

# LIVING WELL WITH HAE

## Healthy Minds

### Tools for Living with Stress & Anxiety

Watch the video: <https://haeaustralasia.org.au/resources/video-resources/>

## WHAT SORT OF MENTAL HEALTH CHALLENGES CAN PEOPLE WITH HAE EXPERIENCE?

Most people living with HAE don't have major mental health problems most of the time. But the unpredictability of HAE and its inherent challenges, and the treatments required, mean that it's inevitable that there will be some negative emotions that come up quite regularly. These include sadness, anxiety, worry, and changes to self esteem which all builds up as stress. This document and the accompanying video, outline some known ways to manage all of those negative feelings.

## WHAT IS THE MOST IMPORTANT THING TO REMEMBER ABOUT STRESS? (VIDEO REF: 00:59)

Stress is the result, less of actual events, and situations, and more from the way we automatically think about those events, and how often we think them. This applies to all of those emotions, worry, anxiety and self esteem.

## ANXIETY (VIDEO REF: 01:29)

In the case of anxiety, fear is the product of our perception that something bad is happening, and we won't cope with it. A phobia is a good example. In that case, the person has a very strong perception that something terrible is highly likely to happen, and they won't cope with it. But their predictions and assumptions are obviously faulty, which is why we call it a phobia. But this applies to all of our fears.



## **SELF-ESTEEM (VIDEO REF: 02:06)**

Self esteem is the result of our thoughts. The way you feel about yourself is not a fact, or set in stone. It's an emotional product of how you judge yourself or evaluate yourself against certain standards and expectations.

## **WORRY (VIDEO REF: 02:46)**

Worry is when our mind is telling us that something bad might happen, and that we need to think about it to be prepared. Maybe we do need to think about it constructively in a time limited way. But our mind automatically tries to get us to fret and think about it on and off for hours or maybe across several days. It's important to remember that worry, fretting or stressing doesn't make us more prepared, or reduce the chance of that feared outcome happening. It just produces worry.

## **STRATEGIES FOR DEALING WITH WORRY (VIDEO REF: 03:28)**

- Name the emotions and let yourself have them before you try any other coping strategies.
- How you would express your emotions?
- How would other people that you know, experience and express their emotions?
- How long do you want to do that for; in a healthy way?

## **THOUGHT CHALLENGING (VIDEO REF: 03:51)**

Thought challenging, is identifying the thoughts that are causing or contributing to our emotions, and asking certain questions to challenge those thoughts.

You could ask questions like:

- What exactly have I been feeling?
- What thoughts are causing this?
- Is that thought 100% accurate?
- Is it the only way to think?
- What would I think about it if a friend said this?
- What would I be hoping a friend would say if they were going through the same thing?
- What evidence is there that this is accurate or helpful?
- Is there a safe way to gather more evidence?
- What would others say about that?
- Is my mind overestimating the likelihood of that feared event happening?

- Is my mind overestimating how disastrous that would be if it did happen?
- Is my mind under estimating my capacity to cope if that happened?
- Is my mind over allocating the time that I spend thinking about this?
- How much time should I spend working on this constructively?

### **SOME EXAMPLES:**

Sue feels guilty and very worried that her three kids, aged 7, 9 and 13 will not cope if she has another attack or needs another hospital admission.

- What evidence does she already have that the kids can and do cope and that others will be there with competence and willingness.
- How many minutes should she allocate to this worry? When?
- And what constructive exercise could she work on to reduce her feelings when she does sit down to 'work' on it.

Bruce feels lousy about himself and even guilty at times because he can't do all the sporty things that his dad used to do with him when he was very young. He feels like his illness could ruin their childhoods.

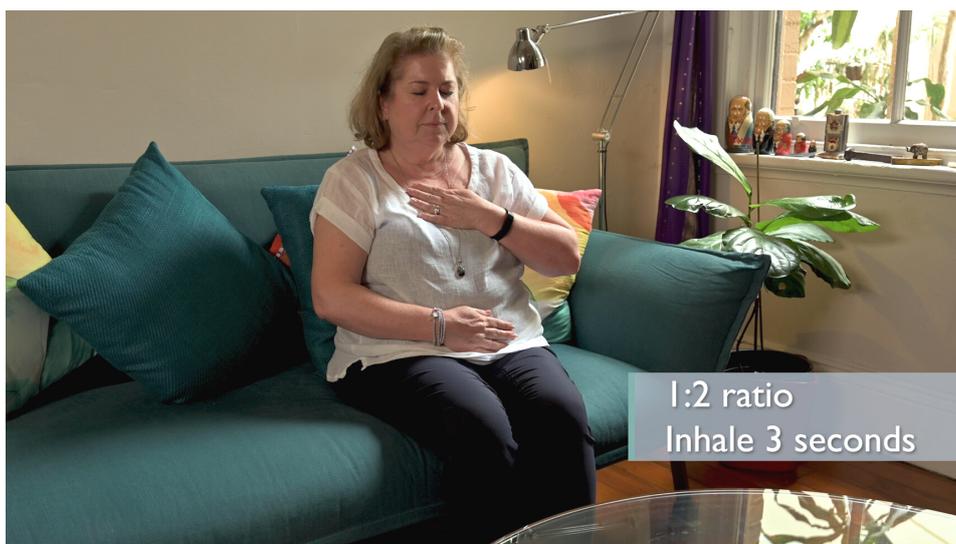
- Would Bruce think and say the same thing about another dad he knows with HAE?
- Is this 100% true – that missing out on physical play can 'ruin a kid's childhood' and that all the other things he does for them does not matter?
- How many minutes should he allocate to this worry? When?

Rebecca notices that she can never relax day or night – in the fear that her 15 year old daughter will have an attack and won't manage it properly possibly ending up in horrendous pain or even death.

- What evidence is there that her daughter is not capable of managing her symptoms? And what evidence is already available that her daughter can manage her symptoms (knows the early warning signs, knows what to do and can do it)?
- Is her mind over-estimating the likelihood of disaster happening?
- Is her mind trying to over-allocate time to this fear? How much time should Rebecca spend on this worry? And when she does 'work'; on it, what could she do in 15 minutes?

## STRATEGIES FOR ANXIETY (VIDEO REF: 05:08)

Strategies for anxiety include slow breathing, sometimes called belly or diaphragmatic breathing. It's a little unnatural so will take some practice. Start by putting one hand on your collarbone and the other on the soft part of your belly. As you breathe in, you want to be able to push that lower hand out and keep your upper hand still. This type of breathing involves a ratio of one to two to inhale to exhale, so if you breathe in for three seconds, you'll be aiming to breathe out through pursed lips (to slow it down) for about six seconds. If you're feeling quite stressed, try taking three to 10 breaths. You could then take a break and do something else and then come back and do a few more.



Another strategy is to combine **distraction and reassurance**. To distract ourselves from anxiety we have reassure ourselves and give ourselves permission to do the distracting. The distracting is when we engage in another activity that will demand our attention.

### Example (Video ref: 06:43)

One person I know, if they're worried about an attack possibly starting, will set an alarm to go off in six minutes. In the meanwhile, they can get on and really distract themselves with some activity, knowing that they don't need to monitor their body or their symptoms or worry about it. And if they have definite noticeable swelling after 6 minutes, then they can do their treatment.



Another person finds it helpful to remind themselves that they have harmless or innocuous, but unexplained physical sensations and symptoms every day. They set a threshold or a line in their mind for severity, and when that's crossed, they will attend to their symptoms and do something about it. Anything going on in their body underneath that line, they give themselves permission to ignore it.

Another way to manage anxiety is to embrace the paradoxical nature of anxiety. A paradox is when we find that the more we pursue an outcome, the further we get away from it. For example, the more we want to go to sleep, the more impossible that becomes. When we want to control anxious thoughts or anxious feelings desperately, then we end up tending to focus on it more.

### **Exercise (Video ref: 08:23)**

Focus on any part of your body, except your left hand. Try not to be aware of any sensations in your left hand or its positioning. What do you notice happens? Most people find that part of their attention gets diverted to their left hand. Now try to bring your attention to your toes, all of your toes but your big toes in particular. Try to wiggle your right big toe without moving any other toes and then the left big toe as well, just really focusing on that. And now think about the degree to which you've been aware of your left hand in the last 30 seconds.



If you're worried about symptoms, then I suggest that you acknowledge that worry and find a way for that fear to be there. And at the same time, bring your attention to another activity or object. Saying "I don't want to fear this" isn't helpful, instead, give your attention to an activity. And if your mind comes back to the fear, then notice that and bring as much attention as you can to the activity that you're trying to do.

## OTHER WAYS TO MANAGE STRESS

Here are some well-known and proven ways to manage stress in our lives and you can ask yourself if you can do them a bit more yourself:

- Regular exercise.
- Invest in good quality relationships within and outside your family.
- Eating well and avoiding bad food and too much alcohol.
- Set goals – make them realistic and meaningful to you and enjoy your progress towards them.
- Spend time outdoors.
- Learn ways to relax your body.
- Develop good problem-solving techniques for making decisions.