HERE AND NOW
Creating a New Vision for Your Life With Chronic Illness
Here and Now

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When you are diagnosed: what to expect

Excuse me, is the room spinning?
You have been told that you have a chronic (kron-ick) illness. That means that your condition may last for a long time and that you may always have it.

You may have a lot of feelings, perhaps all at once, about this news.

This booklet offers you tips on how to move past these feelings, as they may affect your overall health. If you need more help, talk to your healthcare professional.
When you are diagnosed: what to expect (cont’d)

In the early days of a chronic illness, you may deny that the illness is a problem. Or you may give in to feeling helpless and gloomy. You may think that you no longer have choices or that you are not in control of your life.

Take time to grieve for what you feel you may have lost: your plans for the future, your body image, your independence, or your ability to work.

To bounce back, you will need to deal with your problems and create a new vision for your life with chronic illness.

How do I bounce back?

When you are ready to move forward, know this:

You are not born with all the skills you need to adapt, or bounce back, from problems. But you can learn how to rebound from tough times and feel better.

Once you work through your feelings and learn new ways to cope, you will be ready to:

- Make new plans for yourself and take steps to carry them out
- See life and yourself in a positive way
- Work out problems more easily
- Handle strong feelings and impulses better

The next sections of this booklet will give you tips on how to bounce back and how to gain the knowledge that you need.
Getting used to a new outlook: practical steps you can take

Try some new tools
The American Psychological Association has put together 10 tips to help you bounce back. Taking small steps in the areas listed below will help you rebound more quickly from tough times.

1. Connect with people. Reach out to family, friends, civic groups, faith-based organizations, support groups, or Web-based groups. Stay involved.

2. Avoid seeing crises as the end of everything. Hearing that you have a chronic illness may feel like the end of everything. Allow your feelings to come out. Then, try to think of how things may be better in the future.

3. Accept that change is a part of living. Remember…everything in nature changes. Accept that some things can’t be fixed, then focus on the things that you can control.

4. Move toward your goals. If your goals don’t fit your new reality, create new ones. Then take small steps every day to achieve them.

5. Don’t get stuck in denial. Wishing problems would go away will keep you stuck in a painful place. Decide what you need to do to move forward and set your plan in action.
Getting used to a new outlook: practical steps you can take (cont’d)

6. Be open to new strengths.
Adjusting to major life changes can bring you a sense of strength and confidence that you never knew you had. You may also learn to enjoy life in a way that you never did in the past.

7. Believe in yourself.
Trust yourself to make good choices and solve problems well. You will find that you are able to handle more than you thought you could.

8. Keep things in perspective.
Try to put problems and crises into a long-term picture. By doing this, you will be able to see that while problems are painful, they will pass.

Replace negative thoughts with positive ones. Try to trade thoughts of worry and fear for thoughts that good things will happen.

10. Take care of yourself.
Exercise, healthy eating, healthy habits, and time for rest and fun may make you feel better and help you cope with your chronic illness.

These tips have been adapted with permission from “The Road to Resilience.” Available at http://www.apa.org/helpcenter/road-resilience.aspx. Copyright ©2011 by the American Psychological Association.
Living day to day: the need for routine

Okay...what do I do next?
You have learned that it is important to stay flexible. Life is always shifting and changing. Your illness and treatment plan will too. Remembering this will help you avoid feeling shocked by changes.

Meet your basic needs
Try to focus first on the truly important things in life. Your basic needs are number one now. Simplify your daily routine to make sure that you meet your needs for:

• Enough rest
• Healthy, regular meals
• Exercise approved by your healthcare professional
• Taking your medicines
• Daily hygiene

Meet other personal needs
You may also have to adjust your life to meet the needs of your chronic illness. That may mean altering your relationships and your work schedule, rearranging your house so that it is easier for you to get around, sticking to a special diet, changing habits like quitting smoking, and many other things.

Feeling safe by getting the facts
Understanding what is happening to you will help you plan for your future and feel more in control of your life.

Your healthcare professional can help you gain the knowledge you need. You can make the most of your appointments with your healthcare professional if you:

• Get ready for your visit
  ■ Make a list of your medicines to give to your healthcare professional
  ■ Write down your questions
  ■ Think about asking a friend or relative to go with you to take notes and help you remember what is said

• Keep your appointment and tell your healthcare professional about:
  ■ Your symptoms
  ■ Your feelings, worries, and moods
  ■ Your habits, such as smoking or drinking alcohol
  ■ Your diet and what you do to stay active

• Ask your healthcare professional to explain:
  ■ Your medical condition and what you can expect in the future
  ■ Any medical tests that you need
  ■ How to take your medicine and possible problems your medicine may cause
  ■ How to tell if you are depressed. See the back of this booklet for Internet sites that have more information about depression. If you think you may be depressed, tell your healthcare professional right away. Depression can be treated.
  ■ What to do about things that bother you, such as your body image or sexual problems
  ■ Patient assistance programs if you need help paying for your medicine
Feeling safe by getting the facts (cont’d)

Your pharmacist can answer your questions about the medicine your healthcare professional prescribes. He or she can also help you select over-the-counter drugs.

If you are employed, your employer can answer your questions about:

- Missing work because of your illness or to keep appointments with your healthcare professional
- Employee assistance and health management programs

Check for other ways to get reliable information, such as government agencies, community organizations, or social service agencies.

Tips for talking to your healthcare professional

Be sure that you understand what your healthcare professional tells you.

- If you do not understand, ask for things to be explained again or in a different way
- Ask your healthcare professional to draw pictures if that helps you understand
- Take notes
- Tape-record the visit if your healthcare professional says it’s okay
- Bring a friend or relative who can help you remember what is said
- Ask your healthcare professional for other places to find reliable information, such as Web sites, booklets, or tapes for patients

Coping with roadblocks: common challenges and setbacks

For goodness’ sake...now what?

Living with a chronic illness may feel like traveling along a path with one roadblock after another. The journey is not easy. Setbacks may sap your strength and make you feel like giving up.

But setbacks are normal. You can bounce back by staying flexible and maintaining balance in your life. Remember that it will be easier to bounce back if you:

- Let your negative feelings out
- Use your humor, faith, and creativity to help build hope and positive thoughts
- Move forward by dealing with your problems
- Take time to rest and take care of yourself
- Believe in yourself and look to your friends and family for support and encouragement
- Count on yourself as well as others
Coping with roadblocks: common challenges and setbacks (cont’d)

A few words about your well-being
Tough times bring out the best and worst in all of us. If you feel overwhelmed with these new challenges, feelings, or problems, speak up! Let your family and friends support you through this rough period.

Using the tips in this booklet, take the time you need to come to terms with each new challenge. For each problem, the process of accepting it and then dealing with it is the same.

If you need additional help, the back of this booklet lists other resources.

“Learn from yesterday, live for today, hope for tomorrow.”
—Albert Einstein

Making a lasting change does not happen in an instant. You will need to practice each change many times before it becomes a habit. Here are some tips to help you with the challenge of making changes stick.

• Pick one change you want to make. As an example, you may want to get more exercise.
• Set a specific goal. If you want to be more active, your specific goal may be to walk 1 mile in your neighborhood every day after work.
• Plan for things that may go wrong. For example, plan to walk in the mall when the weather is bad.
• Be sure your goal is realistic. If you have regular plans every Tuesday night, you may need to change your goal to walking every Monday, Wednesday, Friday, and Saturday.
• Track your progress. Mark your calendar or keep a diary of how you are meeting your goal.
• Check in with your healthcare professional regularly. He or she can help you work through any problems with meeting your goals.

A sweeping change or many big changes that happen all at once are much harder to keep up over time. Unless you need to make many changes right away, you should take it slowly as you will be more likely to succeed in the long run.

Creating a new vision for your life can mean big changes. Here and now, decide on small steps that you can take to start along your new path. Practice those changes every day. Small, regular changes add up in the big picture.
Helpful resources

General information
Agency for Healthcare Research and Quality
http://www.ahrq.gov/consumer

American Association of Family Physicians
http://www.familydoctor.org

American Psychological Association
http://www.apahelpcenter.org

Cleveland Clinic
http://my.clevelandclinic.org/disorders/Chronic_Obstructive_Pulmonary_Disease/hic_Understanding_COPD.aspx

COPD Foundation
http://www.copdfoundation.org

National Institutes of Health

National Institute on Aging
http://www.nia.nih.gov/HealthInformation/Publications

Emergency Assistance

Call 911 or your local emergency services

(Write local emergency services’ telephone number here)

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