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"In a real dark night of the soul it is always three o'clock in the morning, day after day:" * Working with people with chronic pain, chronic illness and their significant relationships.

*F Scott Fitzgerald, 1945

Introduction

First of all thank you very much for bestowing upon me the honour of presenting this memorial lecture in tribute to one of the pioneers of British family therapy. When I was doing my clinical training at the Institute of Family Therapy (IFT) in the early 1980s - when we had just moved to New Cavendish Street in central London - I had rather mixed feelings about Robin. On the one hand I admired him enormously and on the other hand his presence occasionally became a bit of a burden. On a number of occasions when I was seeing couples and I asked them in the first session what had led them to contact IFT - why now - I received the

response that they had read ‘Families and How to Survive Them’ and it had made a big impression on them and seeing that he was connected with IFT had decided to refer themselves. I felt that I was rather a disappointment to them - that they had somehow expected to see him and they got me. One couple even brought the book with them.

Accessible Complexity

However, one thing was clear. The book by Robin and John Cleese opened up the ideas of family therapy and systemic practice to the general public. And the ideas were readable. Indeed, one of the obituaries of Robin (Schlaporbersky, 2000) highlighted that this approach to therapy - that ideas should be understandable to the ordinary person - was very important to him. For the last few years in my teaching I have been using a term which fits with this idea: an adherence to a principle I have called Accessible Complexity: that our clinical work, our teaching, our writing should be consistent with this idea. And so I hope I present this lecture consistent with this notion.

The title

The F Scott Fitzgerald quote comes from a series of short stories called ‘The Crack Up’ which were published in 1945. Although ‘The Crack Up’ is about Fitzgerald’s psychological state of mind, it is an apt description of those who have a chronic physical illness

because it highlights the psychological feelings of loneliness, isolation, sadness and loss, not least the loss of how you hoped things would be, that much writing, academic and personal, and research has highlighted (for example, see Rolland 1994). And these feelings are often ongoing and in my experience people often come to therapy with the real dark night of the soul with them constantly. Part of this, I think also relates to the treatment journey - both the importance and the often inevitable weariness of it - the GP visits, hospital visits, the X-rays, the medications, the blood tests. This is what the writer Hannah Arendt (1968) has called: “an unbearable sequence of sheer happenings” (p104) where the weight of what has to be dealt with constrains one’s ability to make meaning of what has happened, and is happening, that may help in developing illness narratives that encompass possibilities of hope and resilience. And, of course, this is where we as therapists try to make a useful difference.

My Relationship with Chronic Illness

Before going further I want to say something about my relationship with this area of work. As some of you know, in 1972 I was diagnosed with ankylosing spondylitis (the fusion of the vertebrae in the spine). I began to realise from a personal perspective that the condition was both individual and relational. Individual in the

sense that I had been diagnosed as having a physical identifiable medical condition and relational in that I became aware that, for me, my physical condition had relational implications. How I saw myself managing my condition not only related to my personal physiological state but also to my interactions with significant others. The beginning of my family therapy training in 1980 highlighted, for me, the lack of fit between my own experience of my condition as both physiological and relational and my experience of attending medical appointments where only the physiological was addressed.

In the field of chronic illness clinicians like John Rolland (1994; 2015) in Chicago and Jenny Altschuler (with Barbara Dale) (1997), and Jenny Altschuler (2011) in the UK, utilising a systemic, relational perspective, have made important contributions. In the chronic pain field there has been less progress. It is still very much dominated by an individual patient cognitive behavioural (CBT) approach - and there is a lot of good work done using this orientation- but one only has to look at the programmes for chronic pain conferences to realise that relational perspectives remain at the margins. This state of affairs was what encouraged me to develop the ideas I am talking about here.

Towards a Relational Approach

In the preface to their classic book on pain, The Challenge of Pain, (1982), Melzack and Wall write: "Pain is one of the most challenging problems to medicine and biology. It is a challenge to the sufferer, who must often learn to live with pain for which no therapy has been found. It is a challenge to the physician or other health professional who seeks every possible means to help the suffering patient. It is a challenge to the scientist who tries to understand the biological mechanisms that can cause such terrible suffering. It is also a challenge to society, which must find the medical, scientific and financial resources to relieve or prevent pain and suffering as much as possible" (p. xi). What is clearly left out in this view about the challenges of pain is the one that it presents to the family and significant others - a relational perspective..

In his last book, Wall (1999) finished by stating that the practical question of how to control pain "will not be answered satisfactorily until we understand more of the context in which pain resides. Pain is one facet of the sensory world in which we live. It is inherently ridiculous to consider pain as an isolated entity" (p. 179). This is not to say that the family or relational factors have not been addressed in the chronic pain literature but the focus of

treatment has tended to be on the individual and on the physiological.

For hundreds of years pain was seen as a physical experience (Rey, 1993). This view was known as the mechanistic view of pain - the idea that body mechanisms were separate from mental mechanisms; the mind body dualism of Descartes. Descartes argued that pain is evidenced by the withdrawal of the relevant body part from the noxious stimulus as a result of nerve action, that is, the pain mechanism and consequent behaviour is distinct and separate from the individual's experience of pain and can thus be described in a simple mechanistic way. A hand touches a flame, a message is sent up through the central nervous system to the brain and pain is experienced. Descartes expressed this view of the causation of pain by comparing it to a bell ringing mechanism so that by pulling one end of a rope you strike at the same instant a bell (cf the brain) which hangs at the other end. This perception of the cause of pain was one that would remain influential in western medicine into the mid twentieth century. This way of looking at pain comes under the heading of specificity theory which essentially promotes the idea that there are specific pathways in the body, specific channels, along which pain signals are transmitted and result in the sensation of pain. Causation was seen as linear and psychological factors were ignored. That is, the brain was per-

ceived to have a passive role. It followed therefore that tissue damage was seen as leading to pain. However, as Melzack and Wall (1965) were to highlight with the publication of their gate control theory, this was not necessarily the case. Indeed Descartes himself was challenged by his contemporaries around the single pathway view when they highlighted the phenomenon of the phantom limb and the fact the amputees often indicated that they sensed the missing limb, not just as a whole but in every detail, for example, in the hands and fingers. Descartes went away and thought about this. He responded by inventing the concept of the false signal (see Wall, 1999 p21). The mind had made a mistake. The body is not in error. It followed therefore that if there was no identifiable tissue damage there could be no pain and the pain must be in the mind. There seems to have been little credence given to any idea that, just because tissue damage could not be detected, or because there was no evidence of organic pathology, it did not follow that it did not exist. As Shone (1995) noted, this led to a situation whereby certain people complaining of pain, but where no evidence of tissue damage could be detected, were labelled as malingerers and/or in need of psychiatric help.
However, the gate control theory, with its view that pain is not just a physical experience "but that the physical and the psychological are in a relationship of mutual influence" (Mason, 1999, p. 9),

contributed to a change in the definition of pain by the International Association for the Study of Pain. This definition of pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey et al, 1979, p. 217) acknowledged the role that personal meaning and subjectivity played in pain. The theory contributed to the development of pain clinics and the place of a psychological approach to the management of chronic pain within those clinics. I should note by the way that chronic pain tends to be considered pain that does not disappear within three to six months. The pain is ongoing. Pain that disappears within a shorter period, such as from a broken arm, is called acute pain.
So psychological aspects were now accepted but they were very much individually orientated. With the development of systems ideas in working with relationships, relational approaches began to emerge and these developments, albeit slow, led to my initial research (Mason 2003; 2004) and more recently, research into the management of Fibromyalgia Syndrome. I am now going to highlight some of the findings and clinical implications of these two studies.

The first study

Five men with ankylosing spondylitis and their five female partners. The main part of the (three part) study involved interviewing

each man with their partner and the transcribed data explored using Interpretative Phenomenological Analysis (IPA). All participants were over forty and White British.

Three of the main findings were as follows:

1.**Primary and Secondary Relationships with Pain.** The definition of the relationship with pain both for the person with the condition and significant others can influence how the pain is managed. A primary relationship with the condition is where the pain dominates the life of the individual and the relationship. There tends to be a secondary relationship with getting on with life; getting on with life is in the background. I would suggest that where this situation exists work with clients should explore with them how they can have more of a primary relationship with getting on with life and a secondary relationship with the illness. So living life would be in the foreground and the pain would be in the background. That is not to say that the experience of pain would have disappeared. Indeed, the actual level of pain experienced by the person with the condition may still be the same on a score of 1-10: but the level of pain would be that it was having less of a powerful influence in the relationship.

It should be stressed here that the nature of the pain may be such that attempts to have a secondary relationship with it is sometimes difficult to achieve However, there is a difference between a pri-

mary *episode* of pain and a primary *relationship* with pain. So, for example,

Man 46 with a pain condition:

"Like I see there's giving into it (the pain) in a bad way and giving in to it in a good way. D'you see what I mean.

BM: I have an idea what you mean but can you say a bit more.

*Man: "Well I know that I try to fight the pain not let it overtake me so if I give into it sometimes, (*episodes*) I know it won't happen very often. That's giving in in a good way. But if I always give into it so that it sort of overtook me (*the overall relationship with pain*) that would be giving in in a bad way."*

His female partner added.

"He's right. He doesn't tend to give in to the pain so when he does I know it must be really bad. But if I thought he was giving in to it too much, I would have a go at him because that would be no good for him or me. We'd end up arguing."

2. **Beliefs about Managing Pain**

A lack of fit between patient and significant other's beliefs about managing the pain may accentuate difficulties in managing the pain

There is a great deal that has been written in the CBT literature about beliefs about managing pain. However, much of it relates to

exploring the beliefs of the individual with the illness. My research has highlighted the importance of looking at beliefs relationally. So in the clinical session I would ask:
to the person with the condition: What beliefs do you have about how you should manage your illness?
What beliefs do you have as to how your partner should manage your illness?
And vice versa.

3. **Family of Origin and Newer Emerging Scripts in Coping with Adversity both for the person in pain and significant others can aid/constrain the effective management of the condition.**

An example:
A male female couple both aged 65, White British and working class. The woman had had a chronic back pain condition for over 20 years and was referred to me by a pain management clinic. She had also had two triple heart by-pass operations. Both Mr and Mrs Gibson (names anonymised) were invited to the first session. She was more keen than him. He was somewhat reluctant but had "come for my wife." In the first part of the session she indicated that she felt it was difficult to talk to him about her concerns about her illness. She felt she was a burden to him. She indicated how-

ever that he was very caring in terms of doing things about the house for her, for example, shopping, practical things. After about half an hour I sensed there was an elephant in the room - that he was worried that she would die. I was unsure whether to raise this as I felt he would be reluctant to talk about emotional issues, and that he might not return. Eventually, after about five to ten minutes of considering whether to address my thoughts about what was going on in the room, I took the risk but my anxiety can be seen in my first question. It is probably an understatement to say I go somewhat over the top. However, the man doesn't bat an eyelid.

BM: Do you have a concern that your wife is going to have another heart attack, stop breathing, drop dead?

Mr G: It's on my mind all the time.

BM: Is that something you keep to yourself?

Mr G: Yes

BM: What's it like my asking that question?

Mr G: To ask it and to answer it is a relief. You've asked it and I've answered it and I do find a relief from answering it.

BM: Tell me in what way it's a relief

*Mr G: To hear myself say it out loud and for my wife (*sitting next him*) to hear it. It's always on my mind.*

BM: What prevented you from saying it before?

Mr G: Oh, I don't know. You keep it to yourself. If you say it to someone else, you're giving it to someone else.

BM: (to Mrs G) What's it been like for you hearing your husband say it's a relief to say these things?

Mrs G: It makes a big difference. (And then she said somewhat sadly) I didn't know he cared.

Mr Gibson's comment about "giving it to someone else" seemed to me to be a statement about his beliefs about coping with adversity. It would be like giving someone an infection. I thus explored the beliefs about coping with adversity with both Mr Gibson and his wife. I said:

Can I put the following to you. When we are growing up in our families, communities, we often pick up messages from those who are caring for us/are significantly involved in our lives, as to how we should cope with difficult times in life when they arise - and I think all of us at some time have difficulties of one kind or another. (NB: I purposely use the language of we. (Rolland, 1994). *Sometimes these messages are stated - in my family, for example, I got the message that you just had to get on with things - sometimes the messages aren't stated, they are just there as if in the family at-*

mosphere. So, tell me: what messages did you pick up when you were growing up about how to cope with difficult times in life?

Mr Gibson said that when he was four years old his younger brother died in a fire. When he was five his father died and when he was a teenager his sister was murdered. He said that he learned just to get on with things, that there was no point in moaning. Nothing could be changed. Mrs Gibson said that in her family, she had two brothers and a sister. Their father didn't like talking but she and her siblings and her mother did talk when things got difficult. She said that she was encouraged to talk by her mother, not to "bottle things up."

What began to emerge in the session, and it was elaborated upon in the second session, was that Mr and Mrs Gibson for the first time started to understand the logic, the coherence, of each others script in coping with adversity which had family of origin explanations. Mrs Gibson began to see that her husband wasn't uncaring and he began to see that Mrs Gibson was not being burdensome. Indeed in the last of seven sessions with the couple, when they had both reported significant, positive changes in their relationship, Mr Gibson said - in language that was of another era: "I've realised one thing in particular. The women, the women - they like you to talk." Out of the corner of my eye I saw Mrs Gib-

son smile. *'How do you feel, hearing your husband say that,"* I asked. She replied: *"I feel like a million dollars."*

When I asked Mrs Gibson about the level of pain she was experiencing now (in the last session) compared with when she came she indicated that when she came the pain was very severe - nine out of ten in severity. She said that now it was seven. So there was not a great deal of change in the physical experience of pain. When I asked both of them about their management of the pain when they first came - taking ten as very good management and zero as poor, she said four and he said three. When I asked them what score they would give now, he said seven and she said eight. Their teamwork was better and although there was significant pain still evident for Mrs Gibson, she and her husband seemed to be having more of a primary relationship with getting on with life and a secondary relationship with the condition.

After a couple of years of using this finding from my initial research I had the thought that whenever I see people in therapeutic work, irrespective of whether it is related to chronic pain or chronic illness, I am usually working with people who are coping with adversity. I thus started to ask this question with my clients as a matter of course, and always in the first session. I have found that people are intrigued both by what they hear themselves say and what they may hear from other family members. It is not some-

thing people generally get asked. And often for the first time clients can see the logic/coherence of their own beliefs and of the beliefs of others. (I should add that I ask this question of adults and teenagers but not younger children).

The Second Study: Managing Fibromyalgia Syndrome (FMS)

This second study was commissioned by a branch of the Fibromyalgia Society in the UK. The committee of this branch, particularly a consultant rheumatologist and a clinical nurse specialist had become aware of my earlier research and had initially invited me to come and talk to their members. This resulted in a request to carry out research on the management of Fibromyalgia with members of their branch after the management committee had suggested the idea to them and they had agreed. A research proposal was put forward to the committee and it was approved. I then wrote to the members of the Society asking them to participate and explaining issues of confidentiality, anonymity and ethics.

The study was in two parts. The first part comprised two questionnaires, one for those diagnosed with the condition and one for those who were partners of those with the condition. Twenty seven of those with the condition replied and thirteen of the partners. Thus the total number of participants was forty.

The second part consisted of semi structured interviews with nine of the participants from those who returned questionnaires. Originally there were ten people but one person, (someone with the condition) dropped out before the beginning of the interviews. The interviews went ahead with nine people. As in the earlier research mentioned above, Interpretative Phenomenological Analysis (IPA) was used to explore the transcribed data.

What is Fibromyalgia

The word Fibromyalgia comes from the Latin word for fibrous tissue (fibro) and the Greek words for muscle (myo) and pain (algia). According to the Fibromyalgia Association UK (2008) Fibromyalgia, or as it is more commonly referred to now as Fibromyalgia Syndrome (FMS), can be described as "a chronic condition of widespread pain and profound fatigue. The pain tends to be felt as diffuse aching or burning, often described as head to toe. Pain may be worse at some times than at others. It may also change location, usually becoming more severe in parts of the body that are used most. The fatigue ranges from feeling tired, to the exhaustion of a flu-like illness. It may come and go and people can suddenly feel drained of all energy – as if someone just "pulled the plug"'. The vast majority of people diagnosed with Fibromyalgia are women – by up to nine to one.

Until recently (2010) The American College of Rheumatology (ACR) pain criteria for Fibromyalgia (Wolfe, 2010) suggested that pain/tenderness must be present in both the left and right sides of the body and above and below the waist, that is, in all four quadrants of the body - and have been present for at least three months. Further, that for a diagnosis of Fibromyalgia to be given a person must have had eleven or more of these tender points out of eighteen (nine paired points). However, Since 2010 the ACR have developed new criteria (Wolfe, ibid) and include:

- the presence of pain lasting three months
- presence of other symptoms such as fatigue, waking up tired and trouble thinking
- No other underlying condition that might be contributing to the symptoms.

There is as yet no clear understanding as to the cause of the condition "but there is now a clearer understanding that there is an interaction between the physical and mental aspects of this illness. Fibromyalgia Syndrome is an illness involving both the mind and the body. The amount of pain felt by a person with Fibromyalgia is often affected by the way they are feeling, and the reverse is also true. Feeling depressed, stressed or anxious

may contribute to making the muscular pain feel worse, which may in turn add to the stress and anxiety" (Arthritis Research UK, 2016 p6). Indeed, Preece and Sandberg (2005) found in a study of people with FMS that family and relationship stressors, strains and distress were associated with increased health problems and increased medication usage, whereas an increase in social support from families tended to result in a decrease in health problems and use of medication.

I should add that while FMS has become more widely accepted as a condition and is recognised as such by, for example, the International Association for the Study of Pain (2010), there has been debate as to whether it is a specific condition. (Cohen and Quintner, 1993; Quintner and Cohen, 1998).

The Research Participants (Part One)

The patient group[1]

- Ninety two per cent were female, eight per cent male. This is consistent with the fact that the vast majority of people who are diagnosed with Fibromyalgia are female.

[1]the term patient has been used here as those with the condition referred to themselves as such.

- The average age was fifty nine. This is consistent with the fact that most of the people who have been diagnosed with Fibromyalgia are aged above fifty. In this study eighty nine per cent of the participants in this group were aged between fifty one and seventy years.
- The number of years since diagnosis – average of nine years.
- Four per cent of this group were in full-time employment, fifteen per cent in part-time employment, four per cent were unemployed, forty per cent were retired, twenty seven per cent were unable to work because of their Fibromyalgia.
- Ninety two per cent of the patients with the condition were involved in a relationship with their partner before they were diagnosed with the condition.

The partner group

- Eighty five per cent were male, fifteen per cent were female
- The average age was sixty two years. Sixty one per cent of participants in this group were aged between fifty one and seventy years.
- All the participants were partners of patients with FMS.
- Thirty one per cent of this group were in full time work, twenty three per cent in part-time work and forty six per cent were retired.

Responses to Questionnaires

1. Symptoms

Pain

Generalised Fibromyalgia, by definition, is a condition that almost always includes the experience of physical pain. Ninety-six per cent of the patient group said they experienced physical pain and one hundred per cent of the partner group indicated that, from their perspective, the presence of pain in the person with Fibromyalgia was present. Fifty six percent of the patient group indicated that their pain level in the last three months had been 'high' (forty eight per cent) or 'very high', (eight per cent). Thirty six per cent of this group said that the pain had been 'average'. Only eight per cent indicated that the pain had been 'reasonably low'. No one indicated that the pain had been 'low'.

There was broad agreement between the patient group and the partner other group as to how well the pain was managed by the patient. Ninety two point five per cent of the patient group thought they coped with the pain either, quite good; good or very good. Seven point five per cent of this group thought they coped poorly with the pain. In the significant other group, all the respondents thought the person with Fibromyalgia was 'quite good', 'good 'or 'very good' in coping with the pain. There was a substantial dif-

ference though in terms of the response to whether the patient was very good at coping with the pain. Thirty one per cent of the significant other group thought their partner coped with the pain very well. The patients themselves, however, placed this value much lower – at seven point five per cent. This suggests that people closest to the person with the condition might over-estimate how well the patient is coping with the pain.

Other Symptoms

People with Fibromyalgia experience a range of other symptoms besides pain. Patients were given a list of symptoms associated with FMS and asked to indicate (i) those they experienced, and (ii) the order in which they would put the symptoms in terms of their frequency. The list of symptoms given in the questionnaire was:

- Irritable Bowel Syndrome
- Tiredness
- Sleep disturbance
- Headaches
- Fuzzy head - called Fibre fog.
- Dizziness
- Dropping things
- Restless legs

- Numbness and tingling (of hands and feet)
- Irritable bladder
- Shortness of breath
- Skin complaints
- Mood swings and irritability
- Difficulty concentrating
- Poor memory
- Difficulty in finding the correct words

On average, people with Fibromyalgia in the study had 10 symptoms. When these symptoms were in order of most frequency the following emerged:

1. Tiredness and sleep disturbance (equal rating)
3. Poor memory
4. Difficulty in finding the correct words
5. Difficulty concentrating, restless legs (equal rating)
7. Irritable bladder, irritable bowel syndrome (equal rating)
9. Numbness and tingling of hands and feet, mood swings and irritability (equal rating)
11. Dropping things, shortness of breath, skin complaints (equal rating)
14. Headaches, dizziness (equal rating)

2. **Coping with Adversity**

My research on the management of chronic pain mentioned above, highlighted how the messages we pick up when we are growing up in our families can influence how we manage difficulties in our lives as we grow older. In the questionnaire for the research on Fibromyalgia I wanted to see whether the idea developed in the earlier research was relevant to this new project. I therefore put two questions in the Fibromyalgia questionnaires. First, I asked respondents to reply to the statement: "When I was growing up the messages I picked up from my parents/carers about how I should deal with difficult times were" – and a space left for the replies.

This question was about the past. The next question was about the present. I asked respondents to answer the statement: I deal with difficult times in life now (a) in a similar way to the previous answer (b) in a different way.

Responses

The Patients

Seventy five per cent of those people with Fibromyalgia said that their present way of dealing with difficult times in life was similar to the way they learnt to manage difficult times when they were growing up.

Some of the messages picked up by the people in this group were:

- To be brave and strong and get on with things and accept what life deals you and learn to cope with it.
- If you cry you are weak and you'll be put away in a loony bin.
- Try and talk things through
- Share a problem don't go it alone
- Think carefully before making a judgement or a decision
- Face the trials to be faced head on if the time is right
- Whoever told you life was fair
- Have the ability to deal with whatever difficulties arise through logic
- To face them and come up with a way of overcoming things
- Cope, keep going
- Never give up
- Be careful and look after yourself
- Go to lots of doctors in order to sort things out
- Just get on with it and make the most of a difficult job
- Get as much sympathy a possible

- Get on with it – that's life
- Do the best you can
- Do listen to your intuition
- Keep an open mind
- Have a stiff upper lip
- Shut up about it – get on with it. There are many people worse off than you.

What mainly comes across in these responses is the emphasis on the individual's responsibility to deal with the difficulties faced and to persevere, not give up. Only a few people indicated that to cope with difficulties you could also talk with others. These messages were picked up by many of the participants in this study fifty or more years ago when the culture was different. Talking a problem through with someone – a family member or a professional - was less popular than it is now.

Of the twenty five per cent of the people who changed their way of coping with difficult times in life, there was a common strand. For example:

- **"**I now sit and talk to my husband and children as opposed to not talking and getting on with things."
- **"**I talk now and don't make the situation worse than it is"
- **"**I talk about my feelings. You're not weak if you do this."

The Partners

In this group eighty three per cent of the respondents said that the way they dealt with coping with difficulties now was similar to the way they learned when they were growing up in their families. Some of the messages picked up were:

- Sit down and talk
- Roll with it but ask for help, if required
- To think things through and get on with life
- Face them head on and discuss
- Get on with life and accept the good with the bad
- Be understanding but always talk about your feelings and others feelings openly
- Take one day at a time
- Face the problems and deal with them
- Don't argue
- Get on with things without complaint
- Get over it on your own
- By not seeking medical help
- Be thankful for the things we have
- Seize opportunities when they present themselves

Implications of the figures about coping with difficult times

I would suggest that this finding has a number of implications for clinical work:

a) That the childhood acquisition of how people learned to cope with difficult times in life is likely to stay with most people throughout their lives.
b) Patients and their partners/significant others may need to share with each other their ways of coping with adversity. They may be similar or they may be different. If they are different (for example, one person in the relationship may have a history of coping with difficult times by just getting on with things and not talking about them. The other person in the relationship may have a history of coping with difficult times by talking about them). There may then be a clash, possible tension, arising out of this difference in approach. This may contribute to poor teamwork around the management of the condition. Good teamwork has been shown to be a good indicator of chronic illness being well managed (Rolland, 1994; Mason, 2004). The management of chronic illness is both an individual issue (for the person with the condition) and a relationship issue. Both aspects have to be given due attention.
c) Clinicians, whether medical or non medical can probably obtain a good idea as to how the illness (in this case Fibromyalgia)

will be managed into the future by asking the two questions that were put on the questionnaires.

Stage Two

Semi structured interviews

Findings

Main Themes to Emerge

1. **The importance of diagnosis**

Because the symptoms of Fibromyalgia are often linked to, or overlap with, other chronic rheumatic conditions, it is not unusual for the diagnosis to take a considerable amount of time to be forthcoming. According to the National Fibromyalgia Association in the United States, it takes five years on average for a diagnosis to be made. This time period can be problematic not only for the patient but also for significant others.

In the second stage interviews, both patients and partners expressed clear concerns about the time it took for diagnosis to take place. This seemed, for the patients, to be related to whether people believed their symptoms were genuine. While the patients interviewed all said that close family members believed them, it was still felt by some of them that until diagnosis, that some people,

outside of the immediate family, felt they were 'putting it on' as one person stated, as if they were just complaining without foundation

*'Although she didn't say it to me, (*said one partner*) I think she worried about being seen as a fraud."*

A patient said*: "In the initial stages, before I was diagnosed, my relatives would say, 'there's nothing wrong with you.' And it was very hard. They thought I was lazy, malingering. It was very depressing. I was diagnosed after five years and then they believed me."*

Diagnosis became not only a relief to the patient, it offered legitimacy to the symptoms - that what they were experiencing was real not invented.

In this respect diagnosis might be said to be a transition – from perceived complaint to genuine condition.

2. Problems in communicating an explanation of the condition to others

Both patients and partners valued the explanation of the condition given at diagnosis by the consultant rheumatologist as to what the condition comprised. However, there was a clear problem – for patients in part, and partners in total – as to being able to give a clear explanation to family/friends/colleagues as to the nature of

Fibromyalgia. This is not surprising to some extent, given uncertainties amongst professionals. The research participants, in the main, felt that the explanation they gave was too vague so it sounded like other, non specific conditions, such as general pain, or tiredness because of a lack of good quality sleep. For some of the participants, this inability to give what they felt was a coherent, specific description of Fibromyalgia beyond the general, seemed to contribute to the re-activation of pre-diagnosis feelings that they weren't being believed by others that they had a genuine condition.

Another patient said:

I find it very difficult to talk about Fibromyalgia because I don't understand it. I find it very difficult to explain it to somebody. I do sometimes just feel like saying: "'For goodness sake I feel bloody awful because I am suffering from this, er, damn condition. And you can see with some people that because I can't say what this condition is they think it's not serious or they don't believe me."

Arising out of this finding, I would recommend that professionals working with people with Fibromyalgia address with patients and their significant others whether they might benefit from being helped to become more fluent and confident in be-

ing able to explain Fibromyalgia to others. Indeed, this idea can be expanded to illness in general.

3. Primary and Secondary Relationships with Fibromyalgia

Further to the responses in the first part of the research - the questionnaires - the interviews highlighted that both those with the condition and partners felt they needed to have a primary relationship with getting on with life and a secondary relationship with the condition (Mason, 2004). An example of a person with Fibromyalgia having a primary relationship with getting on with life was particularly evident in a research interview with a female patient.

Patient: I get on with life I don't let my Fibromyalgia take over.
BM: Can you tell me more about that?
Patient: Yes, well I just thought well Fibromyalgia isn't a particularly serious illness in that it wasn't terminal, it was something I was going to have to learn to live with and I thought well, if I have got to share my life with this condition I am not going to let it get in the way of my life. I want to still enjoy what I can do and if I can do it alongside having Fibromyalgia I'm going to do it. I'm not going to let it stop me.

BM: That's an interesting phrase you used there, share my life with the Fibromyalgia. It's in some ways as if you almost, like, externalised it.
Patient: Isolated it. Yes.
BM: Yes, as if you are not going to let it take over, walk through the door and take over. Is that what it feels like? Is that how you view it?
Patient: Yes, very much so I think, yes. Funnily enough, that's the first time I have ever used that phrase – sharing my life with it. But I am basically looking at it like that, you know.
BM: Sharing your life with it but not letting it dominate you?
Patient: Yes. Walking alongside with it, rather than it sitting on my shoulders and bearing down weight on me. Yes.
BM: What's it like hearing yourself say that for the first time.
Patient: Uhm. Revealing, I suppose. Yes, it's a curious way to sort of come out with it, but it's uhm, it's how I view it. I have always thought it's not going to stop me doing things.

But at times, patients, even though overall they may have a primary relationship with getting on with life and a secondary relationship with Fibromyalgia, sometimes cannot not have primary episodes. As the patient referred to above said: it was important for her partner to:

"Treat me normally but understand that there are times when I don't feel my normal self and don't feel like doing things."

What she seemed to be saying was that at times she had episodes of distress associated with her Fibromyalgia, but that, in the main, she wanted to get on with life as normal as possible – that getting on with life – to have that in the foreground – was primary.

Similarly, another patient said:

"I cope with it better now but at one time I would just lie on the bed, just completely quiet. I would be in so much pain, feel so awful, uhm, that was before I was actually diagnosed with it. But now I just get this sort of pain right through my body really – tiredness – just feel you don't want to do, got a job to concentrate on anything. Just feel, just feel you've got the flu, you know, just feel pretty awful. Uhm, that's when I have a bad, bad time – generally for a day, you know, maybe a couple of days or something and then it sort of eases off and then I get on with things again."

4. Independence/Autonomy and Initiating/Requesting Help

For patients, in particular, but also for the partners, there seemed to be a continual struggle between the patient's wish for independence and autonomy while at the same time recognising

that they may need help from their partner: and the partner recognising that they sometimes need/want to give help without doing it in such a way as to contribute to their partner feeling a loss of autonomy.

What also emerged in the interviews was that this struggle, this dilemma, was not necessarily being verbalised between those with Fibromyalgia and their partners.

This was part and parcel of one of the most striking dilemmas to emerge – the balance between requesting help versus waiting to be helped.

For example, one person with the condition said:

"If the Fibromyalgia got worse, if it sort of dominated me, it would probably mean that my husband would have to do more for me but I don't like asking him for help because it would affect our social life – he would feel that I wouldn't want to go out as much and that would affect him and us."

And a partner said:

"Fiona would tell me if she wanted me to do more for her.

BM: Is it easier for her to tell you what she wants from you or is it easier for you to ask her.

Partner: It's easier for her to tell me

BM: How come?

Partner: Because she knows what she is going through. I don't.

The emphasis was on the patient taking the initiative based on the idea that only the patient knows what she wants. Another patient said:

"Right, give me my independence, don't smother me, but you can still ask if I want, want to do that, but don't let me keep asking will you do that, will you do that for me. Because it takes my independence away. And I've said that to him. I said I don't like to keep asking him."

When the concerns were verbalised this could result in the fear of loss of autonomy disappearing. As another patient put it:

"I told him my feelings and we have got a new routine now. I mean, if I cook, he will automatically wash up. And if I haven't hoovered up, he'll hoover up. I don't have to ask and he doesn't ask if I want him to do it."

The importance of the need to talk further emphasises the importance of teamwork; that the successful management of the Fibromyalgia needs a team approach not just an individual one.

5. Teamwork

In the interviews the importance of teamwork came across strongly. For example, a person with Fibromyalgia said:

"As a team my partner and I work together very well in dealing with the Fibromyalgia. Funny enough, we don't talk about it very much but we seem to have an understanding between us. It may seem strange because, as I say, we don't discuss it much. We tend to have a quiet understanding."

A partner said:

*To work together well as a team you (*the partner*) have to be patient for a start, to expect lots of setbacks, get used to the idea that it won't be a smooth ride and be prepared to fit in with what the person with Fibromyalgia is capable of achieving."*

Later in the interview, the same person said:

You've got to talk about things when things get difficult. And you've got to listen. Yes, listen."

Another partner said:

"You have to try and get along with each other well. I think if you didn't get along well with one another you wouldn't talk to one another and I think with this sort of condition you actually have to be pretty open with one another about everything, so if we didn't get along with one another dealing with the Fibromyalgia would be more difficult."

6. Touch

Not surprisingly, given the nature of Fibromyalgia, some partners said they were careful about touching the partner with the

condition for fear of hurting them. They found themselves being hesitant physically. On the other hand, some of the people with the condition were concerned that the tactile relationship with their partner would diminish: they saw this possibility as a major loss. Sometimes they would not say they were in pain or discomfort for fear of not receiving hugs and caresses. In such cases, these feelings had not been openly discussed with each other.

One person with the condition in response to being asked about how she responded to her husband giving her hugs, said:

"He has to be careful but he's good at that. Sometimes I will say, 'oh, that hurts today, you know, just be a bit more gentle', and he's good about that. Sometimes I won't say nothing because I feel it then puts him off touching me, so sometimes I feel, it doesn't really matter, you know, and I just say 'I've got to move now' And that's the way I get round it. I don't want him to stop touching me."

7. Living with Unpredictability and Uncertainty

Fibromyalgia Syndrome, like many other chronic illnesses, is unpredictable. Difficult episodes arrive without much warning and can go away without much warning also. The person with the condition, and other people close to them, particularly part-

ners, have to be able to deal with not only the unpredictability of the condition but also the uncertainty of the implications of this for everyday living, including holidays.

As one partner put it:

*Partner: We were due to go on holiday and she woke up in a really bad way, and the taxi taking us to the airport was almost at the door and in the end we just couldn't go and I spent hours undoing everything (*unpacking*). And, uhm, redoing it a few weeks later.*

BM : I suppose that raises issues about how you deal with uncertainty. Are you good with uncertainty? Is she good?

Partner: I think I live on uncertainty. I can never, I can never really decide that something is going to happen. Uhm, it does. I hope it does.

BM: Are you ok with that?

Partner: Well, I suppose it puts me out of my stride, in that I don't make firm and final arrangements very easily. It gets to that point where it's all tied up, you know, and I say to myself – careful, careful.

BM: So does that mean you have to be, you have to hold back a bit on investing too much in something happening?

Partner: Yes, oh yes. Yes.

BM: What's that like?

Partner: Its, it makes me feel even more sluggish at getting on with things than I am anyway. Uhm. On the other hand, I was brought up to be flexible. I'm fairly used to taking last minute decisions.

BM: And your wife. What's her relationship with unpredictability?

Partner: She likes to know what's going to happen. So she gets frustrated. But at the same time she has learnt to accept the limitations of her condition. So although there are frustrations on both sides we manage them quite well.

8. Medication

There were considerable concerns expressed with regard to the effect of medication on the person with Fibromyalgia and the relationship with the partner. For example:

Partner: My wife was on these pills, the strong ones and she stopped taking them so that she didn't get hooked on them. But her condition got worse so then she went back on them. Now, she realises that she has got to keep taking them all the time – when they are necessary. But the pills make her groggy and she doesn't like being groggy.

BM: So what happens?

Partner: She stops using them. She tells the GP she can't carry on with them.

BM: What happens to the relationship between the two of you when she is a bit groggy?

Partner: She doesn't talk at all. I can understand her not wanting to get hooked on anything, whatsoever, and I think anyone with anything between their ears would recognise that. I don't know. I haven't been in this situation before.

Another partner said:

Partner: I think she should take a minimalist approach. She is not as keen on this. She has been trying quite hard and has been succeeding, but on the other hand it doesn't always help. My worry is about the effects on the liver and kidneys.

Another partner talked about the medication making his partner drowsier, sleepier. While he and his wife still had a close relationship, the effect of the medication, as he saw it (and the condition as a whole), contributed to her having less energy and being less keen to do social things together. He talked about this as if it were a bereavement, which in a way it was. *"I've lost a companion,"* he said, sadly.

There appeared to be a continual balance between using medication to help the person with the condition have a less painful, distressing existence while at the same time not being so med-

icated that it would affect the quality of relationships with people close to them. In this respect, medication can be said to be an individual issue and a relationship issue.

9. Pacing as an Individual and a Relationship Issue

Pacing was a constant theme throughout the interviews for both patients and partners not least in how partners could contribute to appropriate pacing. For example:

Partner: We know people who haven't got a partner to support them and I think it's difficult, more difficult, I think. Because, you know, with Fibromyalgia you get very tired at times, can't do things. You need to pace yourself. You need to have a rest and so on. It's at those times you can have the partner doing the things that have to be done.

Another partner said:

Partner: If I know my wife is getting agitated and hurting I will sometimes leave her to it, because she knows that if I stay we could rub each other up the wrong way. So we give each other space. So I'll just take a book and go upstairs and read for an hour and when she is ready , when she feels better – more often than not she's taken a pill – and she comes up after an hour and says, 'Are you coming down?' so then I come down. But I don't storm off and say, 'That's it, I'm going upstairs'. I used to but

now I just give her space but she does the same to me as well. But normally it's me with her. Give her the space and she will manage the pain in her own way. So it's going at her pace at those times. That's what I've realised.

What comes across in these responses is that while there is still quite a lot of emphasis on the individual dealing with difficulties there is also a little more emphasis than in the patient group of finding ways of coping through seeking help from others, including talking.

Concluding comments

What I hope has come across in this presentation is that the management of illness is both individual and relational. I know from my own personal experience that, while I have developed particular ways of coping with adversity, I have also been aided in having a primary relationship with getting on with life by people close to me - some of whom are in this room. And I thank them for that.

I end with a quote from Susan Sontag's book, 'Illness as Metaphor' (1979) - which I'm sure many of you know. For me, it says something about illness being both individual and relational, and that even if we are well and not ill we will have people close to us at some points in our history who may be ill. Thus we also, relationally, become citizens "of that other place."

"Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place."

Thank you.

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