



# Talking with Loved Ones About a Diagnosis of Epithelioid Sarcoma

It can be challenging to talk about a diagnosis of epithelioid sarcoma (ES), even with the people who know you best. While ES is rare, you're not alone – your family and friends can offer you support throughout your journey.

Your family and friends may feel unsure about how best to support you or talk with you about your diagnosis. Open communication with your loved ones can help them better understand what you are going through and offer support.

**Use these five steps to guide conversations with your loved ones about ES.**

## Step 1: Begin the Conversation

Sometimes the hardest part is starting the conversation. While you may still be grappling with your ES diagnosis, your loved ones probably don't even know what ES is – so start there.

Explaining ES can sometimes seem very medical, so one way of describing it is as a **rare type of soft tissue sarcoma**, a form of cancer that can form in muscle, fat, nerves, fibrous tissues (connecting muscle and bone), blood vessels and deep skin tissues. Since ES is so rare, only about 150-200 people are diagnosed in the U.S. each year, it is often misdiagnosed or takes a while to diagnose.

## Step 2: Share How You Feel

For your loved ones to know how to best support you, they also need to know how you feel – so don't be afraid to tell them.

Once you've shared what you are experiencing, your loved ones will be better equipped to support you each step of the way. Everyone's experience going through a cancer diagnosis and treatment is different. There is no one way to feel.

Here are some thought starters to share how you feel:

- How you are (physically or emotionally)
- What is on your mind as you face ES (treatment side effects, time in the hospital, etc.)
- What you are hopeful about
- Your goals and priorities
- Your fears or worries for the future
- What would a good day look like
- What outcomes are acceptable and unacceptable for you

## Step 3: Help Answer Questions

Now that your loved ones know about your diagnosis and how you feel, they will probably have some questions for you. Below are some commonly asked questions that you may encounter.

- What happens next?
- Will you have to have chemotherapy?

- When do you start treatment?
- How long will treatment last? What kind of side effects do you expect?
- What's your prognosis? Does ES have a cure?
- How can I help and support you?

It may be helpful to think about who among your family and friends will be supporting you the most as you go through treatment, as that may help you determine how much detail to share.

For general questions about ES, you can refer your loved ones to [ESsentialsforES.com](https://www.esentialsforES.com).

## Step 4: Offer Concrete Ways to Help

Often, loved ones are at a loss for how to help, so provide them with specific needs you may be facing so that they can offer you genuine support.

Some ways your loved ones can help out:

- Provide rides to (and company at) treatments and medical appointments
- Care for children during treatments and medical appointments
- Run errands or help with household needs such as grocery shopping, meal prep, laundry or washing dishes
- Help keep friends and family updated on your progress, such as by maintaining a Facebook or CaringBridge.com page

## Step 5: Share What You Know: Support Services for Caregivers

There are several organizations devoted to supporting people who have a loved one living with cancer, or a rare disease. These organizations are highly experienced in addressing the psychological and emotional challenges of navigating a serious illness.

- **American Cancer Society**
- **Cancer Support Community**
- **CancerCare**
- **Sarcoma Coalition**
- **National Organization for Rare Disorders (NORD)**
- **Global Genes**

**Visit [ESsentialsforES.com](https://www.esentialsforES.com) for more epithelioid sarcoma information and resources.**

*This document is intended for educational purposes only. Treatment advice should be provided by your doctor. Please direct questions to your doctor or healthcare professional.*

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### References

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