

Title: Working and Caring for a Child with a Chronic illness: A National Study	
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Outline of Research	Parents of children with chronic illness experience multiple stressors associated with their caring responsibilities. For such parents who are working full time the stressors involved are magnified. Although the impact of caring for a child with chronic illness has been widely investigated, there is a paucity of research on the experiences and support needs of parents who are also working full time. This study aims to identify, through interviews and a national survey, the support needs of parents of children with chronic illness who are working full time, across the metropolitan areas of Australia. To participate in this study, parents had to be working full time or the equivalent, caring for a minor child who has a chronic illness, living in a metropolitan area of Australia, and are fluent in the English language. The term "full time or equivalent" was used to include parents who were self-employed, undertaking multiple part-time/casual roles, full-time study, or in the full-time permanent paid labour force. Chronic illness was defined as a significant illness or disability, which may be physical, emotional or cognitive and continues for at least six months, requiring ongoing medical intervention to treat acute episodes and/or ongoing problems. The first phase involved qualitative, in-depth, semi-structured, phenomenological interviews exploring the experiences of parents who are working full time and caring for a child with chronic illness. The parents studied were recruited through informal contacts of the study investigators, word of mouth and by locating families through a large children's hospital in Sydney, Australia.
Findings to date	The following are results of the initial phase of the study. Nine females and three males were interviewed. The ages of the parents ranged from 30 to 50 years with an average age of 42. All parents worked full time (or equivalent); eleven of the parents had partners who also worked full time. Two parents were caring for another adult as well. Their children had diverse chronic conditions including significant genetic, neurological and systemic impairments. Parents were interviewed and the conversations transcribed and analysed. The areas of concern resulted in nine main themes: 1) Caring responsibilities 2) Issues with Carers 3) Money 4) Relationships 5) Grief 6) Dealing with professionals 7) Information 8) Work life and 9) Workplace. The initial results of this study have confirmed that the stressors involved in working and caring for a child with chronic illness are tremendous and those involved require much greater support. The findings have been used to develop a questionnaire, which is currently being piloted at The Children's Hospital at Westmead. The last phase of the study will involve sending out validated questionnaire nationally with the help of state and national support organisations. This information gained from this study can be of vital importance to policymakers in workplaces, health workers, unions and employer groups, and has the potential to improve the quality of life for those families in need.
Expected start and finish dates	2005-2008