

Chapter 6

Developing services for people with Dementia

“Breaking Down the Walls of Silence”

A Dance

**She is like an oyster-shell closed tight-hiding the
beauty of a pearl within. The disease has stolen life from
her body, words from her mouth and smiles from her face.
To know what she thinks or if she thinks is a mystery. She
is closed in the shell of Alzheimer's disease.**

**A dance-especially to their favorite song-brings her back
to us. To see them dance is a beautiful sight. He with his
arms around her waist. Her, tip-toed, holding softly around
his shoulders. She follows his lead, keeping perfect time
with the music. The shell has opened to reveal a beautiful
pearl. They kiss-the shell closes as the music fades. A
miracle to behold. Even if it is only-a dance!**

***By Kim Henderson, who wrote the poem after watching her parents
dance. Her mother is 63 and has had Alzheimer's for more than four
years. Dancing has been a miraculous connection for her parents.***

In this chapter I tell the story of my involvement in the re-design of services for people with Dementia in and around Swindon in Wiltshire over a three year period. The purpose of this is to reflect on my developing epistemology, an epistemology which is emerging hand-in-hand with my practice, of synthesising my experience and knowledge of creative processes and a growing understanding of complex organisations and applying this to the redesign of healthcare services.

In my abstract I make the claim that *“I have encouraged people to work creatively, critically and imaginatively in order to improve the way they relate and communicate in a multi-professional healthcare setting in order to improve both the quality of care provided and the well being of the system.”*

In writing this chapter and reflecting on my practice throughout the period of this work, I aim to test and to validate this claim. I do this by looking at how my practice is influenced by my values and how these values have enabled me to develop an ontological commitment to a passion for compassion. By showing how I have developed this ontological commitment to a passion for compassion, it is my intention to communicate this as a living standard of judgment which can be used to evaluate the validity of my claim to be seeking to live this value as fully as I can. I also believe that an understanding of one's ontology should be included as a central theme in a self study of one's own practice such as this.

This chapter is also about my learning and how by engaging in a reflective process I have been able to develop a better understanding of and grow more confident in my practice as it has been and continues to emerge.

The Background

In the autumn of 1999 I was appointed as a research fellow at the Kingshill Research Centre in Swindon. The research unit was in the same organisation where I had previously held the post of director of clinical development. By choosing to undertake a full time research fellowship over a three year period I was able to put aside my management responsibility and fully immerse myself in the research of my own practice in order to improve it. I was also able to work freely within the unit alongside both those delivering and using the services.

I was also responsible for developing an integrated care pathway for dementia as well as undertaking a PhD. at the University of Bath.

“The Kingshill Research Centre “aspires to improve ‘quality of life’ for patients and carers by producing high quality research information for use in the development of new treatment alternatives.” (Department mission statement).

Kingshill Research Centre is a service area within the Department of Old Age Psychiatry (DOAP) and part of the Avon and Wiltshire Mental Health Partnership NHS Trust. It is based at the Victoria Hospital in Swindon, Wiltshire, UK.

Kingshill Research Centre specialises in research into dementia and mild cognitive impairment (MCI), investigating:

- drug treatments
- ways of identifying dementia and MCI
- how to assess dementia and MCI
- best practice in dementia care
- the benefits of supporting carers

Within this role I was given the opportunity to use living theory action research to facilitate the process of the redesign of dementia services from early diagnosis to long term care and death.

I approached the task of implementing service improvements in Dementia Services by a commitment to combining my knowledge of creativity with the lessons I was learning from my engagement with

complexity theory. I believe that this project demonstrates that by trusting in the process of change, focussing on the relationships between individuals and organisations and allowing the experience of emerging and novel behaviour to form new perceptions, a greater dynamic in quality improvement can be established. The outcome of this work has been the development of a more coherent, integrated service that I believe challenges much of the old behaviour and relationships among all of the stakeholders.

By facilitating all groups in the process and encouraging emergent behaviour using techniques derived from the creative arts I witnessed transitional phases involved in the development of novel behaviour and new team led dynamics that focussed on implementing improved quality systems and more meaningful relationships between service users and carers and providers. I also used practical creative exercises and storytelling, which demonstrated the powerful contribution made by carers and service users in the treatment of dementia. By trying to enhance the quality of communication and the understanding that can emerge from the use of creative storytelling techniques, decisions relating to care, both clinical and non clinical, contributed to the implementation of a more integrated service for patients. For all the stakeholders involved in the project the process of continual transformation and development had begun, a key feature of complexity theory, and a meaningful exemplar for other teams and organisations across clinical specialties.

The team at Kingshill wanted to improve the service even further by making sure that they were taking a continuous quality improvement approach to dementia care.

What is Dementia?

Dementia is a condition characterised by a progressive decline of mental abilities as a result of disease of the brain, usually of a progressive or chronic nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Impairments of cognitive function are commonly accompanied and occasionally preceded by deterioration in emotional control, social behaviour, or motivation.

Dementia is an important disorder, with Alzheimer's disease alone being the fourth most common cause of death in the Western world. The number of older people in our society is growing and the number of over 65-year-old people is predicted to rise by 10% in the next ten years. The greatest increase will be among those over 80 years of age. An estimated 5% of those over the age of 65 have dementia, rising to 20% over the age of 80. (Naidoo & Bullock, 2001. p.1.)

A recent Audit Commission for Local Authorities and the National Health Service for England and Wales report (2000) entitled ***Forget me not*** found a wide variation in practice and in the kind of resources that were available for the care of people with Dementia and identified that:

“Services for older people with mental health problems are patchy and inconsistent throughout the UK. Older people and their carers have not often received the help they need when they need it.” (Audit Commission for Local Authorities. 2000).

Apart from the suffering of those individuals who have dementia it is also important to consider the invisible burden of their carers. Of people who have dementia, it is estimated that 70% live at home and are cared for by their families, friends and close relatives. They need all the help and support they can get. It was crucial for the success of this project that both

people with dementia and their carers were invited to be fully involved in any redesign that may result.

How the project began

I was keen to apply some of the theory I was developing in my growing understanding of life in a complex organisation. I was learning that our traditional ways of managing organisations and in particular managing improvements had not had the success that had been expected. As people were beginning to draw analogies with complex organisations and with the natural world I was keen to begin to apply what I was learning to my practice. My understanding and engagement with complexity theory and systems thinking in general had led me to believe that I was able to encourage a focus on improving relationships and also to focus on increasing creativity in order it would be possible to encourage emergent and novel behaviour. I also wanted to be able to get inside and be “part of,” rather than to be outside and in some way controlling the change process. Stacey, Griffin and Shaw (2000) make this point very clearly:-

“We are suggesting that members of organisations explore a shift in their way of thinking to a way that places relationships between them as the transformative cause of organisational identity.....This means that people jointly create the meaning of what they are doing when they act into the unknown, co-creating their future interaction with others. From this perspective, they are all participants in the joint inquiry into what they are doing together. “(Stacey, Griffin & Shaw, 2000. p. 194).

I wanted to ensure that my approach was more inclusional and responsive and would therefore involve those with dementia and their carers. I wanted this inclusional practice to begin on day one and not as had happened in improvement projects I had been involved in previously in the health service where the healthcare professionals redesign services and

then ask those using the service for their comments. To be inclusional in this process I was aware that extending an invitation to people was not going to be enough. I would also have to ensure that our behaviour throughout the process was inclusional. In a recent conversation with a service user consultant she was able to describe her experience of this in the following way.

“Just because you have invited me into your space does not mean that I am being included – you can exclude me in many very subtle ways, by your conversation, your use of jargon, your body language. I have attended many events where I have felt unable to participate because of these very things.” (Service user consultant in conversation. August 2004).

So on the day when I found myself in a room in a small hotel with a group of individuals, who were passionate about improving services for people with dementia, I made it very clear that we needed to find a way to practice in a more inclusional way. I was also keen to communicate to this group that I did not want my role to be perceived as anything other than as an enabler. It was important that this process was not controlled in the traditional sense of process improvement. I wanted the steering group to allow me to use the skills that I had developed through my work as an actor, allowing a more improvisatory and responsive process to emerge. I believe that this would allow participants in the process to make sense of what they were creating “in the moment”. My desire to work in this way made some people very nervous, especially the funders. We were very fortunate to have been given some funding from Novartis a pharmaceutical company who are manufacturers of Exelon, one of the drugs used in the treatment of Dementia. Of course their funding was much appreciated but I was aware that it was not given purely for altruistic reasons. They are a multinational company and recognised that if we were developing a process by which more people could be identified as having

dementia earlier in the progression of the illness, there would of course be more opportunity in terms of sales of drugs. I made it very clear from the start of the project that my intention was to improve services for people with dementia and that there would be no special treatment for the funders in terms of publicity or recommendation of Exelon as a preferred treatment. They said that they were very happy with this arrangement.

The steering group that had come together to work on this project met 6 times before the project finally began. The group was made up of a core team including:-

- Myself
- Roger Bullock, a Consultant in Old Age Psychiatry. Roger is also Director of Kingshill and a global expert in Dementia; he also has a passion for improving services for older people.
- Patrick Brooke, a General Practitioner with a special interest in Dementia. Patrick had also worked recently to validate the 6-question cognitive impairment tool that we wanted to introduce, as a quick and simple tool for G.P.s to help them in their diagnosis. (See Appendix 1. Breaking Down The Walls of Silence.)
- Charlotte Rose, who had played a major role in creating my post and finding the funding for the project.
- Nick Bosanquet a Health Economist from Imperial College.
- Sarah, our main contact from Novartis and depending on how she thought we were progressing, a variety of people from communications or marketing or management from Novartis head office.

I think it is important at this point to describe my experience of the way a multinational company like Novartis usually conducts its meetings. To start with they are very formal and usually held in a very nice Hotel and sometimes even held in more exotic locations. Most of the steering group

meetings were held in a country house hotel in the Cotswolds. One meeting was even held abroad on the beautiful Island of Crete in the early spring. The Pharmaceutical Companies see this as a way of giving doctors some supported time out, but unfortunately this does not usually include members of other health care professional groups or service users and carers. Before a meeting begins there is always an agenda that is circulated and this is adhered to rigidly, although individuals are allowed to add to the agenda under the heading of any other business. This way of organising meetings is typical of most organisations and even in the health service. Since the introduction of the internal market there has been a push to make meetings more business like, with the assumption that this level of control will lead to greater output. Although the internal market has now been abolished, at this time, there was still an emphasis on this kind of business planning and of course there are also always minutes of the meeting, a job I will avoid doing like the plague. I have, however, heard some managers saying that it can be very useful to be in control of the minutes of the meeting because you can change them to reflect what you wanted to achieve and most people don't really challenge them.

I had developed a way of working that was different to this and because of the unpredictability it sometimes made people seem to be a little nervous. It was very important not to lose their support and so I knew I had to demonstrate quite quickly that working in this way can be effective. They were also anxious that any changes to services or care should be based on evidence if sufficient evidence were available. I was happy to comply with this. I saw no problem in combining what we have come to call evidence based practice with a more open and creative way of working that also valued experience, relationships and intuition.


The need for the creation of an integrated care pathway for people with dementia was identified by the community team from the Department of Old Age Psychiatry in Swindon. The team had made significant improvements over the previous 5 years from the time when Roger Bullock was appointed as the Consultant, and they were keen to continue with these improvements. In particular the closure of inpatient wards as a result of concentrating more support in the community. Roger and the wider team were concerned that patients were still being referred to them too far down the progression of the illness to be able to benefit fully from their services. There was an obvious need for support and education for primary care to help them to recognise the early symptoms of dementia and develop an understanding of what the service could then do to help. There was also concern that there was not equity in terms of what services were being provided to what patients. These were contributory factors in my use of action research as a methodology for the project. I would be working with healthcare practitioners who would be reflecting critically on their work in order to find ways to improve their own practice. Action research was important because they would also be involved in the research process themselves, researching their own practice in the same way as I would be researching my practice.

After the first couple of steering group meetings I felt that I had managed to persuade the rest of the team that although this was a huge project I believed that it could actually be achieved, but they really did need to put their trust in me, and each other, and the process we were developing, and let us get on with it. What I felt was necessary was to make sure that I kept sight of the whole picture. The care of someone with dementia involves an enormous amount of people, people who on a day to day basis relate to each other and just get on with doing what they have interpreted is what they should be doing. It is however very rare that these people, people from different services and organisations as well as service users

and carers to ever have the opportunity to come together to talk and to share in this way.

An exert from Audrey and Ray's story indicates this:

“Do you know this is the first time in all the years that I have been looking after Ray that anyone has asked me to have a say – not that I haven’t said my bit over the years – well you have to don’t you (sighs). That’s why I come every week – to talk – oh I really do enjoy it as well though – but to get them all together – in the same room – well that’s nothing less than a miracle.”

 You can see Audrey talking about her experience of trying to get help for her husband Ray in DVD Chapter 2, Breaking Down the Walls of Silence. In my introduction to the clips in this chapter I am talking to Shaun about the way in which I was welcomed into the homes of people like Audrey and her husband Ray and also Charlie and his wife Marion. I have chosen to include the clips in this chapter because I believe that this will help me to communicate my embodied values in my practice and by communicating them in this way they have become living standards of judgement by which I can hold myself accountable. As I begin the process of talking to Audrey and to Charlie and Marion I believe that I am communicating my embodied values of inclusional and responsive practice. I also believe that the relationship I am establishing with the people I am talking to is one of trust and love and respect for self and for others.

Audrey's comments were not unusual and were repeated throughout not only by patients and carers but also by other healthcare professionals. One of the speech and language therapists working on the project said.

“For the first time I really feel as if I am part of a team and that I have been able to contribute and be listened to. So often we find, particularly

in the acute setting, that we go in as individuals and never really have anything to do with the rest of the team.”

My previous experience of working across boundaries and with multiple organisations was that this was always a problem area and again I was determined to at least attempt to get these people together in the same room. I wanted them to talk to each other to tell their unique stories and share their experience, as I was sure that we all had much that we could learn from each other. Viewing boundaries in my work in this way I believe is similar to Alan Rayner's view of boundaries. Rayner's perception is that space and boundaries are connective, reflective and co-creative, rather than places of severance. (Rayner, 2004.) It was also important for me that the people involved felt able to be part of the project whatever their level of seniority. Project groups in the health service are very often made up of senior individuals within the organisation. It has been impressed on people that if you are working towards culture change you have to engage those who hold the power. This is true, but if you only involve senior individuals, things will not actually change. It is important to engage, in an inclusional way, those who actually deliver the care at the coalface because it is here that you see changes that improve the service or not. If they are not included they will not have ownership or understand the need for change. They may then feel that their contribution is not being valued. When talking to healthcare professionals about this they have often expressed a concern at being “controlled” from above and this makes them feel that their contribution has not been valued. I believe that this has been the problem with the implementation of standards and guidelines within the healthcare setting. There is the perception from healthcare professionals that they are often meaningless and created with little understanding of the day-to-day activity they are engaged in. Part of the monitoring of the pathway process would involve the development of standards and it was important that these standards were developed by

those responsible for delivering them. It was also important for me that those people I would be working with saw me as a participant, a co-creator and not someone who was presenting them with a grand plan with structure and outcome. I also believe that this requires a shift from being propositional to being inclusional. My development as an actor had taught me a very precious skill and that was the ability to be fully immersed in the moment but to be conscious of the fact that in that moment I am also contributing the shaping and the sense making with the people I am engaging with. I believe this to be a very different way of facilitating a process.

Developing the pathway

We talked at length in the steering group as to what was the best way to include as many people as was possible in the process and decided that we should have a celebratory launch of the project and create as much publicity as we could. We made an extensive list of people that included anyone who may be involved in or interested in the care of a person with dementia. The list included service users, carers, the voluntary sector, care homes, social services, consultants in old age psychiatry, community psychiatric nurses, speech and language therapists, occupational therapists, physiotherapists, psychologists, managers, junior doctors, geriatricians, acute nurses, general practitioners, practice nurses, health visitors, district nurses, pharmacists, educators, clinical governance leads. These people were all identified from the Swindon area and had a local interest in both the process and outcome of this work. Invitations were distributed to these individuals and they were also asked to identify others who we may have overlooked. I also made a great effort throughout this period to talk to as many people as I possibly could. I was battling against great cynicism a lot of the time, particularly from those working within the health service. They explained their cynicism to me as being a consequence of their previous experience of improvement projects which

had either failed or run out of steam half way through because they had not been fully engaged. There was also a great lack of trust amongst different healthcare organisations, between primary and secondary care with the community team stuck very much in the middle. They expressed concern that they found it very difficult to believe that firstly the project would be sustained and secondly that they could actually implement any changes. I asked that they just to come along and talk to each other and try to put their trust in the process that they would develop together. I also persuaded the local radio station to give us a mention, which they did. They have been very supportive throughout the duration of the project. This support has included publicity and reminders when we were holding events. They also ran a series of dementia awareness programmes for the local community which gave information about early signs and symptoms and where to go for help.

There were many individuals that wanted to take part but knew that they would not be able to commit themselves fully at that moment in time. To them I extended a welcome to come to any session that they could, even if it was just the one time, as their contribution was valuable. To those who could not attend any of the sessions I made a promise to make time to come and talk to them about what had happened so that they still had an opportunity to feed in via myself and to be included in the process in this way. This was a very important part of the process, I was determined that as far as was possible; I would be able to demonstrate that I had attempted to include everyone. My experience before this was that some people even seemed to purposefully disengage from this kind of work and I found that I was beginning to ask myself if this was in order to disempower those who were contributing. So many times in the past I had worked with improvement teams only to be slain at the final hurdle because someone who had not been involved in the process didn't like the outcome and refused to take on any of the recommendations. I wanted to make sure

that everyone felt that they really could contribute and influence the process. On reflection I believe that this way of starting the project shows me trying to live my embodied values of engaging in an inclusional and responsive way in my practice.

The Launch

The project was launched at the Swindon Hilton on a very windy December night. Despite the appalling weather over 100 people attended the session. The purpose of the launch was two fold: -

Firstly – to inform - by presenting as much information as possible about dementia care, and,

Secondly – to stimulate a passion for improvement within the audience enough to engage them in the project.

The evening was divided into two halves, the first of which was a series of interactive presentations. Roger Bullock talked about dementia and living with this illness and invited members of the audience to ask questions and to share their experiences. Patrick Brooke talked about the challenges facing general practitioners and the reasons why they often miss the early signs of dementia. Albert Persaud talked about the importance of cultural differences and making sure that ethnic groups were also part of the process. I then talked about the project itself, the way we would be working and what would be expected if you were to become involved. We then gave people the opportunity to talk to each other in a more informal way over food and drink, which always helps, and to ask questions or just to take time out to think and reflect. We told them that after this informal time we would be asking people to sign up to be part of the project. We (the steering group) had decided to divide the project up into smaller, more manageable chunks, which were.

- 1. Recognition**
- 2. Assessment**
- 3. Care management and treatment**
- 4. Review**
- 5. Coping with change**

I had concerns about breaking the work up in this way because I wanted to avoid one group being from primary care and one group from secondary care which really would defeat the purpose of trying to work in a more inclusional way. In the end this wasn't actually an issue because those individuals who committed themselves to the project often came to and participated in all 5 parts. I was happy that we had enough people to start the work. Those who signed up were given the times of all the planned meetings before leaving the Hilton. This again was based on previous experience of trying to get extremely busy healthcare professionals to a meeting at short notice. I wanted to make sure that they knew what the time commitments were going to be right from the start so that they knew whether they were able to make that commitment or not. It was also made clear to those people who were participating that they had a responsibility to communicate with the rest of their professional group any ideas, suggestions or changes that were being put forward. This was again to ensure that as many people as possible felt engaged in the process directly and that their input was valued, even if they were unable to be at the meetings. Some people were very keen to be involved but couldn't make the meetings and I also promised that I would come and talk to them after the meetings and attempt to convey the content of the meeting to them in as truthful a way as possible and to give them an opportunity to be included and to tell their stories, if only from a distance.

The Process

We were finally ready to begin and I was very excited but I was also very anxious. I was being put under tremendous pressure to produce agendas for the meetings, to write aims and objectives and also to ensure that any changes to the way the service was currently organised and delivered were evidence based. This was in direct contradiction with my desire to create an environment where people could talk to each other and engage in an emergent process of discovery, in this way conflicting with my values of inclusionality and responsive practice. There was also an expectation from the healthcare professionals involved that I would in some way direct them to the answers. I can remember the expression of horror on one manager's face when asked, "*what are we covering today?*" I replied, "*Let's just see what emerges from the team.*"

It was however very important that any change in the care and treatment of people with dementia or any change in the way the service was delivered was based on evidence, if indeed evidence was available, as well as from the experience of those delivering the service and those receiving the service. I undertook, with a great deal of assistance from Novartis, a systematic review of secondary research and relevant primary research from 1975 to October 2000. Key words used for the search purpose were dementia, Alzheimer's, guidelines, consensus, assessment, investigation, diagnosis, continuing care and elderly.

Having amassed all this paperwork was one thing but devising a process that would lead to decisions about its implementation was another. There was at the time of this project a growing database of evidence in relation to cholinesterase inhibitors, the new drugs for Alzheimer's disease. As with many new drug therapies it was also quite difficult for many patients to have access to these drugs. The National Institute for Clinical Excellence (NICE) was in the process of producing guidelines for the

prescribing of cholinesterase inhibitors, drugs used in the treatment of dementia, but at the time of the project we were unsure as to whether this guidance would be ready in time to include in the pathway. The project participants agreed that they would be prepared to develop consensus guidelines which we would include until the NICE guidance was complete. This was not the only area where evidence was not available. As expected there was more evidence available for the medical side of the care for people with dementia. The carers and service users involved in the project were disappointed to find that there had been less input into the difficulties faced by them on a day-to-day basis. This project, however, could prove to be a significant leader in developing further research evidence in this area. Once I had gathered all the research evidence available, I went through a lengthy process of putting it into a format that made it more accessible to those individuals who wanted something a little more readable. This evidence was then circulated to all those involved in the project so that they could become more familiar with it before our first meeting. I also made myself available during this period to spend time with anyone who needed me to help them with any part of this process.

I was looking forward to the first session, which we held in the more familiar surroundings of the carers' room at the Victoria hospital. The carers' room is a large comfortable room and has been designed to represent, as much as is possible in a hospital environment, a family sitting room. It is a room that is available for carers to use in whatever way they want and is also where their support and education sessions are held. I felt that holding the meetings here would contribute to making them feel more at ease. I was also a little nervous, as usual. Sarah from Novartis had asked if she could come to the sessions. I had to think about this request, as I didn't want her presence to hinder the openness I was hoping to establish. I agreed with her that she would come to the first session and then we would review the effect, if any, her presence had had on the

dynamic of the group. I also requested that she come to the session as a participant in the process and not as an observer. Sarah was the first to arrive, about half an hour before anybody else. At this point I began to panic a little, what if nobody came, what if this was as far as the project went, would I end up trying to write guidelines myself on behalf of other people who would never implement them? My worries were short-lived as the sound levels in the research centre started to rise and a group of carers and newly diagnosed patients came through the door. They were shortly followed by representatives from all parts of the service.

What was my role?

I have facilitated many different projects but each time my role has had to be different depending on the nature of the project and the participants. I have been able to take on a variety of different roles as a facilitator because of my theatre experience. I learnt as an actor to be sensitive to the needs of the other and also to be aware of my self and how individuals respond to me. This time I wanted to create an environment where individuals who don't usually work in this way together would be able to trust each other and engage with each other in a conversation about their experiences in a way that may encourage new ways of working. I knew that this was going to be a challenge but it was a challenge I was determined to rise to. I wanted to be able to be part of a process where we could make sense of what was happening for each of these individual participants on a day-to-day basis so that together they could create something new and novel. It was my responsibility to make sure that people were put at their ease and were supported. This meant that I would have an understanding of the power relations at play within the group. I also wanted to make sure that the less dominant members of the group were given the same opportunity to contribute as the more dominant members. I wanted to ensure that we used a language that was accessible to all of us and not dominated by medical terminology. My role here was

as intermediary and I was conscious that I needed to hold the space in a way that enabled an inclusional process to emerge.

We started this session with a blank sheet of paper but with a room filled with individual experts who had an incredible amount of embodied knowledge. What ensued was a process of exploration through a sharing of this expert knowledge firstly through conversation and then through the telling of stories. My role within this was to keep the conversation going in a way that encouraged individuals to participate. As people became engaged they began to make connections, in the moment, this would often take the conversation into a completely different and unexpected direction. There also developed a very tangible difference in the way people were telling their stories. The telling of stories is not a new process but is quite often undertaken in isolation as in the case study, or only one story is focussed on. Here we were telling stories collectively and we were listening to each other and were able to question or to add comment. This process was not always easy or comfortable and there was often argument and tension. There were also moments of laughter and fun as the relationships were developed and extended. Patricia Shaw refers to this way of working as *“complex responsive processes of relating”*. She describes this further by saying:

“This way of thinking suggests that we are constructing together a future that is always already given shape by history but which is always open to further shaping as the simultaneous continuity and potential transformation of the patterning process of communicative action.”
(Shaw, 2002. p.43).

By sharing stories in this way we were able to understand more about the things that affect us and this sharing and understanding enabled the telling of our new stories, the story we wanted to tell about the future of our services, would be one that we could now create together. Working in this

more fluid and participatory way does not mean that I did not use some of the tools I had used before, tools like process mapping. I was however trying to make sure that I used these tools when it felt right to do so rather than the tools themselves driving the process. In this way I was able to behave in a much more responsive rather than impositional way.

In this first session we used process mapping to recreate the patient's journey and this was an incredibly complicated process. Starting from the beginning and trying to identify what currently happened on this journey it soon became apparent how complex the whole process was and also to begin to understand how things can very easily go wrong. It was also a surprise as to how much disagreement and contradiction there was about the process from each different perspective. It also became very clear very early on in the process how little we actually know about what each other's role is, what each professional group provides, what we actually do on a day to day basis. A significant part of this process was the story telling. The purpose of this was to immerse ourselves in the reality of each other's experience. We were discovering that there were many assumptions being made by individuals on behalf of each other. This was an opportunity to begin to understand what it is like to have dementia, to be a carer of someone with dementia or to be a busy general practitioner expected to recognise the early symptoms of dementia. This part of the process was very moving as individuals opened up to the rest of the group and told their stories.

The following are excerpts from some of the stories that were told at the first sessions. I have included these stories here because for the group they became the most significant stories. Audrey and Ray's story was and is significant because of its extremity in terms of failure. This story made a significant contribution to our understanding of how we can so easily fail to provide for those people using our services. Patrick's story is also significant because of the important role of the general practitioner as the

gate keeper to services. We very quickly learned that to fail at this point meant a delay in recognition and diagnosis and caused unnecessary distress to people in the early stages of dementia.

Audrey and Ray's Story



Ray

Audrey and Ray are both in their 70's and Ray has been suffering with dementia for more than 17 years. His symptoms began suddenly over a week-end when he was just 57 years old following a stroke. His stroke was not obvious when it happened, as he seemed to have no physical symptoms of the kind usually associated with stroke. Audrey reported that his behaviour was "strange". When I asked Audrey to tell me what she meant by "strange", she explained:

“It wasn’t something specific, not something I could put my finger on. He just wasn’t himself, it was very slight at first, but I could tell, I knew he wasn’t right.”

Ray’s “strange behaviour” continued and Audrey decided to seek medical advice from their general practitioner. He referred her to their local acute hospital where he was examined by a consultant and the diagnosis of stroke was confirmed. They were sent home with the advice that many people have strokes and completely recover and Ray was very fortunate, as he appeared to have suffered no obvious physical damage. Ray was a builder and up until this point in his life had been very fit, both physically and mentally. Following this episode of illness he was never able to work again. Ray and Audrey were in the process of moving house at the time and their move went ahead as planned. The new and unfamiliar surroundings that Ray now found himself in added to his growing confusion. It took a total of 8 years before Ray was actually diagnosed as having dementia. Throughout that period of time as Ray deteriorated they were given very little help and support. Audrey described the day-to-day difficulties facing the carer of someone with dementia.

Extract from Audrey’s story



“I’m going to tell you about my husband Ray...Oh...Where do I start? I’ve been looking after Ray for nearly 17 years (laughs) don’t look at me like that – I’m in my 70’s you know – People always say ‘Oh you don’t look that age’. It must be all the hard work that keeps me looking young. And you know it is hard work, it’s damned hard. You know this is the first time in all those years of looking after Ray that any one has asked me to have a say. Not that I haven’t said my bit over the years – well you have to don’t you. (sighs) That’s why I come here, every week, ooh I do enjoy it as well though – but to get you lot all together in the same room at the same time – talking about dementia – well that’s a miracle. They’re all lovely, especially here at the Vic, but you see they are the experts here aren’t they, they know all about dementia – and that’s the main problem when you go anywhere else, the people don’t know what dementia patients need.

Take Ray for instance, Ray is very different – he’s not your usual dementia patient. Well he can still read the paper – he plays cards. But if he was sitting there with an empty glass, he wouldn’t be able to think ‘Oh my glass is empty, it needs to be filled up.’ He doesn’t make the connections; he wouldn’t make the connection with him being thirsty and his glass being empty. That’s what makes me angry about the respite care. These places aren’t designed for people with dementia. They don’t seem to have any understanding that these people can’t ask for things themselves. Ray has to have a bag now, a urine bag to drain off his urine. So he has to have plenty of drinks, to keep it flowing, but he won’t ask. Do you know some days they don’t even empty his bag. I like to give it a little wash out when I empty it; you know to keep it nice and fresh. Ray always kept himself nice and clean and fresh. That’s one of your biggest worries when you are looking after someone, you worry about something happening to you – you know that everything would just fall apart – that’s what causes you so much stress. I know

that if anything happened to me, Ray would have to go into a home and he wouldn't last 5 minutes in there.


I didn't even want him to go into respite, but it's very hard to cope for 24 hours a day every day, 7 days a week. And it wears you out having to fight for every little thing. It's like his walking, I have to make him get up and have a little walk around every hour or so. He's got a walking frame now because he's a little bit wobbly. But you see they don't do that when he's in there, he just sits all day – they don't walk him around. So when I get him back in the evening he's as stiff as a board and that makes him even more wobbly. Now that's just basic care isn't it? Just basic common sense. It's not right you know. It takes me 3 days to get over the effect of having one day off; it makes you wonder if it's worth it.

I must tell you the shower saga. My Ray's a big chap; well he's not as big as he used to be now. He used to be a builder, he was very fit. As he's got less mobile I found I couldn't get him in the bath. So I talked to the occupational therapist from social services, not the ones from here, the one from the social services. I wanted to see if I could get some help from them to put in a shower for him. Now Ray did very well when he was working and we managed to put a little bit by for our old age. As I had this bit of money I had to meet them half way, I had to pay for half of the shower myself. Now don't get me wrong – I don't mind making my contribution – I don't want charity. I thought that if I was paying for half then I would be able to have some choice in what kind of shower I got. They sent an O.T. around to the house; I don't think she knew anything. Any way what I ended up with isn't a normal type of shower, I've got a room with a plug in the floor and the whole room is tiled. The idea is that I don't have to climb in and out with him; it's supposed to make it easier for him. Now that's fine but she didn't choose non-slip tiles. So you can imagine what it's like when it's wet can't you – me and

Ray just go sliding all over the place. (laughs) Seriously though we're lucky we haven't ended up on the floor. When I turn the shower on I have to keep hold of him so he doesn't slip and I end up soaked. So I rang the O.T. and told her what was happening and she came out to sort it out. She turned up with this plastic frame. It's got 3 sides and he's supposed to wrap it round himself and he won't fall over and I won't get wet. Well Ray might have dementia but I haven't so I told her she has to change the tiles, you can't have slippery tiles in a shower. My daughter's a teacher and she said they've got the very same tiles in the school corridor and when the cleaners wash them and they get wet they have to put up a hazard sign saying 'caution'. And I've got them in my shower, now where's the sense in that. This is the sort of thing you have to put up with. That's the hardest thing when you are looking after someone with dementia. These people don't really know who they are, what their lives were like before they got this illness, they don't know that there is a person there. When my Ray got dementia I lost him, I lost, my husband, my friend my partner, my lover, the father of my children. Yet he is still here and at the same time he is gone.

Audrey's story is a very moving account of her struggle to provide the best possible care she could for her husband. Audrey's commitment to the project was incredible; she attended every meeting of each stage and contributed in a way that will remain with me forever. She welcomed me into her home so that I could share some of her time with Ray and helped me to understand what life for them was like. When we listened to Audrey's story in the group it enabled us to root the work we were doing back into her life. We were able to talk to her about what things would really make a difference to her and to Ray. I was always amazed at the contribution the carers and patients made to improvements in the service. They were full of very simple easily achieved innovative ideas. They were ideas that could make a significant contribution to the quality of their

lives. Working in this way also enabled real partnerships to develop between the users and the providers of the services.

 You can see more of Audrey and Ray in DVD Chapter 2, “***Breaking Down the Walls of Silence***.” In this chapter I have included a clip of Ray looking at some old photographs that Audrey had been showing me, they included photographs of their wedding day. I have included this clip because I believe it shows the inclusional nature of the relationship I had established with both Audrey who was contributing to the video and Ray who despite his difficulty to engage in conversation is still included in the activity.

I have included a second clip of Audrey talking about how she felt in the early days of Ray’s illness, she felt he was neglected and this had an impact on his deterioration. I have included this because at the time it made me feel very angry at the way our services can easily fail to treat people like Audrey and Ray with the love and respect that they deserve. This is also communicated by Audrey in her third clip where she talks about the wider implications of living with dementia. In this clip we can begin to understand the importance of education in nursing and care homes. This conversation with Audrey contributed to the development of characters that I could use as part of a pedagogical approach to developing services.

Patrick’s Story

Patrick is a general practitioner (GP) and has a special interest in dementia. This makes him very unusual as a GP and he has developed a wide knowledge base in the early recognition of dementia. He is also a very busy practitioner and finds it difficult to devote the time he knows that his patients need for a proper consultation. Patrick finds it difficult

but has a great deal of knowledge of the early signs and symptoms. He pointed out that it is even more difficult for those general practitioners who don't have a specialist knowledge and it isn't surprising that many of the early signs and symptoms go undiagnosed for so long. Patrick shared his story with the group.

My average consult is 10 mins

The typical patient usually arrives mid morning (the elderly usually come about 10ish)

I get a polite little knock politely on door, I'm running 15 mins late already by this point and I'm desperately hoping that this will be a simple blood pressure check so I can review the medication and catch up 4-5 minutes time.

The patient comes in, I shake her hand and apologise that I'm running a bit late, she sits down saying that she almost forget her appointment but luckily her daughter reminded her last night, then backs this up with a comment like "I don't know my memory's shot to pieces"

I am running late so I overlook this cue!

"How can I help this morning? Is it your annual check up?"

"Oh yes doctor and I need to ask you a couple of other things whilst I'm here."

I ask what those things are so I can try and manage the time available appropriately – my heart sinks, as clearly I'm not going to catch up time on this appointment.

“Well its my knees they’re starting to hurt a lot when I walk, my daughter has to do a lot of my shopping nowadays, I used to walk into town and back but now I can’t get round the supermarket on my own. Now what was the other thing, oh I can’t remember.” – she rummages in her bag for a list looking at it she says “oh yes that’s it - I’ve also got a couple of moles on my back that I’d like you to look at”

My heart sinks further as I think of the 15 layers of clothing she’s probably wearing and how long it’s going to take her to remove and then put them back on again.

“Oh” I say “let’s start with your blood pressure”, I check this – it’s gone up so I have to increase her medication, I print off a blood form to check her Urea & Electrolytes.

“Right let’s have a look at your back and your knees”

I show her towards the couch in the corner and help her on to it, I fiddle around with her knee for a minute largely because that’s what is expected of me – I already know she’s got Osteoarthritis of the knees and probably also of the hips.

I get her to lean forwards whilst I try and lift her blouse up and move aside various layers of corsets and vests to try and view the offending spots. Again as expected I see two seborrhoeac warts, which I reassure her, are normal and due to the skins repair mechanisms failing due to age and previous sun exposure.

I help her off the couch and leave her to correct her clothes and slowly put back on her cardigan scarf and coat.

After a minute or so (during which I tap away at my computer and write out an x ray card for her knees) she returns to her seat.

I recap what I've found

"Your blood pressures a little up so we need to increase your lisinopril to 10 mg, you need to get this blood test done and see me again in 4 weeks to recheck it." (As I say this I hand her the blood form and the prescription)

"I think your knee pain is due to arthritis 'wear and tear' - we'll get an x ray to confirm this and in the mean time I'd like you to take some regular paracetamol for it, you need to take 2 tablets four times a day."

At this point the patient invariably replies that they've tried paracetamol and it didn't help much.

I reply that taking regular paracetamol is much more effective than taking it occasionally. Pre-empting the next question as to whether this is safe I say 'it's quite safe to take up to 8 paracetamol a day' I also suggest trying some glucosamine from the health food shop or cod liver oil capsules.

Finally I say – "and don't worry about those marks on your back they're seborrhoeic warts, if they cause you any problems we could freeze them off otherwise I'd just leave them alone."

The patient gets up, I shake their hand and say I'll see you in 4 weeks time, as I'm holding the door open for her to leave she suddenly says, "Oh I've forgotten I need all the rest of my tablets, you know my memory really is terrible."

I usher her back to the seat and pull up her prescriptions on the computer, after a little chat about which tablets she needs and does she need any more of her cream I print off the prescription and sign it for

her. As I pass it to her I'm tempted to try and ignore the now multiple cues given to me about her memory worries, I'm now running 25 minutes late but my conscience wins through so I try and broach the subject of memory.

"You're quite worried about you're memory aren't you?"

"Well my daughter keeps telling me I'm getting forgetful; I think she's worried I'm going to go batty like my mother."

"Did she have a problem with her memory?"

"Yes she used to live at home with us when I was little, she got demented."

"You're quite worried about this happening to you aren't you?"

"Oh I'm ok it's just my daughter worrying, anyway there's not much you can do, I don't want to go into a home."

"It's not that bad. But we really ought to check your memory out as there are now things we can give you to help if we get to it early enough."

"No don't worry about me doctor, I'm ok."

"Let's just check your memory out, then you can reassure yourself and your daughter that you're OK, I need a few minutes to do this and I'm sorry but I don't think I've got enough time to do it justice now. Why don't you come back in another appointment or we could do it in 4 weeks time when I re check your blood pressure?"

"Well if you think it's worth it."


"Yes I do, it's really important to check it out now and not leave things until it's too late."

Consultation ends, I stand up and shake her hand again, "I'll see you in 4 weeks or sooner if you'd like and we'll check through things then for you."

She thanks me and we say goodbye again

I return to my computer and try and record what's happened in her notes.

Patrick's story is a very honest and open account of life as a busy general practitioner. His input was absolutely crucial as it is in this relationship, the first encounter with the health service, where things can start to go wrong. We were able to talk openly and honestly about the circumstances where this might happen, what causes it to happen and what we could do to change this and to try to ensure that individuals did not slip through the net. There was also an interesting dynamic between the services provided by secondary care and primary care and a tendency for one side to blame the other for problems that they had encountered. This was not an easy process for healthcare professionals like Patrick to engage in. This process was an emergent process and was enabled as individuals engaged in conversation, as we engaged in a process of making sense of our experiences together.

 A recreation of the first contact with a GP can be viewed in DVD Chapter 2, ***“Breaking down the walls of silence.”*** I have included this clip in chapter 2 because I feel it helps me to communicate the importance I place on the ability for theatre to help as part of an educational and developmental process. This re-enactment was created from the stories we shared based on individual's experience. The theatre was devised and used as part of an ongoing programme of education and development. It was used to stimulate conversation and to encourage other people in other settings to tell their own stories. I believe that by including this clip I am more able to communicate my embodied value of love and respect for self and for others. I do this as I recreate a character that gives voice to those I am working with in a way that pedagogises empathy and shares my

passion for compassion with a wider audience. It also enables my practice to be held to account in a public arena.

I was very encouraged that by being able to hold the space for people in this way I had managed to create an environment where this debate could happen in an open and reflective way. As we went further into the process much of the defensiveness that was apparent in the beginning began to disappear and individuals said that they now felt less threatened and more comfortable with this process. This meant that we were able to focus less on “who does what” and more on “what should we be doing?” Through this process of focusing on the relationship between the different service providers and the relationship between the service user and the provider we were able to identify the parts of the service that we had to improve. Again the service users and carers played a significant part in making innovative suggestions that could have an immediate impact on their quality of care. One of the carers talked about how difficult it was getting enough information from the staff in the day care centre her husband attended a couple of days a week. She said that she didn’t like to ask too many questions, as the staff were always so busy. She also said she didn’t want them to think she was a troublemaker.

A carer’s story

This may seem like a little thing but it is often the small things that become big things. When I pick Jim up at the end of the day I don’t know what he’s been doing all day and even more importantly for me I don’t know what he’s had to eat. Now I can look on his chart and it might say, Lunch, Fish chips and peas. What it doesn’t say is whether he ate any of it or not. That information is really important but the staff haven’t got time to explain it all to me, they are far too busy and I don’t want them thinking I’m a trouble maker. Without that information I don’t know what to give him for his tea, you see if he’s had a good lunch

I can make something light in the evening. If he hasn't eaten much then I need to make sure he's had enough nutrition otherwise his health will deteriorate. I'm also sure that sometimes when he has a bad night it's because he was hungry, as he didn't eat much during the day. The nurse also told me his fluid intake was really important – but I don't know how much he's had to drink. So what I have done is bought a little notebook and they write it all in here and if I've got any questions I write it in in the morning and they will write an answer for me and that way I don't have to keep bothering them all the time.

Another innovative and simple idea came from the discussion following a story told to us by one of our community psychiatric nurses.

I had an urgent phone message on my desk from the matron of a care home where we had recently placed one an elderly gentleman. They were having a problem with him and were finding his behaviour very aggressive and wanted us to find another placement for him. This gentleman had only recently become known to us here and we had very little knowledge of him and his past history. I went to visit him and over the next couple of days got to know a little more about him and what was making him behave in this way. His agitation happened every time they came around with the tea trolley; he would become quite violent and upset and was frightening the staff. What I learnt about him was that he had served in the war, he was very young, only 17. He was posted to India and his camp was on the edge of a tea plantation. Every day he watched the women tea pickers suffer at the hands of their bosses. He often saw them being beaten and in the night they dug a pit to sleep in. He could do very little to help but vowed that he would never drink tea. He was, because of his illness, unable to explain this to anyone but the sight of the tea trolley evoked these memories for him and he became very upset and angry. If we had known a little bit more about him before

he came into the home all this worry and distress could have been avoided.

I was deeply moved by this story, as was the rest of the group. It reminded me how as healthcare providers we often spend too much energy on outcomes and procedures and ignore the most important thing, that we are working with people and very often vulnerable and frightened people. The team agreed that it was very important for the service user and their family to feel that those who were providing a service to patients knew more about who they were, what were their likes and dislikes, their passions in life. One of the carers came up with the idea of creating a “living diary”. This could be an activity that the person with dementia could be engaged in with their friends and family. They would create a diary of who they are. It would contain their living history, their likes and dislikes and whatever they felt they wanted others to know about them when they were in a position where they were no longer able to communicate in that way.


After these early meetings I spent a great deal of time in the local community in order to get to know the older members of the locality a little better. I wanted to know what their understandings of dementia were and how they also may like to contribute to this piece of work. I talked to people about their understanding of dementia and what they thought they would like to be provided for them if they develop the illness in their later years. I also spent a lot of time with older people’s groups sharing information with them, asking them questions and getting them to ask me questions. Again this was a rich source of information and stories about the lives of older people living in our society. At every meeting I went to I was approached by at least a couple of people who were concerned about their memory. Some of the people I met had already mentioned their

concerns to their doctors only to be told that this was just part of the natural aging process and therefore nothing for them to be concerned about. There was still so much to be done to educate and inform. I also spent some time in the homes of people with dementia, both those who were involved in the project and those who were not. This is where I had the great honour of meeting Charlie and his wife Marion. Charlie has chronic emphysema but he does not let this stop the endless devotion he shows his wife. Charlie was unable to come to any of the meetings and so I visited them regularly at home talking through our progress and asking them for their suggestions.

Charlie had also found some very innovative solutions to some of the problems he and Marion were experiencing. Because of her memory problems Marion had started to become very agitated when Charlie leaves the room. Charlie had the idea of buying an electric doorbell. Marion wears the doorbell around her neck and Charlie carries the receiver in his breast pocket. If he is in the garden and Marion forgets where he is and becomes agitated she just has to press the bell and he will respond. This makes them both feel very secure.

Shortly after meeting Charlie and Marion we were given the opportunity to make a documentary about dementia for a medical series. The Director asked if any of the patients and/or carers would like to make a contribution to the film. I asked Charlie and Marion if they would like to be involved and they agreed to help us. I felt it was very important for the filmmakers to meet them both before the filming in order to develop a relationship with them and to put them at their ease. Charlie and Marion handled the whole event with confidence and dignity. The account of their lives together and their love for each other was very moving. The director asked them at one point how they like to spend their day. Charlie replied that they just enjoy each other's company and sometimes they just sit

together on the sofa, quietly, and hold each other's hand. As he spoke he was holding his wife's hand, and although she now finds language very difficult, with her other hand she gently touched his face. As we packed up all the filming equipment the director, who was still very moved by the interview said to me, "***Today I experienced real unconditional love for the first time and that image of Charlie and Marion will stay with me for ever.***"

 You can share some of Charlie and Marion's experience of living with and caring for someone with dementia in DVD chapter 2, "***Breaking down the walls of silence.***" I have included the first clip of Charlie and Marion in their home in conversation with me. In this first clip I have tried to show the life affirming energy of this couple who engaged in a warm loving and trusting relationship with me as they talked about living with dementia. I have included the second clip of Charlie reading from a letter he had prepared for me because he wanted to make sure he was able to communicate his feelings clearly. As I was filming and listening to Charlie I was becoming anxious about Marion who seemed to be drifting away and becoming excluded from what was happening. There follows which is for me a very beautiful and significant moment where Marion, who is now unable to use very much language found another way to communicate. In this moment she catches my eye and gestures behind Charlie's back in a very comical way that she thinks he is being big headed. I have included this clip because I believe it shows that I am being inclusional and responsive in my engagement with Marion and Charlie. I also believe it shows how the relationship I had developed with them both was one of mutual trust and respect.

Marion and Charlie



Creating a Pathway of Care

After the first meeting of each stage of the pathway I would attempt, by using process mapping, to create a flow-chart of what the team agreed should be the way care should be provided. (The flow charts can be seen in the booklet “Breaking down The Walls of Silence”, Appendix 14). We then held a second gathering for each stage where any additional changes could be factored in. This also gave time for me to engage in a consultation period with any one who was unable to come to the first meeting. This would ensure greater ownership and would help when it came to making changes to the service. We then held a second celebratory gathering of all the teams and cemented the whole pathway together. This was a crucial meeting and was also a launch for the implementation of the pathway in Swindon. I had been asked to put together a short booklet describing the process and containing the pathway so that other services could take advantage of the research we had undertaken. I had some

anxiety about this and was concerned that other services would try to implement the pathway that we had created without going through the same process of development, of sharing their stories in an ensemble of conversation, that our teams had gone through. I felt it was really important in order to achieve the level of ownership and understanding that our teams had achieved. I was reassured that the pathway would not be used in that way. It was also agreed that I would create a series of developmental workshops that would assist other teams to go through a similar process. I agreed to put together a short booklet that would: -

1. Describe the reasons for the need to develop a care pathway for dementia.
2. Identify the research evidence.
3. Describe the rationale for the decisions made by this service based on both the evidence and the knowledge of our practitioners, patients and carers.
4. Include our care pathway.
5. Include examples of forms that can be adapted for other services.
6. Include references that other teams may find useful.

I produced the booklet “Breaking Down the Walls of Silence” and this was later published by Harcourt for national distribution (see Appendix 14). I have recently been asked to write a second edition of this booklet for Novartis and this process is now underway. Although I was at first very pleased with the booklet I produced last time, I will approach this second edition in a very different way. I was anxious throughout the writing of the first booklet about the methodology I was developing. To me it felt right to engage all the participants in the way I did. This was not however common practice and to a certain extent I was too insecure about the methods I was using – particularly with regard to the use of creativity. Despite having a wealth of embodied knowledge in the value of working in this way I would not have been supported if I had been explicit about

how I was working. I had to weave creative processes in and out when and where I could. In this way we experienced a much more tentative approach but I am satisfied that this lends itself to a much more responsive way of working with newness. Rather than charging in with something new and novel it was more appropriate for this to evolve in a much more sensitive and self-organising way. This is my way, it is not about imposing my discourse on others it is much more about feeling and responding and engaging together in an ensemble of shared and new knowledge which is being generated in the conversations we have together.

Implementation

The team in Swindon had created a pathway that made recommendations based on evidence, expertise and collective narrative. This did not however reflect current practice everywhere in the locality. We had to plan what would be the best way to implement the pathway in order to lead to an improvement in the early diagnosis and care of people with dementia in the Swindon locality. How would we encourage people to look at their practice, reflect critically and openly and think about how their practice might improve? And would the pathway we had developed enable this process in anyway? Patrick was also keen to implement the pathway in the area he represented which was West Berkshire. West Berkshire was a very different location with a very different service provision and this would be a perfect opportunity to undertake an action research project to do this. It was agreed by the steering group that I should seek funding and ethics approval to undertake a pilot in Swindon and in West Berkshire. This became a very lengthy process where I very soon became aware that action research is not a methodology that ethics committees looking at health service research are very familiar with. My proposal outlined a process that they were completely unfamiliar with. There was no hypothesis and the idea that the questions for research would

be generated by the participants was a challenge for them. I was invited to attend both ethics committees and was able to address their concerns directly and to reassure them that this was an accepted research methodology. Ethics approval was granted for the pilot by both ethics committees and it was agreed that I should facilitate the process. The project steering group also agreed to the use of a creative approach and the continued use of collective storytelling. Patrick, Roger, Shaun and myself planned a workshop for a group of 60 health care professionals in West Berkshire to engage them in the process in the same way that we had launched the project in Swindon. I was very concerned that we would need to engage them in an inclusional and responsive way right from the start so that they would feel the same kind of ownership that we had generated in Swindon, where we started from scratch. Here in West Berkshire they were starting with the Swindon pathway to see if they could use it as a template to improve their own services. I had to make sure that they had the opportunity to make it their own. I knew that this was going to be a difficult task.

This was the first time that we had involved Roger and Patrick in the development of a workshop of this nature. The organisation of the day itself was given to Patrick as he was fitting it into a pre-booked study day for general practitioners. He had been asked by them to provide them with a study day on dementia. I wasn't very happy with this arrangement, as I really had no idea what they were expecting. I was worried that this would have an impact on the outcome of the day. I was also having to design the content of the day in isolation trying to fit in with what I was only guessing was the overall function of the day. This led to difficulty when the 4 of us came together to put the whole day together. We had great difficulty in gaining agreement from Patrick with regard to the content and organisation of the workshop. Although this day was extended to include other healthcare professionals and managers it was

still the case that they were being invited into the GP's space and Patrick was adamant that the participants should work in their own professional groups in the last sessions of the day. Neither had he invited service users and carers to be part of the process. His rationale for this was:

“The GP's will expect some didactic teaching – that's why they come to these sessions and they would expect it to be given by another GP or such like 'expert'.”

“They would feel 'safer' working in their own professional groups. They may feel threatened by each other when they are talking about possible problems with the service.”

Shaun and I were unhappy with this but had to compromise and we agreed to work within this framework on this occasion with an understanding that we would be able to take responsibility for the design of any further workshops. The day also shrunk from a whole to a half a day making me really concerned about whether we would achieve what we wanted to achieve. We agreed that it was important to try to find out what their current thinking about dementia and dementia care was at the beginning of the session and I was asked to start the afternoon session off with some questions in questionnaire format to ascertain some measures of attitude from the group before that start of any development work.

Participants were asked to either agree or disagree with a series of statements:-

1. It is important to identify the symptoms of Dementia as early as possible.
2. An early referral leads to a better outcome.
3. I use a diagnostic tool to assist my diagnosis.

4. There are effective interventions for people with Dementia.
5. I have information for patients relating to Dementia.
6. Improving services for people with Dementia is one of my priorities.

I hoped to be able to have the questionnaire analysed through the afternoon so that the results would be available to the groups when they would be looking critically at their service in the last session of the day.

(See Appendix 1, West Berkshire Report.)

I was not happy with the final programme for the day, (programme is included in appendix 1). I felt that there was a lack of focus and overall cohesiveness to the day. I also felt that there were other agendas being dealt with that we were not party to. I was not sure what they were but Shaun and I agreed that we would try to make the best we could out of it. I am now aware that this dissatisfaction was as a result of me not being able to fully live my values of inclusionality and responsive practice and that these values have become standards by which I am judging my practice.

Outcome of West Berkshire Workshop

Overall the feedback from the evaluation of the workshop indicated that participants had found it to be useful, but I still felt quite disappointed with the whole process. I was unhappy with the way we came across and felt that the whole event was disjointed. We had each worked on our own sessions independently from the other, in theory, each session was linked but in practice this was not the case, leading to some confusion for those participating. As a consequence the participants did not really know what to expect from the day. They were a little perturbed about being expected to participate in games and exercises. They had not been prepared

properly. We were not able to work in an inclusional and responsive way and the separation of the groups in the afternoon did not result in a very trusting relationship with the group as a whole to develop. I disagreed with the need for individuals needing the security of their professional mask. It was also a pity as really important issues arose in the separate groups and the opportunity to talk together about these issues in a patient centred way, I felt, was lost. The group I worked with in the afternoon, which was made up of nursing staff and allied health professionals, were also disappointed that they were working in isolation. I was also incredibly frustrated that I was developing a growing reputation for innovative multi-professional improvement work nationally but was finding within my own organisation that I still wasn't always being taken seriously.

The information we gathered from the series of questions indicated that although people recognised the need for early recognition of dementia there was a need for information to help with this. The questionnaire also identified a need for more education and development for healthcare professionals about the treatment and care for people with dementia, (see the full report, Appendix 1).

Although I remained dissatisfied with the planning and organisation for the day we did achieve something very important and that was a commitment from the participants to work together to improve services for people with dementia and an agreement to take part in the research. They were also able to identify how they wanted this to be taken forward, (see Appendix 1).

Afterwards we held a very lengthy debriefing session and agreed that although as a team we had made some very fundamental mistakes in the planning of the day, especially with regard to communicating with each other, we had still achieved a launch for the pilot in West Berkshire and a

commitment from the participants. I had learnt a lot and in our debriefing session we agreed that we would factor this learning in to our future workshop days for the Swindon Pilot. We agreed that Roger should write a letter on all our behalves explaining the purpose of the day to all those attending. This letter would also include a description of the way we were going to work, placing an emphasis on the participatory and inclusional nature of the day. It was important to ensure in all future work that we were able to spend time developing the relationships of the participants.

Excerpt from Letter sent to participants of Swindon workshop

17th October 2001

“The purpose of the day is to explore current service provision, what we do well, what we do badly, and how we work together and put these findings together into creating a systemic service across all organisations.....It is a long day but is designed to be participatory, stimulating and thought provoking. At the end of the day I hope we will be planning to work across existing barriers rather than patrolling them and that we will have a plan to provide new and exciting services for those unfortunate to have this devastating condition.”

The letter also included the programme for the day

Swindon Older People’s Services – Modernising Dementia Care

Bowood House, Chippenham

Tuesday 27th November 2001

09.30 Myths and issues – chat show

Is dementia a mental health problem?

What is the advantage of early diagnosis?
Do drug treatments work?
What is person-centred care, and what does that mean in
Dementia
Can we give carers what they need?
Can care homes survive in sufficient numbers?
Can the acute hospital agenda fit into the National Service?
Framework aims?
Can we really work together in an inclusional way and be truly
responsive to the people using our services?

11.00 Coffee

11.20 Care pathway

The work done

Who make up the bits of the jigsaw of care in Swindon

11.40 Single organisational groups

Themes from the chat show

Task: *What 10 aspects of dementia care do we do well and what 10
Things could we do better?*

Feedback

13.15 Lunch

14.15 Identification of themes from the first session

14.00 Mixed organisational groups

Task: *Can we create ways to develop the identified themes – simple
rules and bold aims.*

Team building exercise

Perform the task

15.45 Tea and feedback

16.20 The creation of a dementia action team for Swindon

17.00 Close

I felt much happier with the construction of the Bowood workshop than I had been with the West Berkshire workshop. I believe this was because we worked much closer together when creating the activities for the day. We had also consulted those who would be participants at the event in order to engage them in the process right at the beginning and also to find out as much as possible about what they felt their needs were. We were able to spend time at the beginning of the day developing relationships and creating an environment of openness, inclusion and trust. I was also given much more freedom to develop these parts of the day as it was recognised by the rest of the planning team that they needed to let go of their control. They were beginning to trust and to recognise the importance of this kind of facilitation. Starting the day off with the facilitated chat show, a theme that was picked up later in the day allowed participants to begin to take risks and to be truthful about their concerns.

The first half of the workshop work was undertaken in multi-professional teams but with an organisational heading. It was important to allow participants to work in their organisational groupings in order to highlight their strengths and weaknesses. Because the participants were better prepared by the use of creative exercises I believe they were able to demonstrate an openness and honesty when identifying their strengths and weaknesses. It was also interesting how quickly they were able to identify themes. We could also recognise that they were working at a deeper and more appropriate level, talking about real issues that affect them in their day-to-day work as can be seen in what they identified as priorities for them. The themes identified by the Bowood workshop appeared to be more specific and less general than the themes developed without the creative input, (see Appendix 3, Bowood workshop.)

After lunch the groups were mixed both professionally and organisationally in order to have 3 groups with a mix of primary care, secondary care and representatives from care homes. This was potentially a very threatening activity; previous experience of trying to mix these groups together, across their boundaries, had not been very successful. There is a history of mistrust and a culture of blame but these groups moved very quickly into working together in an open, inclusional and reflective way. Individuals who on previous occasions would not talk to each other were planning a cooperative future. There was of course tension and conflict but these tensions were being discussed openly as individuals made sense of what they were trying to create together in their conversations with each other. Patricia Shaw calls this process “*the living craft of participating*”, (Shaw, 2002). I believe it is a craft and I believe that I am able, through the use of creative techniques to help others to develop their craft. Patricia Shaw says that she defines this as a craft because, “*just as we can learn to conceptualise, to design, to communicate and persuade, we can also learn to participate with imaginative concreteness as co-narrators, joint authors, co-improvisers, and in so doing, locate our competence as leaders differently.*” (Shaw, 2002. p. 173).

For me this is a clear indication of how working in this way with a focus on relationship, identity and communication we can enhance the quality of what we do resulting ultimately in better services for those who need to use them. My understanding of this and the way in which my practice has changed and improved has been able to happen because of my inquiry into my practice.

Where are the pilots now?

The project teams have used their potential for self organisation and the pilots have developed a life of their own. The implementation process is

continuing in both localities but with local ownership and in very different ways. The West Berkshire project has resulted in significant improvement in the way people work together. They have also achieved a decrease in the waiting times for people to be assessed by the specialist team. The past practice has been changed from a long wait to see one very overworked Consultant before any treatment could begin, to the development of a team assessment. This means that a new patient who is referred from primary care can be seen by other members of the specialist team almost immediately. There has also been an increase in consultant clinics in the locality. I am also facilitating an action research project in Newbury with Patrick in primary care and the memory clinic in secondary care. We were successful in finding funding for this 18 month project. The memory clinic has been moved into the GP surgery in order to create a holistic, one stop clinic for people with memory problems. Patrick is being trained as the first GP with a special interest in dementia. The clinic is also operated in a collaborative way and includes primary care and secondary care, psychology, social services and the voluntary sector. The whole team are engaged in asking the question ***“How can we improve what we do?”*** the following is an excerpt from the research proposal. (Full research proposal is attached as Appendix 4).

Research Proposal

The development of a more holistic approach to dementia care. A trial across three primary care sites of the establishment of multidisciplinary chronic disease style clinics for dementia patients that would diagnose, initiate and manage treatment of dementia within a primary care setting.

Clinics to provide comprehensive ‘one stop’ style service, using multidisciplinary concepts to organise joint working with voluntary sector (Alzheimer’s Society, Age Concern, Citizen’s Advice Bureau, St

Johns Ambulance, Admiral Nursing etc.), practice and district nurses, psychology, social services, primary and secondary care.

The creation of this clinic means a large change in the way services for people with dementia are currently organised. This care is traditionally undertaken by specialist teams in secondary care. This move will only be achieved if there is cooperation from all those involved to work together. This will be an enormous challenge but a very valuable move in the right direction. This project began in December 2003, as part of the process of the team asking themselves the question *“How can we improve what we do?”* the whole team have been sharing their learning. This has been in the form of reflective diaries and also by regular focus groups where they talk about their experience of this change process. The team have allowed me to video these reflective conversations and have also agreed for this to be available on a new web site for sharing innovation in primary care. As far as I am aware this is the first time that this has happened in this way in the health service and is an indication to me of the trust and strengthened relationships the team have developed as a result of working in a more creative and inclusional way.

The work in Swindon is also ongoing. The relationships between all those parts of the local healthcare community continues to strengthen and develop. This has resulted in the creation of a project to redesign services for older people across the Borough. The difference in this project to previous work is that the whole community is beginning to work together. Traditionally healthcare is designed within sections creating boundaries. This project includes all parts of the healthcare community, the voluntary sector, social services, patients and carers. It is also, for the first time, involving those in the local community who are not directly involved either as users or deliverers of the service but have an interest by the very

fact that they are part of the community. The outcome of this action research project may determine the way we provide services for older people across the country in the future.

The original care pathway created by the team at Swindon is being used by many teams across the United Kingdom as a means to develop their own pathways of care. It is also being implemented in Brisbane Australia, Canada and soon work will commence in Singapore. Although teams across the world are using our pathway as a starting point I have encouraged them to design their own version to suit their very particular local picture. I believe that what is often referred to as the spread of good practice can only be achieved when each team is engaged in a process that is responsive to their own needs, that focuses on their relationships and looks at their whole environment. I do not believe that you can lift good practice from one location and transplant it into another without a focus on context.

I have also been able to help many teams with the implementation of dementia pathways both nationally and internationally by the development of a series of creative workshops designed to enhance this work.

In the following chapter I will describe the process of developing creative workshops for healthcare professionals. I reflect on how I have been able to build on this process creating a series of workshops that acknowledge and respond to the needs of the participants across the health care sector.