

SELF HELP

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This empowering manual offers a simplified explanation of key coping strategies and how to apply them in a variety of stressful life situations. Using the facts-thoughts-feelings framework, it outlines how to relieve stress by changing the things one can and taking control over one's life. It is an excellent reference for individuals, support groups or health professionals for assisting in developing positive coping skills.

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For everyone, and all those touched by illness, whether as a patient, family member, friend or volunteer, good coping skills are paramount. This well written and thoroughly researched book filled with practical, easy-to-master tips and advice is an invaluable guide to coping for cancer patients and those who care for them.

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MASTERING THE ART OF COPING IN GOOD TIMES AND BAD

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Appendix A

Reminders of tips to use during tough times

1. Recognize that no thought or feeling is wrong in itself, it is what we with it that really counts.
2. Become aware of the way your body feels as tension begins to build up - remind yourself to calm down.
3. Recognize that you don't have to go through major stresses alone. Don't hesitate to seek information or counseling if questions or concerns arise. Help is available from a wide range of sources.
4. Improve communication with your family, friends and others.
5. If you are experiencing fatigue or feeling overwhelmed, consider redistributing or reducing your responsibilities for a period of time.
6. Recognize that family and friends have to deal with their feelings too. They may be helpful or unhelpful to you. They are, however, probably doing the best they know how at the time.
7. Do things each day that are nurturing to you. These may include fun activities, relaxation, time alone, and exercise.
8. Accept that guilt and worry about things you can't change are useless and energy-draining.
9. Give yourself credit for whatever level of coping you are achieving. Remember, there is no "instant fix" for stress.
10. Develop a love and respect for yourself - because each of us is, with our strengths, a special and worthwhile person.
11. You can only change and control yourself.

Adapted from *Managing the Stress of Cancer: A Handbook for Patients and their Families*, Ronna Jevne.

Appendix B

Fourteen good tips for dealing with the health care system particularly for any serious illness or condition *(with thanks to Roslyn Fitzpatrick, cancer coach)*

Note that these tips are for both the patient and the caregiver (family member or friend) to keep in mind.

1. Always assume that you as a patient have fallen through the cracks, unless you get proof to the contrary. No news is not always good news. It may mean that someone forgot to do something. Medical care can be complicated and needs a lot of co-ordination among large numbers of people.
2. Never blame anyone. Recognize that everyone working in the system is busy and probably stressed. While you are concerned with your situation, they are juggling dozens of people, possibly hundreds.
3. Create positive relationships with everyone who can help you. Introduce yourself to every nurse, receptionist, technician and doctor that you will need to see again. Ask each for their first name. Remember it or record it. Next time you see them or talk by phone, establish rapport by using their first name and engaging them in personal chat before you get down to business. It only takes a few seconds. It will help you become more than just a file, and will give you some insight into what each person does. It also makes it easier to request things when you need to.
4. Apologize before you make a request. "I'm sorry to bother you when you are so busy, but since I hadn't heard from you, I thought I'd better check whether you were able to make the appointment." If you say you're sorry, you can ask for just about anything - and still be perceived as nice.
5. The patient needs a caregiver or advocate to take with them for any important meeting or procedure. Their job is to remain sane, create

rapport and ask good questions. This way, if you lose it, someone else still has it.

6. Use all your contacts. Surely someone you know knows someone who knows someone who can find out what you need. If you follow tip #3 you will have contacts within the medical system that could help. At times this may be the only way to obtain information, a second opinion or to get in to see someone quickly. If you are hesitant to use your contacts, apologize for bothering them.
7. Be prepared to do a lot of waiting. Make appointments early in the day before the doctor has a chance to get behind schedule or just after lunch. This way you'll see the doctor before she or he gets tired and cranky. Remember to take something you like to do in case you have to wait anyway.
8. Take everything your doctors say as information instead of gospel. Allow yourself time to think about it. Remember that medical professionals are trained to think about and discuss the worst possible scenarios. Ask them what each treatment is supposed to accomplish and repeat that message over and over to yourself to create a goal-oriented mindset within you. Write down your questions prior to your appointment and record the answers or ask your companion to write them down.
9. If you go into your appointments prepared and knowledgeable about what you want to talk about with your doctor, most if not all doctors will agree to let you have copies of your test results. You have the right to see them. After all, this is your life and your body and you have a part in the decision making structure of your treatment plan or follow up appointments.
10. Sometimes bad news can lead to a feeling of loss of control. This can be a very life altering feeling that reaches into every aspect of your life. Take control in the areas that you can regarding your health care.

Be on top of appointments. Book them months in advance if you know, for example, that you have to do them on a quarterly cycle. Keep a record of when you should be seeing various doctors or having various tests. The feeling of control can help immensely to diminish depression.

11. Do what you need to do to stay upbeat and positive. It's perfectly normal to feel depressed and demoralized upon hearing bad news. You can let yourself feel shock, numbness, denial, panic, anger or depressed. Know that this is how you are feeling at "this moment in time" and that you will move on.
12. Hang out with cheerful, upbeat, helpful people. There is only so much sympathy you can take before you begin to believe that you ought to feel sorry for yourself. Only see people who make you feel good - those who make you laugh, who get you out, who bring over lovely things to eat.
13. If people ask you how they can help, get them to make morale-raising food, take you to a funny movie or bring over a good video. Accept people's kindness. Sharing someone's good will can be a positive experience for all involved.
14. If depressing people want to come over, apologize and tell them you're not up to it.

Appendix C

Tips for the caregiver on communication

It is very important to recognize that both the patient and their caregivers are going through a life altering situation and many feelings and thoughts can come to the surface. Here are some tips on how to communicate with each other.

1. Think about your tone and approach and use "I" statements. For example,
 - a) You feel this: "I feel so frustrated that you are in pain." OR "I am so sorry that you have to go through this with me."
 - b) Think about what you want: "I would like you to feel more comfortable."
 - c) Put this into a reasonable request: "Would you consider getting a second opinion at a pain clinic?" or "Would you consider us having a time every day or every week to do something fun with no mention of my disease?"
2. What are your expectations for the conversations? You can only bring up your concerns and offer suggestions for how things could change. The other person can either accept or reject your suggestions. If they stick to their position, you might have to modify your expectations, as difficult as that may be.
3. Think about backing off, once you've expressed your concerns. People often need a little space to take down some of their defenses and more clearly consider a different point of view.
4. Think about the best way to bring up the subject, knowing the communication preferences of the other person. Sometimes it helps to tell the person in advance that you'd like to talk about a sensitive topic and ask when would be a good time. Or, maybe they prefer a direct approach. Would it help if you emailed them or wrote a letter instead? The written word seems less threatening.

5. If you are afraid you'll cry in front of the other person, reflect on this: Tears mean that you care. If you do cry, the person will be reminded that they matter deeply to you and that the situation is distressing right now. In some situations there can be resentment built up if the patient and caregiver are not allowed to cry.
6. Would it help to talk in the company of a third person? It might help to simply say: "You and I are having trouble talking about (the pain in your hip, the role of alternative medicine in your care...). Would you be willing to come with me to talk about it with (our rabbi, that social worker at the clinic...)?"
7. Consider attending a support group for patient or caregivers. Many groups welcome caregivers, with or without the patient, and some groups are for caregivers only. You can just observe the group and see if the members bring up your topic, or you can ask the group how they've dealt with that issue. Group members can offer valuable "been-there-done-that" advice that is hard to find anywhere else.
8. Consider finding a counselor who is familiar with the illness you are dealing with. This person may be able to "coach" you through a difficult topic and help you rehearse how to bring it up, if necessary.
9. Remember that you can always communicate with respect and kindness, even if the other person doesn't treat you the same way.
10. Every person with a serious illness needs to have a folder or notebook or 3-ring binder to keep track of every part of treatment. Include a section for:
 - a) appointments-date and with whom, and a brief note of what the outcome was of each visit
 - b) test and x ray results-ask for copies
 - c) all medications and any changes to the doses with dates
 - d) referrals, consultations with other doctors with their reports
 - e) all the questions you want answered

You will find that your folder with all the above information will be crucial to your care. Take it to every appointment and show it to your nurse or social support worker.

11. Be honest with yourself. Don't hide your fears, guilt or anger inside. No one wants to feel as if they are walking on eggshells when he or she is with someone they love. Often, both patient and caregiver have the same fears and feelings but each thinks they need to protect the other. It is a relief when you can say "I feel...", "I think...", or "I want..." or "I need...", or "I am afraid...", and then express yourself to the one you love.