

**Chronic Disease Self-Management Program  
in Vancouver and Richmond**

**Program Evaluation**

**September 2001**

**Patrick McGowan, Ph.D.  
Institute of Health Promotion Research  
University of British Columbia**

## **IMPLEMENTATION AND EVALUATION OF THE CHRONIC DISEASE SELF-MANAGEMENT PROGRAM IN VANCOUVER AND RICHMOND**

### **A. GOAL OF THE PILOT PROJECT**

In April 2000, the Institute of Health Promotion Research, University of British Columbia received a grant from the Community Health Initiative Fund - Vancouver Richmond Health Board to carry out a pilot study to implement and evaluate the Chronic Disease Self-Management Program (CDSMP) in Vancouver and Richmond. The CDSMP had been implemented in several American states since 1996 and a similar program has been used in all Canadian provinces to assist those suffering from arthritis.

The objectives of the project were to:

1. determine whether the program is feasible, viable, and acceptable to persons experiencing chronic health conditions;
2. evaluate this program in terms of changes in behaviour, health status, and health care utilization;

### **B. PROGRAM DESCRIPTION**

The Chronic Disease Self-Management Program (CDSMP) is a six-week (2.5 hours per week) program taught by pairs of trained lay leaders who follow a Leader's Manual in community settings (senior centers, libraries, hospitals, and recreation centers). Between 10 and 15 people with chronic conditions and their significant others attend each program. The CDSMP teaches the following content:

- how to develop an exercise program,
- cognitive symptom management,
- nutrition management,
- breathing exercises,
- problem solving,
- communication skills (with family, friends, and health care providers),
- use of medication, and
- how to deal with the emotions of chronic illness (anger and depression).

Sessions are highly interactive, with emphasis on strategies to help individuals manage more effectively. It includes skills mastery (accomplished through weekly contracting to do specific behaviours and through feedback) and modeling (accomplished by lay leaders with chronic conditions) and uses frequent group problem-solving sessions.

### **C. IMPLEMENTATION ACTIVITIES**

There were six major implementation activities:

1. establishing a Community Advisory Committee to oversee program implementation and delivery;
2. creating general awareness among seniors and health care professionals;
3. hiring a co-ordinator;
4. training persons to deliver the program;
5. delivering the program; and
6. ensuring program materials are available and used appropriately.

1. Establishing a Community Advisory Committee

A 16-member Community Advisory Committee guided implementation and evaluation activities. Committee members were:

<i>Name</i>	<i>Organization</i>
Heidi Andrie	West End Seniors Network – Peer
Bonnie Boieeie	Chronic Disease Self-Man Leader
Mary Brown	Chronic Disease Self-Man Leader
Julie Crichton	V/RHB Volunteer
Betty Darragh	Healthy Heart Helpers Association
Judy Hunter	Arthritis Society
Yasmine Ghulamali	CHC # 6
Tom Kinloch	South Granville Seniors Centre
Patrick McGowan	Institute of Health Promotion - UBC
Jane Lee	SUCCESS
Munna Prasad	CHC # 6
Dr. Chris Rauscher	Geriatric Consultant - VRHB
Brenda Reynolds	Community Developer, CHC 7
Anne Riddick	Arthritis Society
Val Upton	V/RHB – South Vancouver
Erlene Woollard	Self-Help Resource Association of B.C.

During the course of the project the Community Advisory Committee met four times.

2. Creating Awareness

The project started in April of 2000. Appendix C lists the presentations made to health professional and seniors groups.

3. Hiring a Program Coordinator

The coordinator job description was developed with assistance from the Community Advisory Committee. The position was awarded to Barbara Henn-Pander.

4. Training Persons to Lead the Program

To lead the program interested persons must successfully complete a four-day Leader-Training Workshop led by a Master Trainer. Persons must demonstrate they can lead the program following a Leaders Manual. During the project period (April 200 - March 2001), seven Leader Training Workshops were held and 80 Leaders were trained.

5. Delivering the Program

During the project period the program was delivered 29 times and involved 314 participants.

6. Ensuring Program Materials are Available and Used Appropriately

Program materials consist of the following:

a) The Leaders Manual. This manual was given to each program leader during the four-day Leader-Training Workshop. Leaders follow the protocol when delivering the program.

b) The Master Trainers Manual. This manual was given to the three persons who became trained as Master Trainers. This manual is followed when Master Trainers train new program leaders.

c) The Course Participant's Book. All participants received copies of "*Living a Healthy Life with Chronic Conditions*", a book prepared for use in the program by the program developers.

d) Program brochures. A supply of program brochures was developed and distributed.

## **D. PROGRAM EVALUATION**

Evaluation of the program was conducted by a research team from the Institute of Health Promotion Research, University of British Columbia, headed by Dr. Patrick McGowan. Two studies were conducted:

1. A quantitative study based on the pre-course and six-month follow-up questionnaires;
2. A qualitative study based on in-person interviews with 30 course participants who was completed six months post-course.

### **A - Quantitative Study**

During the project period (April 2000 - March 2001) seven Leader-Training Workshops were conducted and 80 persons became qualified leaders. These leaders led 29 CDSMP courses that involved 314 course participants. Two hundred fifty-nine (259) course participants completed pre-course impact questionnaires (Appendix A) before they started the program, and 105 participants completed it again six months later. The questionnaire contain three basic types of measures:

- 1) Self-management behaviours;
  - Amount of time doing aerobic exercises,
  - Amount of time doing stretching and strengthening exercises,
  - Coping with symptoms,
- 2) Self-efficacy levels;
  - Self-efficacy to perform self-management behaviours,
  - Self-efficacy to manage disease in general,
  - Self-efficacy to achieve outcomes,
- 3) Outcomes regarding health status and health care utilization;
  - General health,
  - Illness intrusiveness,
  - Depression,
  - Physical abilities,
  - Energy and fatigue,
  - Health distress,
  - Fatigue,
  - Shortness of breath,
  - Pain severity,
  - Daily activities,
  - Medical care use.

Descriptive analysis was conducted with data collected from the 259 participants who completed the pre-course questionnaires. Impact analysis was conducted with data from 105 questionnaires completed by persons completing both the pre and post-course questionnaires. To allow for the 6-month time period between the pre- and post-program questionnaires, the analysis was not completed until September 2001.

## Findings

Two hundred fifty-nine participants completed the pre-program questionnaire. The majority of persons (77%) indicated that English was their mother tongue, 36% were married, and 59% of persons had more than one chronic health condition. The most common health condition was arthritis or other rheumatic disease followed by diabetes. Participant ages ranged from 29 to 100 years with the average being 67 years (SD=15). The mean education level was 13 years (SD=3). Eighty percent of participants were female.

Pre- and six-month post-program questionnaires were completed by a total of 105 persons. Health measure scores were computed and compared between the two time periods to calculate whether differences were statistically significant. Table 1 shows the pre- and post-program scores on each measure as well as t-scores and significance levels.

**Table 1. Pre- and six-month post-program scores on outcome measures (n=105).**

MEASURES	Pre	Post	T	Sig. (2-tailed)
<i><b>Self-Management Behaviours</b></i>				
Coping with Symptoms	1.68	1.90	-2.03	<b>.045</b>
Time doing aerobic exercises (min.)	6.46	5.77	.184	.854
Time doing stretching/strengthening	61.38	53.28	1.28	.207
<i><b>Self-efficacy Measures</b></i>				
Self-efficacy to manage symptoms	5.19	6.23	-3.49	<b>.001</b>
Self-efficacy to control/manage depression	5.49	6.38	-2.51	<b>.014</b>
Self-efficacy to manage the disease	6.43	7.43	-3.77	<b>.000</b>
<i><b>Health Status / Health Care Use</b></i>				
General Health	3.30	3.02	3.53	<b>.001</b>
Illness Intrusiveness	30.37	31.11	-.54	.589
Depression	20.47	19.76	.77	.446
Physical Abilities	.29	.35	-1.99	<b>.050</b>
Energy/Fatigue	2.31	2.34	-.38	.706
Health Distress	1.94	1.72	2.57	<b>.012</b>
Fatigue	4.69	4.23	2.33	<b>.022</b>
Shortness of Breath	2.93	2.54	2.01	<b>.047</b>
Pain Severity	4.04	3.47	2.50	<b>.014</b>
Daily Activities	1.36	1.46	-1.30	.199
Medical Care Utilization	3.03	3.17	-1.25	.216

Statistically significant changes (bolded) were observed in 10 of the 17 outcome measures. At six-months post-program, participants:

1. were practicing more ways of coping with their symptoms;
2. had a higher level of self-efficacy to manage their symptoms;

3. had a higher level of self-efficacy to control/manage depression;
4. had a higher level of self-efficacy to manage their disease;
5. believed they had better health;
6. were less limited in their daily activities;
7. were less bothered by their illness;
8. were less distressed about their health condition;
9. were experiencing less shortness of breath; and
10. were experiencing less pain.

## **B - Qualitative Study**

The qualitative survey was based on in-person interviews with a convenient sample of 27 program participants. A member of the research team contacted program leaders and asked them to nominate names of persons who they felt would have opinions about the program. Thirty names were randomly selected, and interviews were completed with 28 persons. The interviews were conducted by four members of the Project Advisory Committee who received training and support from Dr. McGowan.

A set of interview questions (Table 3) was developed by the researcher in consultation with program leaders and then reviewed and modified by the Community Advisory Committee.

**Table 3. Chronic Disease Self-Management Program qualitative study interview questions.**

- |   |
|---|
| <ol style="list-style-type: none"> <li>1. <i>What did you get out of the course?</i></li> <li>2. <i>Has it helped you cope with or manage your condition? (Please explain)</i></li> <li>3. <i>What are the main things you learned - the things that have stayed with you the most?</i></li> <li>4. <i>How has it changed your future outlook? (Please explain).</i></li> <li>5. <i>What are you doing differently now than you were before taking the course?</i></li> <li>6. <i>What did you get out of the course that you have not been able to get elsewhere?</i></li> <li>7. <i>What was it like taking the course as part of a group?</i></li> <li>8. <i>What part did you like the best/the least?</i></li> <li>9. <i>If you wanted a friend to take this course, what sorts of things would you say about it?</i></li> </ol> |
|---|

With subjects' approval, the interviews were taped. The interviews ranged from 30 to 60 minutes in length, with an average of about 45 minutes for each interview. The tapes were then transcribed for analysis. The qualitative analysis was completed by a research assistant and Dr. McGowan and the preliminary findings were reviewed by members of the project advisory committee sub-committee who completed the interviews.

## **Findings**

### **Question 1. What did you get out of the Chronic Disease Self-Management Course?**

Respondents identified a number of short-term and long-term benefits of taking the course, which include: gaining awareness of self and others; building a strong knowledge base; and developing or enhancing coping skills. These benefits were the direct result of the opportunities for group interaction provided in the course; the information presented by leaders; and the text used as course material.

The group format was identified as one of the best features of the course. The majority of respondents reported feeling encouraged in regards to their own situation, and more empathetic towards others:

*"Well it changed my life in this sense, since I've got diabetes. I got a lot of courage out of it. A lot of courage and encouragement... when I saw those people come in with real hardships that they had to live with and some of them still could crack a joke and smile."*

*"Once you get to know people and start talking about your experiences, it's really exciting. We had a lot of laughs."*

*"It was good to hear what other people had to say. And there was a book and it was excellent!"*

*"...going to a course like that, you hear how many problems other people have and how lucky you are to be healthy. There's always somebody worse off."*

*"I think it sort of made me a bit more aware of what people have to deal with on a daily basis and I think that's been helpful and to be maybe a better listener and pick up what people are telling me and maybe get better information from them. So I'm not just sort of taking things for granted."*

Participants developed a sense of camaraderie from working together on common goals. A number of people mentioned feeling accountable for completing their weekly action plans, which helped them in setting realistic goals and working towards completing them.

*"I gained further information on my own condition. I tried listening to other people when they spoke and picked up various points from them."*

*"I liked the accountability factor of having to complete that plan and then what it does is it makes you really actually work on different areas that you're concerned about. I liked the way it sort of as part of the program every week."*

The majority of participants reported gaining or enhancing their awareness of the need to engage in self-care behaviours on an ongoing basis in order to maintain their general health and prevent further complications.

*"I realized how important it is to look after yourself and that certainly preventative is really important."*

*"I got an awareness about the importance of exercise and diet with the condition that I have, which is arthritis, and the reinforcement of having to do certain things every week at a certain time and kept me more mobile than I usually am."*

*"I thought it made me very conscious that you have to look after yourself and your health."*

One respondent noted his difficulty shifting from a caregiver role to a position of self-care. The course helped him gain a new perspective:

*"It gave me the realization that I have to be more serious about my exercises, not to think [that] my problems are not important. I had heart surgery, and I had to do cardiac work-outs, but I never found times for myself. I've been thinking to provide [my spouse]*

*with the comfort and the security, and I didn't realize I had to think of myself. If I don't think of myself, then I won't be able to help her."*

Participants enjoyed learning about different illnesses, which gave people a sense of being better prepared in the future, as well as giving them a more positive perspective on their present circumstances:

*"I listened to everybody you know and I learned what I could do if I ever got anything else."*

*"More confidence in myself."*

The book was also identified as a useful source of information, both as an aid to the course, as well as an ongoing reference. One respondent felt that it was a culturally appropriate/sensitive resource, which allowed sufficient flexibility for traditional cultural practices to be integrated into people's care plans.

Practical coping skills were identified as important benefits of the course. Among them, the action plan, relaxation techniques and communication skills were most commonly noted to have been used by participants in managing their conditions.

*"The most important were the relaxation techniques and how to talk to the doctor and other medical professionals, as well as generally learning about diseases and how to deal with stress."*

*"It helped me manage my condition, and one of the best things that I learned from the class is just being able to communicate with my doctor and set plans for myself. I can manage my condition and be more comfortable with it."*

*"I learned to get a game plan going and to stride to do it every week and that if you're not completely successful it doesn't matter and that even accomplishing a little bit, it's better than not accomplishing anything at all."*

*"...we did the relaxation things from the book, and some of [us] almost fell asleep. They got so relaxed. It turned out to be very helpful."*

*"I thought the course was excellent. I thought it had a lot of good components and I liked the way it had good practical information, but also looked at lifestyle and problem solving and taking things step by step - step by step problem solving, it made a lot of sense. It made me understand the big picture a lot better in terms of adaptations people make to cope with their conditions."*

*"I thought goal setting was good – like you had to have weekly goals and then you assessed yourself and I have kept some of those goals, which helped me feel more in control."*

*"Certain things I found useful like: relaxation techniques, visualization, guided imaging, good communication skills using the "I messages" rather than the "You messages", fitness and moderate amounts of exercises were also helpful and also making go out with action plans. I think that's particularly effective."*

**Question 2. Has it helped you cope with or manage your condition?**

For many participants, the program reaffirmed the need to pay closer attention to their condition. Some people had given up on finding proper treatment and through the program they gained hope and the skills necessary to seek further medical attention. For others, the need to prioritize self-care over other activities was highlighted.

***"I went back to my doctor, after many years of not finding proper treatment for my back, and asked what should I do, where should I go. I ended up having an MRI and finding out what exactly was wrong with my back. Now I know to ask questions, to write down what is important."***

***"It helped me cope a lot because I realized I had to question [things]. I was trying too hard to get too far ahead and fast. And people would say, "you look good, what's the matter, you need some good cracking." And so I was pushing myself! And this [course] thought me. It's true, step by step and you'll get there faster. You'll get there even faster and then you're not putting yourself in any kind of jeopardy by trying to do something that you're [not capable]."***

***"It helped to cope better. It helped me to think of myself, to be selfish in the giving of support."***

Some participants found the group experience itself aided them in their ability to cope. The group format allowed for mutual support and sharing of practical ideas instead of "hiding and hurting" in isolation, as one participant noted.

Overall, the program offered a number of ideas and skills which were immediately relevant for participants, as well as useful in the long term. Many felt better prepared to plan for the future, to be pro-active in taking steps for a healthier lifestyle. As one participant noted, the program encouraged a "positive outlook on life" and being pro-active in planning for retirement and the future in general:

***"I particularly enjoyed the retired medical doctor who spoke in general terms about maintaining a positive outlook on life and about planning ahead before you retire. It was a very inspiring talk about living your senior years, and not only about seniors, but I recall, he related it to young people and how we must continue to involve ourselves with young people."***

The information on nutrition and the interactions between foods and medications was found particularly useful, helping participants make healthier choices in their diet. For pain management, the relaxation techniques were most useful. The majority of participants also identified the physical exercise component of the program to be of great benefit, despite various physical limitations:

***"[The program] helped by bringing the value of good nutrition and exercise to my attention. Although I was aware of it all my life, I think we all tend to ignore it."***

***"[I got my] medications under control and am walking so much. Just even walking in the apartment and being very careful, because I don't want to have another fall."***

***"It's made me realise I needed more exercise than I was getting. I'm diabetic so I have to, you know watch my diet and do exercise or keep mobile."***

***"I have this series of exercises I do everyday and it has helped me to maintain what I have left. And I don't have that much pain now."***

***"One of my action plans was to go out walking, so it's good for me to get some exercise that would help with my chronic fatigue."***

Other practical skills regarded as particularly useful for on-going management included charting and developing an individual action plan. These were skills that helped most to initiate positive change in their lives and later maintain a healthier life-style:

***"I developed my own charts for my medication and then afterwards I used it for a while I added it for vitamins that I am taking, and I find that at least I was consistent in taking my medication which is important. It wasn't you know did I remember to take this and that. I've added something very important in these last couple of weeks. I even have on here what days to fish."***

Perhaps the most significant result of the course was that it gave participants confidence to set boundaries, communicate more openly with medical practitioners and family members, and take greater charge of their own care. Months after the program, respondents felt better able to engage in managing their conditions as well as their daily lives.

### **Question 3. What are the main things that you learned – that have stayed with you the most?**

The majority of participants identified an overall sense of awareness for the need to be actively engaged in the process of managing one's own condition. The idea of being in control over one's own well-being by staying informed and taking a pro-active approach to health management is key to this process:

***"[What stayed with me the most is] the necessity of taking some control over your own health, particularly in this time, when other people don't have resources. And for people who are getting on in years, the responsibility is theirs because you don't get younger - you get older."***

Respondents identified self-discipline as another factor that is important for long-term self-management. While many of the course components were perceived as useful, the main challenge people had was to continue integrating what they learned into their daily lives. The Action Plan was recognized as most effective in reinforcing such consistency:

***"[You learn] to try and look after yourself, try to eat well and to rest. You learn to make a game plan, but not one that's really difficult, and to slowly build on it so that you have a short term goal and then a goal for the week, then a goal for the month and then a goal for 6 months. I think that really made a lot of sense - just do things gradually and you'll turn out doing okay in the end."***

***"It came through a lot clearer for me that it's back to self-discipline."***

For most participants, the book remained an important source of information, serving both as reminder and resource for further inquiry.

***"I wrote down a little thing here, which I'd like to get further help from the hospital and they won't take me because they said they don't have the resources... I've been***

*reading though Chapter 3, "Finding Resources", and finding out where I can go. I feel I can do more than what I'm doing now, so I'm reading that chapter. "*

*"It's a good reference book to look back in for everything and anything. If you want, you can just look it up and the keyword is there. It's a good reference book and if there is anything that I'm concerned about, I can just take the book and look it up and see what they say about it."*

Furthermore, respondents identified concrete program components they had integrated into their daily routines, such as exercise, relaxation techniques, using an action plan, eating a healthy diet, communication, avoiding interactions between medications:

*"...Four things that I found most useful were the relaxation techniques, good communication, fitness and making you go out with the Action Plan."*

*"I do a regular exercise, and then I diet and write everything down that I eat, but basically I now do those horrible exercises that they tell you they'll get you better."*

*"Now I do a little bit [of exercise] every day, whereas before I used to wait until I felt like doing something. I do 45 minutes a day, sometimes just 30 and I tell myself, "I'm a healthy woman looking after a sick poor old lady."*

*"I have changed a bit- I started doing exercises and drinking less coffee."*

*"I have pretty realistic goals, like increasing my water, pacing myself, so that I can break down chores into smaller steps and now I feel confident that even if it takes longer, the chores will eventually get completed."*

*"How to be more aggressive, a little more sure of myself."*

*"I began to really look after myself and to do the things they suggest to you in the program. I mean they tell you what foods are good for you and what it does for you and I really try and manage to stay on top of it rather than just leaving it – to get the best of me."*

*"Relaxation techniques and the action plan, writing down things. If I'm too stressed, if I get too tired, I put on the relaxation tape."*

*"When I get prescribed a medication, the doctors are aware of what else I'm taking. Not only in terms of prescriptive drugs, but non-prescriptive - supplemental vitamins and that sort of thing. I wasn't aware of that before."*

*"Making a plan and sticking with it. I'm walking on the stairs and I'm eating properly, you know looking after myself the best I can. So far I'm successful!"*

Most people indicated feeling better about themselves once they gained the confidence to engage in a variety of self-care activities they had previously perceived as overwhelming. A common conception prior to taking the course had been that the illness defined one's ability to engage in day-to-day activities, leaving many feeling hopeless and lacking a sense of control. The group interaction and practical information provided by the program provided participants with a sense of empowerment, which allowed

them to gradually feel more in charge of their lives, be proactive, and seek creative solutions to daily challenges.

Respondents indicated that being part of a group allowed them a unique opportunity to interact with other people who were often facing greater challenges than themselves. Through this process, participants developed a sense of empathy for others and a better understanding for the need to communicate clearly and openly in their interactions with people, as well as the need to become better listeners themselves.

***"I think it made me more aware of what people have to deal with on a daily basis and I think that's been helpful, and to be a better listener and pick up what people are telling me and maybe get better information from them."***

***"I had forgotten that other people are also having problems -physical, emotional. I came to realize that we are not alone. Just listening to people who presented their problems, I said 'we are not alone; here we are, other people have problems that they have to learn to cope with'... and it just woke me up."***

#### **Question 4. How has it changed your future outlook?**

Most people noted a shift to feeling increasingly positive about the future. Much of this change was attributed to gaining a sense of control over one's own well-being. The course emphasised the link between taking care of oneself and having a better quality of life. As participants focused their energy on self-care behaviours, they were able to experience a number of positive effects, which in turn provided encouragement for continuing and expanding their efforts. Through this process, respondents identified becoming more hopeful about their future, feeling more confident about their abilities, more realistic about their limitations and better prepared to deal with their medical conditions. One participant talked about his experience:

***"When I first realised how bad my heart was, I had no future outlook. I came home and sat and there is where I stayed. I wasn't eating properly. If someone said 'go for a walk', I'd say 'I'm too tired'. But I started attending lectures, getting information. I improved my outlook because I got myself in a stage where I'm content that I have to do these things. I will have to go for heart surgery, but my cardiologist put me on a program exercise, too. And I have improved, really, because I was worse. I'm living the best I can and I'm getting the very best out of each day."***

Other respondents talked about their improved outlook on life:

***"The program definitely made you realise that you got to look after yourself and if you look after yourself, it certainly helps you for the future."***

***"Well [my outlook] changed to the point like where I'm really-really strongly committed to exercise and I feel it's that important to keep it up."***

***"I accepted my future, I am very positive and strong in that one day we all got to go, and this could come unexpectedly. I am looking positively in that at least I have 8 to 10 years to give to my wife."***

***"I think I will manage. With the help of this course, I learned how to keep on exercising, how to keep myself healthy."***

***"It felt that I could have more control of my life and not be so overwhelmed with the pain. So, the future does look more hopeful."***

Once again, people readily identified the course components that contributed to building a more positive outlook. One participant noted the impact of better communication on the relationships with family members, and further the ability to cope with a chronic condition:

***"My outlook is a lot more optimistic. I feel more comfortable managing my condition. My daughter came with me to the course and I feel that she's more comfortable - we can talk about things that might happen in the future and some of those important issues. So, I think it's made me more prepared to deal with things with my family and with my disease."***

Other features of the program that were mentioned as major contributors to improving participants' future outlook include:

- exercise and breathing techniques that help manage physical pain and overall health
- the action plan for helping participants maintain their focus and be consistent
- connecting people with community resources
- communication skills that facilitate information sharing and active participation in one's own care
- the group format as a natural resource and social/support network
- emphasis on the need to be pro-active in seeking information and support

For some respondents, being part of a group where others experienced greater challenges inspired optimism, as they shifted their focus from their suffering to appreciating their abilities. Where the information was not directly relevant to participants, it was perceived to be useful in the event of future medical challenges, thus providing people with confidence for the future and practical, proactive ideas for ongoing self-care.

#### **Question 5. What are you doing differently now than you were before taking the course?**

Participants noted a significant change in their level of awareness, which had a direct effect on their confidence level and overall emotional state. The majority of respondents identified a variety of practical skills they incorporated into their daily routine, which they continued to use months after completing the program. These include: eating better, exercising, using relaxation techniques, communication skills, organisational skills (action plan). People also reported a shift from focusing on the need to cope with a medical condition to focusing on leading a healthier lifestyle:

***"The course really made me aware of the game. It's not just the physical/medical components of illness, but also stress and lifestyle and other holistic kind of components. It's given me a heightened awareness, a more realistic/holistic picture of life."***

***"I'm eating better. I'm just trying to improve myself with everything."  
"I have a different mindset toward the condition."***

*"I'm eating better, I'm getting out, and I've walked more since I took the course. Without the walking I stiffen up and the longer I become immobile, the more immobile I become. I have no desire to wind up in a wheelchair. I also attend an exercise class once a week."*

*"I'm certainly eating better and exercising better, looking after myself and really making an effort to exercise and to set goals that I can reach, that aren't really hard, so that I can gradually build up to a longer term goal."*

*"I'm eating better and I'm climbing stairs. I don't use the elevator. I use the stairs. I try to keep mobile, and that's something I really wasn't too interested in before."*

*"I do more exercise than I did before and I'm more aware of what I'm doing, more intense."*

Some participants also reported a shift in their self-perception, whereby they realized the importance of prioritizing activities related to their self-care. By taking time off for themselves and following a healthier routine, they found that they had more energy to do other things they enjoyed (socializing, volunteering, etc).

*"I got some time off for myself. I go for my walks at least 2 to 3 mornings and I go at least twice to the gym and work out. There are some things that I am not able to do, but not because I'm lazy or forget it, or neglect my health. It's just my situation that does not allow me to do them. But I make sure that I am number one, to be able to give to others."*

Another significant change was registered in participants' interactions with medical professionals. As people applied new communication and practical skills, they became more knowledgeable about their conditions and reported a sense of ownership over their own care. They reported becoming active participants in their treatment, seeking to form collaborative relationships with doctors and other professionals.

*"I'm carrying around a booklet with a record of all my medications when I travel, and I ask my medical doctor when I start taking something new whether the new drugs will interfere with medications that I'm already taking."*

*"Before the course, I would just go to the doctor and tell him that I'm very sick. He prescribed me muscle spasm pills and I would take them 3-4 times, and then he would tell me to try to take less because before long I could be in a wheelchair. My back is so bad, even the MRI people asked me how I could even walk. Now I know that there is something wrong and I have to keep more healthy, so that I can move around. I should not do things that are not good for me."*

The course helped participants feel greater control over their lives. Most respondents indicated a more positive perspective on life in general, while some people identified practical tasks that helped them regain a sense of ownership over their lives. One respondent talked about making final arrangements, securing a will, visiting family graves as activities that were personally meaningful and reaffirming. Others spoke in general terms of their improved emotional and psychological health:

*"I'm not so hard on myself. I find there are other people that look healthy, but aren't healthy, and that's been a major problem in life. People are like "what do you mean*

*you've got [a chronic condition]; I've known you for years, I never knew". So, I just don't tell them now. I just tell them that I'm busy watching a show or something, I'm not telling them my health problems anymore, whereas before I'd have to explain why I was in bed so long. I don't want their pity."*

*"I have more confidence in myself and making my mind work better. I'm firmly convinced about getting better through the mind. It was nice to have that feeling that I was thinking right all along."*

**Question 6.     What did you get out of the course that you have not been able to get elsewhere?**

Most participants identified the emphasis on self-care as one of the main elements unique to this course. While some participants had been exposed to principles of self-management before, the program helped them find realistic and practical ways to integrate and maintain specific self care techniques in their own lives.

*"A lot of it was reinforcement of things that I had learned before, but they brought it together and synthesised the whole picture for me."*

*"I liked the actual practical location of the principles, like the action plan; ...practical things about what to do about when to see your doctor."*

*"I'm certainly eating better and exercising better, looking after myself and really making an effort to exercise and to set goals that are goals that I can reach for and that aren't really hard so that I can gradually build up to a longer term goal."*

*"I wanted to have more exercise. I [started] walking up and down the stairs and I found that the muscles in my legs were starting to get sore. So I knew that I hadn't been using those strong muscles. I thought I got to get something that's a little more rigorous than what I was doing lying in bed, doing aerobics. Some of those exercises in the book are also good, like the top exercises."*

The focus on self-care encouraged participants to place greater priority on their health issues and needs. They realized that unless they took care of themselves first, they would not be able to help their loved ones. The program inspired overall confidence in participants' ability to lead positive, healthy lives:

*"...this brought the focus back on to me. Because if I don't stay well I can't be of any use to anyone else."*

*"Awareness! I think that was the main thing. Aware that you are responsible for your own health."*

*"I got a purpose. I got a lot of confidence out of this, at some times, very much!"*

*"It reinforces the positive aspects of old age to me."*

Respondents enjoyed learning in the group format. This allowed them to exchange ideas, obtain support from others who shared their problems, and establish new relationships.

*"The best thing about the course is the companionship."*

*"A lot of people were exchanging phone numbers and I think that's great. It's very important because a lot of people today are isolated. That would be the most helpful part of the whole thing - the feeling that you're not alone."*

*"I liked the sharing of the pain part. We were all there with some kind of pain. I've never taken a course like that, never as a group. It's always been physio or massage, always one-to-one from a specialist. These were more lay people sharing daily concerns. The emotions that went with the pain and how it's a whole life-style, it's not just "hey, I got a pain". No, it's 'you got pain today and you can't go out today and you have to cancel that wedding or that birthday party you're looking so forward to', and then you get depressed because you're isolated. So I was able to share that part. That was nice."*

*"I've never been to a course like that where I got the support of everybody else. Just having the ideas presented to you made you stop and think about everything and then having the feedback from everybody in the course really made you think that you got to look after yourself. You also get a better outlook on life."*

*"It's just the comfort and support that I've never gotten from my doctor before and it's always been uncomfortable talking with my family. Meeting with people who are dealing with the same things as me has given me a lot emotionally, and I think that's something I wouldn't be able to get anywhere else."*

*"I really liked the people in our class. The thing that I really enjoyed was getting a picture that there are people who are dealing with things on a daily basis in a very good way, who are keen to make good improvements in their life. I was very impressed with that."*

Many participants noted that some of the program leaders were especially approachable and helpful, which contributed to creating an overall atmosphere of safety in the class:

*"I felt that if you wanted to talk to the leaders personally, you could contact them. They were very open with their phone numbers and things of that nature, so I feel like there is a lifeline if you need it, as a resource that perhaps you wouldn't have."*

Lastly, people talked about the book used in the course as a unique and very useful resource. Many people continued to use it as a key reference months after they had finished the course:

*"As a matter of fact I got the book here. I got a lot of this stuff from the book. I do look over it and that."*

*"Excellent book! Just opening it, there's stress and emotion that plays a great deal in our life and [it reminds me that] by getting out walking, you walk away from it."*

#### **Question 7. What was it like taking the course as part of a group?**

The group format was often noted as a positive aspect of the course throughout the interviews. Participants enjoyed learning from each other and developing a sense of camaraderie with people who shared and

understood their problems. For many, witnessing other people dealing with similar or greater challenges, helped them accept their own problems and initiate proactive steps in their self-care. Many respondents noted their initial surprise at realising that they were not alone in their suffering and that there are many people in even worse condition who are able to maintain a positive outlook on life.

*"It was good to be with a group of people and hear their problems and feel sympathetic and know that they were sympathetic to me."*

*"It was good because we got to open up and discuss everything. We did discuss everything!"*

*"When I saw those people come in with real hardships that they had to live with and some of them still could crack a joke and smile. They gave me such encouragement!"*

*"The group was fun. It started out a little bit droopy and gloomy, people were sort of concentrating on the problem and towards the end people were more concentrating on solutions. There were some people like myself... solutions for me are things that make you feel good. You may feel crummy, but I'm always around flowers, animals, nice things and I think anything in your environment that you can do like that to make you feel good is very important."*

*"It didn't make me feel like I was handicapped more than somebody else. I had a chance to see other conditions and how people felt about their condition. A chronic condition is a chronic condition; everybody feels a little different with it. And people have different ways of coping with it. So you find out different methods of coping. It takes you away from yourself when you listen to other people and see what they have to go through, and that it's not just you."*

*"The support was the main thing that I got from the class, in that everybody contributed their ideas about how they were dealing with their problems, and that helped me deal with mine. Sometimes that made me realize that I was better off than I thought I was."*

*"It was good. You were listening to what everyone had. When I heard what this lady had, I thought 'if I think I have a problem'... this woman had so many things."*

*"I just liked the experience of being part of the group and seeing people who are adapting and getting on with things."*

*"When everybody in the group tells you that one person in the group is sick with diabetes, another is sick with back pain, heart disease or something else, you feel a little bit better. I am not alone."*

*"Having it as a group was really good. Everybody at the beginning said their names and what conditions they had. As the weeks went on, we all set goals and some of the goals that were set by other people just seemed like some things were so hard for them to do... Having all these other people there makes you realize how lucky you are and that there's always somebody worse."*

For some participants, being part of a group helped them realize the importance of socializing. This was particularly significant for those who had limited or no interactions with people outside their family.

***"I felt so alone with my problems because I have been stuck in the house. I wasn't getting out, not meeting people. After coming here I realized I've got to get out more and be with people. I was very impressed with the whole thing!"***

People enjoyed the opportunities for informal interactions created throughout the course. For example, participants used the breaks to further get to know others in the group on a more personal level. Some found the group to be a good resource for other issues they had in their lives:

***"At break time, people get to talking and suddenly they'll say "well, you know, I have this situation and I didn't know how to deal with it; have you had it?" And if you say "yes", "what did you do?" And this exchange, trying to get information can be very helpful."***

***"Meeting people... that was nice. We kind of got really down to as if we had known each other forever, which was nice. Yet, they were complete strangers that were sharing intimate things. I had never done a group like that."***

Most participants found the group to be fun. For the majority, no lasting friendships were initiated during the course. However, they found the atmosphere to be friendly and had a sense of safety, which encouraged sharing their experiences in confidence. This brought a sense of mutual support among participants.

***"It was nice meeting with most of the group members, exchanging ideas, sharing some experiences..."***

***"It was good! It was fun! The socializing was very important."***

***"You made new friends. In my group, there was one other Jewish lady, and prior to that I would pass her and she would pass me, but now we stop every time we see each other and we want to know how we're doing and we ask particular questions regarding health."***

***"Well it was friendly, it was relaxed, it was informal."***

***"We don't hear from the others but we became friendly and discussed different source of things – family things and it was quite interesting. I enjoyed it!"***

***"...overall, the social interaction... the part of being a group helped. Knowing that everybody was confidentially in the group, sharing the information..."***

Most respondents credited their success in following through with their individual action plans on their participation in the group. They felt safe sharing their successes and difficulties and felt supported in seeking new and realistic ways to cope with their conditions. If they lacked the motivation to follow through with their plans on their own, having to report back to a phone 'buddy' and then to the group, provided the needed incentive.

***"When we got back together the next week, we would all support each other and kind of pat each other on the back if we achieved our goal. And if we didn't achieve our goal, the rest of us were there to say "oh well, that's okay, you'll do it better next time."***

*"If you make an action plan, you have to tell in front of everybody what you completed, what you did not complete, why you did not complete, and then fix that one. If you cannot complete, you should do it maybe another way. And for that, it is better with a group because you know that other people are suffering from diseases, and that's important. And it makes you stick to your action plan because you have to come back and say something in front of the group. If you are alone, it's easier to say 'I can't do it'."*

*"Well during my group, I was paired up with a phone buddy and I was keeping in touch with him and in some ways that kind of remind me or encouraged me to follow my Action Plans."*

When asked which aspect of the group participants liked most, the overwhelming majority noted the opportunity for socializing created by the group format. This was done in the context of the group through direct participation in formal group discussions, through interactions during coffee breaks and through contact within the 'buddy system', outside of class. Some participants wished that there was a regular follow-up for the course. While most people exchanged phone numbers while attending the course, and most noted having enjoyed the 'buddy system', once the program was over, few of them kept in touch on a regular basis.

*"I enjoyed it. I wish that there was a 2-year social or 1 year coffee or something under \$5, that we can just meet and whoever wants to show up; no commitment, because friendship takes time, but just to meet once in a while and touch base would be nice."*

#### **Question 8. Which part did you like the least of the group?**

Many participants noted that they liked all aspects of the group experience. Some of the older participants noted that they had difficulty being in the same group with younger people who had not had a chance to resolve their feelings about grief and loss.

*"There were young people who were having difficulty in coping with their life and they were much younger than me. They were very nice, but I didn't find it as interesting, really. I think that everybody needs to talk about all kinds of subject, but these people have ideas that I had when I was that age. But, of course, you work through them."*

One participant found it difficult to cope with people who appeared resigned about their condition and the ensuing difficulties or who were not progressing at the same pace as the rest of the group.

*"...some people... I felt like shaking them because they were too entrenched in talking about the problem. Well, do something! I don't care what you do, do something. There is always something you can do. If it's no more than picking up the Yellow Pages. Sometimes people need somebody to be that frank, but that wasn't that type of arena, to be that frank."*

*"It's actually a difficult class. We had one person who had a lot of needs and really wasn't listening. That's a challenge because you can only do so much with someone like that, right? And that was a bit of a challenge for the group and certainly a challenge for the leaders, which I think they managed very, very well."*

A few participants noted structural difficulties with the group. The lack of ground rules regarding

timelines was cited as a major problem for one group:

*"There were a couple there, a man and a woman - very nice to talk to, but they were these people that were always late. And one day we waited for half an hour for them to arrive; and because they were late coming, we couldn't have our break, because they also wanted to leave early. Now, this totally upset me."*

Some respondents had a hard time keeping up with the assigned reading. A few respondents talked about their initial reluctance to share their problems with a group of strangers, while others felt that they did not have sufficient time to share:

*"...having to talk about my personal problems in front of everybody. It was difficult and I felt a little bit awkward... but it was helpful to open it up..."*

*"Sometimes you couldn't spend as much time sharing as you'd like. But on the other hand, the course material was well laid out and positive and I think it had to be done. I think that's always a trick, isn't it?"*

#### **Question 9. If you wanted a friend to take this course, what would you tell them?**

The majority of participants said that they would or have already recommended the course to their friends. They would describe the course as fun, an opportunity to learn new coping skills, to socialise, to be in a supportive environment.

Respondents identified the textbook as a great resource that one can keep after the course as an attractive feature of the program:

*"I thought [the book] was excellent! I gave it to my sister to read because she's got a long-term disability and she was quite impressed with it."*

Participants' comments:

*"I would tell them to take it and expand all their efforts to you know, doing what the course says. I would tell myself the same thing."*

*"Well anybody that I know that has a pain condition or that, I tell them about the course and tell them what the course involved."*

*"I went to the first night and I thought, 'Oh this would be a good course for my girlfriend who has arthritis.'" and so I got her to come the next night and she came for the rest of the time."*

*"I would suggest to anybody who has a problem – get out and take a course like this. It will help anybody."*

*"I would suggest to my friend that there is a lot to learn about medications and about how best to manage them, especially as you tend to increase the number of medications."*

*"It would be good to go, because he would realize what I realized: that he is not alone with his problem, physical or emotional, and in the group he would find most strength. I would encourage him to go."*

*"I already encouraged my friend to go there. At home you are depressed and you don't know anything about the disease. You go there and you get more knowledge and you are aware of what you suffer from. Then, you will be able to manage yourself."*

*"The main thing I would say is that it gives you a new way of approaching the disease and your family's issues about the disease in a whole different way, that you can deal with things a lot more comfortably."*

*"I'll just say it's important that you take it. You'll learn a few things that you don't even think about. It makes you very aware, I found."*

*"I would say it's good because it helps you to take control through small steps."*

*"Just getting the support from the others and all of the ideas that are thrown out make it good. The environment is supportive, there is a cross-section of disabilities..."*

*"That he is not alone with his problem, physical or emotional, and in the group he would find most strength."*

*"I would tell them that your life is more structured to your condition. And it's something sort of to refer to and not be so frightened or depressed about. And you know where to go and what to look for."*

*"I'd say that it really helps in terms of dealing with stress because there are different relaxation techniques and good communication skills that are important in general. I'd say that it would encourage the person to be more active and it would encourage the person to meet goals to improve their health."*

*"It is fun and there is no payment required."*