Closing the care gap: new guidelines for HD care

Closing the care gap: new guidelines to help every Huntington's disease patient get great care

By Professor Ed Wild | April 17, 2012 | Edited by Dr Jeff Carroll

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Huntington's disease may be incurable - but it's far from untreatable. But the care patients receive from professionals can be inconsistent. Now, a series of recently published internationally-agreed guidelines will help 'level up' everyone's care to the best standards.

Mind the gap

The Huntington's Disease Association of England and Wales has as its slogan**Hunting for a cure, with care**, while the HD Society of America promises**Help for today. Hope for tomorrow**.

Like a fine cognac, these new publications distill a wealth of knowledge and expertise into easy-to-swallow guidelines. Mmmmm... cognac.

Rightly, these organizations recognize that scientific research into new drugs to prevent or slow Huntington's disease is not enough. Without proper clinical care, even a perfect drug cannot do any good. Scientific research and care must go hand-in-hand.

Huntington's is often described as 'untreatable'. - but that's simply not true. It may be incurable, but in fact, **many** treatments exist that can help people with HD. Drugs can improve many symptoms of HD, and non-drug treatments like physiotherapy and dietary supplements can often provide dramatic benefits.

For many people, the greatest barrier to living well with HD is not that treatments don't exist - it's that the professionals looking after them aren't fully aware of the best way to help Huntington's disease patients.

That's not to say that these professionals are negligent - even for clinicians who are expert in managing neurological and psychiatric conditions, it can be surprisingly difficult to keep fully up to date with the latest research into caring for patients. And quite often, even the experts can't agree on what the "best" care is.

Levelling up

Thankfully, people affected by Huntington's disease are part of a uniquely connected global community of families, care professionals and scientists. The HD community is really good at working together to share ideas and best practices.

The past few months have seen several initiatives aimed at improving standards of care in HD. They've all come from collaborative groups of professionals, working with patients and family members, to try to produce practical guidelines that have a sound basis in scientific research.

Standards of care

The European HD Network - **EHDN** - recently published a comprehensive set of guidelines for clinicians caring for HD-affected people. Each guideline is the end product of several years of intensive effort by 'working groups' of professionals, guided by their own expertise and the wealth of research into HD.

The guidelines include straightforward advice on physiotherapy, nutrition, feeding, oral care, speech and communication, and occupational therapy.

Helpfully, EHDN worked with the journal Neurodegenerative Disease Management to publish the guidelines as 'open access', so anyone can download them, free of charge.

Treatment algorithms

Open access is a key ingredient of another recent initiative - a series of publications aimed at assisting doctors in making decisions about drug treatments in Huntington's disease.

Many doctors, especially those who aren't expert in managing patients with HD, are either unaware of the range of drugs that can be used to help control symptoms, or have difficulty making rational decisions about the best treatment in a particular situation. Because

treating HD often follows a ‘trial and error’ approach, there are big differences in approaches to treatment in different parts of the world.

In an attempt to bring some clarity to the situation, Dr LaVonne Goodman assembled an international panel of doctors considered world experts in the field of HD. Goodman chose three HD symptoms that are most challenging for non-experts to manage: chorea (the involuntary movements experienced by most HD patients), irritability and obsessive-compulsive symptoms.

> **“Fundamentally, all HD research is about giving people the maximum number of years of good quality life ”**

For each symptom, a survey was used to produce a snapshot of treatment patterns. The answers were then pulled together to create ‘treatment algorithms’ - essentially, step-by-step decision-making tools.

The algorithms were published in the innovative online journal PLoS Currents: Huntington’s Disease and, again, can be downloaded free of charge by anyone.

Quantity of quality

Nobody knows how much time we’ll have on this earth, but - to misquote top wizard Gandalf - “all we have to decide is how to make the most of the time that is given to us”.

Fundamentally, the aim of all Huntington’s disease research is giving HD-affected people the maximum number of years of good quality life.

But what *is* quality of life, and how do we know whether we’re improving it? A surprisingly difficult question - but one that’s crucial to answer. Not only is it important in its own right, but government agencies often require evidence that a drug improves quality of life before they’ll approve them for use.

Thankfully this is another area where we’ve seen significant progress. EHDN’s Quality of Life Working Group, led by Dr Aileen Ho, recently produced the **HDQoL** - the Huntington’s Disease Health-related Quality of Life questionnaire, and published it in the journal Clinical Genetics.

The process began with interviews with patients and carers to identify the most important things in people’s lives that HD affects. A large set of questions about these things was then produced and boiled down to the final set, through a rigorous process of repeated interviews.

The end result is a tool that will hopefully enable us to assess the real impact of any drug or other intervention for HD.

It never stops

These developments, which have all taken place in the past few months, demonstrate how communication, care and science can work together to improve the lives of HD-affected people.

Of course, everyone's different, so no guideline or algorithm can replace expertise and effective communication between professionals and patients. But having internationally-agreed guidelines in place gives every professional a scientifically-sound basis for the tricky business of helping HD-affected people.

So, don't be afraid to point the professionals involved in your care in the direction of these guidelines. Any clinician who's up to scratch will be glad to be made aware of them.

And - as we're fond of pointing out - science never stops. These guidelines will be reviewed, added to and improved. The more we learn about HD, in the lab and in the clinic, the better we get at caring.

The authors have no conflicts of interest to declare.For more information about our disclosure policy see our FAQ...

GLOSSARY

neurodegenerative A disease caused by progressive malfunctioning and death of brain cells (neurons)

chorea Involuntary, irregular 'fidgety' movements that are common in HD
