

Living with Uncertainty

Looking after your emotional well-being when living with an endocrine condition

About AMEND

AMEND is a charity registered in England and Wales (number 1153890). It provides support and information services to families around the world who are affected by multiple endocrine neoplasia and related endocrine tumours. AMEND encourages research into the conditions by awarding annual medical prizes and research awards. It hosts a patient information event every year and runs social media forums connecting patients from around the world.

Please visit our website for more information on AMEND or to make a donation:

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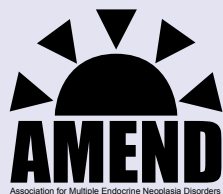
Registered charity no. 1153890

Tel: 01892 516076

Email: info@amend.org.uk

www.amend.org.uk

Membership is FREE



written by Kym Winter

Living with an unpredictable health condition can be very tiring – both physically and emotionally. Feeling anxious and stressed at times is a normal response to living with your condition. But there are ways to help yourself cope with this 'side-effect' of your condition. This short guide is aimed at helping you to look after yourself and helping others look after you.

There are no right or wrong ways of living with your condition. You will find out over time what works best for you. Some days it might be right at the front of your mind, other times you might have moments where it is more at the back of your mind. This will probably depend in part on how much your condition is affecting your everyday life, and/or how worried you are about it overall.

Be Kind to Yourself

Living with any on-going condition entails emotional energy, and can bring up a wide range of feelings. These might vary from day-to-day or moment-to-moment. All of these are quite normal, but remember too that endocrine conditions can also affect how you feel emotionally and it can sometimes be difficult to work out which feelings are to do with your condition physiologically, and which are to do with living with your condition emotionally.

Do check with your GP/Consultant if you are feeling particularly concerned about your moods to see if perhaps there may be an underlying physical difficulty that might be exacerbating or affecting how you feel.

Here is a summary of the common difficult feelings:

Anxiety or worry - you might feel worried about what the future will hold, the impact upon yourself or your loved ones, or about the next set of test results or treatment.

Anger - You might feel angry at the world or other people for not being able to make you better, for not understanding or for making thoughtless remarks.

Unfairness - why is this happening to me? It's not fair!

Envy - of other people for not having to live with your condition, or of their more carefree lives.

Loss - of your sense of self and life before being diagnosed, especially if it has impacted negatively on your work or relationships.

Depression/sadness - this is not what you would choose for your life.

Loneliness - You may have times when you feel no-one understands or cares. Uncommon and complex conditions can compound this feeling as it is not always straightforward to either explain the condition to other people, or for them to understand.

Hopelessness/despair - especially if your symptoms are either not improving, are getting worse, or it is difficult for your Consultant to address or ease the physical difficulties you are experiencing.

Guilt - how will/is this affecting my family or work?

You might want to avoid the above thoughts and feelings, which is very natural. However, it is often helpful to try and acknowledge them, either to yourself or with other people, e.g. partner, family, friends. If you don't feel able to do this, try talking to a trained counsellor (there are more details about this and about ways to cope later on in this leaflet).

Living with your condition might also affect you in the following ways (again, remember that these could also be a result of side effects of either your medication or your treatment, so you may have to weigh this up too):

How else might your feelings come out?

Sleep problems - not being able to get to sleep and/or waking up early or during the night are very common if we are worried (even subconsciously) about something.

Being more snappy or irritable - even if you are not normally.

Restless/agitated - you might find it hard to 'switch off' or relax.

Appetite - either under-eating or over-eating to comfort yourself or to push difficult thoughts and feelings away.

Tiredness/exhaustion - living with these conditions can require a great deal of emotional and physical energy.

Pre-occupations - you may go through times when you cannot think about or see anything other than illness, or worries about the fragility of life - This may be in relation to your own condition or other people's.

Feeling stressed - ordinary everyday things like cooking, shopping or work may feel overwhelming.

Loss of interest - people/activities that you used to find pleasure in now feel tiresome or meaningless.

Feeling out of control - these conditions can be unpredictable. You might find yourself compensating for this by being very controlling in other areas of your life or in relationships, or alternatively, in feeling that there is no point being in touch with what you really want.

Tearfulness - crying is an important outlet for emotions, tension and strain.

Using alcohol/drugs - to try and block out the difficult thoughts or feelings.

Physical symptoms that may be new or unusual for you. Of course, these may be physiologically rooted (check with your GP/Consultant) but may also be the way your body is trying to deal with feelings, e.g. nausea, dizziness, palpitations, digestive problems, tightness in your throat/breathing.

What can help me to cope?

1. Emotional work takes physical energy Remember and accept that a proportion of your emotional and physical 'energy tanks' are being used up just by managing the facts, practicalities and feelings about living with your condition day-to-day.

2. Be gentle with yourself There will probably be times when your condition is 'in your face' especially when you are having to deal with symptoms, tests or appointments. At other times it may recede into the background and 'ordinary' life is more to the fore, such as when your symptoms are manageable and you are not having any imminent treatment or tests. Managing this ebb and flow also takes emotional energy. Make allowance for this in both your relationships and work-life.

3. Let other people know how you are feeling Sometimes this might be trusted family/friends, someone else who knows you well, the health professionals looking after you or a trained counsellor. 'Getting things off your chest' and sharing your experiences or worries can help you clarify what you are feeling, and help stop it going 'round and round your head'.

4. Find other ways of expressing and managing your feelings Taking up art, poetry, writing, walking or doing something creative can be a really positive outlet and distraction for when you don't feel like talking, but have a lot going on emotionally.

5. Reach out to others who share your condition Consider signing up to the AMEND Facebook Groups and forums. Sharing experiences and information with others who know what you are going through can be very comforting. Also give yourself permission to not use them at times if you find it makes you feel more anxious, or you need to switch off.

6. Take time out to do things that are 'nurturing' for yourself This is not 'self-ish', it's 'self-care.' This may be doing things that are 'restorative' or fun (e.g. spending time with people whose make you feel 'good'; reading/listening to music, going out/staying in...)

7. Learn to say NO when you want to. Given that a portion of your 'energy tanks' are used up by living with this condition, don't try to be superman/woman when you don't have to be. Learning to be more assertive can be helpful in all sorts of ways – at work, home and with the health professionals looking after you. There are some links at the end of this leaflet if you'd like to work on this.

8. Help others to help you Try and work out what you find helpful from friends and family. Is it practical support such as cooking a meal for you/your family when you are feeling unwell or having treatment, or taking on some practical tasks for you? Or is emotional support helpful such as asking people to ask you how you are more often? Telling people what you do and don't find helpful is important too.

9. Try to accept your feelings, not fight them We can use up a lot of energy trying not to feel certain feelings because they feel frightening, unacceptable or difficult. Having a range of feelings about your condition is very normal. If you feel you are really struggling, talk to your GP and Consultant as to whether difficult feelings might sometimes be to do with your medication or your condition, or whether a referral to a counsellor might be available.

10. Try to live as normal a life as possible Living with your condition can sometimes feel like 'waiting for the next problem', but enjoy the periods when you are well and make the most of them when possible.

11. Learn to recognise your own stress signs from the list above and slow down/take action to look after yourself.

12. Learn relaxation or Mindfulness techniques These can be really useful as part of your everyday, or to call upon during periods of time when you are unwell, stressed or having tests and treatment. There is more information on these techniques at the end of this leaflet.

13. Try to eat well and regularly Endocrine disorders can be particularly affected by diet and/or erratic food intake. Eating plenty of fresh fruit and vegetables also can help support your mood.

14. Remember that you are not alone! AMEND has a range of free website resources, information events and leaflets all designed to help support you in living life as normally as possible with your condition so that it is just part of your life, not all there is.

Further Information and Resources

1. Eating well - MIND produce a range of leaflets on Looking After your Emotional Health at www.mind.org.uk. Their leaflet 'tips-for-everyday-living/food-and-mood' is worth looking through. The 'Food and Mood Handbook' by Amanda Geary (available online or in stores) also provides a comprehensive introduction to this area.

2. Mindfulness - www.mindful.org provides exercises for this way of helping cope with pain, anxiety, depression, sleep problems and stress. 'Mindfulness for Dummies' is also an excellent resource book (available online/stores).

3. Managing depression and anxiety - www.mentalhealth.org.uk provides a range of leaflets and podcasts to help address issues such as low mood and anxiety, insomnia and relaxation.

4. Assertiveness - asking for what you want, or saying how you feel, can be challenging at the best of times! www.moodjuice.scot.nhs.uk/assertiveness is a great 'how to' guide, and recommended reading before appointments with health professionals!

5. Samaritans are not just available to those who are suicidal. If you are feeling very alone, they also provide an excellent listening service on 08457 909090/ jo@samaritans.org

6. Facebook group - AMEND runs a private Facebook Group for patients. Invitations to join the group are sent automatically by email to new members joining via the AMEND website, or otherwise by email on request.

7. AMEND's Telephone Counselling Service is a free and confidential service for AMEND members, available to book via telephone (01727 752147) or email (kym@kymwintertherapy.org). Further details can be found on the AMEND website.

8. Counselling and Psychotherapy www.bacp.co.uk / www.ukcp.org have 'Find a Therapist' functions on their websites if you are considering talking to a trained and registered counsellor in your local area.

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Written by Kym Winter, Bsc (Hons), UKCP registered, member AAP (AMEND Psychotherapist/Counsellor)