

HOW TO ADVOCATE FOR YOURSELF

Managing the Doctor-Patient Relationship

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Lupus Foundation of America, Georgia Chapter

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How to Advocate for Yourself

Discussion Topics:

- Keys to a Healthy Doctor-Patient Relationship
- How to Prepare for the Office Visit
- Pearls of Wisdom

Keys to Healthy Doctor-Patient Relationship

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Keys to Healthy Doctor-Patient Relationship

1. Arrive on time for office visits and be sufficiently prepared to ask questions and participate in the decision-making process.
2. Keep a detailed, personal medical file, complete with lab results, prescriptions, and a provider list.
3. Take an ADVOCATE to appointments.
4. Recap the office visit “in writing” immediately after the visit.
5. Take responsibility for owning, maintaining and sharing personal medical records with all members of the health care team.
6. Assume ultimate responsibility for managing your condition and use self-care opportunities provided.
7. Do NOT be intimidated!!

Doctor Visit Checklist

Complete BEFORE Doctor Visit

Doctor's Name _____ Phone Number _____

1. Call Doctor's Office (Get to Know the Office Staff)
 - a. Schedule Appointment (Write down Date/Time) _____
 - b. Ask for Office Address and Fax number _____
 - c. Ask for Paperwork (Have Forms Sent to you Before Visit) _____
 - d. Ask for Special Instructions (Can you eat before visit) _____
2. Arrange Transportation _____
3. Ask a Friend or Caregiver to Accompany you (Advocate) _____

Doctor Visit Checklist (continued)

Complete BEFORE Doctor Visit

4. Pack for Doctor Visit:

- a. Bring Insurance Card and Co-Payment _____
- b. Bring All Medications (Prescription and Non-Prescription) _____
- c. Bring Paperwork (Completed Forms and Medical Records) _____
- d. Bring Eye Glasses and Hearing Aids _____
- e. Bring Water, Snack and Book/Magazine _____
- f. Wear Comfortable Clothing _____
- g. Bring this Checklist _____
- h. Bring your Patience _____

5. Prepare List of Medical Concerns (Write down specific questions) _____
6. Review Medications (Write down if you need refills) _____
7. Review your Insurance Plan (What does the plan cover) _____

- Source: Capital Region Patient Advocacy and Atlanta Healthcare Advocacy

Write down SPECIFIC questions

Examples:

- How do I know if my Lupus is under control?
- Why am I so tired all the time?
- Should we change the dose of my Prednisone?
- What did my labs show?
- What did my bone scan show?
- What can I do to treat my insomnia?
- Can you go over my medications and explain what each one is supposed to do?
- How do I get questions answered by you in between appointments?
- Who will see me if I get sick and you are out of town?

Concerns and Questions for Doctor Visit

Complete BEFORE Visit

Before your doctor visit,
it is beneficial to think about any concerns related to:

1. Your **Physical Health** (Use the “systems approach”)
2. Your **Emotional** and **Mental Health**
3. Any **Recent Hospitalizations and Physician Visits**
4. Your **Medications** and **Allergies**
5. Your **Everyday Living**



How to Prepare for the Doctor Visit

PHYSICAL HEALTH—Use the “Systems Approach”

GENERAL: In general, how do you feel?

General state of health, sense of well-being, strength, ability to conduct usual activities, weight loss/gain, exercise tolerance.

For example: I am tired 5 out of 7 days on average. I require at least 2 rest periods during the day. I am missing many days at work each month. I require a caregiver to grocery shop for me. My medication is making me drowsy. I have gained 10 pounds. My life is so unpredictable: I don't know from hour to hour how I will feel. I have so many cognitive problems – the “lupus fog”.

(DOCUMENT, DOCUMENT, DOCUMENT)

HEENT: Head, eyes, ears, nose, throat

Headaches (location, time of onset, duration, precipitating factors), dizziness, changes in vision (blurred vision, double vision, blind spots, eye pain), hearing loss, nose bleeds, sinus problems, sore throat, neck pain

RESPIRATORY: The lungs

Shortness of breath, wheezing, cough (dry or wet, color of sputum), pain with deep breathing, night sweats

How to Prepare for the Doctor Visit

PHYSICAL HEALTH-- Use the "Systems Approach" Continued

CARDIOVASCULAR: The heart and blood vessels

Chest pain, palpitations (irregular heart beat), high blood pressure, blood clots, difficulty breathing with exercise, heart murmur

GASTROINTESTINAL: Stomach, intestines

Pain anywhere in abdomen, nausea, vomiting, heartburn, constipation, diarrhea, blood in stool, recent changes in bowel habits

RHEUMATOLOGY: Muscles and Joints

Pain, swelling, redness or heat of muscles or joints, limitation of motion, muscular weakness, cramps



How to Prepare for the Doctor Visit

PHYSICAL HEALTH Using the “Systems Approach” Continued

NEUROLOGIC/PSYCHIATRIC: Brain and nervous system

Headaches, feeling off-balance, dizziness, blurred vision, hearing loss, weakness on one side of the body, abnormal sensations, seizures, tremors, difficulty with memory or speech, depression, anxiety, hallucinations, psychiatric care

RENAL: Kidneys and bladder

Painful urination, frequent urination (especially at night), change in color of urine, generalized swelling, history of kidney stones

DERMATOLOGY: Skin

Rashes (generalized or localized), skin lesions, moles, itching, “butterfly rash”

HEMATOLOGY: Blood/lymph system

Bruising, paleness, excessive bleeding, blood clots, previous transfusions (including any reactions), lymph node swelling or tenderness, history of cancer or leukemia, history of anemia

ENDOCRINOLOGY: Metabolism

Excessive thirst, excessive urination, diabetes, hormone problems, thyroid problems, intolerance to heat or cold, sexual problems, excessive sweating

How to Prepare for the Doctor Visit

EMOTIONAL and MENTAL HEALTH

How is your mood?

Are you feeling sad, anxious or depressed?

How are your sleeping?

How is your cognitive function?

How is your memory, and thinking?

How to Prepare for the Doctor Visit

EVERY DAY LIVING

- Who are your caregivers?
- Have you had any recent falls or injuries?
- Has your diet changed?
- Has your mobility changed? Canes, wheelchairs etc?
- Do you have an Advanced Directive or has it changed?
- Have your home life changed?

MEDICATION

Golden Rules

1. Include your Doctor and Pharmacist:

Prepare a list of medications you are currently taking and keep it up to date.

Bring the medication list to all medical appointments and hospital visits.

Purchase medications from the same pharmacy

Review medication list with the Doctor or Pharmacist

2. Understand your medications:

Ask the Doctor and Pharmacist questions

Read the printed information provided with the medication

Write down instructions and possible side effects

3. Have a Routine for Taking your Medications

Prepare a medication schedule at the beginning of the week

Use pill boxes and calendar

Keep medications and records in one place

Source: Capital Region Patient Advocacy

MEDICATION LIST and ALLERGIES

MEDICATION LIST SHOULD INCLUDE:

- Name of Medication
- Dose of Medication
- Number of times taken each day
- Date started, Date discontinued
- Prescribing Physician

For example:

Prednisone 10 mg	Once a day	Started 2/08		Dr. Smith
Levaquin 500 mg	Once a day	Started 7/8/09	Discontinued 7/18/09	Dr. Harris

List **ALLERGIES** in **BOLD!!!** : This is critical to avoid life threatening mistakes.

For example:

Penicillin: causes rash and wheezing

ALLERGIES

Always notify

your physician, pharmacist, and
other providers of

drug and food allergies

at each visit

How to Prepare for the Doctor Visit

Recent **Hospitalizations** or **ER visits**

Include dates and diagnosis

Visits with other **Physicians or Providers**

Include addresses and phone numbers

Update **your Surgical List**

Keep a current list of Providers

(Include physicians, hospitals, & outpatient centers)

For example:

Dr. Mary Smith

Rheumatologist

1111 Sunshine Lane

Hope, GA 30000

Office: 770-666-7777

Fax: 770-666-7778

drmarysmith@bellsouth.net

Ask for a copy of all lab-work and test results

- Keep lab and test results organized in a folder.
- Request copies of all labs and test results from all providers (doctors, hospitals, outpatient centers).
- Organize information by date.

DURING THE DOCTOR'S VISIT

During the Doctor's Visit

1. Tell the Doctor Your Medical Concerns
2. Ask the Doctor for the Diagnosis
3. Ask the Doctor to explain the Treatment Plan
4. Repeat Back to the Doctor What you have Heard
5. If you are NOT comfortable with the Doctor's Diagnosis and Treatment Plan----TELL him/her so. Be assertive. Ask for options.
6. Have your ADVOCATE write down what is being said during the visit and have them be assertive in asking questions.

Take an advocate to the appointment

- If possible, take a spouse, a friend, a sister, a brother, or anyone else who can serve as your advocate.
- Have them WRITE DOWN the instructions and the information from the appointment.

How do I document my information for a DISABILITY CLAIM?

- START from today and move forward
- Do NOT become overwhelmed
- Come up with a SYSTEM to organize medical information
 - **Date**
 - **Provider**
 - **Summary of visit**

Example of Disability Claim

DATE	PROVIDER	SUMMARY of VISIT
1/4/09	Dr. Smith (Rheumatologist)	Routine visit: Increased Prednisone
1/31/09	Dr. White (Hematologist)	Anemia, took labs
2/9/09	Dr. White (Hematologist)	Rx Iron and B12 shots
3/5/09	Dr. Sanders (Internist)	Routine visit: Labs done
4/1/09	Dr. Sanders (Internist)	Levaquin for bronchitis
4/7/09	Dr. Smith (Rheumatologist)	Lupus Flare. Labs done. Started CellCept.
4/18-22/09	Piedmont Hospital	Lupus Flare
6/28/09	Piedmont ER	Broken wrist
7/3/09	Dr. Sunshine (Orthopedist)	Follow-up on broken wrist
8/1/09	Northside Outpatient	Bone Scan

Dr. Melissa's PEARLS of WISDOM

- Prepare for the appointment.
- Be pro-active and ask questions.
- Take an advocate.
- Be courteous to the medical staff: They are the key in getting information to the doctor.
- Be on time.
- Be patient: Realize that emergencies happen and physicians often have delays.
- Expect that YOU will get the same time and attention as others when you see the doctor.
- The "Hire and Fire" Theory: On occasion and for many reasons, the doctor/patient relationship just doesn't work. Know that as a patient, you are entitled to FIRE your doctor. The reverse is also true!
- You are receiving the BEST medical care in the world: Be grateful.

Questions?

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"If you start feeling worse, Mrs. Stein,
which is impossible...call me."

Thank you!

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Attachments

Patient Information

Name	
Date of Birth	
Address	
Phone	
Email	
Emergency Contact	
Pharmacy	
Allergies	

Medical Problem List

Date	Diagnosis (Problem)

