

Make
Life



Fostering Hopeful Creativity
in Huntington's Disease Communities

*A Workbook for
People Affected by
Huntington's Disease who
Could Use a Little Hope*

Brian Schrag

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The Story Behind MakeLife|HD

My grandfather—Edward Enns, a dust belt farmer-preacher-singer—was diagnosed with HD in 1961, dying in 1977. His daughter, Marilyn, became my mother in 1962. Our family always knew she had a 50/50 chance of carrying the HD mutation, but as Mom passed her 30s, 40s, and 50s with no clear symptoms, we thought we had dodged the bullet. Eventually, though, we noticed signs and a genetic test returned positive for HD when she was 69.

I responded to this news in part by writing Mom a song that integrates elements of our relationship. When I first left Ohio for college in Rhode Island, I sent her a startlingly colored Autumn leaf for her October birthday. I've continued this tradition for each of the 30+ years since, from Dallas, California, Chicago, France, Congo, and Cameroon. So the title, "Leaves," plays a central role in the song—deep colors evoking ideas of beauty, death, and the promise of life.

A few months later, in December 2010, the results of my own genetic test showed that I also have the mutation. I've dedicated most of my professional life to encouraging communities around the world to use their own arts to connect to God and bring healing. I've seen this approach work with my mom and want to see if we can extend it to others affected by HD. That's why **Make Life|HD** exists.

I'd love to see HD communities develop a deeply flourishing culture, making things for each other all the time. I think you'll be surprised how powerful a little person-to-person creativity can be.

Brian Schrag, 2015
MakeLifeHD.org

The MakeLifeHD Approach

Make LifeHD is a project that helps communities affected by Huntington's Disease make life-giving stuff for each other.

The process needs people to fill three roles

1. **Receiver** - A person who needs the gift of a little life because of HD
2. **Maker** - Someone who can make something that will bring a smile, a moment of contentment, a sign of understanding to the Receiver
3. **Facilitator** - A person who helps the Receiver and Maker complete the life-giving process. Since you're reading this, you are probably the Facilitator.

Note that one person can fill more than one role.

The cycle consists of six flexible steps

1. **Explore** - Identify and describe possible participants
2. **Connect** - Makers and Receivers meet
3. **Learn** - Makers and Receivers get to know each others' arts and hearts
4. **Make** - The Maker creates something that might meet the Receiver's need
5. **Bless** - The Maker presents his or her creation to the Receiver
6. **Celebrate and Continue** - Spark more creativity

For examples of this kind of creativity, explanations of why it works, and access to more resources, see **MakeLifeHD.org**.

1 Explore—*Who is in your networks and what can they do?*

Write your name in the middle of the page, then add other peoples' names around it: family members, friends, friends of friends, and other people who make up your social networks.

Look at the names and add two kinds of notations.

First, write "HD" near the name of each person who may be experiencing stress, dark times because of, or made worse by, Huntington's Disease. This could include people who

- have found out that they are at risk for HD, or someone they love is at risk
- found out that they have the Huntingtin mutation
- feel survivor's guilt for being gene negative when others in their family are gene positive
- are caregivers at the end of their ropes
- are experiencing frustrating, discouraging HD symptoms

Second, write the artistic gift near each person who has some sort of skill and/or joy in making things. These creations could include

- songs, poems, dramatic monologues, quilts, filled-in coloring book pages, hats or other pieces of clothing, dances, piñatas, coffee mugs, paintings, new proverbs, short films, lolcats, short stories, spoken word rhymes or raps, mazes, labyrinths, fruit carvings, or anything that artistically connects to and encourages someone.

more scribblings for Step 1:

2 *Connect-Makers and Receivers Meet*

Reflect on the names you've written, jotting down possible Maker-Receiver pairs. The most likely scenarios: an individual for another individual, or an individual or small group for a group.

Choose a pair, then contact the person with the artistic gift, asking them if they would like to make something for a Receiver.

more scribblings for Step 2:

3 *Learn-Makers and Receivers get to know each other*

The Maker and Receiver may know each other very well, or not at all. In any case, communicate about the subjects below and jot down a few things.

To the Receiver: What is your HD story and needs? What are some of your musical, dance, visual, or other artistic experiences, and what parts of them do you love?

To the Maker: What do you like to make?

more scribblings for Step 3:

4 *Make-Maker creates something that might spark life in the Receiver*

Based on the discussions in Step 3, the Maker gets to work.

There needs to be a tangible form of the creation. If it's a material object—like a drawing or quilt—then this is already taken care of. If it's a performance—like a song or skit or fireworks display—then the Maker should create an audio, video, or still photo recording to give.

Before giving the creation, the Maker should show or talk about it with someone they trust, maybe someone else who knows the Receiver. They can ask for suggestions to make the creation better.

more scribblings for Step 4:

5 *Bless-Maker presents their creation to the Receiver*

Ideally, the Maker and Receiver meet face to face, and the Maker performs and/or presents the gift. If they are not able to meet, the Maker can present from a distance, maybe by videoconference.

Plan the presentation as a comfortable, hopeful, enjoyable meeting. Normally, it will be a private occasion, perhaps including a small group of friends and family. But if everyone agrees, you can make it an extravaganza.

more scribblings for Step 5:

6 Enjoy and Make More—*Receivers and Makers* *think of ways to help someone else*

The Receiver can now integrate the gift into his or her life, a visible or audible reminder of hope.

He or she may be able to make something for someone else, or encourage someone else to make something. Our goal is to spark a continuing tradition of life-giving creativity within the community.

Write down some ideas about sparking more creativity.

more scribblings for Step 6:

more pages to scribble whatever you want

more pages to scribble whatever you want