



## Promoting Evidence-Based Nursing Practice: *Living with HIV related fatigue*

### INTRODUCTION

In this issue we share the story of Nigel (a fictional name) who shared what it is like for him to live with Human Immunodeficiency Virus (HIV) and fatigue. He described how the consequences of this illness have affected his life and how he has learned to manage fatigue.

Nigel participated in a research project undertaken during 2003 entitled *"The experience of fatigue and strategies for self-management among community dwelling persons living with HIV"*

The aim of the research was to describe the experience of fatigue and the strategies for self-management among community dwelling people living with HIV. The research was undertaken because of a perceived lack of available evidence to inform the practice of HIV service providers including RDNS HIV Clinical Nurse Consultants. They had noted that fatigue was one of the most prevalent, yet under-reported, under-recognised and under-treated aspects of living with HIV. The literature supported this assertion (McCain & Zeller 1994, Delmonte 1997, Barroso 1999)

Following approval from the RDNS Ethics Committee, data were generated with 15 participants (13 men and 2 women) who had been diagnosed with HIV. Data were generated from multiple sources (1) individual semi structured interviews, (2) a questionnaire that asked participants "what is fatigue and how it is managed?" and (3) two participatory action research (PAR) group meetings with participants and their partners.

For the purpose of describing the experience of living with fatigue and HIV, the focus here will be data generated during an interview with Nigel.

### FATIGUE IN HIV

Fatigue can often be a hidden problem. The significance of this common symptom goes beyond the idea that sick people get tired. As it is with cancer, people living with HIV now have access to therapies that can significantly prolong their life, particularly when diagnosed early. These therapies have many benefits but are also responsible for intrusive side effects. Increasing longevity has led to HIV being considered as a chronic rather than a terminal illness. This has implications for how health professionals deal with the clinical and social elements of HIV. Health professionals have been encouraged to recognise and respond to fatigue as a problem distinct from a disease process, depression or just a lack of motivation (Trendall 2000). Fatigue has been recognised as the most common symptom reported by people with HIV. Various studies have revealed that prevalence ranges between 20 and 85% of people sampled (Barroso 1999; Breitbart, McDonald et al. 1998; Cunningham, Shapiro et al. 1998; Darko, McCutchan et al. 1992; Sullivan, Dworkin et al. 2003; Vogl, Rosenfeld et al. 1999). In the most recent Australian HIV Futures Survey, 68.5% of the almost 900 HIV positive people surveyed, reported low energy or fatigue (Grierson, Mission et al. 2002).

Despite this, fatigue may be under treated by health professionals (Delmonte 1997). Others perceptions of the problem do not always accurately reflect the actual experience of the person who has fatigue. People with fatigue perceive it as important because it affects their quality of life whereas doctors and other health professionals may not because it is generally non specific from a diagnostic viewpoint (Justice,

Rabeneck et al. 1999; Reilly, Holzemer et al. 1997, Sharpe and Wilks 2002).

### NIGEL'S STORY

Nigel has spent most of his adult life working long hours in the service industries whilst enjoying the lifestyle that was expected of someone "on the way up". He was diagnosed with HIV 18 years ago and even though he experiences fatigue and other symptoms, he continued with a strong work ethic that may be partly responsible for a sense of constant fatigue. At 25 years of age he was diagnosed with both HIV and testicular cancer. This promoted him to decide:

*"I'm just going to go and have a good time until I die. And that's what I did for the next two years."*

A supportive partner encouraged him to question his lifestyle and as time moved on he began to realise that he might live for longer than he had previously thought. He perceives that these lifestyle changes, a range of HIV anti-retroviral medications, combine to keep his viral load undetectable. In addition, he uses antidepressants, strong analgesics for arthritis and neuropathy pain and the "Rosie" drug trial that promotes weight gain.

### The Experience of Fatigue

The experience of fatigue for Nigel was being constantly tired and a loss of motivation for undertaking life's activities. Nigel spoke of losing the *"oomph in your engine..."* He gave the example of housework, where prior to HIV he had been able to vacuum his entire house without a break, now he did not feel like doing it, and had to break the chore into smaller tasks such as vacuuming one room each day.

Fatigue was not relieved by, or modified positively by sleep. Some mornings felt like he had been up all night despite having had a long sleep. He made numerous comments like:

*"I wake up in the morning sometimes and I feel like I'm 100. That's exactly how my body feels. I feel like I've got this young mind in this old body that just can't go as fast."*

Fatigue may often not be obvious to others, so could create frustration when people made demands on Nigel that he could not meet. He perceived there was little understanding from people who had not experienced this symptom.

The inability to cope emotionally and physically with tasks that were taken for granted prior to HIV resulted in anger, frustration, a reduced tolerance to pain, and an inability to relax or concentrate on tasks. This resulted in Nigel *"giving up"* on a task much sooner than he previously would have. He stated:

*"I'm not as patient as I used to be. The fatigue affects the way I feel in the tolerance sense. It just turns me into a narky, nasty person and people notice it. I don't notice it at the time, though. I don't realise that I'm being that way, but I don't seem to have that ability to control how I'm feeling if I'm feeling like crap".*

Fatigue caused Nigel to withdraw from many activities outside of the home including full time work and a lot of socialising. Entertaining at home had also been significantly curtailed creating a sense of social isolation. By the time all the

preparation was done, Nigel often felt too tired to enjoy the event.

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## How is Fatigue Managed?

Redirecting activity into work that provided personal meaning countered some of the physical demands placed on Nigel. When Nigel left full employment he actually became busier in terms of time spent working but was doing something that he felt passionate about and on his terms. This change of outlook made it possible for him to continue to keep up a busy pace for some time until his body started sending him signals he could not ignore.

*"I'm doing it more for me. It's more for my enjoyment. More so that I get to still have interaction with people. And so that I'm not stuck at home on my own all day."*

"Fuelling the engine" in terms of regular healthy meals was essential to counter fatigue. Making sure that he consumed three healthy meals a day was the key to maintaining energy stores. By preparing them himself there was a sense of satisfaction that he did not have to rely on others for this task.

Other successful self management strategies for fatigue included getting enough rest and sleep time, scheduling physically strenuous activities early in the day, smoking marijuana as a relaxant and appetite stimulant, reducing emotional stress and not consuming excessive alcohol. Reducing stress was not as easy as it would seem as Nigel had high expectations of himself to perform and function in his daily activities. He aimed to reduce his marijuana intake.

Nigel's work ethic was the driving force to continue working late in the day despite fatigue. Work provided a distraction. Overriding many of the previous strategies was the belief that if fatigue was worked through, the actual work itself will take Nigel's mind off how tired he felt.

## Contextual issues that hinder or help self management of fatigue

Depression has been part of Nigel's life for many years and was exacerbated by fatigue.

Other clinical issues Nigel had such as asthma and peripheral neuropathy (related to HIV) caused pain, weakness and dyspnoea that reduced strength and endurance and therefore contributed to fatigue. Many of the tasks that Nigel felt motivated to undertake required a level of dexterity and strength. His love of gardening is a case in point where he struggled to do heavy tasks and could only work for short periods before needing to rest.

Intensely busy days were fuelled by a sense of urgency not to waste a single minute of life, a concern for what others think of him, as well as an ingrained work ethic. This resulted in Nigel pushing himself to the point of exhaustion many times over. This notion appeared throughout Nigel's interview transcript. An example amongst many is:

*"I'll feel guilty if I'm not doing anything, when really it's the best thing for my body some days. But I don't know how. I don't know how to control that feeling that I want to be "doing" all the time."*

## Transition

The profound fatigue that Nigel experienced led to a reappraisal of his work and life priorities that resulted in a transition to more rest, relaxation and less work. Also, the realisation that he was not as likely to die as promptly as he had first thought, (common now for many HIV positive people taking newer, more effective therapies) coupled with the death

of his mother, led him to reappraise where he was heading and to commit to making the most of every minute of his life. This change in mind-set was not easy for Nigel as he still struggled to make sense of the changes he had been forced to make during the last 16 years.

What was most important was that there was a future however different it was from what was planned for before HIV came into his life.

*"I suppose the main thing is that I've learnt that you know, there is a future, regardless of how simple it may be. You know, you can learn to accept the way things are and be happier. For me, that's the most important thing."*

## IMPLICATIONS FOR DISTRICT NURSING PRACTICE

Nigel's story provides us with an understanding of the multi-dimensional nature of fatigue. Although the focus has been on the experience of living with fatigue related to HIV, District Nurses care for many people in the community with fatigue from diverse aetiologies. It is imperative that we consider the social, emotional and spiritual realms of a persons life when assessing fatigue and planning care. For many of our clients, despite being a constant companion fatigue fluctuates in intensity. At one moment, all may be relatively well, yet our next encounter may find the person unable to perform even the simplest of activities of daily living. Pushing the boundaries one day to ensure an important task is completed may result in increased fatigue but this needs to be seen as self management too, not a form of deviance or non compliance with our expectations. Fatigue is life for these people. They are the experts of their own bodies and lives. We need to work along side them in this.

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