Overview
For the last six years The Guthrie Center and Laurel Lake Center have sponsored a “Summer Saturday for Families” touched by Huntington’s Disease (HD). Our programs have featured physicians, psychologists, nurses, rehab therapists and other health care professionals known for their unique experience. We have also hosted a nearly equal number of family caregivers and folks with HD who’ve brought their talent and treasure of experience and insight to us. We go to great effort to make these days upbeat, helpful, real and inspirational. Together we’ve laughed a lot, been touched deeply from time to time and found new friends and allies in the cause. We’ve launched balloons, raised toasts, wished and prayed together for a cure. For all the challenges that HD puts before your family, we want you to feel at home here at The Guthrie Center. This summer’s program will continue in that spirit with a different program format.

This Year’s Program
Over the last several years I’ve been the guest of associations and families touched by HD all over the world, primarily in Europe, but rarely here in the USA. I’ve seen many, many families caring for their folks with HD in many different types of settings and arrangements. I’ve collected many ideas from them and my colleagues, seen different ways to look at problems and listened to the challenges that you face from hour to hour, day in and day out. Nobody’s hiding any easy answers to problems but they endure in their quests to figure things out that will make life a bit easier.

From these collaborations and experiences I’ve come up with a series of presentations, talks, demonstrations, workshops and activities about practical concerns and problems facing family caregivers. Because many of the problems are common, I trust that they will help in some way.

We warmly invite old and new friends to spend the day with us. This year’s program focuses on topics of special interest to family members caring directly or indirectly for loved ones with HD and those who oversee their care in nursing homes or residential settings. We know it’s difficult for caregivers to arrange coverage care in their absence. I hope this early notice will help a bit.

If you have HD yourself, we ask that you pass up this day. The risk of unintentionally offending you or hurting your feelings in some way tends to inhibit us as we try to figure out ways to become better partners in your struggle with HD.

We have always welcomed children to The Center at past HD-related events. However, this year’s program may be difficult for them as we address some practical topics. They’ll continue to be welcome in the future!

The Guthrie Center
40 years ago this year (Yes, forty years!) Arlo Guthrie was convicted of litterin’ on Thanksgiving Day! As unlikely as it may have seemed way back then, in the intervening years he went straight and has become an upstanding citizen! Among his contributions to the community was the founding of The Guthrie Center in the old Trinity Church in Housatonic where The Alice’s Restaurant Massacre saga began!

The Center’s programs, staffed and coordinated by volunteers, cover a variety of topics in health, music, art, education and spirituality. A not-for-profit Interfaith Church Foundation, the Center meets the changing needs of the local and universal community in a tradition of service and compassion.

The Center is located in the Housatonic section of Great Barrington, Massachusetts about 7 miles south of Mass Pike Exit 2 on Route 41. It’s about a 2-1/2 hour ride from both Boston and Manhattan, and about 40 minutes from Albany.

Schedule

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<tr>
<th>Time</th>
<th>Activity</th>
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<tr>
<td>9:15 a.m.</td>
<td>Register &amp; Continental Breakfast</td>
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<tr>
<td>9:30 a.m.</td>
<td>Program Begins</td>
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<tr>
<td>12:45 p.m.</td>
<td>Break for Lunch (Included)</td>
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<tr>
<td>1:30 p.m.</td>
<td>Afternoon Program Begins</td>
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<tr>
<td>4:00 p.m.</td>
<td>Day Ends...Safe Trip Home!</td>
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Topics

A Caregiver’s Introduction to HD
Everyone knows the symptoms and basic facts about HD. This is a review of just those symptoms which make understanding and living together so difficult at times.

Less Apparent Aspects of Movement Disorder
You may not have been told about these features of HD’s movement disorder. But they present the most difficulty to caregivers and have a greater impact on one’s experience having HD than involuntary movements. We’ll begin with dystonia.

Why the Cognitive Disorder is So Difficult
We healthcare professionals have collectively failed to clearly show, especially to spouses, the impact that HD has on thinking, behavior and “misbehavior.” This is an exercise in awareness that will dramatically show how delayed processing feels and how it influences what we all do, with or without HD.

A Basic Review of the Signs of Depression
HD masks many things. This makes closely watching for the signs of depression very important. It’s difficult to sort out what’s HD and what you should report to a doctor. The general public shares a stereotype of depression. As caregivers we need to fine tune our awareness of its signs and symptoms.

Huntington’s Disguise
As HD progresses friends are fewer in number and visits less often. Even family caregivers may feel a distance from the previously warm expressive face of the one they love. This can often be traced to subtle changes in the face, posture, processing delays and “motor impersistence.” Learning to identify the elements of the disguise help you remove it and teach others to see through it.

The Importance of Routine
Folks with HD find comfort in consistency and power in routine. They tend to hate surprises and may have difficulty adjusting to changes in their daily routine. The reasons for this are based on their neurologic changes as HD progresses. We’ll show you some general principles of developing a routine in your home and some common pitfalls that others have encountered that you can avoid.

The Importance of Proper Positioning
Ever notice that someone’s leaning to one side while sitting in the car or in front of the TV. Are they always slouching? Learn the basic concepts of positioning. And we’ll have time to practice them.

How To Give A Shower
Familiar with the cognitive changes of HD, there are some common principles that can be applied to showering, bathing and all self-care. We’ll review them and come up with new ways to look at assisting folks in the bathroom.

Keeping Folks Engaged in More Advanced HD
It’s a common misconception that all folks in the later stages of HD don’t really understand the depth of your interaction or conversation with them. We’ll cover some techniques and tips that other family members have come up with to really engage them in shared interests.

Other Topics
Briefly, we will also discuss:
• Some New Observations About Feeding Tubes
• A Few Words About Haldol
• Problems with Smoking

About Laurel Lake Center
Laurel Lake Center for Health and Rehabilitation in nearby Lee, Massachusetts offers a specially nursing home program to folks in the mid- and more advanced stages of HD and an assisted living program to folks in its mid stages. For a tour of Laurel Lake contact Jim Pollard at (413) 243-2010.

The HD Memorial Quilt
A project of HUNT-DIS, an online mutual support mailing list, there is no greater symbol of the collective years of care given by family caregivers to their loved ones than this quilt. It will be on display throughout the day.

Speaker
Jim Pollard, a special education teacher and healthcare administrator has worked with people with Huntington’s Disease for the last 18 years. He’s toured England and Wales speaking to healthcare professionals for the HD Association of Great Britain. A regular speaker at biennial meetings of both the International and European Huntington’s Associations, he is the former administrator of Sunbridge for Lowell (MA) and current program director of the Laurel Lake Center’s HD programs. He is the editor and author of “A Caregiver’s Handbook for Advanced Stage Huntington’s Disease” which has been published by HD societies in seven countries in North America and Europe. He helps run HD-related events at The Guthrie Center in Great Barrington, MA, including the annual Family/HD Scientist Thanksgiving Dinner. For the last several summers he has organized an event at the Woody Guthrie Folk Festival in Okemah with the OK chapter of HDSA. He taught special education, behavior analysis and child development at the graduate level for many years.

Relax!

This is a day for caregivers. Caregivers need care, too! Dress casually! You are among friends! As is our tradition, we cater our breaks with shrimp cocktail, penny candy, ice cream bars and other surprises.

Our mailing list is very limited. People often feel that we overlook them but that’s not the case! Please help us to invite other families that we may have forgotten or not met yet. Call us with their name and address and we’ll send them a brochure. If you’d like more brochures for meetings, clinics or support groups, just let us know. Call Jim at 413-243-2010.

Registration

Space is limited to 65 people. Please register as soon as possible but no later than Monday, July 25th.

Name
Address
City
State Zip
Phone (___) ___
E-mail address

Other Family Members Coming:

Registration is $10.00 for the first member of a family, $5.00 for each additional family member. Lunch is included. Please make checks payable to “The Guthrie Center,” all proceeds go to support its work. Mail this form and your check to:
Jim Pollard/Summer Saturday 2005
Laurel Lake Center
620 Laurel Street
Lee, MA 01238

If you have a question, please contact Jim at the Laurel Lake Center at (413) 243-2010 or e-mail him at jipollard@comcast.net. Let us know if there are any special concerns that you’d like addressed. Directions will be sent to all that register. Again, dress is casual.

Our Seventh
Summer Saturday at the Guthrie Center
For Families Touched by Huntington’s Disease

A Day of Friendship, Food and a Variety of Topics Related to Family Caregiving for Advancing Huntington’s Disease

July 30, 2005
9:15 a.m. - 4:00 p.m.

Hosted by
The Guthrie Center
Housatonic, Massachusetts

Sponsored by
Laurel Lake Center for Health And Rehabilitation
Lee, Massachusetts
(413) 243-2010