

HLC Self-Management Affinity Workgroup e-Newsletter

June 2013

What is self-management?

Self-management is what people do every day. They decide what to eat, whether to exercise, if and when they will monitor their health or take medications. Everyone self-manages. It's all about the decisions you make. Sometimes you may choose to do things that improve your overall health and well-being and other times you may make choices that are not in your best interest.

TABLE OF CONTENTS

What is self-management?	01
Chronic Disease Self-Management Program (CDSMP)	02
Sickle Cell Disease- Related Self-Management Articles	02
Self-Management Affinity Workgroup Members	03
Relevant Grants	03
Self-Management Resources	03

Chronic Disease Self-Management Program (CDSMP)

Brittney Dawson, a participant and group leader of the CDSMP at Cincinnati Children's Hospital, talks about the CDSMP and her experience.

Q. Why did you decide to participate in the CDSMP?

A. I decided to participate in the program because I felt that it was beneficial to my chronic illness and I thought that I could learn a lot from it. I decided to become a facilitator because I wanted to help others and learn to improve their daily lives with their chronic illness.

Q. When did you finish?

A. I finished taking the class in May (2012) and became a certified facilitator in October (2012).

Q. What was most rewarding about your experience in the program?

A. I learned how to achieve my goals by making action plans and I met a lot of great people that shared the same concerns and difficulties.

Q. What was the most challenging part of the program?

A. It was difficult at first to set reasonable goals (not too big!) and to remember to bring my book.

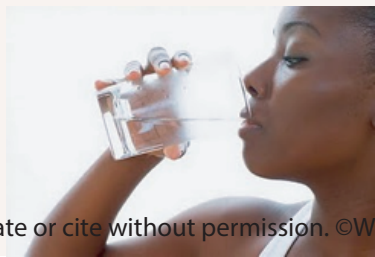
Q. How have you been using what you learned in the CDSMP since finishing the program?

A. I still make action plans to complete my weekly goals! I also use meditation techniques to help me take less medication.

Q. Would you recommend the CDSMP?

A. Yes, because it gives you the chance to meet people with your condition and similar difficulties. I really enjoyed getting help and support from people who have gone through the same types of things that I have. They were able to motivate me to reach my goals.

Additional information regarding the CDSMP can be found on the Stanford School of Medicine website at: <http://patienteducation.stanford.edu/programs/cdsmp.html>



Sickle Cell Disease- Related Self-Management Articles

[A qualitative analysis of best self-management practices: Sickle cell disease](#)

The authors conducted a panel discussion to find out what adults who successfully managed sickle cell disease did to be healthy. The most important strategy was self-awareness, which included having a positive attitude, journaling, and having a good relationship with physicians. Spiritual support, as well as support from friends and family, was also important. Another focus was obtaining training/education beyond high school and getting a job with health benefits. Panel members thought it was important to participate in advocacy activities. Additionally, knowledge of the disease, and personal medical history were key. Participants also discussed the importance of exercise and proper rest. Finally, they often used paired alternative treatments, such as acupuncture and massage.

self-management in children with chronic illnesses.

Tanabe, P., Porter, J., Creary, M., Kirkwood, E., Miller, S., Ahmed-Williams, E., & Hassell, K. (2010). A qualitative analysis of best self-management practices: Sickle cell disease. *Journal of the National Medical Association*, 1033-1041.

[Enhancing self-management in children with sickle cell disease through playing a CD-ROM educational game: A pilot study](#)

The authors studied the effects of playing a SCD-focused CD-ROM game in children with sickle cell disease. Knowledge about SCD increased after playing the game. Confidence levels of symptom management and practice also increased. These results show promise for interactive games as educational interventions.

Yoon, S. L., & Godwin, A. (2007). Enhancing self-management in children with sickle cell disease through playing a CD-ROM educational game: A pilot study. *Pediatric Nursing*, 33, 60-72.



Self-Management Affinity Workgroup Members

TEAM	NAME
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TDP OH	Amy Short, Tiffany Diers
TDP NJ	Terry Ann Baxter, Mary LaMar
NBS TN	Bernard Lewis, Consumer, Brittany Covert
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Relevant Grants

National Institutes of Health

<http://grants.nih.gov/grants/guide/pa-files/PA-11-072.html>

US Department of Health and Human Services

<http://www.hhs.gov/acl/2012/09/20/new-grants-help-people-with-medicaid>

Stakeholders Collaboration to Improve Student Health

http://www.stakeholderschicago.org/site/epage/69480_485.htm

Self-Management Resources

Below is a list of sites for web resources, articles, apps, and handouts related to the self-management of sickle cell disease.

Web Resources

• Center for Disease Control Sickle Cell Page

<http://www.cdc.gov/NCBDDD/sicklecell/index.html>

• Living with Sickle Cell

http://www.everythingsicklecell.com/coping_skills.html

• Sickle Cell Disease Association of America

<http://www.sicklecelldisease.org/>

Handouts

• Living Well with Sickle Cell

http://www.cdc.gov/ncbddd/sicklecell/documents/tipsheets_living.pdf

• Living with Sickle Cell in College

http://www.cdc.gov/ncbddd/sicklecell/documents/SCD%20factsheet_9steps.pdf

• Infection Prevention

http://www.cdc.gov/ncbddd/sicklecell/documents/tipsheets_5.pdf

• When to see a Doctor

http://www.cdc.gov/ncbddd/sicklecell/documents/tipsheets_guide.pdf

• Sickle Cell Self-Care Toolkit

http://www.cdc.gov/ncbddd/sicklecell/documents/LivingWell-With-Sickle-Cell%20Disease_Self-CareToolkit.pdf

Relevant Apps

• MyMedSchedule (free for apple or android)-assists patients in remembering to take medication

<http://www.mymedschedule.com/>

• Sickle Cell Disease Tracker (free for android)-tracks iron due to transfusions

<http://appaware.com/app/sickle-cell-disease-tracker/com.novartispharmaoncology.sicklecelldiseasestracker>

• SCD Resource Locator (free for android)

<http://appaware.com/app/scd-resource-locator/com.FamousInteractive.SickleCell>

• Pain Coach (free for apple or android)

<http://www.webmd.com/webmdpaincoachapp>

Want to get started with self-management?
Consider making an action plan.

What is something you would like to change related to exercise, sleep, medication, diet or taking care of your health over the next week?

It may be something like walking 15 minutes on Tuesday and Thursday this week or eating one less snack on Monday, Wednesday and Friday.

1. Come up with a goal.

2. Write it down.

3. Make sure you write down: What you will do? How much? When? How often?

4. Finally, work on the action that you feel confident will help you reach your goal.

Good Luck!