

HAPPe-News

The Huntington's Asymptomatic Positive People newsheet April 2001

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Website: coming soon



Welcome...

to this the first newsheet for the unofficial support network for presymptomatic Huntington's people. My name is Tracey and I went through the predictive testing procedure in June 1998 and received a gene positive result. Since then, I have been trying to find ways to make it easier for people in this situation, to access support, information and ideas on how to make the most of every day. I hope that this newsheet will help provide some of these

As well as me, others will be contributing to the content of this monthly newsheet, in particular my sister and a couple of friends. But, if you have any websites or publications to recommend or just some ideas to share, please send them to PO Box 517, Claremont, WA 6010, AUSTRALIA or email Tracey at insomnia@highway1.com.au



About this newsheet...

This publication is directed first and foremost at gene-positive people in the Huntington's community. However, it is distributed free of charge by email or by mail on a monthly basis so, if you would like to receive it on a regular basis, please contact Tracey at the details above to add your name to our mailing database.

Website to Check out...

The Huntington's Disease Advocacy Centre

<http://www.hdac.org>

An attractive and professional site which is easy to navigate through and also includes a search facility. The content is exceptional, ranging from personal stories to professional information to Frequently Asked Questions and provides a balanced and comprehensive overview of Huntington's. With online



surveys, a "Political Activist" page and even a HD card template, the site provides practical assistance as well as information. Although the site could be updated more regularly, this is a 'must see' for anyone curious about Huntington's and of course doubly relevant to those with a more personal interest in the disease.

We will endeavour to bring you reviews, up-to-date research information, positive sayings and practical information about Huntington's and about smiling a lot. If you have any requests or suggestions about the content, just let us know.

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A thought...

There are two ways of meeting difficulties:

*you alter the difficulties,
or you alter yourself
to meet them.*

Phyllis Bottome

What's new in Research?

One research technique that is being trialled is that of transplanting foetal cells into the brains of people with HD to study whether this can slow, stop or reverse degeneration. Details of the procedure and the results are available at www.thelancet.com

Another study which is still ongoing is the PHAROS or Prospective Huntington At Risk Observational Study which began in mid 1999 in the US and Canada. Volunteers at-risk of HD are being observed over a lengthy period to identify initial symptoms, factors affecting onset and symptoms and so on. More information is available at www.Huntington-Study-Group.org

Good Ideas...

How do you make positive thinking work?

Decide to make your life an adventure - a game. You will be confronted with problems and challenges. The negative thinker is overwhelmed by the awesome threat of it. The adventurer is excited by the challenge of it.

When confronted by a problem, don't panic in thinking about the obstacles and giving up.



Make a conscious effort to list, either mentally or on paper, the positive and constructive things you can do to resolve it. Gather whatever information you need to make the decision or take the necessary action. That may require research, reading or consulting people whose advice you trust. Concentrate on what you can do, not on what you can't.

Don't waste time and energy worrying about what you can't do, or what might happen. Worry is rehearsing for failure.

When you start practising this positive mental attitude, you may find it hard to begin with. You may be shocked to find that your first reaction to a tough or threatening situation is negative. That's understandable. It seems easier to think negatively in response to a situation because that way you don't have to struggle and you don't have to work at solving it. It's easy to slip into the rut of the negative response.

AA Milne, the man who wrote the delightful Winnie the Pooh stories wrote, 'The third rate mind is only happy when it is

thinking with the majority. The second rate mind is only happy when it is thinking with the minority. The first rate mind is only happy when it is thinking.' Henry Ford's comment is also worth remembering: 'Thinking is the hardest work of all - and that's why so few of us do it.'

You may also find positive thinking tough going because you are surrounded by so much which is negative. You've only got to read the first five pages of the daily paper or watch the first ten minutes of the news on television, to feel that it's a pretty gloomy old world out there.

You may feel overwhelmed by the odds when you are confronted by a problem or a crisis. Someone illustrated it well this way: the diamond miners patiently shift tons of earth for the sake of finding a few gems no bigger than your little thumb nail. It would be easy to become discouraged by the mountain of soil and overlook the value of the precious stones. It is easy to be overwhelmed by the size of the problem and overlook the value or the importance of the solution. Once you develop the positive thinking habit - and it is a habit - you'll be amazed how much more optimistic you become, how much sooner you are able to find solutions to problems.



Yet, for some strange reason, we often respond negatively to situations. Montaigne, the French philosopher, once wrote, 'Most of my life has been full of terrible disasters - most of

which never happened.' Isn't that true for all of us? How many times have you lost sleep, or been unable to eat simply because your imagination ran riot with all the negative possibilities facing you and then things turned out OK? Three days later you ask yourself what on earth you were worrying about.



Many of us live overshadowed by some negative possibility or some nagging self-doubt. We are crippled before we begin. How about you?

Let's face it, failure is a fact of life, as is grief, disappointments and making mistakes. However, I think we learn more from our failures than from our successes. We usually don't analyse our successes; we may enjoy them, celebrate them, even bask in the moment of glory they bring, but it's usually the setbacks, failures and frustrating disappointments that stop us in our tracks and make us ask why. Success is sweet, but failure can be the teacher if we develop the right attitude to it.

Sometimes we are reluctant to try because we fear failure and we fear what others might say. Abraham Lincoln had a courageous attitude: 'I do the very best I can, I mean to keep going. If the end brings me out alright, then what is said against me won't matter. If I am wrong, ten angels swearing I was right won't make a difference.

This is an excerpt only. If anyone recognises this text, please let us know where it is from.