

Minding your Mental Well-being

Caring for a Family Member with Huntington's disease

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Caring for a family member with Huntington's disease can be a rewarding experience, one that can enrich relationships, however, it can also be a stressful one. It is important that you, the carers, are cared for and looked after in order to be able to maintain your caring roles.

A diagnosis of Huntington's disease (HD) is a stressful experience for the individual and the family. However, the landscape of HD is a shifting one and as time progresses, the nature of this stressor can change, as symptoms arise and doing certain tasks is no longer as easy as before. As time passes, your family members may need more help in certain activities; they may need you to help compensate for what is more difficult for them now.

This may be reminding them to take their medication, if their memory is not as good as it once was, or it may be helping them to walk down the street, if their mobility is difficult and safety may be an issue. With time, the changes that your family member encounters can result in changes in their role and yours; roles within the home and roles within life. Where once your family member may have been the person in the house to look after the finances and do most of the driving or child care, with time, they may be no longer able to do so.

Within all relationships, we fulfil certain roles and these can shift with changing circumstance, however HD can force these shifts in role and can mean that as well as continuing to fulfil all of your own roles and tasks, you now take on more.

Some roles can suit us well and we can slip seamlessly into them, however others can feel more burdensome; some roles are practical and entail taking on tasks, others are more psychological and entail taking on stressors. As well as being spouse, parent and primary child-care provider, you may also find yourself taking over the role of manager of the household finances, disciplinarian to the children and primary breadwinner, as well as carer to your partner.

Some of the changes we encounter when caring for a family member can be unwelcome, all are uninvited. Despite this, some changes can show you the inner strength you may never have known you had. They may give you the chance to "give back" the time, care and acceptance once shown to you.

The caring role may show you a new side of yourself; that you have many more abilities than you may have once given yourself credit for. As a clinician, I am always taken aback at how the carers I meet are managing to juggle so much in terms of their caring role and all with the general demands of life added on top.

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I am amazed at all you achieve and, far too frequently, how little you give yourself credit for. The carers I meet can often focus on the small things that they have not managed to do that day; I see the hundred and one things that you have. Although it may be difficult, you need to see this too; you need to value what you have managed to do; you need to stop and think to yourself "What do I need in order to keep managing all that I am? What is going to put a smile on my face; give me a belly-laugh; give me a sense of peace and rejuvenation?"

"What do I need?" is a question that the carers I meet often rarely ask themselves. It's a question that often comes with a sneaking sense of guilt, a sense of being selfish. In the caring professions, we are taught about "Self-care", the importance of looking after yourself, as an essential in our work.

It is instilled into us as a necessity to ensure that we can keep going, can keep giving; to ensure that we avoid burn-out. For family carers the concept of self-care, can often seem alien; the carer themselves is at the bottom of the daily to-do list.

Some carers have even told me that they are not on the list at all. Think for a moment about your own list. Where do you feature? Is doing something for yourself on there? Having coffee with a friend; playing a game of tennis; sitting down and reading a book or watching your favourite box-set; having a long bath; whatever you enjoy. Cognitive Behavioural Therapy or CBT, as you might know it, is a psychological therapy approach which is effective for people with low mood, anxiety and a host of other difficulties; much of the advice of CBT is useful for all of us in managing our mood.

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Part of this approach emphasises the importance of two things - Pleasure and Mastery. In order to keep stressors at bay and to keep us feeling as good as we can, we each need to do things everyday that give us a sense of Pleasure, something that we enjoy, and Mastery, something that we feel we're good at.

Making time for the things that you enjoy and that give you joy and a sense of accomplishment is so very important when you are in a caring role, because in order to maintain that caring role, you need to be feeling as good as you can be mentally and physically. You need to be in the full of your mental and physical health in order to take on all of the roles that come with caring; to keep up with the shifting landscape of new symptoms and to adjust to the changes that come as time passes and HD progresses.

For the carers I meet, there are four things that I emphasise:

- **You are doing all that you can, give yourself credit for it.**
- **Looking after yourself is important - make time for it!**
- **Do whatever gives you a sense of wellbeing.**
- **Put yourself ON and UP the list!**

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