Chapter 1

Living with a rheumatic disease: the personal perspective

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1.1 Introduction

> Attention to human suffering means attention to stories, for the ill and their healers have many stories to tell…. The need to narrate the strange experience of illness is part of the very human need to be understood by others, to be in communication even if from the margins (Mattingly 1998, p. 1).

The aim of this chapter is to ensure that your focus is, from the outset, on the personal experience of living with a rheumatic condition illustrated by composite narratives informed by the many personal stories we have listened to and collected in the conduct of our research. We are conscious that in adopting this approach, we depart from the traditional structure of many clinical textbooks which usually start with an overview of the aetiology, pathology and clinical management of impairments. However, as suggested by Frank, 'not all stories are equal. The story of illness that trumps all others…is the medical narrative' (1995, p. 5). In a clinical textbook, it is easy for the clinical/medical narrative to dominate, and even though occupational therapy practice is informed by person-centred working, the voice of the person is often lost within the clinical story.

As occupational therapists who have worked clinically in rheumatology before moving into research, we are struck by the different narratives we hear when undertaking research to those we heard within our daily clinical practice. As researchers, we are alert to the emerging stories shared with us and those we work with are more obviously aware of their role as storyteller. Within our therapeutic encounters, some of these stories are unconscious revelations which still require due care and attention as highlighted by the following example. On a project looking at the social interaction of the client/practitioner

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relationship, there was an observation of a health professional taking the initial history of a woman who was being admitted to an inpatient rheumatology unit:

Interviewer, I; Hattie, H
I: Who is your next of kin?
H: Not my eldest daughter, she done my husband's funeral. She gets so terrible upset so she can't take no more.
I requests the name, address and telephone number of Hattie's younger daughter and it is supplied.
I: Would she be there at night if we ever needed to contact her?
H: They wouldn't have to get in touch with her would they?
I: No, it's only if there was an emergency, we need to have someone we can contact.
H: Because I don't get on with her husband you see.
I: No, it's only if there was an emergency.

—Hattie, 65 years, rheumatoid arthritis (RA)

Thus it is that in an effort to find out a factual piece of information (a contact telephone number), this person revealed information about:

- the death of her husband,
- problems experienced by her elder daughter and
- relationship problems with her son-in-law.

These issues were not acknowledged nor was an explanation given about what would constitute an emergency within the ward setting; however, the example serves to illustrate the centrality of narrative in our lives. Similarly, working alongside a client and asking a straightforward question can reveal how seemingly ordinary people have many stories to tell (Box 1.1).

Changes in healthcare delivery mean that there are far fewer opportunities for stories to be revealed in everyday therapeutic encounters. In a person's home, not necessarily being known as a healthcare professional, with more time to listen and a focus on understanding an experience as opposed to obtaining clinically relevant information, a different story is told that we wish to give voice to.

Narratives are described as collections of 'events, experiences and perceptions that are put together into a meaningful whole and understood/told as a story' (Goldstein et al. 2004, p. 119) and, when seen as a component of occupational therapy practice, through their telling, enable therapists to develop a greater understanding of people's worlds and experiences and how their lives are shaped by therapy (Mattingly 1998).

Narratives are constructed for an audience, they are told to people, and the way in which they are constructed and what is told is influenced by the audience. The clinical narrative recounted in textbooks is constructed primarily to educate healthcare professionals about the clinical management of rheumatic conditions, which by its nature seeks to address the problems and challenges with which people are faced. Within clinical practice, the personal narrative is often constrained by the structure imposed upon it by the questions posed; it is a guided narrative which seeks to convey specific information within limited time primarily focused on identifying issues to inform

Box 1.1

Betty came into the rheumatology inpatient unit, was assessed and treatment aims were established. She had to increase the range of movement and muscle strength of her shoulder, elbow, wrist and hand and improve her precision grip to increase her ability to perform personal care and writing tasks. Using the medium of batik, Betty produced a wall hanging depicting a tranquil scene of a church with a pond with ducks and bulrushes in front and a clear blue sky behind. The task fulfilled the aims of treatment, she gained satisfaction from completing each component part of the task and her function improved.

As part of the small talk that goes on in a treatment session, Betty was asked about her design. She began to talk about her childhood. She had been in Singapore during World War II and had been captured and placed in a camp. She spoke about how desperate life felt for her and how she retreated into her imagination of a scene very much like the picture she had produced in the treatment session. After talking for some time, Betty took stock of what she had been discussing and revealed that she had never told anyone about the image she had used. The aim of the session was to increase shoulder range of movement, increase stamina, and achieve the mindfulness of being absorbed in an activity with a view to increasing functional ability. What emerged as an extra dimension was Betty's need to tell her story about her childhood experiences. As Betty had revealed this aspect of her life, it was important to pursue it, offering other support services to allow her to explore this aspect of her life. On reflection, Betty decided that she felt at ease with the disclosure and had achieved enough by telling her story (Betty, 72 years, RA).

clinical interventions. However, these are partial narratives which focus on specific aspects of a person's life.

People participate in research for different reasons, but a common thread running through studies we have undertaken is the desire to give voice to an experience to enable others to understand. As suggested by Frank (1995), 'storytelling is *for* another just as much as it is for oneself'. In the reciprocity that is storytelling, the teller offers themselves as guide to the others. The resources listed at the end of this chapter illustrate how personal narratives have been used in this way.

When given the time and the opportunity to recount their story with little or no structure being imposed, the personal narrative assumes a different dimension in which illness is located within the much broader context of a person's life. At the end of conducting a research interview, it is common for people to comment that they have never had the opportunity to talk in such detail about their experiences before. The process of telling a story is one of making sense and giving meaning to an experience and has been used by researchers working within the social sciences to give voice to an alternative understanding of the experience of living with and managing long-term conditions, one grounded in personal experience (this work is explored further in Chapter 2).

1.2 Living with a rheumatic condition

The point at which occupational therapists come into contact with people with rheumatic conditions is often at the point in their illness trajectory when they are trying to make sense of what is happening to them. In Chapter 2, we will explore how this process is fundamentally about developing some kind of causal explanation. This is especially relevant to people who are often faced with medical uncertainty about the cause on their illness and seek to find an explanation for what is happening to them (Box 1.2).

Personal narratives also provide insights into how symptoms are labelled and categorised and how complaints are interpreted within a particular context or life situation (Kleinman 1988). For many people, obtaining a diagnosis can take time with symptoms being interpreted in different ways and even doubted by others until a definitive diagnosis is made, whilst others experience a rapid onset of their condition which turns their life upside down (Box 1.3).

Box 1.2

I work as a warehouse manager and have probably had AS for about 15 years or so but it's hard to tell really. It's only been diagnosed in the last 2 years. I've had back pain and pain in my neck and shoulders for years. At the time I put it down to the lifting and carrying I did at work and all the sport I played. I went to the doctors several times and was told I'd got a bit of lumber pain and to just get on with it basically so I put up with the pain on and off for years (Keith, 37 years, ankylosing spondylitis (AS)).

I keep trying to work out why it started when it did, as no one else in my family has it. All sorts of things go through your head. I remember having really bad flu and not really getting better very quickly but I can't really think of anything. Mum and dad hadn't been so good at the time and were needing a lot of support, and I was under a lot of stress trying to juggle looking after them and the family and my work; they say stress can be a cause don't they? (Sarah, 41 years, RA).

I have been a primary school teacher for 25 years. I hadn't been feeling well but thought it was because of the busy run up to Christmas. When I didn't feel any better after the Christmas holidays, I thought I had better see my GP. I am not sure he believed me at the start, probably thought 'oh here's another woman with a bit of a midlife crisis'. The back of my neck ached and felt stiff and it spread to my arms, hands and down my back; even my ribs and hips ache sometimes. I went to bed feeling tired and woke up even worse. The more tired I got, the worse the pain became. I started getting a lot of headaches and thought it might be eyestrain, so I went to the opticians but she said my eyes were good for my age! (Gemma, 50 years, fibromyalgia (FM)).

Box 1.3

About 2 years ago I got back pain which came on pretty quickly and didn't go away, and I just felt ill. Eventually, I went to my doctor's and she did an x-ray, but nothing showed up. Then she sent me for an MRI scan and I saw another doctor who told me it was ankylosing spondylitis. It was a relief after all these years to actually give it a name and know that something can be done (Keith, 37 years, AS).

At various points in time they have played with diagnoses of chronic fatigue syndrome, RA, lupus, depression and just back pain. My doctor did a load of tests and as each one came back negative he could tell me what I didn't have rather than what I did! He referred me to a rheumatologist who came up with the diagnosis of fibromyalgia; he pressed the places that were aching and they REALLY hurt (Gemma, 50 years, FM).

When I developed arthritis my daughter was literally a few weeks old; it just came on, all my joints were hot and swollen and painful, I was a mess. My parents lived close by and luckily had retired so were able to help otherwise I don't know how we would have coped. They were here every day. I couldn't pick her up, change her or feed her; you can imagine how I felt as a new mum having to watch someone else do all the things I had longed to do (Sally, 39 years, RA).

The variable nature of rheumatic conditions poses significant challenges affecting the ability to forward plan and commit to activities. It can also inhibit significantly people's social networks and social lives and impact upon their family life as flexibility has to be incorporated into people's lives. It also adds complexity to the maintenance of key roles, especially with regard to employment where people are required to accommodate variation into their working lives whilst continuing to undertake the requirements of their jobs (Box 1.4).

Alongside accommodating variability in the impairment, living with a rheumatic condition throws into uncertainty a person's ability to plan for their future.

> If it stays the way it is now I'm fine, but I do worry in case I'm going to get worse as I get older (Jo, 51 years, RA).
>
> I don't want to be self-employed and then this [RA] comes on again or everything stops working and I can't move and I have to quit, because I've got a mortgage (David, 37 years, RA).

Whilst previously people's perception of their future may have been associated with a deterioration in their condition, the recent introduction of anti-TNFα treatments has, for some people, opened up new possibilities.

Box 1.4

My lower back aches most of the time. If I don't keep on the move I can get pretty stiff. That's the trouble with having a desk job, but I suppose I'm lucky as I can walk around the warehouse. Sometimes it's worse than others; it's inexplicable really, there's no accounting for it. I can feel exceedingly tired and I don't know why that is. I might have a bad flare up for a week or so. Suddenly you can't walk without a lot of pain, you can't turn your head very easily and even turning in bed is difficult. I can't stand up to go to the toilet, and going downstairs is hard. I never understand why it comes and goes like this, and I've tried to work out if anything I do triggers it off (Paul, 39 years, AS).

I don't like being off work, I needed money, rents to pay, so while I was off work it did ease up [his symptoms], but when I had to give up work I was at my lowest point. I felt very depressed actually; I felt like it was a blow to the male ego (Colin, 55 years, AS).

It does stop you going out sometimes because if I was to fall over it I'd just be laying there because I couldn't get up and just the thought of something like that, little kids like they'll just laugh at you (David, 37 years, RA).

You just have to tackle a day at a time. You can't say to people, 'I'll do such and such with you' because you just don't know how you will feel until the day arrives (Brenda, 48 years, RA).

I stopped making any plans, you couldn't really plan or book anything to go and do, because you just didn't know you would feel OK (Mary, 62 years, RA).

My friend's daughter was getting married and I bought an outfit weeks before. On the Tuesday and Wednesday I had two really good days, but by the Friday I felt terrible, really awful and I thought, 'oh I'll just rest', you know, but I just couldn't go, I felt terrible on the Saturday and I just couldn't make it (Sally, 56 years, FM).

The pain you have to go through just getting up in the morning, just to try and put your shoes on, it's a bit of a nightmare (David, 37 years, RA).

> I haven't got to worry about anything and I'm a man again because I'm earning, you see, it sounds daft but you like to be the provider, I used to hate sitting at home here and I'd be farting around hoovering and doing a bit of ironing knowing that the wife's been up since five in the morning, she's had to go to work and I felt pathetic (Colin, 55 years, (AS)).
>
> [I can] take the children out for a day to a theme park, before I just used to be the bag person I looked after the bags, now, I can go on fairground rides, I don't have to think about it and I can enjoy it, it's like being a teenager all over again (Jane, 44 years, AS).

Although people on anti-TNFα often report feeling better, they do not necessarily experience complete recovery, 'I am just having a better life, I know my limitations they are not going to change' (Janet, 74 years, RA).

> I had a year out of the gym, went back and I got a different programme. I don't do any classes now, I do Pilates, I can't really do them [the other classes] because anything with weights I can't put the weight on my wrists, it's all kind of saving them for the future. I need to keep my joints moving and everything, but anything that's more heavy impact can't really do, so even though I have gone back to the gym I still can't do the stuff that I used to do there's still a little bit of negative with it (Naomi, 20 years, RA).

The symptoms most commonly experienced by clients living with rheumatic conditions are pain, fatigue and stiffness (Box 1.5).

Whilst healthcare professionals often focus on the extent and duration of morning stiffness, clients will experience stiffness at different times of the day, especially if sustaining a fixed position for any period of time such as undertaking a long car journey or sitting at a computer for extended periods.

Box 1.5

Fatigue

My muscles ached and I felt constantly tired. I went to bed feeling tired and woke up even worse. People think I am just being lazy. The more tired I got, the worse the pain became (Gemma, 50 years, FM).

It's just that you're so much less of what you are because you just don't have the energy, probably people get a bit cheesed off or they do their own thing because you aren't there (Philip, 43 years, AS).

You sit at a bus stop and you're nodding and I fall asleep and that's what I call dangerously tired and that's bad because you can't keep your eyes open (Lily, 54 years, RA).

Pain

I seem to get really bad pain in my neck, like, real stiffness and when I went to the hospital last time he actually said, 'Well, don't paint the ceilings just concentrate on the skirting boards'. I did laugh but…that was one of sort of my main concerns, but then he laughed it off (Rob, 51 years, RA).

I was always in pain, always, it spoilt things for me and made life just pretty miserable (Alan, 56 years, AS).

Medical management

With the diagnosis of a long-term condition comes the need to engage with a range of healthcare professionals and to develop an understanding of the systems associated with the provision of health and social care. The majority of people will, for the first time, experience the need to take medication on a long-term basis, which, for many people, raises significant concerns:

> If I had my way I'd take none of them, it's all toxic no matter how good or how much it helps there's always a price for it, I haven't got the choice but if I had my way, if I thought I could get through it I would (Terry, 58 years, RA).

For some people, such choices are perceived in terms of a choice between quality or longevity of life:

> …the issue I decided to take the drug on was quality of life, 'cause all these drugs shorten your life end of story, so the question is do you want to be old and crippled or do you want to die younger' (Sally, 56 years, RA).

Finding the right combination of medication can be seen as a process of trial and error with, over time, different medications and different combinations of medication being taken.

Given the long-term nature of rheumatic conditions, the relationship developed with the healthcare team is often established on a long-term basis with, when it goes well, trust developing between the client and the members of the team.

> He's on my wave length that guy. I'm going places with my arthritis (Jo, 51 years, RA).

This relationship can, at times, be challenged when a person may feel at odds with the advice of the team and not want to put that relationship in jeopardy.

> I mean obviously if I do come off he has every right to say I told her to do it and she didn't so it's no wonder she's not getting better. I'd hate him to wash his hands of me cause I do like him and I trust him and I don't want to ruin all that (Lisa, 39 years, RA).

Challenges are not only posed by differing views about medication but also about other aspects of management such as engagement in exercises for people with AS. For clients and healthcare professionals, there is the need to establish an effective working relationship which recognises and respects an individual's right of choice and self-determination. Coming into ongoing contact with healthcare professionals requires people to develop an understanding of the nature of these relationships and responsibilities within them; people will have differing views about what these are:

> I think it is your responsibility to try and make yourself better. The medical profession can't offer you a cure so I think you need to do your bit as well (June, 45 years, RA).

The long-term engagement with healthcare services will potentially have benefits if there is a shared understanding and, therefore, an increasing familiarity with the expectations of the client, but the requirement to frequently retell the personal story can have negative effects as well:

> This is so frustrating, relating my problems over and over again is emotionally draining, it's like facing up to it all over and over again. I just want to be pragmatic and get a solution not have to relive the nightmare of having RA again and again (Catherine, 43 years, RA).

Such emotions are often associated with completing official forms such as applications for welfare benefits which require a person to describe in detail the level of incapacity and activity limitation they experience.

Psychological impact

The variable nature of rheumatic conditions coupled with symptoms such as ongoing pain and fatigue and the impact of these impairments upon levels of activity can pose significant psychological challenges. Whilst, within a clinical context, attention can be focused on anxiety and depression, there are a wide range of challenges with which people are required to contend. Pain and fatigue can impact on levels of concentration:

> Unfortunately I was unable to get much done and what I did do wasn't very good, I was just too tired to concentrate (Claire, 29 years, AS).

The inability to do things that had previously been taken for granted and the need to ask for assistance often cause high levels of frustration:

> I sometimes think the frustrations worse than the disease at times. You get, I don't know about other people, but I get to tears sometimes because I'm so frustrated I desperately want to do something and just can't do it (Kate, 54 years, RA).

Activity limitation can lead to increasing work for other family members as they are required to undertake more tasks and feelings of guilt are often expressed due to this:

> There are times when because you haven't done it, you know you're too tired or in pain, you feel guilty, really guilty and then your husband comes in from work and has to start preparing the meal or doing the ironing (Karen, 56 years, RA).

Some clients experience changes in their appearance, either due to the development of visible deformities, changes in gait and posture or the requirement to use appliances or dress differently to accommodate their impairment, all of which have the potential to mark them out as different:

> Your self-esteem goes down sometimes. I mean you walk along the street and sometimes you get glanced at for your feet. I've heard people say I as they walk past me, 'did you see her shoes' (Brenda, 48 years, RA).

There can be an element of loneliness and isolation associated with living with a long-term condition highlighting the very personal nature of such an experience. Close friends and family develop an understanding of what is being experienced, but even on such a personal level there is a limit to how often they may be prepared to listen or a client feels able to discuss how they are feeling or the difficulties with which they are contending. Within a person's wider social context, there can be a feeling that such issues need to be concealed to reduce the impact of an impairment on the friendship:

> It's far more difficult to keep a friendship going because if you bug them with how ill you feel they are just going to go away, they're not going to put up with it. So there's no point in telling them how you really are. So there's a pretence that goes on you know, 'I'm fine thank you', when you're not fine, if you talked about it endlessly they'd just think, 'Oh it's her again' (Rebecca, 42 years, (FM)).

The accumulated impact of all of these factors accompanied by ongoing levels of pain and fatigue can, for some people, lead to periods of clinical depression:

> It's easy to say 'I'm depressed', because everyone does don't they but I mean it's that sort of, you know, where I want to sit and not move a muscle or not do anything whatsoever. But I do get up and I just go from one television to another and think, 'ee there's got to be more than this' (Linda, 61 years, RA).

> He said he was sorry I had lost my job but perhaps it was for the best. Which I thought was an absolute load of rubbish because I was very bitter about it and I was very depressed about it (June, 56 years, RA).

As well as the psychological impact of living with a rheumatic condition, when located within the wider context of people's lives, it is common for people to describe how stress related to another aspect of their life impacts upon their impairment, especially with regard to increased pain and fatigue:

> It's been bad for a few weeks and I went to see the doctor, but I think it was because I was worrying about my husband, he has been so ill (Mary, 53 years, RA).

Given the long-term nature of rheumatic conditions, over time people develop a repertoire of strategies to minimise the impact of the impairment on their lives.

1.3 Developing new skills and learning

As people live with an impairment, they develop a repertoire of skills and expertise which enable them, to varying degrees, to manage their impairment and the impact it has on their lives. Many of the chapters in this book provide detailed insights into the role of occupational therapists in facilitating this process with a specific emphasis on managing the symptoms and maintaining independence. In this section, we wish to draw attention to some of the wider challenges people face when locating the management of their impairment within the wider context of their lives.

A challenge of living with a long-term condition associated with change is one of adapting to each period of change as it occurs. Over time, people's accumulated experience of living with and managing a rheumatic condition becomes situated in their prior learning and informed by their past experiences (Box 1.6).

People accumulate and obtain knowledge from a wide range of sources, including self-help forums, the internet and a wide range of social media. Accessing such resources

Box 1.6

I have to have my full lunch break; my boss would let me work through if I wanted to and pay me for it, but I have to have time away from the (sewing) machines; I know if I push myself too hard, I will suffer at the end of the day (Jo, 48 years, FM).

I do still get these horrible tired feelings but I give into them easier now. I used to push myself and make myself carry on but now I can say, 'right you're tired sit down' (June, 45 years, RA).

If I'm in a lot of pain I will have a warm bath and put in a little bit of oil of comfrey or lavender and just rub where I am aching, and then have a warm drink and I've got an electric blanket, and I will just have a lie down for a while (Angela, 56 years, AS).

Box 1.7

I don't care what anyone says. I know that when I eat certain things like tomatoes or oranges my joints hurt more. When I've told the doctor she just smiles and I know what she's thinking but it happens every time. The same with the weather; I know what the day is like before I open the curtains in the morning (Claire, 59 years, RA).

The problem is that unless you have actually experienced living with FM it is hard for others to understand exactly what you are going through. When I meet others with FM, you don't have to explain it; they just know what you are going through (Kate, 54 years, FM).

Box 1.8

Even if I'm really tired I push myself to go out in the evening. I think living on my own I always try and plan into my day at least talking to someone or seeing someone, because otherwise I will go all day and I won't have talked with anyone (Claire, 29 years, AS).

I really do know what caused the problem. We had my daughter's wedding 3 weeks after I came out of hospital so you can imagine what I was doing. Things that I probably shouldn't have been attempting and going for longer period without resting to get things done. So I know I overdid things. I was absolutely shattered on the wedding day; I don't know how I got myself there, but I did and it was fantastic (Pam, 62 years, RA).

and exchanging experiences with other people living with rheumatic conditions leads to the development of shared community forms of truth and sense making (Box 1.7).

For healthcare professionals, understanding these community forms of truth can provide valuable insights into people's beliefs and understanding about a number of illness-related factors and can help occupational therapists to identify beliefs which may need to be addressed to increase the adoption of certain therapeutic interventions. As occupational therapists, we may seek to promote strategies such as pacing and energy conservation but, when located within the wider social context of people's lives, decisions to use such strategies are balanced against a host of competing demands and priorities. There are times when other things assume greater importance, and conscious decisions about a certain course of action are taken in full knowledge of the consequence (Box 1.8).

Situated learning does not necessarily mean not repeating mistakes or not doing things which make the condition worse but can enable a person to understand and prepare for the consequences of certain courses of action. A wide range of factors influence a person's decision to push themselves to their limits which include not wanting to let people down:

> I would rather leave everything and keep an appointment rather than phone up and say I can't make it. I have to be really ill and in an awful lot of pain. I would rather take double the pain killers and go and meet them, than say I'm not coming (Paul, 49 years, AS).

and the desire to continue to fulfil key roles and responsibilities:

> I feel it is my responsibility to try to do as many of the things now as I used to before I had RA, the personal things, the housework, cooking of the meals this sort of thing. Playing my part as a wife, mother and grandmother (Pam, 62 years, RA).

The narratives of people with rheumatic conditions often use terminology associated with combat such as 'fighting', 'battling' and 'not being defeated'. Independence is valued highly and asking for help is often associated with 'giving in'.

> If I'm honest I don't want to let my AS interfere with my life in any way. I want to just go on doing what I've always done and if I can't that would be like giving in. I think I see it as a bit of a challenge (Peter, 41 years, AS).

> I absolutely hate asking for help, it makes me feel like I am a burden on others. The other day I was watching my son do my garden and thinking about all the things he should be doing for his own family (George, 69 years, osteoarthritis).

The need to negotiate assistance within the family is not always an easy process. In the following extract, Karen, who is newly married, describes how she has recently employed a cleaner but has not told her husband:

> Well it's all done when he's at work. She comes here during the day and then any ironing I drop down during the day and she drops it off so he doesn't know at the moment (Kate, 34 years, RA).

This was due to the fact that she felt she should be fulfilling what she felt to be her duties as a wife and not wanting to 'let him down'. Clients may also have to confront the emotions associated with needing help from their children:

> I have this ongoing argument in my head that says, 'it's me that's got RA not the children'. I didn't have them to look after me (Brenda, 48 years, RA).

who, as Brenda went on to describe, can at times be both vocal and forthright in making their position clear:

> …she's 14 and she said, 'well you know dad,' because she knew he was going to say something, 'well you know dad I've had a busy day and I don't know what Mum's done all day but I've been very busy,' Well you sort of curl up in a ball and laugh and cry at the same time (Brenda, 48 years, RA).

Thus it is that negotiating assistance is closely linked with saving face, the nuanced interplay of trying to fulfil desired occupational roles and thereby protecting valued occupational identities. People engage in complex and complicated calculations of how they balance what they have to do, what they can do and what they want to do. Being sensitive to the subtleties of these calculations is an important part of our therapeutic repertoire and is an essential part of facilitating occupational balance.

1.4 Summary

The focus of this book on lifestyle management highlights the fact that having a rheumatic condition is one facet of a person's life which can only be understood when located within the wider context of their personal narrative. The stories of people living with rheumatic conditions tell of struggles and challenges, but they also tell of achievements, of hopes and aspirations which have nothing to do with their impairment and of a desire to transcend the 'illness narrative' and to be understood as a person with many stories to tell. Successful occupational therapy management is predicated on understanding the multiple narratives a person has to tell and the influence that different facets of a person's life will have upon therapeutic interventions.

Resources

National Rheumatoid Arthritis Society

The National Rheumatoid Arthritis Society (NRAS) website contains a wide range of resources, including a section on personal narratives written by people living with RA describing the impact it has on their life. http://www.nras.org.uk/about_rheumatoid_arthritis/living_with_rheumatoid_arthritis/case_studies/female/default.aspx. Accessed on 14 November 2012.

Healthtalkonline

A specific section in healthtalkonline provides information about RA and people talking about their experience of living with and managing it. http://www.healthtalkonline.org/Bones_joints/Rheumatoid_Arthritis. Accessed on 14 November 2012.

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