

FOR A LOVED ONE LIVING WITH LUNG CANCER



LUNG CANCER
SUPPORT LINE
(844) 835-4325
A FREE resource for lung
cancer patients &
caregivers

About the Lung Cancer Research Foundation

The Lung Cancer Research Foundation is the pre-eminent national nonprofit focused on funding innovative, high-reward research with the potential to extend survival and improve quality of life for people with lung cancer. In addition to funding research, the organization focuses on lung cancer awareness and education.













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Introduction

We hope this booklet will aid you in understanding your new role as a caregiver for someone living with lung cancer. This booklet provides an overview of the caregiving role, what to expect when caring for someone undergoing lung cancer treatment, and how to take care of yourself. At the end of this booklet you can also find helpful resources.

A special thank you to our participants in this booklet who graciously shared their personal experiences and advice as caregivers.

FIND ADDITIONAL INFORMATION at LCRF.org

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WHAT IS A CAREGIVER?

A caregiver is defined as a person who helps to take care of another. While the definition may seem obvious, the role of a caregiver, particularly when caring for a patient with lung cancer, can feel complicated and confusing. A caregiver can be a partner, family member or close friend. As a caregiver, you play a very important role in supporting your patient throughout this journey. There are many different people who may be involved in the care of the patient, either daily, weekly, monthly or as needed, depending on where the patient is in the treatment journey.

WHAT IS THE CAREGIVER'S ROLE?

Your role as a caregiver is unique. The medical specialists involved in your loved one's care focus on the treatment of the lung cancer. As a caregiver, your focus is on your loved one's personal needs and their overall well-being. This goes beyond their lung cancer diagnosis. Here are just a few examples of how a caregiver is involved:

- Provide emotional support to a loved one
- Help around the house or with day-to-day tasks
- Assist in keeping track of a loved one's medical information

Emotional Support

Perhaps the most important way to provide emotional support for a loved one is by communicating with them regularly. Talking honestly with your loved one lets you both share your feelings and needs. Emotional support is about allowing the open communication of positive and negative emotions as they occur. Some of you may be caregiving from a distance. Even though you might not live in the same area, you can still offer emotional support to both your loved one and any locally involved caregivers.

You are a team on this journey. It may be helpful to begin this journey by reminding them that they are more than their lung cancer diagnosis and together you can find ways to maintain everyday life the same way it was before they were diagnosed. Now that their treatment is being incorporated into their everyday life, some planning and preparation may be needed to maintain this balance. Here are a few ways in which caregivers such as yourself have maintained this balance.

- **LL** Keep living every day, every moment. Find something to do, something to do with other people, stay busy, stay happy and keep living."
- **LL** I'd try to plan little things for down the road, in the near future, so that he would always have something to look forward to... like a concert or a ball game."

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CAREGIVING THROUGHOUT THE PATIENT JOURNEY

Diagnosis

Receiving a diagnosis of lung cancer is difficult. The moment a patient hears the words "lung cancer," all other information given by the healthcare team may or may not be heard.

A caregiver can help organize and record information. It's helpful to keep a list of things you don't understand or questions that you, the patient, or other family members have.

After an appointment, continue to talk about what you heard and write down any questions that may come up so that you can get the answers you both need. Talk to your loved one about what they have learned about their lung cancer diagnosis from their healthcare team or elsewhere and help them interpret information given to them as best you can. If something seems scary or confusing, talk to the healthcare team about it.

There's a lot of information out there, and it's not always the most positive... It's good to use the internet as a source, but you can't hold that much faith in it. A lot of things have changed in medicine since the time that these articles were written."

11 Provide information you learn to your loved one as they are ready for it."

Choosing a Treatment

Once the results are back, the doctor will explain treatment options. Make sure you understand what is being offered, feel free to ask questions until you understand those options. Ask what side effects might go with those treatments offered.

In choosing a treatment, take time with your loved one to discuss their wishes and choices. For example, some people might not want to choose a treatment that would cause them to lose their hair (if there are other options available), or perhaps they would not be able to do a treatment that meant traveling daily or weekly to the clinic. Talk about these concerns with the doctor so the best treatment can be chosen.

For more information on types of treatment, please see *Living with a Diagnosis of Lung Cancer*, available at LCRF.org/resources.

During Treatment

Once a treatment plan is decided, you may want to work with the healthcare team to develop a personalized cancer care plan, which is like a road map for everyone involved in the treatment and care of the patient. It will list the planned cancer treatments, other medicines or therapies, possible side effects, and symptoms.

Basic Outline of a Personalized Care Plan:

- Treatment provided
- Treatment purpose (cancer treatment, bone strengthener, ease of breathing, etc.)
- When to take (daily, weekly, specific dates)
- How to take (after meals, before bed, with water, etc.)
- When and where to go for treatments

- Side effects, which are normal and which need urgent/emergency care
- Contact information outside of normal office hours or for urgent matters/ emergencies
- Follow-up needed and follow-up date(s)

If you are not given a personalized cancer care plan, you can download a template at LCRF.org/care-plan.

OTHER CONSIDERATIONS

Biomarker Testing

Many of the latest treatment options for lung cancer require biomarker testing. Some treatments target specific markers on cancer cells (targeted therapy), and biomarker testing is needed to understand if a treatment is appropriate for specific patients. Understanding test results and talking to the oncologist about what the results mean is important.

For additional information on biomarker testing, please see Biomarker Testing For Lung Cancer, available at LCRF.org/resources.

Dealing with Stigma Associated with Lung Cancer

Lung cancer has been conclusively linked to smoking, and most have either read or seen one of the many campaigns aimed at helping people stop smoking in an effort to prevent lung cancer. An unintended side effect of these campaigns is the stigma or blame that is often associated with a lung cancer diagnosis. Not everyone with lung cancer is or was a smoker. In fact, 20,000 to 30,000 people who have never smoked are diagnosed with lung cancer every year. For patients who did smoke or are smokers, it's important to remember that no one deserves cancer. The best way to begin to change the conversation on lung cancer stigma is to educate yourself and talk to others about the facts.

Clinical Trials

Clinical trials are medical research studies that test new ways to prevent, diagnose, or treat diseases such as lung cancer. Patients participating in clinical trials may have the opportunity to receive cutting-edge cancer treatments that have shown promise in early research. Some think they should consider a clinical trial only after they have exhausted standard treatment options. However, no matter where your loved one is in their treatment process, a clinical trial could be a good option. In fact, many trials are available for people who have just been diagnosed or who have early-stage lung cancer. Insurance coverage and/or the trial itself will usually pay for the care received in a clinical trial. When discussing treatment, ask the doctor for referrals if a clinical trial is an option for your loved one.

Other Helpful Tips from Experienced Caregivers

1. Packing a "go" bag

Some caregivers like to prepare and keep a "go" bag packed for both them and their loved one. A go bag contains items that are helpful during an appointment and may be useful if a treatment visit lasts longer than expected or results in a hospital admission. Items to consider packing are for comfort such as a sweater, blanket, hard candy or snacks, water bottle, and a notebook and pen can often come in handy.

When you have to get up and go... so you don't have to stop and think about what you need to do because going to those appointments is stressful enough. Having a bag prepared for both of us, especially during chemo... was something that really helped."

The Lung Cancer Research Foundation offers information about clinical trials at LCRF.org/clinical-trials. You may also call our Lung Cancer Support Line toll-free at (844) 835-4325 for help.

2. How to advocate for your loved one with their insurance company

Keeping track of deductibles, copays, what is covered and what isn't, and other bills can be complicated. It is important to stay organized and on top of what should be covered and act as a strong advocate for the patient if something is denied that you feel is in error. Sometimes, treatments that are initially deemed not covered can be covered by insurance if the physician's office or you are willing to push for payment.

Most drug companies have programs to help patients get the drugs they need when insurance, co-pays or other money matters get in the way. Your nurse, social worker, or patient navigator can help you contact the drug company.



the insurance company for him to get his medication.... I had to make numerous phone calls to get them to pay for the medication.

Just keep fighting for it; don't take no for an answer. If they say no, come back at them again and tell them why you need that medication."

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Caregiver Stress SPECIAL SECTION BY DR. DIANE SANFORD



Caregiver Stress

One of the most common problems of caring for someone with cancer is the resulting caregiver stress. While caregiving is essential to someone with lung cancer, caregivers often feel depleted, exhausted and overwhelmed if they are not taking time to care for themselves. Since each of us has only so much emotional and mental energy, caregivers must learn to recognize when they are becoming stressed and what they can do to rest, restore and regain their own health and well-being. It is true that caring well for someone else begins by caring for yourself.

Signs of Caregiver Stress

While the signs of caregiver stress are different for everyone, the following are some common ones that occur:

- Trouble falling asleep or staying asleep
- Overeating or eating too little
- Physical symptoms including headache, gastrointestinal problems and muscle tension
- Irritable or short-fused
- Fatigue and lack of energy
- Increase in negative thinking and worry
- Feeling overwhelmed and anxious

- Feeling down, weepy or sad
- Decrease in joy and life satisfaction
- Inattentive and forgetful

Recognizing Your Stress Profile

In Stress Less Live Better: 5 Simple Steps to Ease Anxiety, Worry and Self-Criticism, 2018, PraeclarusPress.com, the mindful stress reduction program I've developed, students learn to identify when they're experiencing stress by noting the situation they're in and the thoughts, feelings and bodily sensations that occur. In mindfulness practice, noting your thoughts, feelings and sensations is called the triangle of awareness. By learning to notice changes in these three categories when we are under stress, we can learn to identify our stress profile and realize when stress is affecting us negatively.

Here's an example of what one caregiver noticed when she began to tune it to her stress warning signals: Most of the time at the start of her husband's illness, she felt OK except, when there was a doctor's appointment or treatment meeting. On these occasions, she noticed that she wouldn't sleep well a couple nights before or have much appetite. She would worry more and begin imagining what it would be like to be

without her husband, which caused her to feel anxious and sad. She would be impatient and distracted the day of her husband's medical appointments, and her stomach would be distressed. Once the visit was over, her short-term stress eased and her stress and stress signals lessened over the next few days, until it was time for another medical visit.

By noting what occurred—thoughts, feelings and bodily sensations—the caregiver began to map out her stress profile. You can do the same. For the next two weeks, tune in to your stress and identify your warning signals if stress rises above 5 on a 10-point scale, with 1 being the lowest. Record the situation that triggered your stress to exceed 5, and in each of three columns, write down your thoughts, feelings and bodily sensations. Include what you did to try to cope with your distress. Perhaps you coped with an action, by going for a walk or overeating. Or maybe you attempted to redirect your thoughts, such as imagining something that brings you comfort or getting carried away with how bad things might become. Write whatever happens. Don't censor or sugarcoat your reaction. Being aware of your experience is the first step in choosing healthier coping skills.

Choosing Healthier, More Effective Coping Skills

Although it is true that as stress increases, we are more likely to fall back on our less healthy and more immediately gratifying ways of coping (i.e. overeating, drinking too much, over-working, smoking more and other addictive behaviors), we can learn through practice of mindful stress reduction to choose options that enhance health instead. In mindfulness practice we say that we become aware of reacting on autopilot and soothing ourselves with unhealthy options and instead begin to respond with choice. This doesn't mean that using these skills makes us feel better or relieves stress in the moment. However, over time these mindful stress reduction strategies are more likely to be stress reducing and improve our mind-body health. In fact, regular practice of mindfulness strategies can boost immunity, improve mood and increase well-being by decreasing anxiety, depression and worry.

Practicing Self-Care as a Caregiver

The greatest obstacle that caregivers face in practicing self-care is themselves. Most times

they will sacrifice their own needs for health and comfort because they believe that their needs are unnecessary and self-indulgent. However, when you neglect your own health and wellbeing, you compromise your ability and energy to care for someone else. That's why flight attendants tell passengers to put on your oxygen mask first. Without taking care of your own needs, you will be more susceptible to burnout, resentment, compassion fatigue, stress, anxiety and depression and have less to give in your caregiving role.

The challenge is to convince caregivers that this is true and for caregivers to replenish their own health and well-being. Think of yourself as a plant or flower. Without the proper nourishment, you will wither and stop growing or possibly die. If someone else in your life needed nourishment, would you let them neglect it? You wouldn't allow someone else to be undernourished, so why you? Self-care is the nourishment that people need, especially in times of heightened stress. It is the soothing balm that reduces stress and increases comfort. Remember, an ounce of prevention is worth a pound of cure. Invest in self-care now and the payoffs to you and your loved ones will be worth it.

How to Rest, Restore and Regain

In my *Stress Less Live Better* program, self-care practice involves paying attention to nutrition, exercise, sleep/rest and stress reduction. I call these the Four Pillars of Health. To maintain optimal health and well-being during stressful times, it is important that at least your basic needs in each of these four areas are being met. While it is easy when we are caring for someone else to neglect ourselves, remember that without adequate self-care, we won't have the energy and emotional strength to be available for the patient receiving our care.

Guidelines for practicing each of the Four Pillars of Health



1. **NUTRITION:** Make certain to eat three to four small meals each day. When you start to feel physically hungry, stop to eat something. Make healthy food choices 75% of the time. Hydrate with water often. Satisfy your emotional hunger with activities and people you enjoy.



2. **EXERCISE:** Participate in regular physical activity and exercise three to four times a week. Make certain your program allows you to develop strength, flexibility and balance. Exercise boosts physical immunity, improves mood and declutters your mind. Move your body often. Stay mentally active, too.



3. **SLEEP/REST:** Get adequate sleep at night, preferably eight to nine hours. Wind down an hour before bedtime and disconnect from electronic devices. Create a soothing bedtime routine. Follow periods of expending energy with relaxation and restorative time.



4. STRESS REDUCTION: Know your stress profile (i.e. warning signs that stress is building, such as trouble sleeping or an upset stomach). Choose healthy coping skills, such as exercising, more often than unhealthy ones, such as drinking or smoking. Learn what thoughts, feelings and sensations trigger stress for you and how to manage these better in your everyday life. Build your coping skills toolkit with more effective ways to ease stress, anxiety and worry, such as the ones found in my *Stress Less Live Better* program or other mindfulness-based interventions. Make your health and well-being a priority even when you're a caregiver.

How to Stress Less and Live Better: 5 SIMPLE STEPS TO EASE ANXIETY, WORRY & SELF-CRITICISM

As a caregiver, you do not have much time in the day for your own stress reduction. So, here are my five skill sets with an exercise for each that you can do in five minutes or less. It is more important to practice regularly than to sit for long periods of time meditating on a yoga mat — although certainly this can be very helpful. Instead, opt for practicing one of the following exercises four to five days a week. (Order my book for even more suggestions.) You can also go to www.drdianesanford.com, click on Resources, and follow me for guided exercises.

Simply Breathe: The Power of Presence

In Simply Breathe, we learn how being in the present moment helps to ease stress and to calm our body and mind. We start noticing our present-moment experience by focusing on our breath as it's occurring. There's nothing we need to do but become aware of our breath flowing in and out of our body.

Simply Breathe exercise:

Sit comfortably with your eyes open or closed. Take three deep breaths and see if you can notice where your breath is occurring most strongly in your body in this moment. It may be around your lips and nostrils, in the rise and fall of your

belly or the rise and fall of your chest. Next see if you can follow it from inhalation to exhalation and back again or from fullness to emptiness. Do this for a few minutes. When thoughts, feelings or sensations try to hijack your attention, note them and return your attention to your breath. You can also think to yourself, "Breathing in, I breathe in. Breathing out, I breathe out." Don't judge your experience but simply notice it. After a few moments, take three more deep breaths and open your eyes if they're closed.

Soothe Your Body: The Power of Paying Attention

In Soothe Your Body, we learn to direct our attention intentionally instead of letting it wander aimlessly. We deliberately tune in to the experiences in our body to retrain our minds to go where we want, unlike an "unruly puppy" (Ronald Siegel PsyD, The Mindfulness Solution). We can reduce stress further by imagining ourselves breathing warmth and comfort into the tight places.

Soothe Your Body exercise:

Sit comfortably, where you won't be disturbed for the next five minutes, with your eyes open or closed. Take three deep breaths in and begin to notice a part of your body where you are experiencing some discomfort. Rather than labeling it bad or being judgmental about it, simply notice the qualities of how it feels. Is it warm or cool? Loose or tight? Soft or hard? Vibrating with energy or still? Once you become aware of what it feels like, if you want, imagine yourself breathing warmth and relaxation into this part of your body, softening and loosening any discomfort. Take three more deep breaths and open your eyes if they're closed.

Savor the Moment: The Power of Savoring Sensory Experience

Savoring the moment involves sensing the experience that we're having through all five senses: sight, sound, touch, taste and smell.

Current research in positive psychology indicates that savor-enhancing experiences can improve mood and decrease stress. Savoring can be done with activities that already occur in our daily lives by focusing our awareness on sensory experience.

Savor the Moment exercise:

Pick an activity you perform daily, such as brushing your teeth, taking a shower or washing the dishes. Pay attention with all five senses to what you're doing. Be aware of the sights, sounds, tastes, smells and touches that accompany it. For

example, if you choose washing the dishes, be aware of seeing the soap bubbles, smelling the scent of the dish soap, hearing the water running, or touching the dishes or bubbles.

When thoughts or feelings try to steal your attention, simply note them and go back to focusing on the sensory experience of what you're doing. Practice savoring the same experience four to five times in a week.

Settle Your Thoughts: The Power of Letting Go

In Settle Your Thoughts, we learn to note that thoughts are occurring and to let them pass without getting too attached to them. We witness how they come and go and are constantly changing from moment to moment. We consider the idea that thoughts are not facts but instead passing mental events. Likewise, we practice not getting caught up in the stories we tell ourselves, instead realizing that we can't know with certainty what's going to happen until it does.

Settle Your Thoughts exercise:

Sit comfortably with your eyes open or closed in a quiet place where you will be undisturbed for the next five minutes. Take in three deep breaths and notice how thoughts come and go, one after

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the next. Resist the urge to start telling yourself a story about your thoughts, and instead picture them changing from moment to moment, like waves on an ocean, leaves flowing down a stream or clouds passing through the sky. Your thoughts are always changing, but you, as the witness of your experience including thoughts, feelings and sensations, are constant like the ocean, the stream or the sky. Let thoughts come into your awareness, and then let them go once you notice them. Do this for five minutes. Then take three deep breaths and open your eyes if they're closed. Practice this daily for a week.

Self-Compassion Always

Self-Compassion Always involves accepting yourself fully, strengths and flaws, without self-criticism or self-judgment. Many people, especially caregivers, women and people in the helping professions, are much harder and critical of themselves than they are anyone else. Rather than paying attention to what they're doing right and how much they're doing for others, they

often dwell on the mistakes they've made or how they could be doing better. In this skillset, we learn to "befriend ourselves" and be kind to ourselves like we are to those we love.

Self-Compassion Always exercise:

Sit comfortably with your eyes open or closed in a quiet place where you can sit undisturbed for five to 10 minutes. Think about this past week and recall a time when you were self-critical or judgmental of something you did or thought. Next imagine that one of your friends or loved ones had done something that caused them to be critical or judgmental of themselves. Think of what you'd probably say to them and then say these words to yourself. For example, "Everyone makes mistakes. Stop being so hard on yourself. Think about all the good things you've done." Once you can say something self-compassionate and accepting, repeat this a couple of times. Then take three deep breaths and open your eyes if they're closed. Practice this daily for a week.

To learn more about Dr. Sanford and her book,

Stress Less Live Better: 5 Simple Steps to Ease Anxiety, Worry and Self-Criticism,
see these websites: drdianesanford.com • praeclaruspress.com

Resources

Lung Cancer Support Line

Lung Cancer Research Foundation

LCRF.org/support-line; (844) 835-4325

The Lung Cancer Support Line provides callers with education, connections to resources and opportunities for meaningful engagement to help patients and caregivers better face the challenges of lung cancer. This service is offered completely free of charge to patients and their caregivers.

Lung cancer information

Lung Cancer Research Foundation

LCRF.org; (212) 588-1580

The Lung Cancer Research Foundation is dedicated to improving the lives of patients with lung cancer. We fund research focused on the prevention, diagnosis, treatment and cure of lung cancer.

The Lung Cancer Research Foundation offers a suite of educational and informational resources for patients and their loved ones, covering important topics, including:

- Finding an oncologist
- Clinical trials
- Biomarker testing
- Research updates

Download *My Lung Cancer Care Plan*, which will help you track treatments, appointments and other aspects of your care, at LCRF.org/careplan.

Cancer.net

cancer.net/cancer-types/lung-cancer; (571) 483-1780 or (888) 651-3038

This website, sponsored by the American Society of Clinical Oncology (ASCO), provides expert information to help patients and families make informed healthcare decisions.

Global Resource For Advancing Cancer Education (GRACE)

cancergrace.org/lung

This organization is dedicated to improving care for cancer patients. Through online information resources, they provide education on current and emerging cancer management options in order to empower patients, caregivers and health professionals to become direct partners in cancer care.

National Cancer Institute (NCI): Lung Cancer

cancer.gov/cancertopics/types/lung; (800) 422-6237

This website, sponsored by the U.S. federal government, describes lung cancer, its causes and treatments. The site also provides information on clinical trials and research related to lung cancer as well as a glossary of cancer terms.

Support groups

Cancer Hope Network

cancerhopenetwork.org; (877) 467-3638

Cancer Hope Network matches someone going through a diagnosis and/or their caregivers with a trained volunteer cancer survivor who had a similar cancer experience.

CancerCare

lungcancer.org; cancercare.org; (800) 813-4673

This organization provides free, professional support services for anyone affected by cancer. Lung cancer support groups are available in person, online, and by telephone. Trained oncology social workers answer every call, providing counseling, education, financial assistance, and practical help.

The Cancer Support Community

cancersupportcommunity.org; (888) 793-9355

This organization, created through a merger of Gilda's Club and The Wellness Community, provides professional programs for emotional support, education and hope for people affected by cancer at no charge. General cancer support groups are available at Cancer Support Community centers around the country, and some centers also have specific support groups for lung cancer patients.

Other support services

A number of websites allow patients and family members to share information on health updates,

receive encouragement from friends and request specific assistance:

Caring Bridgecaringbridge.org

Livestrong Rally livestrong.org/rally

Lotsa Helping Hands lotsahelpinghands.com

MyLifeline mylifeline.org

Financial assistance

Drug Companies

Most drug companies have programs to help patients get the drugs they need when insurance, co-pays or other money matters get in the way. Your nurse, social worker or patient navigator can help you contact the drug company. You can also call the Lung Cancer Support Line toll free at (844) 835-4325 for a Resource Guide.

Needy Meds

needymeds.org; (800) 503-6897

This organization helps patients find assistance programs that help cover the costs of medications and other healthcarerelated expenses. You can search by drug name to see whether there is a specific assistance program for your prescribed medication.

CancerCare Co-Payment Assistance Foundation

cancercarecopay.org; (866) 552-6729

This organization addresses the needs of individuals who cannot afford their insurance copayments for cancer medications.

Cancer Legal Resource Center

disabilityrightsadvocacycenter.org; cancerlegalresources.org; (800) 843-2572

This organization provides free information and resources on cancer-related legal issues to cancer survivors, caregivers, healthcare professionals, employers and others coping with cancer.

Partnership for Prescription Assistance

pparx.org; (888) 477-2669

This organization helps qualifying patients without prescription drug coverage get the medicines they need for free or nearly free. This service offers a single point of access to more than 475 public and private programs.

United Way

unitedway.org; 211

This organization leads and supports a network of nearly 1,800 community-based organizations. Local United Way chapters can help with basic living expenses, including rent, mortgage, utility payments and food.

Clinical trials

The Lung Cancer Research Foundation offers information about clinical trials on its website at lcrf.org/clinicaltrials. You can also call the Lung Cancer Support Line toll free at (844) 835-4325.

Cancer Hope Network

cancerhopenetwork.org; (800) 552-4366

Through their Talking About Clinical Trials (TACT) program, patients considering a clinical trial are matched with someone who has been through a clinical trial.

Smoking cessation

Smokefree.gov

smokefree.gov; (800) 784-8669

If you smoke and would like to quit, smokefree. gov offers web resources, instant messaging and a quit line staffed by counselors to support you in your efforts.

Becomeanex.org

becomeanex.org

Becomeanex.org helps you develop a 3-step plan to quit smoking, and offers an online community to support you.

Ask your doctor if there are any local or inperson resources to help you quit smoking.

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 $\label{thm:lemmake} \mbox{Help make future research possible by visiting LCRF.org/support research.}$



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