



# Let's Talk

A comprehensive guide for productive discussions with your doctor

**Benlysta**  
(belimumab) 

## You live with lupus every day

But you probably see your doctor only once every few months. With appointments that often last less than 15 minutes, your time together is valuable. **Being prepared can help you make the most of it!**

If you will be asking about BENLYSTA, a complete picture of your life with lupus will help you and your doctor decide together if BENLYSTA is right for you.

## What is BENLYSTA (belimumab)?

BENLYSTA is a prescription medicine used to treat people with active systemic lupus erythematosus (SLE or lupus) or active lupus nephritis (lupus-related kidney inflammation) who are receiving other lupus medicines. It's unknown if BENLYSTA is safe/effective in children under 5 years when given in a vein or under 18 years when given under the skin. BENLYSTA is not for people with severe active central nervous system lupus.

## Important Safety Information

Do not use BENLYSTA if you are allergic to belimumab or any ingredients in BENLYSTA.

### The most important information about BENLYSTA

Immunosuppressive agents, including BENLYSTA, can cause serious side effects. Some of these may cause death.

- **Infections:** fever, chills, pain or burning with urination, urinating often, coughing up mucus, or warm, red, or painful skin or sores on your body. Infections could be serious, leading to hospitalization or death.

Please see full [Important Safety Information](#) on pages 11 and 12 and accompanying [Important Facts About BENLYSTA](#). Please see [Prescribing Information](#) and [Medication Guide](#) for BENLYSTA.

# Welcome to *Let's Talk*

What's the best way to make good use of your time with your doctor? **One word: Preparation!** Use the *Let's Talk* guide and enclosed Conversation Guides to help you prepare for your appointments.

Knowing what to share and practicing how to say it can help you get the best possible care. And even if your next visit is a few weeks away, now is the perfect time to get started!

**Begin by reading this guide.** At the end of each section, you'll find a checklist to help you make sure you're ready for each step along the way. Keep our Conversation Guides handy to use for future appointments.

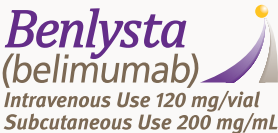
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Before your appointment

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## Starting Today: Track your symptoms

Use a checklist or app to take note of any symptoms you may be feeling. Make sure to record all your symptoms, even ones that may not feel like lupus.

**Why track symptoms?** A detailed record helps your doctor understand what's been happening with your lupus since your last appointment. It will jog your memory, too!

## How can you tell if it's a lupus symptom?

When you're tracking symptoms, it can be hard to tell whether what you're feeling is related to lupus or not.

Fortunately, it's not your job to figure that out. Just describe your symptoms the best you can, and let your doctor take it from there.



Your doctor knows the way you feel today may be nothing like what you were feeling last week. But it's up to you to fill in the blanks. **The details of your symptoms over time can tell your doctor if your lupus is active and what might need to be done to manage it.**

Please see full [Important Safety Information](#) on pages 11 and 12 and accompanying [Important Facts About BENLYSTA](#).

Please see [Prescribing Information](#) and [Medication Guide](#) for BENLYSTA.

## **ASAP:** Choose an appointment buddy

An **appointment buddy** helps you with important tasks during your appointment so you can be free to talk to your doctor. Your buddy might act as an extra pair of ears or take notes. Your doctor will want you to do most of the talking. But it's okay to ask your buddy to help you express your feelings if you need it.

Just make sure you're clear about what you need from your buddy. **They need to know what their job is!** Remember to also give them all the details about the time and location of your appointment. **And if you can't bring your buddy into the doctor's office, don't worry—just loop them in by phone!**

When it's over, do something nice for your buddy. Show them they're a valuable member of your team.



## **What to look for in an appointment buddy**

- Someone you trust
- Not judgmental
- On time
- Listens carefully
- Takes good notes



## 2 Weeks Before: Gather your medical records

If you've been to another doctor, an ER, or an urgent care center since your last visit, find copies of any appointment notes. This could include notes in the chart, blood test results, and other important information.

Doctor's offices are not all connected electronically. Unless you know for sure, take copies of ALL your records since your last visit.

**Why are records so important?** Your doctor needs to know what other providers have observed and what treatments they have prescribed.



## 2–4 Days Before: Complete a Conversation Guide



Through the links below you'll find two Conversation Guides. Whether you have 15 minutes, 30 minutes, or more with your specialist, our guides can help you make the most of your time. One is focused on prepping for your rheumatology appointments, and the other for your nephrology appointments. Take some time to read through the instructions, then complete it for yourself.

[Click here to download](#) the Conversation Guide: Rheumatologist.

[Click here to download](#) the Conversation Guide: Nephrologist.

**After you've finished the Conversation Guide, practice speaking it out loud so you can be direct with your doctor.** It might feel silly to practice before a doctor's appointment, but it's not! It can be hard to describe your symptoms, ask all your questions, and express your concerns during a brief appointment. If you take time to practice, you can help yourself be heard.

**One more  
important thing**

Remember to be honest. This is not the time to worry about whether you're making a good impression. **Just describe what your symptoms have been, even if they're hard to talk about or hard to explain.** Your doctor can't help if they don't know what's going on with you!



## The Night Before: Get your things ready

You might not be feeling well on the day of your doctor's appointment, so be sure to have everything ready the night before. Come back to *Let's Talk*, open to this checklist, and mentally check off the steps:

- ☐ Take a list of all your medications along with the dose, the strength, and how you take it (including vitamins and supplements)
- ☐ Collect any records or test results in a folder
- ☐ Make sure you have your insurance card
- ☐ Take something to do in the waiting room, such as a crossword puzzle or a good book
- ☐ Call to confirm with your buddy
- ☐ Lay out the clothes you'll be wearing
- ☐ Pack a snack and a bottle of water
- ☐ Feel confident and prepared

**You've done all the hard work, and now  
you're ready for your appointment!**

Before your appointment

# CHECKLIST

☐

**STARTING TODAY:**

Track your symptoms

☐

**ASAP:**

Choose an appointment buddy

☐

**2 WEEKS BEFORE:**

Gather your medical records

☐

**2–4 DAYS BEFORE:**

Complete a Conversation Guide

☐

**THE NIGHT BEFORE:**

Get your things ready

## Important Safety Information (cont'd)

### The most important information about BENLYSTA (cont'd)

- **Allergic (hypersensitivity) reactions:** itching, swelling of the face, lips, mouth, tongue, or throat, trouble breathing, anxiousness, low blood pressure, dizziness or fainting, headache, nausea, or skin rash. Serious allergic reactions can happen the day of, or in days after, receiving BENLYSTA and may cause death.
- **Mental health problems and suicide:** thoughts of suicide or dying, attempt to commit suicide, trouble sleeping (insomnia), new or worse anxiety or depression, acting on dangerous impulses, other unusual changes in your behavior or mood, or thoughts of hurting yourself or others.

### Before receiving BENLYSTA, discuss with your healthcare provider if you:

- think you have an infection or have infections that keep coming back. Do not use BENLYSTA if you have an infection unless your healthcare provider tells you to.
- have or have had mental health problems such as depression or thoughts of suicide.
- have recently received or may need a vaccination. If you are receiving BENLYSTA, you should not receive live vaccines.
- are taking any medicines, including prescription, over-the-counter, vitamins, and herbal supplements.
- are allergic to other medicines.
- are receiving other biologic medicines.
- have or have had any type of cancer.
- have any other medical conditions.

Please see full Important Safety Information on this page and the next page and accompanying [Important Facts About BENLYSTA](#).

Please see [Prescribing Information](#) and [Medication Guide](#) for BENLYSTA.

## Important Safety Information (cont'd)

### Before receiving BENLYSTA, discuss with your healthcare provider if you: (cont'd)

- are pregnant or plan to become pregnant. It is unknown if BENLYSTA will harm your unborn baby. Talk to your healthcare provider about whether to prevent pregnancy while on BENLYSTA. If you choose to prevent pregnancy, you should use an effective method of birth control for at least 4 months after the final dose of BENLYSTA
- become pregnant while receiving BENLYSTA, talk to your healthcare provider about enrolling in the BENLYSTA Pregnancy Registry. You can enroll in this registry by calling 1-877-311-8972 or go to <https://mothertobaby.org/ongoing-study/benlysta-belimumab/>.
- are breastfeeding or plan to breastfeed. It is unknown if BENLYSTA passes into your breast milk.

### Possible side effects of BENLYSTA

- **Progressive multifocal leukoencephalopathy (PML).** PML is a serious and life-threatening brain infection. PML can result in death or severe disability. Tell your healthcare provider right away if you notice any new or worsening medical problems: memory loss, trouble thinking, dizziness or loss of balance, difficulty talking or walking, or loss of vision.
- **Cancer.** Medicines that affect the immune system, including BENLYSTA, may increase your risk of certain cancers.

The most common side effects of BENLYSTA are nausea, diarrhea, fever, stuffy or runny nose and sore throat, persistent cough, trouble sleeping, leg or arm pain, depression, headache, and pain, redness, itching, or swelling at the site of injection (when given subcutaneously). These are not all the possible side effects of BENLYSTA. Call your doctor for medical advice about side effects.

**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

Please see [Prescribing Information](#) and [Medication Guide](#) for BENLYSTA and accompanying [Important Facts About BENLYSTA](#) on pages 27 and 28.





At the office

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## Arrive early

It's rare to visit a doctor's office without having to wait. Even so, arrive 15 minutes early to handle any paperwork. If you can complete it online beforehand, that's great. But arriving early is still a good idea so the staff has time to get everything ready for you to see the doctor. Make sure you're not late because some offices may ask you to reschedule.

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## Make the most of your wait

Hopefully you've packed something to do in the waiting room. As frustrating as waiting is, try to think of it as time for yourself. Or, if that doesn't help, remember that many patients (maybe even you) have medical issues that require extra time. Your doctor may need to take extra time with some patients, even if it means running late.



### At the office

# CHECKLIST

☐

Arrive early

☐

Make the most of your wait



During your appointment

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## Make introductions

If you have a buddy along, introduce them to your doctor and explain their role.

*"Dr. Smith, this is my friend Alicia. She's going to take notes for me today."*

## Express yourself

Your doctor might start out by asking how you've been doing. Or they may begin by reviewing test results or covering something else. The order doesn't matter.

What's important is the chance to ask questions, share information, and address your key issues. **If time is running short and you haven't expressed all your concerns**, simply let your doctor know.

*"We're running out of time, and I want to be sure we talk about the joint pain I'm having in my fingers."*

## There are no stupid questions!

Lupus can be confusing, and everyone's symptoms may not be the same. So no question is a bad question! Ask your doctor anything and feel proud of your questions. Remember, the more you understand, the more you can become an expert in *your* lupus.

## Ask for eye contact

Doctors and their staff often have a lot to enter into your record. And that means they may have to spend some time on the computer. That's to be expected. But if you're not getting enough eye contact with your doctor, it's okay to respectfully ask for a moment of computer-free, eye-to-eye discussion.

*"I know you have a lot of notes to enter in the computer. But if we could talk just for a moment without it, I would feel more comfortable."*

## Feeling overwhelmed?

Strong negative feelings can be a painful part of living with lupus. If you're feeling sad, scared, angry, or anything in between, it's a good idea to share it with your doctor. They can help you find the resources and support you need to care for yourself.

Please see full [Important Safety Information](#) on pages 11 and 12 and accompanying [Important Facts About BENLYSTA](#).

Please see [Prescribing Information](#) and [Medication Guide](#) for BENLYSTA.



## Check your understanding

Before leaving, repeat back to your doctor the key points you've heard. This might mean repeating back your diagnosis, treatment plan, or medication instructions. This gives your doctor a chance to correct anything you may have misunderstood. And if you aren't sure about something your doctor has said, this is the time to ask them to explain!

*"I'm going to have some additional tests on my kidneys and come back in a week. Did I hear that right?"*

## Make sure you have what need before you leave

Before you leave the office, make sure you have all you need to follow up on your doctor's instructions. This could mean:

- A list of tests, including when and where they will happen
- A list of medication changes
- Follow-up appointments with this doctor or another
- Lifestyle recommendations, such as changes in diet, rest, or exercise

Some offices will provide a printout of this information. But, if not, **be sure to understand exactly what's ahead before you leave**. If you need help making your own list, it's okay to ask your buddy or a staff member.

*"Ms. Taylor, Dr. Scott covered a lot in our appointment, and I'm not sure I understand everything I need to do. Would you mind helping me make a list so I don't forget anything?"*

During your appointment

# CHECKLIST

- ☐ Make introductions
- ☐ Express yourself
- ☐ Ask for eye contact
- ☐ Check your understanding
- ☐ Make sure you have what you need before you leave





After your appointment

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## Take a moment to feel proud

Playing an active role in your doctor's visit may be new to you. And even if you didn't say everything you wanted to or get everything done that you had hoped, it's still a huge step in the right direction. Any positive changes you've made should be celebrated. Making the most of your doctor's visit is a huge step in caring for yourself while living with lupus!

## Review your notes

Go back through your notes and ask yourself:

*"Did I have a chance to discuss my concerns?"*

*"Do I understand my treatment plan, including tests, medications, and referrals to specialists?"*

*"Have I marked my calendar with dates for tests, follow-up appointments, medication refills, etc.?"*

## Contact the office with questions

Maybe you don't understand how to take your new medication. Maybe the specialist your doctor recommended isn't taking new patients. Whatever the question or issue may be, call the office.

You may have to leave a message and wait for a return call. Or, if the office uses a patient portal, you may be able to email your questions.

Please see full [Important Safety Information](#) on pages 11 and 12 and accompanying [Important Facts About BENLYSTA](#).

Please see [Prescribing Information](#) and [Medication Guide](#) for BENLYSTA.



## Make another appointment, if needed

If you look back on your visit and feel you didn't get your questions answered, or if a new issue comes to mind, a nurse might be able to help. But if it's something important, you may need to schedule another appointment to discuss these concerns.

*"I'd like to make an appointment with Dr. Rogers before my follow-up in May. I need to discuss the joint pain I am having in my fingers."*



After your appointment

# CHECKLIST

- ☐ Take a moment to feel proud
- ☐ Review your notes
- ☐ Contact the office with questions
- ☐ Make another appointment, if needed

# Looking ahead

Being an active part of your doctor's visits means some preparation beforehand. This includes paying attention to your body and tracking your symptoms every day—not just when an appointment is coming up.

It may take practice to express yourself clearly to your doctor, and to speak up if you're not getting what you need. It's worth the effort. **Helping your doctor see what's happening between visits is a powerful tool.** Plus, when you express your questions and concerns, it's easier for your doctor to provide you the best possible care.



**You and your doctor can be a great team.  
Together, you have the power to manage  
your lupus.**

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Even if your next appointment is a few weeks away, now's the perfect time to start preparing for your time with your doctor.

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 **BenlystaCares**

Have questions or need assistance?  
Call **1-877-4-BENLYSTA**  
(1-877-423-6597)

Personalized Support

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Exclusive Resources

Whether you need treatment support or financial assistance, BENLYSTA Cares may be able to help.



## IMPORTANT FACTS ABOUT BENLYSTA

The risk information presented here is not comprehensive. To learn more, talk to your healthcare provider (HCP). Visit [www.BENLYSTA.com](http://www.BENLYSTA.com) or call 1-877-423-6597 to get FDA-approved product labeling, including Medication Guide and Instructions for Use.

### What is the most important information I should know about BENLYSTA?

**Immunosuppressive agents, including BENLYSTA, can cause serious side effects. Some of these side effects may cause death. Tell your HCP right away if you get any of the following signs or symptoms while receiving BENLYSTA:**

- **Infections.** Infections could be serious, leading to hospitalization or death. Symptoms can include: fever, chills, pain or burning with urination, urinating often, coughing up mucus, warm, red, or painful skin or sores on your body.
- **Allergic (hypersensitivity) reactions.** Serious allergic reactions can happen on the day of, or in the days after, receiving BENLYSTA and may cause death. Symptoms can include: itching, swelling of the face, lips, mouth, tongue, or throat, trouble breathing, anxiousness, low blood pressure, dizziness or fainting, headache, nausea, skin rash.

- **Mental health problems and suicide.** Symptoms can include: thoughts of suicide or dying, attempt to commit suicide, trouble sleeping, new or worse anxiety, new or worse depression, acting on dangerous impulses, other unusual changes in your behavior or mood, thoughts of hurting yourself or others.

### What is BENLYSTA?

BENLYSTA is a prescription medicine used to treat people with active systemic lupus erythematosus (SLE or lupus) or active lupus nephritis (lupus-related kidney inflammation) who are receiving other lupus medicines.

It is not known if BENLYSTA is safe and effective in people with severe active central nervous system lupus. It is not known if BENLYSTA is safe and effective for use in children under 5 years of age when given in a vein (intravenously). It is not known if BENLYSTA is safe and effective for use in children under 18 years of age when given under the skin (subcutaneously).

### Who should not use BENLYSTA?

**Do not use BENLYSTA if you** are allergic to belimumab or any of the ingredients in BENLYSTA.

### What should I tell my HCP before receiving BENLYSTA?

**Before you receive BENLYSTA, tell your HCP about all of your medical conditions, including if you:**

**Important Facts About BENLYSTA** continued on next page.

## Important Facts About BENLYSTA (cont'd)

- think you have an infection or have infections that keep coming back. You should not receive BENLYSTA if you have an infection unless your HCP tells you to. **See “What is the most important information I should know about BENLYSTA?”**
- have or have had mental health problems such as depression or thoughts of suicide.
- have recently received a vaccination or if you think you may need a vaccination. If you are receiving BENLYSTA, you should not receive live vaccines.
- are allergic to other medicines.
- are receiving other biologic medicines or monoclonal antibodies.
- have or have had any type of cancer.
- are pregnant or plan to become pregnant. It is not known if BENLYSTA will harm your unborn baby. You should talk to your HCP about whether to prevent pregnancy while on BENLYSTA. If you choose to prevent pregnancy, you should use an effective method of birth control while receiving BENLYSTA and for at least 4 months after the final dose of BENLYSTA.
- become pregnant while receiving BENLYSTA, talk to your healthcare provider about enrolling in the BENLYSTA Pregnancy Registry. You can enroll in this registry by calling 1-877-311-8972 or go to <https://mothertobaby.org/ongoing-study/benlysta-belimumab/>.
- are breastfeeding or plan to breastfeed. It is not known if BENLYSTA passes into your breast milk. You and your HCP should talk about whether or not you should receive BENLYSTA and breastfeed.

**Tell your HCP about all medicines you take**, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

## What are the possible side effects of BENLYSTA?

### **BENLYSTA can cause serious side effects including:**

- **Progressive multifocal leukoencephalopathy (PML).** PML is a serious and life-threatening brain infection. Your chance of getting PML may be higher if you are treated with medicines that weaken your immune system, including BENLYSTA. PML can result in death or severe disability. Tell your HCP right away if you notice any new or worsening medical problems such as: memory loss, trouble thinking, dizziness or loss of balance, difficulty talking or walking, loss of vision.
- **Cancer.** BENLYSTA may reduce the activity of your immune system. Medicines that affect the immune system may increase your risk of certain cancers.

**The most common side effects of BENLYSTA include:** nausea, diarrhea, fever, stuffy or runny nose and sore throat, persistent cough, trouble sleeping, leg or arm pain, depression, headache, and pain, redness, itching, or swelling at the site of injection.

These are not all the possible side effects of BENLYSTA. Call your doctor for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

### **Keep BENLYSTA and all medicines out of reach of children.**

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