



Coping With a Serious Illness



Trinity Health



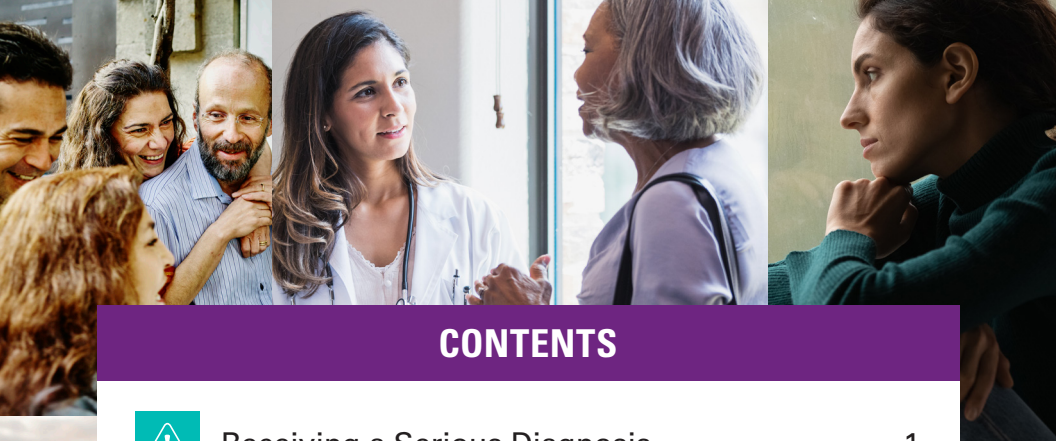
To all that is chaotic in you, let there be silence...

Let there be a calming of the clamoring, a stilling of the voices that have laid their claim on you, that have made their home in you, that go with you everywhere, but will not let you rest.




Let there be an opening into the quiet that lies beneath the chaos, where you find the peace you did not think possible and see what shimmers within the storm.

May that peace be yours this day to anchor you, to give you courage, and to lead you in hope.

Adapted from "A Blessing in the Chaos" by Jan Richardson



CONTENTS

	Receiving a Serious Diagnosis.....	1
	Sharing Your Diagnosis.....	2
	Planning for Your Doctor's Appointment.....	3
	Making Treatment Decisions.....	4
	Managing My Feelings.....	5
	Identifying Your Challenges.....	6
	Focusing on the Positives.....	7
	Finding Simple Pleasures and Ways to Cope.....	8
	Ways to Self-Affirm.....	10
	Family & Friends.....	12
	Always Thank Others.....	13





Receiving a Serious Diagnosis

Illness can change your life in a heartbeat. When you receive news of a serious diagnosis, you can find yourself feeling overwhelmed. Your thoughts and routines, self-perspective, and goals may change. Your life, relationships, and work may also change.

Your new focus will be on how to manage your diagnosis, treatment decisions, and doctors.

Most patients find the first few months of diagnosis and treatment to be very stressful. You may feel sad, fearful, and worried about your care and your future. These feelings are normal. There are things that you can do to help yourself cope:

- Many people find journaling helpful. You may want to write about your diagnosis, details about what you have learned, and how you are feeling.
- Make a list of your worries, focusing on things that you can influence to change or make better.
- You may find yourself crying and feeling sorry for yourself. Allow yourself to feel these emotions but maintain as much normalcy in your routine as possible. Continue to live your life and look for joy in small things.



Sharing Your Diagnosis

A serious diagnosis can create an overwhelming rush of emotions. Who you tell about your diagnosis is a personal choice.

Here is some guidance:

- Share with those who can help you through this journey. The people you share with should be able to provide support to you. Secrecy can create barriers with those people who are the closest to you.
- If you do not wish to discuss your diagnosis, thank them for asking and change the subject.

The focus needs to be on using your energy to stabilize your health and managing your day. Establish healthy boundaries.



Planning for Your Doctor's Appointments

Most patients feel inundated by their recent diagnosis. It is important to write down your questions before your doctor's appointments. It may be helpful to keep an ongoing list of questions.

Some questions are:

- What is my diagnosis?
- What are my options for treatment?
 - What are the benefits?
 - What are the burdens?
- How long will I be in treatment for?
- What can I expect regarding side effects?
- What is my prognosis?

Take notes and ask questions to be sure you understand. Choose the amount of information that you would like to receive from your doctor. Friends or family members can make good listeners during your appointments.



Making Treatment Decisions

Treatment decisions require knowledge and are an important part of managing most illnesses. You can make good decisions based on the knowledge you gain at your physician visits and your own research about treatment choices. In the end, after gathering the information, it is always your choice.

Some considerations are:

- Treatment protocols and outcome goals may vary. If time permits, consider seeking additional medical opinions.
- Keep track of the information from different doctors including diagnosis, treatment, medications, and dosage, frequency, and duration of treatment. Create a document that has your medical history, including tests and where they were performed.
- Once you decide on treatment, it is important to adhere to the recommendations. A therapist may be helpful, providing support as you receive treatments.
- Consider seeking spiritual guidance for additional support.



Managing My Feelings

The following reactions to a serious diagnosis can be quite common to anyone struggling with an illness:

- Anxiety.
- Distractedness and forgetfulness.
- Weight gain or loss.
- Depression - may lead to loss of appetite, sleep problems, sadness, crying, an inability to get things done, or chronic fatigue. Medications may help treat the depression.
- Physical changes due to treatments or surgeries, e.g., chemotherapy can lead to hair loss.
- Intense dread or anxiety over your medical treatments.
- Challenges meeting demands in your everyday life due to change in energy levels.
- Changing social relationships.
- Concern regarding your own mortality, pain, and physical dependency on others.



Identifying Your Challenges

Allow yourself time and the physical and emotional space needed to process the diagnosis while maintaining as many routines as possible. If you have children, you need to communicate with them about what is happening with your health. Consider the age of your child when talking with them. Use words that are simple and age appropriate. Expect their emotional reactions. Ask them questions. Talk with your family about ways you may need help.

Remember the following:

- Despite your best efforts, some days will be better than others.
- Manage personal demands while giving your body the rest that it needs to heal. You may have to delegate, delay, or cut back for a while.
- Anticipate potential changes in finances and health insurance.
- Ask family members or close friends for short-term financial assistance if you need it.
- Ask about FMLA and/or short-term disability from work.
- Contact your physician's practice for additional resources, including medication assistance and guidance on Medicare, Medicaid, Social Security, etc.
- National agencies may be able to help. Consult local heart, cancer, or other health agencies that can assist with specific resources, research, and consultation. Look to understand credentials and goals of agencies and groups.



Focusing on the Positives

Some considerations are:

- How can you build on the positive things in your life?
- What is most important to me?
- What do I need to modify or scale down?
- What brings me peace and joy?
- What do you look forward to after treatment? Parties, get-togethers, special occasions, or trips to a pleasurable destination are important.



Finding Simple Pleasures and Ways to Cope

Some coping choices are better than others. Every day, focus on setting small goals and use your physical and mental energies to do something, great or small. Tell yourself to take one day at a time and focus on living each day fully.

Some possibilities include:

- Go for a walk, yoga.
- Meditate, mindfulness, and imaging techniques.
- Call a friend or family member.
- Write a letter or send a note.
- Journal.
- Pray, if you are religious.
- Snuggle with your pet.
- Read a magazine, book, watch a movie or listen to music.
- Find a hobby or learn something new.
- Go to a museum, art gallery, or library.
- Organize a space in your home.
- Go out to lunch, eat a food you love.
- Garden.
- Bake for someone else.
- Take a nap.



The day before a test or treatment you should prepare yourself. Do the following:

- Tell yourself that you must, can, and will get through the test or the treatment.
- Consider taking music and/or a book to your appointment.
- Perform relaxation exercises.
- Plan out the foods that you will eat before and after the test and treatment.
- Plan out your transportation. Ask for a ride.
- Always have things prepared at home for your return from the test or treatment.
- Plan out a reward for getting through this (the day before and after).
- Take medications the provider prescribes for side effects of treatment. If you are having symptoms, let your provider know. There are medications to minimize most side effects. Do not be the silent sufferer.
- Ask about palliative care resources for additional support.

If having severe depressing or anxious thoughts, seek professional advice from your physician, counselor, or spiritual advisor.

- Seek information about your illness only if the information is a source of comfort for you, but not if it generates more worry and depression.



Ways to Self-Affirm

How you think about your illness will have a powerful effect on your life and your overall recovery.

Some examples of affirmations are:

- I have faith and trust that I can cope and manage my care.
- I will find personal strength and courage to get through this test and treatment.
- I can make compromises in my life to allow my body to heal.
- It is my choice to handle the effects of this illness with dignity and resistance.
- I can accomplish one meaningful task each day.
- Most housework can wait.
- I am prepared for whatever comes my way.
- I will keep normalcy and routines as much as possible.

There are things to avoid:

- Overly negative friends or family members.
- Dwelling too much on your problems, illness, limitations, or bodily symptoms.
- Spending too much time focusing on your prognosis.



Family & Friends

Patients turn to their families and friends to cope with chronic or serious illness. Remember when managing relationships with family and friends that they can have both positive and negative aspects. There may be times when people say hurtful things and behave poorly, so expect it and do your best to cope with it.

Identify what kind of help (emotional, physical, financial) you need. Once you understand this, the next step is to identify where you can get that assistance. There are times when a family member or friend may be able to help you, but they do not. Look for different ways to obtain the help you need including church, friends, neighbors, coworkers, etc.

Remember to be sensitive to other's needs and obligations. Rotate your dependence on others as much as possible. If you begin to feel smothered, be sure to share your feelings with the person helping you. It can be challenging to find the right balance.



Family & Friends

Here are tips for managing these relationships:

- Ask for assistance; no one can help if they do not know what you need.
- Ask softly and receive graciously.
- Be sure to thank individuals for their help.
- Tell your support people when you need a pep talk.
- Limit contact with family members and/or friends who upset you.
- Expect that your illness will affect both you and other persons close to you.
- Understand that roles, responsibilities, and routines in your home may change.
- It is important to identify your Power of Attorney for HealthCare/Healthcare Proxy for medical decision making. They can help gather medical information. They can help you sort through information and organize it. It is important to choose someone that will honor your decisions.

Friends may not know what to say or do when you are ill. Help them out by opening a conversation with them. Think about ways on how your friends can help you. Examples include:

- Carpooling kids or taking them to practice.
- Helping to maintain your house or doing a load of laundry.
- Running an errand, grocery shopping or picking up a meal.
- Listening or giving a pep talk.
- Sharing thoughts and opinions.

Limit the amount of time you devote to discussing your diagnosis and treatments, unless you are using a friend to help you gather medical information or make a treatment decision.



Always Thank Others

Always take the time to thank others for their support, time, and generosity. A few kind words can really make a difference.

Here are a few examples:

- Your kindness has really made a difference to me.
- Your thoughtfulness really cheered me up.
- I so appreciated your help and could not have done it without you.
- I am thankful for your company. It makes me forget about my illness.

Some Final Thoughts

Enjoy each moment of life. Focus on short-term things that help bring you and others around you joy such as a birthday, an anniversary, a holiday, or a graduation. Remember that “statistics are only true in the aggregate, not in the individual case” (Siegel).

- Be kind to yourself.
- Be flexible regarding the expectations you have of yourself.
- Adjust plans depending on how you feel.
- Pace yourself based on your energy level.
- Find activities and projects that take your mind off your diagnosis.
- Commit yourself to a healing way of life.

This booklet was written by a multi-disciplinary panel of experts across Trinity Health.



References: Blaha Decker, V., & Weller-Ferris, L. (2000). *Pocket Full of Miracles* (no longer in print)
Siegel, B. (1998). *Love medicine and miracles*. HarperCollins Publisher.

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