

**LUPUS**  
**ONTARIO**  
Life Without Lupus



# **Your Treatment and Support Teams**

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# Your Teams

- Your treatment team is made up of the licensed and registered healthcare providers.
- Your support team is made up of family, friends, support group members, psychological professionals, community and church groups and others.
- We will look at each of these in detail.
- Refer to your team worksheet.

# You The CEO of Your Team

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

# Your Treatment Team

- The most common people most lupus patients think of are family doctor, rheumatologist and nephrologist.
- There is so much more.
- First you need to know who you already have.
- Look at your team worksheet after this module and write in the team members you already have.

# Your Treatment Team

- Questions to ask yourself.
- My Treatment Team today is made up of:
- I would like my Treatment Team to include:
- There is space to write your answers on the team worksheet.
- Payment for your treatment team will come from several sources: provincial health care plan, extended health insurance, self.

# Your Treatment Team

- The bare minimum treatment team I suggest is family doctor, rheumatologist specializing in lupus, registered holistic nutritionist or dietician, physiotherapist or kinesiologist.
- Helpful to have: naturopath, ophthalmologist, acupuncturist, massage therapist, osteopath, chiropracist, nurse, laser therapist, occupational therapist, chronic pain specialist.

# Your Treatment Team

- Specific organ/system involvement requires others such as:
  - Nephrologist for kidneys,
  - Cardiologist for heart,
  - Respiriologist (pulmonologist) for lungs,
  - Neurologist for CNS and brain,
  - Dermatologist for skin,
  - Ophthamologist for eyes,
  - See worksheet for other suggestions

# Your Treatment Team

- Cost is always a factor.
- When completing your worksheet focus on what you need, not what you currently have funding for.
- The purpose of the worksheet is to discover what you really need.
- Finding a way to pay for it is a separate exercise.



# Your Support Team

- Questions to ask yourself.
- My Support Team today is made up of:
- I would like my Support Team to include:
- There is space to write your answers on the team worksheet.
- Payment for your support team will come from several sources: provincial health care plan, extended health insurance, mostly self.

# Your Support Team

- Most lupus patients think of their family and friends.
- There is much, much more to support.

# Your Support Team

- The bare minimum support team I suggest is lupus peer support group, qualified therapist, true friends, family members who care enough to educate themselves about lupus, spiritual director.
- Helpful to have: life coach, volunteer drivers, prayer partners, babysitter or eldercare respite.

# Your Support Team

- I repeat here → Cost is **always** a factor.
- When completing your worksheet focus on what you need, not what you currently have funding for.
- The purpose of the worksheet is to discover what you really need.
- Finding a way to pay for it is a separate exercise.

# Your Teams

- This is the most important promise you can make in your commitment to living well with lupus, **“I promise myself to make a real effort to include the following new members to my treatment and support teams:”**
- List the team members you need on the worksheet.
- This is a short term and ongoing SMART goal.

# Communicating With Your 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.

# Communicating With Your Team

- 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.

# Communicating With Your Team

- 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 providers requires commitment and work, just like any other relationship.



# Communicating With Your Team

- 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.

# Communicating With Your Team

- 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.

# Communicating With Your Team

- One way to help get the most from your provider's time is to prepare an agenda of what you expect from your visit.
- See the communication handout for more tips on how to prepare and how to give feedback.

# Communicating With Your 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.

# Communicating With Your Team

- You **will not** get much support if you continually portray negative expressions, postures, words and tone.
- Criticism will kill your supporters fast. They will disappear.
- Everyone deserves respect and gratitude.

# Communicating With Your Team

- 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.

# Communicating With Your Team

- 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.

# Communicating With Your Team

- 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.



# Communicating With Your Team

- 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 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.

# Communicating With Your Team

- This applies to conversation, email, fax, texting, facebook, instagram, telephone calls and regular mail.
- This includes telemedicine, online audio/video appointments.
- It also means not gossiping or bashing anyone to a third party.

# Communicating With Your Team

- 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.

# Communicating With Your Team

- You might be shocked by how often I hear patients being totally rude, aggressive and offensive when communicating with their team members.
- It does not help you get what you need and can even get you fired/discharged as a patient.

# Communicating With Your Team

- 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.
- Practice an attitude of gratitude every day.

# Communicating With Your Team

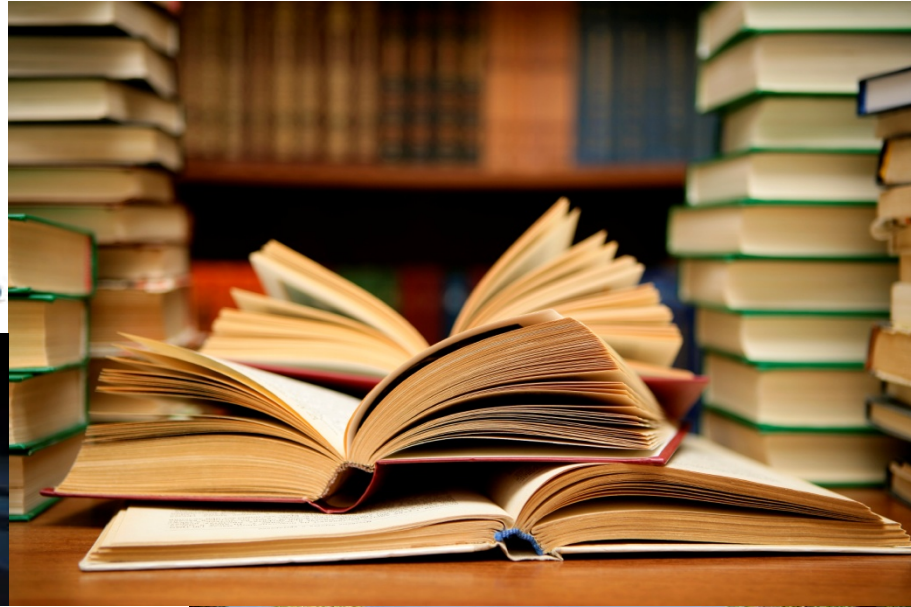
- When you do not feel well, such as when you have a lot of pain, difficulty moving, a lack of sleep, anxiety, depression, anger, frustration, cognitive challenges or other symptoms, it can be difficult to stay positive and treat everyone with respect and gratitude.
- You need to try regardless of how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

# Communicating With Your Team

- 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.
- You have choices.



# Resources





# Resources

- Patient Self-help Guide: How to Talk to Your Doctor (Paperback) by Jane Williams
- The Intelligent Patient's Guide to the Doctor-Patient Relationship: Learning How to Talk So Your Doctor Will Listen. Barbara M. Korsch MD and Caroline Harding. New York: Oxford University Press; 1997. ISBN 0-19-510264-9. 272 pages.
- How to Talk to Your Doctor: Getting the Answers and Care You Need (The Best Half of Life) (Paperback) by Patricia Agnew (Author)

# Your Team

- Sharing, caring, listening, self education and support with honesty and integrity are within your control.
- The choice is yours.
- **Live well with lupus.**
- **You are worth it!**