



# **The Experience of Chronic Illness in Rural Australia**

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I certify that the substance of this thesis has not already been submitted for any degree and is not currently being submitted for any other degree or qualification.

I certify that any help received in preparing this thesis, and all sources used, have been acknowledged in this thesis.

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Geraldine Mary FitzGerald

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## **Abstract**

This is an interpretive phenomenological study of the experience of chronic illness. The meanings of living with chronic illness have been extrapolated from the narratives of eighteen people, with various long term health problems, who helped with the work. These people gave rich descriptions of their everyday lives of living with chronic illness in a rural Australian setting.

The experience of living with chronic illness is re-presented in terms of the past, present and future. The study reveals predicaments which the participants share. The experience of chronic illness for these participants entailed a life which was full of struggle to maintain a reasonable quality of life for the person and their family. The participants in the study took stock of the effects chronic illness has made to their lives and what they have lost or missed through long term illness. They have had to learn to exert themselves in order to maintain their precarious health status and they are learning to receive help from a variety of sources in order to maintain their social existence. They face lives of continued worry about their health, and periods of extreme loneliness.

From the narratives it was evident that there were gaps in the service provided to the participants. Living in rural Australia presented some of the participants with problems travelling to see specialists and this meant they were limited in their choice of medical specialist. While they were all given professional medical treatment, professional care was not evident.

These apparent shortfalls in the service deserve further investigation. Indeed, they could become fertile ground for the expansion of nursing services to meet the challenges presented by people who are chronically ill.

## Prologue

### The Winter of 1991

*At seven thirty on a freezing English morning it was still dark; the day had no more inclination to wake than the nurse who wearily leant her weight to open the swing doors at the top of the ward. Turning into the office she noted in the darkness a red light blinking at the end of an 'air flow' bed in the first four bedded bay. 'Someone frail must have been admitted during the night,' she speculated, before greeting the others gathering for the morning shift.*

*Frail was an understatement. Ms Thorne was like a bird, lying crunched up almost totally engulfed by the best bed technology could provide to relieve pressure on her emaciated form. The nurse watched her for a while before approaching the bed. Ms Thorne was a 'North Oxford Spinster', a reverent term for the breed of strong women who live in shabby gentility in the best part of the city. Some of them were among the first women at the university in the 1920s and 1930s. By repute they have useful social connections and are frightened of no one, particularly 'young' consultant physicians. Ms Thorne was not asleep. She lay there unmoving, a frown upon her forehead.*

*At midnight she had been brought in from home following a haematemesis. This was probably a side effect of the non steroidal anti-inflammatory taken to reduce the pain of her rheumatoid arthritis. She had a stage III pressure sore on her sacrum and more superficial ones on both heels and along the dorsal spine. The nurse saw her elbows, hips and knees were contracted and her hands knotted and gnarled. Her sunken, dark-ringed eyes betrayed pain, no sleep and dehydration; her body was a portrait of malnutrition.*

*The nurse sat on the arm of the chair by the side of the bed; she did not touch her. Ms Thorne opened her eyes and moved her arm to gesture 'hello'. Her joints creaked and her face twisted with pain. She laid her arm down again. Slowly, as the morning wore on, the two talked a little. Ms Thorne had been barely coping by herself for some time. The pain was frightful. She ate biscuits and went out only to the local store and sometimes to visit the general practitioner. The pressure sores were caused from sitting in an armchair for hours at a time with feet resting on a low foot stool.*

*Later, amid the mists of morphine, the nurse gently undressed her and washed her. She saw this little person naked with lesions gleaming and was shocked at the neglect. She thought, 'This is not right, this person has been receiving treatment for arthritis for nearly twenty years. How could she get like this?'*

*'Who has been helping you?' she asked. Ms Thorne answered, 'My dear, nobody can help me.' With genuine confidence the nurse said, 'We will help you now,' and she thought, 'What this person needs is a good nurse.'*

*When the nurse telephoned the registrar to discuss the best way to help Ms Thorne, the registrar said, 'You know, she is about right. We cannot help her, just loving care now.' The nurse regretted that Ms Thorne died in the afternoon. She thought again—'This is not right. What has been happening all these years?'*

*The research question was born.*