

Chapter 8: TIPS FOR LIVING WITH HUNTINGTON'S DISEASE

Making yourself stronger

Both my husband Phil and older son Brom read a lot of self-improvement books to help them become stronger in dealing with HD. So, I asked Phil to put this chapter together...

Here are a few ideas for how to gain and maintain the strength you need to deal with HD. Different members of our family have used all of these tips and will continue to do so. We're talking months and years here for this to take effect, but HD moves slowly, so you can keep pace or keep ahead of it:

Dump the emotional baggage

We all carry emotional baggage around with us. I mean the insecurities and self-doubt that lie under the surface. Within us, often subconsciously, are the fears that developed from unhappy experiences, the sense of our own limitations that became set in concrete every time we failed or were told we had failed, or every time we got hurt.

To become stronger so you can deal with Huntington's, you may want to deal with these inner demons. It's like cleaning house. If you don't get them tidied up and put away in their boxes, they will be a constant distraction, tugging on your coat tails and sapping your energy. If you fail to deal with them, you'll be quicker to anger, less confident and have less of a buffer of calm to draw on. And you'll be more tired. Some of the steps below can help.

Talk yourself stronger

...with family, selected friends, counsellor, shrink, doctor, other people with experience of HD, support workers, other carers or people at risk. HD can seem so big that you feel powerless to talk about it without sinking into depression or anger. Not talking about it lets all your fears about it stay unformed and scary, like a knot in your stomach. Have the occasional rant to selected friends: you will soon know which one or two can deal with it and which can't. Counsellors can be a great source of techniques for re-thinking things, steering your thoughts away from negative "I can't do this!" paralysis. So can friends and family. Talk to other carers about what they do if you are a carer.

Don't go it alone

This is really part of 'talk yourself strong'. Ask for help and advice. It's often the small problems that are SO frustrating. People come up with brilliant ideas to solve them. We were having increasing trouble getting Sandy's contact lenses in once a month and discarding the old ones. She could no longer do it herself. I took over, but after a few months I couldn't do it either. We got to the stage where she had only one lens in for a couple of weeks, giving her a cock-eyed view of life, and headaches. I was getting desperate. She didn't seem bothered!

Sandy's mum said 'I've been thinking about your problem: If she lies on her back with her head on a pillow, her head can't move as much.' It was a stroke of genius and worked immediately. Instead of twenty increasingly frustrating minutes of Sandy sitting on the edge of the bath or standing in front of the bathroom mirror, with me reaching around to her eye from behind and dropping the lens endlessly, it was in her eye in seconds. A daft example, maybe, but a sound principle: constantly ask other people for ideas on how to solve all the small problems that HD throws up every day.