



Starting an HDSA Support Group

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Huntington's Disease Society of America

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Presenter Disclosures

Seth J. Meyer

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

**No relationships to disclose
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**Huntington's Disease
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HDSA Support Groups

Why a support group?

- “[Caregivers] who attended... groups had less caregiver-related burden (e.g., guilt, shame, fewer leisure activities, financial strain) than parents who did not attend a support group”¹
- All studies show that caregivers who attend support groups are better able to handle the stresses of caregiving.
- People with chronic illnesses who are part of a support group “...reported (1) a more positive outlook on life, (2) greater satisfaction with the medical care they receive, (3) reduced psychosomatic symptoms, (4) increased sense of mastery, (5) increased self-esteem, and (6) reduced feelings of shame and estrangement.”²

1. Cook, J. A., Heller, T., & Pickett-Schenk, S. A. (1999) “The Effect of Support Group Participation on Caregiver Burden Among Parents of Adult Offspring with Severe Mental Illness.” *Family Relations* 48, p. 405-10

2. Hinrichsen, G.A., Revenson, T. A., et al, (1985) “Does Self-Help Help? An Empirical Investigation of Scoliosis Peer Support Groups.” *Journal of Social Issues*, 41(1) 65-87

Why an HDSA support group?

- There are over 160 support groups around the country in 45 states.
- HDSA Support Group Leaders receive support from the HDSA national office as well as local professionals.
- HDSA Support Group Leaders receive training on Huntington's disease and support group theory to provide basic information on running and maintaining a support group.

Because families with HD need your help!

What are the types of support groups?

- Paid support groups:
 - The support group facilitator is a professional who is paid to manage and facilitate the group.
- Volunteer support groups:
 - The support group facilitator is a volunteer.
- Caregiver's Support Group
- At-Risk Support Group
- Support Group for People with HD
- All Inclusive Support Group
- Youth Support Group

What are the requirements for facilitating a support group?

- Must have an e-mail address that is regularly checked and phone number where messages can be left.
- Must have successfully completed training with the help of a Social Worker Mentor.
- Must provide a mailing address and updates regularly and as required by circumstances.
- Must have some knowledge of Huntington's disease.
- Must agree to give a list of support group members to their Mentor quarterly.

What is the process?

- Fill out the support group application, found at www.hdsa.org/sgapp.
- If the support group is a paid support group, the Community Services and Resource Development Manager (CSRDM) will ask for approval from the Regional Development Director
- If the support group is led by a volunteer, the CSRDM will talk to the local chapter, as applicable, and the RDD to discuss the possibility of having this support group.
- The CSRDM talks to the potential support group leader about the process and the responsibilities of running a support group.

What is the process?

- Once the support group is approved, the potential support group leader will be connected to a mentor.
 - The mentor will help the potential support group leader through the training manual via phone.
 - The mentor will help the potential support group leader feel comfortable with the information at hand.
 - The mentor is available once the support group has started to answer questions and walk through difficult situations.

What is the process?

- Once you complete the training, you set up a time for your first meeting. You will work with your Regional Development Director and your chapter representative (as appropriate) to do outreach for the group.
- You and your mentor can discuss how to set up your first meeting, including topics of discussion.

Why might my support group be denied?

- Not enough need in the area
- There is a support group in the area at a similar time
- There is no money in the budget at this time to support the group

There are other ways to help the HD community besides support groups

What is the support group training?

- The support group training manual is a tool to learn about running a support group and support group theory.
- The HD 101 training is about Huntington's disease, it's symptoms, and how it affects loved ones.

All potential support group leaders must complete both parts of the training

What do I do next?

- If you are interested in starting a support group, fill out the HDSA support group application, found at www.hdsa.org/sgapp.
- If you have any questions, please feel free to contact me at smeyer@hdsa.org or via phone at (212) 242-1968, ext. 240.

Resources

- Cook, J. A., Heller, T., & Pickett-Schenk, S. A. (1999) “The Effect of Support Group Participation on Caregiver Burden Among Parents of Adult Offspring with Severe Mental Illness.” *Family Relations* 48, p. 405-10
- Hinrichsen, G.A., Revenson, T. A., et al, (1985) “Does Self-Help Help? An Empirical Investigation of Scoliosis Peer Support Groups.” *Journal of Social Issues*, 41(1) 65-87
- Yalom, I, and Leszcz, M., (2005) *The Theory and Practice of Group Psychotherapy, 5th Edition*, Basic Books, New York, NY

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Questions and Discussion