Ways to Compensate for Swallowing Difficulties

HD affects each person differently. All of the following suggestions may not be helpful to you. You should stay in close contact with a physician and speech-language pathologist to evaluate your swallowing and receive specific instructions. A swallowing evaluation may be required prior to making recommendations. The following suggestions might make eating easier for you and lower your risk of choking and aspiration.

1. Sit upright for all meals, snacks or drinks. This is generally the safest position. Stay upright for 20-30 minutes after a meal.

2. Take small sips and bites (1/4 to 1/2 tsp). A small spoon will help you remember this. Blend food to make it easier to chew. Some people find it easier to use a “nosey” cup or weighted spoon. Occupational therapy can help you use and find the appropriate equipment.

3. Think “swallow”. Hold the food in your mouth and think about swallowing.

4. One bite at a time. Be sure to swallow all the food or drink in your mouth before taking another bite.

5. Concentrate. Always eat slowly and carefully. Turn off the television or radio. Eat in a relaxed, quiet atmosphere. If possible, avoid eating when upset or fatigued. Avoid talking while eating.

6. Keep your chin down. Keeping your chin down as you swallow may make it easier and will reduce the risk of food going into your airway. (A pillow or rolled towel behind the head may be helpful for this position)

7. Try to eat smaller meals more often. Eat four to six meals a day instead of three big meals, especially if you tire easily. Try and make the most of your eating by eating nutritious foods.

8. Try soft, blended foods. Blended foods tend to be easier to swallow. Avoid hard or stringy foods. Thickened liquids (honey to milkshake consistency) are generally easier to swallow. A commercial thickener can be purchased to thicken liquids.

9. Supervision or assistance helps to control rate and amount. Provide verbal cues to swallow, slow down or place food correctly in mouth.

These are general guidelines. Please check with a speech pathologist or physician to receive a full evaluation.

This list compiled by the University of Iowa Hospitals and Clinics, Speech and Swallowing Services

Health Care Reform

There will certainly be a debate about health care reform in the new Congress starting in January 2009. The budgets of families, business and government are being stressed by the rising cost of healthcare. According to a group of leading corporations, there is a better chance of passing legislation than previously, when much of the discussion was private and did not include major players, like pharmaceutical companies and insurance companies.

Who are these major players?

Of course President Barack Obama will have a plan. The leading corporations were brought together when Tom Daschle was introduced as prospective Secretary of Health and Human Services and they are very interested in new legislation. The group includes the head of Business Roundtable who speaks for leading corporations; the chief executive of Pfizer, a known pharmaceutical
company; the President of America’s Health Insurance Plans; the spokesman for the National Federation of Independent Business; AARP, the senior citizens organization. Divided we Fail has also been outspoken about the need for the Congress to work together. Tom Daschle, is the former South Dakota Senator who understands Capitol politics and has written a book on healthcare reform. The other committees that support change include the head of the Senate Finance committee, Max Baucus, Montana Democrat. The chair of the Senate Health, Education, Labor and Pensions is Massachusetts Senator, Ted Kennedy. He has worked on health care reform during his tenure as Senator and has a pressing need to pass this legislation before his ailing health prevents this. In the House of Representatives, Henry Waxman, Democrat California, is the new chairman of Energy and Commerce and Representative Charles Rangel, Democrat New York, Ways and Means chairman will also have a voice in this process.

David Broder of the Washington Post says “it will really test the whole political system to determine if the fragile emerging consensus on the need for major reform can overcome the thousand particular issue battles that are certain to erupt.” Mr. Broder wonders if representative government can work.

**NEW STAFF**

**Nancy Hale**
is a new clinical trials coordinator. She is a nurse and has worked in psychiatry research since 2001. In her free time she enjoys gardening, reading and biking as part of a triatholon relay team.

**Mycah Kimble**
was born and raised in Iowa City and has a BA in psychology from the University of Iowa. Her family includes her 7 year old daughter, her fiance and two kittens. She is excited to be part of the wonderful work done in the lab and looks forward to meeting participants and their families.

**Pat Ryan**
is the new PREDICT site coordinator in Iowa. She comes to us with Masters degrees in Social Work and Sociology and experience in counseling, social research and data processing. Pat and her husband live in Iowa City with two cats. She has family in San Francisco and New York City. She spends her vacations travelling from one side of the country to another. Pat is excited about meeting our fantastic PREDICT participants.

**Hoop Season 2009**
Join the Iowa HDSA chapter in spring hoop-a-thons to raise money and awareness of HD. Shoot some hoops and support the Iowa chapter of HDSA that, in turn, helps fund the HDSA Center of Excellence at the University of Iowa.

**Des Moines** Saturday, March 14  
AIB College Activity Center  
**Audubon** Sunday, March 29  
Audubon High School

**Storm Lake** Saturday, March 21  
Storm Lake Middle School  
**Cedar Rapids/Marion** Saturday, April 4  
**Bedford** Saturday, March 28  
Bedford High School
CIT-HD: Citalopram and Huntington’s Disease

Researchers at the University of Iowa are looking to improve cognitive and daily functioning in persons with early HD. This study began in spring 2007 and today is a multi-site trial evaluating 16 weeks of treatment with citalopram (Celexa) compared to placebo (an inactive substance) on daily activities such as working, attention, thinking ability, and muscle movement in adults who are HD gene positive or diagnosed with mild HD. The University of Iowa, University of Rochester and Mayo Clinic in Scottsdale, AZ are conducting this study and welcome speaking with anyone interested in participating.

What are we trying to learn in CIT-HD?
- How citalopram affects daily activities and other measures of functional ability (e.g., work productivity, attention, psychiatric status, etc.) in individuals with early or mild HD
- How citalopram affects brain and motor functioning
- If certain genes (other than the HD gene) affect an individual’s treatment response to citalopram

Who can participate in CIT-HD?
- Participants must have a gene positive HD test (or, if untested, an HD diagnosis)
- Participants must have early or mild HD symptoms
- Participants must be between age 18 and 65
- Participants must report a concern with their current attention and/or thinking skills
- Participants cannot currently take medications for depression. However, individuals taking over the counter supplements (e.g., St. John’s Wort) may still be eligible.

What study procedures will occur?
- A screening visit will determine whether this trial is right for you
- The trial involves nine outpatient visits (1-3 hours each) over the course of 20 weeks and one telephone contact
- Research visits include physical exams, neurological exams, thinking tests and surveys. There are blood draws (less than half of a normal blood donation) to evaluate health and safety. We will also collect your saliva one time for genetic analysis.
- University of Iowa participants may be invited to participate in an MRI evaluation.

What else do I need to know about participating?
- Compensation for participation is provided, as is some reimbursement for travel
- Study visits can be set up around your schedule (e.g., specific dates, weekends)
- Optional studies on other HD-related topics (e.g., functional brain imaging, eye tracking, genetic discrimination) may be completed during a CIT-HD visit

Who is paying for CIT-HD?
- The National Institutes of Health (NINDS to Leigh Beglinger, Ph.D.)
- The Cure Huntington’s Disease Initiative Foundation (CHDI).

How can I find out more information about CIT-HD?
**University of Iowa:** Contact William H. Adams at: 319-353-4411 William-H-Adams@uiowa.edu
**University of Rochester:** Contact Amy Chesire at: 585-341-7519 Amy.Chesire@ctcc.rochester.edu
**Mayo Clinic, Scottsdale, AZ:** Contact Amy Duffy at: 480-301-475 Duffy.Amy@mayo.edu

An institutional review board (IRB), also known as an independent ethics committee (IEC) or ethical review board (ERB), is a committee that approves, monitors, and reviews biomedical and behavioral research involving humans with the aim to protect the rights and welfare of the research subjects.

The Research Act of 1974 defined IRBs and required them for all research that receives funding, directly or indirectly, from what is now the Department of Health and Human Services (HHS). IRBs were developed in direct response to research abuses earlier in the twentieth century. Two of the most notorious of these abuses were the experiments of Nazi physicians during World War II and the Tuskegee Syphilis Study, an unethical and scientifically unjustifiable project conducted between 1932 and 1972 by the U.S. Public Health Service on poor, illiterate black men in rural Alabama. IRBs also oversee clinical trials of drugs involved in new drug applications. IRBs are most commonly used for studies in the fields of medicine and psychology. Studies may be clinical trials of new drugs or devices, they may be studies of personal or social behavior, or they may be studies of how health care is delivered and might be improved.

The purpose of an IRB review is to assure, both in advance and by periodic review, that appropriate steps are taken to protect the rights and welfare of humans participating as subjects in a research study. The chief objectives of every IRB protocol review are to assess the scientific merit of the research and its methods, to promote fully informed and voluntary participation by prospective subjects who are capable of making such choices (or, if that is not possible, informed permission given by a suitable proxy) and to maximize the safety of subjects once they are enrolled in the project.

wikipedia.com