



## SECTION I RESOURCES

## **What is the Chronic Disease Self-Management Program?** (known in Oregon as Living Well with Chronic Conditions)

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The Chronic Disease Self-Management Program is a workshop given two and a half hours, once a week, for six weeks, in community settings such as senior centers, churches, libraries and hospitals. People with different chronic health problems attend together. Workshops are facilitated by two trained leaders, one or both of whom are non-health professionals with a chronic diseases themselves.

Subjects covered include: 1) techniques to deal with problems such as frustration, fatigue, pain and isolation, 2) appropriate exercise for maintaining and improving strength, flexibility, and endurance, 3) appropriate use of medications, 4) communicating effectively with family, friends, and health professionals, 5) nutrition, and, 6) how to evaluate new treatments. Each participant in the workshop receives a copy of the companion book, *Living a Healthy Life With Chronic Conditions, 3<sup>rd</sup> Edition*.

It is the process in which the program is taught that makes it effective. Classes are highly participative, where mutual support and success build the participants' confidence in their ability to manage their health and maintain active and fulfilling lives.

### **Does the Program replace existing programs and treatments?**

The Self-Management Program will not conflict with existing programs or treatment. It is designed to enhance regular treatment and disease-specific education such as Better Breathers, cardiac rehabilitation, or diabetes instruction. In addition, many people have more than one chronic condition. The program is especially helpful for these people, as it gives them the skills to coordinate all the things needed to manage their health, as well as to help them keep active in their lives.

### **How was the Program developed?**

The Division of Family and Community Medicine in the School of Medicine at Stanford University received a five-year research grant from the federal Agency for Health Care Research and Policy and the State of California Tobacco-Related Diseases office. The purpose of the research was to develop and evaluate, through a randomized controlled trial, a community-based self-management program that assists people with chronic illness. The study was completed in 1996.

The research project had several investigators: Halsted Holman, M.D., Stanford Professor of Medicine; Kate Lorig, Dr.P.H., Stanford Professor of Medicine; David Sobel, M.D., Regional Director of Patient Education for the Northern California Kaiser Permanente Medical Care Program; Albert Bandura, Ph.D., Stanford Professor of Psychology; and Byron Brown, Jr., Ph.D., Stanford Professor of Health Research and

Policy. The Program was written by Dr. Lorig, Virginia González, M.P.H., and Diana Laurent, M.P.H., all of the Stanford Patient Education Research Center. Ms. González and Ms. Laurent also served as integral members of the research team.

The process of the program was based on the experience of the investigators and others with self-efficacy, the confidence one has that he or she can master a new skill or affect one's own health. The content of the workshop was the result of focus groups with people with chronic disease, in which the participants discussed which content areas were the most important for them.

### **How was the Program evaluated?**

Over 1,000 people with heart disease, lung disease, stroke or arthritis participated in a randomized, controlled test of the Program, and were followed for up to three years. We looked for changes in many areas: health status (disability, social/role limitations, pain and physical discomfort, energy/fatigue, shortness of breath, psychological well-being/distress, depression, health distress, self-rated general health), health care utilization (visits to physicians, visits to emergency department, hospital stays, and nights in hospital), self-efficacy (confidence to perform self-management behaviors, confidence to manage disease in general, confidence to achieve outcomes), and self-management behaviors (exercise, cognitive symptom management, mental stress management/relaxation, use of community resources, communication with physician, and advance directives).

### **What were the results?**

Subjects who took the Program, when compared to those who did not, demonstrated significant improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress, fatigue, disability, and social/role activities limitations. They also spent fewer days in the hospital, and there was also a trend toward fewer outpatient visits and hospitalizations. These data yield a cost to savings ratio of approximately 1:10. Many of these results persist for as long as three years.

**For more information on the Living Well with Chronic Conditions program in Oregon, please contact us at (971) 673-0984 or email [living.well@state.or.us](mailto:living.well@state.or.us)**



# Review of Findings on Chronic Disease Self-Management Program (CDSMP) Outcomes:

*Physical, Emotional & Health-Related Quality of Life, Healthcare Utilization and Costs*

## Summary of health effects

The major published studies on healthcare utilization & CDSMP were reviewed; all were accessed through the National Library of Medicine (see attached chart, and summary of studies below). There is strong evidence across studies that CDSMP has a beneficial effect on physical & emotional outcomes, and health-related quality of life. This statement is based on high-quality information, standardized measures and is made with a high degree of confidence. The program consistently results in greater energy/reduced fatigue, more exercise, fewer social role limitations, better psychological well-being, enhanced partnerships with physicians, improved health status, and greater self efficacy. It is generally (although not always) associated with reductions in pain symptoms.

## Summary of utilization effects

There is evidence that CDSMP results in reductions in healthcare expenditures. There is a range in the amount of money saved and the healthcare settings in which these cost savings/utilization decreases occurred, but the research points to moderate expenditure reductions. The statement “CDSMP results in reductions in healthcare expenditures” is made with a reasonably high degree of confidence. This finding is consistent with the available evidence, but is limited by the fact that measurement approaches differ across studies and utilization decreases are not uniform. In four studies there were fewer emergency room (ER) visits, in three studies there were fewer hospitalizations, and in four studies there were fewer days in the hospital. In two studies there were reductions in outpatient visits. All of the preceding studies were able to demonstrate statistical significance. We found no studies in which costs were increased.

There is evidence to support the notion that CDSMP saves enough money in healthcare expenditures within the first year to pay for the program. This statement is made with a moderate degree of confidence. This degree of confidence reflects the range of cost estimates used for CDSMP and that there is no common cost accounting used to calculate program costs.

The available evidence also suggests that CDSMP results in more appropriate utilization of healthcare resources, addressing healthcare needs in outpatient settings rather than ER visits and hospitalizations. While CDSMP is not a cost-cutting strategy in

and of itself, it almost certainly results in improved health-related outcomes and reduced healthcare utilization sufficient to render the program cost neutral. Further work will be needed to more precisely calculate the CDSMP return on investment in various settings and with various populations, using uniform cost methodologies and utilization metrics.

### Summary of other benefits

Effective across chronic diseases: The program addresses a wide variety of chronic illnesses. This can result in efficiencies of scale, as CDSMP is designed to meet the needs of those with a variety of diseases. This obviates the need for many different disease-specific classes with the accompanying recruitment and scheduling problems.

Effective across socioeconomic and educational levels: The program's benefits are also seen across the spectrum of socioeconomic and educational levels. CDSMP is used among various ethnic groups in the US and internationally. CDSMP is currently offered through the National Health Services of England and Denmark, and in many parts of Australia, Japan, China, Norway and Canada. This attests to the program's broad reach and appeal.

Enables participants to manage progressive, debilitating illness: Those who have taken CDSMP do not experience greater healthcare utilization, even when their disability worsens. ER visits and hospitalizations would be expected to increase with progressive disability, but this is not the case for those who have taken CDSMP. While disability does tend to progress in those with chronic illness, those who participate in CDSMP classes generally do not use more healthcare resources.

Important health benefits persist over time: Those who enroll in CDSMP maintain many of their health and behavioral improvements over time. Significant improvements in exercise and social/role limitations can be seen over a two-year period.

Supported by decades of federal research: CDSMP has been developed through 20+ years of federally-funded grants from the National Institutes on Health, the U.S. Agency for Healthcare Research and Quality, and the Centers for Disease Control & Prevention.

### Summary finding

CDSMP results in significant, measurable improvements in patient outcomes and quality of life. CDSMP also saves enough through reductions in healthcare expenditures to pay for itself within the first year.

## Summary of studies reviewed

Thirteen CDSMP studies were reviewed. Analysis was conducted on eight studies which contained sufficient utilization data. Six studies are domestic and two are from the UK. Two of the six domestic studies targeted Spanish-speaking Hispanics. CDSMP participants were generally 40+ years of age. Sample sizes ranged from a low of 171 to a high of 1,140 with a mean of 682.

## About the authors

The Centers for Disease Control & Prevention (CDC) is working in partnership with the National Council on Aging on the issue of financial sustainability for evidence-based health programs for older adults. Catherine Gordon, RN, MBA is a Senior Public Health Analyst in the Office of the Director, and Tracy Galloway, MPH is a Public Health Analyst in the National Center for Health Marketing at CDC.

Study	Population Characteristics	Physical, Emotional, Health-Related Outcomes	Utilization & Cost Outcomes	Length of Study
<p><b>Journal of Epidemiology and Community Health (UK) 2007; 61:254-261 (Kennedy, Reeves, et al.)</b></p>	<p>Study conducted in the UK.</p> <p>629 patients with a wide range of long-term chronic conditions.</p>	<ul style="list-style-type: none"> <li>• Greater self-efficacy</li> <li>• Greater energy</li> <li>• Considerably greater health-related quality of life</li> <li>• Fewer social role limitations</li> <li>• Better psychological well-being</li> <li>• Lower health distress</li> <li>• More exercise and relaxation</li> <li>• Greater partnerships with clinicians</li> </ul>	<ul style="list-style-type: none"> <li>• No statistically significant reductions in routine health services at 6 months.</li> <li>• The overall small reduction in inpatient utilization meant that the costs of provision of the program were offset. This reduction was not statistically significant.</li> <li>• Authors' conclusion: Overall CDSMP is associated with improvements in health-related quality of life at no increased cost, and is likely to be cost effective. 70% probability that it's cost effective.</li> </ul>	<p>6 month study</p>

<p><b>The Diabetes Educator;</b>  <b>2005, 31; 401 (Lorig,</b>  <b>Ritter, and Jacquez)</b></p>	<p>445 persons  2/3rds with diabetes  Hispanic  Mean age 61</p>	<p><u>At 4 months:</u></p> <ul style="list-style-type: none"> <li>• Significant improvements in eating breakfast, mental stress, self-reported health, aerobic exercise, shortness of breath, pain, activity limitation</li> </ul> <p><u>At 1 Year:</u></p> <ul style="list-style-type: none"> <li>• Improvements in eating breakfast, mental stress management, self-reported health, aerobic exercise, health distress, C15self-efficacy, communication with physicians</li> </ul>	<p><u>At 4 months:</u></p> <ul style="list-style-type: none"> <li>• No significant changes in hospital or ER use</li> <li>• Physician utilization showed a statistically significant increase</li> </ul> <p><u>At 1 year:</u></p> <ul style="list-style-type: none"> <li>• Fewer hospital days</li> <li>• Data indicates increased use of physicians while decreasing hospitalizations, suggesting more appropriate health care use</li> </ul>	<p>Results at 4 months and 1 year</p>
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<p><b>British Journal of Health Psychology 2005 (UK); 10, 589-599 (Barlow, Wright, et al.)</b></p>	<p>171 participants Mean age of 54 years Mean duration of disease = 16 years</p>	<ul style="list-style-type: none"> <li>• The purpose of this study was to determine whether changes identified at 4 months were maintained over time.</li> <li>• No significant changes in self-efficacy, cognitive symptom management, communication with physicians, fatigue, anxiety and depressed mood and health distress occurred between month 4 and month 12, indicating that the effects of the program are long lasting.</li> </ul>	<ul style="list-style-type: none"> <li>• Most had no change from 4 month to 12 month follow-up with respect to the number of nights hospitalized and number of visits to accident and emergency rooms, specialists and GPs.</li> <li>• No significant <i>changes</i> in the median number of visits to specialists and GPs occur between month 4 and month 12.</li> </ul>	<p>The study was a 12-month follow up.</p>
<p><b>Nursing Research 2003; Nov/Dec Vol 52, #6 (Lorig, Ritter, and Gonzalez)</b></p>	<p>Hispanic – majority born in Mexico. Spanish speakers, residing in northern California. 551 individuals included (327 in intervention and 224 in control) 79% female. Mean age was 57 years</p>	<ul style="list-style-type: none"> <li>• Improvements in: <ul style="list-style-type: none"> <li>- health status</li> <li>- health behavior</li> <li>- self-efficacy</li> <li>- self-reported health, distress, fatigue, pain/physical discomfort, role function</li> <li>- exercise- communication with physicians</li> <li>- mental stress management</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Fewer ER visits</li> <li>• Reduction in ER visits was small, with a .2 difference in first 4 months, and .12 fewer in months 8 and 12. The high costs of ER visits suggest that these differences are important.</li> <li>• No difference in hospitalizations</li> <li>• No difference in physician visits</li> </ul>	<p>Results examined at 4 months and at 1 year.</p>

<p><b>The Permanente Journal, Spring 2002, Vol 6, No 2 (Sobel, Lorig, and Hobbs)</b></p>	<p>952 patients</p> <p>50% Kaiser Permanente members</p> <p>Aged at least 40</p>	<p><u>At 6 months</u></p> <ul style="list-style-type: none"> <li>• Improvements in: <ul style="list-style-type: none"> <li>- frequency of cognitive symptom management</li> <li>- communication with physicians</li> <li>- health status, health distress</li> <li>- fatigue</li> <li>- disability</li> <li>- social activity limitations</li> </ul> </li> </ul> <p><u>At 2 years</u></p> <ul style="list-style-type: none"> <li>• Reduction in health distress</li> <li>• Increased self-efficacy</li> <li>• Self-rated health status improved</li> <li>• Improved fatigue</li> <li>• Increases in disability (consistent with what is expected)</li> </ul>	<p><u>At 6 months</u></p> <ul style="list-style-type: none"> <li>• Fewer hospitalizations (0.22 fewer hospitalizations)</li> <li>• Fewer nights in the hospital (0.8 fewer nights)</li> <li>• Used an average CDSMP program cost of about \$70; and hospital cost of \$1000/day which resulted in a saving of approximately \$750</li> </ul> <p><u>At 2 years</u></p> <ul style="list-style-type: none"> <li>• Made fewer visits to physicians and emergency departments (2.5 fewer visits)</li> <li>• No significant increases in numbers of hospitalization or days in the hospital, despite worsening disability</li> </ul>	<p>6 months and 2 years</p>
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<p><b>Effective Clinical Practice (ACP Online 2001; <a href="http://acponline.org/journals/ecp/novdec01/lorig.htm">acponline.org/journals/ecp/novdec01/lorig.htm</a> (Lorig, Sobel, et al.)</b></p>	<p>613 Kaiser Permanente patients; 489 had complete baseline and follow-up data</p>	<ul style="list-style-type: none"> <li>• Improvements in: <ul style="list-style-type: none"> <li>- exercise</li> <li>- cognitive symptom management</li> <li>- communication with physicians</li> <li>- self-efficacy</li> <li>- fatigue</li> <li>- health distress</li> <li>- shortness of breath</li> <li>- pain</li> <li>- role function</li> <li>- depression</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Fewer visits to the ED (.04 visits in the 6 months prior to baseline; compared with .3 in the 6 months prior to follow up.)</li> <li>• Slightly fewer outpatient visits to physicians (not statistically significant)</li> <li>• Slightly fewer days in hospital (not statistically significant)</li> <li>• One year after exposure to the program, most patients experienced statistically significant improvements in a variety of health outcomes and had fewer ED visits.</li> </ul>	<p>1 year outcomes</p>
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<p><b>Medical Care, 2001 Vol 39, #11, pp 1217-1223 (Lorig, Ridder, et al.)</b></p>	<p>831 community-dwelling patients 40+ yrs old, average 2.2 diseases</p>	<ul style="list-style-type: none"> <li>• Improved health behaviors (exercise, cognitive symptom management, communication with physicians)</li> <li>• Improved self-rated health and participation in social/role activities</li> <li>• Reduced disability, fatigue, and distress over their health</li> <li>• An increase in disability was seen at one year. Even in the face of increasing disability, their activity and role functions did not decline.</li> </ul>	<p><u>At 1 year</u></p> <ul style="list-style-type: none"> <li>• Fewer visits to physicians and ERs (0.689 fewer visits) - this study groups physician visits with ER visits</li> <li>• Fewer days in hospital (0.111 fewer days)</li> <li>• Fewer hospitalizations (0.012 fewer hospitalizations)</li> </ul> <p><u>At 2 years (compared to baseline)</u></p> <ul style="list-style-type: none"> <li>• Fewer visits to physicians and ERs (0.564 fewer visits) - this study groups physician visits with ER visits. Author's conclusions:• Each year, participants made fewer visits to ERs and physicians, despite some increase in disability.</li> <li>• The total reduction during two years was approximately 2.5 visits per participant.</li> <li>• Two year savings due to reduced hospitalizations and outpatient visits was approximately \$590 per participant (\$490 in hospitalizations and \$100 in outpatient visits)</li> <li>• CDSMP cost was estimated at \$70-\$200 per participant, depending on economies of scale. Therefore, the actual amount of money saved over the two-year period was between \$390 and \$520 per participant.</li> </ul>	<p>Study measured outcomes over 2 years, at 1 and 2 year intervals.</p>
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<p><b>Medical Care, 1999 Vol 37(1), pp 5-14 (Lorig, Sobel, et al.)</b></p>	<p>1140 participants (664 intervention; 476 control) 952 completed 6-month follow-up study</p> <p>Age 40 and up</p>	<ul style="list-style-type: none"> <li>• Improvements in: <ul style="list-style-type: none"> <li>- exercise</li> <li>- cognitive symptoms</li> <li>- communication with physician</li> <li>- self-reported health</li> <li>- health distress</li> <li>- fatigue</li> <li>- disability</li> <li>- social/role activity limitations</li> </ul> </li> <li>• No difference in pain, shortness of breath, or psychological well being</li> </ul>	<ul style="list-style-type: none"> <li>• Fewer hospitalizations (decreased by 0.07)</li> <li>• Fewer days of hospitalization. Spent .8 fewer nights in the hospital.</li> <li>• No significant differences in physician visits. (very slight decrease)</li> </ul>	<p>6 month follow-up</p>
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## The Chronic Disease Self-Management Program (CDSMP): Experiences with Diverse Populations

By 2008, the Chronic Disease Self-Management Program (CDSMP) was being implemented in 43 states throughout the U.S. and 18 other countries. This program offers a broad-base appeal with a focus on multiple chronic conditions and fills gaps in existing disease-specific education and rehabilitation programs. As such, it has been integrated into regional and governmental health organizations in the United States, as well as national alliances, demonstration projects, and health initiatives, most notably in Australia, the United Kingdom, and Canada.

As the CDSMP continues to spread to additional populations, more is being learned about the great in diversity in program participants and how to successfully engage them. This paper summarizes a literature review of 52 articles that provide some insights into the acceptability of the CDSMP in various settings, for people with different chronic conditions, and for diverse cultural groups.

### **Diversity of Participant Populations:**

The CDSMP has been translated into at least 10 different languages, and educational materials are available in English, Spanish, Chinese, Japanese, and Korean. Populations that the CDSMP has been used with or adapted for include:

- People with diverse medical needs, including those with arthritis, diabetes, hypertension, stroke, chronic pulmonary obstructive disease, coronary heart disease, cancer, multiple sclerosis, and low back pain; deafened adults; parents of children with chronic conditions; people with mental illness; and people with learning difficulties;
- Ethnically and culturally diverse populations who live in a variety of nations, including Latinos; African-Americans; Native Americans and Pacific Islanders; Aboriginal people; Chinese; Koreans; Vietnamese, Greeks; Italians; Dutch; and Bangladeshis; and
- A wide range of organizations, including those in urban and rural settings; health plans; clinics; health centers; university and community hospitals; the Veteran's Administration; state and county health departments; area agencies on aging; community colleges; community-based organizations; residential settings; and councils and service organizations.

### **Qualitative Participant Feedback:**

Qualitative feedback about the participants' perceived benefits from the program indicated that the CDSMP was beneficial and satisfying for participants. In particular, participants reported satisfaction with the following areas:

- Improvement in self-management behaviors or skills (especially action planning, cognitive techniques, and communication with health care providers);
- Increased confidence, control, and motivation;
- Increased or reinforced knowledge and awareness about their condition, making them more involved in their care; and
- Satisfaction with program format, including increased social interaction, contact, and support; decreased feelings of isolation; and sharing and exchange of information and ideas.

Participants did offer suggestions for changes in the content, which often reflected the differences in culture or type of chronic condition.

### **Recruitment:**

Recruitment strategies were similar across populations and countries. Direct targeting approaches included mailings, print media (flyers, posters, brochures, pamphlets, and public service announcements), radio, television, and presentations for a variety of existing community-based service organizations, voluntary health agencies,

churches, clubs, and libraries. Participants were indirectly targeted through letters and/or presentations to providers for patient referrals, but this strategy yielded fewer participants. Approaches were tailored to be more acceptable and relevant in certain ethnic or cultural communities by using specific health messages, languages, and presentations from staff or lay leaders from the community.

### **Implementation:**

Experiences with CDSMP implementation and evaluation in these various settings can facilitate future program dissemination and success. Factors that were found to increase successful implementation include:

- Pre-plan to identify where the program fits with your organization's mission and find capable partners who can collaborate on implementation. This includes identifying leaders, participants, and program sites by working with community organizations that have ties to specific communities; consulting or contracting with universities for assistance with program and outcome evaluations; and partnering with health organizations, insurance companies, and funding agencies to share resources and increase program sustainability.
- Create an advisory group and steering committee that actively involve the lay community at the program outset to advise on program direction, implementation and evaluation. This requires lead time and budgeting resources, but helps ensure positive experiences and longer-lasting benefits.
- Make the program more marketable and relevant to the community by renaming it and starting with a pilot to determine what, if any, adaptations may be needed for specific target groups (e.g. language). Obtain permission from the authors before adapting program content.
- Provide clarity of the program's purpose and scope through the name, in the publicity materials, and at the time of inquiry/registration to assess suitability for participants. This will help increase program retention.
- Use community outreach and lay persons or potential participants from targeted communities to assist in the various phases of the program.
- Offer incentives to increase recruitment and retention, especially for underserved and low income populations and those with restricted mobility or who live further away from sites (e.g. course fee waivers, child care, gift certificates, transportation).
- Identify ways to recognize, acknowledge, and reward the lay volunteers for their involvement and contributions at all levels (e.g. from membership on steering committees to facilitating workshops).

In addition, this literature review identified some potential limitations or challenges with implementation and program sustainability past the initial trial. Limiting factors mentioned were:

- The organization's capacity to administer the program given competing priorities and demands, participant interest, and the availability of resources (e.g. funding, leaders, space).
- The recruitment, training and retention of competent leaders, especially with monitoring leaders' readiness and skills to ensure program quality and perhaps prevent participant attrition.
- Barriers to participant recruitment related to a person's perceived suitability for the program, such as social and family roles, spiritual beliefs, and/or the social stigma or label of having a chronic condition, especially when targeting the general public.
- Limited provider involvement and low referrals that may be due to competing local, state and federal initiatives for health care providers' time and attention; lack of incentives to refer due to concerns about reimbursement or remuneration for case management; and/or personal attitudes or skepticism about "self-management" programs.

Please contact Nancy Whitelaw, PhD ([nancy.whitelaw@ncoa.org](mailto:nancy.whitelaw@ncoa.org)) at the Center for Healthy Aging, NCOA with any questions. More information is available at the Center for Healthy Aging website at [www.healthyagingprograms.org](http://www.healthyagingprograms.org) and the Stanford Patient Education Research Center at <http://patienteducation.stanford.edu/programs/>.