

What You Need to Know as a LAM Caregiver

Who are the caregivers and what do they do?

Please keep in mind as you read this information, all topics presented may not pertain to your situation. Some women with LAM have much less and slower decline in lung function than others. This is simply a guide to help you, as a caregiver, deal with some of the things you may be facing.

Caregivers are unpaid loved ones which give women with LAM physical and emotional care. They may be spouses, partners, parents, adult children, other family members, or close friends. Most often, they are not trained for the caregiver job. Many times, they may be the lifeline of the woman with LAM. Caregivers have a huge influence over how the patient might deal with their illness.

Here are a few things caregivers may need to help the woman with LAM do:

- Shop for and prepare food
- Housecleaning and laundry
- Provide childcare or transportation for children's activities
- Pay bills, manage finances and insurance issues
- Find emotional support
- Get to and from doctor appointments and tests
- Manage medical problems at home
- Coordinate LAM care
- Decide when to seek health care or see a doctor for new problems
- Advocate for their needs

All of this work costs caregivers time and money. There may also be a cost to the caregiver's health and well-being, but often the caregiver just keeps doing what needs to be done and may suffer in silence.

You may want to put the well-being of the woman with LAM above your own well-being. And your love for this person may give you the energy and drive you need to help them through the difficult times. Still, no matter how you feel about it, caregiving is a hard job!

Here we will try to cover some of the more common challenges caregivers may have to deal with while helping a loved one with LAM. It may help to know that **caregivers who take care of their own needs and get the information, help, and support they need are better prepared to take care of their loved ones.**

We will give you ideas on how to take care of yourself and where to find the support and help that you need. We'll also give you tips on how to be ready for some of the problems that may come up. Being a caregiver is a tough job, but it's an important and rewarding one, too.

Communication

Good communication allows you to express yourself, help others understand your limits and needs, and understand any possible limits and needs of the woman with LAM. You will need to be able to talk to the patient, the medical team, friends, family, and even concerned people you barely know. This can be hard to do. And when you need information from the medical team, it may not be possible without signed paperwork.

A few tips to help you with good, clear communication are:

- Respect your own feelings, needs, and desires, as well as those of the patient.
- Speak up for your feelings while being sensitive to others.
- Try to use "I" statements rather than "you" statements. For instance, say, "I need a break" instead of "You never help me!" Beware of statements like, "I feel like you ignored me," which says to the patient that she did something wrong. Instead, try "I didn't hear a response when I mentioned _____", or "I need help with this problem."
- Focus on the present rather than bring up old patterns or hurts.

How do I talk to the patient?

Start with the patient. Let her know that you want to be there for her and you want and need to be included in her care. Try something like:

- "This is a scary time for both of us, but I want to be here for you and will help you get through this. You are not alone."
- "I will do whatever I can to help you through this. I may do the wrong thing sometimes, or not know what to do, but I will do my best."
- "We can do this together. Let's try to be open with each other and work with each other no matter what happens."

It's good to set a goal of openness and sharing right from the start. Remind each other that you're "on the same team." Say something like, "I want you to be open and honest with me, and I will do the same for you." Share your fears and worries. Sometimes it may be hard and

you'll disagree and maybe even fight, but openness will allow you to deal with the conflict. It will also help you to keep supporting each other and reduce distress and anxiety. Acceptance and sharing will help keep your relationship strong.

How do I talk with the medical team?

First, get the patient's consent.

The caregiver is often the link between the patient and the medical team. In general, the medical team can share information with you anytime you are with the patient. But there are laws that protect private health information. These laws, called HIPPA Laws, affect what medical information your loved one's health care team can talk to you about when the patient is not present. Still, there are ways you can get information on behalf of the woman with LAM. The simplest and most common way is for the patient to fill out a release form that allows the doctor to discuss their care with you.

Talk to the doctor about what steps need to be taken so that the health care team can discuss the patient's care with you. Then be sure that there's a copy in the patient's records and keep the release form up to date. It's also a good idea to keep a back-up copy for your files. When you call the doctor's office, you may need to remind them that they have the form and they can discuss the patient's care with you.

If you don't have a form like this completed yet, you probably won't be able to get certain kinds of information. But you can still share information with the doctor. You can tell the office staff you are not asking for information, you are giving it. Even without the patient's consent, you can try asking for general information about problems the patient has; for example, "Are mouth sores one of the side effects of the medication that Jane got this week?" Or you can ask for hypothetical advice; for instance, "If Jane has been coughing for 3 days, should we come in to see you?" Even though you may not get details of Jane's care, you may be able to get some help in deciding what to do next.

Keep in mind that there are different forms that are signed for different purposes. Here we are talking about a release form that allows the doctor to share medical information with you. This type of release does not give you permission to make decisions about the patient's care.

Which doctor do I talk to?

LAM treatment may involve more than one doctor. There may even be a team of doctors, nurses, and other people taking care of your loved one, especially if your loved one is being seen at a LAM Clinic. You may get information from many of these people, but it's a good idea to pick one doctor to be the one you go to with questions. Most people choose the doctor they see most often. In choosing the doctor as your main contact, some things you may want to ask are:

- Will you be the one to coordinate care?
- Will you keep the other doctors updated on what's going on?

The woman with LAM should feel at ease with the doctor, and you should too. But sometimes, it may take a little time and work before this happens. Take the time to ask your questions and make your concerns known. The doctor should also make the time to answer your questions and listen to your concerns. If you, the patient, and the doctor feel the same way about sharing information and making choices, you will probably have a good relationship and you can get what you need.

Most health experts who work in the field of LAM are there because they care about the needs of people with LAM and other rare diseases. When you look back on this experience, some of your strongest memories may be of those health caregivers who were with you through a really hard time.

Should I go to the doctor with the patient?

Going to see the doctor with the patient is a good way to learn more about her medical condition. This can be very helpful when caring for the patient later on. It can also help the patient who forgets to mention problems to the doctor and comes home without the information you need. And finally, if you need a referral, maybe for a specialist, social worker, or medical supplier, you may be able to get the names of people who can help.

How do I use time with the doctor well?

The average doctor's appointment is about 10 or 15 minutes, so it helps to be ready for each visit. Work with the patient to figure out the most important issues before you go. Make a list of questions and concerns. What are the most important things you need to talk about? You may want to write them down, too. For instance, what symptoms do you need to tell them about? When did they start? Having a list will help you to use your time in the office well. And it means you won't forget anything important.

Don't leave the office until the doctor addresses your concerns and you both understand what to do next. Nurses can also be great sources of information, and you may get to spend more time with them than the doctor. Take notes on what is said to you. This will help you keep track of what you should remember. If you are getting back test results, be sure you understand the results before you leave. If blood work, pulmonary function tests or other tests were done, find out when and how you will get the results. Also, ask who will tell you what the results mean.

A voice recorder can also be a useful tool. Most doctors and nurses are comfortable with their patients using one, but ask before you do.

What should I know about new medicines?

If the patient gets a prescription for a new medicine, be sure you know the name of the drug, what it is for, and why she is getting it. Some other things you need to know are:

- How and when should the medicine be taken?
- What is the dosage?
- Should it be taken with food or water?
- Are there side effects? (Like sleepiness, nausea, or dry mouth?)
- How will you know if it's working? How long before you can expect it to work? Will it interfere with any other medicines or supplements the patient is taking?
- Are there foods, vitamins, or medicines that should be avoided while taking this drug?
- What should you do if a dose is forgotten? Take another? Skip it?
- How much does it cost? Will health insurance cover it? Is there a generic substitute?

Be sure you add this medicine to the list of all the medicines the patient is taking. (See the section called "Staying organized")

How can family meetings help?

Today's families are very busy, and it can be hard to keep everyone up to date on what is happening with the patient. Family members may feel frustrated and left out. They may not understand the medical condition, especially if the patient isn't having visible problems. They also may not know that their help and ideas are needed, or how to best help.

One way to keep everyone informed is to have a family meeting. Include immediate family, close friends, anyone who the patient wants to be involved. Some things to discuss may include:

- The latest report from the doctor
 - o How are things going?
 - o What can we expect to happen next?
- Sharing of feelings and concerns
- What does the woman with LAM want and need?
- How much time does each family member have to help out or visit?
- Other ways each person can help. What other help might be available?
- Financial concerns about caregiving:
 - o How much will it cost? o How much work can family members afford to miss if needed?
 - o Is other financial help available?

- What sort of support does the main caregiver need?
 - o Need for a break from caregiving from time to time
 - o Help with meals, shopping, cleaning, laundry, yard work, childcare, etc.
 - o Emotional support by phone or email
 - o Help with medical care, like taking the patient to the doctor's appointments
 - o Help with sharing news and updates on the patient's condition so that the main caregiver doesn't have to spend time repeating the news

Every family has a history with each other. This history affects each person's role within the family, how members relate to each other, how they feel towards the woman with LAM, and how they deal with illness. There are unspoken rules about what can be expressed and what emotions are OK. It may be hard to hold family meetings if the patient's condition requires the group to discuss these taboo topics. If you think this will be a problem, you may want to think of ways to defuse the situation beforehand. Sometimes a wise family member can help you. Or you may want to talk with a social worker or other professional about how to bring up delicate subjects.

Try to get everyone to focus on the issues at hand. You may even want to keep a list of issues or questions and have everyone look at it and add their own. This way there is a specific agenda for the family meeting.

Understanding the Health Care System

Going into a hospital, doctors' office, or talking to a health insurance company can be scary and stressful. The people may seem to speak a different language, everyone may seem rushed, and you and/or the patient may feel overwhelmed by everything that's going on. This is normal. It takes time to get to know a doctor and feel comfortable with him or her. It also takes time to get to know how the health care system works.

The patient is an important partner in their own health care, and so is the caregiver. You have a right to be treated with respect. Each health expert who sees the patient should listen to your concerns and spend enough time with you to answer your questions.

As you may already know, not all health professionals are skilled in talking with patients and families. Many forget that the terms, procedures, and machines that they use every day are new and possibly frightening to others.

Don't be afraid to ask questions. And then don't give up until you receive and understand the answer.

Making Health Decisions

The health care team will always discuss major health decisions with a patient if the patient can think clearly and share their thoughts. And the patient's decisions about their own health will be followed when their decisions do not create safety issues.

Sometimes what the patient wants is not what others want or will do for them. When patients need help carrying out their wishes, it can be hard on those who want something different from what the patient wants.

What if we can't agree on something important?

It's good to know that you and the patient don't always have to agree. Some of the decisions and problems that come with a LAM diagnosis can be very tough and very emotional.

Remember to let the woman with LAM make decisions about her care whenever possible.

There are some things you can do to help her make the best choice:

- Explain your needs and wants clearly and let the patient do the same. As an example, the patient may be having difficulty dealing with a decision as to whether or not to use oxygen outside of the home even though the doctor has prescribed it. You may need to explain that it is difficult for you to watch her struggle to breathe but that you want her to still enjoy the daily activities of life.
- Offer choices or a time limit when decisions need to be made. A change in medicines is a good example. "Let's try this inhaler for a while and see if it helps you. If not, we'll talk to Dr. Smith about trying something else."
- Focus on your energy and influence on the issues that are important. Let the patient make as many choices as possible. For example, arguing over what clothes to wear probably isn't the best use of anyone's energy. But not taking medicines or not following activity restrictions may be issues that you cannot ignore. If reasoning with the patient doesn't work, explain that you will talk to the medical team and get their help—then do it.

Again, open communication with the person you are caring for is the most important part of your role. Speak up for the patient and her needs. Help the patient get needed information. Get input from other team members and then offer your support and encouragement.

When do I call the doctor?

Sometimes it is hard to know if something is "bad enough" to call the doctor when it's after hours or in the middle of the night. The best way to know when to call is to ask. Ask the doctor or nurse what they want to know about right away, no matter what time it is. This may be things like fever, new pain, or some other symptom. You can also ask what symptoms can wait until the next day or the next appointment.

Also, be sure you know whom to call after hours, on weekends, and on holidays. If you do not have 24-hour access to someone on the medical team, find out what you should do if there are problems. Should you call your pharmacist if there are problems with a medication? Should you go to the ER? It often seems like problems come up when the doctor's office is closed, so be sure you have an emergency plan in place.

How do I know what the patient wants?

Everyday choices are easier to make if you understand the patient's preferences, habits and values. What is most important in her life? Everyday choices include things like what to wear, when to bathe or eat, and what else to do after that. But even these simple choices can be overwhelming and hard to make when dealing with LAM. Sometimes a small crisis can cause the woman to be unable to express what she wants or needs. As much as possible, honor the woman's wishes. But sometimes there may be limits on what you or other caregivers can do, as discussed above.

What if the patient won't do things for herself?

This can be a frustrating situation for a caregiver. You feel sure that she can do some self-care, but you do all of it because she won't. Sometimes there are medical or emotional causes for the problem, such as fatigue or possible depression. If you are not sure, take her to the doctor and state the problem clearly. The medical team can help you figure out what may be going on.

It is not always needed and may seem hard to do, but sometimes you might need to set some limits with the patient. For example:

- Try to figure out what self-care tasks she can safely perform. If you don't know what she can do, get the help of the medical team to evaluate her. Social workers and occupational health professionals may be able to help with this.
- Encourage her to do self-care on her own as much as possible.
- Encourage her to talk about things she enjoys so that the conversation is not always about LAM and illness.
- Let her make as many personal choices as she can. If she is overwhelmed with decisions, give her simpler choices by saying, "Would you prefer chicken or fish for dinner?" Sometimes making smaller decisions can help take the mind off of the larger decisions for a temporary time.
- Get others involved if she is not following through on the doctor's orders. Other family members or close friends can be a strong source of influence. Rally them for support.
- Once a decision has been made, accept it and move on. If you disagree with the decision that was made, remember that it is her decision to make. Congratulate her for

being able to make the decision, especially in cases of oxygen usage or transplant evaluation.

Remember that professional help is available to you. It's normal to sometimes feel frustrated, upset, and stressed when caring for someone with LAM. Use the resources and services of the health care team when you need them. They can help you find the support you need, such as mental health counselors, home care services, and sometimes even financial assistance, so that both you and the woman with LAM can have the help you need.

What if the patient won't share information with me?

It's normal to want to protect the people you love and care about. But sometimes this can become a problem. For instance, if the woman with LAM is having certain symptoms or worsening symptoms and they do not tell you or their doctors about them.

Try to understand her reasons for withholding information. Is she normally a very private person? Is she trying to protect you? Is she scared and trying to deny what is happening?

You may want to start gently, keeping in mind that she is probably already distressed. Sit down with her. Ask if there is something that she'd like to tell you. If the answer is no, ask if there's something that she *doesn't* want to tell you. Give her a moment to consider it. Point out to her that you have noticed signs of a new problem or worsening symptoms. Remind her that this may be something that her doctors could really help with and need to know about. Say something like, "I really want to be able to help you. But, in order to do that, I need you to be open and honest with me."

If she still denies that there are any problems or refuses to discuss it, you can enlist the help of other trusted loved ones. Or, you can call the doctor to share your concerns and find out if there is something else that you can do. You can't give the best care unless you know what is going on and how to help handle it.

How do we deal with uncertainty?

When a woman has LAM, she may go through different stages. Your understanding and your care will change over time as well. There will be times when you don't know what will happen next, and an illness like LAM, that's a scary place to be. If your loved one is taking treatment for her LAM, there are no guarantees or predictions about the possible side effects. It can be hard to deal with this constant state of "not knowing" – for you and for her. Here are some ideas that have helped others deal with the uncertainty and fear and feel more hopeful:

- Learn what you can do to help keep the woman with LAM as healthy as possible, and learn about the services available to you. This can give you a greater sense of control. And don't forget to keep yourself as healthy as possibly too.

- Know that you do not have control over many aspects of LAM. It helps to accept it rather than fight it.
- Try to let go of your fears, but don't deny them. It's normal for these thoughts to enter your mind, but you do not have to keep them there. Some people picture them floating away, or being vaporized. Others turn them over to a higher power to handle. However you choose to do it, letting your fears go can free you from wasting time and energy on needless worry.
- Express feelings of fear or uncertainty with a trusted friend or counselor. Being open and dealing with emotions helps many people feel less worried. People have found that when they express strong feelings, like fear, they are better able to let go of these feelings. Thinking and talking about your feelings can be hard. And while it is important not to let LAM rule your life, at times that may be hard to do. If you find that you are thinking about little else besides LAM and your loved one's health, it may be helpful for you to find a way to express your feelings.
- Use your energy to focus on wellness and what you can do to stay as healthy as you can. Remember to take care of yourself as well as your loved one.
- Find ways to relax.
- Make time for regular exercise and be as active as you can.
- Control what you can. Some people say that putting their lives back in order makes them feel less fearful. Being involved in your loved one's health care, keeping your life as normal as possible and making changes in your lifestyle are just a few of the things you can control. Even setting a daily schedule can give you more power. And while no one can control every thought, some say they've resolved not to dwell on the fearful ones.

You play an important role in your loved one's health, but you cannot control how they are doing physically or emotionally.

How do we adjust to the diagnosis?

With time, the patient and her loved ones will start to adjust to the LAM diagnosis. This is a time of change and action. Everyone is getting used to the unexpected and scary situation that they now find themselves in. Even with all the possible activity surrounding a diagnosis, some people do go through their days feeling numb and disengaged. Others may be sad, edgy, or angry. Emotions may change from minute to minute as you all deal in your own ways. Things may not feel settled for a long time, but there are appointments to keep, things to discuss and plans to make.

Staying organized

It helps to be organized. You will be getting a lot of information. New information can be hard to understand and it helps to keep it all in one place. Take notes. A notebook or a small file box might work well for you. Some people rely on their electronic organizers (laptop, iPad, etc.). Whatever you use, be sure to bring it with you to your loved one's medical appointments. Learn as much as you can about LAM and about the possible treatments. It will make it easier for you to talk to your loved one and to the doctors.

Keep a list of all medications that your loved one is taking, including prescription and over-the-counter medicines, and any vitamins, herbs, or other supplements. This list should include the:

- Name of the drug
- Dose (number of milligrams {mg} per pill; this is usually on the medicine bottle)
- Schedule (which days of the week and what times of the day it's taken)
- Reason for taking it
- Doctor who prescribed it (if the patient sees more than one doctor, one may not know what the other has prescribed)

Don't forget the medicines that the patient takes on an "as needed" basis, for example, an inhaler, drugs for pain or sleep, etc. Keep this list and take it to each of your loved one's doctor appointments and if there is ever the need for a trip to the emergency room.

Help your loved one keep up with medical expense records as well. Keep doctor and hospital bills, pharmacy receipts, and insurance statements.

Taking care of yourself

No one plans for a health problem like LAM. Nothing about it seems easy. There are many causes of stress and distress in caregivers. Dealing with a disease like LAM in someone you love, the uncertain future, financial worries, decisions that need to be made, and unexpected and unwanted lifestyle changes are just a few. Fear, helplessness, confusion, doubt, anger, hopelessness, and guilt can take a toll on both the woman with LAM and her caregivers. While the focus tends to be on the woman with LAM, all of this affects the physical and mental health of the caregiver, too. Common reactions resulting from caregiving might be such things as:

- Denial
- Anxiety and fear (loss of control, changes in roles and relationships, worry over finances, fear of the unknown or uncertainty about the future, concerns about pain and suffering, worry about doing a good enough job or not knowing what to do)
- Anger or resentment (about the illness, disruption of routine, having to take on additional roles, less time for self, changes in future plans)
- Guilt (for being healthy, not being able to do enough, for being able to do things the patient cannot, for being resentful)

- Feeling overwhelmed and powerless (exhaustion, worry, inadequate resources, not being able to fix the situation)
- Isolation (less likely to reach out for help, less social interaction)
- Changes in your own physical health (increased pain, headaches, fatigue, reduced immune response, difficulty concentrating)
- Depression and sadness (40-70% of caregivers have symptoms of depression)

Depression is a common problem in caregivers, but caregiving does not always cause depression.

And not all caregivers have the difficult emotions that go with depression. Everyone is different. Everyone has emotional ups and downs, but when the caregiver always feels down, has no energy, cries a lot, is easily angered, or when sadness significantly interferes with thoughts, behavior, mood, and physical health, it may be a warning sign of depression. Many people see the feelings of depression as a sign of weakness rather than a sign that something is out of balance, but ignoring it or denying these feelings will not make them go away.

Early attention to symptoms of depression can make a big difference in how the caregiver feels about their role and how well they can do the things they need to do. There are ways to reduce stress and remind you to enjoy life. They may help prevent the development of a more serious depression over time:

- Support from family and friends
- Caregiver support groups
- Exercise
- Healthy diet (eat balanced meals)
- Rest/practice good sleep hygiene
- Spiritual support, such as religious activity, prayer, journaling or meditation
- Recreational time
- Help from a trained mental health professional
- Ask for help with caregiving (schedule shifts if need be)
- Relaxation strategies
- Take a break... this is OKAY!

Where do I find support?

There are many kinds of support programs, including one-on-one or group counseling and support groups. There is most likely no LAM specific support groups in your area, since LAM is such a rare disease, but there are probably general support groups for caregivers in your area. A support group can be a powerful tool. Even if the support group is not LAM-specific, you will

most likely find that many of the issues facing caregivers dealing with other diseases are very similar to yours. Your loved one's doctor (or your own) may be able to provide you with a list of support groups in your area.

Online support groups may be another option. If you use Facebook, there is a closed group for caregivers of LAM patients. The administrators are family members or close friends of women who have LAM. They do their best to ensure that there are no LAM patients in the group. The group is not public and is monitored by LAM Foundation staff. It is a great forum for discussing questions or concerns that you may have. You may find that this is an easier way to get support than from a face to face support group. Because it is an online community, you can post questions at anytime of the day or night.

The LAM Foundation holds a unique conference every year which brings top researchers and physicians working with the scientific and clinical aspects of LAM. At the same time, there is the annual LAMposium, which is a conference geared toward LAM patients, their family members and friends. This is an incredible experience and a way for you and your loved one to meet others who are dealing with the same issues. There are educational sessions, Doc Talks, and social opportunities. The conference registration fee is waived for LAM patients and there are scholarships available to help with the cost of travel and hotel for any LAM patient with financial need.

Religion can be a source of strength for some people. Some find new faith during a life changing experience such as a LAM diagnosis. Others find that it can strengthen existing faith or that their faith can provide new strength. If you are a religious person, a minister, rabbi, or other faith leader can help you identify your spiritual needs and find spiritual support.

People who are not religious may find spiritual support in other ways. Meditation, journaling, and being outside in nature are examples of different ways a person may feel they are part of something greater than themselves. For others, becoming involved in volunteer work may renew their energy.