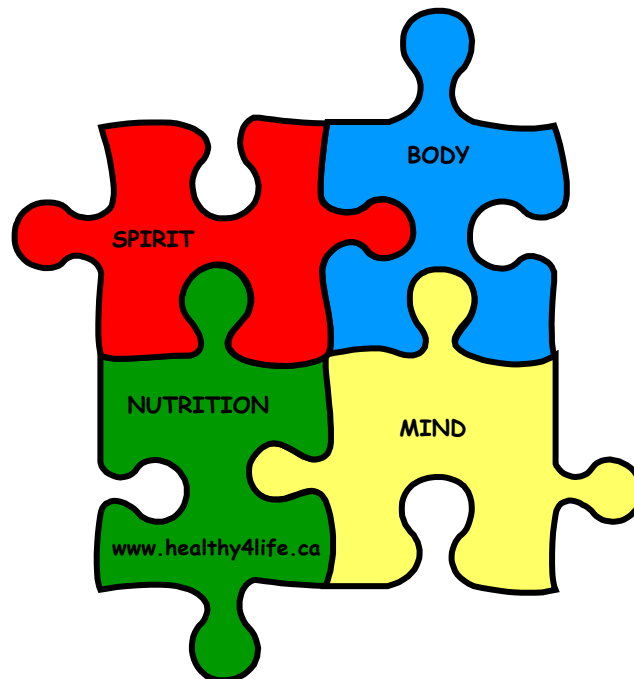


Nutrition and Lupus

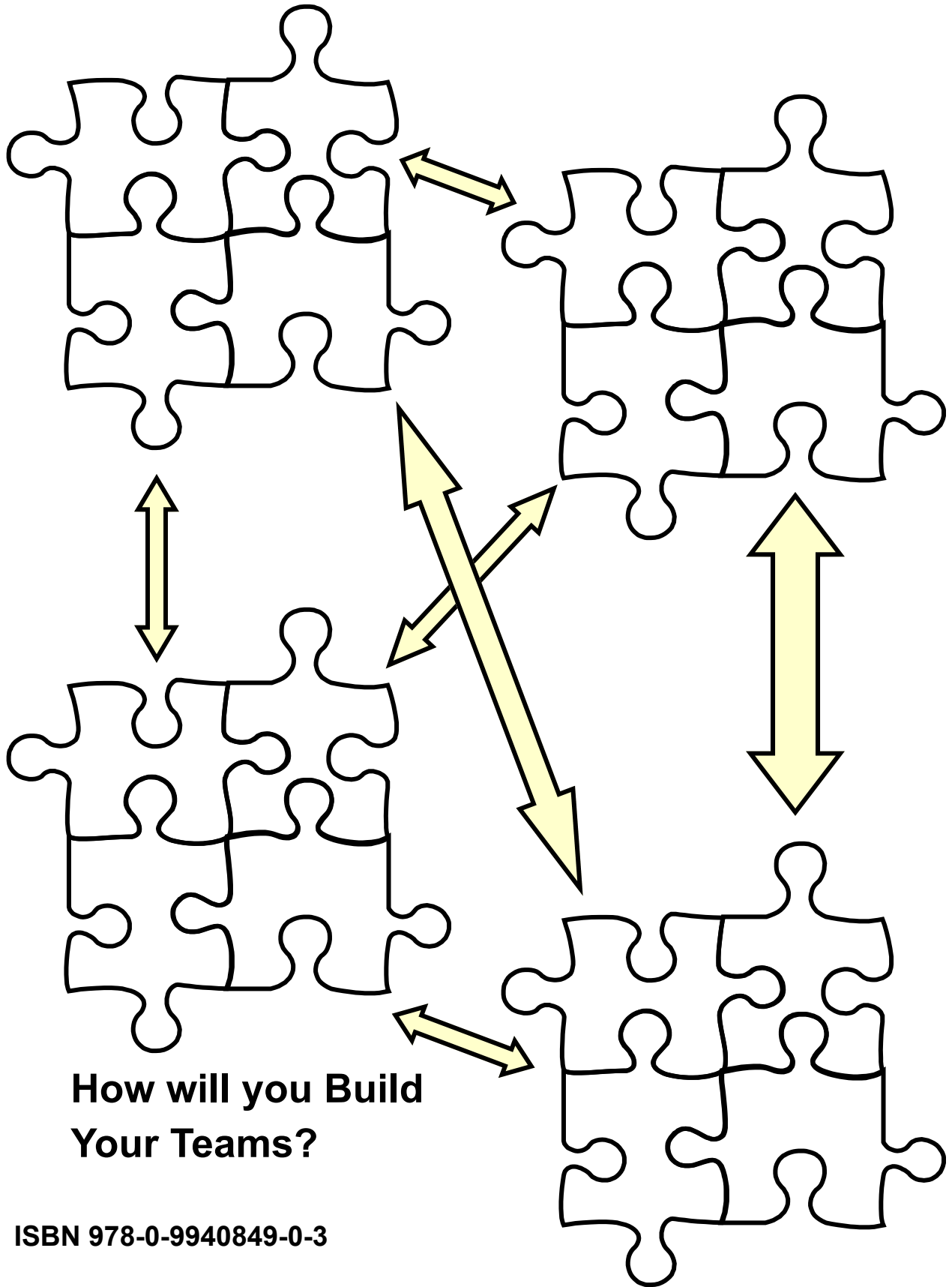
Book 4: Your Treatment and Support Teams

Living Well With Lupus

KNOWLEDGE AND HOPE



Cathy Ferren RHN
Registered Holistic Nutritionist



**How will you Build
Your Teams?**

ISBN 978-0-9940849-0-3

Nutrition and Lupus Book 4: Your Treatment and Support Teams

1st Edition - Digital

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Warning This book is a distillation of current nutrition science and stress management, as interpreted by Cathy Ferren based on her understanding and experience. Its purpose is to educate and inform those who wish to better understand the role of nutrition in health. It does not diagnose any disease or ailment. The author and publisher shall have neither liability nor responsibility to any person or entity with respect to any loss or damage caused, or alleged to be caused, directly or indirectly by the information contained in this book.

Dedication

This book is dedicated to lupus patients everywhere and to all of my lupus friends, treatment teams, instructors, spiritual advisors and support team members over the years.

Each of you shares in my journey with lupus with all of its challenges and rewards. I am humbled by and grateful for the wisdom and knowledge each of you has given me.

Introduction

I share this fourth book in the series with you, as a product of my own life experiences learning to live with chronic illness, and learning how to use nutrition to improve my symptoms and wellbeing.

I may not be able to control the disease process, however, I can have a beneficial effect on my physical symptoms, psychological wellness and my spirituality through good nutrition and healthy lifestyle choices.

My hope is that in these pages you will find practical ideas to incorporate into your own wellness plan so you can live well with lupus.

Other Books by Cathy Ferren

Nutrition and Lupus Book 1: The Basics

Nutrition and Lupus Book 2: Movement

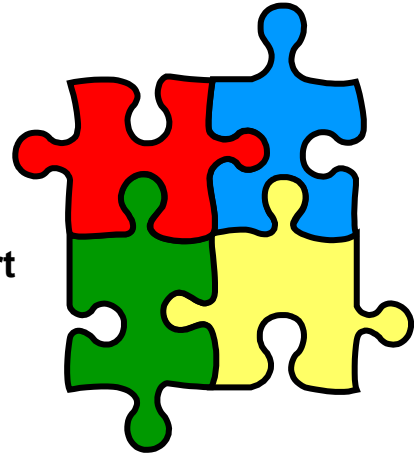
Nutrition and Lupus Book 3: Relaxation Plus!

Nutrition and Lupus Book 5: Spiritual Health

Smoothies Easy and Nutritious

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Build Your Teams

You Are In Control

You, The CEO of Your Team

You make the choices that build or destroy your team. The choices and therefore the control are yours.

The tips and guidelines in this book will give you tools you can use to help build the team you need and want with the ultimate goal of living well with lupus. This involves the mind part of holistic nutrition's body, mind & spirit.

Communication

Communicating With Your Health Care Professional

Your health care team is made up of many different specialists; doctors, rheumatologist, cardiologist, respirologist, neurologist, endocrinologist, dietician, physiotherapist, occupational therapist, psychotherapist, pharmacist, naturopath, chiropractor, osteopath, acupuncturist, massage therapist and others in the health care field. Your specific symptoms will determine which types of specialists make up your health care team.

Living with lupus requires the development of a positive relationship with a health care team. This is often a challenge for many people because you may feel intimidated by professionals who use words you don't know or become nervous about asking for further information if you do not understand. This anxiety can stop you from sharing important things with your health care professional.

Your doctors and other health care providers are also responsible for communication with you despite a busy schedule. As a patient, you deserve the right to information about your health. It is important to remember that the relationship developed with your doctors and other health care provid-

ers requires commitment and work, just like any other relationship.

However, there are two things that may help you in developing that much needed positive relationship with your health care professional.

The first point is understanding that members of your health care team are human as well. They too have stresses to deal with on a daily basis. They may experience frustration when they are not able to offer a cure to someone with a chronic and often disabling condition such as lupus.

The second thing in developing a positive relationship is making good use of the time you have together. When you feel pressured for time, messages are not always delivered with the same care that having more time would permit. Misunderstandings can occur. One way to help get the most from your provider's time is to prepare an agenda of what you expect from your visit.

Take the time to prepare for every appointment!

Write or type out a list of concerns or questions. Try to be realistic with your list as your provider can only deal with so many concerns during a single visit. Writing your concerns down also allows you to remember and prioritize them. Be sure to mention your main concern at the start of the visit, then move on to your other concerns and questions.

Be as clear as possible.

Describe the symptoms with regard to when they started, how long they have lasted, what makes the symptoms better or worse, and any possible contributing factors.

Bring a written list of any current medications that you are taking and any test results you think may be relevant. Have a second copy of these to give to your health care provider.

Asking questions and getting the information that you need is important in receiving good care and is a positive self management skill in dealing with lupus. Taking notes or having someone else attend your appointment as an advocate can be helpful. If you are uneasy with your current provider relationship or the care you are receiving, asking for a second opinion is acceptable.

It is helpful to repeat back to your doctor or provider what you have heard in the appointment to ensure you have clearly understood. Repeating helps to clarify any miscommunication and you can also ask your doctor to write down instructions or recommend further resources for you to follow

up on at a later date. If you can't follow the orders recommended, let the doctor know and explain your reasons why. This way adjustments can be made that are more suitable to your situation.

You also have the right to give your doctor feedback about the way you are being treated and your level of satisfaction with that treatment. If you are pleased with the care you have received then provide positive feedback. Everyone appreciates some positive feedback and being told how their efforts are helping. This includes everyone: the support staff, nurses, receptionists, doctors, nutritionists, technicians, etc.

Further Reading on the Doctor/Patient Relationship:

A helpful reference book is *Living a Healthy Life with Chronic Conditions* by Lorig, Sobel, and Gonzales. There are many different version of this book. Some are geared to a specific chronic illness and some are Canadian content editions.

Patient Self-help Guide: How to Talk to Your Doctor (Paperback) by Jane Williams (Author), Lorraine Griffin (Editor).

The Intelligent Patient's Guide to the Doctor-Patient Relationship: Learning How to Talk So Your Doctor Will Listen by Barbara M. Korsch MD and Caroline Harding. New York: Oxford University Press; 1997. ISBN 0-19-510264-9.

How to Talk to Your Doctor: Getting the Answers and Care You Need (The Best Half of Life) (Paperback) by Patricia Agnew (Author).

Communicating With Your Support Team

Your support team is made up of many different people, some will be from your family and friends, some as peer support and some in a professional relationship.

Relationships do not just happen. They require input from both parties. To build positive relationships you have to listen to their needs and not just be communicating what you want all the time. If a support person only hears a constant flow of negative words and only sees bad behaviour, they will get worn out and may not be there for you. This applies to professionals as well as family and friends. If a therapist only hears how bad you have it, how no one else suffers as much, that nobody understands, that no one

will listen to you; that is almost guaranteed to drive away your support people. In any kind of psychological therapy, it is not their job to “fix you”. It is their job to help you see what your words, actions, thoughts, feelings and behaviours are and to help you learn ways to deal with them. This usually comes under the headings of CBT cognitive behavioural therapy, life skills coaching, psychotherapy, counseling, NLP, and others. All of these require you to take responsibility for your progress or your lack of progress. It also requires that you make a choice to work on yourself, your issues, whatever it is that is causing you to suffer instead of allowing you to live well with your chronic illness. In peer support situations, either one on one or in groups, the same rules apply. There will be more information on support groups later.

Respect

Respect is key to any relationship. You have the right to expect to be treated with respect, however, you also must treat each person on your team with respect as well. This applies to conversation, email, fax, texting, facebook, instagram, telephone calls and regular mail.

It also means not gossiping or bashing anyone to a third party. If you have an issue or a problem with someone, you need to speak to them directly. Gossip and slander will only hurt you in the end.

You do not have to like everyone, yet you do have the responsibility to treat everyone with respect and dignity.

Some people who refuse to do this will find themselves without all the help and support they need. Be genuinely grateful for the help you do receive and express your gratitude to your team members.

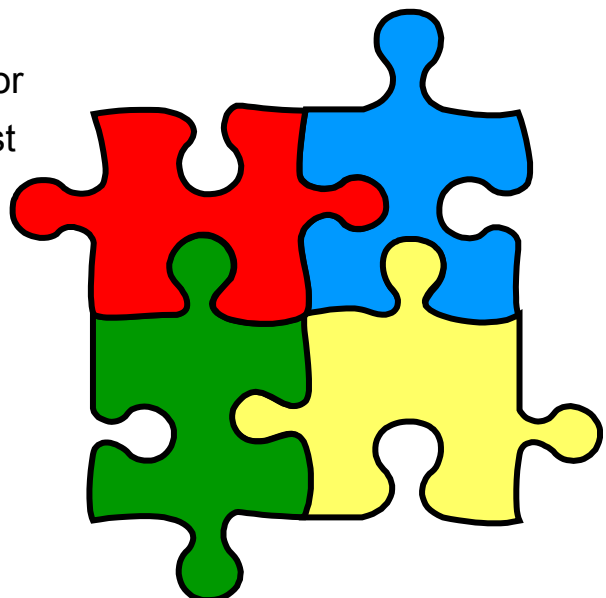
When you do not feel well, such as when you have a lot of pain, difficulty moving, a lack of sleep, anxiety, depression, anger, frustration, cognitive challenges or other symptoms, it can be difficult to stay positive and treat everyone with respect and gratitude. You need to try regardless of how you feel.

You also need to ask for and accept help when you need it. This is part of

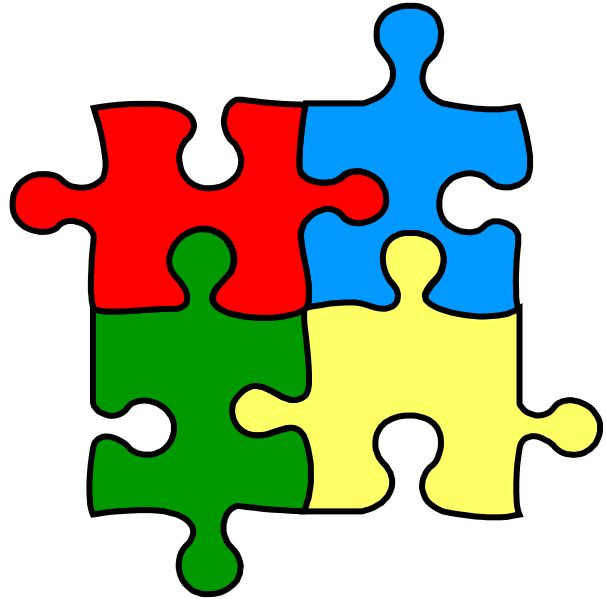
having respect for yourself and taking care of your self. You may need help for physical, psychological or spiritual symptoms or a combination of these.

Some Possibilities for Your Treatment and Support Teams

- Acupuncturist
- Aromatherapist
- Babysitter
- Cardiologist
- Chiropodist
- Chiropractor
- Community Care Access Centre Coordinator - CCAC
- Cook
- Dentist/Dental Hygienist
- Dermatologist
- Dietician
- Endocrinologist
- Family – Child, Father, Mother, Grandparent, Parent, Sibling
- Financial Planner
- Fitness or Exercise Coach
- Friend
- General Practitioner or Family Doctor
- General Practitioner Psychotherapist
- Grandparent
- Holistic Nutritionist
- Homeopath
- Housekeeper
- Immunologist
- Internist
- Kinesiologist



- Landscaper
- Life Coach/Health Coach
- Lawyer
- Massage Therapist
- Mindfulness Instructor
- Naturopath
- Nephrologist
- Nurse Practitioner
- Occupational Therapist
- Ophthalmologist
- Optometrist
- Osteopath
- Pain Specialist
- Paralegal
- Personal Shopper
- Pharmacist
- Physiotherapist
- Podiatrist
- Prayer Minister
- PSW Personal Support Worker
- Psychiatrist
- Psychologist
- Psychotherapist
- Relaxation Coach
- Reflexologist
- Registered Holistic Nutritionist
- Respiriologist
- Rheumatologist specializing in _____ example Lupus
- Shiatsu Massage Therapist

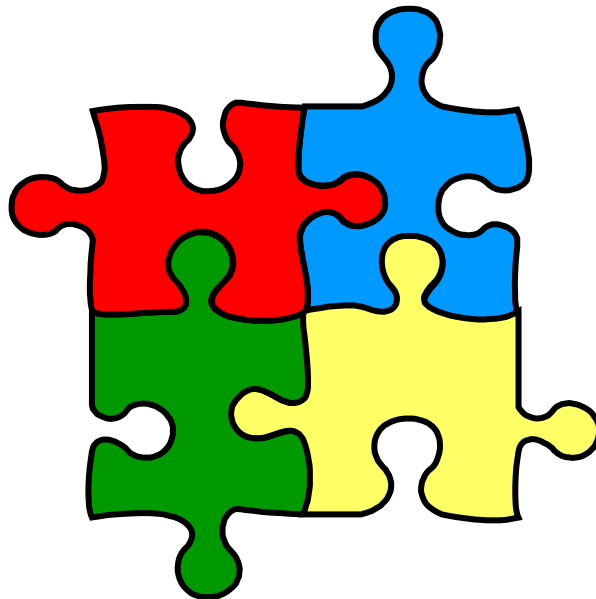


- Social Worker/Social Service Worker
- Specific Disease Association
- Spiritual Advisor/Spiritual Director
- Spouse or Partner
- Student Volunteer- Local High School
- Support Group Member
- Union Representative
- Urologist
- Volunteer Driver

As you can see there are many choices. It would be impossible to list them all here. This list gives you some ideas to think about.

USE ALL THOSE THAT YOU NEED

**BUILD
YOUR
OWN
TEAM
PERSON
BY
PERSON**



Types of Support Groups

There are different types of support groups. Here is a definition:

From Wikipedia, “In a support group, members provide each other with various types of help, usually nonprofessional and nonmaterial, for a particular shared, usually burdensome, characteristic. The help may take the form of providing and evaluating relevant information, relating personal experiences, listening to and accepting others' experiences, providing sympathetic understanding and establishing social networks. A support group may also work to inform the public or engage in advocacy.”

Peer Support

- From Wikipedia, “Peer support occurs when people provide knowledge, experience, emotional, social or practical help to each other. It commonly refers to an initiative consisting of trained supporters, and can take a number of forms such as peer mentoring, listening, or counseling. Peer support is also used to refer to initiatives where colleagues, members of self help organizations and others meet as equals to give each other support on a reciprocal basis. Peer in this case is taken to imply that each person has no more expertise as a supporter than the other and the relationship is one of equality. A peer has "been there, done that" and can relate to others who are now in a similar situation. A self-help support group is fully organized and managed by its members, who are commonly volunteers and have personal experience in the subject of the group's focus. These groups may also be referred to as fellowships, peer support groups, lay organizations, mutual help groups, or mutual aid self-help groups. ”
- “Self-help/mutual aid was defined as; a process of learning with and from each other (similar to adult education). Participants provide each other with mutual aid/peer support in dealing with a problem, issue, condition or need. Participants learn to work together while acknowledging the diversity of their personal situation among the similarities of their shared issue. Together they investigate alternative solutions and are empowered by this process.” Rabbani 2002.

- In Lupus Ontario, a “peer” is someone who has lupus or is a caregiver for someone with lupus. A support group leader is most often one of these two or, he/she could be a volunteer who has educated themselves about lupus. A telephone/email support person is a lupus patient who listens to other patients and family members in the same way as they would at the support group meetings. It is not counselling.

Open Group

An open support group is open to anyone who wants to learn to live better with lupus, learn about lupus and share with others living with lupus. There is no start date or end date. There are core members who may stay for years and others who gain knowledge and coping skills and move on. Members can join at any time.

Closed Group

A closed group has a defined membership and time frame. People must sign up before the group begins, and for a specific time period such as once a week for 8 weeks, or once a month for six months. All people start on the first night and the group closes after the prescribed number of meetings is over.

Facilitated Support Group

A professionally facilitated support group is led by trained professionals who understand the issues that challenge a person with lupus, such as psychotherapist, social worker, psychologist, registered nurse, life skills coach, health coach, etc. Currently, Lupus Ontario does not offer any professionally facilitated groups. It does offer professional telephone support with a staff social service worker through the 800 number in addition to their patient telephone/email support people.

Education Series

Sometimes people have a need for education more than sharing. Some groups are structured like educational workshops or seminars on specific topics with formal presentations/teachings or as life skills sessions.

Workshop Hope I will trust

I will share authentically Respect

Gratitude Self nurturing

Self respect Groups

Education

Face to Face Meetings

For peer support, face to face or in person meetings are the most effective. People feel more comfortable in a casual, comfortable environment where they can hear and see everyone. Body language is an important part of communication.

This is the preferred method for lupus support groups whenever possible. Some people due to geography or mobility cannot attend a face to face support group. There are other options.

Internet

From Wikipedia, "On-line support groups

Since at least 1982, the Internet has provided a new and successful venue for support groups. Discussing on-line self-help support groups as the precursor to e-therapy, Martha Ainsworth notes that "the enduring success of these groups has firmly established the potential of computer-mediated communication to enable discussion of sensitive personal issues."

Support groups have long offered companionship and information for people coping with diseases or disabilities, and on-line situation oriented groups have expanded to offer support for people facing various life circumstances, especially those involving personal and cultural relationships. Diverse remote networking formats have allowed the development of both synchronous groups, where individuals can exchange messages in real time, and asynchronous groups, where members who are not necessarily simultaneously connected to a network can read and exchange messages. [E-mail](#), [Usenet](#) and [Internet bulletin boards](#) have become popular methods of communication for peer-to-peer self-help groups and among facilitated support groups.”

There are also other types of support groups such as Instant Message - Internet Chat - Internet Phone Meeting for example Skype/NetMeeting/ WebEx/GoToMeeting and Secure or Restricted Facebook Groups.

**Your Team brings
Healing and Hope**

**You can build or
change your team!**

Authentic Sharing

Open honest sharing in the first person using I statements, active listening, confidentiality and respect are key in making the group a safe place.

The people you deal with are vulnerable and must be treated with dignity and respect. Only then can trust be established with you and with the other members of the support group.

I statements keep you out of preaching and keep you truly present in the moment by sharing your own experiences honestly. It also avoids people perceiving you as fake, insincere or know it all. When the words, “you, we, they, people” are used instead of “I”, some people in the support group will shut down, withdraw, get angry, leave, won’t participate, speak badly about the group to others, complain generally, etc. and may be hostile.

Active listening in the support group setting is listening attentively, making eye contact, without speaking or making verbal noises, without excessive body language. It is not repeating back everything the person has said as you might do in a business situation. That would make support meetings unbearably long and prevent many people from having the opportunity to share. You may wish to paraphrase and repeat back to someone what they have said in an individual sharing or coaching situation but not in the support group meeting.

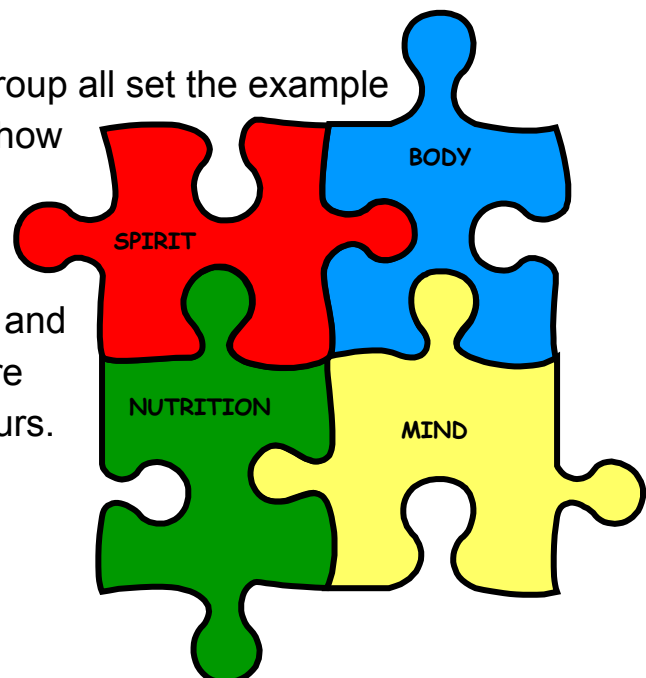
You and every other person in the group all set the example for your group on how to share and how to listen. Respect and caring.

Your Team

Sharing, caring, listening, education and support with honesty and integrity are within your control. The choice is yours.

Live well with lupus.

You are worth it!



Building Your Team Worksheet

My treatment team today is made up of:

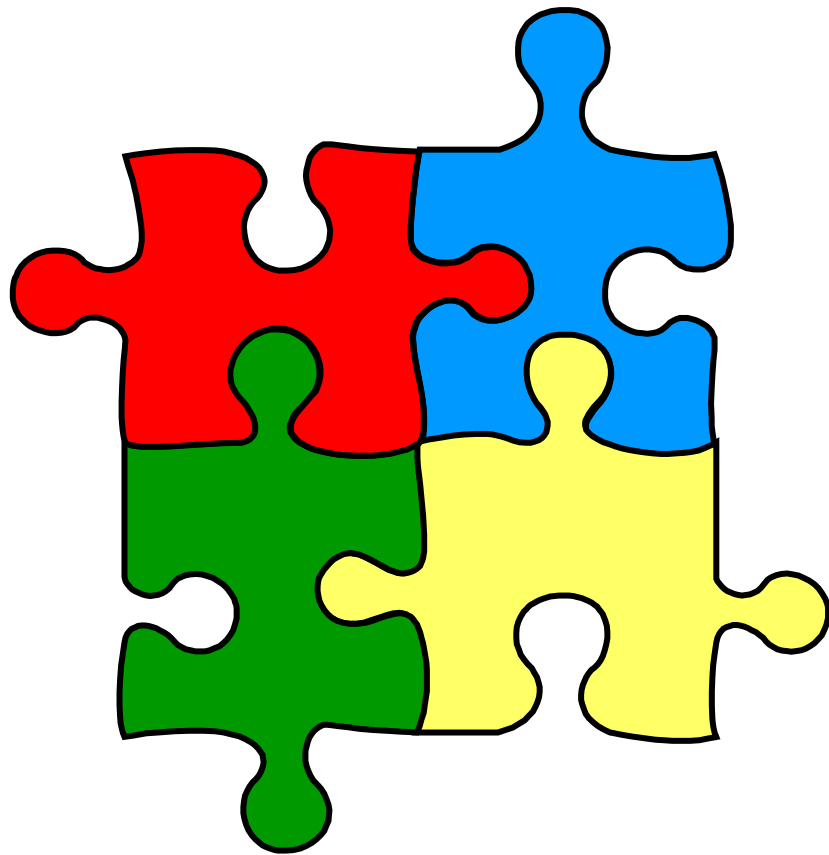
I would like my treatment team to include:

My support team today is made up of:

I would like my support team to include:

I promise myself to make a real effort to include the following new members to my treatment and support teams:

Build Your Team



You are the Captain

About The Author

Cathy Ferren RHN MAATO is a registered holistic nutritionist, life skills and health coach and instructor, certified Personality Dimensions® instructor, relaxation techniques coach and prayer minister working across Canada. She incorporates her over 35 years of experience in architectural technology into barrier free design consultations for her clients to help them meet their mobility needs.

As a lifelong volunteer in many non-profit organizations, she brings her experience, compassion and focus to her clients. She is passionate about helping people improve their wellness in all areas: body, mind and spirit.



\$4.99

ISBN 978-0-9940849-0-3