

Cost of Illness Study

**An Assessment of the Economic Costs
of Relapsing-Relmitting Multiple Sclerosis
in the Canterbury / Westland Region
of New Zealand**

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Preface

This research report is of a cost of illness study of multiple sclerosis in the Canterbury / Westland region. It outlines the economic costs of relapsing-remitting multiple sclerosis to the people with the condition, those that support these people and the government. A summary of such costs has not been established in New Zealand before now. The findings in this report will be of interest to all people affected by multiple sclerosis, regional and national health funding agencies, and health and other social policy analysts in New Zealand.

A member of the AERU assisted the Multiple Sclerosis and Parkinsons Society of Canterbury Inc. in conducting this study. The main research work was undertaken independently by the Society. The AERU has agreed to further assist by publishing the report as an AERU Research Report.

Ross Cullen
Director

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We would like to thank all the people with Multiple Sclerosis in the Canterbury / Westland area that gave of their time for this research. For many respondents the information they provided was of a sensitive, personal nature, however it greatly enlightens the picture of the economic costs associated with MS in New Zealand. Acknowledgement is also extended to the Canterbury District Health Board and the people in the records departments of hospitals and other health professional offices, who assisted by confirming many of the actual economic costs incurred by MS patients.

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Summary

Conclusions:

- Cost findings here are conservative due to the limited research sub-population, that is, people with relapsing-remitting multiple sclerosis (RRMS) matching diagnostic criteria from 1984 to 1995 inclusive, and unrecorded indirect costs. An in-depth national study across all levels of MS would show higher costs, which would be comparable to other international studies.
- Costs are higher for people that have had RRMS for a shorter time (0-9 years), however people with RRMS longer (10+ years) cost the government more.
- The use of alternative treatments among people with MS appears to be high. Research on the frequency of alternative use, and rationale of people in choosing these options, is warranted.
- There may be an incentive for those in policy making regarding funding treatments to target MS at an earlier stage in an attempt to reduce morbidity and delay disability. The aim would be to encourage financial independence, therefore reducing longer-term government costs.

Background and Rationale:

- Various international studies have been conducted on the costs of MS at national levels.
- There is no information about the economic costs of MS in New Zealand.

Research Objectives:

- A main objective was to measure costs of RRMS within the Canterbury / Westland region.
- The key research questions were what are the economic costs of RRMS, and in what way do costs change over time?

Methods:

- This was a cost of illness study using a prevalence approach, and bottom-up method. The information was gathered using structured questionnaires in one-to-one interviews.
- Seventy-three people fitting diagnostic criteria for relapsing-remitting multiple sclerosis were identified as the target population, from which 59 were interviewed.
- Two diagnostic groups were established for cost over time analysis. They were Group 1 (24 respondents diagnosed from 1984 to 1989, inclusive) and Group 2 (35 respondents diagnosed from 1990 to 1995, inclusive).

Results:

- The total cost of MS to the 59 research respondents for 1999 was \$1,171,593. The mean annual cost of MS per person was \$19,857.
- Direct costs were 50.5 per cent and indirect costs were 49.5 per cent of all costs.
- Government paid about one third (35 per cent) of all costs associated with MS and just over one in five respondents (22 per cent) did not receive any form of government assistance.
- The highest cost category was Income and Employment Costs (loss of earnings) with 53 per cent of all costs. Second highest was Resource Costs at 31 per cent.
- The three highest separate costs were: 1. Potential annual income lost; 2. Benefit assistance; and, 3. Family informal assistance. Only benefit assistance was a direct cost.
- The three most commonly incurred costs were: 1. Transport costs; 2. GP costs; and, 3. Personal resource costs. The six most common costs were paid for by people with MS.

- On average, people who have had RRMS for longer cost the government more (i.e. transfers) and require more personal assistance than people who have had MS for a shorter time.
- On average, people with RRMS for the shorter time incurred greater: medical expenses; personal expense for resources, services and other costs; and loss of potential income. Overall, they paid more MS related costs themselves, had proportionally less assistance from government and had the greater total of MS related costs.

Chapter 1

Introduction: Background, Objectives and Methods

1.1 Introduction

There have been economic assessments of the costs of multiple sclerosis (MS) undertaken in a number of different countries. The “cost of illness” studies have used different methods, with varying results, to determine economic costs associated with MS. A common consensus in the different analyses is that the economic costs are shared between those with the condition, close friends and family, the State and the community in which people with MS live. The proportional differences between those who share the costs within society depend on the levels of community and State assistance that exist for social services, particularly health, housing and employment. New Zealand has a similar assistance structure to many other countries, however a study of the cost of MS had not occurred in New Zealand to date.

People with MS will not only incur the real costs associated with managing the illness, but also the costs associated with the changes they make in their lifestyles. This report examines the cost of an MS sub-population in the Canterbury/Westland region of New Zealand, and determines the proportions of economic costs for this condition borne by this country’s central government and the people with MS.

1.2 Background

The literature on MS reports the social and psychological impacts of the disease, and assessments of economic cost. Research often uses any one of a number of scales for the assessment of the extent of MS.

Research on economic costs of MS has established that they are high but the estimates are quite variable. Inman (1984) has addressed the important issue of assessing economic costs associated with each stage of disability as measured by a mobility index. Results showed that United States families face annual medical costs plus annual loss of earnings of as much as US\$15,000, per family, and individual lifetime costs may be as high as US\$151,000. Inman goes on to calculate the current and future costs to society of MS and to consider optimum insurance design. Bourdette et al. (1993) found in a retrospective study of 165 MS patients that total health care costs averaged US\$35,000 per annum, and that total costs correlated with the scores on the Expanded Disability Status Scale (EDSS) and the Incapacity Status Scale (ISS), ($r = 0.61$ and 0.64 respectively). They also found that over three years there were 40 hospitalisations, which may have been preventable with outpatient management that had a total cost of US\$412,800. Todd (1995) cites research by Brown that showed that Canadian average healthcare costs for MS patients were \$4,000 per person in 1993 versus \$1,600 per person in the Nova Scotian population. MS patient treatment costs increased with patient age. Research by Holmes *et al.* (1995) sampled members of the UK MS Society to estimate that the total annual cost burden was 1.2 billion sterling. Whetten-Goldstein et al. (1996) estimated that the annual cost of MS for a random sample of 606 sufferers and their households in the United States was nearly US\$35,000. The estimated annual cost for chronic progressive MS was US\$50,000. Costs included personal services, alterations to home and vehicle, purchase of special equipment and lost earnings.

Lissovoy and Lazarus (1994) outline the rationale and methods used in ‘cost of illness’ analysis noting that there are two approaches. First, the human capital approach measures the burden of

illness in terms of direct and indirect costs. Direct costs include diagnosis, treatment, medication, rehabilitation, transportation to obtain care, special equipment and alterations to property. Other direct costs include aggregate costs such as the cost of medical research, professional training, clinical facilities and health administration¹. Indirect costs include lost earnings, the estimated market value of home help and workplace effects (e.g. reduction in work effectiveness and reduced opportunities for promotion). Previous studies tend to concentrate on hospitalisation, outpatient care and drug treatment. Indirect costs relate to the loss of production due to short-term illness, disability or premature death. Also included is the loss of productivity for family members. Second, the willingness-to-pay approach measures the amount a group of individuals is prepared to pay to reduce their risk of incurring or dying from a disease. This approach is not considered in the present research because the human capital approach can be applied to MS patients effectively.

1.3 Research Objectives

The aim of this research was to estimate the costs associated with patients who have MS, including costs related to exacerbations and costs that derive from the consequences of MS. The research hypothesis was that:

1. The economic costs of MS are high.
2. The economic costs of MS are positively correlated to time with MS.

It was expected that if duration with MS lead to increased frequency of relapses or the development of long-term disability then it was likely that both personal and societal costs incurred in managing or treating the disease would also increase. The key questions then became: what is the economic cost of MS, and in what way do costs change over time?

The main objective of the research was to measure the economic cost of MS within the Canterbury region. The specific research objectives were:

1. To use the resources of the Multiple Sclerosis and Parkinsons Society of Canterbury Inc. and the Christchurch Hospital Neurology Department to identify and categorise MS patients in detail.
2. To measure the medical, personal and societal economic costs for each MS patient.
3. To assess the changes in costs for patients over time and thereby indicate what costs savings may result from any intervention to slow progression of MS.

To achieve the research objectives it was necessary to measure the economic costs associated with people who have MS. Specifically, it was essential to examine the costs of exacerbations and/or the cost of disability. An exacerbation or relapse was defined as: “the occurrence of a symptom or symptoms of neurological dysfunction, with or without objective confirmation, lasting more than 24 hours” (Poser et al., 1983). A remission was defined as a definitive improvement in signs or symptoms, or both, for at least one month (Ibid.). It must be noted that the assessments of costs in this research only focussed on economic costs and not on measuring the social or psychological costs stemming from the stresses caused by MS for both patients and their families.

¹ The MS Forum (1995) stated that direct costs relate to detection, treatment, prevention, rehabilitation and long-term care, they are, the resources allocated to the treatment of MS.

1.4 Methods

The research approach parallels methods considered when estimating the economic burden of a disease, as outlined by the MS Forum (1995). For this study a prevalence approach was utilised, that is, costs were calculated for a given year, 1999. The prevalence approach is appropriate for a study of MS costs, as it can be related to annual healthcare expenditure. The data received was analysed using a bottom-up method, where the costs for the MS sub-population are established. The sub-population costs can then be extrapolated over a whole population to provide total (national) cost figures. This study attempted to calculate the direct and indirect costs of MS, though did not attempt to establish the intangible costs² of MS, as little is known about these costs. Criteria for direct and indirect costs were based on descriptions provided by Lissovoy and Lazarus (1994) and the MS Forum (1995). The criteria used were:

Direct costs:

- Treatment, prevention and care costs related to orthodox medical care only.
- Additional services, equipment and other resources used to assist in the continuous living with MS.
- Financial assistance provided by government agencies to people with MS to assist with health costs, supplement income and provide resources.
- Other costs associated with accommodating a lifestyle with MS, such as home and vehicle modifications.

Indirect Costs:

- Alternative medical costs, which are generally self-directed by the individual. These are considered non-essential costs by many professionals involved in MS treatment, though they do remain real expenses, even if elective, for the individual with MS.
- Costs of informal assistance received by family, friends and other voluntary support.
- Income lost by the individual due to illness associated with MS.
- Other indirect costs, either not consolidated into the final analysis, or not considered in this research, include loss of income for partners and other family members, potential income tax loss for government and economic costs from loss of production for employers.

The data collection method decided upon was a structured questionnaire to be completed in a one-to-one interview. The patients who were included in the study were those with relapsing-remitting multiple sclerosis (RRMS) on the computerised diagnostic database of the Neurology Department at Christchurch Hospital, who had been first diagnosed between 1984 and 1995 inclusive as having clinically definite, laboratory supported definite, clinically probable or laboratory supported probable multiple sclerosis. The criteria of Poser et al. (1983) were used to categorise subjects (See Appendix 1). The hospital case notes of all living patients who were diagnosed as having multiple sclerosis between these years were ordered. The Medical Records Department managed to locate 147 such records, which were reviewed by a neurologist and those fitting the above criteria were selected. Patients with primary progressive multiple sclerosis were excluded but some of those in the study subsequently developed secondary progressive disease. The notes of three of Christchurch's neurologists were accessed, however the patients of a fourth neurologist were not available on the computerised database. After intense investigation of records a total of 73 people (58 females and 15 males) were identified as matching the criteria for the research.

² Intangible costs are "the economic burden on the family that may arise from the psychological impact of the disease and stress related to disease symptoms" (MS Forum, 1995).

The next task was locating those identified as the research group. The initial contact information was based on the addresses held with medical records at Christchurch Hospital. Over half the address details were incorrect. Telephone books for Canterbury, Westland and South Canterbury were used to update the contact information. In some instances, all people with the same surname were telephoned and directory service assistance was used. General Practitioners in the smaller, rural areas and Multiple Sclerosis Society staff in the three regions were also telephoned in attempts to contact some people. Confidentiality and the privacy act were important issues, which added to the difficulty of locating people.

Regional electoral roles were consulted for the outstanding addresses. A small number of new addresses were confirmed. For a significant number of cases the contact information remained outstanding. It was decided, therefore, to wait for the new electoral role. Overall, it took over a year to identify and locate all the people who were to be asked to participate in the research.

The researchers aimed to contact all 73 potential participants by correspondence and follow up telephone calls. The letter outlined the research, the nature of the proposed interview and questionnaire, with an emphasis that all responses would be anonymous. It also explained that subjects would not be asked to become members of the Multiple Sclerosis and Parkinsons Society of Canterbury Inc. After two weeks, a follow-up call was made to all subjects who received a letter to check their willingness to be interviewed and arrange a meeting.

Almost all interviews were conducted in person and the remainder four interviews were conducted over the telephone. Two of these participants were reluctant to be interviewed in person, one was seriously ill and awaiting surgery, and another lived in the North Island. Interviews were held in Timaru, Ashburton, Darfield, Rangiora, and the West Coast. Apart from the telephone interviews, all but five interviews were held in the participant's own home. Three were held at the participant's place of employment, one at a rest home where the person was living and one person elected to be interviewed in a coffee shop. All interviews were conducted by the same researcher.

Consent forms were completed at the interview, along with release forms for contacting relevant health professionals to confirm information, where relevant. A few consent forms needed to be posted back to the interviewer. In these situations, stamped self-addressed envelopes were provided. Two consent forms were not returned after interview even after several follow-up letters and telephone calls. Reimbursement of transport costs was available to any subject who wished to be interviewed at the interviewer's office.

When there was any question that the interviewee may have cognitive difficulties, a spouse, partner or family member who was familiar with the individual's situation, was asked to be present for the interview. The spouse of one person, who had severe cognitive changes, was interviewed in place of the subject. The MS staff member working with the family was also present.

A total of 59 questionnaires were completed, that is, 81 per cent of all people identified as matching the research criteria. Of the 14 people who did not complete the questionnaire two people chose not to respond; ten people were not located; one person lived overseas; and one person was deceased. In effect, the sample of 59 out of the original 73 was a sample of 59 out of the 61 available people. The sample can be taken as representative of the research population and we will refer to it as the latter.

In line with a main objective of the research, there were two groups: those diagnosed from 1984 to 1989, inclusive (Group 1); and those diagnosed from 1990 to 1995, inclusive (Group 2).

Table 1 outlines the distribution of these two groups. Group 1³ was the smaller in size with 24 respondents (41 per cent) and Group 2 had 35 respondents (59 per cent). The purpose of the two groups was to establish the characteristics of the groups, and a comparison of their costs to ascertain differences over time.

Table 1: Diagnostic Groups

Group	No.	%
Group 1 (1984-1989)*	24	41
Group 2 (1990-1995)	35	59
Total	59	100

*Includes one from 1981

All interviews, except for the first six used to pre-test the questionnaire, were performed in 1999. The questionnaire (See Appendix 2) was arranged into four cost sections of medical costs, personal care (resource) costs, employment and income costs, and other associated costs. When completing the questionnaire care was taken to ensure only details of costs directly associated with the subjects' MS were included. Other details relating to the participants condition, such as, when they were diagnosed and what symptoms they experienced, were also recorded.

Visits to hospitals, GP's and other health professionals for MS in the last six months were recorded, including needs assessments. This timeframe was regarded as being a reasonable period for the respondents to be able to remember. When calculating annual costs the figures provided were doubled. Medical hospital costs either as inpatient, outpatient or day-patient were obtained from hospital medical records. Generally, these were over a three-year period leading up to the time of the research. Annual figures were established by dividing individual totals by three. It is also noted that costs in this section have been under-represented, as some expenses proved impossible to verify in hospital records. For example, one respondent had suffered a hand injury at work as a result of numbness in the hand due to MS. The subject attended the emergency department at Christchurch hospital and a day surgery at another, but no information about these visits could be obtained.

Costs for prescribed medication were identified, as well as costs for treatment from alternative therapists and any other self-directed treatments. The costs for prescribed medication were obtained by consulting a list of the base prices. The head pharmacist at Christchurch Hospital provided this list. Three community pharmacies were also contacted in order to reach an overall cost calculation for government and patient costs for each medication.

The next section of the questionnaire covered personal care resources in the last six months, including whether the subject had been in alternative living care. The costs of resources (services and equipment) obtained from or used within the hospital systems within six months were recorded. Service providers were consulted to confirm the accuracy of the costs received from the respondents. No changes were required to the information obtained at interview.

The process of confirming costs with hospitals and service providers proved very time consuming. It involved considerable contact with a wide range of health professionals and service providers who completed significant work on the researchers' behalf. All were co-operative and without their help information would not have been as accurate.

³ One person included in Group 1 was diagnosed with MS in 1981, but did not meet the Poser et al. (1983) criteria until the 1984 - 1989 period.

Details of the respondents' living arrangements were recorded. Information was gained as to whether people with MS lived alone, and if not, who they lived with, whether anyone in the home provided assistance and what cost could be associated with that help. Informal voluntary help from outside the household was also recorded. Informal assistance was calculated as an indirect cost with a value of \$10.00 per hour. Informal assistance of less than two hours per week was not recorded.

The income and employment cost section identified who had experienced reductions in income due to MS, including reduced hours, time off through sickness or complete loss of employment. Those not in paid employment were asked why, and, if due to MS, how long they had not been working and their annual income at the time they left paid employment. Where there was a partner involved, respondents were asked whether they had reduced or increased their paid employment hours, or left work temporarily or permanently because of the respondent's MS. Maximum annual incomes for subject and partner, before the subject reduced hours or left paid employment, as well as current income for partner and subject were recorded. This enabled a before and after income comparison.

Details of any means tested benefits received because of MS were recorded. Information regarding other income assistance from private grants, Accident Compensation Corporation, or the New Zealand Lottery Board was obtained.

Expenditure on a wide range of options including home alterations in the last five years, sale of assets, moves to cheaper or more expensive housing, other privately funded services (such as, gardening and private home help), informal financial help from family, and items purchased or maintained was recorded. In one case, a subject, living alone following a divorce, had moved from an old, high-maintenance house with stairs at the front and back entrances and a large garden, to a smaller, though more expensive, modern, one-level town house, with little garden. This had required a significant addition to the mortgage.

Government funded home alterations in the last two years were also recorded. A two-year period was chosen to ensure that hospital records would be available. These costs were confirmed by contacting the occupational therapist authorising the work.

The final section covered transport costs and included only those related to MS. Upgrades of cars funded either privately or through government grants, hand control purchases, lottery grants, driving assessments and weekly total transport costs were included.

While not all cost details were supported by official records, every effort was made to verify costs that had been incurred by the individuals. Where no official details of hospital, GP or resource expenses could be obtained, the information was not included. When calculating the overall costs for individuals and the entire research group it was expected that figures were of a conservative nature, as totals tended to be under-valuations of the actual costs experienced.

1.5 Report Outline

Throughout the report the economic cost information is presented in terms of direct and indirect costs. For this research the separation between direct costs and indirect costs is based on criteria that were outlined in the methods section.

The direct or indirect cost interpretations are applied in analysis in Chapters 3 and 4. Before them, however, Chapter 2 outlines the characteristics of the people with RRMS that were

studied. In line with an objective of the research the respondents are divided into two groups based on when they reached diagnostic criteria. This is to enable comparisons of cost over time, which feature later in the report. Some characteristics of the research population and diagnostic groups are examined. Characteristics detailed include, where respondents were diagnosed, duration of MS, symptom range, age, living arrangements and employment status.

Chapter 3 begins the lower level analysis of separate costs associated with the four main cost categories, namely: medical costs, resource costs, income and employment costs and other associated costs. Each category is analysed by the main cost bearers, that is, the people with MS and the government. Analysis also occurs by direct and indirect costs. The cost category totals are carried over to the overall cost analysis in the following chapter.

Chapter 4 is a higher level analysis of costs associated with MS. By utilising the totals of the categories derived in Chapter 3 the overall costs are examined. The first section examines the direct costs of MS by cost category by cost bearer. An indirect cost analysis follows, though only personal indirect costs were recorded. A comparison of the total indirect and direct costs of MS finishes this section. The next section examines all costs together. It avoids any distinction from what is considered a direct or an indirect cost. The total costs are examined by cost categories as they stand for individuals and government, and as the final total of all cost categories. Other analysis lists all the separate costs that make up the cost categories to ascertain the ten highest costs and the ten most commonly incurred costs. The final section of this chapter compares the means of costs for people diagnosed from 1984 to 1989 (Group 1) and those from 1990 to 1995 (Group 2). The intention of this analysis is to test the relationship of cost with the time people have had MS. Before the study it was assumed that a person's costs would be higher the longer they had MS. This hypothesis is not supported by these findings.

For Chapters 3 and 4, the key economic information on the costs is presented in a standard table format (See Table Example). The headings of the tables represent the key cost being analysed and discussed. The first columns of the table present the numbers and percentages of the research population that responded to that particular variable. The second category of information provides the mean calculated from the whole research population of 59 respondents. This corresponds with an aim of the report to present the costs as they apply to the entire research population. Another central tendency figure, the median, is provided next, which is also applied across the research population. The next column presents the maximum figure for that variable. In many cases the maximum figure is representative of the range, as the minimum is mostly zero. In some case there are negative minimum results that will be highlighted where applicable. The final column is the total costs for that variable. If readers wish to they can calculate the mean for those who responded by using the total cost column and response number data from column one.

Table Example

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				\$	%
Total / Summary							

Chapter Five is the summary and conclusion of the report. It reviews the information provided throughout the report and discusses some of the implications of the economic costs of MS in the Canterbury region and for the rest of New Zealand.

Chapter 2

Results: Respondent Details

2.1 Introduction

The details of the respondents that participated in this study are outlined in this chapter. Some areas analysed for the report cover the clinical features of respondents, including where their MS⁴ was diagnosed, the duration of the condition, and the symptoms associated with their disorder before and after diagnosis. The analysis then focuses on characteristics of the respondents, including their age, living arrangements and employment status. Most of the tables present the information for the total respondents and the two diagnostic groups: those diagnosed from 1984 to 1989, inclusive (Group 1); and those diagnosed from 1990 and 1995, inclusive (Group 2).

2.2 Diagnosis and Symptom Details

From the 59 people that participated in the study, 56 were able to state who diagnosed their MS. By naming who diagnosed the respondent with MS it was possible to identify where they were diagnosed. This was based on knowledge of location of the doctors named. Table 2 shows 53 respondents (95 per cent) were identified as being diagnosed with MS in Christchurch. Only three respondents were diagnosed outside Christchurch: two within New Zealand and one outside of New Zealand. It should be noted, however, that these three had not fulfilled the study entry criteria until they re-presented with MS and were investigated in Christchurch.

Table 2: Where Respondents Diagnosed

Location Diagnosed	No.	%
Christchurch	53	94
Outside Christchurch	2	4
Outside New Zealand	1	2
Total	56	100

Table 3 summarises the number of years since respondents first experienced MS symptoms, years since reaching the diagnostic criteria for RRMS and the gap between these. With 1999 as the year of the study, the average respondents had experienced symptoms of MS for 14 years, with a range of respondents experiencing MS symptoms for four through to 42 years. The average since reaching diagnostic criteria was eight years. The range of years since diagnostic criteria was from four to 18 years. This signifies a broad range of people with MS and experiences of living with the condition. The last duration statistic shows that, on average, a respondent had an interval of six years between their first symptoms and eventual diagnosis. One respondent experienced a 32-year gap between first symptoms and diagnosis.

⁴ Generally, throughout the discussion of research findings (Chapters 2,3 and 4) and conclusions (Chapter 5), instead of the expression RRMS (relapsing-remitting multiple sclerosis) the abbreviation MS (multiple sclerosis) is used, though it implies the RR sub-group of the condition. Also, it is important to note that people within other sub-groups of MS were not included in the selected research population. However, by the time of the interviews some people in the study may have advanced further in their condition since reaching relapsing-remitting diagnostic criteria.

When the same analysis was applied to the diagnostic groups the results were representative of their time with the condition. Group 1, on average had 19 years since their first symptoms, while Group 2 had 12 years. Group 1 averaged 12 years since reaching diagnostic criteria and Group 2 six years.

Table 3: Years Since First Symptom(s) and Diagnosis

Category	Mean			Min.			Max.		
	G1	G2	T.	G1	G2	T.	G1	G2	T.
Years since first symptom	19	12	14	10	4	4	42	29	42
Years since reaching diagnostic criteria	12	6	8	10	4	4	18*	9	18
Years between symptom & diagnosis	6	6	6	0	0	0	32	25	32

* One person diagnosed as “possible” MS in 1981

A first distinction to be assessed was the identification of the differences in the symptoms experienced by people with MS before and after reaching diagnostic criteria. The establishment of the symptoms experienced by the groups and the total population is important for the analysis of economic costs. The needs of the people with MS normally relate to the medication and assistance they require due to symptoms they experience. That is to say, that different symptoms will have different economic consequences for people with MS. This report does not place a value on the symptoms, as that would require a more in-depth study.

Table 4 presents the most common symptoms experienced by respondents before they were diagnosed with MS. Respondents were asked to state their primary symptom(s) before diagnosis. The top five symptoms listed were: (1) sensory impairment (61 per cent); (2) fatigue (53 per cent); (3) vision change (47 per cent); (4=) weakness (39 per cent); and (4=) imbalance (39 per cent). When separated into Group 1 and Group 2 there was a small difference in order of symptoms, and the inclusion of one other symptom. Group 1’s top five symptoms were: (1) sensory impairment, (2=) vision change, (2=) mobility, (4) imbalance, (5=) fatigue and (5=) weakness, while Group 2’s top five symptoms were: (1) fatigue, (2) sensory impairment, (3) vision change, (4) weakness and (5) imbalance. Sensory impairment, fatigue, vision change, weakness and imbalance symptoms featured in the top five of both groups and the total population. The one difference was the inclusion of mobility, which was second equal as a symptom for Group 1.

Table 4: Most Common Symptoms Before Diagnosis

Symptoms	Group 1 (n=24)		Group 2 (n=35)		Total (n=59)	
	No.	%	No.	%	No.	%
Sensory impairment	16	¹ 66	20	² 57	36	¹ 61
Fatigue	9	⁵ 37	22	¹ 63	31	² 53
Vision change	11	² 46	17	³ 49	28	³ 47
Weakness	9	⁵ 37	14	⁴ 40	23	⁴ 39
Imbalance	10	⁴ 42	13	⁵ 37	23	⁴ 39
Mobility	11	² 46	11	31	22	⁵ 37

Percentages not equal to 100 as multiple responses recorded.

Table 5 shows the most common symptoms for the groups and total population after they were diagnosed with MS. The top five symptoms experienced after diagnosis were: (1) fatigue (75 per cent); (2) imbalance (69 per cent); (3) weakness (63 per cent); (4) mobility (59 per cent); and

(5) sensory impairment (56 per cent). For Group 1 the order was: (1) mobility, (2=) fatigue, (2=) imbalance, (4) weakness and (5) co-ordination, and Groups 2's order was: (1) fatigue, (2=) sensory impairment, (2=) imbalance, (4) weakness and (5) bladder dysfunction. Fatigue, imbalance and weakness related symptoms feature in the top five of both groups and the total population.

Table 5: Most Common Symptoms After Diagnosis

Symptoms	Group 1 (n=24)		Group 2 (n=35)		Total (n=59)	
	No.	%	No.	%	No.	%
Fatigue	18	²⁼ 75	26	¹ 74	44	¹ 75
Imbalance	18	²⁼ 75	23	²⁼ 66	41	² 69
Weakness	17	⁴ 71	20	⁴ 57	37	³ 63
Mobility	19	¹ 79	16	46	35	⁴ 59
Sensory impairment	10	42	23	²⁼ 66	33	⁵ 56
Spasticity	12	50	16	46	28	⁶ 47
Bladder dysfunction	8	33	18	⁵ 51	26	⁷ 44
Co-ordination reduced	13	⁵ 54	12	34	25	⁸ 42

Percentages not equal to 100 as multiple responses recorded.

There were some differences in symptoms before and after diagnosis. For Group 1 the change in symptoms from before diagnosis to after diagnosis saw the inclusion of co-ordination reduced, and the exclusion of sensory impairment and vision change. For Group 2 vision change was included as a symptom before diagnosis, but not after diagnosis where it was replaced by bladder dysfunction. For the total population it was vision change again that was not included in the after diagnosis top five. It was replaced by mobility related symptoms. It is important to note that for both groups and the total population there was a noticeable increase in the numbers of people experiencing the consistent symptoms of fatigue (total: before 53 per cent; after 75 per cent), imbalance (total: before 39 per cent; after 69 per cent), weakness (total: before 39 per cent; after 63 per cent) and mobility (total: before 39 per cent; after 59 per cent).

2.3 Age Groups

Table 6 presents the breakdown of the two diagnostic groups and the total research population by age groups. For the total population, most respondents were aged in their forties, that was, those “40 to 44” years old (24 per cent) and “45 to 49” years old (19 per cent). The next highest age group followed from those in their forties to the “50 – 54” year olds (17per cent). The youngest respondent was 27 years old and the oldest was 74 years. The average respondent's age was 46.5 years.

When examining the difference between diagnostic groups there was a noticeable distinction in ages. Most respondents diagnosed from 1984 to 1989 (Group 1) were in the 40 to 54 age group (sub-total 47 per cent). However, Group 1 had a higher representation of people over 60 years (sub-total 30 per cent), while Group 2 had considerably less (sub-total 6 per cent). This was further verified by the youngest person in Group 1 being 34 years, while the oldest was 74 years. The average age in Group 1 was 51 years. Group 2, those diagnosed from 1990 to 1995, also had the most people in the 40 to 54 year range (sub-total 68 per cent). The youngest person in Group 2 was 27 years and the oldest was 62 years. The average age of Group 2 was 44 years. The data confirms that Group 1 respondents tended to be older than the Group 2 respondents.

Table 6: Respondents' Ages

Age Groups	Group 1		Group 2		TOTAL	
	No.	%	No.	%	No.	%
25 – 29	0	0	2	6	2	3
30 – 34	1	4	4	11	5	9
35 – 39	4	17	2	6	6	10
40 – 44	3	13	11	31	14	24
45 – 49	3	13	8	23	11	19
50 – 54	5	21	5	14	10	17
55 – 59	1	4	1	3	2	3
60 – 64	3	13	2	6	5	9
65 – 69	3	13	0	0	3	5
70 +	1	4	0	0	1	2
Totals	24	102*	35	100	59	100

*Column not equal to 100 due to rounding.

2.4 Living Arrangements

Later in the discussion economic considerations are made for the informal assistance provided by family members and the income costs to partners who may have to change, reduce or leave work to support the person with MS. For those reasons, understanding the living arrangements, that is, with whom people with MS live, is very important. Multiple Sclerosis not only affects the person with the condition, but also those that live with and support the individual. The details on the living arrangements assist in understanding the extent of these flow-on costs.

The range of living arrangements is presented in Table 7. From the 59 respondents only four people (7 per cent) stated that they lived alone. The greatest proportion (23 people, 39 per cent) lived with their partner and children. When separated into Group 1 and Group 2 the highest representation was in living with a partner or spouse (42 per cent) for Group 1, and partner and children (45 per cent) for Group 2. The other living arrangements included living with children only (14 per cent), other family based arrangement (5 per cent) a hospital or rest home (2 per cent), and other arrangements, such as, flatting (3 per cent). Ninety-three per cent of people with MS lived with other people at the time of the study. The nature of MS and the known affects on individuals during times of attacks and severe fatigue will flow on to those in nearby proximity as the need for physical assistance increases.

Table 7: Respondents' Living Arrangements

People live with...	Group 1		Group 2		Total	
	No.	%	No.	%	No.	%
Live alone	2	8	2	6	4	7
Spouse / Partner	10	42	8	23	18	30
Children only*	3	13	5	14	8	14
Partner and children*	7	29	16	45	23	39
Parents	0	0	1	3	1	2
Other family arrangement	2	8	0	0	2	3
Hospital / Rest home	0	0	1	3	1	2
Other e.g. flat with friends	0	0	2	6	2	3
Totals	24	100	35	100	59	100

*Includes adult children > 18

2.5 Employment Situation

Another important component in the analysis of MS costs is the indirect costs associated with loss of income for people with MS. The first step in the analysis of income losses was to establish the employment situation of people included in the research. Table 8 shows that 31 respondents (53 per cent) were in paid employment at the time of the study. Twenty-eight respondents (47 per cent) were not in paid employment. When the breakdown of employment status was applied across the two diagnostic groups the ratios appeared different. Group 1 had more people not in paid employment (16 people or 67 per cent) and Group 2 had more people in paid employment (23 people or 66 per cent).

Table 8: Respondents Currently in Paid Employment

Paid Employment	Group 1		Group 2		Total	
	No.	%	No.	%	No.	%
Yes	8	33	23	66	31	53
No	16	67	12	34	28	47
Total	24	100	35	100	59	100

The people not in paid employment (n=28) were asked the reason they were not earning (Table 9). Twenty-one people (75 per cent) not in paid employment attributed this to having MS. MS fatigue was the most common factor that prevented working. The remainder of people not working were either retired (14 per cent) or had another reason (11 per cent), such as being made redundant or looking after their children. There were 16 people in Group 1 that were not in paid employment. For ten of these people it was due to MS; five were retired and one was not working for another reason. Twelve people from Group 2 were not in paid employment. Eleven people were not working due to MS, and one was not in paid employment for another reason.

Table 9: Reasons Respondents Not in Paid Employment

Reason Not Working	Group 1		Group 2		Total	
	No.	%	No.	%	No.	%
MS Related	10	63	11	92	21	75
Retired	5	31	0	0	4	14
Other	1	6	1	8	3	11
Total	16	100	12	100	28	100

The people not working were also asked details on how long since they had been in employment. The analysis shows the average time people had been out of paid employment was 7.5 years, with a range from under one year to 28 years. For Group 1 the mean period for being out of employment was nine years, with a range from under one year to 27 years. For Group 2 the mean period for being out of paid employment was six years, with a range of under one-year to 28 years.

The people with MS who were in paid employment (n=31) were asked whether they were full-time, part-time or self employed. Table 10 shows that for the total population there was an even split of 13 people working full-time and 13 people working part-time. Four people were self-employed, while one person did not specify their arrangements. The people with MS in paid employment were also separated into Group 1 (n=8) and Group 2 (n=23). Only two people in paid employment from Group 1 were in full-time employment, while the remaining six people

were part-time. For Group 2, 11 people were full-time, seven were part-time, four were self-employed and one person's employment arrangement was unspecified.

From the total population, the 13 people in full-time employment worked weekly hours ranging from 35 to 70 hours. There was an average of 42 hours per week worked by people with MS in full-time work. For the 13 people in part-time work the weekly hours ranged from 3 to 35 hours, with an average of 23 hours per week. From the remaining self-employed individuals, two worked under five hours a week, while the other two worked a 30 and a 50-hour week.

Table 10: Respondents' Employment Arrangement

Employment Arrangement	Group 1		Group 2		Total	
	No.	%	No.	%	No.	%
Full-time	2	25	11	48	13	42
Part-time	6	75	7	31	13	42
Self-employed	0	0	4	17	4	13
Unspecified	0	0	1	4	1	3
Total	8	100	23	100	31	100

2.6 Summary

The analysis shows that 95 per cent of all the people who participated in the study had an initial diagnosis of MS in Christchurch. The average respondent had experienced MS symptoms for 14 years and it had been eight years since they reached the diagnostic criteria used for this study. The average respondent also experienced a gap of six years between their first symptoms and eventual diagnosis. Before diagnosis the most common symptoms experienced by respondents were sensory impairment, fatigue or vision change. After diagnosis the most common symptoms were fatigue, imbalance or weakness. Most respondents were aged in their forties, with an average age of 46.5 years. Eighty-three per cent of respondents lived with a partner or spouse and/or their children. Only seven per cent of respondents lived alone.

When the research population was separated into diagnostic groups there were some differences between them. Group 1 respondents tend to be older and were less likely to be in paid employment than Group 2 respondents. This suggests that people in Group 1 may be more dependent on family and government for assistance in living with MS. The two lists below highlight these and other differences:

Group 1: Twenty-four people matched the study diagnostic criteria between 1984 to 1989. Their main symptoms before diagnosis were: sensory impairment, vision change and mobility. Their main symptoms after diagnosis were: mobility, fatigue and imbalance. Eleven people (47 per cent) were aged 40 to 55 years old. Seven people (30 per cent) were over 60 years old. The youngest was 34 and the oldest was 74, while the average age was 51. Twenty people (84 per cent) lived with a partner or spouse and/or children. Two people (8 per cent) lived alone. Eight people (33 per cent) were in paid employment; 16 people (67 per cent) were not in paid employment. From those not working, ten people (63 per cent) were not working due to MS. From those working, two people (25 per cent) were full-time and six were part-time (75 per cent).

Group 2: Thirty-five people matched the study diagnostic criteria between 1990 to 1995. Their main symptoms before diagnosis were: fatigue, sensory impairment and vision change. Their main symptoms after diagnosis were: fatigue, imbalance and sensory impairment. Twenty-four people (68 per cent) were aged 40 to 55 years old. Two people (6 per cent) were over 60 years old. The youngest was 27 and the oldest was 62, while the average age was 44. Twenty-nine people (82 per cent) lived with a partner or spouse and/or children. Two people (6 per cent) lived alone. Twenty-three (66 per cent) were in paid employment; 12 people (34 per cent) were not in paid employment. From those not working, 11 people (92 per cent) were not working due to MS. From those working, 11 people (48 per cent) were full-time; seven were part-time (31 per cent); four (17 per cent) were self-employed; and one (4 per cent) was unspecified.

Having described respondent details in order to provide important background information, the report moves on in Chapter 3 to the cost categories relating to medical, resources, income and other costs.

Chapter 3

Results: Costs Associated with Multiple Sclerosis

3.1 Introduction

The findings of the cost categories, around which the questionnaire was based, are analysed in this chapter. The categories are medical costs, resource costs, income and employment costs and other associated costs⁵. The main analyses are by cost category and cost bearer. Indirect and direct costs are also incorporated into the analysis. All the costs are presented as either confirmed costs or estimated costs for the year 1999. The information provided will be for the total research population. An analysis of the costs by the two diagnostic groups does not occur until Chapter Four.

The medical costs section examines all the costs associated with the medical control of MS. The medical costs were analysed by three perspectives. First, the direct medical costs of GP and prescription costs paid by the individuals with MS. Second, the direct medical costs of hospital treatment, other health professionals and prescription costs paid by the government through health funding arrangements. Third, the indirect costs, or elective costs, associated with an individual's decisions to try alternative treatments and medication.

The resource costs section divides the cost of resources (including services) utilised by the people with MS, as those paid for by the individuals and those paid by the government. It also offers insight into the indirect costs associated with informal assistance from friends, family and other volunteers.

The next section summarises the indirect income cost (lost income and lost income potential) of individuals. It then outlines the direct costs to government in supplementing this income loss, either through a range of benefit options, ACC assistance or other forms of grants. The costs to the individual and to the government are amalgamated to establish a total income cost of MS.

The final cost category is other associated costs. Here the costs of upgrading or altering homes and vehicles, plus the transport costs associated with MS, are summarised.

3.2 Medical Costs

Direct medical costs are hospital, general practitioner (GP) and prescription costs as they are for the person with MS and the government. Table 11 shows the annual direct medical costs incurred by people with MS, specifically the personal costs of GP visits and prescriptions to manage and/or treat symptoms. The total paid in 1999 for all personal medical costs by all respondents came to \$21,447. This figure averages \$364 per person (median = \$80) per year for direct medical related costs. It is important to note that not all of the respondents expected to pay any personal costs for 1999, as many considered themselves to be quite healthy. Two thirds (64 per cent) of respondents listed personal medical costs. The maximum amount paid in direct treatment costs by any one of the individuals surveyed was \$6,920. This person had received advice from their GP to try a range of alternative medicines, which were included as direct

⁵ The raw cost data was collected in various time frames, for example, GP costs over six months, hospital costs over two years and home alteration costs over five years. The timeframe variations result from considerations about the ability to collect information from third party sources and the ability of people to recall costs over time. The analysis of each cost type and the ability to collect and confirm information were considered before questions were designed about cost categories.

prescription costs as a result. The next highest personal direct medical cost was \$2,840. This person's costs were associated with a high number of GP visits at a cost of \$960, and prescription costs of \$1,880 which were inflated by use of Phenylalanine, also a non-orthodox treatment, valued at \$1,660.

Table 11: Total Personal Direct Medical Costs

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
GP visits	34	58	\$168	\$44	\$1,920	\$9,902	46
Prescriptions	29	49	\$196	\$0	\$5,000	\$11,545	54
Total / Summary	38	64	\$364	\$80	\$6,920	\$21,447	100

Information about three government costs associated with the medical treatment of MS was obtained. The first was hospital treatment costs which relate to the cost of treating MS for acute exacerbations, other illnesses, events associated with MS, such as urinary tract infections and falls, or a combination of these. The respondents were asked to report the number of relapses they experienced for the years 1996, 1997 and 1998, whether they had received treatment and the form of treatment they received. This information was cross-referenced with hospital records and a costing of each patient's treatment was established. The figures were then divided by three to establish a one-year summary of the costs of treating MS. Many relapses noted by the subjects were not treated or notified to any health professional and were managed informally and without cost to the subject or the government. The second government medical costs are associated with the consultation of other medical professionals, such as, other physicians, physiotherapists, occupational therapists and needs assessors. The third are the proportion of prescription costs that were paid for by the government drug funding agency, Pharmac.

Table 12 shows the figures for each of the three main government costs. The largest cost was the amount paid in hospital treatment, with a total of \$27,627 paid for all respondents. The mean hospital treatment cost to government for each respondent was \$468 a year. The next highest was the cost of other health professionals, such as occupational therapists and physiotherapists, with a total of \$11,331 for 1999.

Overall, the government was estimated to have paid \$47,016 in medical related cost for all respondents in 1999. The mean paid per person with MS was \$797 (median = \$110) a year. The maximum paid by the government in medical costs for any one individual was \$4,395. This was the same maximum figure paid in hospital treatment costs. Hospital costs were consistently the highest component of government direct medical cost totals. Fifty nine per cent of respondents had partial or complete medical cost paid for by government.

Table 12: Total Government Direct Medical Costs

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Hospital treatment ⁶	22	37	\$468	\$0	\$4,395	\$27,627	59
Other health professionals	15	25	\$192	\$0	\$3,856	\$11,331	24
Prescriptions	21	36	\$137	\$0	\$992	\$8,058	17
Total / Summary	35	59	\$797	\$110	\$4,395	\$47,016	100

⁶ Hospital costs are an aggregate of all costs incurred by the MS sufferer for various types of treatment at inpatient and outpatient levels. Does not include Interferon treatment, as it was unavailable in 1999.

Table 13 is a summary of total direct costs paid for by the people with MS and the government based on the results presented in Tables 11 and 12. It was established that 41 respondents (70 per cent) included in this study incurred some form of medical cost, whether it was for treatment, other health professional consultation or prescription costs. More people paid their own medical costs (64 per cent) than had them paid for by the government (59 per cent). Government medical costs (\$47,016), however, were over twice the personal medical costs (\$21,447). The average medical cost for the whole study group was \$1,161 (median = \$601), with a total of \$68,463 paid for the year 1999. The highest direct medical cost of \$8,540 was for the person with \$5,000 in alternative medication prescriptions. The second highest direct medical costs were \$4,909. This was the person with the second highest personal medical costs of \$2,840, plus government assisted medical costs of \$2,069.

Table 13: Total Direct Medical Costs by Cost Bearer

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Personal direct medical	38	64	\$364	\$80	\$6,920	\$21,447	31
Government direct medical	35	59	\$797	\$110	\$4,395	\$47,016	69
Total / Summary	41	70	\$1,161	\$601	\$8,540	\$68,463	100

Not everyone with MS settles for “mainstream” treatment options. Many people try alternative medication or treatment methods, or both. These costs have been separated from the regular treatment costs, as they may be considered elective. Nonetheless, there were considerable numbers of people (n=26, 44 per cent) who tried alternative medications or treatment outside those provided by the health system.

Table 14 represents the costs of alternative therapy and self-directed medication costs incurred. Alternative therapies are treatment methods engaged by individuals, outside those that are provided by the health system, as outlined for direct medical costs. Examples of alternative therapies listed by respondents include kinesiologists, naturopaths and osteopaths. Common forms of self-directed medications used by people with MS were vitamins B, C and E, amino acids, evening primrose oil, bee pollen, garlic, other herbal remedies and the Cari Loader programme. Forty two per cent of the respondents spent money on self-directed alternative medications. This summed to \$14,518 during the year of the study. This figure is the primary cost in the overall total of \$17,068 spent on medical alternatives, with an average of \$289 per year spent by each respondent. The maximum paid by one person was \$5,400. These costs consisted of \$3,000 for a Cari Loader programme and \$2,400 in naturopath costs. The next highest cost for alternative treatment was \$1,200.

Table 14: Total Personal Indirect Medical Costs

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Alternative treatment	7	12	\$43	\$0	\$650	\$2,550	15
Self-directed medication	25	42	\$246	\$0	\$5,400	\$14,518	85
Total / Summary	26	44	\$289	\$0	\$5,400	\$17,068	100

Table 15 combines the overall personal medical costs, whether they were professionally directed or self-directed treatments, as presented in Tables 11 and 14. A total of \$38,514 was paid by individuals for the treatment of MS during 1999. This averages to \$653 per respondent (median

= \$256). The maximum paid in medical costs by any one individual was \$7,440. This, again, was the person with high medication costs associated with regular use of alternative medications prescribed by a GP. The next highest personal medical costs were \$5770, followed by \$2,840. In 1999, 46 respondents (78 per cent) personally paid medical costs that stemmed from either their initiative or from health professional directions.

Table 15: Total Personal Medical Costs

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Direct medical	38	64	\$364	\$80	\$6,920	\$21,447	56
Indirect medical	26	44	\$289	\$0	\$5,400	\$17,068	44
Total / Summary	46	78	\$653	\$256	\$7,440	\$38,514*	100

*Does not equal sum of totals due to rounding.

Table 16 summarises all the medical costs associated with MS. These are all personal and government direct medical costs and all personal indirect medical costs. Eighty-one per cent of people experienced medical costs related to the treatment of their MS. The greatest total cost was paid for by government at \$47,016. However, when combining personal direct and self directed treatments the total was \$38,514, which was a difference of only \$8,500. This indicates that for many people living with MS they pay almost as much as that covered by the government to assist in alleviating the effects of MS. People with MS are also prepared to pay almost similar overall amounts in alternative treatment options, as they do for orthodox medical treatment.

For each person included in the study an average annual cost of \$1,450 (median = \$731) can be attributed to medical related treatment. The maximum in medical related treatment was \$10,165. This person paid \$370 in GP costs, plus \$5,400 in self-directed alternative treatments. Further, the government paid \$4,395 in hospital treatment, which was associated with regular visits to a neurologist. The next highest medical costs incurred by individuals were \$9,060 and \$5,104.

Table 16: Summary of All Medical Costs by Cost Bearer

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Personal direct medical	38	64	\$364	\$80	\$6,920	\$21,447	25
Government direct medical	35	70	\$797	\$110	\$4,395	\$47,016	55
Personal indirect medical	26	44	\$289	\$0	\$5,400	\$17,068	20
Total / Summary	48	81	\$1,450	\$731	\$10,165	\$85,531	100

3.3 Resource Costs

This section examines the costs of resources utilised by people living with MS. Resources include services, equipment, and other items (and maintenance of equipment and items), that are used to assist people with MS. Table 17 is a summary of the resource costs as paid for by either the people with MS or by the government, mainly through Health Funding Authority (HFA) arrangements. The first row shows the resource costs paid for by the individual. This is a sum of services, items and maintenance that were not supported by health funding arrangements. Examples of services paid for by the individual include gardening help, meals on wheels, private home help, childcare and personal help (such as, daily showering). Items and equipment that may be paid for, and not assisted by central funding, include shoes, catheters, walking frames,

incontinence pads, shower stools and garage door openers. Respondents were asked to provide details of purchases they had made in the last two years (1998 and 1999). The total figure was divided by two to provide an annual cost of items and equipment included in resources costs. From the population 56 per cent had paid for resources. The total spent on resources was \$55,334, with a maximum of \$8,623 paid by one person. The mean over the entire research population was \$938 per person.

The second row represents the resource costs paid by the government, mostly through the HFA that was still in existence in 1999. Assisting services that were paid for through the HFA included, domiciliary occupational therapists and physiotherapists, district nurse visits, needs assessment, personal and domestic support. Some of the more common equipment paid for were wheelchairs and elbow crutches. The total amount paid in resource costs by the health authority calculated into an annual figure was \$118,206. The mean was \$2,003 per person, with a maximum cost of \$23,632 paid for one person with MS. Only one third (32 per cent) of respondents received financial assistance in resources.

Overall, 66 per cent of the people included in the study incurred some form of resource related expense. A total of \$173,540 was paid by people with MS and the government, with a mean resource cost of \$2,941 (median = \$520) per person being incurred.

Table 17: Total Direct Resource Costs by Cost Bearer

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Personal direct resources	33	56	\$938	\$140	\$8,683	\$55,334	32
Government direct resources	19	32	\$2,003	\$0	\$23,632	\$118,206	68
Total / Summary	39	66	\$2,941	\$520	\$29,772	\$173,540	100

For people with MS, not all assistance is delivered through formal channels that incur direct, tangible costs. Often assistance comes from family, friends and other voluntary workers that are not direct, “out of pocket expenses”, though a number of people do pay some form of “pocket money” for chores. An attempt was made to place a value on costs associated with this informal work. In the research the hourly rate attributed was \$10, with any relevant work over a minimum of two hours per week being included. There may be contention about placing a dollar value on some daily tasks, for example, for domestic chores normally shared amongst family members. People were asked, nevertheless, to value the work performed by spouses, children, other family members and friends, which they were unable to do themselves due to MS. Table 18 outlines these cost results. Twenty-nine respondents (49 per cent) provided details of informal assistance. A total figure of \$195,420 was established for this unofficial cost over a one-year period, which calculated a mean indirect cost of \$3,312 per person in the study. The highest amount claimed in the unofficial capacity was \$29,120 by one female respondent who was receiving full-time care from her husband.

Table 18: Total Personal Indirect Resource Costs

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Family assistance	25	42	\$3,054	\$0	\$29,120	\$180,180	92
Other assistance	7	12	\$258	\$0	\$8,400	\$15,240	8
Total / Summary	29	49	\$3,312	\$0	\$29,120	\$195,420	100

3.4 Income and Employment Costs

The questionnaire examined the indirect (personal only) and direct (government only) costs of lost income for people with MS. A person may be in permanent employment before the onset of MS, but miss days, reduce working hours, or leave work altogether due to being unwell. There are also income effects for the spouses and partners of people with MS. Further, the cost of lost income spreads to government responsibility as it pays the various benefit entitlements for people whose employment or income status has altered as a result of having MS. MS has the potential to have a dramatic impact on the economic lives of many people, even if the lost income is supplemented with social welfare benefits and other payments. For many people there is a loss of income from the time of the onset of symptoms associated with MS. It is expected that the greater the symptoms of MS in an individual's life the greater the impact on the income earning potential. Another association with the cost of MS is the loss of production that may be experienced by some companies, due to staff not being available to fully meet output requirements, though this is not examined in this research.

This section first looks at the costs of lost employment for the people with MS and the government. The totals presented here are carried over to analysis of overall totals in Chapter 4. The section then presents the costs of lost employment to the partners of people with MS. The aim is to highlight that economic consequences of MS stretch beyond the individual with the condition. Due to a lack of responses regarding the costs to partners, this information will not be carried over to the following chapter.

3.4.1 Personal and Government Income and Employment Costs

Reasons for income lost by individuals were categorised into: days missed at work, income lost through reduced working hours and income lost due to loss of permanent paid employment all due to illness associated with MS. The value of working days lost was established by personal details of days that had been missed due to MS in the last six months. A value was placed on this time off using daily or hour rates based on normal wages or income. Not all days lost through sickness are covered by the individual, as many have sick-day allowances as part of their employment contracts. The assumption, however, is that the majority of the time lost through sickness is covered by the individual, because many have no remaining allotment due time with MS.

Six people stated that they had missed days from their job in the last six months due to MS. The largest number of days missing for any one person was 60 days, while two people experienced five sick days. The total number of days lost for these six people was 123 days in six months. To establish an annual figure, the cost was multiplied by two. Table 19 shows that a total value of \$30,770. The average was \$521 per person involved in the research.

Many people with MS manage to maintain permanent work, though some can only work part-time. Respondents were, therefore, asked whether they had reduced the number of hours they work as a result of MS. Fifteen people (25 per cent of all respondents, and 48 per cent of all people in paid employment) had reduced work hours at some time. This had occurred over a period of one to 16 years, with the average time experienced of reduced hours being six and a half years. Two of the fifteen respondents, had returned to previous working arrangements and one person was no longer working. From the remaining 12 respondents who had reduced work hours, nine (15 per cent) provided details about their decreased hours, which ranged from two and a half hours to 35 hours a week. The average for the nine people was a weekly reduction of 12 hours. While nine respondents provided details of their reduced hours, ten respondents (17

per cent) provided details on income lost through work hours reduced. From these the annual sum lost was \$61,990. Over the population (n=59) this gave a mean of \$1,051 per person. The maximum income lost through hours recorded for any one individual was \$12,600.

The potential annual income lost of the 21 people who had stopped working because of MS (See Table 9, Chapter 2) is based on the difference between their earlier income less the income they received at the time of the study⁷. The total income potential lost was \$275,278, which was 75 per cent of the total. Over all respondents there was a mean income loss of \$4,666 per person. The maximum income difference experienced by a respondent was \$90,228. This person was self-employed before developing MS. The next highest personal indirect income costs were \$34,520 and \$27,000. Two people were marginally better off financially. The total cost of lost income figures show that 28 respondents (47 per cent) experienced a loss of income. The total lost was \$368,038, which averaged to \$6,238 for all respondents.

Table 19: Total Personal Indirect Income Costs

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Working days lost	6	10	\$521	\$0	\$18,000	\$30,770	8
Reduced hours	10	17	\$1,051	\$0	\$12,600	\$61,990	17
Annual income lost	16 ¹	27	\$4,666	\$0	\$90,228 ²	\$275,278	75
Total / Summary	28¹	47	\$6,238	\$0	\$90,228²	\$368,038	100

1. Not including two people better off; 2. Minimum (-\$8000), Range \$98,228;

Further details were sought on the income status of the people who left work due to MS. From the 21 people who left work because of MS, 19 were able to indicate their annual income when they were forced to finish paid employment. The mean income at the time of leaving work was \$22,398, with a range from \$4,160 to \$99,840. These figures become more relevant when compared to income figures of these same people at the time of the study. Seven people stated that at the time of the study they had no income, while the remainder had benefit income ranging from \$2,626 to \$22,860. The mean income for people who have lost paid employment due to MS was \$8,013. This was a reduction of the mean income of people not in paid employment of \$14,385 per annum.

The cost of lost income borne by the government is primarily reflected through the benefits and compensation provided to supplement income shortfalls. Government benefits are supplied through various sources, such as, sickness and invalid's benefits, disability allowances, community services and high use cards and accommodation allowances. Thirty respondents (51 per cent) received some form of benefit assistance from the government, however only 21 (36 per cent) was because of MS (See Table 20). The total benefit assistance paid to people in the study because of MS was \$223,475, which averages to \$3,788 per respondent. Seven people had received ACC assistance, and only one had received a grant⁸. The total financial assistance paid by government agencies was \$239,336, with the average per respondent being \$4,056. The maximum paid for any one person was \$22,860, which was a benefit only. The next six highest government income costs ranged from \$19,039 to \$17,284. Only one of these six did not completely consist of benefit assistance.

⁷ Not all of the 21 people who had stopped work provided income details.

⁸ To assist in the purchase of a scooter

Table 20: Total Government Direct Income Costs

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Benefit assistance	21	36	\$3,788	\$0	\$22,860	\$223,475	93
ACC	7	12	\$167	\$0	\$8,834	\$9,866	4
Grants	1	2	\$101	\$0	\$5,995	\$5,995	3
Total / Summary	24	41	\$4,056	\$0	\$22,860	\$239,336	100

In many cases, the loss of income had a two-fold effect on the overall income cost, that is, there was less income for the individual plus there was government expenditure in supplementing the lost income⁹. For example, the maximum total income cost for one person was \$108,674 (See Table 21). This incorporated a personal income loss of \$90,228 plus government assistance of \$18,446 (benefit and ACC). The next highest income costs for individuals were \$47,042 and \$43,786. Table 21 summarises the total income costs for both individuals and government. Sixty-one per cent of respondents detailed some form of income cost. The total income cost in one year for the respondents was \$607,374. The average was \$10,294, with a median of \$4,948. The proportion of personal indirect income costs (61 per cent) was higher than government direct income costs (39 per cent).

Table 21: Total Income Costs by Cost Bearer

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Personal indirect income	28 ¹	47	\$6,238	\$0	\$90,228 ²	\$368,038	61
Government direct income	24	41	\$4,056	\$0	\$22,860	\$239,336	39
Total / Summary	35³	61	\$10,294	\$4,948	\$108,674⁴	\$607,374	100

1. Not including two people better off; 2. Minimum (-\$8,000), Range \$98,228;
3. Not including one person better off; 4. Minimum (-\$2,834), Range \$111,508.

3.4.2 Partners' Loss of Employment Costs

The information about living arrangements showed whether people were supported by a spouse or partner. Forty-two people (71 per cent) were living with a partner, while 17 people (29 per cent) did not have the support of a partner (See Table 22). However, there were only four people living alone.

Table 22: Respondents with Support of Partner or Spouse

Partner	No.	%
Yes	42	71
No	17	29
Total	59	100

⁹ It is acknowledged that there may be a case for double counting of both personal income lost, and payments by government to offset lost income. One is an economic cost (income lost) and the other (government payments) is a transfer. For our purposes both are considered expenses of MS, therefore it is appropriate to add them together.

Support from partners can be physical, emotional and financial, therefore there can also be detrimental consequences on these aspects. A partner may be forced to take time off work, reduce their hours or leave work altogether to assist the person with MS. There are also circumstances of increasing work hours and other commitments to better financially accommodate the personal costs associated with living with MS. It is assumed that many of the partners that have left work altogether are now receiving some form of benefit assistance.

In Table 23 it is established that from the 42 partners, 31 experienced a change of income as a result of supporting the person with MS. Eleven people left work temporarily, while four left work permanently. Ten people reduced their working hours to assist. Six people increased their work hours, and correspondingly their income, as a result of their partner's MS condition. In total, 25 partners of people with MS experienced reduced incomes.

Table 23: Why Partners' Income Changed

Partners' Income Change	No.	%
No change / not indicated	11	26
Left work permanently	4	10
Left work temporarily	11	26
Reduced work hours	10	24
Increased work hours	6	14
Total	42	100

There was a lack of information to properly assess partners' economic costs of lost income or productivity. Many respondents chose not to, or were unable to, provide details of their partners' income. This has meant that a reasonable approximation of lost income for partners has not been calculable. Table 24 shows the information about income lost by partners that was available. Nineteen respondents (45 per cent of those with partners) provided details of their partners' income changes due to the respondents MS. Only 17 respondents (40 per cent of those with partners) were able to provide details of their partners' income losses, while the research established that 25 partners (60 per cent of partners) experienced an income loss. From the information provided, there was a total loss of partners' income of \$192,812 for the year 1999. The average income loss for partners across the entire sample of 59 people was \$3,268. The maximum loss for one person was \$36,000. While the income loss figures for partners have not been carried to any final totals, this information does prove that the economic impact of MS is not just for the patient and the government.

Table 24: Total Partners' Indirect Income Costs

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Partners' income loss	11 ¹	19	\$2,332	\$0	\$36,000 ²	\$137,562	71
Partners' other income loss	10	17	\$936	\$0	\$16,640	\$55,250	29
Total / Summary	17³	29	\$3,268	\$0	\$36,000⁴	\$192,812	100

1. Not including three people better off; 2. Minimum (-\$15,000), Range \$51,000;
3. Not including two people better off; 4. Minimum (-\$11,000), Range \$47,000.

3.5 Other Associated Costs

The last cost category examined is other expenses associated with MS, including the cost of alterations or upgrades of motor vehicles and houses, and transport costs. Table 25 is a summary of data for other associated costs paid by individuals. The first aspect summarised is the cost associated with housing. This figure is the total money spent by individuals with MS on altering their house to accommodate their MS needs, plus any costs people incurred in moving to another property because of their MS. Twenty five per cent of respondents detailed costs in this area. The total cost for this group, adjusted from a cost over five years to a one-year period, was \$32,159. The next personal costs are for car alterations, which includes modification to hand controls and the purchase of modified vehicles. Only eleven respondents (19 per cent) had car alteration costs, which resulted in a cost total of \$14,400. The travel costs incorporate petrol, taxis, bus fares and other expenses associated with the transport for MS related reasons, for example, doctor and hospital visits. Forty respondents (68 per cent) had travel expenses. Weekly costs were ascertained then multiplied over 12 months to a total annual figure of \$55,056, which was 54 per cent of all other costs. Overall, there is a total of \$101,615 for all other costs paid for by the individual, with a mean of \$1,722 per respondent.

Table 25: Total Personal Direct Other Associated Costs

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
House associated	15	25	545	0	10,016	32,159	32
Car associated	11	19	244	0	3,600	14,400	14
Transport	40	68	933	\$520	6,916	55,056	54
Total / Summary	42	71	\$1,722	\$1,040	\$11,316	\$101,615	100

Table 26 presents other costs paid for by government agencies. The costs included home alterations paid for by hospitals and car suspensory loans. Only eight per cent of respondents had such expenses, which totalled \$8,114 per year.

Table 26: Total Government Direct Other Associated Costs

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				\$	%
Home alterations	3	5	\$59	\$0	\$1,580	\$3,480	43
Car suspensory loans	2	3	\$79	\$0	\$2,394	\$4,634	57
Total / Summary	5	8	\$138	\$0	\$2,394	\$8,114	100

The personal and government other associated costs are summarised in Table 27. Personal direct costs dominate this analysis with \$101,615 (93 per cent) of the total \$109,729. The mean other associated cost was \$1,860 per respondent.

Table 27: Total Other Associated Costs by Cost Bearer

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Personal other costs	42	71	\$1,722	\$1,040	\$11,316	\$101,615	93
Government other costs	5	8	\$138	\$0	\$2,394	\$8,114	7
Total / Summary	42	71	\$1,860	\$1,040	\$11,316	\$109,729	100

3.6 Summary

Chapter 3 has examined the MS cost categories of medical costs, resource costs, income and employment costs and other associated costs. For each cost category there was a presentation of indirect and direct costs, whether they were for the individuals with MS and for the government, and as a total for that category. The following summarises the key results for each cost category:

Medical Costs

- Thirty-eight people with MS (64 per cent of respondents) experienced direct medical costs, which totalled \$21,447 for 1999. This was a combination of GP costs (\$9,902) and prescription costs (\$11,545). The mean personal direct medical cost was \$364 for 1999.
- Thirty-five people with MS (59 per cent of respondents) incurred direct medical costs that were paid for by the government. The total cost to government was \$47,016 for 1999. The total was the sum of hospital treatment costs (\$27,627), other health professional costs (\$11,331) and prescription costs (\$8,058). The mean cost of each person in the study to the government was \$797 per year.
- The total of direct medical costs was \$68,463, or \$1,161 per person per year.
- Twenty-six people experienced self directed alternative (indirect) medical costs. These indirect costs were kept separate due to their elective nature. Total indirect costs, which were incurred by individuals only, were \$17,068, or \$289 per respondent.
- All medical costs, direct and indirect, paid for by cost bearers had a total of \$85,531. The mean was \$1,450 per person for 1999.

Resource Costs

- Direct resource costs include people, services, equipment and maintenance of the resources and equipment used to assist living with MS.
- The total personal direct resource costs was \$55,334. The total of government direct resource costs was \$118,206. The total for both cost bearers was \$173,540, with a mean direct resources cost of \$2,941 per person.
- Indirect resource costs apply to individuals only. They are an estimate of the cost of informal assistance provided by family, friends and other volunteers. The total informal assistance cost was \$195,420, with a mean of \$3,312 per person.

Income and Employment Costs

- Personal income can be lost through sick days, reduced work hours and loss of permanent employment.
- Six people experienced sick days in 1999 due to MS at a cost of \$30,770. Ten people had to reduce work hours, with an income loss of \$61,990 for 1999. Sixteen people lost of potential income for 1999 of \$275,278 due to having to stop work altogether because of MS. The total potential income lost for the all individuals was \$368,038. The mean across all respondents was \$6,238 per year.
- Income losses were supplemented by the government via a range of benefit options.
- Twenty-four people received financial support for government because of their inability to earn enough money to support themselves as a result of MS. The total direct income costs for government were \$239,336, with a mean of \$4,056 per respondent.
- Across individuals and government the total expense of lost work was \$607,374. For all 59 respondents there was a mean of \$10,294 per person for 1999.
- Seventeen partners of people with MS experienced an income loss of \$192,812.

Other Associated Costs

- Other costs are alteration and upgrades of homes and vehicles, plus transport costs.
- Personal other costs for 1999 equalled \$101,615, while government other costs were minimal at \$8,114. Total other associated costs was \$109, 729. The mean was \$1,860.

The next chapter brings together the costs categories summarised above. The cost category totals are brought forward to give final totals on direct costs, indirect costs and all cost summaries, across cost bearers (personal and government) and cost categories.

Chapter 4

Results: Total Costs and Summaries

4.1 Introduction

Chapter 4 summarises the results presented in Chapter 3. The aim here is to present overall findings and establish the larger picture of total economic costs of RRMS. There will be a presentation of total costs by direct and indirect cost comparisons, personal and government cost comparisons, and all costs summaries. By dividing the analysis into these sections, the aim is to present what are considered the key perspectives that will interest most observers of the findings. The chapter finishes with a comparison of costs for Group 1 and Group 2 to examine the changes in costs over time.

4.2 Direct and Indirect Costs

Individuals with MS only incur three of the four cost categories as direct costs. These are medical costs, resource costs and other associated costs (See Table 28). The most expensive personal direct cost category was other associated costs with a total of \$101,615, which was 57 per cent of total. This incorporates costs associated with the living and transport arrangements, and home and vehicle alterations for people with MS. Forty-two respondents (71 per cent) indicated that they had expenses in the other cost category. The medical costs were the lesser cost category of all the personal direct costs at \$21,447. The total personal direct costs was \$178,395, which averages to \$3,024 per respondents. A very large proportion of respondents (92 per cent) indicated that they paid some form of direct cost associated with MS. The maximum direct costs paid in one year by any one person was \$15,599, which included direct resource costs of \$8,683 and other associated costs of \$6,916.

Table 28: Total Personal Direct Costs by Cost Category

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Medical costs	38	64	\$364	\$80	\$6,920	\$21,447	12
Resource costs	33	56	\$938	\$140	\$8,683	\$55,334	31
Other associated costs	42	71	\$1,722	\$1,040	\$11,316	\$101,615	57
Total / Summary	54	92	\$3,024	\$1,596	\$15,599	\$178,395*	100

*Does not equal sum of totals due to rounding.

Table 29 presents the data for the direct costs that are paid for by government. In this analysis all four cost categories are incorporated. Medical costs, which was the lowest cost category for individuals, was the second lowest cost for the government. However, the total government medical costs at \$47,016 was twice the total of personal medical costs. The highest government cost category was income costs. These included benefits, ACC allowances and an assistance grant. The total income costs was \$239,336, which relates 41 per cent of respondents. The average per respondent was \$4,056. Overall, the government experienced direct costs of \$412,672 in 1999 for the 59 respondents (71 per cent actually acknowledged government related costs). The mean cost to the government across all respondents was \$6,994. The maximum paid for any one individual was \$38,763. This was the same person that experienced the greatest personal direct costs. Their government direct costs included costs of medical assistance

(\$2,408), resources and services paid for by the government (\$17,909), plus government benefit assistance (\$18,446).

Table 29: Total Government Direct Costs by Cost Category

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Medical costs	35	59	\$797	\$110	\$4,395	\$47,016	11
Resource costs	19	32	\$2,003	\$0	\$23,632	\$118,206	29
Income costs	24	41	\$4,056	\$0	\$22,860	\$239,336	58
Other associated costs	5	8	\$138	\$0	\$2,394	\$8,114	2
Total / Summary	42	71	\$6,994	\$1,439	\$38,763	\$412,672	100

Tables 30 and 31 summarise total direct costs. Combining personal and government direct costs, Table 30 provides a total summary by the four costs categories. The highest portion of costs were those related to income (\$239,336; 40 per cent), which were government costs only, as individual income costs were indirect. The next highest were resource costs (\$173,540; 29 per cent), then other financial costs (\$109,729; 19 per cent), and the last was medical costs (\$68,463; 12 per cent).

Table 30: Total Direct Costs by Cost Category

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max. Cost	Total	
	No.	%				Cost	%
Medical costs	41	70	\$1,161	\$601	\$8,540	\$68,463	12
Resource costs	39	66	\$2,941	\$520	\$29,772	\$173,540	29
Income costs	24	41	\$4,056	\$0	\$22,860	\$239,336	40
Other associated costs	42	71	\$1,860	\$1,040	\$11,316	\$109,729	19
Total / Summary	54	92	\$10,018	\$5,428	\$54,362	\$591,068*	100

*Different to total in Table 31 and 33 due to rounding.

Table 31 presents total personal and government direct costs. From the table it can be seen that 92 per cent of respondents incurred personal direct costs and 71 per cent accrued direct costs for government. However, total government direct costs (\$412, 672; 70 per cent) outweighed total personal direct costs (\$178, 395; 30 per cent). Both Tables 30 and 31 show that the total figure for direct costs was \$591,067. This averaged to \$10,018 for each respondent for the year 1999. The mean personal direct costs was \$3,024 and mean government direct costs were \$6,994.

Table 31: Total Direct Costs by Cost Bearer

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Personal direct costs	54	92	\$3,024	\$1,596	\$15,599	\$178,395	30
Government direct costs	42	71	\$6,994	\$1,439	\$38,763	\$412,672	70
Total / Summary	54	92	\$10,018	\$5,428	\$54,362	\$591,067	100

All indirect costs recorded in this research were attributed to the individuals with MS. While there may also be indirect costs for the government, such as, less tax due to income loss, there

was not enough information available to determine actual values. Further, the same applies for other potential indirect costs of partners' lost income and loss of production for employers, these have not been considered in the final analysis.

The names of the cost categories in the following table of indirect costs are different, in two cases, to the cost categories used in the direct cost summaries above, however they are related. The first category presented in Table 32 is "self-directed medical costs" (Cost Category: Medical Costs). These include the alternative and self directed treatment costs incurred by individuals. They have been classed as indirect due to the elective nature of the cost. This cost was the lowest of the indirect costs at (\$17,068; 3 per cent). The second category is "informal assistance costs" (Cost Category: Resource Costs). Informal assistance costs are the values placed on the assistance provided by voluntary support, such as family members, friends and other voluntary workers. This was the second highest indirect cost at \$195,420, or 34 per cent of the total indirect costs. This averages to \$3,312 per respondent per year, although only 49 per cent of respondents had this form of cost. The highest indirect cost to individuals was income and employment costs. This incorporates income lost through sick days, reduced hours and unemployment because of MS. Forty-seven per cent of people recorded losing such income. The total potential income lost for the group in 1999 was \$368,038, or 63 per cent of total indirect costs. The maximum indirect costs for any one individual was \$108,428. This was the ex-self-employed person who had high income costs. The next highest individual indirect totals were \$48,600 and \$37,160.

Table 32: Total Indirect Costs by Cost Category

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Self-directed medical costs	26	44	\$289	\$0	\$5,400	\$17,068	3
Informal assistance costs	29	49	\$3,312	\$0	\$29,120	\$195,420	34
Income costs	28 ¹	47	\$6,238	\$0	\$90,228 ²	\$368,038	63
Total / Summary	44³	75	\$9,839	\$2,270	\$108,428⁴	\$580,526	100

1. Not including two people better off; 2. Minimum (-\$8,000), Range \$98,228.

3. Not including two people better off; 4. Minimum -\$3,320, Range \$111,748

Table 33 shows the difference between the direct and indirect categories, with a final total for all costs. This is the first time the total cost of MS is presented. There was no notable difference in the total figures of each, with an almost 50/50 split of the overall total. Over 90 per cent of respondents experienced direct costs, while 75 per cent experienced indirect costs. There was a total cost of \$1,171,593 for the 59 people in the study for 1999, with a mean of \$19,857.

Table 33: Total Costs by Type (Direct / Indirect)

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Total direct costs	54	92	\$10,018	\$5,428	\$54,362	\$591,067	50.5
Total indirect costs	44 ¹	75	\$9,839	\$2,720	\$108,428 ²	\$580,526	49.5
Total / Summary	55	93	\$19,857	\$10,705	\$162,790	\$1,171,593	100

1. Not including two people better off; 2. Minimum (-\$3,320), Range \$111,748.

4.3 All Costs

In this section the economic costs of MS are presented as a variety of final summaries. There is no distinction of direct and indirect costs. All costs are presented by comparing cost bearers and cost categories. The first section is an analysis of the features of the highest and most frequent separate costs.

Table 34 is a breakdown of all costs that are components of cost categories outlined in this report. The separate components are sorted from highest cost to lowest cost. Each cost is classified in two ways: as individual (I) or government (G), and as direct (D) or indirect (I). The shaded areas are the details of the highest ten costs. The highest cost was the individual indirect cost of “potential annual income lost”. This cost accounted for 23 per cent of the overall cost total. The second highest cost was the highest direct cost of “benefit assistance” paid by the government. This cost’s value was 19 per cent of all costs. The highest individual direct cost was fifth, that is, “resource costs”, which was 5 per cent of total costs.

Table 34: Rank Order of All Costs – Due to MS

Cost Description	Response		Mean (n=59)	Max.	Total	
	No.	%			Cost	%
Potential annual income lost (I/I)	16	32	\$4,666	\$90,228	\$275,278	23
Benefit assistance (G/D)	21	36	\$3,788	\$22,860	\$223,475	19
Family assistance (I/I)	25	42	\$3,054	\$29,120	\$180,180	15
Resources (G/D)	19	32	\$2,003	\$23,632	\$118,206	10
Reduced working hours (I/I)	10	17	\$1,051	\$12,600	\$61,990	5
Resources (I/D)	33	56	\$938	\$8,683	\$55,334	5
Transport (I/D)	40	68	\$933	\$6,916	\$55,056	5
House associated (I/D)	15	25	\$545	\$10,016	\$32,159	3
Working days lost (I/I)	6	10	\$521	\$18,000	\$30,770	3
Hospital treatment (G/D)	22	37	\$468	\$4,395	\$27,627	2
Other informal assistance (I/I)	7	12	\$258	\$8,400	\$15,240	1
Self-directed medication (I/I)	25	42	\$246	\$5,400	\$14,518	1
Car associated (I/D)	11	19	\$244	\$3,600	\$14,400	1
Prescriptions (I/D)	29	49	\$196	\$5,000	\$11,545	1
Other health professionals (G/D)	15	25	\$192	\$3,856	\$11,331	1
GP visits (I/D)	34	58	\$168	\$1,920	\$9,902	1
ACC (G/D)	7	12	\$167	\$8,834	\$9,866	1
Prescriptions (G/D)	21	36	\$137	\$992	\$8,058	1
Grants (G/D)	1	2	\$101	\$5,995	\$5,995	1
Car suspensory loans (G/D)	2	3	\$79	\$2,394	\$4,634	0
Home alterations paid HFA (G/D)	3	5	\$59	\$1,580	\$3,480	0
Alternative treatments (I/I)	7	12	\$43	\$650	\$2,550	0
Total / Summary	55	93	\$19,857	\$162,790	\$1,171,593	100

Table 35 is a portion of the information presented in the above table. It presents the ten most frequently reported costs. The same classifications applied in Table 34 are used here. The most common was transport costs, with 68 per cent of respondents having some form of expense in this area. The next three most common costs were GP costs (58 per cent), resource costs (56 per cent) and prescription costs (49 per cent). The top four most common costs were all personal direct costs. The most frequent government cost was hospital treatment costs, which was seventh on the list, with 37 per cent of participants generating expenses in this area.

Table 35: Ten Most Frequently Reported Costs

Cost Description	Response		Mean (n=59)	Max.	Total	
	No.	%			Cost	%
Transport (I/D)	40	68	\$933	\$6,916	\$55,056	5
GP visits (I/D)	34	58	\$168	\$1,920	\$9,902	1
Resources (I/D)	33	56	\$938	\$8,683	\$55,334	5
Prescriptions (I/D)	29	49	\$196	\$5,000	\$11,545	1
Family assistance (I/I)	25	42	\$3,054	\$29,120	\$180,180	15
Self-directed medication (I/I)	25	42	\$246	\$5,400	\$14,518	1
Hospital treatment (G/D)	22	37	\$468	\$4,395	\$27,627	2
Benefit assistance (G/D)	21	36	\$3,788	\$22,860	\$223,475	19
Prescriptions (G/D)	21	36	\$137	\$992	\$8,058	1
Resources (G/D)	19	32	\$2,003	\$23,632	\$118,206	10

Tables 36 and 37 show the breakdowns of total cost categories as they stood for individuals and government, respectively. The highest personal and government costs were income related. Personal income costs were \$368,038 and government income costs were \$239,336. Second highest were resource costs with personal resource costs at \$250,754 and government resource costs at \$118,206. They also differed slightly in percentage of the total for each cost bearer, that is, personal income costs were 49 per cent of the personal total, while government income costs were 58 per cent of the government total. Resource cost differences were personal costs, 33 per cent, and government costs, 29 per cent. There was a difference in the order and percentages of the lower two cost categories, which was, medical costs and other financial costs. Personal medical costs were \$38,514, or 5 per cent of all personal costs. Government medical costs were \$47,016, or 11 per cent of all government costs. This order reversed for other financial costs. Personal other associated costs totalled \$101,615, or 13 per cent of all personal costs, while government resource costs totalled \$8,114, or 2 per cent of all government costs. For resource, medical and other costs the expense to the person with MS is greater than that to the government

Table 36: Total Personal Costs by Cost Category

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Medical costs	46	78	\$653	\$256	\$7,440	\$38,514	5
Resource costs	42	71	\$4,250	\$1,165	\$29,302	\$250,754	33
Income costs	28 ¹	47	\$6,238	\$0	\$90,228 ²	\$368,038	49
Other associated costs	42	71	\$1,722	\$1,040	\$11,316	\$101,615	13
Total / Summary	55³	93	\$12,863	\$5,943	\$124,027⁴	\$758,921	100

1. Not including two people better off; 2. Minimum (-\$8,000), Range \$98,228;

3. Not including one person better off; 4. Minimum (-\$489); Range \$124,516

Table 37: Total Government Costs by Cost Category¹⁰

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Medical costs	35	59	\$797	\$110	\$4,395	\$47,016	11
Resource costs	19	32	\$2,003	\$0	\$23,632	\$118,206	29
Income costs	24	41	\$4,056	\$0	\$22,860	\$239,336	58
Other associated costs	5	8	\$138	\$0	\$2,394	\$8,114	2
Total / Summary	42	71	\$6,994	\$1,439	\$38,763	\$412,672	100

When the cost bearers were compared the difference between personal costs and government costs became more noticeable. Table 38 shows that personal costs outweigh government costs by 65 per cent to 35 per cent of the overall total cost of \$1,171,593. This difference was reflected further in the mean cost of MS per person, which was \$19,857. The cost bearer means were personal costs of \$12,863 and government costs of \$6,994. There was also a 22 per cent difference in the number of people that experienced costs themselves (93 per cent) as opposed to receiving some form of government assistance (71 per cent). These statistics indicate that government covered around one third of all costs associated with MS, and just over one fifth of people did not receive government assistance.

Table 38: Total Costs by Cost Bearer

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Total personal costs	55 ¹	93	\$12,863	\$5,943	\$124,027 ²	\$758,921	65
Total government costs	42	71	\$6,994	\$1,439	\$38,763	\$412,672	35
Total / Summary	55	93	\$19,857	\$10,705	\$162,790	\$1,171,593	100

1. Not including one person better off; 2. Minimum (-\$489), Range \$124,516.

Table 39 represents the overall analysis of all costs by cost category. This analysis brings all costs together but does not present any new findings. This information does, however, enable a summary of the overall economic situation to be highlighted. The total costs that the 59 research subjects could attribute to the one-year period of 1999 was \$1,171,593. Ninety three per cent of respondents experienced or generated some form of cost associated with MS. The highest cost category was income costs with \$607,374 (53 per cent of all costs) for the year. The lowest cost category was medical costs at \$85,531 (7 per cent of total costs). The most common cost category was medical costs with 81 per cent of respondents recording some form of expense. The highest cost associated with any one person with MS for the one-year period was \$162,790. This respondent had \$108,428 in indirect costs of income lost and informal assistance, with direct costs of \$54,362. The indirect figure consists of informal assistance costs from friends, family and volunteers (\$18,200) with an annual income loss (\$90,228). The direct cost figure consisted of individual medical costs (\$2,408), government resource costs (\$17,909), individual resource costs (\$8,683), government assistance (\$18,446) and individual other financial costs (\$6,916). The next highest maximum costs for individuals with MS were \$88,844 and \$71,219. The highest contributing category for both these individuals was resource costs of \$45,972 and \$47,724, respectively.

¹⁰ Table 37 representing Total Government Costs presents the same information as Total Government Direct Costs (Table 29). There was no change in the government cost totals as there were no indirect costs to be incorporated into the final total.

Table 39: Total Costs by Cost Category

Cost Description	Responses		Mean (n=59)	Median (n=59)	Max.	Total	
	No.	%				Cost	%
Medical costs	48	81	\$1,450	\$731	\$10,165	\$85,531	7
Resource costs	44	75	\$6,253	\$1,560	\$47,724	\$368,960	31
Income costs	35 ¹	61	\$10,294	\$4,948	\$108,674 ²	\$607,374	53
Other assoc. costs	42	71	\$1,860	\$1,040	\$11,316	\$109,729	9
Total / Summary	55	93	\$19,857	\$10,705	\$162,790	\$1,171,593	100

1. Not including one person better off; 2. Minimum (-\$2,834), Range \$111,508.

4.4 Comparison of Costs Over Time

A main objective of the research was to ascertain whether there was a positive relationship between costs of MS and how long a person had experienced the condition. The hypothesis was that costs associated with MS would increase over time. To test this hypothesis two groups were identified within the research population. The groups were based on when respondents had been first diagnosed with MS. Group 1 consisted of 24 respondents who were diagnosed with MS from 1984 to 1989, inclusive. Group 2 consists of 35 respondents who were diagnosed with MS from 1990 to 1995, inclusive (See Table 1, pg. 5). If a positive hypothesis between time with MS and cost was to be confirmed then Group 1 was expected to have higher costs than Group 2. This research does not fully support this hypothesis.

Table 40 compares the means and proportion percentages for Group 1 and Group 2 across the range of primary cost totals. The higher means and proportions are shaded. The other columns show the summary of means and proportions for the total research population. These will not be discussed, though they do offer a reference point for each group.

For the 24 respondents with MS in Group 1 the mean cost for all aspects of MS for 1999 was \$17,660. For the 35 respondents with MS in Group 2, the mean cost for all aspects of MS for 1999 was \$21,364. In only six cost totals out of a possible 21 did Group 1 have greater mean costs than Group 2. These were: Government Direct Resource Costs; Personal Indirect Resource Costs (Informal Assistance); Total Resource Costs; Government Income Costs; Government Direct Other Costs; and Total (and Direct) Government Costs. Further, there were two other costs for Group 1 where the proportion was higher than that for Group 2. These additional two totals were: Government Medical Costs and Total Direct Costs. These figures indicate that people in the study that had MS longer were incurring higher government costs for the use of services and resources, benefits and other associated costs. They also had a higher value for assistance from family and friends. This suggests that people who have had MS for longer require more assistance than people that have had MS for a shorter time. They also cost more to the government than people who had MS for a shorter period. They do not, however, have the greater overall cost for living with MS.

The remaining costs were all greater for people in Group 2 who had MS for a shorter time. A synthesis of the differences indicate a number of aspects about Group 2. They personally paid greater amounts in medical costs. The medical costs were also greater across direct and indirect means. The higher medical costs may indicate that people more recently diagnosed with MS were more likely to try a range of medications and treatments. They also experienced greater costs to themselves in resources and services used and other costs than those that had lived with MS longer. Group 2 respondents also encountered far higher income costs through lost work.

They paid more in personal direct costs than Group 1 respondents. They also experienced greater indirect personal costs.

As mentioned, Group 2 had a higher mean total cost of \$21,364, while Group 1 had a mean total cost of \$17,660. The difference was \$3,704. The proportion differences for personal and government total costs across Group 1 and Group 2 are also worth noting. For Group 1 the ratio was personal, 57 per cent; government, 43 per cent. For Group 2 the ratio was personal, 69 per cent; government, 31 per cent. This indicates a heavier cost burden for a person more recently diagnosed with MS. Respondents who had MS for a shorter period not only incurred higher costs across a range of expenses, but they also incurred the greater total costs for themselves, and for the final total of MS related costs.

Table 40: Difference in Cost Over Time

Cost Summaries	Group 1 (n=24)		Group 2 (n=35)		Total (n=59)	
	Mean	%	Mean	%	Mean	%
Personal Direct Medical Costs	\$281	25	\$420	25	\$364	25
Government Direct Medical Costs	\$711	64	\$856	51	\$797	55
Personal Indirect Medical Costs	\$124	11	\$402	24	\$289	20
Total Medical Costs	\$1,115	100	\$1,679	100	\$1,450	100
Personal Direct Resource Costs	\$508	6	\$1,233	24	\$938	15
Government Direct Resource Costs	\$2,672	34	\$1,545	30	\$2,003	32
Personal Indirect Resource Costs	\$4,774	60	\$2,309	46	\$3,312	53
Total Resource Costs	\$7,955	100	\$5,087	100	\$6,253	100
Personal Indirect Income Costs	\$2,958	42	\$8,486	68	\$6,238	61
Government Direct Income Cost	\$4,066	58	\$4,050	32	\$4,056	39
Total Income Costs	\$7,024	100	\$12,536	100	\$10,294	100
Personal Direct Other Costs	\$1,421	91	\$1,929	94	\$1,722	93
Government Direct Other Costs	\$145	9	\$132	6	\$138	7
Total Other Associated Costs	\$1,566	100	\$2,061	100	\$1,860	100
Direct Costs by Cost Bearer:						
Total Personal Direct Costs	\$2,210	23	\$3,582	35	\$3,024	30
Total Government Direct Costs	\$7,594	77	\$6,584	65	\$6,994	70
TOTAL DIRECT COSTS	\$9,803	100	\$10,165	100	\$10,018	100
All Costs by Category:						
Total Medical Costs	\$1,115	6	\$1,679	8	\$1,450	7
Total Resource Costs	\$7,955	45	\$5,087	24	\$6,253	31
Total Income Costs	\$7,024	40	\$12,536	59	\$10,294	53
Total Other Associated Costs	\$1,566	9	\$2,061	9	\$1,860	9
All Costs - Indirect/Direct Costs:						
Total Indirect Costs	\$7,857	44	\$11,199	52	\$9,839	49.5
Total Direct Costs	\$9,803	56	\$10,165	48	\$10,018	50.5
All Costs by Cost Bearer:						
Total Personal Costs	\$10,066	57	\$14,781	69	\$12,863	65
Total Government (Direct) Costs	\$7,594	43	\$6,584	31	\$6,994	35
TOTAL COSTS	\$17,660	100	\$21,364¹¹	100	\$19,857	100

¹¹ Group 2 has one case with exceptionally higher Income and Total Costs. Analysis with this case removed does change the mean comparisons between Group 1 and Group 2 and produces a more even Total Cost comparison, though the general picture remains constant. The cost areas where prominence between the groups changes are Total Direct Costs (Group 1 \$9,803; Group 2 \$8,856) and Total Costs (Group 1 \$17,660; Group 2 \$17,204). It also enhances the prominence in Resource and Government Costs for Group 1 in most cost areas.

4.5 Summary

This chapter reports the overall costs of MS. The analysis provided breakdowns of total costs by cost bearer (personal and government) and cost category (medical, resources, income and other cost) perspectives within direct cost, indirect cost, and all cost totals. There was also a comparison of costs over time using two diagnostic groups. They were Group 1 (24 respondents diagnosed from 1984 to 1989, inclusive) and Group 2 (35 respondents diagnosed from 1990 to 1995, inclusive). The key findings from these analyses are as follows:

Direct and Indirect Cost Summary

- The highest personal direct cost was other associated costs at \$55,334, or 57 per cent of total personal direct costs of \$178,395.
- The highest government direct cost was income costs, mainly consisting of benefits, at \$239,336, or 58 per cent of total government direct costs of \$412,672.
- Income costs were also the greatest overall direct cost for both personal and government, being 40 per cent of total direct costs of \$591,068. Second highest was resource costs at 29 per cent. Direct other costs were 19 per cent and direct medical costs were 12 per cent.
- Government bore \$412,672, or 70 per cent, of total direct costs.
- Personal income costs were the highest indirect cost at 63 per cent; Informal assistance costs were 34 per cent and self-directed medical costs were only 3 per cent of all indirect costs.
- Direct costs were \$591,418 (50.5 per cent) and indirect costs were \$580,526 (49.5 per cent).

All Cost Summary

- The three highest separate costs were: 1. Potential annual income lost (\$275,278, 23 per cent); 2. Benefit assistance (\$223,475, 19 per cent); and, 3. Family assistance (\$180,180; 15 per cent). Only benefit assistance was a direct cost.
- The three most frequently reported costs were: 1. Transport costs (40 per cent of respondents); 2. GP costs (34 per cent of respondents); and, 3. Personal resource costs (33 per cent of respondents). The top six most common costs were incurred by individuals.
- The highest costs encountered by people with MS were income costs of \$368,038, or 49 per cent of total personal costs. Second highest was resource costs of \$250,754, or 33 per cent. Other costs were 13 per cent and medical costs were five per cent.
- Total government costs are the same as total government direct costs, as there were no government indirect costs.
- Personal costs were for 65 per cent of all costs and government accounted for 35 per cent.
- Ninety-three per cent of respondents paid MS related costs, while 71 per cent had government assistance for some MS costs.
- The highest overall cost was income costs of \$607,374, or 53 per cent of all costs. Next were: resource costs, 31 per cent; other costs, nine per cent; and, medical costs, seven per cent.
- The totals cost of MS to the 59 research respondents was \$1,171,593. The average costs of MS per person was \$19,857.

Group 1 and Group 2 Summary

- People that had MS for a longer duration cost the government more in all aspects than people who had it for a shorter period.
- The people that had MS for a shorter time incurred greater expenses for medical costs, greater personal expense for resources, services and other costs. They had a greater loss of potential income for the year of study and cost the government more in benefit assistance. Overall, they paid more MS related costs themselves, had proportionally less assistance from government and had greater total MS related costs than people who had MS longer. They also spent more on alternative treatment options.

Chapter 5

Discussion and Conclusion

5.1 Discussion

The research method used here was a prevalence approach, bottom-up cost of illness study. This means that the study of costs was for a given year, and based on the total costs for a defined sub-population with MS. In this research the study year was 1999 and the sub-population was people with relapsing-remitting multiple sclerosis, diagnosed from 1984 to 1995 inclusive¹² and living in the Canterbury / Westland area.

This study found that the economic costs of RRMS per individual were relatively high at \$19,857 per person for 1999, with a total for all 59 respondents of \$1,171,593. There was almost a 50/50 split in the total between direct and indirect costs. The proportions of total costs by cost bearer were personal, 65 per cent, and government, 35 per cent. Ninety-three per cent¹³ of respondents incurred MS related costs, while 71 per cent had government assistance for some MS costs, which was a 22 per cent difference. Therefore, government covered about one third of all costs associated with MS and just over one in five respondents were not receiving any form of government assistance. Further, the costs of MS were not greater for people that had the condition longer (10+ years). People who had MS for a shorter time (0-9 years) incurred the greater level of costs, most of which were paid for by themselves. People with MS longer required more informal assistance and had greater government costs.

There are three notable reasons for underestimated costs in this study. Firstly, the findings are limited by the size of the MS sub-group (relapsing-remitting MS, in the Canterbury / Westland region, matching diagnostic criteria from 1984 to 1995 inclusive), which realistically is a “less expensive” representation of people with MS. Secondly, there is a lack of details regarding some aspects of the indirect economic costs of MS. The final totals do not include partners’ loss of income, loss of tax revenue for the government, cost of lost productivity for employers, and flow-on cost effects to family and friends that care for a person with MS. Partners’ loss of income was \$192,812 (See Table 24, p.23), though was not included in the final total due the inability of many respondents to provide details of their partner’s earnings. Another cost not included in the final total was loss of tax revenue. Other international studies include lost tax revenue in their overall economic assessments (Holmes, 1995). While not purposely isolated in the research, there is a possibility that a tentative figure for tax revenue lost could be based on the potential income lost by individuals. A suggested calculation works as follows: Total Personal Income Costs of \$368,038 divided by the number of people with income costs (30 people) gives an average income of \$12,268. The tax on this amount at 19.5 per cent is \$2,392 per person. For the 30 people the estimated tax loss is \$71,767. This figure would be higher if tax from partners’ lost income was also considered. Thirdly, the intangible costs that stem from the psychological, stress-related impacts of MS on the person and their carers are also not included. As a result of these three factors, the findings presented are a conservative representation of MS costs for the Canterbury / Westland for 1999¹⁴. In the absence of New Zealand information, however, this study provides valuable information such as identifying the types of costs of MS in this country. The results are, therefore, valuable and useful despite having limitations. There is scope for future research to improve on the measures adopted here.

¹² With there being an average of eight years since matching diagnostic criteria.

¹³ The remaining seven percent provided no cost details.

¹⁴ Also attributable was the systematic method of under-estimating costs during the information gathering stage.

The findings also suggest that living with MS is the cause of financial limitation for many people, for example: Fifty-nine per cent of respondents had partners with income. This left 41 per cent of respondents reliant on single incomes, whether they were single, had partners and/or families. The average annual income of the respondents was \$18,755. The average personal direct costs (MS “cash” costs, except alternative treatments) was \$3,024. This means that for two out of five respondents potentially 15 per cent of their income was committed to MS costs. This is a sizeable proportion of income committed to MS related expenses for people already in an economically deprived group. If indirect costs are also included then the proportion of costs to income will be considerably higher.

This study identifies that the cost of MS was greater for people more recently matching RRMS diagnostic criteria, which was not the expectation before the research began. There was no particular aspect that identified why this has occurred. It is a reasonable assumption, however, that during an initial period of acceptance, transition and adjustment people are likely to experience changes in their employment arrangements and try different methods of medication (including alternative options¹⁵) to manage their condition, which in combination have a notable personal financial impact. People that have had MS for longer are likely to be more settled in living with their condition and have had time to understand their circumstances, have found what works best and obtained their financial and service entitlements from government sources. They are also more likely to be older and to have retired from work (either forced or natural), and may have become accustomed to financial limitations that come with the MS condition.

There is a further reflection of the financial impacts on newly diagnosed people with MS that connects to the decisions they make surrounding the treatment of their condition. All respondents, in their search for methods to control and alleviate their conditions spent 44 per cent of personal medical costs, or 20 per cent of all medical costs, on alternative options. While all medical costs were only seven per cent and the alternative options just over one per cent of all costs, it was significant that forty-four per cent of respondents had spent money on alternative treatments and medication in 1999. The level of spending on alternative treatment suggests that there is a need for a review of policies regarding the education of people to ensure they are making informed choices about their treatment. Further research on the types of alternative options and perceptions of and reasons for use would be useful.

The results of this study are reasonably in line with those in developed countries, such as the United States, Canada, the United Kingdom, Norway and Sweden. A brief comparison of findings from a range of international studies is presented in Table 41. The most consistent aspect across the national studies over different years is that the indirect costs of lost earnings are commonly the highest costs. The Canterbury / Westland study resembles these and had lost earnings and the cost of benefit assistance as the highest costs. This study has a difference in the ratio of direct to indirect costs, while other nations have indirect costs as a much greater proportion of all costs than direct costs. If the reasons for underestimation, highlighted earlier, are taken into account then the ratio between direct and indirect costs in this study would likely closer represent those of other nations. It would also make the estimated annual cost to New Zealand greater than the NZ\$69.5 million that is shown.

The table also outlines the national cost of MS for each study and the average cost per person, where possible. The figures are not conducive to an accurate comparable analysis due to differing time periods and currencies. A more accurate comparison would consider the individual fluctuations of national inflation rates and exchange rates to one fixed currency (i.e. the United States Dollar) for each study since their completion. This was not in the scope of this particular research. The results confirm that the national and individual costs of MS across

¹⁵ Most recent diagnosed people spent more on alternatives than those that had been diagnosed for a longer time.

various countries are significant, and in some cases, the costs are increasing. This conservative New Zealand regional study shows that the cost of MS are high, but evidence from other countries, plus understandings of non-included indirect costs, suggests that they are likely to be higher. It is likely that costs would be confirmed as greater in a comprehensive national study.

Table 41: Comparison with International Studies of MS Costs¹⁶

Study Country & Reference	Study Year	Annual National Cost	Cost Per Person	Direct / Indirect Ratio	Highest Cost Category
New Zealand (This report, 2001)	1999	NZ\$69.5 million (est.)	NZ\$19,857	D - 50.5 % I - 49.5 %	Lost Earnings, and Benefits
Canada (Burden of Illness Study Group, 1998)	1995		CD\$24,415 ¹⁷	D – 19 % I – 81 %	Lost Activity/Leisure Time and Productivity
Canada (Asche et al., 1997)	1994	CD\$502.3 million	CD\$18,673	D – 37.5 % I – 62.5 %	Lost Productivity
Sweden (2) (Henriksson and Jonsson, 1998)	1994	SEK 1,876 million		D – 20 % I – 80 %	Lost Earnings
United Kingdom (Holmes et al., 1995)	1993 - 1994	GB£1.2 billion	GP£13,750 ¹⁸		Lost Earnings
United States (Whetten-Goldstein et al., 1996)	1994	US\$9.7 billion	US\$35,000		Lost Earnings, and Informal Care
England and Wales (2) (Wood, 1994)	1993/4	GB£273.2 million		D – 8 % I – 92 %	
United States (Veterans) (Bourdette et al., 1993)	1988 - 1990		US\$35,000		Benefits and Homecare
Sweden (1) (Jonsson, 1995)	1991	SEK 1,525 million (US\$ 216 million)	SEK 190,625 (US\$ 27,000)	D – 29 % I – 71 %	Lost Earnings
Norway (Midgard et al., 1996)	1991	NOK 34.4 million		D – 17 % I – 83 %	Lost Earnings
England and Wales (1) (O'Brien, 1987)	1986/7	GB£125.4		D – 15 % I – 85 %	Lost Earnings

¹⁶ For a recent and critical review of major MS costs of illness studies in literature see Grudzinski et al. (1999).

¹⁷ Average of three MS groups of mild, moderate and severe MS (Burden of Illness Study Group, 1998).

¹⁸ Average of three MS types over state burden and individual burden (Holmes et al., 1995).

In addition, it must be re-emphasised that this study has only included people who have presented with relapsing-remitting MS. This is not the case with all of the other studies in Table 41. Primary progressive MS produces a gradually accumulating disability and would be expected to result in quite a different pattern of economic effects. Inclusion of this category of MS would be expected to substantially increase the annual national cost.

Beyond the parallels to international results, the findings of this New Zealand regional study opens discussion and raises questions about the way MS is affecting the individual and the wider society. A better overall understanding of individuals' emotional, physical and financial needs, when facing a life with a debilitating condition like MS, would assist in government and the wider community's responses to the needs of people in less fortunate circumstances. The fact that the greatest costs of MS is the personal expense of lost income, which in many cases would result in considerable changes in lifestyle, tend to be overlooked by many who see benefits and health funding as primary social costs. There may also be a need for government policy makers and health funding providers to consider that paying for treatment that enables longer periods of financial independence and normality of life, which may have greater longer term economic and social benefits than funding on an as-needed, deterioration basis.

5.2 Conclusion

The cost to people in the Canterbury / Westland region with the relapsing-remitting MS, the people that they live with and the New Zealand Government is relatively high. The figures presented in this report offer a conservative picture of MS in comparison to other nations' studies, but there is no doubt that there are significant financial consequences for this country. These findings also show that the costs of relapsing-remitting MS do not necessarily increase the longer a person has the condition within the timeframe studied, that is, with an average of eight years from diagnosis. In fact, these results indicate that people with MS longer incur less overall costs, yet they do accumulate higher cost for government. Whereas, people with MS for shorter periods have greater overall cost, and noticeably higher personal costs. The economic impact of MS appears more relevant for single or low-income families of people recently diagnosed with MS. Views surrounding what are the real costs will differ depending on the association a person makes to the importance of indirect costs, such as, loss of income, voluntary assistance and alternative medical expenses. The reality is, however, that for a person or family on a single or low income the proportion of costs associated with MS will be financially detrimental, whatever the accepted cost structure. This indicates that there may be more of a need to alleviate symptoms as early in the development of MS as possible. By keeping people well enough to work reduces lost income effects for the individuals, their partners and their families, particularly at the earlier stages, and will push back the reliance on government and informal carers at the later stages. It would seem that there would also be an alleviation of the "intangible costs" of psychological impacts and related stresses associated with the tangible financial consequences of a diagnosis of MS. Further, the costs and flow-on impacts would be greater for all concerned when considering more advanced MS than relapsing-remitting.

The findings and their supporting discussions are not attempts to influence discussion or policy surrounding any particular forms of treatment of MS in New Zealand. An aim of this research was to understand the costs associated with MS in New Zealand. It is accepted that this research is a precursor to a more efficient economic evaluation, that is, a comprehensive national study. It does, however, establish a base from which initial estimations of the cost of MS over a lifetime¹⁹, the national cost of MS²⁰, categories of costs associated with MS and the proportions

¹⁹ If the average time with MS is 25 years, and if the average cost of \$19,857 remained constant, then the total cost over a lifetime equals \$496,425 (personal = \$321,575; government = \$174,850).

of costs can be made in a New Zealand context. Apart from these, the quantifying of costs associated with MS at this level, at least, provides a clearer picture than there was before. Further, the information gathered has other values in highlighting and informing other topical issues surrounding MS, such as the use of alternative treatments and the impacts of intangible costs. There is considerable scope for greater investigation of the economic and social costs of MS in New Zealand. This research sets the stage for beginning to enhance our understandings of the range of these economic and social consequences. The obvious contending topics for further investigation are summarised as follows:

- *Alternative treatment use:* The use of alternative treatments by people who have MS appears significant, (44 per cent). Whether this is higher than in other chronic illnesses is not known. Neither is it known whether the level of usage could be related to cognitive changes, which can affect judgement, or to a lack of knowledge regarding available orthodox treatments. This could be a field for further investigation. Increased education for people with MS regarding orthodox symptom management may be helpful as well as additional information resources for General Practitioners.
- *In-depth national study of the costs of MS:* Undertake a comprehensive national study of MS. Ensure there is wider consideration of all stages of MS, representative of all people with MS in New Zealand and unrestricted by where and when they were diagnosed; and incorporate the indirect costs of loss of tax revenue, partner and family member income losses and loss of industry productivity.
- *Study of intangible costs:* To consider and begin to understand the greater ‘social’ and ‘emotional’ consequences of MS.

²⁰ An estimate from MS Society sources stated that there were 3-4,000 people with MS in New Zealand. For an average of 3,500, the total cost of MS in New Zealand in 1999 would have been around \$69.5 million (personal = \$45 million; government = \$24.5 million).

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Appendix 1: Clinical criteria for relapsing-remitting MS

(Reference: Poser et al. 1983).

Clinically Definite Multiple Sclerosis (CDMS).

1. Two attacks and clinical evidence of two separate lesions.
2. Two attacks, clinical evidence of one lesions and paraclinical evidence of another, separate lesion.

Laboratory Supported Definite Multiple Sclerosis (LSDMS).

The laboratory support consists of demonstration in CSF of IgG oligoclonal bands of increased CNS synthesis of IgG. Oligoclonal bands must not be present in the patient's serum, and the serum IgG level must be normal.

1. One attack; either clinical or paraclinical evidence of one lesion; and CSF OB/IgG.
2. One attack; clinical evidence of two separate lesions; and CSF OB/IgG.
3. One attack; clinical evidence of one lesion and paraclinical evidence of another, separate lesion; and CSF OB/IgG.

Clinical Probable Multiple Sclerosis (CPMS).

1. Two attacks and clinical evidence of one lesion.
2. One attack and clinical evidence of two separate lesions.
3. One attack; clinical evidence of one lesion and paraclinical evidence of another, separate lesion.

Laboratory Supported Probable Multiple Sclerosis (LSPMS).

1. Two attacks and CSF OB/IgG.

- Weakness
- Spasticity
- Balance
- Co-ordination
- Tremor
- Other

6. What are your main symptoms now?

- Fatigue
- Vision
- Mobility
- Sensory
- Bladder
- Bowel
- Pain
- Memory
- Depression
- Weakness
- Spasticity

- Balance
- Co-ordination
- Tremory
- Other

7(a). How many attacks do you think you had in:

- 1996
- 1997
- 1998

7(b). How accurate do you think that is?

- Very accurate
- Fairly accurate
- A guess

8. Are you having an attack at present?

- Yes No

If NO go to Question 11

9. Are you having treatment for this attack?

- Yes No

10. List treatments.

- Methylprednisolone
- Prednisone
- Other

11(a). Do you usually receive some medically prescribed treatment for your attacks?

- Yes No

If NO go to Question 12

11(b). List treatments.

Methylprednisolone

Prednisone

Other

12a. How many attacks have you had treated in the last three years?

One Two Three Four plus

12b. Were you treated with methylprednisolone each time?

Yes No

13. How often in the last six months have you seen your neurologist or the hospital registrar?

Number of times

14. Were you seen privately or in the public health system?

Private Public Both

15. Who is your current neurologist?

16(a). In the last six months, how often have you seen your G.P. for M.S. related problems?

Nil Once 2-3 4-5 6 plus

16(b). Please tell me what for:

.....

.....

17. Have you seen any other health professional in the last six months because of your M.S.?

Yes No

If NO go to Question 19

18. Please tell me who you have seen.

		Number of times
Specialist (e.g. urologist, ophthalmologist)	<input type="checkbox"/>	_____
Physiotherapist	<input type="checkbox"/>	_____
Occupational Therapist	<input type="checkbox"/>	_____
Speech Therapist	<input type="checkbox"/>	_____
G.P. Nurse	<input type="checkbox"/>	_____
Domiciliary Nurse	<input type="checkbox"/>	_____
Needs Assessor	<input type="checkbox"/>	_____
Continence Nurse	<input type="checkbox"/>	_____
Podiatrist	<input type="checkbox"/>	_____
Optometrist	<input type="checkbox"/>	_____
Splint Department Nurse	<input type="checkbox"/>	_____
M.S. Society staff	<input type="checkbox"/>	_____
Other hospital staff (e.g. spinal unit)	<input type="checkbox"/>	_____
Hospital dental staff	<input type="checkbox"/>	_____
Other	<input type="checkbox"/>	_____

19(a). Are you currently taking any other medication prescribed by your G.P., your Neurologist, or other medical specialist, for problems associated with your M.S. ?

Yes No

If NO got to Question 20

19(b). Please tell me what medications you are taking from these people.

.....
.....
.....
.....
.....

20. Including at the moment, in the last six months, have you consulted or received treatment from an alternative therapist for M.S. related problems?

Yes No

If NO got to Question 22

21. Please tell me what treatments you received.

.....
.....
.....
.....

22. Are you taking anything else based on your own decision, e.g. from the chemist, herbal shop etc. for your M.S.?

Yes No

If NO go to Question 23

If YES list:

.....
.....
.....

23. Have you received Intravenous Methylprednisolone in the last six months?

Yes No

If NO go to Question 26.

24. Were you an:

In patient? Outpatient? Day patient?

25. Where were you treated? Name of facility

26. In the last six months, how many other times have you been at a hospital for your M.S. or M.S. related problems (e.g. bladder) either as an in patient, day patient, or outpatient? (*Circle number*)

Inpatient	1	2	3	4	5	6 plus
Day patient	1	2	3	4	5	6 plus
Outpatient	1	2	3	4	5	6 plus

Total

PERSONAL CARE SECTION

1(a). Have you been, in the last six months, into some kind of alternative living care because your M.S.?

Yes No

If NO go to Question 2

1(b). Please tell me where and for how many days.

.....

2. Have you had a medical assessment at P.M.H. or Burwood Hospital in the last six months because of your M.S.?

Yes No

If NO go to Question 4

3. How many days did this take?

Up to 3 4 – 7 8 – 10 11 – 14 more

4. Have you had a needs assessment in your home in the last six months because of your M.S.?

Yes No

5. Have you used any of the following services in the last six months because of your M.S.?

Yes No

If YES then itemise. **If NO** go to Question 7.

Continence clinic	<input type="checkbox"/>	Meals on Wheels	<input type="checkbox"/>
District Nurse	<input type="checkbox"/>	Child Care	<input type="checkbox"/>
Home Care 2000	<input type="checkbox"/>	Needs Assessment	<input type="checkbox"/>
Nurse Maude home support	<input type="checkbox"/>	Lifelink	<input type="checkbox"/>
Personal Care	<input type="checkbox"/>	C.C.S Home Health	<input type="checkbox"/>
Domestic support	<input type="checkbox"/>	Equipment	<input type="checkbox"/>

- | | | | |
|----------------------------|--------------------------|--------------------|--------------------------|
| Dom. Services (O.T., P.T.) | <input type="checkbox"/> | Patient appliances | <input type="checkbox"/> |
| New Equipment (last Mth) | <input type="checkbox"/> | Private home help | <input type="checkbox"/> |
| Other | <input type="checkbox"/> | Orthotics | <input type="checkbox"/> |
| Carer Support | <input type="checkbox"/> | | |

List of all equipment:

.....

6. What are you using at the moment?

- | | | | |
|---------------------------|--------------------------|--------------------|--------------------------|
| Continence Clinic | <input type="checkbox"/> | Meals on Wheels | <input type="checkbox"/> |
| District Nurse | <input type="checkbox"/> | Child Care | <input type="checkbox"/> |
| Home Care 2000 | <input type="checkbox"/> | Needs Assessment | <input type="checkbox"/> |
| Nurse Maude | <input type="checkbox"/> | Lifelink | <input type="checkbox"/> |
| Personal Care | <input type="checkbox"/> | C.C.S. Home Health | <input type="checkbox"/> |
| Domestic Support | <input type="checkbox"/> | Equipment | <input type="checkbox"/> |
| Dom. Services (O.T.,P.T.) | <input type="checkbox"/> | Patient appliances | <input type="checkbox"/> |
| New Equipment (last Mth) | <input type="checkbox"/> | Private Home Help | <input type="checkbox"/> |
| Other | <input type="checkbox"/> | Orthotics | <input type="checkbox"/> |
| Carer Support | <input type="checkbox"/> | | |

List all equipment

.....

7. Do you live:
- | | |
|------------------------------|--------------------------|
| Alone | <input type="checkbox"/> |
| With a spouse/partner | <input type="checkbox"/> |
| Children under 18 | <input type="checkbox"/> |
| Adult children | <input type="checkbox"/> |
| Parent/s | <input type="checkbox"/> |
| Other Relative | <input type="checkbox"/> |
| Other, e.g. flatmate, friend | <input type="checkbox"/> |

Hospital/Rest home

8(a). Do any of these people provide you with any assistance because of your MS?

Yes No

If NO finish

8(b). Who

8(c). How do they help you? List tasks:
.....
.....

8(d). Does anyone else provide you with help? e.g. relative, friend etc.

Yes No

INCOME/EMPLOYMENT SECTION

1(a) Are you currently in paid employment?

Yes No

If NO go to Question 8. If YES complete question

1(b). Full time Number of hours:
Part time Number of hours:
Self employed Number of hours:

2. Are you able to do your paid work from home?

Yes No

3. Approximately how many days have you lost from paid work in the last six months because of M.S. related problems?

.....

4(a). Have your work hours ever been reduced because of your M.S. related problems?
Yes No

If NO go to Question 7

4(b). If YES, in what year did your first reduce your hours?

5. Have your work hours returned to their usual level?

Yes No

6. If NO, by how many hours have you reduced your paid work per week since you have had M.S.?

Number of hours: Hourly rate: \$..... (if known)

7. Have you changed, at any time, the type of paid work you do, because of your M.S.?

Yes No

If YES go to Question 11

If NO, list changes, go to Question 11

.....
.....current position year started:

8. Why are you not in paid work at present?

9. How long is it since you were in paid employment?

Weeks Months Years

10. What was your annual income when you left paid employment?

11. For people living with a partner. Has your partner left paid work to assist you?

Yes No

11(a) Ever left work to assist you?

Yes No

PARTNER

12. This question to partners. Have you reduced your hours of paid employment because of multiple sclerosis?

Yes No

PARTNER

12(a) Have you increased your hours of work because of MS?

Yes No

13. Are you able to remember what your maximum annual income was before you stopped paid employment, or reduced your hours because of your M.S.

Amount: person with M.S. Year:

Amount: spouse/partner/carer Year:

14. How much is your annual income now?

Amount: person with M.S.

Amount: spouse/partner/carer

15(a). Are you receiving any means-tested benefits?
(Explain if necessary, e.g. sickness, invalids)

Yes No

If NO go to Question 16

15(b). Which benefit/s are you receiving? (Tick all appropriate)

AMOUNTS

Sickness Benefit
Invalid's Benefit
National Superannuation
Family Support
Widows
Accommodation Allowance
Domestic Purposes Benefit
Unemployment and Training
Independent Youth Benefit
Job Search Allowance
Training Incentive Allowance
Special Benefit
Emergency Benefit

- Disability Allowance
- High Use Card
- Community Services Card
- Other

15(c). Which of the benefits that you receive are because you have M.S.?

.....

16(a). In the last five years have you had a grant from lottery (not for a car) or any other private trust or source (e.g. Hyman Marks Trust)?

Yes No

If NO go to Question 17.

16(b). What was the grant for?

16(c). How much was the grant?

17(a). Have you received any support form ACC due to injury related to your M.S (e.g. a fall, burn)?

Yes No

If NO go to Finance Section.

17(b). **If YES** please tell me what support you received (e.g. home help, personal care hospitalisation, income).

List support received:

.....

.....

FINANCIAL SECTION

All costs recorded relate directly to multiple sclerosis costs only

1. In the last five years have you paid for any alterations to your home?

Yes No Amount: Year:

1(a) Have you had any home alterations paid for by the hospital system in the last two years?

Yes No Amount: Year:

2. In the last five years have you sold anything to assist your finances because of your M.S.? (e.g. house, car, land)

Yes No

3. What? Amount: Year:

4. In the last five years have you moved into cheaper accommodation because of your M.S.?

Yes No Year:

5. In the last five years have you bought a more expensive house to accommodate your M.S.?

Yes No Year:

6. In the last five years have you paid for any of the following additional services over the last 12 months because of your M.S.?

- | | |
|---|------------|
| Gardener/lawn cutting | p.w. |
| Home help (private) | p.w. |
| Meals service | p.w. |
| Child care | p.w. |
| Personal help (e.g. showering) | p.w. |
| Podiatrist (private) | p.w. |
| Shopping | p.w. |
| Other, list: (e.g. hairdresser at home) | |
| | p.w. |
| | p.w. |
| | p.w. |
| TOTAL | p.w. |

7. Do you receive any informal financial help from anyone, e.g. family members?

Yes No Amount: p.w./month

8. Have you paid for any other items to assist you (e.g. commode, new bed, garage door opener, continence supplies) in the last two years?

Yes No

If NO go to Question 10

9. Please tell me what they were:

List	Cost	Date bought
.....
.....
.....

10(a). Have you spent any money on maintaining equipment to help your M.S. in the last two years?

Yes No

10(b). Please state the item/s amount

..... amount

..... amount

TRANSPORT SECTION

1. Do you drive?

Yes No

If YES go to Question 2

If NO go to Question 3

2. Have you upgraded your car in the last five years only because of your M.S.? (e.g. automatic, power steer, etc.)

Yes No

3. Have you had a car suspensory loan in the last five years?

Yes No Amount: Year:

4. Have you ever had one?
Yes No Amount: Year:

5. Do you still have that car?
Yes No

If NO explain

6. Have you had hand controls fitted or other alternations done?
Yes No Amount: Year:

7. Did you pay for these?
Yes No Amount: Year:

or DID NZISS/SRHA pay?

Yes No Amount: Year:

8. Do you have a NZISS/SRHA car loan now?
Yes No Amount: Year:

9. Have you had a lottery grant for a car?
Yes No Amount: Year:

10. Have you had a driving assessment at Christchurch Hospital?
Yes No Year:

What forms of transport do you use?

- Family or own car
- Car driven by other person
- Taxi/maxi taxi
- Maxi taxi only
- Bus
- Other

Total weekly transport costs

N.B. Questions relating to M.S. transport costs will be itemised in relation to G.P. visits, hospital visits/treatments, etc. as M.S. related transport costs.