had said yes you must come, and helped me with that part of it, with some sort of clarity ...*

The other thing we do badly, although it is getting better, is not letting go with chemotherapy. We should say you've got metastatic cancer and it's not got any better with three or four lines of chemotherapy, so we should stop and assess the progress of the disease. When the reality is that there is clearly progression on the scan or the tumour markers, it's a very difficult conversation to have, and much easier to say come back for another time.

*We have this in pain management as well: we have patients in chronic non-malignant pain. They seem to think there is a special BNF that only pain doctors have despite the fact that they have been tried on everything; but actually they fail to understand that they have incurable pain. We have to be able to say: "there is nothing that is going to make this pain go away and you will have it for the rest of your life, but you are already living with it." And that's the difficulty with cancer that when people say isn't there anything else we can try and you say no, they think that you just don't know about it, and there must be somebody else who knows more ...*

... and this is not helped by Google. When it first started the Google phenomenon – there are more than a million Google sites, most of them are rubbish, but a few are good – and patients said : what about this drug? - I would go out of the room and look it up on the nurses' computer, but now I have just given up, and admit that I have never heard of it (but the younger doctors go out to the computer as they don't want to admit they don't know something...!) It does change the dynamic, especially with the anger involved in the whole thing. You get stressed, fed up and cross, and this is of course not the way to handle things. I've only twice in my professional career had a big argument with a patient (on both occasions they were angry with me about something that was essentially beyond my control). I try to hide my anger, but it doesn't generate a good relationship.

*Before you refer them to palliative care couldn't you arrange a little case conference with the patient and the family and someone else – another kind of therapist? - and present all the options: you can either spend the next nine months having more therapy or go on a cruise ... Instead of all this being on your shoulders you could maybe spread it out ...*

*I'm a family therapist and it sounds like you need a family therapist! But even in that little conference we were talking about your need for a strong scaffolding and lots of support to get the family ready to sit in a room with each other, to hear what is said and to check with them what they heard, the meaning they ascribe to what they have heard, and how to process it afterwards. You would need more than a one-off meeting – you talked about 80 visits – arguably you need almost as many for people to understand and process what those visits mean in their lives.*

*But would it all be worth it? Going back to uncertainty for a moment and the difficulty of living with uncertainty: in some ways uncertainty is what makes things liveable with at all. There is a certainty that we are all going to die; what that makes it dealable with, for most of us most of the time, is that we don't know when that will be ...*

I have a friend who is a captain in British Airways and he says that if there is going to be a delay they exaggerate it and then people are truly grateful that they haven't had to wait for two hours! It's the same with cancer treatment: if you have low expectations you're not going to grumble. The Marsden now have a programme for managing expectations which is probably good.

The other phenomenon is second opinion chasing, so you go round and round getting multiple second opinions. When you've got metastatic cancer there is no need to see the patient . There is a group of us who are trying to avoid this at all costs. It doesn't matter if they are NHS or private patients – if they've got metastatic cancer you can read the letter and tell that there is nothing more that can be done. If they have been treated at a decent place like Oxford or Cambridge or the Marsden it's not likely that there will be any benefit, but the family don't see that. They want their elderly relative to go chasing or crowdfunding....

*A lot of people don't necessarily go to that extreme. There may be hiding underneath the uncertainty. Doctors can't tell me I've got six months; they can only tell me the average is six*

*months, and it may be shorter or longer. Somehow I can live with that if I have the hope that I will be one of the anecdotal cases that live much longer, and I can cling on to that. Should we really stop people from clinging on to that? - and saying that people should not be in a state of denial? There seems to be a lot of 'should' and 'should not'; couldn't people be left to deal with things in their own way?*

*Hope is a huge issue: we all go along in life hoping a problem will go away and give way to something better. The alternative is the worst-case scenario. Often what I have done talking with the family of someone who may or may not survive is to ask them, and see what their understanding is before we have any discussion to try and find some common ground. Very often we have a feeling that one of the options is that one; if the outcome is better everybody is happy, but if it is the worst outcome it comes from them and not from me. That's a responsibility for them ... a lot of people are saying giving a diagnosis is handing that responsibility to the patient. They come and ask me what it all means when they first come in contact with it, but then they shuffle off because they ... you can talk for half an hour and gain nothing*

*Also the letters can be very threatening; we use an awful lot of confusing medical terminology; and if patients don't understand the words they may infer something really awful or if you explain them they aren't really any better. There are a lot of areas we need to improve to communicate better with our patients.*

Hope is absolutely vital. If you are going to be brutally frank with somebody you may be removing the last vestiges of hope and maybe people don't want that. Some may want it and others don't - it's very difficult to judge. It's back to time: if you have more time - and in any healthcare system time is a limiting factor - you could explore the patient's feelings more. We had a joint project with the British Cancer Health centre, and the Institute of Complementary Medicine about twenty years ago when it was unfashionable (now it is fashionable). It was all safe stuff we were doing; there was nothing bizarre. The biggest confrontation between the Bristol team and the orthodox team from the Hammersmith was about hope. Bristol always gives hope; we sometimes have to say there is no hope - you've got to be honest with people about this.

*Does it depend on what people hope for? Thinking about the Lockerbie bomber we can look from the outside and think his life was horrendous but if he used those two years to reconcile himself to what he did - I really don't know, but it could have been valuable if he was working through that process. How can you do different things for people - some people get there on their own but perhaps that could be a big part of the caring 'industry' (in its broadest sense) to help people find that meaning and that hope - not just about days on the calendar - perhaps in some spiritual way - who knows.*

*This is a very personal perspective but I think that chemotherapy is presented - certainly in Australia in far too positive an attitude. My husband developed lymphoma two years ago. He saw first a physician and then an oncologist. There was really no question asked; it was assumed that he would have chemotherapy. My background is surgical so I read all the information about chemo, and there were many side-effects mentioned. But the thing that wasn't mentioned was that there could be profoundly disabling and permanent effects. For example, regarding peripheral neuropathy, it was mentioned that this could occur but there was never any suggestion that this could be profoundly disabling. Luckily the physician had enough sense to say to the oncologist - "enough". What happened was that you have someone who was normally active, and suddenly they can't walk or drive, they can't pursue their hobby because they can't pick up stamps and can't organise their vast collection - and so on. The thing that I found most frustrating was the personality change which was permanent. There are people here who knew Harry as a very intelligent, philosophical,*

*cheerful kind person with a whimsical sense of humour. Suddenly he became very grumpy and difficult. This affected not only his last months but his daughters' memories of him. I just feel that it was so wrong. We were angry, not because he had the chemotherapy, but because we were never told what it would really mean.*

The difficulty is that there is huge variation in how people react to chemotherapy, and we don't understand it. Although all the emphasis in research and personalised medicine is to find the drugs which will be of the most benefit to an individual, we should also be putting more effort into trying to work out neuropathy which can be very disabling. I have patients who can't do anything after they have had certain drugs. Only a very small percentage will get neuropathy but it is a risk, and it should be explained - but the trouble is that if you are a patient and I say this drug is the best one for you but it does have a 5% chance of causing neurological damage which could be permanent, do you still want it, most people will say yes, because that is the way it is presented to them. We all get better at reducing toxicity by predicting which patients are likely to get more or less toxicity with certain drugs and choosing them around that. Ultimately in fifty years' time there will be a computer sitting there and we will put a few cancer cells and a few normal ones in a little black box, the DNA will be analysed, and out will come a print-out of what to do for that patient based on the optimal combination for whatever the type of cancer, but that's still some years off.

*Don't you think it is paradoxical that on the one hand we have more and more individualised treatments pushed at us: personalised medicine is going to save us money, improve treatments and outcomes; and on the other hand you have NICE arguing for more and more standardisation – that there is something called the standard patient and you can calculate the worth of life years in terms of the cost of treatment. What you are describing is the enormous tension in the NHS, and this is a very important ethical question: do we put limited resources into offering standardised care to the most patients, accepting that many will not have treatment that is optimal for them, or do we provide more individual care for fewer patients? Will we return to filling in 50-page forms for an anonymous centralised being to make decisions for us?*

Different doctors have different ways of doing it. A colleague of mine, Justin Sterby, is in trouble (It's been in the papers so it's not a secret) He is a very good oncologist and what he has been doing is giving very active treatment towards the end of life. He has been reported to the GMC and faces suspension. There was an article in the Telegraph last week about 'Dr God' and he's not like that at all but he may be a little reluctant to accept mortality with people even with widespread cancer. That's one extreme – he doesn't want to give up. At the other extreme you have an elderly post-retirement oncologist at some remote hospital in the North and I bet what he is giving is way below what is given in the South of England. There is this huge variation and the difficulty is measuring what it really means in terms of patients' outcomes. As we have heard, overall survival is not a measure of how successful you are; you have got to measure the quality that goes with that survival. A month extra of life lying in bed in pain fuddles with opiate drugs is probably not as good as a week when you are running around.

*Could I bring up the subject of medical education? You have presented a much more optimistic and encouraging picture than the rather dismal one in Gawande's book. He maintains that our medical training leaves us quite unprepared to deal with the implications of what we can do now. He says we have been brought up only to deal with the downhill stretches of the bumpy trajectory. It seems that you and our colleagues are getting very good with the sort of problems we have been talking about, but a lot of the damage has been done long before people see you - you are not the first doctors by any means that people have seen since they received this diagnosis. You implied that a lot of people that come to*

*are you bewildered and angry - can we do anything to prevent this? What is the potential for education? ... are medical and nursing schools taking this on board and trying to educate people into better attitudes at the beginning of their careers?*

Communication skills are a very important part of the training of all professionals. The difficulty is that some people are good at it and some are bad. There is not a huge amount of evidence that you can take the bad people and make them good at it. You can give scenarios, videos, role plays etc, but do people get better after a lot of time spent on this sort of thing? – we just don't know. People are studying this ... And then there is selection for medical schools. At the moment there are ten applications for every place. They all need three As to qualify for medical school. Maybe we are selecting the wrong people? Do you need three A's to be a good doctor? What tests would you use? At Buckingham we have a selection day next week ...we don't have forms asking why you want to be a doctor any more. They do multiple stations; ten stations around a room and they move on to the next one when the bell rings – it's made completely objective so there is no empathy between the assessor and the student.

The best one is quite amusing – an actress who plays someone with learning difficulties and you have to help them to construct a car out of Lego bricks. You will lose marks if you construct the car yourself. The actress plays as if she doesn't understand - she puts the brick on her head – and they can't connect. The poorer students don't understand what they have to do which is to encourage them if they do something right and gently admonish them if they get it wrong - instead they tend to grab everything and start doing it themselves. What does that mean - does it make you a better doctor if you can do that?

*Is medical education too technical nowadays?*

Medical education itself has become an industry. On day one of all medical courses you get an iPad preloaded with everything you need for the next five years. It has been totally transformed. It is much safer - in our days it was see one, do one, teach one. We were doing fairly risky things: I was putting in pleural drains in the emergency room as a student when I had no idea what I was doing. That's all gone. But in terms of this morning's discussion, can you train people to deal with patients better when they are at the end of life? It's very difficult to know how to structure it. It takes an enormous amount of time. It's much easier to give someone a list of chemotherapy drugs and formulas and tell them to learn that.

*I suppose I was thinking as much about postgraduate training, especially of GP's, as of students.*

*It would help if the people learning could have access to an experienced colleague. There is nothing better than being in a room with someone who is doing it well .*

The old days of the apprenticeship model have gone, and it's not feasible to bring them back, but having role models is really important.

*Why is it not feasible?*

I guess the numbers have changed dramatically.

*I don't think so. I guess the emphasis on what doctors are supposed to do has changed. We're not doing very different jobs from what we were doing when I was a student. What is different is the emphasis on targets and waiting lists ...*

... and the technology ...

... so there isn't time to teach the other stuff

*I worked for many years as a Sister in palliative care and on the wards everybody did night duty in rotation. Most of us accepted this as it was a wonderful opportunity to have time with patients. When you were doing your last drug round several patients would ask: "if you've got a quiet moment could you come back and have a talk" because they knew that you would have time – and time is of the essence for these difficult conversations. One particular night at about two o'clock in the morning someone had needed some attention – someone with motor neurone disease. She was awake but she could no longer speak.. When I and my colleague had finished helping her, everything about her told me that she wanted something else, although she couldn't tell me what. On her bedside there was a book of poetry. It was open at a page so I asked her if she would like me to pick one out and read it to her. She was able to give a slight nod so I spent about quarter of an hour quietly reading until I was called away to somebody else. The next night when I was doing the ten-o'clock drug round one of the other patients in the room said: "Chris, was it you talking last night to Mary in the next bed?" I replied that I hoped I hadn't disturbed her. She said: "We were all listening. I have to say now that this is my third visit to the unit for symptom control. Listening to you I realised that even when I can't speak or make my wishes known there will be people like you still there for me. I am going home tomorrow and know that the next time I come in may be my last. I can't tell you with what reassurance I shall be going home. That little thing – I hadn't said a word to the other patients ... The way we relate to people in every way ... you don't know what effect you are having... in a strange way these things do give hope to people just by the way you behave.*

## Taking Care of the Person in Chronic Illness

Sara Booth

I'm going to talk about chronicity, and about inflammation which is becoming more and more recognised as a mechanism of chronic disease across the board: COPD, even schizophrenia - almost anything you can think of seems to have an inflammatory component. I'm going to highlight some aspects of care that are often overlooked. A lot of my focus will be on non-pharmacological ways to attenuate the impact of illness and enable people to have the best health possible, and I will be describing the 'War of attrition' model for chronic illness which makes it very different from acute care. I will also be discussing the 'Five ways to Wellbeing'.

### Breathlessness

The best definition of breathlessness was penned by Comroe in 1966: Dyspnoea is "... is an *unpleasant* type of breathing, though it is not painful in the usual sense of the word. It is *subjective*, and, like pain, it involves *both* the **perception** of the sensation by the patient and his **reaction** to the sensation"

If you are running and out of breath, it's not unpleasant - it can even be exhilarating. This is subjective, I can't say you're not breathless. Some of the sensation of breathlessness is about our lungs, heart and thoracic wall, but the important part, the bit in which we can intervene in chronic breathlessness, is the patient's reaction to the sensation. And not only the patient's reaction but also the way the people around them react, because that has a huge impact.

Interestingly, the severity of dyspnoea in patients with COPD is a much better predictor of 5-year survival than measures of airway obstruction. That is surely because breathlessness is a measure of many other things about the person: their motivation, their psychological status and their family circumstances etc., whereas the objectivity of the lung function tests fails to take these measures into account. Lots of people with very poor lung function can be quite active and mobile, while others are in bed.

Breathlessness is a terrifying symptom. We had someone to talk to us about torture last year and they said that the feeling of suffocation is far worse than any pain.

"It's like being strangled while you have a big weight on your chest"

"Will I get much shorter of breath? Can I manage it? Is something terrible going to happen?"

"It's terrible to see it ... and you feel so helpless, so useless – I don't know how you can help"

Breathlessness can be invisible; if someone is sitting down but has severe breathlessness on exertion it may not be noticed by clinicians.

COPD is classified into four categories according to severity.

- A is low risk, less symptoms
- B is low risk, more symptoms
- C high risk, less symptoms
- D is high risk, more symptoms.

The only thing that can move you from category D to category C is not better bronchodilators but palliative care that reduces your symptoms.

In the breathlessness intervention service, we use a complex intervention consisting of a number of non-pharmacological treatments including breathing retraining, and cooling the face with a fan to reduce the perception of breathlessness. We are also tackling the ways people think about their breathlessness and encouraging them to be more active, as activity and muscles strengthening are the best ways of reversing deconditioning across a wide range of medical conditions. So we came up with this scheme:

Breathing	Thinking	Functioning
Breathing techniques	Relaxation techniques	Pulmonary rehabilitation
Handheld fan	CBT techniques	Exercise/activity
Airway clearance techniques	Mindfulness	Walking aids
Singing therapy	Self-hypnosis	Pacing
Inspiratory muscle training	Acupuncture	

This is a huge list, so how do we prioritise?

When we see someone we try to determine whether they have got into an inefficient dysfunctional breathing pattern that involves increased work, for instance by increased respiratory rate or overuse of accessory muscles, or dynamic hyperinflation as occurs with COPD.

Is it their thoughts about breathlessness that are holding them back? Paying too much attention to the sensation of breathlessness during exercise can increase breathlessness, but desensitisation programmes can improve symptoms.

Have they had bad past experiences, for instance with someone they know who was dying and very breathless? Do they have feelings of anxiety, panic, frustration and anger? (Anger is often not recognized in medical practice.)

Are they having problems with functioning? Have they got the idea that if they push themselves they will get worse? Do they need to learn that they are not going to harm themselves by being more active – and that if they feel breathless on exercise it is a good sign, although it feels uncomfortable, because they are doing more?

Have they stopped moving around and become deconditioned? ... and so it spirals on, and they end up with more side effects from drugs like steroids.

So the breathing/ thinking/ functioning model makes sense to people about what is happening. It explains breathlessness perpetuation. It talks about potential triggers and helps people to understand why the symptom may seem out of keeping with the disease severity. Sometimes,

instead of explaining why, people are told: “you shouldn’t be so breathless - you’re not ill”, and that is demeaning, and makes them feel disbelieved. It helps people who have motivation and gives them control.

When you have a chronic disease, having an internal locus of control and a sense of being able to master what goes on it will help you to have a better medical outcome. To take a simple example, if you have someone who is becoming overcome with breathlessness after a few steps every time they go out, you give them a fan and explain that it is a trigger that they can initiate safely at any time. You explain that it will reduce the sensation of breathlessness. You are giving them back some control and enhancing their perception of being in control. The model also gives the clinician some idea of where to start when there is such a huge range of pharmacological and non- pharmacological options, the latter listed above. Singing therapy is increasingly being recognised as important to people with lung disease. CBT is useful, for example, to help people to learn that just because breathlessness is unpleasant it doesn’t mean it is actively harming you. Only 4% of people who are eligible for pulmonary rehab get it and yet the evidence that it works is overwhelming. Exercise and activity, perhaps facilitated by walking aids, increases fitness and therefore decreases breathlessness. Pacing sounds simple but learning not to try to do six things at once instead of over two or three days is difficult for patients to master but enables them to achieve more in the long run.

The idea that symptoms are important has only recently been recognized. The GOLD (Global Initiative for Chronic Obstructive Lung Disease) guidelines (2017) which are used by most respiratory physicians for the diagnosis, management and prevention of COPD, stress this. Pharmacological therapy may be of value in reducing patients’ symptoms even if they have little effect on pathophysiology. The guidelines highlight the importance of rehabilitation and physical activity and stress the importance of assessing co-morbidities including depression and anxiety. Dealing with these can affect mortality and hospitalisation. Many people with COPD go into hospital three or four times every winter and come out with their medical condition unchanged. The new guidelines mention breathlessness and palliative care services for the first time.

## Management of breathlessness – a success story

I’m going to tell you about a young person - not very typical as he is only 19 – to bring together some of these ideas. He was treated for acute myeloid leukaemia but had a recurrence soon after finishing chemo. A stem cell transplant was complicated by graft versus host disease, and he has finished up with the horrible lung disease bronchiolitis obliterans. When we saw him during his university vacation he could only walk about ten yards and had to park his car outside the lecture theatre. He was obviously having difficulty managing his course, and he could see no way he could ever leave home and earn an independent living. We assessed him on a home visit; I discussed his problems with his mother and the physiotherapist saw the patient. Young people with chronic illness often get left out and excluded from their peer group. Not only do they have the illness and its symptoms, but they also feel very isolated and have little prospect of finding employment. It turned out that his mother was preventing him from walking upstairs or taking any exercise. She had been terrified during the chemotherapy and pleased he had got through, but now felt that his heart had been damaged (which had probably been mentioned as a possibility but there was no evidence that it had occurred.) At my request the haematologist wrote a letter to the mother reassuring her on this point and saying that exercise would be a good idea. So that took care of the ‘thinking’ part of it. The physio gave him some exercises and we also involved him in golf classes, starting with just putting and progressing to driving. Over the course of the next year he started to swim, then to run, and six years later he did the London Marathon in seven

hours! He is now living independently and has a new job. That involved both the change in his mother's thinking and enabling him to exercise.

### Chronic illness as a war of attrition.

Chronic illness can be regarded as a war of attrition. Unlike acute disease there are endless new insults coming every day and these must be dealt with. Uncertainty, not knowing where or when the next thing is coming from, is fantastically difficult to live with. It is well recognised that cancer and its treatment, like chronic illness, can be attended by a wide range of physical and psychological effects that do not recede with time. Just because we don't notice or people don't bring them up doesn't mean that people don't have these problems. We aren't very good at asking about them.

'Cancer survivors experienced altered lives and had needs related to *fear of recurrence* and facing the spiritual aspects of having *survived* a life-threatening illness'

*Oncology Nurses Forum: 1995, 22(6):915-922*

Cancer and its symptoms, as we recognise in palliative care, are associated with an activated inflammatory response. But we have to think of the impact of disease, both malignant and non-malignant, in terms of physical *symptoms*, and the GOLD guidelines of 2017 are only just beginning to acknowledge this. As well as complications of illness and of treatment, psychological symptoms, psychosocial impact and questions about self and about spirituality loom large. There are losses, some which are necessary to best health – it's no good feeling that you can keep doing all the things you were doing before. There are also problems with money and employment questions about mortality that need to be dealt with.

Many diseases are becoming chronic that were once acutely life-limiting. There are new personalised treatments appearing all the time, not only in cancer. Survival times are increasing, and many people have morbidities and symptoms that persevere over many years. This goes across age groups and I'm sorry to say a lot of young people get missed out. They don't fit in to one of the big chronic illness groups and therefore don't get the sort of help they need. This is certainly the experience of a lot of people with LAM (Lymphangioliomyomatosis: a rare cause of heart and lung disease in young women that affects only about 100 people in the country.)

Your family can have a profound impact on outcome; preventing someone from taking exercise is a prime example. Societal attitudes impact on lives of people with cancer, the social origins of disability, how we prevent people from living a full life - these are important subjects I haven't time to talk about now.

How did I come to think of moving from a breathlessness service to a long-term condition service? Well, when I was a palliative care consultant at Addenbrookes I saw a 32-year-old man who had had Crohn's disease since he was 11. It was a painful encounter for me because I had a great sense of helplessness. He had experienced interrupted schooling, and although he had worked, intermittent illness caused loss of employment on 'capability' grounds. He was too ill to support himself in a self-employed capacity. He was admitted for nutritional support, but I got a very strong sense of his isolation and despair. His parents were distraught; they didn't know how he could ever manage without them, although I didn't think he would live for very long, partly because of his psychological state. I never saw this man again.

I could see that at the age of eleven, if things like nutrition, exercise and symptom control had been more actively pursued he might not have been in the state he was now in his early thirties. He had no hope; he didn't fit into the hospice pattern as it was then, so where could he go?

If we look at chronicity in someone with an illness they have suffered for 20, 30 or 40 years ... you know that with compound interest if you invest something at 0.25%, twenty years later you're a millionaire – it's the same the other way round with disease. If you don't intervene with things like poor nutrition (and we know that some diets are pro-inflammatory) and exercise ... if you do half a percent more exercise every year for twenty years you'll be in a very different place. You lose your social network year by year with things like breathlessness, as people don't like being breathless or coughing in public. They are too tired to go out, so end up confined in their sitting rooms. But we know that a social network is good for your health.

## Psychoneuroimmunology and Inflammation

We are learning more about psychoneuroimmunology and the links between psychological stress and immune downregulation, for instance of natural killer (NK) cells, because of the role that they may play in malignant disease. In addition, distress or depression is also associated with two important processes for carcinogenesis: poorer repair of damaged DNA, and alterations in apoptosis.

The possibility that psychological interventions may enhance immune function and survival among cancer patients surely suggests that we should take this further. There is also evidence suggesting that social support may be a key psychological mediator. These studies and others suggest that psychological or behavioural factors may influence the incidence or progression of cancer through psychosocial influences on immune function and other physiological pathways.

It has been suggested that because chronic inflammatory states have such a close relationship with cancer prognosis, (a high CRP predicts worse survival regardless of stage and grade of tumour or metastatic spread), in this era of personalised medicine we need to take an anti-inflammatory approach from the beginning with things like omega-3 fatty acids, Vitamin D and cytokines inhibitors. Supportive care ... just as we know that the way we manage anaesthetics in high risk patients with transfusions, ventilation and adequate fluid balance makes a difference to surgical survival .. so we need to include a non-pharmacological approach in our management of people with chronic illness.

We need to take this anti-inflammatory stance from the beginning, with impeccable symptom control linked to other anti-chronic disease approaches (which I shall say more about) allied with access to nutrition-rehabilitation programmes. The aim should be to strengthen and maintain function and control fatigue. (Muscle mass gives you a guide to how well people stand chemotherapy. There was a talk at an oncology meeting last year by an oncologist who gets people to exercise while they are waiting to start treatment.) We also need a change in research priorities to reflect the importance of chronic inflammatory syndrome.

Reading around wellbeing I came across the concept of *inflammaging* which has been mooted by Francheschi, and suggests that diseases of old age and associated multi-morbidity are associated with chronic low grade inflammation, and accelerated ageing is associated with an inflammatory process. It may be that the body's inability to inhibit inflammation contributes to the level of multimorbidity in chronic disease. Many chronic illnesses like COPD and diabetes are associated with accelerated aging. It may be that osteoporosis, coronary artery disease and sarcopenia are all part of that same process. The mechanism seems to involve cellular senescence and shortened telomere length. Peter Barnes, a respiratory physician and a very eminent researcher, is looking into drugs that may

inhibit this process. This slightly worries me because all of these drugs which we happily take for years and years have eventually proved to have an unexpected adverse effect.

For those of us who believe that the promotion of psychological wellbeing is an important part of our practice, one of the most important papers to emerge in recent years is that by Tawakol et al (2017). This focuses on the association between amygdalar activity (as assessed by PET scan) and cardiovascular disease events, which seem to be mediated by increased bone-marrow activity and arterial inflammation involving cytokines and inflammatory mediators. The amygdala is part of the brain which acts as a guard; if we have amygdalar overactivity when we are highly stressed we tend to see threat when it is not there. The amygdala can be a powerful mediator in the sensation of breathlessness. Other symptoms such as pain, thirst, panic, are also mediated in our central nervous system.

Looking further into the inflammatory response, there is now evidence that if there is pre-existing vulnerability to a disease, an event such as physical attack or sexual abuse may trigger the disease through the arterial inflammatory response. Vulnerability seems heightened during adolescence when the immune system is still developing. There may be evidence for this in schizophrenia, there is evidence in cardiovascular disease, and certain evidence in auto-immune disease. (I have an autoimmune disease, lupus, and a bereavement I suffered in adolescence seems to have been a forerunner of autoimmune disease later in life.)

Pattinson, who works in Oxford, has shown that peripheral generators and central processors both offer approaches to amelioration, and we can use a person's interests and work to influence their use of imagery. We need also to look at the 'priors' that may act as triggers. So sometimes when you meet someone with very serious breathlessness you may find that they got worse when they retained sputum and panicked, thinking they were going to die. A respiratory physician I was talking to the other day said he had a patient who had been told that she had very serious COPD. Actually she didn't, but from that moment her condition sharply deteriorated. Changing these over-perceptions – priors – can make a huge difference. Pattinson has shown that pulmonary rehabilitation correlated with reductions in prior-related activity in the insula and anterior cingulate cortex (ACC), and increased activations in attention regulation and motor networks involved in breathlessness-anxiety. These were people who said they were worried about walking upstairs or frightened when they went out, and improved if attention was paid to these things in pulmonary rehab.

## Hypnotherapy

When I was an SR at the John Radcliffe in Oxford, and later as a palliative care consultant at Addenbrookes, I found a huge unmet need in the people I saw who lived with chronic illness for a long time, particularly those with respiratory disease. This need was greater even than among those at the end of life. I realised that particularly with regard to neuropathic pain in cancer and breathlessness, there were limits to what we could do with drugs or other interventions. So I acquired a diploma in hypnosis as part of the search for other ways of helping. Self-hypnosis offers a way of managing one's own condition.

Leslie Walker, a psychologist who has done a lot of work in this field, writes that:

These studies have provided evidence that relaxation therapy, guided imagery and hypnotherapy can be very beneficial in helping patients cope with the diagnosis and treatment. Intriguingly, there is some evidence that they may prolong life.....

Walker, *Contemporary Hypnosis*, 21:35-45

Hypnosis has been defined as ‘trance plus suggestion’ and its benefits may have something to do with plasticity in the nervous system. There have been several clinical trials of hypnotherapy in cancer. A systematic review by Cramer (2015) of thirteen RCT’s with 1397 participants showed positive effects on alleviation of pain, distress, nausea, fatigue and hot flushes. The word hypnotherapy can be misleading because most of us using it in medical, nursing and psychotherapeutic practice think of it as an ancillary treatment and a way of improving other drug or non-drug treatments. And it is the imagery rather than the actual trance which is the treatment.

The use of hypnosis in the context of psychoneuroimmunology exploits the ability to reach control of conscious and unconscious processes as well as biologic and somatic processes. This is accompanied by activation and deactivation of several brain areas and circuits (e.g., the default modality network and pain neuromatrix) with a relevant overlapping between the two.

A typical patient was Mrs A.B. who had a slow-growing spinal tumour of which she was unaware until sudden onset of tingling and weakness in her legs. She was told she needed surgery the following day as the tumour, which she had probably had for years was threatening to cause paralysis. When I saw her she not only had neuropathic pain in her legs but feared the breakup of her marriage. She was frightened to take exercise because she had a vision of it damaging her back, and she was utterly exhausted. The first objective of hypnosis was reduction of anxiety and distress. We did this by giving her ways of protecting herself from emotional distress, and facilitating psychological rehabilitation leading to greater physical freedom.

The sort of imagery we use in palliative care includes a visor to protect from pain, (sometimes people need that kind of protection from hurtful or damaging remarks) or metal gates within the pain pathway, and a gate preventing pain - represented by a snake - reaching the spinal cord. We also employ the psychosocial effects of hypnotic intervention to improve general health.

We also use hypnosis to treat hot flushes, as with a 35-year-old woman who was facing separation from her husband and had a young daughter. The imagery she used included ice, cool sheets, a waterfall, and a tap that could be turned on and off at will.

People often use rapid self-hypnosis only when they are in trouble, but it can be used regularly, such as each time you stop your car, or during everyday actions like washing up. New post-hypnotic suggestions can be introduced, such as ‘every time you touch a door knob you know that your pain is diminishing.’

The beauty of hypnosis in cancer and palliative care is that it is dynamic and creative. It can be energising. It can enable people to relive lost activities: I helped one woman who wanted to remember how she was perfect before she became paralysed. I thought that would be painful for her, but she wanted to relive her happy memories. Another lady was facing losing her legs and the imagery we used included a beach walk in Cornwall, the bridge of the Starship Enterprise where she could control her neurological circuitry, and a rucksack full of heavy stones which she could leave and walk on. There were also issues outside the trance like pacing activities and working on family relationships. Hypnosis is a staged procedure; you look to see where the main problem (like pain and distress) is, and deal with that first, then manage other issues like anger and family relationships later. It can obviously be combined with other medical interventions.

Karol (Sikora) mentioned anger and I have often found that people who have had a delay in diagnosis are the angriest. Mrs. F had a slow growing but inoperable spinal tumour, and looking through her notes I saw that there had been a delay in diagnosis. She was plagued by uncertainty with intrusive sensory affects which shifted and changed so she never knew what would be next. She had lots of somatic symptoms from her drugs and was worried about long-term adverse effects of these. She wasn’t sure about hypnosis, but by the second

session she was able to use imagery like bringing a pebble to chemotherapy to remind her of pleasant times on a beach, and a film, the Green Mile, which she could use to imagine the cancer leaking out of her. I gave her a CD with short mindfulness tracks, recorded some of her rapid self-hypnosis and she had some long sessions with me. I also worked with her family.

During our work with hypnosis an unexpected finding was that patients liked it when we concentrated on what was still working in their lives rather than on what had been lost.

## Mindfulness and Meditation

There is an overlap between hypnosis and meditation. Meditation, mindfulness and mind/body practice are tools to build resilience, and to use in the treatment of specific problems. Often in medical practice we send people from one appointment to another, treating the disease in a reactive way. We don't spend time proactively building up resilience to symptoms. The psychology of resilience and wellbeing focuses on thriving rather than morbidity. Personal resilience can be learned or at least enhanced, firstly by focussing on engagement with the world, for instance, with patients with COPD who spend a lot of time in their rooms. These patients can be encouraged to look for meaning in their lives, perhaps through involvement in something bigger than themselves. They can be encouraged to seek pleasure – some people find it hard to believe that pleasure can be part of their treatment.

Mindfulness has been described as a way of paying attention to the present moment, actively, compassionately and non-judgementally; and as 'learning to shut down the autopilot.' It is 'a way of paying attention which means consciously bringing awareness to our experience, in the present moment *without making judgments about it*, such as jumping to the conclusion that a pain is a sign of returning cancer. One of the most important things that many patients to learn is to stop judging themselves and accept what has happened.

I became very interested in mindfulness-based stress reduction (MBSR) but could see that there were many barriers to using it in hospital patients because it involved an eight-week course of two-and-a-half hour group sessions and one whole day of retreat, as well as daily practice at home. But I was keen to pursue it because I saw that it would facilitate reduced distress concerning interpretation of physical disorders - in other words, stop patients interpreting every pain as cancer coming back. It involves full use of one's five senses, practising a 'relaxing body scan'. Body scanning entails quietly lying on one's back and focusing one's attention on various regions of the body, starting with the toes and moving up slowly to the top of the head. Mindful attention is paid to one's breath, ambient sound (hospitals can be noisy) and movement, and stretching exercises derived from yoga.

The efficacy of mindfulness-based stress reduction on the mental health of breast cancer patients was demonstrated in a meta-analysis (Zaindal et al, 2012), with a moderate to large effect. How many antidepressants can this be claimed for?

The importance of non-pharmacological interventions is that they get to the root of what is causing the issue. In mindfulness you reduce rumination by reducing that impact on the story. You transform yourself from judgement about failure, like not getting to the doctor quickly enough, and you choose not to engage with harmful feelings or thoughts.

Because we knew we couldn't get patients to do an eight-week course we did a brief self-administered psychological intervention over a 6-week period. We asked patients to write down a record of three good things that had happened in each day, to plan and carry out a pleasurable activity each week, and a 10 minute 'body scan' twice daily. This was only a feasibility study but it showed a trend towards reduced anxiety and depression. From that we developed a journal; a more comprehensive MBSR approach with space to write down good things in a day, and some beautiful images from the Fitzwilliam museum and some encouraging but hopefully not facile quotations. We provided prompts for people to use their

senses for good things, prompts to use five ways to wellbeing, and space for personal happy reminders. Especially for chemo patients we put in a space for 'something important for me at this moment' which they could use when they went for treatment. We stressed paying attention to the positive even in bad times.

I believe we need a multifaceted approach to include symptom control with as much attention directed to this as to diagnosis, a psychologically informed approach using psychological interventions. Exercise and activity are key to increasing wellbeing and resilience. The role of nutrition is controversial but it probably has a part to play. Support for carers and family is essential.

## The Five Ways of Wellbeing

The Five Ways of Wellbeing are part of Foresight's Mental Capital and Wellbeing Project. They offer a framework rather than a formula. Rather than relying on a Guru to tell you what to do to you have to work out the best way for yourself .

**Be active ...** Walk, run, cycle, garden dance .., find a physical activity that suits your level of mobility and makes you feel good.

**Take notice ...** Be curious. Notice beautiful and curious things. Savour the moment, whatever you are doing, rather than dwelling on the past or worrying about the future. Be aware of the world around you and your feelings about it.

**Connect ...** with the people around you – family, friends, colleagues and neighbours. Building these connections will support and enrich you in every way.

**Give ...** Do something nice for a friend or a stranger. Volunteer your time or join a community group. See yourself and your happiness linked to others.

**Keep learning ...** Try something new or rediscover an old interest. Learn a new skill: riding a bike, playing an instrument or knitting. Set yourself a challenge you will enjoy achieving. Learning new things will make you more confident as well as being fun. Even if you have a serious or life-threatening illness you can keep your brain alive.

We put twelve fine art prints in the Wellbeing journal, one for each month of the year, and invited people to record a happy memory associated with each one.

The Comprehensive Lifestyle Intervention has become more general in cancer. The early report of a trial of diet, exercise and mind-body practice is positive about the experience. A study of personalised respiratory medicine concluded that: 'Systems biomedicine has the potential to transform biomedical research and clinical practice from a reactive to a proactive practice of medicine'. In his study of teaching heart failure patients how to breathe Coats suggested that

'.... There are more ways to improve symptoms than stimulation of the failing organ, and the progress of disease in human beings is complex and multifactorial and offers multiple approaches to amelioration.'

## Discussion

(KS = Karol Sikora  
SB=Sara Booth)

*That was all most interesting but what I found most fascinating was what you said – or at least implied – about the literally mysterious relationship between what goes on in consciousness and brain activity and what goes on in the body right down to a cellular level or even a biochemical level.*

SB: I have heard somewhere that if someone has a transplanted limb and they don't like the one they have been given they reject it. These instances are so subtle and amazing – things affect us in ways we could hardly have believed a few years ago.

*As Karol said earlier we can't necessarily train people to be good communicators but we could at least help people to be more careful in their use of language. So much of the language that doctors and other health professionals – or lay people - use can be very damaging. One word which frequently comes up – not so much from doctors as in its almost universal use in death notices and obituaries, and often about living people who are experiencing chronic illness or dying, is fight (and battle).*

KS: Military metaphors are everywhere - war on cancer, collateral damage, magic bullets etc. That is fine in the active stage of treatment but there comes a stage when you've got to give up on that and use language like caring and wellbeing. We must change the metaphor.

SB: I think those metaphors are very unhelpful. I worked in Bristol in the 1980's and people there were made to feel bad if they didn't stick to the guide. In those days it was a very punishing guide and very exclusive. People were made to feel bad if they didn't feel positive all the time and that was why their cancer came back. It's much better to focus on the things they can do than those they can't help. We should say these are the things you can do to help your illness – be active, take notice, give etc– rather than the battle thing which is always about losing your battle which implies failure – there must be something the matter with the way you fought, perhaps because we celebrate great generals who overcame great odds. I have a friend who had a bone marrow transplant in 1991 and was told at that time that with the type of leukaemia she had, she only had a five-year survival even after a transplant. When she got a very rare tumour a year or so ago she was informed that her odds were so poor then (it was a secondary neuro-endocrine tumour) that she spent thousands looking for treatments that weren't there. The way she was told not to have treatment didn't help, and that all involved a tremendous amount of anger. So what we say to people is incredibly important. In hypnosis we say all language is hypnotic. But I don't know how you get around it because it's culturally so strong.

KS: The title of this meeting is really great – living well right to the end: that is the challenge. All the technology, all the military metaphor ... but when you come to the end all you have is the psychosocial support, including religion, family ...

SB: We know the value of early palliative care which is at least as effective as some third stage cancer drugs. But the problem with all these non-pharmacological approaches is that although the effect size of non-pharmacological treatments for cough and breathlessness shows higher effectiveness for lower cost in people with lung cancer., there is no-one promoting them. They are more complicated to take on and you can't find a drug company to promote them. And they sound second rate - if you can't have a drug that will cure you have got to have these.

*Thinking about this morning I have been struck by the contrast between disease and illness. I was a rheumatologist and rheumatologists only worry about disease but not illness at all... Pain is the main symptom, but no rheumatologist knows anything about pain or how to deal with it. I was very interested to hear that respiratory physicians are moving away to some extent from the disease model to the illness model. I wonder if that is what we should all be doing, particularly towards the end of life. Oncology operates entirely on the disease model.*

SB: With chronic illness - that has to be the illness model because otherwise you lose all these other things: activity and the psychological stuff. If you want to live well to the end of life it's better to start a bit earlier, because the last thing you want to do is to teach someone mindfulness and hypnosis in the last stages ... they have enough problems ...

*Maybe if we helped our patients switch from the disease model to the illness model from the beginning ...*

SB: I think that is the answer.

*A patient who worked in the NHS who had a very aggressive breast cancer but had a spontaneous remission for about six months told me that those six months were the best in her life. But actually, she could have had that life earlier if she had had the insights ...*

*Don't you think it's telling that around this room there is a lower proportion of doctors, and who is giving information to patients? – it's doctors. And as doctors value these things ... [inaudible]... if we're not valuing it how can we communicate that value to our patients. I'm not talking about us as individuals, but as a profession. We learned a lot from other healthcare professionals because they do value health in the larger sense of the word as opposed to cure, which is what doctors value ...*

SB: But do you also think you get sliced out of your job; jobs become task orientated. Luckily in palliative care the task does involve non-pharmacological measures. I was examining a PhD candidate and a fellow examiner was someone who looked after people with sarcomas. I was horrified to hear that when they were dealing with young people facing mortality how little time they were allotted to talk about chemotherapy, let alone anything else. It's not that it needs loads more time ... when you look at that very young patient with breathlessness ... but you can use your authority in a different way so you do have to have some time to touch on the other things. I think it's happening in respiratory medicine. There is an article in the Lancet saying that we need to be more holistic in COPD because people see the futility of getting people in and out of hospital with no change in their pulmonary function.

*A slightly different topic which I think connects the two talks together: we tend to be dismissive or critical of people with mobile phones who are losing communication between persons. This certainly is a group who would benefit from communication. Someone was talking about healthy networking and whatever happens mobile phones and networking are things that are here to stay. One particular example is a 20-year-old lad that lives near the hospital who is looked after by his family... [inaudible] ... with awful pain and pressure sores. His life was based around facebook. He had hundreds of followers – the whole world was open to him. He was communicating with other people as well – but it was a very positive thing and it converted me to the benefits of social media in chronic illness. It was life-changing for him. It could however be argued that the negative aspect of it is that, like computer games, it encourages people to live in an unreal world. But is it an unreal or a parallel world and can we use that ...*

KS: If you're going to live well till the end computer games are a reasonable thing to do – to get away from intolerable reality ...

*I know someone who plays computer games for eight hours at a stretch – the only time he is not in pain - he completely changes his identity ... why not?*

SB: people can connect with people in the same circumstances, with a rare cancer for instance - being able to connect widely is a great boon.

*Virtual reality has been used to help people having wound dressings changed*

*The other thing that was impressive was what you [SB] were saying about low cost compared with very high cost treatments - pretty well everything you have said is about time and thought and spending time with patients which is expensive in its own way.*

*Do you [KS] have a positive feeling about NICE?*

KS: Any technology has got to show value for money in any health care system. I don't see how we can get away from that. Unfortunately, although it's not as expensive it involves time, and the trouble here is that there are no hard numbers to collect and it's so difficult to predict. There have been trials of complementary therapy – obviously not RCT's - which show anecdotal benefit.

SB: The evidence for the efficacy of exercise etc in treating breathlessness and cough is conclusive, as are its benefits in depression. It does require more commitment and the long-term gains from pulmonary rehab are not always as good as they might have been as some people stop doing their exercise. But there is something about trying to promote lifestyle changes across the board. The Five Ways of Wellbeing were composed by a group of neuroscientists and neuropsychologists who were commissioned by the Chief Scientific Officer to identify what actions people needed to take to maintain mental health and resilience. I don't think doctors can do all that or even specialist nurses or allied health professionals as we are only seeing a tiny number of people, but we can use our clinical authority to say this actually works, instead of always recommending drug treatment.

*There is a fantastic video called Understanding Pain in less than Five Minutes. It was produced by Mike Nichols who was in charge of public health with an interest in back pain in Australia. The intervention was six months of nightly spots on prime-time TV every night for six months. Then they looked at population-based interventions, peoples' knowledge about back pain and whether they should rest or keep moving, and so on. They put a lot of money into buying all these TV spots and the health benefits were maintained for five years. We tried to replicate that in Europe with radio spots in Glasgow on a local station, and in Scandinavia with a much lower budget than they used in Australia, and - guess what - neither of those interventions was successful. From that they concluded that this wasn't an effective intervention. But the point is that unless you start with the right kind of education targeted at the right audience at the right intensity ... You have a choice: if you have a limited health budget either you spend it on drugs or TV spots.*

*I want to talk about touch. For a lot of elderly people who live on their own, their pain is so much greater because they are alone, and they don't get touched or cuddled. When I was doing massage some of them couldn't cope with it because it was too strong but just touching in a loving way took the levels of pain down. Now there isn't time and we're told we shouldn't cuddle people, but I do, I give clients a hug if they want one because I think it's really important.*

*... kissing?! ... [drowned by laughter]*

*... In medicine we used to touch people a lot more when we were examining them ... now they just get sent for a scan ...*

*... just putting your hands on someone's shoulders or even shaking hands at the start of a consultation ...*

*Touching helps someone to concentrate on what you are saying*

*Authenticity is important ... when I was teaching communication skills I found that some people, culturally, weren't used to touching people. But because it was being taught on the communications course students would move forward and touch someone; and the actor would say that it felt very strange because it wasn't what they authentically would do. And it is almost about what you would do as a normal human – not about a technique you can teach. You can't teach people to be more empathic if they aren't naturally empathic, but you can at least help them to avoid using harmful language, such as saying 'you've got very serious COPD and you will have to learn to live with it'.*

*I think the point about authenticity has absolutely nailed it. It's not so much about touching – it's actually about whether you give a damn, and whether the other person knows you give a damn. It may involve touching, the words we use or even kissing, but it's the authenticity of how you respond in a way that communicates successfully that you really care that is at the bottom of all of this.*

*I agree with you completely, but touching is a specific thing that particularly elderly people don't get at all, and it can be very healing.*

*People with skin diseases feel that ... if you touch the rash or psoriasis ... you don't really need to touch it but other people recoil ... you 'contaminate' them.*

*I think it's much about attitude and tuning in to where the patient is. In the pain clinic in Norway where I am nurse I begin with a 'motivating' interview with the patient to try to find a better approach. We start with open questions like 'how are your days?' - 'what do you know about your illness?'- 'what is the most important thing we can help you with today?' That can be very strengthening...*

*... It establishes the patient's agenda. And it doesn't necessarily take longer. ... You may take them down a path they don't necessarily ...*

*... it's amazing how much they can tell you in a short time if you are open to them. And they are happy that I am a nurse because I can say "now we can help the doctors!"*

*The other question which is important is 'what do you think is causing your pain?', or 'what do you fear most about the future?'... like 'am I going to be paralysed?'*

*A lot of people tell me about loss of relationships ... unless you create a space where people can ask ... or you give them permission to ... if you get to the point you can cut out the rubbish, so if people are living with uncertainty and you go straight to the heart of the matter you can save time.*

*It would be really great if all these things could be introduced at the first appointment instead of the heavy stuff about drugs and only then these other things ...*

SB: ... we can suggest things you can do for yourself to make your treatment more effective. Often with a medical condition it's a question of filling in the gap before the test results come through and you can initiate specific treatment, and you can say "in the meantime we can get on with finding a way that helps you ...". Most people don't require specialist psychological intervention ...

*... You put the patient in charge at the start ...*

... exercise is a good start ...

*You were talking about communication skills and some people are fortunate enough to have them. But we were taught about the golden minute, and if you allow the patient to ramble they will run out of steam in between 40 and 90 seconds. If you allow that time with active listening and engagement you save time. I'm sure there must be evidence for this. We were talking about time as the essence. When I worked in the pain clinic I had the privilege of 45-minute appointments, but I could discharge a lot of patients after this time because all I did was listen, and nobody before me had done this. I wonder if we are creating a problem which we could actually solve right at the beginning if we created a space - it could be only 15 or 20 minutes - but by discovering what a patient's agenda is before you start telling them anything you could save time and trouble – and anger - at the end.*

SB: People get referral letters, so they then start working through all the things that could cause dyspnoea, but they don't then listen to the experience of being breathless. And in fact when we were evaluating the breathlessness programme, two things took me into positive psychology. One was understanding what was working in people's lives and reinforcing that. How many times when someone tells you a long story of what they had been through do you say: "gosh you've been through so much and you've done really well to manage all that". When we started ... it's changed a bit now ... we did what is called a pragmatic trial, where some people got to the breathlessness service immediately, and some after four weeks. The people who didn't get to the service immediately did get to talk to Morag, our research clinical nurse, or one of her colleagues about the experience of being breathless, an opportunity they probably had never had before. (A lot of cancer patients do get psychological care which is streets ahead of other types of physical medicine). We evaluated the effectiveness of talking to Morag in the group that had delayed access to the breathlessness service (in a way that is the only sort of placebo you can have in a trial of a breathlessness intervention) and it almost diluted the effect size of the latter!

*... Paying attention to people is ...*

The whole point about listening actively is that it involves showing that you are listening and even repeating back what people have said and showing that you have understood

*We had a waiting list for patients in primary care, complaining of anxiety and depression, to see counsellors. Whilst they were on it, one of our therapists would phone them once a month or more frequently, and some of these people didn't need counselling in the end! Just chatting to somebody who cared ...*

*There was a study a few years ago looking at peoples' experience of communication with doctors at all levels in the system, and their number one dissatisfaction was nothing about overuse of technical language or failure to explain things properly, but that they felt that doctors weren't listening to them.*

*NICE is very opposed to placebo. They go to great lengths to include only studies which deliberately exclude placebo response because they suggest it's not worth paying for a placebo response. It's frightening that we now have the prospect of NICE guidelines for persistent pain – we've already had them for back pain, sciatica and neuropathic pain, but they are all medication-based, and for back pain they also favour mind-body exercises. For persistent pain placebo is all that we seem to be talking about ... if you take away the therapies which are really vehicles for a placebo response; we do injections but actually that's not what works... it's the hope that it will work – the hope that comes with the needle. Sara touches them, I needle them, Carol kisses them ...!!*

We know that placebos activate the same pathways in the spinal cord as opioids and when you look at a lot of 'me too' kind of opioids they're not actually adding much. The end of life NICE guideline doesn't look at anything other than pharmacology (although they do recommend 'considering non-pharmacological methods for breathlessness etc., without any description of what these might be). Actually, a lot of palliative medicine is mostly placebo – simply care ... one reason they don't look at other approaches is because their resources are limited.

*Going back to listening: I had a client who had been in mental and physical pain for 25 years. I asked her what had happened 25 years ago, and it turned out that her husband had been shot in front of her and no-one had ever found this out before.*

*There have been open placebo trials where people know they are getting a placebo and it still works.*

## Creative Approaches to Palliative Care

Kate Binnie

Before I even came across the concept of total pain I was very aware in my work in a hospice that pain was more than a physical sensation, and that addressing the emotional, and spiritual aspects of pain could reduce the experience of physical pain. So my interest is in asking the question: how does working with non-physical aspects affect symptoms? That seems to me to be really important.

So how did I get here? I am on a journey and this is the thread of enquiry that I am developing. I started off as a singer and musician. My first degree was in English literature and music. For many years my parents practiced yoga so I was introduced to it at an early age. I got into it seriously in my thirties when I was having my children and also had a bad back. I had a previous career as music agent but after having my children I took a career break and trained both as a teacher and as a music therapist. I found that the music training was quite psychodynamic; the body was never really mentioned. I developed an interest in how it feels to be in a body, and how the body presents so much of our pain and suffering. The body is everything that the mind says. The two work together so now I work with the body, the breath, the psychodynamic stuff and with music as a mode of expression. Music involves the relationship between breath, sound and voice. I wanted to develop the ways in which that relationship could be used therapeutically, in palliative care, with children with learning difficulties who can't necessarily speak, with people with severe brain injuries and in dementia care.

There are many aspects of music care through which we can relate to people without using words. There is something about the voice that enhances relationships; it doesn't have to be words that people understand; it's the sound, the tone, the timbre, the shape and the phrasing of the voice that is so conducive to making connections and forming a relationship. Voice can be used for self-expression and for self-soothing. The breath seems to be a particular link to self-regulation and symptom-control.

I was in a hospice one day and was asked to see a very agitated and delirious patient on the ward while the nurses got some sedative medication for her. I sat with her, held her hand, and started to regulate my own breathing, and then invited her to breathe in time with me. Breathing in ... letting go and breathing out ... you get the picture. I started to hum so my breath became a sound. I didn't really have a plan – it all happened quite naturally. It was some sort of improvised lullaby in three-time (lullabies all are) and I was both self-soothing and soothing her. The nurses came back with the drugs but the patient had gone back to sleep.

I talked to my team about this and thought I better start some training, got in touch with Sara (Booth) and ended up going to the Cicely Saunders Institute in King's College London where I blagged my way in to do some research on pain. This took me three years (it should have been two but my father died) My thesis project was a narrative synthesis of mind-body interventions, particularly Yoga, for pain across nine conditions in the palliative care unit, and to build a systematic review of the management of symptoms in advanced diseases including heart failure, neurological disease as well as cancer. I looked for any evidence for Yoga in this context and of course there wasn't very much, but I did find a systematic review. The outcome measures that people used for pain were really interesting; they were not interested in the subtle concept of total pain for which of course there is no objective measurement. So, now I'm looking for funding to do my PhD at Bristol University, building on a theory of affect that I started to develop for my Master's, looking at what is happening when people breathe in a certain mindful way and notice that something is happening, and

looking at the role of the limbic system. And I am hoping to develop an intervention for breathlessness from this.

## Total Pain

Total pain defies objective measurement. When I was at King's I attended a lecture by a pain specialist on the advanced management of pain and she said: "Pain is a cake and if we can only treat half of that cake with drugs. ... she talked about Ketamine and Gabapentin and Morphine and all the other drugs and I was waiting and waiting for her to talk about the other half of the cake but then she packed up and left! As she was on the way out she was asked about the other half and she replied: "oh, that's the psychological stuff" and walked out!

'Total pain is a holistic concept that demands a phenomenological approach. I confess that I didn't know what phenomenology was until I met up with Havi Carel and her work. I came to understand that phenomenology is actually what I do and what I am interested in. We really need to be thinking in this way. We are talking about a concept that defies objective measurement, and needs this approach, described by Havi Carel as 'giving precedence to the *lived experience* and the embodied nature of human existence'. I recommend Havi's book *'Illness'* if you haven't read it.

## Embodiment

Everything you do, have done or will do, we will do in our bodies.

Walt Whitman

It's a revelation: I am in my body. We can't get away from that. People are living in their bodies. If the body is in pain what happens to me, where am I - how am I going to process it? I also want to think about breath as the foundation of our experience. The first thing we ever do is take a breath and it is the last thing we will ever do. Breathing book-ends our life; it is the driver, the engine, of everything.

Breath is the bridge that connects life and consciousness and body to thoughts.

Whenever your mind becomes scattered use your breath as the means to take hold of your mind again.

*Miracle of Mindfulness* Thich Nhat Hahn (Buddhist monk)

We know from neuroscience that the breath really is the regulator of other body systems. It is an emerging science but the ancient physicians knew it and now we are rediscovering it and putting people in an MRI scanner to prove it. (Which is great: otherwise this stuff will never be taken seriously.)

## Mindful Yoga

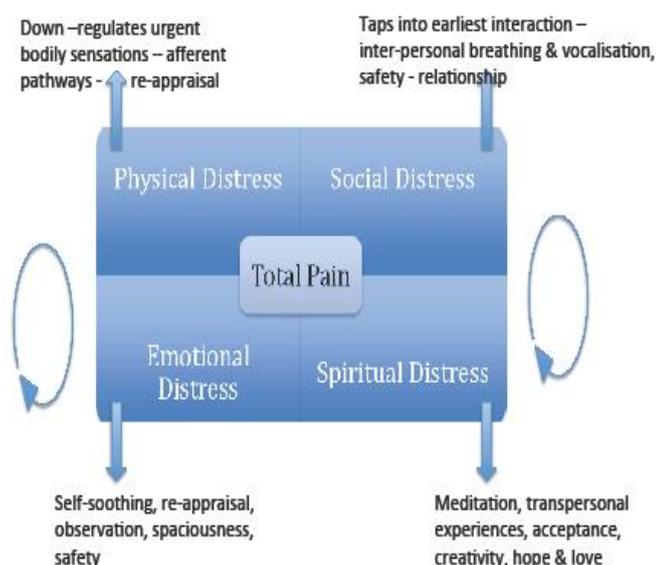
I don't have different hats; when I'm working as a Yoga therapist I use stuff from my music training. I focus on breath, meditation and concentration, mindful inner awareness and introspection. I also use Nada Yoga which is the Yoga of sound.

I have been running a group in a hospice in Oxford for six and a half years which can include people who are completely immobile, can't even move their heads or speak. I have recently done a qualitative evaluation of this group based on feedback from patients over the six years by collating the replies to a questionnaire. People reported that mindful Yoga helped them to cope and live with pain better although their pain scores may not be better.

This is a very important outcome but difficult to measure. People also talked about acceptance, relatedness, spiritual awareness, about embodiment and self compassion towards the body in pain, and about wellbeing and breath, that they found to be a 'tool for life', ("which I can use when I go into a scanner or when I'm lying awake at four in the morning or can't catch my breath or living with uncertainty ....")

When people are in physical pain mindful Yoga with a focus on breath can down-regulate bodily sensations, through afferent pathways. This is not a 'top down' cognitive behavioural approach; this is bottom up: body first, mind later. This is getting into the body and working with the HPA (Hypothalamic–pituitary–adrenal) axis. People can quite quickly feel better, like the lady in the hospice ward. Within a few breaths she was able to downregulate her urgent bodily sensations. I believe that the breath taps into the earliest interaction – the baby in the womb hearing the whooshing of its mother's blood and the sound of her breathing. When you hold a baby in your arms and make eye contact and breathe together ... this is a very deep and early safe space. When we breathe with somebody we are tapping into this and holding them in a very deep and simple way. In music therapy we talk a lot about 'mothering': the earliest communication between mothers and babies – the cooing, the facial expressions 'affirming' the baby. This allows the release of hormones, like oxytocin, involved in making a secure attachment. I firmly believe in working with people and holding them like this; the therapist teaches them something and then they can find something for themselves, useable daily for the rest of their lives.

## The management of total pain



I have created this model of the management of total pain, trying to illustrate these cycles of effect which I find in my research and correlate with my practice.

By spiritual distress I don't necessarily mean anything to do with religion – nor have I time to discuss the difference between religion and spirituality. But I do believe that spiritual distress is not talked about enough in palliative care. We have to find an inclusive language for this. The word spiritual can be quite worrying for some people: they either think it means religion or if you talk about Yoga they associate it with joss sticks or the occult. So I try to

create a space for people to find their own expression of what spirituality means to them; and allow space for that to flourish, whatever it is for that person. The way I work is aimed at enhancing creativity, hope and love. Patients often ask me what I believe in (with regard to dying) and I tell them that I believe in love, because I believe that that is the basis of everything.

We can relieve emotional distress by working together in this way to enable self-soothing; the breathing, the rocking as in a mother's arms

Facing death can be traumatic. People respond to fear and to the thought: I am going to die – to cease to exist, in a variety of ways which have been categorised as fight, flight, freeze and fold. The fight response includes anger and the urge to blame somebody or something. The flight response is expressed in many ways: anxiety, health seeking behaviour, looking for more drugs, crowdfunding, or running away and hiding. Freezing is the classic dissociative response: 'this isn't happening'. The depressive, 'fold' response involves 'shutting down'.

Working with the breath and the body immediately brings awareness to and then enables downregulation of urgent bodily sensations.

## Music Therapy

I have the advantage as a music therapist of having loads of time. Sometimes I work with people for two hours, during which I see the patient, the family and talk to the nurses. I'm not coming in straight away with my violin! – I am seeing what is in front of me: the breath, the body posture, the facial expression. Before I even listen to the words I look for these things that this person is showing me and that I can work with. That forms an immediate bond and the beginning of a relationship. We can then start to do the other work like talking about the past or what they are hoping for; what is going to happen next, writing a song for his wife or whatever. So working with the body and breath *before* cognition is the very key to this way of working. This may develop into play. As animals we don't play or make love or any of the fun things when we are frightened – we shut down. So there is something about making a safe relationship with patients and then allowing this creativity and play to emerge. A wonderful creative spiritual flowering can then occur.

Nigel Hartley, the distinguished music therapist, says: "creativity moves us on so I might not know what I think about something until I paint a picture or write a poem or a song about it". There is something about creativity that helps us to shift in our thinking and experience of something difficult.

We talk about 'tuning in' to someone in common parlance; we know when it is happening or not happening. You know when you are talking to someone and they are not listening. I find watching the breath is a very subtle way of tuning in to someone in a non-threatening way, and especially when words are difficult. I work with people with learning difficulties or brain tumours who can't express themselves or may say something different from what they intend, and for whom talking therapy is simply not going to work. So music is a gift in this situation.

Breath is a basis for inter, intra and transpersonal communication; that is, my relationship with myself, my relationship with you and my relationship with the divine. It is an extraordinarily powerful bridge between these. In therapy it may, but not always, become voice.

Allan Schore, an American psychologist, has written the unmissable book: ' *The Science of the Art of Psychotherapy*'. It looks at the theory of attachment between mother and baby and how to repair early trauma. I emailed him about my belief that non-verbal communication is extremely powerful and that it is subtle things, such as the way that we talk to someone – the

sound of our voice, and the way that we touch them, that are more important than anything else. I suggested that there was a huge connection between his work on mothers and babies and working with the ill or dying. He agreed: when you are working with someone right at the end of their lives and perhaps unable to speak there is something about relationship that we have to fall back on. This is important for all clinicians and something I feature in my courses at Sobell House.

I do a lot of work with musical “life review”: recalling significant events and people, exploring their impact, meaning, and relevance to social bonds. I see people for a period of about six months. They will have been referred to me, for instance by a palliative care community team, because they are struggling, anxious or having relationship problems. I get them to look back at the music that has been important to them in their life (like Desert Island Discs or the Inheritance Tracks). This can often be a way into my therapeutic relationship. Sometimes we make CD's of songs with good associations for them, like the one playing when they met their wife at a dance. It's a powerful way for people to feel 'I am here', I was here, this is me, this is who I am. Sometimes I encourage exploring fantasies. I met a man with a brain tumour who couldn't drive any more which he found terribly frustrating. He wrote a song with me imagining himself flying round the world seeing all the places he had never been to. We played this to his wife and it enabled her to find some joy in their relationship again as it spoke of their flying together over the Rocky Mountains. It wasn't just a bit of fun; it had far more depth to it as an intervention and her experience of his dying was held in a new and positive way, although it had gone on and on. I often write songs with people which can become a 'bridge' for bereaved families; the way how the period up to death goes can have an enormous impact on them.

I sometimes use Lullament, a mixture of lullaby and lament, which is very powerful and may reduce the need for sedation. (I have written a research protocol which I haven't yet got funding for) My experience of music and prayer at the bedside is that it is a downregulator of the anxiety shared by patients, families and staff, and can sometimes defuse a lot of tension and even anger.

## Two songs

*[which the audience heard recordings of]*

The first was written and recorded by an elderly gentleman in the terminal stages of COPD, telling his wife how much he loved her and how good their life together had been. It remains his wife's most treasured possession.

The other was by a young woman with three small children. She had been a nurse at GOS and had metastatic breast cancer. When I met her she had refused to come into the hospice but she didn't want to be at home either as she wanted to protect her children, so she finished up in a cottage hospital which was mainly used for rehab of elderly patients with hip replacements. The community nurses asked me to go and see her because it was one of those situations where everybody was devastated. She was unable to walk, she had suppurating wounds and she couldn't speak. She was just about able to write with her left hand. People felt that it was quite hard to reach her, but she had extraordinary dignity. When I met her she was sitting, surrounded by cards and flowers, waiting. I asked if she would like me to play for her, so I got out my fiddle. The way I work involves using my breath and mindfulness to 'tune in' to what I feel is in the room. When I played something on my violin she started to cry but I carried on playing. When I had finished she leaned forward, took my hand and we just sat there together. I carried on seeing her; sometimes her children were there so I brought my big box of instruments and we played together to her. But it remained

hard for me to get any closer to her. I used to sit outside in the car wondering what else I could do to reach her.

## Authenticity

Authenticity is something I value in my life and my relationships. I'm sure it is the same for all of us. A good death, for me, really has that quality of authenticity, honesty, communication and dignity which has been summed up as "forgive me, I forgive you, thank you, goodbye." When I am working one to one with a patient the breath and the music is a task that needs to get done. When we write a song the music between us is very much about facilitating that reconciliation. Havi Carel says that "serious illness is a violent invitation to philosophise". I think this work is facilitating that to happen. How people die really affects us and how we think about our own death.

What does this all mean in terms of funding in cash-strapped times? – paying for time, staff training, outcome measurements etc. It is a challenge to the deficit model.\* There are not many jobs for people like me because there is not much funding and not a lot of evidence which is why I am trying to evaluate and demonstrate the importance of my work.

A creative, relational approach offers meaning-making, empowerment, and engagement to the end of life and into bereavement.

The longer I live, the more I am satisfied of two things. First that the truest lives are those that are cut rose diamond fashion with many facets. Second, that society is always trying in some way or other to grind us down to a single flat surface'

*'The Professor at the breakfast Table'* Oliver Wendel Holmes

## Discussion

*... One of the many frustrations in my life is the endless meetings with commissioners that I have to go to and constantly having to justify why we provide the services in a particular way. There is a constant flux: can we do it better, can we do it cheaper, see more patients etc. etc.? I tried to make that process more fair to patients by bringing in a patient representative. She is the chair of our user's group and a very articulate and assertive lady who speaks with a quiet breathy voice; her whole demeanour is very effective and everything she says has a huge intellectual punch to it. She was devastating and had the commissioners eating out of her hand! Nobody ever thinks of bringing the patient into the room. If you have to have a confrontation with big scary consultants and big scary commissioners please bring a patient.*

We have talked about how we can get people – medical students - to be more empathic; and it's listening to the stories-that's how we learn. The emotional heft of hearing someone's heart narrative: that's what makes the connection. I have been invited to take part in training nurses at Worcester and I'm getting asked for more of this sort of thing.

\* This attributes public scepticism or hostility to science and technology to a lack of understanding, resulting from a lack of information.

*...Working with children...*

In Oxford there is a children's hospice and I have been asked but at the moment I don't think I can hack working with dying children; I have children of my own. But other people do and there is a big tradition of music therapy for children. I have worked with young people with severe learning difficulties.

*...I have worked with a young girl of 5 in primary school who had never communicated with anyone since she was at nursery. I said ... if I can work with her one to one I can guarantee that I can get her to communicate before she goes on to secondary school. ... I played contact games with her and got her to start to communicate. I read to her a lot. She started to get the odd words out and then to talk quietly to me, but she wouldn't in front of other people. I decided to make a recording and asked her to sing a little song for me. I asked her if I could let the teachers hear her beautiful singing and we got the class together and she agreed to let them hear her recording. Her classmates who hadn't believed she could talk started to talk to her and build relationships, so she came out of herself.*

When I was working at King's a dying teenager and his brother made an incredible film of snapshots of their lives including the unpleasant things like bloodstained sputum in the sink but also the music they made together and just talking. It was a brilliant creative project that showed both the anger and the bond between the brothers. It was only three minutes but it said something really powerful about the use of creativity to explore lived experience.

*I was struck by the similarities between your work with dying people and the use of music therapy for people with PTSD for which there is no conventional treatment. I have worked with PTSD although having had it myself in the past I can't work too closely with these people. It has been described as 'soul separation'; to recover from PTSD you have to reintegrate your soul back into your mind and body and music can allow that to happen. It seems to me that what you are doing is to allow the soul to separate from the body in a peaceful way. It struck me as a rather beautiful juxtaposition of two phenomena.*

I have never thought about it like that. This is my toolkit: my voice, my heart and I use it intuitively - and this is what I offer ...

*Do you think other people can learn to do what you do?*

Oh yes, lots of people. We all work in different ways. I train physiotherapists to use the breath so they can help people to relax. This is less about the music and more about relationship. Indeed it's all about relationship.

*Unfortunately qualitative material is not well accepted at the moment. I once submitted a paper about the lived experience of living in pain to the journal 'Pain' but it was rejected. When I asked why the editor (Patrick Wall) said "we publish all the time our lived experiences; we just put numbers in"!*

When I did my Master's at King's I was the only non-medical person and I felt like the token ... they had let me in because they wanted to show that they were open, but their thinking was essentially biomedical. It made me realise that there was so much work to do but communication is everything. I don't know what to do about the hierarchy in the pain fraternity and guidelines and all that. Perhaps one day I'll do a randomised controlled trial!

*We have to explain that these things cannot be approached by the RCT. It's just the wrong technology for this kind of experience, and we have to educate people*

*Your point about how the way you die affects other people reminds me of a paper in the 1970's on the sociology of depression and about trauma in childhood causing depression and problems later in life. Unfortunately healthcare economists only think about the short term. Qualitative data are becoming more acceptable and you can use so called mixed methods using both numbers and qualitative data, as we have done with the breast cancer service, to look at survival, and ask survivors about their experiences of what made a difference. That might get funded.*

I'd like to do that.

When I was in the middle of my Master's my own father died of cancer. Although I thought I knew everything that was going on and was bustling around saying "perhaps we should try more Morphine ...", when I look back on it, in the last days when he was delirious and agitated, even though I knew what was going on I was still totally freaked out by it. No-one came to explain or talk to us or hold our hands – it was a nightmare. I am educated in palliative care but I didn't know what the hell was going on. I think we can do a lot better.

*Patients get empowered about a lot of things. They get empowered about breast-feeding and their own pain control with PCA and so forth but the one thing patients and families are not empowered about is dying. It's a really taboo subject. There is no online support group or any information on the internet.*

*You might try one of the funding bodies that actually believes in qualitative work*

I am optimistic about sharing the perception that we can encourage people to feel: body first and mind later.

*Regarding nurse training: when I started nurses didn't need degrees but we had a lot of experience. What happens now – what I saw in my last hospice job – is that nurses come in and do a little time in a hospice and then they move on and do another course or degree – they never actually stay and do the work. So when it came to the actual dying bit they'd hardly ever been with dying patients. And the same is happening with doctors. They couldn't tell relatives what was going to happen because they didn't know. They just didn't have that kind of experience. It's often not the professionals that are actually there at the bedside. There is so much you can do in those last few days and a lot of it is preparing the family. The patient has gone beyond that. Of course you're going to do everything to make sure the patient is comfortable and not distressed, but the family were often awake and you had to spend a lot of time just talking to them. When I worked for Marie Curie a lot of my colleagues were care assistants, not trained nurses but they knew what the changes were going to be. They didn't need a PhD in palliative care to be able to talk to families in this way.*

If you don't know what is happening in any relationship ... when you know what is going on you can deal with it.

*My experience in general practice is that often you are not there when patients die but it's often the Marie Curie nurse and the District nurse that are. When I go I leave my bag at the door and sit down, perhaps have a cup of tea, and a chat. On the whole patients don't ask too many questions. Everybody knows something is going to happen. I've never been asked awkward questions. But the family know you are a professional and someone with authority there with them. You don't do anything wonderful other than just being there.*

## Living to Die: Deep Acceptance

Andy Graydon

What I want to help you to understand this morning is the difference between what is passing and what is lasting; what is fleeting and what is here to stay. To do so, let us begin with self-observation: our ego observing what the body and mind feels, thinks, and does. Our 'I-ness' observing and commenting upon our 'ME-ness.' I imagine most of us believe we do such observation most of our waking life?

Observation quickly alerts our conscious awareness that this I is not the same as that ME. The 'I' is mysterious, indefinable, unfathomable, but 'ME' is what we see, hear, and feel with our sensorium. What you say about yourself does not define you, it just provides a convenient label to describe the attributes of the ME. I am a doctor - I am a priest – a nurse – a Christian - a Moslem – and so on.

The actions of the psychophysical creature are apparent to all. However, the rationale for many of the creature's actions remain hidden from that part of our psyche which chooses one action over another. We do not even know where in the brain it resides; still, we feel the indefinable part exists. The mystics have always known this. They have come up with the question: how can the I observe itself? ... can the knife cut itself? Can the tooth bite itself? Can the eye see itself?

I work in mental health. Patients come into the hospital where I work and say, "I am depressed." Clearly, they are erroneously ascribing their dysphoric mental state to the observing ego rather than recognizing that it is secondary to the operation of their brain. What they really should be saying is, "My observing 'I' recognizes that this creature is experiencing a state of clinical depression at this moment."

The same holds true for euphoric states. Such as, "I am delighted." A properly educated observing ego understands that the creature is the source of the delight and not itself. Moreover, the observing ego has come to learn that mental states are transitory, arising like a wave upon the surface of the ocean and passing quickly if not re-stimulated. It doesn't last; nothing ever lasts, pleasant or unpleasant, all is transient and impermanent. The ME is always going to be a changing experience. Sometimes it will change against you; sometimes you might change it yourself. The I has no need to change. You can change your name but not this.

Some of you may remember Cat Stevens, a singer in the 60's and 70's. He was a Christian but became disillusioned with Western Christianity. He decided to change his religion. (By the way, religion is always a ME thing) He also changed his name from Cat to Yusuf Islam. Now you can change your name, your religion and your beliefs, but does this change the I? I think not. Changing these things might help you to understand a bit more who you truly are – your true essence - the depth of your being – in other words the 'I'. Discovering who we truly are requires moving beyond our attributes, biases, and beliefs.

Many of the problems in the world are due to over-identification with states and actions of our creature, the ME. Even religion can be dangerous, if you over-identify with it. It can become such a powerful thing in your life that you lose sight of who you are. You see this with fundamentalists, Christian and Moslem. At one time we had Christians saying to Moslems, "if

you don't change we will kill you.' Suicide bombers, what's gone wrong there? The beliefs in your head can become so obsessive that you lose sight of the I. Most suffering happens because we over-identify with the ME, the creature with its hates, desires, beliefs and so on. Pain is inevitable, but suffering is optional. It has been said that:

**Pain + resistance = suffering**

If we fight against what is - reality - we are going to suffer. If my pain is happening to ME and I say "this shall not be! – it's not right - it's not fair" the creature will suffer. If we identify with ME things we will begin to suffer in some way.

The book of your life:

I want to help you to understand a little more about the inner I employing a meditation on this book of your life. Whenever you pick up a book, you automatically see the words. But, behind every word there is the whiteness of the paper; often unnoticed, rarely appreciated, mostly ignored, but essential to hold the words and capture the story. I doesn't matter what the story is; it could be a war epic, a comedy or a romance – the paper doesn't mind. It will hold each word unconditionally.

The paper doesn't get upset when the main character dies; it doesn't worry about the ending of the story – it accepts it all without fear or worry. Your book of life – your autobiography – is not yet complete. From the perspective of the mind - the ME – your story is yet to be completed and your mind is working out the best way to end it. It wants to resolve the unresolvable; to tie up loose ends and fix things so that the story can be completed. As you get older, it becomes more involved. But from the perspective of the paper, your inner self, your true I, there is nothing to complete.

Let's move on to a film screen. It is called the Screen of Acceptance. When we shoot a movie and it appears on a screen, the screen doesn't mind - it accepts everything. Even when the main character dies, the screen remains active. When the main character is dying it is in no way diminished. It doesn't matter what the story is, be it a horror film, a comedy, a silent movie from 1912 or a blockbuster from 2107, it does not matter to the screen. The film will end, but the screen remains. It behaves like pure love; pure acceptance. It doesn't desire the movie, neither does it cling to it.

Pure love – pure acceptance: that's what you are, all of you. When we are able to accept whatever happens to us in our lives the ME, or the form that we get – the forms that we associate with are all passing. You know when you have met somebody you haven't seen for 15 or 20 years, one of you says to the other: "My God, what has time done to you?" – a few more wrinkles etc. - this is what time does. But there is another time for the screen.

[*producing a lemon, an onion and a potato well beyond their sell-by's*] This is what time has done to them. If you look closely and then look back into your own selves you will feel a connection. Of course we are living in a culture which avoids all this. You will never see these in a supermarket. Even in people's homes things get thrown away if they are past their best before's. Nobody ever sees anything last past its time or moving on – they don't recognise it. A nice fresh apple .. [*like this*] ... that's what we like to see. A fresh apple and a fresh 20-year old are fine but put 50 years on them are they become more like the wrinkled vegetables. That's important; that's what we are going to be like in many ways, and yet there are many people who are so totally and obsessively identified with their physical form that

they will do anything to keep it as fresh as possible – make-up and Botox and so on. But they often don't realise that they are exclusively identified in this way. They aren't in touch with the I – there is only this. If all the world was coloured green then the colour green would not exist, because there would be nothing to compare it with. If you are completely identified with form you probably won't realise it because you will have nothing to compare it with. But once you start recognising that form is going to resolve you are already on the road to liberation. Because you are aware of what is fleeting it means that there is something eternal present. The more we recognise what is fleeting and diminishing the greater chance we have of discovering what is truly important.

What is another word for what is diminishing? *Dying*. The difference between the apple, the lemon, and myself is that I have a flowering of human consciousness, potentially, so I can begin to realise that I don't need to be over-identified with anything. If you want to become free and at peace, then let the identification dissolve. The more you resist identification with labels and forms, the more you will experience the freedom and peace that is within you. To diminish identification with the composite of ME is enter the road to freedom, peace and liberation. Jesus said if you try to save your life you will lose it – perhaps that is the same thing.

Let's put this into the perspective of everyday life – like mine in the hospital. The main thing is that I'm not doing this for other people. I'm not trying to get people to think in this way, because when I get into this myself and live it out then I become a witness to others. I'm sharing this with you so we can reflect on it together. All of us are slowly dying. Death is already with you - it's catching up with you. The scriptures tell us to die before you die. Dying to the ME is an invitation to live more fully and with more freedom. Titles, labels, status – all these things we are attached to – are all going to die, but not what is essential: that will always continue.

I started off talking about self- observation It seems like only human beings possess such an ability fully. A dog looking in a mirror wouldn't recognise itself . (But then again when he was passing a mirror I am quite sure my dog Sammy stopped to admire his own reflection!) What an amazing gift it is! It's not terrible thinking I'm going to die when we have that freedom within us – when we appreciate this beautiful gift of life. And all of this have been given this – there are no exceptions. If you want to live as fully as possible die to the ME.

## Discussion

*When I go to these meetings and my friends ask me why I call it my existential angst meeting which I need to exercise at least once a year. You have got right to the middle of that: what are we, are we alone. My question is: firstly, why have you dichotomised I and ME; secondly, I don't know how you fit consciousness into that model.*

For me consciousness – pure consciousness - is one means to get to the 'I' - one description of it. You can play with words to try to grasp understanding: consciousness, pure spirit, heaven ...whatever. Those words are the nearest I can get to describing the essential presence – who we are.

*Do you think only humans have consciousness?*

I don't know. I'd like to think that consciousness is everything and we all come from consciousness. We are self-conscious; dogs are conscious, but perhaps not self-conscious. When I look out of the window at a beautiful scene, I'm not separate from that beauty.

Creation is expressing itself for the first time through human beings - it expresses itself through us. That is why we are so much part of it. We cut ourselves off from nature; in fact, we think we're above it sometimes which is why we destroy it. To me consciousness is embracing everything.

*I'm still unhappy about the dichotomy. But the other thing is what happens to the 'I' and the 'ME' in states prior to death, including dementia. My mother had dementia for many years: was she still there? – was her 'I' still there? That's difficult.*

There are a myriad of issues which are not easy to sort out. I have noticed that people with dementia (I work quite a bit with them), apart from the times of agitation, are living in the present moment. There is a sense of "I'm not getting tied up by this crap!" They are in one sense in terms of I want this or that but ... there is often a sense of real oneness with them. Sometimes it comes through in spite of all the messy things

*You don't think that consciousness is emergent from the brain? – generated by physical processes?*

I think it's the other way round.

*There is a new book out called The Cosmic Hologram by Jude Currivan which provides an explanation from physics as to why consciousness is universal and out there, and how the whole universe is conscious; it's not just our brains generating it. If you want a scientific explanation try and read this book. I can't understand a word of it ... [laughter] ...it's all about quantum mechanics. Her metaphor is of the universe as a hologram: an information hologram that we are connected to.*

*Are we then a kind of illusion?*

*Yes, I think that's her point - the physical is illusory.*

*Some animals can recognise themselves in a mirror. An elephant with a white spot painted on its ear will examine its own ear with its trunk when shown it in a mirror.*

*Where does memory come into the picture?*

I think brain function may be part of this. Memories come and memories go, weaken and change. It's only when you get hooked on certain memories that you're going to have problems.

*I think I'm thinking more about group memory. People who have lived through an event together ...[inaudible]*

... lived memory ... It's true of all indigenous tribes and cultures. There is a connection with all kinds of culture, whatever people are part of. Our ancestors are part of that too. We all retain some of that. There is a lovely story of two Americans: one asks, "are you voting Republican?" "No, I'm a Democrat – my father, my grandfather and my great-grandfather were all Democrats" ... "that's crazy logic.

If your father was a horse thief and your father, grandfather and great-grandfather were all horse thieves, what would you be?" ... "I'd be a Republican" !! It's like my family - they have always voted Labour.

*When you say that the 'I' is love ... I see love as an emotional concept and I'm not quite sure how it is a purely disembodied consciousness phenomenon. It seems like the I - consciousness is a neutral thing – it doesn't have being.*

Again it's trying to grasp the depth of it. Whatever love is it's something to do with the I. We've messed up love and made it into a ME thing. It's the same with God – God is a concept, a thought pattern but the true meaning of the word ... [...inaudible ...] ... it's an abused word

*What about humility? I'm the most egotistic person I know and I would say that for me the ego is ME?. I spend my life trying to achieve humility which I think of as that part ... that place of not having that ego state around ... not making those kinds of judgements ... just total love and acceptance of all. I guess my question ... is: could you use the word humility? ... we need words to understand things ... but I find words really hard.*

*You said you used this model to help you; do you use it to help dying patients?*

Most people are not ready ... unless they connect with what's going on to their lives at that moment and sometimes they can tune into that. Mental health patients are more difficult, but in the hospice where I work I do find this concept very helpful. Sometimes you can have a full discussion about it with people depending on the situation. It does work with a number of patients, but with some you just have to let it be.... Is that still denying it? ... Sometimes people are only going to find this true thing after death.

*You may not have to explain this concept to another person, if you are the 'I' present there in the room. The other person is relieved of the pressure because you are coming openly and accepting what is before you. Which is different from what we usually have: "are you wearing this watch or those posh glasses I can't afford ...you're not one of my kind". You immediately have these barriers, but if you have this openness maybe you are going to get through them. When we have what we can call a 'presence' in a room, and you feel that this person that is closer to the I than the ME that allows you to be less me and more I. You don't have to 'battle', to go back to these unhealthy terms that we discussed yesterday. You just accept and it's easier. When I sit in surgery what I am trying to do, without having to be really conscious of this concept ... when I have a patient come in to sit with me for 10 minutes ... unless I am completely I for them I'm not there in that room for them. When I've had a problem with a patient I am worried about often that happened because I wasn't really there.*

*You're probably not conscious of that. From childhood I have always wondered: why are trees green – why not brown or yellow? Is what I see real? What is reality?*

*When you were talking about being with a patient is that not letting go of ego? In a sense your focus is completely there, in that moment. Are you saying that that is your interpretation of the I?*

*I work with 'energy' healers and they tell me that you can't help other people to heal, and channel energy which is their usual metaphor, unless your ego is completely out of the room; you have to get rid of your ego as part of the preparation for healing activity, You are a healer and you (the speaker [above] who talked about humility) understand that. I find all these concepts quite difficult, but I sort of connect with the idea.*

*I'm wondering if some of the words we use cause problems. For example the word consciousness: if I'm working with junior doctors and I say consciousness they will quote the Glasgow Coma Scale; they are interested in someone alert who responds – a totally different word. So I was wondering if when you are with a medical audience sure they thinking of a totally different concept? I am also wondering how difficult it is to let go of the ego if you are dealing with a patient and what is in your head – and their expectation is that I am going to cure them. And you have that: I need to listen to this to see how I can cure them. Is that all mixed ...?*

Are you ... [inaudible] ... going to channel for it? ... humility again ... it's not you. If anything happens and something heals that's fine but you can't take any credit for it.

*Does the 'I' have agency?*

*'Suffering is optional' is an interesting idea but it's very hard to say to someone who is actually suffering. How do you help someone out of suffering by telling them that it is optional for them? – I know you wouldn't put it like that.*

I think a good example ... if somebody is in pain – physical or mental, emotional – you can soon discern if they are adding to their pain suffering by becoming the story of the ME. Once you can recognise that you can help them to accept what is happening and give them more energy to cope with pain.

*If people in their last days are going to take comfort from this is it necessary for them to believe that something of their I or their consciousness is going to remain after death?*

If they're ready for that. If it is made clear at some stage that it is what they need. You have to choose your words sensitively ... I wouldn't talk about eternal life to an atheist unless somehow it came into the conversation. Usually the dying process isn't conducive to intellectual conversations – but sometimes you can get people to appreciate that life isn't all about ME stuff. It all depends on their situation.

*Thinking about Kate's presentation and the Truro cathedral organist ... about relationship. I work from a social construction stance that there is no I without thou, however you construct that thou, be it your relationship with your primary carer or your parents or something bigger than that: the thou might be God or some life force, there is still a relationship, there is still a thou. And in any relationship, you have values, you have communication, you have responsibility for each other, be it God or your mum. But all the application we have here how you relate to your parents the music for the woman marooned on a desert island; that's about relationship, about connecting people up with those around them and the bit that's missing from your model is that there are no values.*

It's interesting you should say that as all my work is relational. More than anybody in the hospice my work depends on ...

*... but how does this model help this? ..... it's the relational stuff that sometimes makes the 'scaliness' of the 'I' more bearable. In a sense the 'I' is tremendously unfathomable – it's very ungrounded and the source of existential angst ... is it really just me? - the feeling of a streamlined consciousness underneath everything. The relational stuff is what gives us the opportunity to bear some of that great mystery a little more easily.*

*We'll never really understand it - the brain can't compute.*

*If you are having a relationship in a pure sense (of connection), in a way this isn't about the words it's something within you - a feeling that you receive or give; it's a meeting almost in another dimension .....being...*

*Someone asked earlier what happens in dementia. I am in the process of caring for my Mum who lives in Yorkshire, fortunately sharing this with my brothers and sisters. in the five years since we recognised what was going on. Sometimes she is there and sometimes is not. She doesn't care about washing herself, she wouldn't notice if her sheets were never changed, she doesn't clean her teeth ... and yet in a strange way she is very happy still. She is still in her own home, she still has her dog and her lovely garden – she gives bird food to the fish and goodness knows what to the dog, so that side of her is gone and the ME side has completely fallen apart. But in a strange way she is still there. She can't tell you what she has done. I take her out a lot and when we get in the car I put the radio on and she immediately becomes alive and says: "I know him ..." it may be 50's pop music she remembers dancing to or old wartime things... All the time I'm trying to find ways of connecting with her. She loves going out for the day but as soon as we get home she has forgotten all about it. But she is happy and I have realised that she can't relate what she has done or why she is happy; that's gone., But she is content in herself because she senses that she is loved, that we are there. She is in a safe environment with professional careers as well as the five of us. She has no reason not to be happy. And she picks up on this even if she can't express it. And I think there is a lot of that goes on when you are stripped of all the other things. She is surrounded by love in a very practical sense ... It's wonderful you see it that way.*

*Someone asked why you used the word love and you are coming at it from a religious point of view and as a Christian you would see it that way because God is love; in our purest form, when we are born, we are innocent and pure ...*

*...still are!!... It's the way we express it that's important. Someone else may see a big problem which needs to be sorted out ...*

*... but, it's not like that; there is still something there – the essence of my mother is still there even though all the other things have gone ...*

*It says more about you than about your mother. It means that you have come to accept quite a bit about this [the I ME model].*

*There is an idea that there is something bigger out there that we don't quite understand and perhaps this is what universal consciousness is. At some point in human evolution the numbers got down to a few thousand and we were under threat of total extinction from disease and whatnot, and it has been suggested that the ones who survived that are the ones that happened to have this concept that there is something out there that they could identify with and was helping, protecting and nourishing them They were the ones that persisted. Their immune systems weren't better but they had more social cohesion and they are us. We are the survivors – naturally selected out. So it may be an artefact that is not real but we have this strong sense of something.*

*Is there an equation there?(I + ME) Do we need to change the plus sign to a multiplication? I think it is critical that the I is very closely related to the ME, and the stuff we need to study includes relationships and also could be benefits, negation, compensation, accreditation, validation etc and that is what we see in the pain clinic – we see people with pain, yes, and they are suffering, but more and more as I go on am looking for reasons why people are not coping with their pain. Most people have exactly the same bodies and the same all round*

*problems but are not expressing pain and are not coming to the pain clinic. We only see a small proportion of people with pain and these seem to have some resistance or obstacles to coping. That is a very complex thing but it does seem to involve multiplication. If you can turn that volume control down with something like hypnosis, then it results in less suffering.*

You're right. If I'm ever do another session I would like to do the next one on self-confession. People often paint themselves ... for various reasons.

*When I was doing intensive care I looked after brain-injured patients. Is it the 'I' that leaves the room when the when the patient is no longer alive? There may be something ... animal ... subcortical ... there but I'm not sure how we get this information. You can look at someone on a ventilator and tell that they are dead.*

I would say it is the 'I' because the 'I' is not limited to the body.

*But can we then access the 'I' when the body is gone?*

The 'I' is not personal. That is what connects us all.

*But, it takes a form so it must leave a form, mustn't it?*

It doesn't take a form. Form emerges and then disappears.

*In our individual form do we have a responsibility to manifest that form in some kind of ethical way. If the screen doesn't care what is projected on it this would imply that there is no ethical responsibility.*

It identifies with nothing, but allows a parade of identities within it.

*But if the screen doesn't care you could project the Holocaust or the work that people here do on it. So, if the screen doesn't care where does the value come into what is projected on the screen?*

That would depend on your judgment. If you have been abused and messed about with over the years you may end up expressing that to others. Now ... are you responsible for that? I would say no. Through my own coming to understand my I more fully I know that the way through is not going to be too judgemental or condemnatory an approach, but rather trying to get the hang of pure love, forgiveness, compassion and healing. That would be my way of dealing with it rather than taking it on the level of good and evil.

*But, if the I is universal, you just said my I, so that must be between ME and the universal I there must be an individual I.*

What I meant was ME getting more tuned into that.

*I've had the experience since I was a teenager of knowing, when the telephone rings, who it is calling before I lift the receiver. I don't know if this is déjà vue or my mind playing games or whatever, but also if I am sitting reflectively and I have thought about a patient and decide to ring them and they say: "thank you for calling – I was just thinking of calling you. Is this tapping into the I, do you think? When I am receptive I can tap into this, but if I'm non-receptive; if I'm too busy with ME, with my own personal life events, work, I'm rushing around,*

*I'm about 95% ME. This is where our patients are and are too long in that place and have lost that connection.*

I remember once in the hospice there was a lady who was dying. I stood at the foot of her bed and she started saying "I'm coming home, Maria." I found out that she had a sister called Maria who had died some years previously. She told the nurses that she was going home tomorrow; they thought she was hallucinating but of course she was referring to her home in Heaven. Even in the dying process, sometimes that connection opens up the oneness of being.

*There is a big literature on near-death experiences of this sort which I find very convincing.*

*I had a very dear friend who was a vicar. He had a stroke and when he was dying in a hospice, everyone said "he's not making any sense". I sat with him and it took – in our time – half an hour for us to have a conversation. It went like this: (him) - "I don't know what to do". (me) - "don't know what to do about what?" "I don't know which way to go". "Which way could you go?" "Well, I could go to the east or to the west". "What lies to the west?" "Sarah" "What lies to the east?" "The others" "You mean Kate and Sandy." "I really think I need to go west." Sarah was his daughter who had died many years before. To me, as I was lucky enough to have the time and patience to try and follow the conversation, it made complete sense to me. He made his decision and he died a few days later. That was an extraordinary experience, and I think it says a lot about that connection.*

*People who are coming to the end can ditch a lot of the labels and as they are slipping away the formality goes ... and they are connecting ... but people visiting don't take that step and that is why they are so upset.*

## Coming alive at last

### Jeremy Swayne

All of us, I am sure, have been intimately involved with the dying and the death of loved ones, friends, patients, or even strangers encountered as victims of accidents or violence. We know very well the impact that these experiences can have on us, and on all concerned; whether they are timely or untimely events; expected or unexpected. Ideally we want to mitigate the distress and the loss, and the suffering if there is suffering. Whatever the circumstances, I suggest we want it to be, and seek to make it a healing experience. It will not always be so. But that is what we should aspire to.

At a conference with this title, it would be wrong for us to distance ourselves from our personal experiences of dying and death, because it is those experiences that will, we hope, make us better able to help others, and depending on our role better able to teach others; and help to bring some measure of healing into this inevitable climax of our shared humanity.

So to encourage us to reflect on our own experience, I am going to tell you the story of my brother, nine years younger than me, who died eighteen months ago at the age of 65. It is a story of how a tragic situation was transformed and a damaged person healed; and just one example of how skilled and compassionate healthcare, and the care of friends and family, made this possible. I am sure you will have many stories yourselves of different situations of tragedy and trauma, hopefully with similarly good outcomes, from which we can learn, and which you may like to share.

### Chris

Chris suffered from schizophrenia - undoubtedly compounded by drug taking at and after university. It was not severe, but as you will hear, bad enough to diminish his life significantly. His delusional thinking, and his dislike of the medical profession, and his refusal to countenance any form of social care, caused him to misinterpret, conceal and deny the symptoms and progressive effects of prostate cancer; which eventually metastasized to his spine causing cord compression and paraplegia.

I was the only family member who was close to him. Even though I had to invent some pretext to enable me to do so until he actually collapsed, I had the privilege of spending a great deal of time with him once he became ill. And of appreciating the quality of the care he received - from consultants to care assistants. This is the essence of the tribute I gave at his funeral:

Chris had a self-deprecating turn of phrase that he would use to cast doubt on the possibility that other people might actually like to spend time with him: "There's not much in it for them", he would say. And I suspect that if I had told him I would be talking about him at his funeral (let alone at a conference), he would have said the same - "There's not much in it for them!". But he would have been wrong. Behind the smokescreen of confabulation and delusion that could make it difficult to relate to him, was a very lovable and very interesting man. And the healing paradox of his illness and dying has been, I believe, his recognition, in the attitude of many of us who knew him, and of many who met him for the first time and looked after him, that this was true.

In hospital and nursing home he had people around him, and friends who visited him, who accepted him, valued him and cared for him. He bore the indignities and frustrations of his paralysed state with fortitude, and the kindness and skill with which he was tended and

nursed I am sure affirmed him in his own eyes. As the weeks went by he was able to speak to some of us of his hurts and regrets, and to let go of the obsessions that burdened him. And in the end, I believe he found a peace of mind that he had not known for a long time, and was perhaps free of the sense of waste and failure with which he tended to judge his life.

It would be easy to share his harsh judgement of himself – a schoolboy scholar and Oxford graduate with a first class degree in law, a very good student actor, no mean sportsman, and an attractive man, who spent the last 20 odd years of his life as a cleaner and virtual recluse.

But he was wrong to think like that; and so would we be. Because to do so would misrepresent the mystery and meaning of his life. Amidst the apparent chaos of much of Chris's thinking, which could be so bewildering when we tried to engage with it, were precious insights of beauty, truth, wit, and wisdom; even a mystical quality.

In years gone by I offered to distil some of these insights by editing his writing. And encouraged him to bring greater clarity to his work with a précis of his essential ideas stripped of the complicated narrative in which they were embedded. But Chris would have none of it. His stream of consciousness was sacrosanct, and he would brook no interference. Consequently the letters and manuscripts that many of us received over the years, and which he sent to a variety of academics and scientists, met with incomprehension. This must have been so disappointing to him.

But this was a trait in Chris that I came to respect. He was aware on some level of the mistakes he had made, and of his mental state; and of the life choices and experiences that had contributed to these. But reading between the lines of oblique conversations with him, I realised that he was determined to live out his life on his own terms; to refuse to deal with the medical and social systems that might have comprised his genius, for example. This might seem like stubbornness; cutting off his nose to spite his face. But I came to see his acceptance of a menial role, while devoting himself to his creative urge, as brave and humble; a mark, in fact, of self-respect and integrity. I came across this quotation from a psychiatrist in a recent edition of the *British Medical Journal*: "I went to medical school planning to become a GP", she said, "but I met people with psychoses. I was humbled by their courage, creativity, strength and humour despite a challenging illness and stigma." I believe that was true of Chris.

And his creative output was astonishing. His three main themes were:

- *Cosmic Conscientiousness, Human Power and Authority, and the Rule of Law*;
- his exploration of wave and curve form in his treatise *delta-Pi*;
- and his several volumes of historical fiction about Wessex.
- 

That's quite a vast realm of thought and knowledge.

In his few weeks in the nursing home, following his discharge from hospital and attempted rehabilitation, it was well established that there was nothing that he did not know, or upon which he did not hold a strong opinion! I certainly cannot say how much of his work was fact and how much was invention. But I have discovered the very considerable amount of research, and the huge amount of mathematical calculation (which I don't begin to understand), that underpinned it.

I have spoken before of glimpses of truth, beauty, wit, wisdom and even mysticism in his writing; a sense of some important reality running as a thread amongst all the apparent unreality. Many remarkable people who achieved fame have had to reconcile creative inspiration with a troubled mind. Chris did not achieve fame but he had to struggle with the same conflict, and I can well believe that he was at times in tune with that cosmic consciousness that he once wrote about.

He remained intellectually sharp to the end. He enjoyed watching and competing in 'Countdown', and answering questions in television quizzes. He consistently beat me at Scrabble. And when I taught him new card games in the hope of gaining some advantage, he beat me at them, too. He could be very good company and a good and amusing conversationalist; when lured away from one of his flights of fancy by a change of subject or a joke. He was witty, and had a good sense of humour. And the best way to bring him down to earth was through humour.

Chris had his abrasive moments, but was also very sweet natured. And for all his reluctance to be medicalised, when paralysed, and he could no longer escape being cared for, he was very appreciative and grateful; particularly to caregivers who attended to his most undignified organic needs. The care he received in hospital, rehabilitation unit and nursing home was exceptional; in particular the kindness, courtesy and patience of the unqualified care home staff.

I want to conclude by bringing you back to the essence of Chris; those special almost mystical insights that I mentioned. Much of what he wrote was not lucid. But he wrote a lot of poetry and some of this is completely lucid. His philosophical, mathematical and historical theses were certainly not lucid, but here is a paragraph from *Delta-Pi*, his book about the mathematics of Wave and Curve Form.

"Measurements and shapes are as mechanical as maths. But living things, creatures imbued with soul and spirit are far more subtle. They move with the breath of life which is somehow transcendent. Life forms develop in ways too profound for machinery. The spirit of life is composed of love too small. Thus it is that the language of curve, the language of waves can offer us means whereby to shield the limits of life's own inner wonder from the hard world knocks and shocks, lumps and bruises of mechanical toil. There has to be a small space left somewhere for sheer unadorned beauty."

And this poem, although it was written in the early years of his mental illness, many years before his death, is to me moving and beautiful, and prescient of the healing that he found at the end:

#### 'GOT TO GO'

Got to go, got to go.  
 Got to take my poor light to the darkness where it shows.  
 There I'll find some secret hollow,  
 Where I am sure the winds will follow.  
 There I'll plant a seed and watch it grow  
 Got to go, got to go.  
 Got to take the light of morning with me, make it show.  
 Got to find a place that feeds me,  
 Got to find the face that needs me,  
 There I'll feel my burden fall below.

This I know, this I know.  
 I must journey onwards out towards my soul.  
 Leave behind desires that bleed me,  
 Leave the signposts that deceived me,  
 Find the garden where my seed was sown.  
 Got to go, got to go.  
 I must find that secret garden where love grows.  
 High up in the walls of mountain  
 Lies the spring that feeds the fountain,  
 There the ring of light will surely show.  
 Got to go, got to go.  
 Where all fickle memories' waters cease to flow.  
 If I leave the past behind me,  
 Some tomorrow fate will find me,  
 Take me in her arms and free my soul.  
 This I know, this I know.  
 Somewhere out there, through the darkness, love must grow.  
 If I leave the thorns that bind me,  
 Leave behind the fears that blind me,  
 I will find the path that builds my goal.  
 All alone, all alone.  
 Travelling forever out towards that throne.  
 Through the mists and storms of sorrow,  
 Onwards to a new tomorrow  
 Where the Lord of life makes me his own.

That was read by our son, Oliver; one of the people who visited Chris during his final illness, and encouraged him to talk about his life and revisit some of his poetry. As a postscript, it was remarkable that two old friends of his youth who had drifted away from him because of their inability to cope with his strangeness, visited him just before he died. And to their astonishment, they found his conversation absolutely lucid and rational. Was this an exceptional example of syndrome shift, or what? I don't know.

## Reflection

Standing back from the poignancy of the whole experience, and reflecting on it, I believe it exemplifies something of the coming alive that we hope that we ourselves, our loved ones, and our patients might experience at the end of life; and the means by which being really well cared for can help to make it possible.

## *Medicine's responsibility*

Medicine cannot divest itself of its responsibility for healing and wholeness because its task is to care for whole persons with spiritual aspirations as well as troubled bodies and minds. Its task is not to prolong the uncomfortable existence of an aging and ailing body; not just to fend off premature death; and certainly not to delay timely death. But to help people to live as fully as possible till they die. A goal particularly well exemplified by the hospice movement; a practical demonstration of the activity of the human spirit in the service of that spirit; promoting life in the midst of suffering and at the point of death; helping people to *live* until they die. It makes real the proposition that 'dying is a spiritual experience with medical implications'<sup>i</sup> rather than the other way round.

### *Spiritual experience; medical implications*

Death and dying are adventures of the human spirit; whether or not you associate 'spirit' with God, the soul and an after-life. Birth and death are the two poles of our earthly existence. But the life that lies between those poles is more than mere existence, and to quote priest and journalist George Pitcher, "transcends our utility and function as biological human beings. Every human life is of unique and limitless value and should be cherished, treasured and defended, even (and especially) when that life is frail or vulnerable, oppressed or *in extremis*, or the object of contempt and marginalisation"

And it is healthcare professionals, with the help of the clergy, who have to bear much of the responsibility for affirming this.

At a previous conference I asked how this group regarded the almost universal habit of speaking of the 'battle' against cancer or some other disease. There was unanimous agreement that this is misguided. Healthcare of any kind should never be a battle that makes our disordered body or mind an enemy to itself. The war-like metaphor misrepresents the nature of the journey through illness and towards death. A journey that is our common experience; that should, in the broadest sense be a healing journey, and that it should be our vocation to assist.

Whatever our personal philosophy life is a journey, an adventure. Often, we hope, joyful, but always precarious; sometimes or from time to time tragic, fraught with danger or suffering. Medicine's task is to help people accomplish that journey and to live it as fully as possible when it is threatened by the afflictions that medicine is equipped by its science and its humanity to treat or contain. It is a journey towards some kind of personal completion. Medicine has a responsibility to enable that process of completion; if possible so that it does not end prematurely. But always understanding that death or disability do not necessarily render the journey incomplete or leave the person unfulfilled

## To let the patient live and die with dignity

Frida-Sophie Borge

How do you feel when you look at this picture?

*[a beautiful cold winter scene in Norway]*

If you are young you might want to jump into the snow, but if you are old and cold you might want to keep away from it. It depends on which eyes are looking at it.

*[Next a picture of a cliff]* Do you want to climb this?

Some of you might, but most of you would probably be very reluctant. However you can just see in the corner of the picture that there is a footpath round the cliff.

As health workers we have found that pathway, and can use our experience to tell people that we can help them around their problems.

*[last a picture of the Alhambra palace]*

We can all have a common feeling about this one in that this is a nice place to be. It is the same with human beings in sickness and their varieties of experience.

### Dignity

Dignity has been defined as “The quality or state of being worthy of esteem or respect” or “the importance and value that a person has, that makes other people respect them or makes them respect themselves.”

In his book *Defining Moment, To choose between right and right*, Joseph L. Badaracco Jr. maintains that we all have a moral starting point in life. He quotes Alasdair MacIntyre :

I am someone’s son or daughter, someone else’s cousin or uncle;  
I am a citizen of this or that city, a member of this or that guild or profession.  
I belong to this tribe, that clan, this nation. I inherit from the past of my family, my tribe, my nation, a variety of debts, inheritances, rightful expectations and obligations.  
These constitute the given of my life, my moral starting point. This is in part what gives my life its own moral particularity.

That is our starting point; what is ahead of us? Are we like lambs who know nothing about our future? Or when we look at a gravestone do we get the message that we will be the next one? Do we look on life as wide open or do we remember that there will be a closure? This perception is crucial. Do I have that vital lesson of life before me?

The Danish philosopher Søren Kierkegaard wrote regarding suffering:

In order to help another effectively, I must understand what he understands. If I do not know that, my greater understanding will be of no help to him ... Instruction begins when you put yourself in his place so that you may understand what he understands and in the way he understands it.

We all know the IASP definition of pain “*as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*”. Cicely Saunders recognised the inadequacy in the care of the dying that was offered in hospitals. So often, patients and families were told that “there was nothing more that could be done” which Dame Cicely refused to accept. Throughout her time at St

Christopher's her watchword was "there is so much more to be done." She introduced the concept of total pain: physical, emotional, social and spiritual or existential. These are all important in our behaviour and also what we experience of sickness or pain.

Are you a participant in your life or do you just watch it passing by? We have our personalities also in sickness, and also our emotional response i.e. how do we deal with our problems and experiences? Also how we are taught to react when something happens. All of that will play a part when we experience pain and suffering.

You will see in this model, which we use in our pain clinic, that wellbeing is in the centre, as it is in so many areas.

The book *The Primacy of Caring, Stress and Coping in Health and Illness* by Benner and Wrubel (1989), made an important contribution to my education as an anaesthetic nurse, stressing as it does the importance of the patient's situation, what you need to know about the patient and her background to be able to help her. Benner describes five levels of nursing experience: novice, advanced beginner, competent, proficient and expert. The basic structure of Benner and Wrubel's approach is that real nursing practice is a "caring art" based on ethics. The primarily ethical world revolves around perception and a "universe of meaning" that is at the root of such terms as "health" or "illness". In many cases, these terms are relative to the situation the patient finds herself in, especially the patient's mental state. The meaning of "care," "expertise" and "health" are embedded in actual practice. Care in this context means helping a patient "cope" with all the stresses of illness rather than just following clinical protocols.

The real upshot of this approach to nursing is the basis for all nursing practice. The body of the patient is more than just a set of anatomical variables, but it is also a part of a broader social and mental sphere that is as much a part of "health" as anatomy. Peace of mind, for example, can be just as important as actual physical bodily health.

Benner draws a parallel between this and research into the training of airline pilots. They have prescribed routines but these may have to be abandoned in an emergency and they may have to eject. The same is true of nursing: if you want to become an expert you may have to learn to jump from routine (including 'measuring' pain and evaluating treatment with all the scales and algorithms that we are too familiar with), to concentrate on what is most important to the patient at that specific time.

## Case History

Patient C was a 69 years old widow, with five children and eleven grandchildren. Her husband had died six years before. Curative treatment for her lung cancer had been abandoned, and she came into our hospital in terminal pain. Her scans confirmed metastases in her left hip and thoracic spine.

She came from an care home for the elderly with poor facilities in advanced palliative care. Her pain was managed just with an opioid patch.

At our first meeting she was silent and was overwhelmed with pain. Only the doctor and I were initially present but we explained that our whole staff of psychologist, priest, physiotherapist, social worker and nutritionist could be called on if she wished. She did not feel she needed any of them, not even the priest.

The doctors responsible for the ward she had entered planned 5 doses of radiation, but our senior palliative care persuaded them to just give one dose each to her hip and thoracic spine. He also ordered a continuous s/c infusion together with multi-modal analgesics which gave an improvement.

When I next saw the patient, on Friday around lunchtime, she appeared to be pre-terminal. She looked at me with the most wonderful eyes, which I complimented her on. She smiled, and I assured her we would help her. Her daughter was at her bedside. She was happy with her mother's treatment but told us that they wanted her to come back to the elderly home near where they lived so they could more easily visit her. They also had experienced good care from there, at the time their father died. We advised that she should not be moved until we could see that her pain was controlled over the weekend.

On Monday she appeared to me to be terminal. The senior doctor at the ward had given the family permission to move the patient to the elderly home if they wanted to. Her granddaughter, a young girl of 18-20 was in the room. She told me that she was training to be a care assistant. The family had planned that there would always be someone from the family with their grandma. A younger grandchild who was sitting in the corner colouring in a book, looked insecure and said that the family wanted grandma back to the other home, and looked at me to respond. I told her that we should ask the most important person, her grandma, what *she* wanted.

When I came to the bed patient C opened her eyes, recognised me and answered my hello. Then she fell back to sleep. She was so weak that she only had at the most 10-20 seconds responsive time before resting. I asked if she had a wish to move anywhere else instead of being here, she answered clearly '**no**'.

I was silently looking at her, her eyes were closed again ... Then she says ... "It takes me so long" ... I asked, "what takes you so long?". No answer, waiting.... I asked "is it the sickness?" She nodded, ... "is it to die?". She answered weak but clearly... "Yes". (Her granddaughter was crying silently...) I waited.... The patient seemed to go into herself, almost as her words went deep down inside her. I waited to see if there was more to come...

I repeated the question about the priest, but she answered, "no, not yet, not necessary." Then I asked, Is it ..., is it too silent? ... too tedious? She opened her eyes and looked deeply into my eyes. They were still crystal blue with a lot of sparkles like diamonds, still showing power and intelligence. I really wanted to lighten her mood from her deepest thoughts, so I followed the same tack and I complimented her on her eyes again - almost flirting. "I think you have had tons of compliments for those eyes throughout the years?" She melted totally, ... and gave me a big smile.

I asked if she normally listened to the radio? Then the granddaughter replied from the corner that Grandma was very lively and always had the radio on, especially Country music. She did crosswords and had a lot of those books you know with synonyms. She loved playing cards and hated losing. Grandmother and granddaughter both laughed. I wrote in the notes that the patient does not wish to be transferred.

Next day the patient's son and another grandchild were there. The TV was on a bit loud and the little boy was toddling about ... just like home! Another doctor from the palliative care unit went to turn off the TV. I told her about yesterday, the conversation we had had and as I was telling her I saw in the corner of my eye that the patient's eyes were shut, but she was smiling.....

That evening she died peacefully, and I would say, with dignity.

## Discussion

*I liked the way you mentioned context. I was recently in hospital to have a hip replacement and I had to fill in a five page form and I was asked what religion I was so I put 'shopping'!*

*Nobody ever reads those forms but they use them instead of making a connection. There is no follow-up to these huge things.*

*One thing that came across very strongly in your talk, the music therapy talk and Jeremy's*

*paper was that communication is often missing and you made such a difference. I know in my personal life that two or three people have died and I feel that I never really got to know them, which I very much regret as I could have got a lot from knowing them better. Jeremy was obviously very close to his brother but still ... how much more would have come out had there been more communication earlier. We are very insular as individuals. The 'I's need to come together.*

... It was very clear that that grandchild was insecure and sitting in the corner not connected with her grandmother at all...

*We were talking yesterday about social media and the way the technology we have now perhaps means that we are not communicating about the things that really matter. This is a challenge for us.*

You have to have the experience and you have to be able to tune in: it was a scary moment when I saw her eyes turning inwards and I thought - what is going to happen now? She was so weak ... but I wanted to bring her back to something positive. Was this the right thing to do?

*You waited rather than coming in with something to cover your own embarrassment and that was a beautiful way of just being with her ...*

*... rather than being professional ... you put that role to one side ...*

*... words can get in the way. I remember St Francis of Assisi said: "Preach the Gospel at all times, when necessary use words!"*

*Basil Finer wrote a brilliant paper in the nineteen fifties about good contact.*

*I've often wondered how people who work in hospices cope with frequent contact with people who are dying. One way is by being detached, but you were clearly very much involved and I wonder if you derive from this some sort of energy to keep going? Energy may not be quite the right word but do you see what I am driving at?*

Yes - and the patients immediately know if you are interested in them ...

*... but how do you look after yourself? ...*

The Vikings cried a lot! This was a beautiful moment of achieving something ... you bring it as a gift. If you work in a palliative care unit you must look for the positive differences you can make. The doctor who was with me is quite high in the hierarchy so he has influence. Very often we are like a rescue team – often patients are treated and treated and we come in and ask, "isn't it time to stop?" We ask questions to make them think. The patients don't have to take all the tablets and treatments in the last days of life. They can stop all the treatment and fluids etc. ...

*(Inaudible) ... when breathless patients are seen by ... all the time is taken up by measurements and actually if the same amount of time were used to understand the patients' experience and what they really need – it's not the time but the way you use that time ..... They just want to chart respiratory decline so they go back every three months for more measurements...*

*... Havi Carel talks about her dreadful experience of this ...*

*If you work in palliative care and are frequently intimately involved in situations such as you*

describe – sometimes two or three times in a day – people ask you: how on earth can you work so closely with death? But anyone who works in hospices or palliative care units will say they are the most amazing places to work in. People are very positive and very supportive. You are working with a team of people – whether they are the kitchen maid or the cleaner, the care assistant or the consultant – everyone is there because they have made the choice to work there. They love what they do. One thing they do have is the time which you don't get in the NHS so you can have conversations with people. A lot of it is intuitive ... you know your patients, and you obviously do a lot of listening. But as for coping – we supported each other. There was access to a psychologist if you felt you needed this and there were group sessions for staff, especially after difficult deaths like patients with NMD who chose not to be sedated – that is a terrible thing to have to witness, but you were doing what the patient wanted – and there was always support.

On a personal level it helped you put your life into perspective. We all had our lives 'outside' - I was widowed while I was working in a hospice and my consultant insisted that I take a year or eighteen months off – and I had an interesting experience after I came back with a patient with a glioblastoma, the same as my husband. I was often asked to look after these patients as it was felt that I would have useful insights but I didn't tell the families that I had been there. Some time after one of them had died I met his wife and she told me that she had found out that my husband had also had a glioblastoma. She said: "I always sensed that you were ahead of us all the time, and always thinking of extra things which would help us to communicate ... I wish you had told us". That surprised me because it's not considered appropriate to disclose something like this, but she said that she didn't feel that anyone else understood where she was coming from in the same way, and it would have been helpful to know.

I had a half-hour journey home and put some music on - this was a wonderful opportunity to get my ordinary hat back on: I had four children and a lot going on at home. I am a Christian so I used to just offer it up. There were things I couldn't resolve and things we couldn't change. But the work has given me an incredible zest for life - the things I do with Jumbulance are a continuation of this; helping people to live right to the end. So it hasn't made me a miserable person – quite the opposite.

We have a good team with outreach to the whole hospital, not just the surgical unit. We have an outpatient pain clinic, palliative care and we also do outreach to the medical, geriatric and surgical units. It's a small hospital so the team is quite tight and cohesive. We have a little joke amongst ourselves which helps us to cope and we call it 'oversharing'. The first commandment of the pain team is 'Thou shalt not overshare' which means that you're in the room with the patient to be, to listen, to witness, to hear what you have to hear from them, but you're not there to disclose. You can be empathetic and compassionate, but you don't have to disclose to have a good therapeutic relationship.

Can you share their distress?

You don't have to share it – you just have to witness it.

But it's difficult not to if you're human.

Do you know the phrase "detached compassion"? (or compassionate detachment - that you can witness suffering without getting involved in it. It's a practice like mindfulness, which allows you to witness and appreciate the suffering that a person is going through. But it's theirs, not yours. You're not coming from the same place as them.

Can I ask both of you involved in this wonderful work with death and dying? The problem of burnout in the medical profession is now huge, particularly in primary care. One might think

*that is because there aren't any support mechanisms any more - no sharing of problems as Chris was describing. Does anybody know whether there is more or less burnout in palliative care than in the rest of medicine?*

*There is, which is why we set up these systems*

*[inaudible comment]*

*Everyone should have outside supervision. This is priceless - you can go and say anything you want and really unburden ... I don't know why it's not done more in your profession – something to do with macho-culture?*

*In my profession we have to pay for it ourselves.*

*You said outside supervision. Where inside supervision is provided people don't go to it because they see it as part of line-management. It's an area that chaplains get involved in because people would rather talk to them than a manager or supervisor.*

*We have a priest in our team. We do an hour's 'reflection' with him every other week, so if someone has something on their heart, they can talk about it.*

*We're required to do CPD ... no-one running a marathon would dream of doing it without going to general training. If you aren't taking care of your emotional life, you're not doing the training. You have to practice that: allowing yourself to hear and feel and get involved but at the same time be available to all the other people who need you.*

*For so many hours we have to do so much supervision. We have to pay for our own supervision so if it's not provided you have to go out and find it – and that's going to stop people being burnt out.*

*The Faculty of Pain Medicine of the Royal College of Anaesthetists is setting up a scheme for mutual mentoring. You can choose to be a mentor or a mentee, or whether you are happy to be both. It's a way of connecting people in different Trusts, presumably not too far away. That wouldn't cost anything and both parties could get a lot from it.*

*We actually initiated something like that from this group about 15 years ago! I was wondering whether to some extent burnout in general practice and in health professionals generally, is not so much the workload as the sheer frustration of not being able to do the job you thought you were paid to do. You know what you want to do but haven't got the time or facilities to do it.*

*There is a website you can get off the BMA. Burnout is very clearly not just for doctors, anybody can go on it they have an inventory and a scoring system (which I don't like) to reflect on. The questions are fantastic like why do you do what you do, is it what you intended to do, would you recommend it to a third party ... you don't have to provide answers. It's just mulling over the questions which is so helpful in making decisions. Sometimes there are answers. I was working 12 hour shifts and I had an hour each way to travel and I just couldn't do it any more. It's a bit like a frog and hot water: if you throw the frog in the hot water it will jump out but if you heat the water very slowly the frog will be cooked. I think this is what has happened in a lot of the clinical professions and scenarios that the workload very slowly creeps up over two or three years until there isn't enough time in the day to do all the jobs that you are supposed to be doing. This is the way to burnout. This can be a very difficult time to make decisions because you can't change the*

*environment. By the time you realise you have a problem you are too tired to have the energy to change anything. This is often why people are in crisis. They are sitting there and have forgotten the bigger picture.*

*I wonder if people would agree that the best antidote to burnout is job satisfaction and if people are denied that it just aggravates their problems.*

*In primary care it's the sheer volume. You get there at 8 o'clock and you are on the go all day. You eat your lunch with one hand with the telephone in the other, you don't stop and you are still there at 7 or 8 o'clock at night. You just work and sleep.*

*As if ploughing through the work all the day you have incidents like one. I had in a rural practice where I had spend an hour and a half to go out to a dying patient in the middle of the day.*

*One of the things I have seen in mountain rescue is that there is no exit interview because of time pressures and no-one knows why someone is stopping. The team based in Ambleside are doing three or four call-outs a week in the middle of the night and people give up because they can't keep doing it. The same is true of hospitals that I have worked in because the staff decide the pressures are just too much and they are going somewhere else. But no-one actually asks them why. If they did they might do something about it.*

*In our hospital everyone has an exit interview but it is private so the people that need to know don't know.*

*I think another feature of this is lack of control over our lives. Our profession in general feels it's got less and less control. I just feel and hear that in palliative care you have kind of figured this out a bit better than the rest of us.*

*That brings us back to the **I** and the **ME**: the **ME** that we don't have control of takes over and becomes dominant.*

*As doctors we are very much imbued with the idea that we mustn't intrude on the vulnerability of the dying patient by proselytising or such-like. In my experience of being with dying people they virtually never say anything particularly profound and I just wonder if they would have if had they been given the opportunity. But without asking questions? Also there is this cultural approach that, unless invited, you don't discuss the fact that they are dying. Can you suggest guidelines as to how you think we can give the patient permission to do that?*

*I try to find something to complement them on the first time I see them. That, or something like commenting on a picture by their bedside, very often opens a connection. If I greet them with something positive they give me something positive back. It connects them to something outside the hospital and all the stuff about their treatment. It is also important to sit down. The patient gets the impression that you have spent much more time with them if you are sitting than if you are standing. I will ask a them if there is anything they want to talk about but I don't usually mention dying.*

*You have to know a bit about the patient, their context, to be able to use metaphors. You have to tune in on every level.*

*You recounted how when you said how beautiful her eyes were she smiled. Someone dying may be only able to communicate using their eyes, but people didn't want to give time for this, and then how helpful the family had found this approach.*

*It is said that 80% of communication is non-verbal*

*Do you facilitate dying at home? [in Norway]*

The problem is that people - families - get scared. Even if the patient has four hours of professional nursing that still leaves 20 hours when they are on their own. The extended family nowadays is often widely dispersed.

## Contemplative Care

### The use of skilful means

#### Narapa Steve Johnson

I'm here because I got an email a few months ago, by quite a roundabout route via Buddhist centres in London and Manchester, looking for someone to give a talk to this group. I asked Maureen what she wanted me to talk about and she replied: "whatever you think is important - whatever you are passionate about." So I thought I would say a little about Buddhism and a bit about some work I have done which makes a link between Buddhism and healthcare.

People have been asking me about my name Narapa. Steve Johnson is my birth name, and about ten years ago I was ordained into a Buddhist order and given this name. You are given a name either in recognition of the qualities you have or qualities it is thought it would be good to aspire to. I am fortunate in my background in healthcare which started as a military paramedic 45 years ago, and I have kept a link with that ever since, and I am now a trainer for mountain rescue. The name Narapa means protector of man. (That means man as a species, not as a bloke!) I do some work in the NHS as chaplain for three hospitals in Lancashire. I tend to work in the mental health units in these. I also work with an organisation called Breathworks, a charity concerned with mindfulness for health, and with my own business Tao Mountain. A lot of people see their pain as a big overwhelming solid object like a mountain, and yet, and as we have seen here over the last couple of days, the mountains change all the time.

#### Basic Buddhism

All Buddhists are taught the Four Noble Truths:

- There is suffering
- There is a cause to that suffering
- That cause can be removed
- The way to do that is to follow the path

The first is the one that gives Buddhism a bit of a reputation. At the start of his teaching the Buddha said: "there is suffering". So people say: "Buddhists – aren't they a miserable lot? – all they think about is suffering." Well, they are not. One of the issues is that the words used in the ancient Hindu Pali language don't actually transfer well to British English. Some people get hooked up on the Buddha's apparent preoccupation with suffering. But when you think about it, Aryurvedic medicine has been around for five thousand years. The man who lived 2,500 years ago lived within the Hindu tradition of Aryurvedic medicine. Aryurvedic medicine says there is disease with a cause and if we can change the cause we can remit the disease. Buddhists learn, and you can see that there is a bit of a pattern here, that there are three marks of existence, of life:

- Suffering (dukkha)
- Impermanence (annica)
- Insubstantiality / no- self (anatta)

These are directly linked to what I am going to say this morning and which applies across all spiritual traditions: this idea, this word for suffering, called Dukka in Pali, which is better

translated as 'constantly changing'. The other idea is that nothing is permanent. This building wasn't always here. These hills are beautiful but the fields, the walls and the sheep are man made. There is this concept that nothing is fixed. There is no fixed self. There is no independent self: we are totally interconnected with everything around us.

So we have the four noble truths, we have this idea that there is suffering, and that everything is impermanent.

The last truth is that there is a way of dealing around suffering. That way is normally called the Eightfold Path:

Right Action	Right Effort
Right Livelihood	Right Speech
Right Concentration	Right Understanding
Right Intention	Right Mindfulness

The purpose of pursuing the Eightfold Path is to achieve a state where there is no suffering: Nirvana. It's not heaven or anything like that; it's just a place which people achieve that when they opt to stay around to help everybody else.

It is also sometimes called the threefold path:

Morality	or:	Ethical Behaviour
Concentration		Meditation
Wisdom		Wisdom

I like that way of thinking about it because it is very hard to meditate if you don't live ethically. It's very hard to be wise if all you do is rip people off. It is hard to be still if you don't live ethically. There is a danger in trying to hold these separately. You can see some building blocks for people to live an ethical life



Right livelihood: most people go into medicine or nursing or care because of their calling to help others. Are you actually following your calling and doing the right thing?

Right Intention: are you committed to helping?

Right Speech: are you saying the right things? Notice it says the *right* things, not are you telling the truth. You might try to be truthful but this person doesn't want to hear the truth at this time, so right speech may be saying something that helps the person to move on.

Right understanding: this is an important one for health care people. Are you seeing what is actually there or what you want to be there? We have been talking about looking after people and looking after the carers. Are you pushing yourself enough, not enough, or too much?

The story goes that when the Buddha first stood in front of a crowd he held up a lotus. The lotus is a really tight ball that lives in the mud at the bottom of the pond – all that existence stuff – and it gradually reaches up and lets everything drop off – the water, the mud and the grit, until it blossoms into this beautiful thing. That is the concept we are trying to get over.

## The language of Buddhism

When I first started looking at Buddhism I wondered why we had to keep using these Pali or Sanskrit words. I remembered that having gone to a Jesuit grammar school where I learnt Latin I was actually really disappointed when they stopped teaching Latin because for me there was a mystery behind it. I feel the same about Buddhist terms. There is an issue about how they translate e.g. to 'conditioned co-production' There is a whole phrase in Pali which translated sounds a bit odd, but says "this being that arises from the arising of that which arises ceases to exist on the ceasing of that which ceases". Basically it means that I am here because of all the stuff which has gone on around me. If any of that stops this being would not exist. This is much the same as what Andy (Graydon) was saying about forms and labels.

So what is the point of all this and how does it start to link? One of the things that Buddhists practice and one way of helping others is by reaching certain states which are commonly called the 'sublime states'

Metta - kindness

Koruna - generosity

Mudita - joy

Upekkha - equanimity

People start learning mindfulness with breathing and body scans and things like that. Those meditations all start with yourself and being kind to yourself. But the sublime states involve going out to reach others. It's very interesting that that is the highest state. To me, equanimity is the place where we love suffering and are able to hold everything that's happening. A bit like the woman on top of the Old Bailey with the scales of justice, able to balance everything. The word skilful in the title means: how we go out and reach people and help them to move on from suffering. People think that Buddhism is full of weird stuff and it is – until you start to understand how the weird stuff has come about!

This figure is called Avalokitesvara. It's not a god; in Buddhism there are these figures which are more like role models.

Just as when Christianity came to Britain it assimilated a lot of pagan festivals, when Buddhism moved from India to Tibet it took on a lot of their traditions including shamanistic stuff. The idea is that this person tried to help everybody but there were so many people

needing help that his arms exploded and sprung into a thousand arms. If you look closely you can see that in the centre of each palm there is an eye. So the idea is that if you reach out to someone you can actually see what they need. And then the myth goes that he was so concerned with helping people and so many people needed his help that his head exploded so he has thirteen faces.

If you forget the mythology and think 2500 years ago: "I've got an audience of uneducated people. How do I teach them about generosity and kindness?"- this figure represents compassion. Isn't it a great example of compassion – how to reach out in every direction and help people?



Conceptual is the 'thinking' bit, which often involves catastrophising; 'oh God, my life's over'. Experiential is all the things to do with our senses.

The idea of mindfulness practice is to recognize where people are normally at and where they are doing lots of overthinking of everything and move them into an area where there is a lot of sensory experience as well. You're not saying "don't do that" – you're saying "this will help". If it works you get comments like this:

"[Now] I try not to get too hooked on the diagnosis; I just think, well, "What is my experience in this moment?" I don't think, "What's it called? - What's the label?"... I think there comes a point where it can be very liberating, to get away from the labels."

"I found if you give pain space it's a lot better, rather than trying to get rid of it, 'cos then you build emotions up and things tense and this brings more pain on."

"It's only now that I'm actually learning to breathe into the pain rather than tighten around it...living with pain means learning this difference."

Andy was talking this morning about pain x resistance = suffering. There is a Buddhist teaching on this: the image of two arrows. When the first arrow hits you get pain, but when you start to resist that pain it is like being struck by another arrow.

If you stretch out your arms in front of you and clench your fists tighter and ever tighter your arms will begin to shake – and you may notice that you are holding your breath. If you focus on the breath it won't happen.

Sometimes, for example when I am working with kids, I will say: "OK, stand up and make yourself into a robot. And they will stand rigid. Back in the 50's, if you are old enough to remember or have seen films of the era, people at school or in the forces were told: stand up straight, head up, chest out, stomach in ... you can't breathe! People in pain often hold themselves rigid to try to 'contain' the pain.

" My pain was so solid – everlasting. The perception I got through the course was that everything is always changing including my pain. That helps me ... it gives me a life that is liveable."

## Nature Connectedness

When people come on my course I ask them to do a 'sense awareness inventory'. You have a column for each of your senses. Under each column you write down the things that make you smile, make you happy or give you pleasure, or make you feel good. Some of the things on the list may fire off each other: you may like the smell, the taste and the texture of fresh bread, so it goes in each column. You may find if you are doing this with clients or patients, that there is an area they have real difficulty with that they are pushing away from. For example, people in pain may want to avoid touch, so some of the work I will do with them, for example outdoors, feeling a rock, is relearning what things feel like – to help them to develop the touch column.

It's interesting to see some of the insights that can come out of a tool as simple as a piece of paper and a pen. If these are the things that make you happy and give you pleasure, how

many are free or low cost? And how often are you doing them, how often are you noticing or engaging with them?

That is what I start my mindfulness programmes with. There are various definitions of mindfulness and the one that I use is *'being fully engaged in life'*. If you can have that engagement without any entanglements your life will be richer.

## My nature-based mindfulness programme

We do all sorts of activities based on peoples' different abilities: anything from bird-watching to hill-walking and rock-climbing, including kayaking and canoeing, all linked to the mindfulness programme. We start with the sense of awareness and motivational interviewing. I have a problem with the [prescribed] eight week course – two and a half hours every week for eight weeks with 45 minutes a day of personal practice - which doesn't work for many people. My PhD thesis was on the reasons why the people who had tried mindfulness and failed couldn't get it. One former nurse told me "They keep telling me to take my awareness somewhere and soften! - I can't do gooey"! So all my programmes are tailored.

### Roy

*(All names have been changed)*

Roy has PTSD. He served in Northern Ireland in the parachute regiment, where he was involved in shooting and saw friends and Irish people killed. He came out of the army more than 30 years ago and had a successful career in the fire service; going from fireman to senior fire officer. When he retired he came to Cumbria where he lives in a fantastic farmhouse and barn which he converted himself. While he was converting the barn for a holiday let, the smell of the drill going into the wall reminded him of the smell of cordite in a shooting incident. He ran away. He wanted to kill himself. There was a big search for him and he was arrested by the railway police and charged with endangering life because he was found on a railway line. Suicide and attempted suicide ceased to be a criminal offence in 1961 but he still ended up in court. He was in a secure mental health unit and sectioned five times. He went to a Combat Stress course in Scotland but left it because other people were committing suicide. We ran a mindfulness programme for him which included walking by Coniston Water and after this he said:

*"The programme has shown me that there is a path better than my suicidal behaviour, and has shown me lots of techniques to deal with flashbacks and nightmares, and helped me develop different interests in the natural environment to help me cope".*

An I-poem is where you take a piece of text and pull out every phrase that begins with I. This is Roy's:

I served  
 I have PTSD  
 I attempted suicide  
 I was an inpatient and I ran away  
 I was arrested  
 I was charged

I ran away  
 I was arrested  
 I have a caseworker  
 I am learning  
 I am enjoying nature  
 I am calmer  
 I'm much better

One of the problems I have with mindfulness is the way it is being taught with no sense of connection. I find it bizarre that mindfulness teachers have to go on a retreat; they are always in places like this surrounded by beautiful countryside and go for lovely walks but when they go back to London to teach their course there is no mention of nature or interconnectedness.

## Carol

A former nurse with the Royal Signals and the NHS, Carol had been out of work for eight years, living on benefits and some help from a nursing charity. She was subject to chronic fatigue and hypervigilance. She had been present when a number of nurses died and although she was not responsible the investigation treated the staff abominably. Her hypervigilance is such that she is scared of everything. She lived in supported housing. She was referred to Cumbria's special trauma centre. She started with us in June 2015. She was not accepted immediately; too many people respond to an advertisement for a mindfulness course without any idea what it involves and I think we have to get to know people first. After the course she wrote:

"I'd lost the ability to function in the world through long-term illness and acute anxiety, yet, through the work that Steve is doing with me... I've started to feel that I can take responsibility for myself again.... I can take this experience and confidence back into my "every day life" so I can become a functioning part of the community again. You may ask, why can't I do this normally, well it's because with acute anxiety and being on high alert all the time, I simply get worse in busy environments. Being out in a "natural" environment calms my state down and you become connected again with your surroundings. The confidence gained from this is starting to spread into my daily life i.e. being able to cope with people, problems etc."

Her poem was very simple:

I've lost the ability to function  
 I simply get worse  
 Yet  
 I've started to feel  
 I can do this

## David

David was another participant who became a good friend. I know there are supposed to be boundaries in one's relationship with patients and clients but if you work with someone for a long time they are bound to become friends. Sadly he died of cancer; having been told he was likely to live for three years he suddenly went rapidly downhill and died during the programme. He wrote this poem:

Standing like a mountain rooted in the ground,  
 Seeing clouds and thoughts drift by  
 Feeling the wind and the rain, Knowing yesterday has past  
 And tomorrow does not exist, There is only now and now and now

Thoughts may not be reality and that's a fact  
 And it may not matter if you do or don't,  
 Just as long as you remember to breathe  
 To walk mindfully on the earth,  
 And to take the chance to dance with life.

## Outcomes

The funding for these programmes comes from the CHA Invited Guest Trust. When people stay in the Lake District a percentage of the money from the hotel goes to this. When I went to request funding I sat with the Lord Lieutenant and the chairman of the Ramblers Association. Roy came with me and told them that the programme had saved his life, and had certainly saved the NHS £40000 in hospitalisation costs and he had stayed out of prison. Carol is looking at getting back to work, and another participant, Duncan, is now free from alcohol and drugs.

## The practice tree

The root: If you are asking people to make changes you need the root practices of awareness, acceptance, appreciation and interconnection

Fertile ground: If the tree is to flourish and survive it needs the fertile ground provided by communication, a desire for change, willingness to explore and a supportive family, friends and community

The branches - practices we employ which include:

Movement practices: walking and climbing as well as Tai Chi and bowls

Stillness practices: Mindfulness, meditation breathing, body scanning

Reflective practices: art and poetry

Engagement practices: 'Sit spot', where people choose to stop and engage with what is around them, work, volunteering and the community

## Caring for the Carers

When we fly we are always told to put on our own oxygen masks before trying to help our children or anyone else. We need to focus on how we care for ourselves. The following story shows how difficult this can sometimes be, and how mindfulness can help.

### April

April is currently a health visitor, and a former army captain. In theory she is part time, by which I mean that she is paid by the NHS to work eight hours a day for three days a week. In practice, when she came to see me she was doing twelve hours a day for four days and not being paid for the extra hours. She suffers from work related anxiety – partly due to the new computer system she has to take with her. She hadn't been for a walk in the hills for ten years. When she came on the programme, she talked about the things she had noticed when she came from seeing a family; she thought the parents would think she was 'bad' and didn't understand, and she felt embarrassed. Sometimes when she went in she thought: "I don't know what's wrong here - this baby is sleepy ... it will dehydrate ... it's going to die ... what am I going to do?" and panicked. The constant stress of working with some of the most difficult families in her area was really challenging.

As a result of the programme she started to notice different things, with greater awareness of internal process through mindfulness practice. She became less anxious and less prone to panic as she learned to process information more effectively and to differentiate between her initial thoughts about what was happening and the secondary thoughts that were piled on top of that; to see different choices and acknowledge her anxiety.

She didn't have to do 45 minutes of meditation every day. All we asked her to do was, on her way home from work in the city, to stop in a lay-by that had a good view – her sit spot - and just notice what was around her, the smell of the grass, the air temperature ... and then go home. She would 'come down' before she walked through the door and started dealing with teenagers. On the last day of her programme we went to the tarn above Grassmere where she was able to fulfil what she wanted to do.

This isn't new stuff. Two hundred years ago Wordsworth wrote:

One impulse from a vernal wood  
 May teach you more of man,  
 Of moral evil and of good,  
 Than all the sages can.

(from 'The Tables Turned')

## Discussion

*I was very pleased to hear what you said about mindfulness ... some years ago when I was supervising some practitioners I found a certain rigidity in people. When I asked them whether they were doing mindfulness practice many didn't answer because clearly they weren't - and yet they went on teaching it. That creates a gap in what people believe about the practice. You can't teach something if you're not doing it.*

In any teaching role you have got to speak with integrity of what you know.

*I find that some of my patients who are very religious, particularly if they belong to some evangelical churches, are very resistant to anything that smacks of Buddhism. And even though some of the techniques are extremely useful, it's very hard to get them to accept the idea that they could borrow something from something different ...*

There are a lot of contemplative Christian traditions like the Desert Fathers who have been meditating ..., the same in Islam. There are some traditions that have difficulty: for instance I had a Jehovah's Witness friend who seemed to think that if you practiced meditation your mind could be stolen! But we can sit in a wood quietly together – he's really up for that but we just don't call it mindfulness.

*In our work on healing we find that people say that nature is very important a lot of the time and your idea of nature being alongside mindfulness is great. Do you have a theory or a view as to why this is important?*

The research I did for my PhD involved adults with chronic conditions. What came out universally was that they had all had contact with nature from childhood and some of that was really powerful; they could go into nature because they found it a place of safety where they could hide. My personal theory is that we are nature – we are part of it – so how can we distance ourselves from it?

One of the problems we have in this area is that people are for ever posting pictures on Facebook of sacks of rubbish they have brought back because for some reason people can carry rucksacks of beer cans and packs of sandwiches to the top of a hill but can't carry them back down when they are empty!

The way some things in some religious texts are stated concerns me: the idea that God gave man dominion over everything. The way people interpret that is: "I can do what the hell I like and exploit nature because I've got dominion over it."

*If I could push you a bit further on the idea that we are part of nature because the contrary view of how to improve our lives and our wellbeing is to make connections with other human beings, which we have also been stressing in this meeting. So where do you think this difference lies between the power of us of connecting with other people and the power of us being alone in nature?*

It's quite difficult to be alone with nature. I do some programmes where people work up to being a few days on their own with nature; it's really difficult and they need to be prepared if they haven't done it before. It's interesting to see how much threat some people perceive to be out there, which gives rise to some resistance to being alone.

We are all used to engaging with nature: some of you walked down to Ambleside through the fields and down the side of the stream when you could have walked all the way on the footpath by the road, because it was a more pleasant environment to have a chat.

*I went alone - I felt safer!*

There is lots of research on nature connectedness. I have a real problem with the local NHS trust that I am a governor of because they won't look at any nature programmes. I talked to them about programmes in Norway where people go into farms to be healthy, and farmers are involved in delivering healthcare. We have farmers here that are going broke and we are not engaging with them. It would be cheaper than some of the hospital treatment.

*Are there people who just don't get on with nature – and prefer to stay in an urban environment?*

Yes, but that probably doesn't mean they don't get on with nature, it's just that they don't get on with being outdoors. Sitting and stroking a dog - for some people that's a connection with nature. I'm not sure about dogs having consciousness but, if I sit and I sob, my dog climbs up on the sofa beside me and licks my face; it knows I am sad.

You can have nature indoors as well: plants and fish as well as pets. In one study people were shown pictures and they felt better after seeing one of a good view. A few years ago I did a project for the NHS in Manchester going round hospitals seeing how people engaged with different things, including music. I went to St. Steven's Hospital in London which had a fantastic atrium with a big balcony which was just outside the post-op recovery suite, and on Thursday morning the London Philharmonic rehearsed there! On Thursdays the level of post-op pain and the amount of drug use went down!

So it's anything that engages our senses - not just nature.

*In our hospital [in Norway] we have clowns who play with the children and get in touch and interact with them. This is great for children who have got very stiff and withdrawn after a lot of treatment and pain.*

*Nobody has mentioned play. Several years ago I went to a eurhythmic hospital in Germany. It was completely alternative – no sniff of drugs or surgery or nerve blocks – and they treated the most difficult cases such as chronic fatigue and fibromyalgia, people whose function was pretty much zero. One of the ways they got through to the patients was play, so they would have a room like this where everyone was sitting in a circle. There was nothing challenging and the patients didn't even have to talk. They put a balloon in the middle of the circle and asked them to move the balloon with a foot - not kick - or blow on it or something – and by the end of the session were playing happily! People in wheelchairs who never walked were laughing and it was completely therapeutic.*

... kayaking is playful! Going back to St Steven's; in the children's department the walls were painted in primary colours and padded, and they had a train that went right round and big cushions and all sorts of balls - that was in the waiting area so kids could play rather than sit there being told to keep quiet. Yes, play is definitely important but there is a lack of funding. My local hospice has just got funding for a walk through some woods where there is a play area so that grandparents can go and watch their kids playing and that makes them smile. In the 'sense of awareness questionnaire' the answer to 'what makes you smile' is often 'children laughing'.

*In Paul Brand's book 'Pain - The Gift Nobody Wants', he describes the dehumanising, very unnatural environment in a hospital where you can't even look out of the window, and how that increases pain. It struck me that when you look at our environment the more sick you are as a person the less nature will be there. The worst case scenario is someone in a wheelchair who can't go up and downstairs and has to live with artificial stuff around them all*

*the time. What you said earlier is fantastic ... people rolling around on the floor! The older we get, the stiffer, the more upright we are, and at the end of life we are trained to think that there is nothing worse than falling in case we can't get up again. The other thing is laughing; there are groups of eight or ten people who get together and all they do is laugh. This sounds so silly but it's liberating because you can't behave like this outside or you'll be looked at.*

The language that we use; we're constantly being told "oh, grow up" if you're being a bit playful or childish. What's wrong with that?

This idea of space:-

In the trust that I am a governor of we have a mental health unit that failed a CQC inspection and was rated as poor, so it was closed. The local MP campaigned furiously to get it reopened. So we said: "There is a need for people to be in a secure mental home. It's not right but we have nowhere else to replace it with". So we agreed to reopen it. As a chaplain I spent many hours there and I would make a totally different decision now and campaign in the governor's council for it to be closed again. There are no windows that can be opened, no views, the wards are multi-person, there are no ensuite facilities – nothing that should be in a secure unit. After a few hours there I want to slit my wrists. It's dire. When anybody kicks off - and they're not wrong to do so, everyone disappears and locks themselves in the toilet. They will do anything to not be in that space. It's not appropriate.

## Healing while dying

Emmylou Rahtz

I came to this work a few years ago when I was finishing a PhD where I was working with major trauma patients, looking at their mental health states and their vulnerability to PTSD. I observed that their physical care had been phenomenal; people were surviving injuries you wouldn't expect them to and recovering function in their limbs and bodies, but when it came to their psychological care there were very high rates of distress which was having a severe impact on their lives, and there wasn't really a lot of attention given to this aspect of their care. So I started banging a drum about seeing the body as more than a machine and looking at the whole picture.

Around that time I saw Paul Dieppe's work looking at the placebo effect and the need to re-characterise that as a healing response and treat it as something useful which needed research. So I hassled him until he gave me a job which I have been doing for the last couple of years with two projects on healing. The direction I want to take this is towards healing at the very end of life. This is a new area for me; I am a researcher, not a clinician, so I shall be very grateful for your feedback and comments, and any advice you can give me about funding.

### The meaning of Healing

In one sense we all know what it means and in another it is incredibly complex and abstract. The word comes from an old English word meaning 'wholeness' – the idea of a unified self. It involves balance, but balance is a static thing – once you have got to it you stay there, so 'dynamic equilibrium' better conveys the necessity for constant rebalancing. Congruence and reintegration are useful concepts: we can often think of ourselves as fractured beings and present different selves at different periods of our lives. With healing we can unify all these fractured selves. I like the idea of flourishing because it suggests that we don't have to unwell or stressed to need healing; you can be in quite a good state but can get to an even better one to make the most of yourself. Kate Binnie told us about the pain specialist that described pain as a cake that you could only treat half of with drugs, and we are dealing with the other half.

"The word 'healing' signifies what is inevitably left over as a need for the patient and as a task for the clinician. Healing is what remains after what can be specified is done but neither suffering nor care are finished. The physician Rachel Naomi Remen evokes this quality of healing as remainder when she says, speaking of biomedicine: "We thought we could cure everything, but it turns out we can only cure a small amount of human suffering. The rest of it needs to be healed". Healing attends to the rest."

Arthur Frank 2014

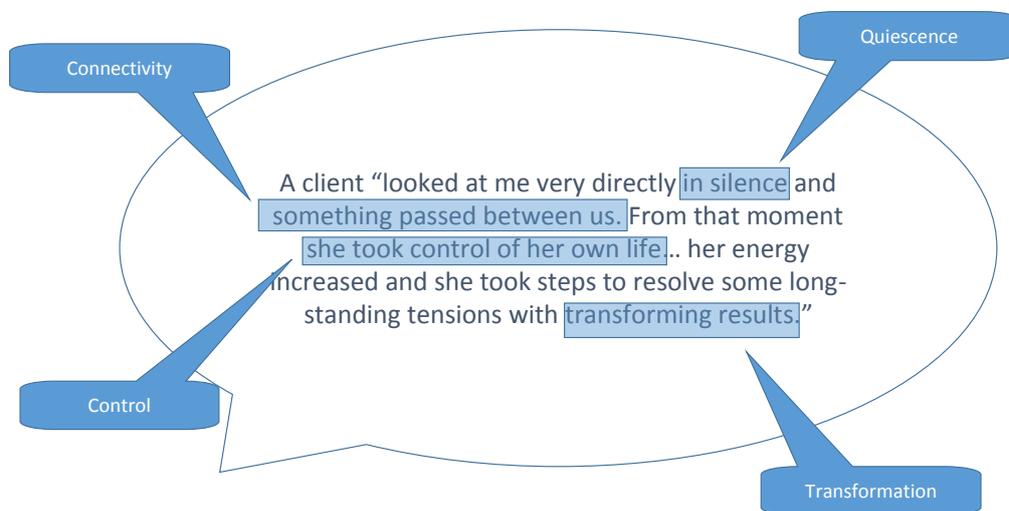
This captures two ideas that come up again and again in healing research. One is that healing is kind of in opposition to biomedicine and mainstream medical thinking. If you look at nursing research, complementary medicine and psychotherapy, biomedicine is not a term that is used a great deal. The terms healing and curing are often juxtaposed with curing seen as 'fixing' the body as a machine, and healing looking at the whole

person. This evokes echoes of Cicely Saunders's words: "when medicine says there is nothing else to be done there is always something else to be done".

## Healing Moments

This is the subject of a paper: *Transformational changes in health status: a qualitative exploration of healing moments*, Emmylou Rahtz, Sian Bonnell, Sarah Goldingay, Sara Warber and Paul Dieppe, to be published in *Explore, The Journal of Science and Healing*. I'm not going to talk in a lot of detail about the methods, although some of them were quite innovative, but very briefly, we talked to a group of about 70 healers and got them to write short stories on postcards about what healing moments meant to them. Some of these responses are quoted below.

We did a qualitative analysis from which we drew four overall themes, Connectivity, Control, Quiescence and Transformation.



Connection can involve physical touch or communication with another human, a higher spirit, nature or animals. A lot of the quotes incorporated the idea of quiescence and calmness, peace, the meditative state. Control, as in taking control of one's life and becoming empowered was often featured. The overarching theme, however, was *transformation*: making a significant change, however small, in your life and health.

## Transformation

Some of the quotes had a magical feel to them:

Watching a bed sore physically disappearing [during] Reiki healing practice!"

"When I took the needles out her pain had completely gone and did not come back. This immediate effect surprised us both."

"EFT [Emotional Freedom Technique] is particularly effective to dissipate flare ups most magically"

The phrases they are using imply that there is something miraculous going on – the silver bullet we all hope for when we are ill. Others were more moderate:

“A 'healing' moment for at least one to two days meant a lot to a palliative patient

“Cancer patient receiving Reiki – only time she is pain-free is after treatment... for a few days. Her wellbeing is better due to being pain free”

This isn't the same sort of miraculous transformation; it's more modest but still very important to people experiencing these sorts of changes who were often those with very serious conditions.

## Connectivity

This could refer to eye contact and touching but more often to communication:

“... approaching the healing point... is a moment in an interaction when both people feel they can trust each other enough to let go... a point of mutual trust... that is when you get to the healing point”

... that sense of connection of a frisson between two people. Mutuality is reported; the lovely idea that it's not all the healer giving to the client; they get something back because they are in that place and that moment:

“When I can get lost in the massage and lose track of time I also feel the benefit in my own body energetically”

“... when the connection leads to true understanding of the 'problem' by both parties... there is a 'frisson' and both know there was a healing moment that will be built with subsequent treatment”

Some of the accounts were of one sudden moment, a turning that solved everything; for others it was more of a journey and the building of a relationship between healer and client.

Giving healing feels “like pure love”

The theme of love didn't appear in a lot of the accounts but where it did it was so strong we felt we had to include it. It seems important for healers to feel love for their clients.

## Quiescence

There was a prevalent sense of calm and peace.

“During a treatment session the client went into a deep sleep or deep relaxation moment and it felt as if everything in the room were very still or quiet feeling”

“My clients either fall asleep or feel deep peace”

To me this sounds like a relaxation response or a hypnotic state, and I suspect that a lot of the time both healer and client are in that state, and that is helping to build this healing space.

Sometimes the sense of quiescence was related to death:

“Healing calmed the fear and allowed her to die peacefully and gracefully”

“A close friend died last week. I sat with 2 other men who were also close to him an hour after he died. It was in a church. A release of emotion and deep peace occurred.”

Death cropped up quite a few times in these accounts and it was interesting that some people thought of healing at the point of death.

### Relinquishing control vs taking control

The perception of relinquishing control and becoming a channel is best summed up in this quote:

“... in Native American traditions they talk about becoming the hollow bone ... then spirit can flow through you and do whatever it is that’s needed ... you don’t want your intention in the way.”

You often see in healing that you don’t have the active/passive roles as you often have in the doctor/patient relationship: the healer is more like a guide on a healing journey.

“I often feel guided to say or do unplanned things in therapy session – it usually becomes clear why afterwards!”

Healers reported their hands being involuntarily, even ‘physically’ moved to particular parts of the body, and the feeling that they were being guided in how to deliver the healing by becoming a channel.

Healers found that they often received healing as well. A lot of people come to healing because they have been healed. In this they talk about taking control; becoming empowered.

“I had the ‘aha’ moment that I am causing my pain and that gave me the tools to begin to heal”

“I have been in remission for five years due to my self-healing and care”

I hope some of these themes may provide inspiration for commissioners. These are perhaps things that clinicians could find clinically useful but in a constrained system like the NHS it is hard to find time.

## Public views of healing

The project we are working on at the moment involves asking members of the public what they think healing means. We used another innovative method, giving people crayons and paper and asking them to draw what healing means to them. We chose this because if you ask people verbally they will try to answer cognitively and logically. When they draw, something creative happens. You get different things coming out. When they start drawing they may not be sure what it is but then they start to describe: this is about roots, this is about growth etc. We record those conversations to give the drawings context: what that picture means to them. None of it is high grade art but does have a certain charm! We are in the early stages of a qualitative thematic analysis.

The circle is a very strong recurring image and often represents wholeness. Colour seems to be important; people will say “obviously this needs to be blue – or orange – because they are healing colours. This seems to be a very individual thing. Sometimes circles represent the sun with energy flowing out. Connecting is another important theme, as in the previous analysis. This includes physical touch – it is amazing how many people draw hands. One depicted the hand of Christ reaching down to heal someone in a hospital bed. Connection can be with other humans, a divine power, with animals. We see a lot of hearts which represent love and emotional wellbeing; family love, romantic love. Some of the ideas are a little more complex: one picture was of a nurse who had been particularly caring towards the respondent’s mother and had helped her emotional state when she was ill. An abstract one was from a healer who had talked about needing to go out to find people who were suffering emotionally, draw them towards her and heal them. Sensory awareness and pleasure from being in nature was reflected in a picture of a skylark soaring as well as those of trees and flowers; the colour green featured frequently.

A related theme was that of transcendence - the sense of being connected with something greater than yourself. For some people this came from the idea that we are at one with the planet. For others it was connection with a higher or divine being, or a sense of universal consciousness shared with all other humans. One picture depicted energy flowing out from someone’s aura. An abstract one represented the movement from chaos to order in the universe.

So we are trying to make sense of our collection of images. The themes seem to be similar to those that emerged from the other study.

## Healing at the very end of life

It is very clear that dying is very overmedicalised and technologised in our society. It’s not discussed a lot; people find it scary and ‘other’. I’m probably talking specifically about British culture here; in one of these conversations someone from Eastern Europe said that there they don’t necessarily have the funding for all the technological stuff at the end of life so they

have to rely more on healing and of the simple things like hand-holding. In Ireland you typically sit with the body; most of us not involved in clinical practice don't see bodies and we don't even think about them. We don't think this is an issue but there is a culturally specific idea in this.

Is healing possible when physical cure is impossible? This comes to the whole point of healing. You can still have pain but reach the state of being healed. As Andy [Graydon] said, pain is inevitable but pain is optional. We have been talking about dying well; how does a 'good' death differ from a healed death? The external factors: good care, pain controlled, family around you etc. can be right and ensure a good death but healing relates to something internal. A lot of healers work in hospices; one of the few situations where they are generally acceptable in health care.

"In the past few decades, medical science has rendered obsolete centuries of experience, tradition and language about our mortality and created a new difficulty for mankind: how to die"

Atul Gawande, *Letting Go*, New Yorker

Advances in technology have encouraged us to rely on these things and neglect traditions of care.

"We keep trying to provide technical solutions to existential problems"

Iona Heath

Undoubtedly there is a place for technological solutions in medicine and end of life care but we need to look more broadly at existential matters.

The literature on end of life care paints quite a gloomy picture. The Office of National Statistics report of 2014 highlights unmet needs in terms of dignity, spirituality and emotional care. Bartel and Clements-Cortés, (2004) and Fenwick et al (2010) acknowledge that psychological, social and spiritual factors are often overlooked by medical researchers. It is terrifying to think that as many as 40% - 50% of dying people experience clinical depression (Spiegel, 1996). But I did find some vestiges of hope in the research. A recent study by Goransen et al (2017), assessing the ratio of positive to negative language employed in blogs by people with terminal illness, revealed that the language of people near death becomes more positive as death gets closer. They then asked members of the public who were not dying to *imagine* that they were writing a blog about facing that situation. They wrote quite negative blogs because it was scary and terrifying. This suggests that our perception of death as something scary is not borne out by the experience of people approaching it that it is not as bad as we think it will be. They repeated that study with prisoners on death row and found the same thing: the closer prisoners got to death the more positive their language. We live in fear of death but it may not be all that bad.

The Death Café movement offers an informal space to talk about death. You don't need any qualifications or even experience; it's open to anyone. Nakashima (2007) found that many patients dying in hospices found it a positive experience

There are a few recurring themes in the literature about dying that have echoes of the findings of our healing research. These include connecting: (with healthcare professionals, family, community etc.) the idea that you need the health professional to look the dying person in the eye. Spirituality, religion, transcendence and the ways they can bring peace and give meaning to the dying process crop up time and time again. Meaning making –

finding a narrative that will make sense of what you are going through - is a common theme in healing research.

## Proposed research

In the project I am hoping to pursue

I aim to address the research questions:

- What are the defining elements of a 'healed death', in the view of people in end of life care, family, carers and staff?
- How relevant are the concepts of 'sense of coherence' (meaning-making, managing and making sense of your condition, finding the resources for dealing with what life is throwing at you) and 'serenity' (a less off-putting word than spirituality to healing at the end of life)?

I hope to develop a theory of the components and mechanisms of healing within end of life care.

I shall use a mixed methodology, employing qualitative evaluation of interviews with both patients and professionals, and our more creative drawing approach. This is such an abstract concept that you need people's own words to get at the essence of their experience. But I also want to use qualitative research to anchor our findings with those of others and draw parallels with measures such as the serenity scale with the reliability that biomedicine demands. The two methods inform each other.

I have been talking to the palliative care consultants at the Royal Cornwall Hospital in Truro and they are happy to co-operate and to find patients and to help me to access them. I am focussing on cancer to give some homogeneity the project. There is a new Macmillan cancer care centre on the hospital site and it promises to be a friendly environment for my research.

There will be three main phases: the first will be engagement with patient groups and professionals. It will be difficult to talk to people in end of life care themselves at this early stage in the research so I shall be talking to patient groups that already exist and are used to giving feedback on projects and helping to shape them. This isn't my area of expertise and I want to be guided by patients and professionals who have gone through that thinking process. Then I shall do fairly traditional qualitative interviews and our crayon drawings, and lastly quantitative questionnaire research using coherence and serenity scales. I shall probably use a quality of life measure (I am not quite sure what these tell us but they are so widely used this is probably worth having for comparison) and a brief anxiety and depression measure.

## Ethical concerns

This is often the first thing that people ask me about. When I have looked at other research a lot of time it is the researchers and ethicists who have been worried about upsetting people. Patients themselves tend to say "it's my right to take part in this research and I want to contribute". When I gave a summary of this research to an existing patient group that

operates within the University of Exeter they gave me some really helpful feedback and helped me to change my views. A typical comment was:

“this research has been long needed... it is often not talked about because it is uncomfortable but actually it’s very comforting, reassuring and helps process answers.”

So I hope this will be a really sensitive and useful project.

## Other projects

I just wanted to finish by telling you about a couple of other projects that we are collaborating in. Alison Day is a wonderful nurse and poet. She worked in the A&E department of Musgrave Park Hospital but was also involved in a project: ‘Conversation: a dying art?’ about the end of life, having conversations across the hospital with the CEO staff and patients. The way she frames the questions conversationally is to ask: what makes life enjoyable for you? She has made her findings into a poem which has been exhibited throughout the hospital. We have also put on an exhibition there entitled ‘How are you Healing?’ of some of the drawings and quotations from our healing research, at the invitation of the hospital the Art and Life team which includes some brilliant artists and curators. It includes a section on the end of life.

## Discussion

*This is a very well thought out project and I wish you luck with the ethics committee. When I presented some qualitative work to my local one the only person who was really keen was the lay member who thought it was wonderful. I later heard that she had died.*

*I liked your drawings. I once put some patient drawings in a paper on back pain and when it was published I showed it to one of the patients. She said “it’s very nice but you’ve put it in upside down!”*

*Have you looked at the work of Maggie’s Cancer centres? They are based on the beliefs of a woman who died of cancer and her response to her treatment. The woman, Maggie Jencks, was determined that people should not ‘lose the joy of living in the fear of dying. More than 17 international architects such as Richard Rogers, Zaha Hadid and Rem Koolhaas have designed centres, often for free, and always built from scratch. They include a lot of healing space and space where people can come together and talk to each other. Charles Jencks, Maggie’s husband is a leading architect and owns a 30 acre plot of land in Scotland where he has designed his ‘Garden of Cosmic Speculation’ with pyramids and spirals and other things designed to promote nature and wonder.*

We spent some time at our exhibition talking to people that were looking at it. It was wonderful the way different people responded to different things.

*Sarah Dixon who used to come to these meetings was a Yoga teacher and had worked at the Maggie Centre in Oxford. Sadly she has been very ill herself with severe rheumatoid arthritis so has had to stop work but she would be a very good person to interview.*

*Palliative Care services and hospices are always looking for outcome measures, because their managers don't think they make a difference and don't want to fund them. And no-one has been able to quantify what it is that they do. Your word for spirituality – serenity – is brilliant; how to measure those sorts of concepts? – your approach could be amazing if ...*

*... someone will fund it ...!*

*Most people die in hospital rather than hospices or at home. And the places that really need the interventions are the acute hospitals, which is where people are dying surrounded by technology. It would be lovely if everybody who was terminally ill could go to a hospice. The hospice I work with, St Nick's in Bury St Edmunds, has widened their definition of who is eligible for hospice care because they have had a very generous community supporting them. (None of the hospices I have worked in have been NHS; they have all been private foundations) They will take MND, heart failure, COPD, end stage MS. But hospices don't take the biggest group which is the Alzheimer's patients, because they lack the expertise to look after them.*

*There is one Alzheimer's hospice in Oxford.*

*Most people with dementia die in nursing homes. As a GP I look after one lovely place. If there is any possibility of healing you see it there because of the very caring staff. But also relatives feel that it is a safe space - it creates the environment of trust, love and care that they want for their loved ones. It's by no means ideal because nobody there is trained in this area, but people have been given a challenge so they get on with it. There are enough staff there who lead as role models to provide a really good outcome. I am so privileged in a way because so many nursing homes are places where people just die; this place is not so very different in terms of staff setup, but somehow they just have the right mix of people. There are still, however, unnecessary admissions to acute hospital where people are seen to be mad and allowed to die. There was one man who kept asking for beer which they didn't like but was the only communication they could get from him. They sent him home to die. When he came back he drank 2 ½ litres of water. The nursing home staff could see what he wanted but the people in the acute hospital had no time to try to understand. I could have cried when I heard that.*

*I wonder how you get a nursing home to have that supportive atmosphere?*

*Frankly, it's pure luck. You need to have the right staff and management who do the right things with the staff. But I have been in places - talking about burnout – where the staff tell me horrendous stories. These people are saints - they work for next to nothing and are expected to do jobs that you and I would struggle to do for many reasons. It's not just the toiletry and cleaning stuff but it's not very dignifying. You have to be very strong as a person. And it's not just a job, it's a vocation. That's lost much of the time in the health profession. This is probably where healing starts. Dying well incorporates healing and the staff will need that as well – it's not a unidirectional process.*

*Don't you think it's got a lot to do with who owns and runs the nursing home? My mother was in one which was run by a nurse and an occupational therapist who couldn't find anywhere when their mother was dying so they set up their own home and the healing and the care that came from that went right through the staff.*

*One of your slides had the caption 'Healing takes Courage' which was something I had never thought about before...*

“Healing takes courage, and we all have courage, even if we have to dig a little to find it.” That’s a Tori Amos quote. We [Emmylou and Paul] picked up a lot of quotes from people like her as well as famous thinkers. Different quotes connect with different people - this one obviously connected with you – and convey different aspects of the meaning of healing.. I think this meeting takes courage!

*One of your slides mentioned Theodore Roszak* Undoubtedly there is a place for technological solutions in medicine and end of life care but we need to look more broadly at existential matters.

*and his seminal work on ecopsychology\*. That has generated a massive field of research into the difficulty of healing yourself when you see all the damage to beauty and links to Joanna Macy and her work on Deep Ecology*

*A lot of places like Addenbrookes have art projects. They are tending now to use established artists but it you may be able to get your exhibition into it. .*

We are aiming to take it round to lots of hospitals. Interestingly the doctors take no notice of this expedition as they go down the corridor; the nurses are entranced by it. A lot of nurses have said to us: how wonderful to have the word ‘healing’ used in a hospital.

\*The study of the relationship between human beings and the natural world through [ecological](#) and [psychological](#) principles. The field seeks to develop and understand ways of expanding the emotional connection between individuals and the natural world, thereby assisting individuals with developing sustainable lifestyles and remedying alienation from nature.

Wikipedia [.11](#)

See also paragraph on pain and ecopsychology in the same article

## My recent training in hypnosis

Tim Johnson

Last year's meeting was about the power of the mind and we didn't touch on dying, but I think it's important that we carry these things through. Indeed there are themes from last year that we have carried through to this year.

I was very impressed by the whole of the meeting last year. It was my first acquaintance with hypnosis and having spent 25 years in the pain clinic I have picked up things there that I'd never really understood. One of the most powerful was David Reilly's use of the illustration of a video clip of a taxi ride through New York played twice to 2 different sound tracks [*one gentle light classical music and the other fast jagged discordant jazz. One making the buildings and people seem pleasant and friendly and the other making them seem threatening!*] (Lufthansa advert: [www.youtube.com/watch?v=VPjmJOzsP28](http://www.youtube.com/watch?v=VPjmJOzsP28)).

The way you see and feel it, is completely different depending on the sound track. His analogy was with people living their lives to the wrong sound track. In taking that back to the pain clinic, it was immediately obvious to me that the sound track - what was playing in the patients' backgrounds - was unhelpful. That was very powerful.

A lot of what we were hearing in the context of pain in the sessions on hypnosis was about not focussing on the pain. You don't mention the P-word. You don't talk about discomfort, you talk about comfort. You don't talk about tension, you talk about relaxation. If someone tells you not to think about a pink elephant, it's the first thing that comes into your mind! And this applies to pain.

When I went back to Salford one of the first things I did, was with one of our pain management programmes. I spent an hour and a half doing the 'medical' part of the introduction for the patients. Every time I said the word pain it felt like I was driving a nail into them! Then we started talking about pain within the group process and when everyone starts talking about their pain then it becomes pain, pain, pain. Surrounded, immersed in pain - the word pain, the language of pain and the behaviour of pain. And all of a sudden this seemed terribly wrong.

Ann Williamson, who was one of the main speakers last year, and did some demonstrations of hypnosis, visited Salford as a representative of the British Society for Clinical and Academic Hypnosis meeting (British Society of Clinical & Academic Hypnosis - bscah.com). They do a taster session for clinical teams which I would recommend to anyone who is interested. They got a mixed response from our unit, a group of about 25 doctors, psychologists, nurses and physiotherapists. My doctor colleagues were equivocal – it was a bit too touchy-feely for them. The nurses were very interested They were seeing these sorts of problems we were talking about on the wards: people with anxiety and acute pain that could potentially benefit from some hypnosis input. My psychology were less interested, which I found surprising. I decided to go ahead anyway and explore hypnosis myself and I did the three weekend BSCAH course in Warrington, run by Ann Williamson and her colleagues. Having done that I felt, with some reservations, confident about treating some of my patients in the clinic. In the course of the programme I identified about a dozen who I thought might benefit. What I was seeing (going back to the soundtrack) when talking to patients in the clinic made me realise anew how distressed this group of patients is, and how life has treated them in ways which many of us probably wouldn't understand. There was also the fear that in talking about sensitive emotional issues and taking into account things

like obstacles and resistance that Steve [Johnson] was talking about yesterday, together with all the complexities, the bad things that have happened to people, I wondered whether in some cases I might get myself into a lot of trouble. I did come across some difficult situations, for example with people who could not “image” their pain who might be helped by the sort of art work we were talking about this morning. I also felt in a way that I was offering little by suggesting to patients who’d previously had all sorts of injection treatments, that they could be helped by undergoing some sort of trance. I had some self doubt as a therapist - the sort of things I was suggesting just cannot work (it’s just too good to be true). But I went back to Eamonn Coveny’s talk and recognised that a common factor in the exponents of hypnosis is they all have confidence and charisma. And it comes back to what we were discussing about healing this morning: the charm, the confidence, that silence, that transfer of something, whatever that is.

## Case Histories

A 60-year old lady whom I had been seeing for about 20 years, had been referred from a neighbouring hospital where they had become unnerved about her having repeated stellate ganglion blocks for her CRPS. She struck me as an unhappy woman and I am fairly sure that there were things in her background that hadn’t been easy for her. She had a supportive husband. So for the last 20 years we had continued with the repeated stellate ganglion blocks, despite the other hospital’s doubts that they were doing any good. She was adamant that she wanted them. So we allowed her to come back every four or six months to have the blocks repeated. She was one of the patients who helped me to come up with my concept of injections for pain as being a hug with a needle - perhaps an example of the healing touch. There was so much fibrosis in her neck around the ganglion that it was really getting impossible to inject the anaesthetic, and I was getting to the point of thinking that this was a placebo and feeling very uncomfortable about the procedure being repeated. So I told her that as it was getting more and more difficult, I felt that we shouldn’t be doing it any more. I told her, however that we could offer something else, namely hypnosis. So I tried glove anaesthesia with her to start with. We ‘went’ to Norway with lovely mental images of ice hanging on the trees, and she imagined herself within trance taking a handful of crisp crunchy ice from the tree and the sensation of crunching it in her good hand, and when that had gone numb demonstrating that by pinching, and then transferring the numbness to the painful hand. That was quite easy to do and worked very well. When she came back she said the only problem was that the hand normally feels fairly cold and it would be better if we could make the hand go warm. So we had her sitting by the fire within trance and feeling the warmth; and that actually has solved most of her problem. She still has some discomfort and her husband has to do the washing up and other things that she would otherwise do, and I think pain remains as an important control within their relationship.

My second case is me (50’ish!). During my hypnosis training with Ann we talked about phobias, and Ann asked if there was anyone in the room who had something that troubled them. So I put my hand up and recounted something that was still giving me sleepless nights and has been bothering me for a while. About three years ago I was attending to a complex problem and I made a clinical error which resulted in the patient becoming unconscious and needing to spend several days in a critical condition on ICU. Not only did I feel very bad because that was a patient I was supposed to be helping, but I started thinking: if she died, could this be construed as manslaughter? Was this gross negligence? I believe it could have been interpreted as that, which would probably been the end of my medical career. The patient survived in good health thanks to my ICU colleagues but the incident continued to bother me at a deep level. With a simple induction; it took Ann less than ten minutes to hypnotise me (and by the time we had finished the course we could hypnotise each other, or ourselves, in a matter of seconds). She took me back on a magic carpet to that day when I

made the error. She introduced me to myself, as I was at that time, and asked me what I wanted to do or say to myself. And it just felt natural to give myself a warm hug which is what I did in my trance. Since then I have not been troubled by those thoughts. At the time I had been very well supported by my colleagues who knew how bad I felt about it and rang me up to ask if I was OK. This was very important support but the problem was that *I wasn't supportive to myself*. I was indeed very cruel to myself.

So if I hadn't done that course I wouldn't have had that that benefit. I am still very much a beginner but it has changed the way I see people in pain.

## Discussion

*Did you have any closure on your case? I always find closure very important to healing. You were very fortunate to have that support but you were waiting for closure from that scenario. However there never is complete closure. It can disappear off the horizon; you can think that because haven't heard from a solicitor for over a year the case is closed.*

I assume a legal case is rumbling on in the background. That's not something that terribly bothers me. I have no excuses for what happened – It was a genuine and regretful error. The patient and family have had an enormous worry and that needs to be addressed. I work in a trust that is very transparent. About ten years ago we had a big notice outside the A&E department of the Salford Royal saying we make 'n' thousand errors a year in this hospital. That was a very brave thing to do but it has led to a culture of transparency in the hospital.

*That can make such a difference as I have so many clients come to me who have made complaints to the hospital simply because all they wanted was for someone, as you have, to admit "I made a mistake". They're not after big money or anything like that - they just want someone to say "I'm sorry".*

The closure I had was, metaphorically, to give myself a hug. I no longer wake up in a sweat in the middle of the night, over it. I'm not sure why that should be but it worked very well.

*Thank you for sharing that very powerful story. It also demonstrates the wider importance of values and culture: something which has been rumbling along in the background for this whole meeting, the importance of working in an organisation whose values you share, in which there is a supportive culture of transparency, and where you feel empowered to say things like, yes, that was completely my fault. There isn't anyone in this room who hasn't made a mistake, sometimes as a result people have got very ill and some have died, directly or indirectly, as a result. Working in an organisation where you feel supported if you are honest is a huge thing. One of the issues comes up in situations like Stafford and other failing trusts is that people don't feel supported to be honest with patients and families. If they are, they are ostracised and not supported. How do we help each other protect that culture of openness?*

## Valuing Health near End of Life:

Peter Bennett

In the very first talk at this meeting you will recall that Karol Sikora said he was out of his comfort zone and in some ways I am out of mine. I see no patients. I am talking about 20 years as a civil servant - you can call me a bureaucrat if you wish - and my experience of death and dying is confined to friends and family. That is frankly enough. But what I do think is relevant here is that there are ethical issues and dilemmas that thread right the way through from policy issues ( which is essentially what I was dealing with as a civil servant) through funding right down to people who like yourselves are actually on the front line. So I want to share with you some of those ethical issues as they are seen from the general perspective of how to do the best you can for a population, and how that links eventually with what actually happens on the ground.

I am going to talk a little bit about QALY's (Quality Adjusted Life Years) ; I will skip over some of the early bits of the talk and perhaps revisit them at the end because I want to get at the meat of the dilemmas as I need as it were to get to the end.

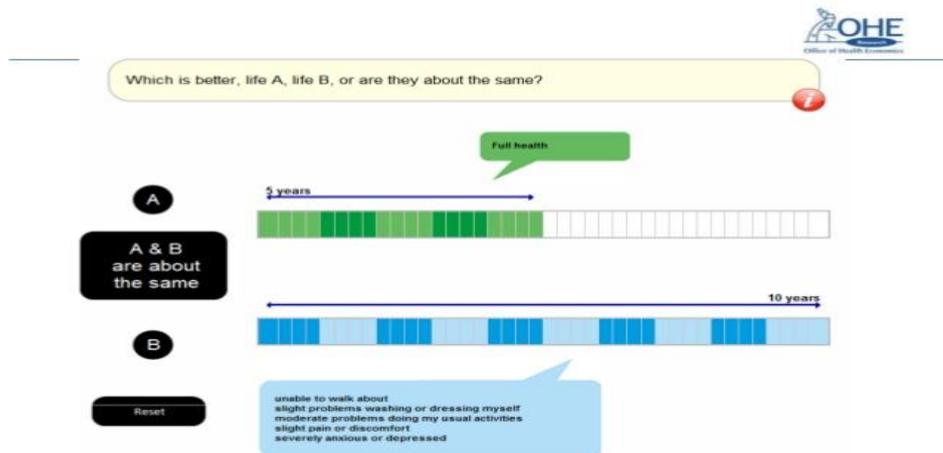
There are still two cultures around in which you either talk about the touchy-feely stuff like ethics and values, or you talk about numbers. A lot of what I had to do in my professional life was to do with numbers. I headed a small team of economists and statisticians, looking primarily at the cost-effectiveness of things. That can all sound very technical and some of the people doing it hide within that technicality and the mathematics with their own internal logic. Some of my immediate colleagues were prone to do this. But they are not two different things. The numbers, and the way that you do the numbers, reflect ethical judgements, either yours or whoever it is that you have taken that set of values from. The technical bit and the ethical bit – the value judgements - are inextricably linked.

There are changes afoot in the way that cost-effectiveness is likely to be done at Governmental level. And those changes are fundamental in terms of the values that we want to use in our health system. They also bear very directly on the trade-off that people want to use between quality of life and longevity - would you like to have a slightly shorter life in better health or cling on to life at all costs as long as you possible can.

### Measuring quality of life

Any individual health state can be measured on five dimensions: anxiety/ depression, mobility, ability to self-care, ability to partake in usual activities whether it's work-related or leisure (if I couldn't go sailing my quality of life would go down considerably) and pain/discomfort. The idea is that somehow what you are trying to do is the best you can in terms of improving peoples' length and quality of life. These are measured using some sort of self-assessment questionnaire such as the one below. The question then is how can people value one dimension with another; how can you trade off a bit more mobility versus a bit less of something else, and all of those things against longevity, as the second figure attempts.

# Time trade-off



<p><b>Under each heading, please tick the ONE box that best describes your health TODAY.</b></p> <p><b>MOBILITY</b></p> <p>I have no problems in walking about <input type="checkbox"/></p> <p>I have slight problems in walking about <input type="checkbox"/></p> <p>I have moderate problems in walking about <input type="checkbox"/></p> <p>I have severe problems in walking about <input type="checkbox"/></p> <p>I am unable to walk about <input type="checkbox"/></p> <p><b>SELF-CARE</b></p> <p>I have no problems washing or dressing myself <input type="checkbox"/></p> <p>I have slight problems washing or dressing myself <input type="checkbox"/></p> <p>I have moderate problems washing or dressing myself <input type="checkbox"/></p> <p>I have severe problems washing or dressing myself <input type="checkbox"/></p> <p>I am unable to wash or dress myself <input type="checkbox"/></p> <p><b>USUAL ACTIVITIES (e.g., work, study, housework, family or leisure activities)</b></p> <p>I have no problems doing my usual activities <input type="checkbox"/></p> <p>I have slight problems doing my usual activities <input type="checkbox"/></p> <p>I have moderate problems doing my usual activities <input type="checkbox"/></p> <p>I have severe problems doing my usual activities <input type="checkbox"/></p> <p>I am unable to do my usual activities <input type="checkbox"/></p> <p><b>PAIN/DISCOMFORT</b></p> <p>I have no pain or discomfort <input type="checkbox"/></p> <p>I have slight pain or discomfort <input type="checkbox"/></p> <p>I have moderate pain or discomfort <input type="checkbox"/></p> <p>I have severe pain or discomfort <input type="checkbox"/></p> <p>I have extreme pain or discomfort <input type="checkbox"/></p> <p><b>ANXIETY/DEPRESSION</b></p> <p>I am not anxious or depressed <input type="checkbox"/></p> <p>I am slightly anxious or depressed <input type="checkbox"/></p> <p>I am moderately anxious or depressed <input type="checkbox"/></p> <p>I am very anxious or depressed <input type="checkbox"/></p> <p>I am extremely anxious or depressed <input type="checkbox"/></p>	<p style="text-align: right;"><b>The best health you can imagine</b></p> <p>1. We like to know how is your health today.</p> <p>2. This scale is marked from 0 to 100.</p> <p>3. 100 means the best health you can imagine. 0 means the worst health you can imagine.</p> <p>4. Mark an X on the scale to indicate how is your health today.</p> <p>5. Now, please note the number you marked on the scale in the box below.</p> <p style="text-align: center;">Your Health Today = <input style="width: 40px; height: 20px;" type="text"/></p> <p style="text-align: right;">             100              95              90              85              80              75              70              65              60              55              50              45              40              35              30              25              20              15              10              5              0  <b>The worst health you can imagine</b> </p>
---	--

Figure 1 – EuroQOL-5 Dimensions score. To the left, the descriptive system that defines the health-related quality of life in five dimensions (HRQoL) and to the right, the visual scale in which the patients indicate the perception of their health status (Visual Analog Scale – VAS).

It's important to note that whereas the first form is usually used for people to report their actual health state, the second is usually asking the population as a whole to make that judgement hypothetically - to imagine that they are in one or other undesirable state and how it would be to have a slightly shorter life. It can be debated whether you ought to rely on the general population or whether you ought to ask the people who are in those health states how bad it is after the event. So the second form asks: would you rather have A: five years in good health, or B: ten years unable to walk about, have slight problems with washing and dressing, moderate problems doing my usual activities, slight pain or discomfort, and be severely anxious or depressed. If the answer is that A and B are about the same it suggests that the person has been asked a rather difficult question, but that 10 years in poor health would be worse for them than 5 in good health. These are blunt instruments but the challenge is to think of anything better.

If you want to evaluate any policy intervention like a screening programme, vaccination, or approving a new cancer drug, or indeed spending more on palliative care, you have a common currency. You ought to be able to say how many QALY's you are actually buying for the population and how much it is going to cost. Looking at it on an individual level: somebody does something which gives an individual patient another year in full health you give them one QALY. If you have a policy that gives 1000 people 10 extra years of life in full health that is 10,000 QALYs. If you have a life-enhancing intervention that gives 1000 people 10 years of life at 0.5 QoL rather than the 0.3 they would have done otherwise, you have 2,000 QALYs. And so on. Of all the things you could spend money on, which one do you prioritise? A good answer, or at least a defensible one, is that you should spend the money you have where it will do the most good, either by extending peoples' lives or increasing their wellbeing – it's a composite thing.

So much for the 'technical' bit. But before I go on to end of life care, I just want to say that one good thing about this kind of measuring is that it is completely egalitarian. It doesn't matter if you are a duke or a dustman, a barrister or a barista, from a government point of view a QALY is a QALY. Before this sort of measure came in the ways of valuing life or valuing the cost of ruining somebody's life usually came from the courts: a court judgement on how much compensation you should give someone or their relatives and that was very full of how much this person – a barrister or a barista - would have earned. That is a very important point to hang onto; regardless of what people may think about QALY's, everybody in this scheme of things is equal. That may be changing.

## End of life care

End of life care is where the dilemma between length and quality of life really hits hardest. To go back to Karol Sikora's point, we do have a dilemma here between what he described as the American approach where everything you can do to prolong life you have to do regardless of any cost either monetarily or in terms of sheer bloody suffering. But that depends very much on how you ask the question. If you ask: should we be prioritising life saving versus life enhancing treatment, people will say yes perhaps because life saving is the wrong term. If you talk about life saving it sounds like rescuing someone from drowning, in which situation considerations of cost would probably go out of the window. It's probably a

misnomer in medical terms as all you ever do is extend life, at least if you are talking about the end of natural life and extending it by a small increment. But if you ask: would you or your loved ones have a slightly shorter life versus a slow painful death, people will opt to avoid the latter. There is a huge framing issue here. When asking people to make a technical judgement about what they would prefer you have to be really careful about how you ask them.

The next problem is that individual answers vary. This is one thing that you can't get down into at a policy level. Patient A takes the view that I would rather be properly alive or properly dead. I'm not interested in this half alive stuff. My individual trade-off is that if I can't have a quality of life of, say, 80%, really and truly I would rather be dead. Some people take that view very consistently even when they are actually faced with the issue. Others of course say that but may change their minds. Patient B's priority is to see her first grandchild born which is due in six months. Comparing individuals is a difficult trade-off. In terms of policy I don't know how any government, however well-intentioned, trying to decide how much to pay for the latest cancer drug versus a screening programme, can actually avoid working with population averages.

There are ethical dilemmas that come from using QALY's. You can say a QALY is a QALY but this can discriminate against the elderly. There doesn't seem to be any way round that. Personally I don't have any problem with it. I think my life is less worth saving now that I am 66 than it was when I was 26; otherwise the last 40 years of my life have been worth nothing. Does it discriminate against those in poor health or disabled? This is a more difficult one. If you've only got half a quality of life anyway, is saving your life then only worth half what it would be if you were in good health? Towards the end of life people bring up one other equal and opposite arguments. One is the 'fair innings' argument. There are different versions of this. The first one has some traction as far as I am concerned. I shall be 80 in a few years' time and if I am in pretty good health perhaps I shall think: 80 is a good age - thank you very much, that's a good innings and I don't feel the need for heroic efforts to give me another 1½ QALY's at the end of that. But you've also got the counter-argument that says well actually it's the number of QALY's *remaining*. This is where you get some traction from the argument that to count something comes into it to some extent: I've only got six months to live and another six months, for me, would be a huge increment – it would be double what I would otherwise get. If you try to apply that you get into all sorts of difficulties although you can see the attraction of it. And all of those use numbers very differently.

QALY'S are egalitarian, but they are also highly individualistic, as all you are measuring is the intrinsic value of somebody's life and health, and the population's willingness to pay for that; the hypothesis that it could be you that benefits from this. (I haven't been talking about monetary valuation)

Should we really ignore wider societal benefits & costs? – which the current way of doing cost benefits probably does. The argument then goes: OK, well, we shouldn't. People who are well enough to do either paid or unpaid employment add value to others. If you are well enough to care for somebody else, then that surely increases the common good. Conversely, if you are not, and if all you are is a recipient of care, you are a drain on resources, and

unable to contribute much to others' care – and an economic black hole. So what you should do then is look not just at QALY's but also the wider societal value of the life that you are saving, prolonging or improving. The benign version of this is to say: suppose you are able to improve the health of somebody of working age to the point where they are actually able to take a job, that has a huge multiplier effect; it's not just the contribution they are making, they are also needing less care from others, they are able to pay taxes, and it is of huge psychological benefit to them (but that should be captured by the QALY's in any case). It sounds sort of good and plausible when you look at it that way round. It becomes more difficult when you look at it the other way round. The way the argument is going at the moment within health economics is that you *should* be looking at the wider societal benefits. That will have a number of important consequences if it gets taken seriously and used to determine how resources are used. Firstly, if you look at where the money will go, it would go massively more to things like mental health and arthritis: the things that actually stop people of working age living a fulfilling and productive life, and taken away from pancreatic and other terminal cancers that you can't do much with. Possibly there will be a swing from that sort of end of life towards palliative care; from trying to prolong life to making the end of life better. My only worry is that although it is not the intention, the way this is going to end up going in the current economic world we live in is that we are going to lose the egalitarianism; we are going to go back to the situation where the barrister rather than the barista that gets the dosh. There is quite enough of the differential between the richest and the poorest as it is. In the borough of Kensington and Chelsea where the Grenfell Tower fire was the difference in life expectancy between the richest and poorest postcodes is 14 years. Anything that allows that is simply not to be countenanced.

My own feeling is that prioritising funding end of life care over prolonging lives in poor health would be quite welcome. I have a sneaking suspicion that if that is the case we will end up doing the right thing for the wrong reasons.

## Discussion

*Regarding the medico-legal situation; the size of compensation claims is going up so fast that if you draw a line of this increase versus funding for the healthcare system and the trend continues the whole system will collapse. People are now talking about there being an equal but fair distribution of compensation so if you are a barrister and claiming for someone to polish your Bentley and that your compensation should be massive you will get the same as the dustman. That will pay for a comfortable standard of living for life but will get rid of the multi-million pound claims.*

*You were talking about asking the public about wanting more years in poor health versus fewer years in poor health. My experience with people that have done advanced directives, particularly those with motor neurone disease who you do try to talk to quite early on about*

*what they want, is that it shifts; they adjust to being fed by tube and other interventions and even if you would think their life was totally unbearable, and we are only talking about months, they will still decide to go on having this or that. So asking the general public when they are not disabled or in ill health is never going to be accurate.*

This is a recognised methodological problem, and there is a debate about which group you ought to ask. The majority view is that you should ask the general public, and that you should scratch around things like coping better ... although you are actually asking a prospective question

*I was looking at the transcript of a previous meeting where Havi Carel spoke and she made the point that a paper she had read about QALY's seemed to suggest that as someone with a disability a year of her life was only worth half of someone else's. When you look at your slide about what half a QALY would entail, which could be not being able to walk or being severely depressed, I would choose the former any time. How do they 'mark' half a QALY?*

## Homeward Bound

Gillian Bartlam

I first became interested in healing when I was three when I went through something very traumatic and what happened to me in that trauma made me very unconscious on some levels. I made two decisions at that point in my life. One was that whatever anyone did to me I was going to be *me*, and no-one was going to stop me. Which was quite a big decision to make at the age of three, and probably why I am a little bit eccentric! I have been very moved and struck by the people who have talked here and my mind has been excited by several different things. I'm not really a public speaker – I'd rather just sing to you - however several of the things that struck me about the healing in dying process is that a lot of people have said to me, when they have spent their last days with someone who is dying and has been agitated, they have suddenly decided to talk about something that has happened to them in terms of their trauma in life. There was one particular instance of a man whose father was a mine clearer and so had come across a lot of really horrible stuff which he had never spoken to anyone about. When he finally did talk about these things his son was gently stroking and massaging him and just listening to him and he came out with it all. He was crying and all the pain he had from that time came out in those last few days, but he after that he became very peaceful and was able to die peacefully. And I do wonder whether the peace we see sometimes in people who are dying is because they have healed themselves in a psychological way.

Every day  
 Every hour  
 Every minute  
 Every second  
 The preciousness of time  
 The tiny details

I think those tiny details – or the lack of them - are really what we have been talking about today. This is something we can take away and think how we can change.

This is a very good book called 'The Pits', written by Elizabeth (Liz) Stockley about a woman's experience of, and journey with, a pituitary tumour. It is self-published but you can get it from the pituitary association and the proceeds from it go to this. The title refers to the pit stops she made during her illness and recovery.

But what I really wanted to talk about today is the play *Homeward Bound* which is the true story of Leslie Goodburn and her husband Seth, who at the age of 49 was diagnosed with pancreatic cancer. There were just 33 days from when he started to feel a little unwell till his death. It has been published by the National Council for Palliative Care and can be used as a vehicle for teaching in all kinds of areas of care from hospital cleaners to social workers, to inform, provoke questions and discussion.

I am going to read a short extract from near the end of the play where the two characters, Leslie and Seth, are reflecting on what they went through together.

*Leslie:* (who has been called to the hospital because Seth has taken a turn for the worse) " When I arrived he was distressed

and anxious. He had been having vivid dreams and described a conversation with the doctor who told him that if his heart stopped they would let him die. I didn't know if he had imagined this, so I just spent the afternoon comforting him. I looked at the Trust's website which said that the patient must be treated with respect and dignity; so why was he left feeling frightened and upset. The doctor had just come in and said: "well, if you are here we've reached the stage where the side-effects of treatment are impacting on your quality of life and we need to discuss some difficult questions with you." And he did all of this with Seth on his own with no support.

*Seth:* Five weeks ago I had everything to live for. Three weeks ago I was diagnosed with Stage 4 pancreatic cancer which had spread to other organs. The consultant told me that if I had a stent fitted it would buy me a bit more time. I signed the consent for Leslie's sake. I waited three hours, only to be told that the stent couldn't be fitted after all and I was returned to my room. For the staff it was another day, another dollar, another procedure. For me, it was entering the final stage of life. The oncologist told me that they had exhausted all possibilities and I should think about my options for my final days and hours. It was like being on death row. I was on a feeding tube at this point; I wanted it out. The nurse told me that it was not in my notes to have it out. I was dumbfounded. Carol, the staff nurse overheard. She said that the patient's wellbeing came first.

*Leslie:* I told Carol that Seth had been denied a fan

*Hygienist:* Not if the fan is concealed – I'll get you one.

*Seth:* I'm sweating - it's so hot in this place. They do have lollies and ice cream - they just didn't think of offering them until Les asked them. I don't know how a less assertive person would manage. "You get yourself home, Les," I said, "Take that bag of stuff – I won't be needing it again."

In the next scene:

*Leslie:* I've never driven so fast. I knew this was the end. I arrived on the ward at 4.45 a.m. The door was locked. I banged on the door – I tried to phone – I shouted - I was desperate to see my husband one last time. I only managed to get in when someone else came out. Seth was sitting on the edge of his bed being comforted by a healthcare assistant. I took over. I talked to him; I told him that whatever it was that we were facing we were facing it together. Everything would be OK. He became restless and fearful. He was at the end. Nobody told me he was at the end. Nobody had a conversation with me about what I might need to do to help. Nothing, just nothing. He died at 9.45 a.m. We were together.

*Seth:* I died just before 10 a.m. on the 24<sup>th</sup> of June 2014 after a short illness borne with fortitude and dignity. I could write a book about that stay in hospital. Like the time the lovely dinner lady popped in. I still had the feeding tube in so she announced “it’s fish and chips and mushy peas for you, Seth”! Then there was the well-meaning physiotherapist who wanted to do an assessment. I could barely get out of bed and he wanted me to stand and raise first one leg and then the other! Honestly, you couldn’t make it up. And oh, that toilet: the shredding toilet. It took 2 ½ minutes to flush, and was as noisy as a jumbo jet. And do you remember the girl whose job it was to fill the plastic bag dispenser. She just barged in and fiddled about with it for ten minutes. It wasn’t that she didn’t care - *she just didn’t think*.

*Leslie:* Seth had made it very clear that he wanted nobody to see his body after death except me and the immediate family.

*Seth:* I just had this thing about the indignity of it all. I didn’t even like the thought of people seeing me ill, let alone gawping at my body.

*Leslie:* They didn’t close the door properly and left the curtains partly open so everyone passing could see you laid out. It was so undignified. It was as undignified as me sitting on a hard chair in the corridor crying my eyes out. Nobody offered to console me, or to find a quiet space for me, or told me about the procedure. They didn’t say anything but I could tell they were itching to reclaim the bed.

*Seth:* I was homeward bound but I didn’t make it. I just wish that some people in the hospital would have been more sensitive to our needs. I wanted to feel supported and safe, but I felt neither. And the last word goes to my dear wife – the love of my curtailed life.

*Leslie:* I so needed someone who could help and support me. I wanted a quiet place where I could sit and be comfortable and comforted. Hospitals are busy, busy places. Space must be at a premium but I too needed dignity and respect. I know it’s a big ask, but maybe our story can inspire more thought and consideration. Seth’s courage and compassion sustains me and gives me the strength to share our story in the hope that hospital care may be a little more patient centred and a little more bearable – and much more supportive. Love is a freely given gift of the heart. Care comes at a cost.

The whole play is actually half an hour and it is divided into units so it can be used as a reflective/learning exercise (what are the learning points, what went well, what could have been done differently etc.)

One of the things that helps people to understand what others are thinking is to somehow be able to put themselves in their place through song, poetry and listening. One of the ways I work, for example, is with .... which is a kind of drama therapy. I had a client whose parents were very strictly religious; they were good people but they were very bound by their religion. They weren't able to see outside the box of what it meant symbolically. They agreed that their son could go to Hawaii for a course that he wanted to do. He went to Hawaii and set up a wonderful life for himself; for the first time in his life he felt really happy and free. He was gay, which wasn't accepted by his parents, and half way through the course his father made him stop it and come back. When he came to see me he was very angry with his father whom he hated. He could intellectualise but he couldn't get past the anger. So I just said: "OK, so your father is sitting there in that chair; tell him!" The venom and fury that came out of his mouth was enormous. Then I said: "now go and sit there and be your father". For about 15 minutes he sat there and didn't say anything. It was time to stop the session and off he went. The next week he came back a completely different man. I asked him what had happened. He said: "When I sat in the chair I couldn't say anything. I knew ... I felt ... suddenly, my father. He didn't know what to say: he didn't have the words or the understanding or the experience - he had no idea." He had completely forgiven his father and there was a huge understanding that I don't think he could have got in any other way.

So part of our job is to try to enable people to put themselves into those situations somehow or other. It works differently with different people, and we need to find these creative ways of getting that message across so we can all get to know what it must be like for that person who is dying and the people trying to support them.

## Discussion

*It's not just hospital managers. There is an analogy to this. I spent a week at Guy's and St. Thomas's a while ago and one of the things they introduced there was a video called something like Doris's Journey, which tells the story of an 80-year old lady who comes in initially with mild dementia; looking at the hospital experience from her point of view: the noise, the confusion, the way people talk to her: they tend to shout at her and talk very slowly as if she was deaf or stupid which she isn't, and things like that, through to her developing more severe dementia and people not being able to deal with that. Eventually she falls and breaks her hip and dies. It's not a happy story. Everybody from hospital management to nurses and care assistants and consultants has, as part of their induction, to go through the experience of that video. They reckon that that has done more than anything else to change the culture of how people ...*

Talking to people like that happens everywhere. I have a friend who only has one leg but she doesn't have a stump so she just uses crutches. People speak to her as if she's an idiot.

*Everybody needs to have a bit of that kind of vicarious experience to get a bit of what it feels like.*

*I work in a small hospital; the nurses are really good and we have separate rooms, individualised care, but the consultants insist that everyone has to sign a do not resuscitate document. There is no support in there – just a bit of paper that has to be done; they don't teach the junior doctors how to do it – they must get this from signed. It gives the message: it's futile to try and resuscitate you – but it's your decision!*

It's going back to that thing ... we are all responsible ...

*A very severely disturbed young man was admitted to our hospital with a first presentation of psychosis. My husband who is a psychiatrist was asked to assess him. When he went on to the ward he couldn't find a single nurse that would speak to him - nobody said "can we help you?" or tell him what was going on. He had a name badge that identified him as from the mental health trust. He asked for a room to assess the patient and the answer was no, we haven't got any, so he had to do the assessment in a six-bedded bay with the curtains drawn ... it's not just dying people, it's a lack of recognition of the place for privacy in acute hospitals which is being driven by this culture of 'get 'em in, get 'em out ...*

Children are put outside the curtain as if they can't hear their mum or dad being told they are about to die.

*I have a friend who came to one of our meetings who is now a nurse consultant in palliative care, trying to teach palliative care on all the wards and to help them to understand the needs of patients and how to improve the whole experience of patients with complex problems. That is so needed, and needs to be taken into all sorts of things including dementia.*

The way that it is taught is so important. When I'm teaching counselling I organise the class as though it was a counselling session so that they know things right from the word go - the way that we speak to each other. Everything is a reflection and therefore needs to be taught in that reflective way so that people really feel what is going on

## Final discussion

[Unfortunately the first few minutes of this were not recorded]

*... there is no us and them ... these dichotomies are unfortunate ...*

*I think there is an us and them, but by getting together and communicating can we pull together. 'Enemy' is an unfortunate term for people who perhaps aren't able to yet share our view.*

*I think that's a better metaphor. We are all on a journey. I was one of 'them' - the enemy – for the first half of my career. I thought biomedicine was the answer; I thought I was going to find a cure for osteoarthritis. Now I am in a very different place. I don't want to get into battle mode.*

*Science has cured lots of things; there are treatments that work but they just don't work often enough. It's not us or them. But the contribution of the healing approach isn't actually rated or costed. So you don't get the time. The social system: the social view of disability stops quite a lot of disabled people being able to contribute. Hospitals stop healing. The whole setup of hospitals and primary care at the moment doesn't prioritise the healing aspects. It has to be either one or the other so in a way it's abolishing that contribution. Actually I suppose in a way that is what I am groping at is that we can see the cellular effect of non-pharmacological approaches and perhaps one day we will understand that, and that will make it easier for the 'cure' scientists among us to understand that this is just as important as good medicine.*

*We have been talking about military metaphors; 'fighting', 'battles', 'enemies', etc. – really interesting language, and I was trying to think about the way in which wars are settled. There have to be diplomats, there have to be spies and people carrying messages from one side to the other so that no side has an advantage. The difficulty that I am seeing is that the biomedical people seem to have all the weapons! But I do feel that their disadvantage is that they are full of judgement. One of the things that is very interesting about this group and other similar ones is the lack of judgment. And I think each one of us could help by just challenging that judgement when we see it, hear it, or when it comes up in conversation; why are you judging? – what is the judgement about? Can you put aside the judgement and just listen? Maybe this is the way to start to build a bridge.*

*One of the things we haven't really talked about much is the over-riding importance of having some sort of meaning and purpose, as much at the end of life as all through it. A book which is very pertinent to our theme is *When Breath Becomes Air* by Paul Kalanithi, which illustrates the conflict between length of life and its quality. Kalanithi was a brilliant young American neurosurgeon of Indian parentage who was diagnosed with lung cancer just as his career was taking off. What kept him going was having a driving purpose in life which in his case was to be a successful neurosurgeon. It is a very moving account of how he battled (perhaps an appropriate term in his case) with his cancer in order to fulfil what he felt was his purpose in life.*

---