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# Living Well with Chronic Health Conditions: Chronic Disease Self-Management Education in Virginia

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## Case Study

### Living Well with Chronic Health Conditions: Chronic Disease Self-Management Education in Virginia

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(Case studies contributed by  
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#### Educational Objectives

1. Review the impact of chronic disease on population health and health care costs.
2. Describe Chronic Disease Self-Management Education (CDSME) programs.
3. Discuss research findings that demonstrate how the Chronic Disease Self-Management Program addresses the triple aims of better care, better health, and lower costs.
4. Explain how CDSME programs are delivered through the *Live Well, Virginia!* Network.
5. Highlight initiatives to expand CDSME to new target areas and populations.

#### Introduction

Chronic disease is a significant issue in this country and elsewhere across developed nations, with aging populations and adults with disabilities especially vulnerable to its effects. In the United States, approximately 80% of older adults have one chronic condition (CDC, 2011) and nearly 70% of Medicare beneficiaries have two or more (Lochner et al, 2010). This can result in higher risk for premature death, poor functional status, unnecessary hospitalizations, adverse drug events, and nursing home placement (Kramarow E. et al., 2007; Parek, A.K. et al., 2011).

About 95% of health care costs for older Americans can be attributed to chronic diseases (CDC, 2013). Additionally, adults with disabilities experience health disparities when compared with the general population. For instance, adults with disabilities are more likely to have chronic health conditions, such as having high blood pressure, being overweight or obese, not engaging in fitness activities, and receiving less social-emotional support, than adults without disabilities

(CDC, 2010). Further, in a 30-day period, people with disabilities experience an average of nine days of restricted activity due to poor health, more than four times the rate of their counterparts without a disability (CDC, BRFSS 2007-2009).

#### Chronic Disease Self-Management Education

Clearly, chronic disease affects not only individual well-being but the nation's culture and economy. Through the *Live Well, Virginia!* Chronic Disease Self-Management Education program, individuals coping with chronic diseases can take steps to improve their overall health, feel better, and live life to the fullest.

Why self-management? Kate Lorig, one of the program's developers, explains: "*People spend 99 percent of their time outside the health care system, and what they do outside largely determines their quality of life. This prepares them for the 99 percent.*"

Chronic Disease Self-Management Education (CDSME) is an umbrella

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term covering a range of programs originally developed at Stanford University. The core program of the CDSME is the Chronic Disease Self-Management Program (CDSMP), a six-week, 2.5 hours a week workshop that offers tools and information to help participants manage their chronic illnesses and engage more fully in life. CDSMP is the generic workshop designed for adults living with any kind of chronic health conditions. This is because there are several common issues and strategies that cross the lines of diagnosis, such as medication management, working with healthcare professionals, getting a good night's sleep, and healthy eating.

Workshops are highly interactive and include many opportunities for contributions by participants. The curriculum includes "lecturettes," where leaders share basic information on relevant topics like healthy eating and physical activity, but the essential element of CDSME is the involvement of group members. In fact, many of the best ideas come from participants.

Two key activities are brainstorming and problem-solving. During brainstorming, a question is posed to the group to which participants "shout out" responses. Examples of brainstorming questions include: "What are some of the ways to get a good night's sleep?"; "What are some ways to deal with difficult emotions?"; "What are some of the things you can do to manage or avoid shortness of breath?" The purpose is to generate as many ideas as possible in a short period of time. Leaders do not offer suggestions until the group has fin-

ished. Through this process participants see that they and their peers have many useful ideas on managing their health. Problem-solving offers a way to address challenges that arise, through a structured process that involves clearly identifying the problem, then listing and choosing from possible solutions. These and other activities underscore the emphasis on offering an array of tools from which participants can select to manage their conditions.

Action planning is a central, ongoing activity in the CDSMP. Each leader and participant, working together, develops a weekly action plan and reports the next week on how well it was accomplished. An action plan describes something that the person wants to do (rather than what someone else decided he or she should do) in very concrete terms. Because it is important for each participant to feel confident that his or her plan can be accomplished in the next week, a reasonably high confidence level is also part of the action plan. Very briefly, the idea behind the action planning process is to break things down into small, achievable pieces so participants can experience success rather than be overwhelmed with the tasks and challenges they face.

If a participant encounters a snag in completing the action plan, such as when rain all week prevents a walk outside, leaders help the person to focus on finding solutions to the problem. The participant may think of solutions, but if not, the group can help brainstorm options from which that person can select one to try, like walking on an indoor track.

An important takeaway from this process is that, although barriers and challenges are common, they do not have to be insurmountable.

### Other Topics Addressed in the CDSMP

The other topics covered in the workshop series are diverse and comprehensive. They include: using your mind to manage symptoms, getting a good night's sleep, dealing with difficult emotions, doing physical activity and exercise, preventing falls, making decisions (where a structured decision-making process is practiced), pain and fatigue management, better breathing, healthy eating, communication skills, medication usage, making informed treatment decisions, dealing with depression, working with your health care professional and organization, weight management and future plans. A companion book, *Living a Healthy Life with Chronic Conditions*, supplements the workshop content and is available to all participants.

The CDSMP employs a train-the-trainer model to assure fidelity (adherence to the program). The national Self-Management Resource Center trains "T-trainers" who train Master Trainers from communities, who in turn train workshop leaders. Two leaders facilitate each workshop, preferably with personal experience with chronic health conditions so they can serve as positive self-management role models. The program has been developed based on proven research, so it is essential that all of the workshops within a type (e.g., CDSMP) adhere to program guidelines regardless of where they are

offered. There are standardized materials and training, as well as protocols for leading activities like how to conduct a brainstorming activity or how to facilitate action-planning. Fidelity monitoring of workshops helps to assure that workshops meet these standards.

If CDSME was developed to improve outcomes for individuals with chronic health conditions, how well does it work? A recent study offers supportive findings. Ory et al. (2013) conducted a CDSMP National Study with some 1,170 participants who enrolled in CDSMP workshops from 2010-2011. The researchers collected socio-demographic, health status, and behavioral data from participants at baseline, six, and 12 months, with 825 participants providing 12-month data. Participants reported improvements in meeting the Institute for Healthcare Improvement's *Triple Aims* of better care, better health, and lower cost. Findings included:

- **Better Experience of Care:** Increased minutes of exercise, improved communication with health care team, better medication compliance, and improved health literacy.
- **Better Health:** Reduced symptoms of depression, less fatigue/improved sleep, improved quality of life, fewer unhealthy physical days, fewer unhealthy mental health days, and improved self-assessed health.
- **Lower Costs:** Reduced emergency room visits (5%) at six and 12 months and reduced hospitalizations (3%) at six months. Taking into account the average cost of a workshop, the researchers calculat-

ed a potential net savings of \$364/participant. This could result in a national savings of \$3.3 billion if just 5% of adults with chronic conditions participated in a workshop.

In Virginia, four different types of workshops are offered in the *Live Well, Virginia!* initiative offered through the Department for Aging and Rehabilitative Services (DARS). The most commonly available is the Chronic Disease Self-Management Program, with the Diabetes Self-Management Program being next. Cancer: Thriving and Surviving, and the Chronic Pain Self-Management Program are also available in limited areas. Area Agencies on Aging (AAAs) throughout the Commonwealth coordinate and deliver these four programs. Since 2010, AAAs have hosted 1,066 workshops with 13,499 enrollees. Of these, 10,326 have completed the workshops, attending at least four of the six sessions. In most areas, the workshops are offered at no charge to participants.

AAAs deliver these workshops that fall under the Chronic Disease Self-Management Education (CDSME) umbrella to diverse audiences in a wide range of sites throughout Virginia, including: hospitals and clinics; faith based organizations, like churches and mosques; senior centers; senior living complexes and other residential settings; homeless shelters and programs; Centers for Independent Living; behavioral health programs; substance abuse recovery programs; prisons and adult detention centers; clubs and community programs; and the Wilson Workforce and Rehabilitation

Center.

### Chronic Disease Self Management with Persons with Dementia

DARS is also reaching out to individuals with early stage dementia and their care partners in collaboration with Virginia's four regional chapters of the Alzheimer's Association: Central and Western Virginia, Greater Richmond, National Capital Area, and Southeastern.

Providing background and impetus for this initiative are the findings of a 2010 joint study by the Centers for Disease Control and the Alzheimer's Association, entitled *Chronic Disease Self-Management Programs: Relevance for Persons with Dementia* (Silverstein et al., 2011). Silverstein's research team distributed a survey to CDSMP Master Trainers in 39 states, the District of Columbia, and five other countries.

Some 353 Master Trainers responded, each having had participants who they suspected as having dementia. The overwhelming opinion of respondents was that CDSMP is helpful for persons with dementia (PWD), particularly for persons with early stage dementia and when accompanied by a care partner. The Master Trainer respondents noted that opportunities to brainstorm with other participants facing the same challenges and to receive peer support were especially helpful.

The Master Trainers further suggested a number of adaptations to make the workshop a positive and constructive experience for persons with dementia, including buddy and

pairing activities, and providing extra attention from leaders (during breaks, before/after, calls). They also suggested reducing distractions (e.g., arranging for the person to sit in front or near the leader), redirection, cueing, reinforcement (praise, encouragement, modest expectations), extra repetition, using a slower pace, simplified action plans, and encouraging writing.

The Master Trainers also reported many benefits for the care partners. These included: seeing the PWD as more capable; better understanding the concerns and fears as well as the limitations and needs of the PWD; learning how to work with and support the PWD; understanding the importance of self-care; having tools for caregiver stress (muscle relaxation, better breathing, guided imagery); acquiring skills to manage difficult emotions; developing action plans to cope with stress; brainstorming and problem-solving caregiving challenges; and learning how to navigate the health-care system and access resources.

There are several potential long-term benefits to the DARS, Alzheimer's Association chapters, and AAA collaboration in bringing CDSMP to persons with early stage dementia and their care partners: 1) Persons with early stage dementia will be encouraged to focus on their health overall rather than becoming discouraged by the diagnosis; 2) Care partners will learn to focus on taking care of themselves earlier in the disease progression to help reduce burn out; 3) Those with other chronic conditions who attend the workshops will have the opportunity to observe participants with early stage dementia being engaged

in a community activity, promoting a more positive perception, and reducing the stigma around the diagnosis; and 4) Persons with early stage dementia and their care partners will have an opportunity to share and socialize, keeping them connected to the community.

DARS has managed the statewide CDSME initiative since 2010, due in large part to generous support from the U.S. Administration on Aging, initially through the American Reinvestment and Recovery Act funds and later through the Prevention and Public Health Fund of the Affordable Care Act. Support through these grants has enabled DARS and local partners to expand CDSME programs to previously unserved or underserved populations and to reach all Area Agencies on Aging in Virginia by July 2018.

In addition, Health Quality Innovators (HQI) a Quality Innovation Network funded by the Centers for Medicare and Medicaid Services, also provides support. Through its Everyone with Diabetes Counts initiative, HQI reimburses AAAs for program deliverables. DARS and the AAAs will soon receive referrals and reimbursement from Virginia Premier for its members participating in CDSME through the Managed Long Term Services and Supports program for Medicaid beneficiaries. This is an exciting new era in Virginia's CDSME program where managed care organizations pay for beneficiary participation in order to improve member wellbeing and reduce healthcare costs.

## Case Study #1

Shelly, a 64-year old female, attended a Chronic Disease Self-Management Program (CDSMP) workshop. The chronic conditions she listed were Type 2 diabetes, high blood pressure, and obesity. She also stated that she struggles with anxiety and depression and has recently been homeless for two years.

While homeless, Sheila occasionally stayed at a Salvation Army Homeless Shelter. While there, she was invited to attend a Diabetes Self-Management Program (DSMP) workshop but was reclusive and hesitant and chose not to participate. However, she heard positive feedback from other workshop participants and expressed some regret that had not participated. She was in poor health and was making unhealthy food choices, including often drinking two liters of Coke every day.

Shelly began to take advantage of support services and qualified for housing in a new subsidized unit for people who were previously homeless. During this time, she heard about another CDSMP workshop being offered at Our Community Place; she decided to enroll. One of the workshop Leaders had worked with her while she stayed at the Salvation Army shelter and they had formed a positive connection that made it easier for Shelly to commit to attending.

Action plans were a completely new concept for Shelly, but she totally embraced the idea, setting small but achievable goals each week and successfully completing

them. Again, an action plan is something the individual wants to do that is achievable, action specific, and answers the questions what, when, how much, and how often. Six months later she is still making and completing action plans.

One of Shelly's action plans was to decrease the amount of Coke she was drinking. During the six-week workshop she was able to cut back to one 20-ounce bottle every two days; she says she now drinks Coke only occasionally. Action planning has also helped her get her finances under control; her rent is paid up six months in advance. She is currently working on issues with hoarding and reports that the urge to hoard items she doesn't need or use is decreasing.

Shelly's A1C level (measuring blood glucose) has been reduced and is close to 7, the level that her health care provider recommended. She has been able to lose some weight and continues to be interested in taking better care of herself. She is doing much better with managing her anxiety and depression, since she is no longer homeless and continues to use support services.

Shelly appreciated the group support during the workshop and continues to use the book *Living a Healthy Life with Chronic Conditions* as a resource. She would like to take the DSMP workshop when it is available.

## Case Study #2

Charles is an 81-year old male diagnosed with early stage dementia, Alzheimer's type, as well as high cholesterol and hypertension.

He had been struggling with being able to plan and follow through with activities that he used to enjoy, such as golfing and travel. His mood suffered and eventually he became depressed.

After being referred by his neurologist, Charles and his wife Judy attended a CDSMP workshop near their home. They weren't sure what to expect, but felt confident that the workshop would be useful because Charles' doctor had recommended it.

After attending the workshop, Charles stated that the action planning was the most significant tool in helping him to manage symptoms. He said that writing weekly plans and having the accountability of reporting out to the group aided him in staying on task and renewed his interest in traveling because it focused on what he wanted to do. He and Judy used action planning to help with trip logistics, and in fact are planning a trip to Europe in the fall. The process of action planning enabled Charles to see that he still is able to do the things that he always enjoyed; it was just a matter of breaking things down, so they felt manageable and doable. As a result, he felt more positive overall about managing his conditions.

Judy found that the activities that involve pairing up and sharing concerns gave her an opportunity to connect with another care partner who was experiencing the same issues as she. She felt validated with many of the emotions she was experiencing since her husband's diagnosis. As a result, she has maintained contact with some of the members of the group.

Overall, Charles and Judy found the support of others in the group to be invaluable. It gave them a sense of not being alone. Both said that they appreciated the group's willingness to share experiences and items of interest. They enjoyed the workshop so much that they are registered to take it again next month.

## Conclusion

The DARS *Live Well, Virginia!* Chronic Disease Self-Management Education initiative includes a series of evidence-based workshops for individuals living with a variety of chronic illnesses and conditions. The workshops are powerful in their effect, improving outcomes in three key areas called The Triple Aim of Healthcare Reform, namely, better experience of health care, better health for participants, and lower health care costs. Workshops are available throughout Virginia in a wide array of settings and are beneficial for diverse populations, such as veterans, offenders, individuals in recovery, homeless populations, and people with early stage dementia and their care partners. For more information about the *Live Well, Virginia!* workshops and/or the initiative to reach persons with dementia and their care partners, contact April Holmes at [april.holmes@dars.virginia.gov](mailto:april.holmes@dars.virginia.gov).

## Study Questions

1. Why is chronic disease a serious public health issue?
2. What are the characteristics of Chronic Disease Self-Management Education that make it uniquely effective for individuals living with chronic health conditions?
3. Why would it be a wise invest-

ment by organizations, governments, and private insurers to support CDSME for their constituents?

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