



Promoting Evidence-Based Nursing Practice: *Living With Schizophrenia*

INTRODUCTION

The focus of this issue is to reveal the words of George (a fictional name) who described his experiences of living with schizophrenia, being on anti-psychotic drugs and living in boarding house accommodation. The aim of telling George's story is to reveal the burden of this illness and how it shaped every aspect of the world in which he lived.

George was a participant in a research project that aimed to develop continence promotion strategies for community dwelling people diagnosed with a mental illness. Community clinicians working with people living with mental illness in Supported Residential Facilities (SRFs) identified that urinary and faecal incontinence seemed common for this group of people. SRFs provide hostel type accommodation that is similar to a boarding house and are excluded from major government funding programs. As private enterprises they operate for profit, which creates a paradox when they are charged with caring for some of our community's most disenfranchised people. Ethics approval was obtained and the project time line was 12 months. In this project, data was obtained from multiple sources, including participatory action research (PAR) group meetings with 12 men diagnosed with mental illness. However, for the purposes of understanding the experience of living with schizophrenia, we focused on data generated during interviews with George.

WHAT IS SCHIZOPHRENIA?

Schizophrenia is the name given to a group of serious but treatable mental illnesses that affect the brain and can interfere with a person's ability to think, feel and act. It is associated with symptoms such as social withdrawal, incongruent affect and disordered thinking (Coffey 1998). The symptoms of schizophrenia and the effects of prescribed anti-psychotic medications can be devastating. The illness often impedes people from carrying out essential aspects of daily life, such as self-care, household management and developing and maintaining interpersonal relationships (Hultman *et al* 1997; Walkup and Gallagher 1999). People with mental illness encounter more barriers to employment, have fewer social supports (Clinton *et al* 1998; Walkup and Gallagher 1999), tend to be in poorer physical health (Lawrence *et al* 2002) and have more contact with the legal system than people who have not been diagnosed with a mental illness (Semple *et al* 1997). When the ability to function in daily life is impaired by mental illness, SRFs, hostels and boarding houses offer long term accommodation where food and basic care is provided (Burdekin 1993).

GEORGE'S STORY

George was a 42-year-old physically large man. We suspect he paid particular attention to his hygiene and dress on the days that he met with us because he perceived participation in the project as an 'outing'. He had a sharp wit and an engaging sense of humour. Diabetes aside, his protruding 'belly' was testament to a fondness of food.

LISTENING TO GEORGE TALK ABOUT...

- **being diagnosed**

George described the protracted and difficult period in his life before he received a medical diagnosis and psychiatric treatment:

When I was nineteen I was told to see a psychiatrist but I didn't till I was 25. I got sick in 1985. I remember that I would hibernate in my room. My sister would come over and tell me to get out of bed and have a shower. I wouldn't shower for months. Then one day I drove to my sister's place – I left my car in the middle of the road. I didn't know what

was going on. I started screaming out. I was having a nervous breakdown. The coppers came and put me in the back seat. They said take him to Hillcrest. I ran for my life. But they caught me. They took me to Hillcrest. I went off me tree. Mum and Dad came and saw me. They were shocked, I was really round the bend. All these voices in my head. I didn't have a job because I wasn't well. I didn't get a pension. I kept saying I'd get well. That's why I'm still here on the planet.

George has moved on from his time of diagnosis. He has reconciled with the illness and perceives his approach and responses to the impact of schizophrenia to be different from those of other people he has known.

Yes, I am diagnosed with schizophrenia. I'm not the only one though. Years ago people would just give up. But I'm not like that. Most of my good friends are dead. One of my friends hanged himself at his farm. Another woman died in hospital.

The early experiences of living with schizophrenia were not unlike others who came to a slow realisation that something is wrong with their mental health. People around them often observed bizarre behaviors but it was not until a crisis occurred that intervention for treatment was possible.

- **medication: the saviour and the culprit**

Medication was central to his life. George identified an anti-psychotic medication called Clozapine, in particular, as both a major saviour and culprit affecting his life. Sleeping in a semi-comatose state twelve hours a day was typical, and drowsiness in his waking hours was evident. The many side effects made life more complex and difficult but George knew that he needed the medication in order to function in the community:

The psychiatrist and I talked for a long time before I went on Clozapine because it can kill you. I had to sign a bit of paper. Suddenly I was on it. It's a good drug but half my days are gone because I can't get up and I can't eat properly. Since Clozapine I've been all right. With my mental illness I have it under control. I am doing all right. I'm all right now as long as I keep well. But I go to hospital for a rest every two or three years.

I'm well as long as I keep taking tablets. I do get stressed at night-time, I don't know why. I thought I wanted to talk to someone about what is on my mind. I get depressed at night-time. I've got to that stage again. I'm not sick, I don't hear voices. I'm a bit stressed lately. If I move out I'll get the same situation or whatever. I don't know where to go for help. I can't sort out what to do with my life. I can't really go back to work, that's the killer bit. If I go over the border I have to get my tablets you see. That's why I buy x-lotto. I think about pissing off. The main thing I do is take my tablet. I haven't eaten today because I can't get up in time.

- **overcoming incontinence**

George revealed that negotiating his way to the toilet during the night whilst heavily sedated and with a full bladder were the main obstacles to nocturnal continence. He drank water rather compulsively, and although persistently high blood glucose levels may have explained his overwhelming thirst, psychogenic polydipsia had not been dismissed.

I'm on Clozapine... it makes me too relaxed and I don't know what I'm doing. I wake up but I'm too relaxed on these tablets. I'm really tired and I can't get out of bed. Three weeks ago I was in bed sleeping and at 3am in the morning I feel myself wet, waking up, got into the passageway, don't know where I'm going, so just do it anywhere and go back to bed. The tablets knock you around too much. So you don't know where you're going so you wet yourself, go back to bed. ...Um, I just don't want to stay in bed with wet blankets over me, it's uncomfortable. I wasn't having the problem before. It's the tablets...Clozapine. The Doctor said you might wet the bed, get fat... I don't care about getting fat. The worse bit is everyone else knows I've wet the bed. Not only the workers, but other people say 'you've pissed yourself'. I feel embarrassed.

Incontinence was both an embarrassing and humiliating experience for George:

At mum's I had tea. I wet myself and she asked 'can't the doctor do anything about that?' I felt embarrassed in front of mum and dad – I wet twice that night.

With support from the Participatory Action Research (PAR) group process and guidance provided by a Continence Nurse Advisor, George became active in developing self-management strategies that would promote nocturnal continence:

What I've been doing recently is having a milo at night, get up and go to the toilet, then take my tablets. I don't have any drinks at night time. If I do, I wait and go to the toilet. Things are better now.

- **not worrying about diabetes**

The complexities of life with schizophrenia were compounded by diabetes, however, he chose to ignore this condition. He knew what he should do to gain control of his high blood glucose levels but was unable to transfer that knowledge into his everyday living. Priorities in life were not focused toward physical health:

Um, I don't know. I don't think there is nothing wrong. I don't worry about it. I don't know what's happening.

Coping with daily life amidst schizophrenia was all consuming, and there was little capacity to also deal with the restrictions of a diabetes diet.

- **feeling trapped**

George revealed an overwhelming sense of being trapped in his current situation of poverty, social isolation and boredom. Mundane outings for blood tests and collection of medications provided a distraction in the day:

I'm sick of lining up for a meal and stuff like that. I'd like a little extra money. I'd like to manage my money and cigarettes. I don't want to stay there and put up with TV. That's not life for me ... there's more out there. There is no point sitting around and watching TV. I go and have a blood test. That gets me out for a while. That's an outing. Picking up tablets on Tuesday is an outing. I'm trapped. I'm only getting \$10 a week for dishes. I can't get a full time job because they put it in public trustee and I'm working for nothing. You think to yourself your life has finished. You gotta keep going but I have given up a lot.

George wanted more for his life, but this seemed beyond his grasp. A personal vision for the future was obstructed and possibilities for taking action in the areas of his life that were important for him were denied.

- **feeling abandoned**

A sense of abandonment from significant others in his life was profound. Mental illness imposed on the possibility of forming close relationships, which created dark voids of loneliness and boredom in his days. He was drawn to the childhood memories of security and nurturing from his parents, but was aware that they found it difficult to 'handle' him.

Not many people go to their family for lunch because they don't want them, even some of my family don't want me. Mum said last year she can't handle me, so I think about that all the time. All these memories! I couldn't keep it to myself. I go to mum's but I get depressed when I go back [to the SRF]. I went to see mum because it's normal and that's what I feel in my heart. When I go home I get depressed again.

- **deciding what is important**

The restrictions on George's life were keenly felt. He had little choice in how daily life was constructed or little direction for his future. Travelling was important, but paying for rent and food at the SRF used up most of his Government sourced income. What little money was left over was spent on cigarettes, coffee and 'hot chips'. He turned his focus towards winning money and sometimes thought of stealing so he could achieve his

dreams. Money was perceived as empowering and the key to a changed life with a secure future.

I want to keep well and get some money to get going. All I need is to win \$25,000, give mum and dad \$1000 each, have a party and get on a bus to WA, train ride on the Ghan. I don't want to sit around and watch the TV. Travelling is fun. I want to change my life. Yes I want to change my life. Sometimes in my head because I want money I feel like breaking in and taking someone's money. I don't want to sit here and keep on saying it. I want to get a life – you can't get one in a boarding house. It's different if you're sick. I feel that if I'm well I should do what I want to do. I've told that story lots of times. That's life. I can't stay home and watch TV all my life, can I? Shit what a life hey, what a situation! What am I going to do? Sit around, drink coffee and watch the idiot box? Well I just want my money to go away. This is why people commit suicide because they can't do what they want to do.

George's story revealed that the symptoms of schizophrenia shaped every aspect of his life and intruded upon any sense of certainty for the future. The relationship between anti-psychotic drugs and side effects such as nocturnal incontinence was evident. Clozapine, in particular, was identified as having a major impact on daily life. The medication meant George was able to live outside the confines of a mental health institution. Anti-psychotic drugs induced a deep sleep that made him oblivious to the need to urinate or impeded his ability to locate the toilet on time. The sedative effects of anti-psychotic drugs taken early in the evening rendered George into a semi-comatose state during the night and the reduced awareness of bladder sensations led to urge incontinence when he woke.

ACCESS AND EQUITY: THE IMPLICATIONS FOR DISTRICT NURSING PRACTICE

Although the focus has been on the experience of living with schizophrenia, District Nurses care for many people in the community with mental illness. There is bountiful evidence that these people are often disadvantaged in both the acute and community health care sectors. People with mental illness require access to a full range of treatment and rehabilitation services to lessen the impairment and disruption produced by their condition. In terms of equity, we should offer people living in boarding type housing, assistance in navigating access to available community health services. This project has provided some new understandings about the experience of having a mental illness that should challenge the practice of District Nurses. Driven by primary health care principles, community nurses can play an important part in the development of comprehensive care for this client group. It is important for District Nurses to acknowledge the challenges confronting people with mental illness, and provide care within a holistic framework that incorporates the clients social, physical, spiritual and emotional needs.

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this project can be accessed at www.rdns.net.au**