

LIVING WELL WITH HAE

Healthy Minds

Empathy & Emotions

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

DEALING WITH EMPATHY GAPS (VIDEO REF: 00:18)

There are two types of empathy gaps. The first type is when other people cannot comprehend what it's like to live with HAE. Even if you explained the challenges, the missed opportunities, the memory of past swelling or attacks, knowing other people who have HAE, anticipating future attacks, needing to deal with doctors and medical systems that don't always have a good understanding of HAE, people don't understand.

The second type is when having a very serious life affecting illness like HAE, shifts your sense of what is bad, or upsetting. So, when a friend is going through something that they find very upsetting, for them it might be a 9 out of 10, it can be hard to empathise. Because after everything that you've been through, that would now be about a 4 or 5 out of 10 for you.

Both types of empathy gaps are manageable, though. With type one, it can help us be more compassionate if we ask ourselves questions like:

- In what way is it understandable that this person cannot comprehend what it's like living with HAE?
- What sort of expectations can I have?

You could help increase somebody's empathy by giving them a page to read, or directing them to certain web links or videos.



For **type two** empathy gaps, if you're having trouble empathising with others, you could try a couple of questions like:

- In what way is it understandable that for them, this is very serious, and this is upsetting?
- Is it not understandable that I find it hard to hear that they're so upset just about this?

And then we're free to respond to their stress, like it is a 7 or 8 out of 10, because we now see that for them it is.

WHAT SORT OF SADNESS, MISSED OPPORTUNITIES AND LOSSES DO PEOPLE WITH HAE EXPERIENCE? (VIDEO REF: 03:01)

There are many sources of sadness, and missed opportunities for people living with HAE. Children and teenagers living with HAE might report that they miss out on important activities to them like sleep overs and school camps. Others report that they feel very self-conscious when being asked about why they look different, or why they swell, or why they have so many days absent from school. Examples in adults, might include missing out on activities like family outings, travel, and camping. Many others have talked about the impact on their career progression. All these will lead to feelings of sadness and missing out.

Coping strategies (Video ref: 3:58)

- Name the emotions and let yourself have them before you try any other coping strategies.
- How would you 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?

TIP: It's not in seconds, because that's not long enough, but it's not hours or days either, because that's just dwelling on it. But it is important to let ourselves actually acknowledge our feelings before we try to do anything else.

The alternative would be just invalidating your own feelings, which is never helpful. Telling ourselves to pull ourselves together or pull up our socks and just keep going doesn't make us a better person or a better copier. It just means that we're pushing our emotions aside. It's hard to imagine you'd say that to somebody else, and it's not helpful to say it to ourselves.

A way to extend on that is:

- Find a place for all of your emotions.
- There are no bad emotions, we have positive feelings and negative feelings, but none of them are bad.

Exercise (Video ref: 05:27)

You can imagine that your mind is like a room. And there's lots of space in this room for big emotions and small emotions. All of them can have a place. Trying to suppress emotions usually doesn't work. Blocking a feeling, can actually make it more prominent in your mind.



Exercise (Video ref: 05:49)

For the next 15 seconds. try your hardest not to think about the last time you felt you were missing out on something, or you felt a bit ripped off. What happens if you try to forget that memory and push that emotion aside? A lot of us feel it even more.



Now for another 20 seconds just accept that it is unfair. And while you're accepting that injustice does happen sometimes, I want you to try to recall the last three lunches that you had, starting with the last one that was either today or yesterday. Where were you? What did you have? Did you like it? And the lunch before that, where were you? Can you remember what you had? And the lunch before that, what did you have?



What happens to that feeling of injustice, or sadness. You didn't try to get rid of it, you actually let it be there. But it goes into the background. And it's then easier to shift your attention to what you do have.

Another strategy is to consciously make time to think about what you do have in your life, so that we focus more on what we have than what we've lost. Have a think about what assets you have that you might take for granted. Gratitude can be very helpful. It's hard to feel sad and down when we're feeling appreciative.

You could try keeping a gratitude diary, once a week, or even daily.



Another strategy is how to **keep things in perspective**. This can be hard, because it's all about perception in our mind, and we can get caught up with things. Some examples of perspective are when someone might say:

- If I didn't have HAE, I know that I would still have problems and hassles because all of my friends do.
- I'm just grateful that I'm alive and that I have medication that has changed my life.
- I appreciate any days or weeks that I'm symptom free and I do not take my health for granted anymore.

HAE inevitably brings negative emotions to anybody's life. We hope these strategies can help you actively manage those negative emotions.