



**HUNTINGTON'S DISEASE
YOUTH ORGANIZATION**

Nurturing Social Bonds

December 21, 2025

HDYO has more information about
HD available for young people,
parents and professionals on our
site:

www.hdyo.org

Huntington's Disease (HD) can often create a perceived barrier between individuals and their support networks. The significant emotional and physical challenges associated with HD can frequently strain friendships and family relationships.

Encouraging individuals and families to maintain connections, even through minimal interactions, can substantially impact their mental and emotional health. This guide offers simple, practical strategies for professionals to share, helping those impacted by HD nurture social bonds and build a resilient network of support throughout their HD journey.

Understanding Why Social Life Becomes Challenging

For the person impacted by HD, feelings of misunderstanding are common. They may be concerned about judgment or pity from others or simply be too physically or emotionally exhausted to socialize. The uncertainty of the future, or the weight of genetic status knowledge, can also make individuals feel deeply isolated. While withdrawing may initially feel protective, professionals should recognize that it often leads to chronic loneliness.

For the caregiver, the role is frequently overwhelming. It can be easier to avoid social outings rather than making plans. Caregivers may worry about how others will react to changes in their loved one's condition or fear that social events will be too stressful. Over time, this dynamic can significantly narrow a caregiver's social world, depleting the emotional support they critically need.

It's also important to address external factors. Friends and extended family often struggle with how to help, if they are not considered a caregiver for the person with HD. They may unintentionally maintain distance because they are afraid of saying or doing the wrong thing. This fear leads to greater disconnection during a time when social support is most important.

Facilitating Simple Connections

Professionals can guide their clients toward small, actionable steps that counteract feelings of isolation. Encourage the following strategies:

- **Adjust Expectations:** Stress that social interaction doesn't require perfection or a significant time commitment. A brief phone call, a shared cup of tea, or a quick, scheduled visit can be highly beneficial for the emotional well-being of the person impacted by HD or their caregiver.

- **Leverage Technology:** When in-person interaction is difficult; suggest utilizing technology. Sending a simple text message, scheduling a video call, or sharing a photo/update online are all effective ways to maintain a sense of connection.
- **Normalizing and Clarifying the Need for Help:** It's vital to normalize the act of asking for help, assuring individuals that it's perfectly acceptable to seek support. It is also important to encourage individuals to communicate clearly about what is happening in their lives and the concrete ways people can offer support. For example, asking for small, specific favors as a caregiver, such as picking up groceries, running an errand, or sitting with a loved one so a caregiver can take a short, necessary break, gives people a clear, manageable task, making it easy for friends and family to step up and provide the assistance. Encourage individuals to make a list of favorite foods, so that people who would like to help by “dropping off a meal,” know what foods are preferred or need to be avoided.

Helping Individuals Find New Connections

Building new social ties is a vital strategy for combating HD-related isolation.

Professionals can encourage individuals and caregivers to seek out community through avenues tailored to the resources available in their area.

In countries with established national or regional HD associations (which typically host local chapters, support groups and events), professionals can recommend the following avenues for connection:

- **Recommend Joining a Support Group:** By attending, those impacted by HD can connect with others who share a genuine understanding of their experience. In this environment, they don't have to spend energy explaining the disease or its emotional toll.
- **Suggest Attending HD Events:** Encourage participation in events hosted by HD organizations. These gatherings serve a dual purpose: they offer opportunities for education and learning and create a natural setting for meeting others who are navigating a similar journey.
- **Facilitate Getting Involved:** Volunteering can be a powerful way to foster new connections. This involvement provides a constructive outlet. It shifts focus outward and cultivates a strong sense of purpose and belonging.

For individuals in countries or regions without an established HD association or limited local services, professionals can still guide them toward finding connections by leveraging online and non-HD-specific resources:

- **Explore Online HD Communities:** Encourage the use of social media platforms (e.g. dedicated Facebook groups, online forums) or virtual communities related to HD. These platforms transcend geographical barriers, offering access to shared experiences, emotional support and information from people worldwide who

understand their situation.

- **Utilize General Online Support Resources:** If HD-specific connections are scarce, suggest finding support through online resources focused on caregiving, chronic illness, or mental wellness. Connecting with people managing similar challenges, despite the fact that the underlying condition is different, can still significantly reduce feelings of isolation.

Conclusion

No one should face the challenges of Huntington's Disease in isolation. By encouraging and facilitating these proactive steps, individuals can adjust their expectations and actively work towards finding their community. Professionals can help them successfully move towards decreasing isolation and secure the strength, understanding, and support network they need.



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