My Tracking Diary

Helping you track your treatment and more

IMPORTANT SAFETY INFORMATION INCLUDING BOXED WARNING

ZILBRYSQ is a medicine that affects part of your immune system. ZILBRYSQ may lower the ability of your immune system to fight infections. ZILBRYSQ increases your chance of getting serious meningococcal infections. You must complete or update your meningococcal vaccine(s) at least 2 weeks before your first dose of ZILBRYSQ. If you have not completed your vaccinations or have not been vaccinated and ZILBRYSQ must be started right away, you should receive the required vaccine(s) as soon as possible and receive antibiotics to take for as long as your healthcare provider tells you.

Call your healthcare provider or get emergency medical care right away if you get any signs and symptoms of a meningococcal infection. Do not use ZILBRYSQ if you have a serious meningococcal infection when you are starting ZILBRYSQ treatment. ZILBRYSQ may also increase the risk of other types of serious infections caused by encapsulated bacteria, including *Streptococcus pneumoniae*, *Haemophilus influenzae*, and *Neisseria gonorrhoeae*. Call your healthcare provider right away if you have new signs or symptoms of infection. Pancreatitis and pancreatic cysts have happened in people who use ZILBRYSQ. The most common side effects of ZILBRYSQ include injection site reactions, upper respiratory tract infections, and diarrhea.

ZILBRYSQ is a prescription medicine used to treat adults with a disease called generalized myasthenia gravis (gMG) who are anti-acetylcholine receptor (AChR) antibody positive.

ZILBRYSQ®
(zilucoplan) Injection

WELCOME!

The My Tracking Diary is designed to support you as you start your new treatment. It provides a useful way to monitor your treatment and how your symptoms may change over time.

This gives you and your healthcare team useful information to help you manage your condition and treatment. Using the Tracking Diary only takes a few minutes each day.

Here's an overview of what you'll find in the Tracking Diary.

Treatment tracking

ZILBRYSQ® (zilucoplan) is a once-daily treatment that is injected under the skin. It's important to take it as prescribed, every day, at approximately the same time of the day.[1]

This tracker gives you a visual reminder and space to keep note of the injection sites used. Injecting medication as prescribed is important for the medicine to be able to work as it is intended.

Symptom tracker

Tracking your symptoms gives you a picture of changes over time. A diary is more accurate than trying to remember how you were feeling. The symptom tracker in this diary is based on a scale doctors often use. There's also space for you to make notes of any other factors that might be affecting your symptoms and day-to-day life.

As you go through this booklet, you'll find tips and helpful questions to ask yourself as you get used to your new treatment. At the back of the diary, there's space to keep a list of questions for your healthcare team – and any other notes you may want to make.

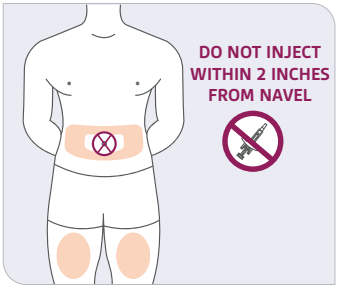
Treatment tracking

When you have your self-injection training, your healthcare professional will explain how to choose and rotate injection sites. Rotating injection sites means choosing a different spot to inject each time you give yourself an injection. This helps to prevent irritation to the skin and a buildup of tissue that can occur if you inject in the same place.

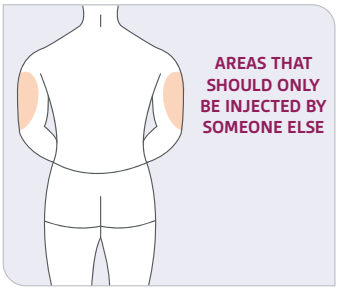
Here's a quick reminder.

If you're self-injecting, you can choose a site in one of these areas[1]:

- your stomach (abdomen), except for the 2-inch area around your belly button (navel)
- the front of your thighs

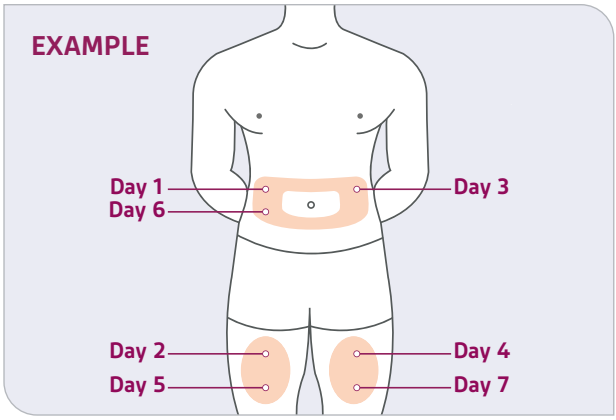


If someone else is injecting you, they can also inject you on the back of your upper arms.[1]



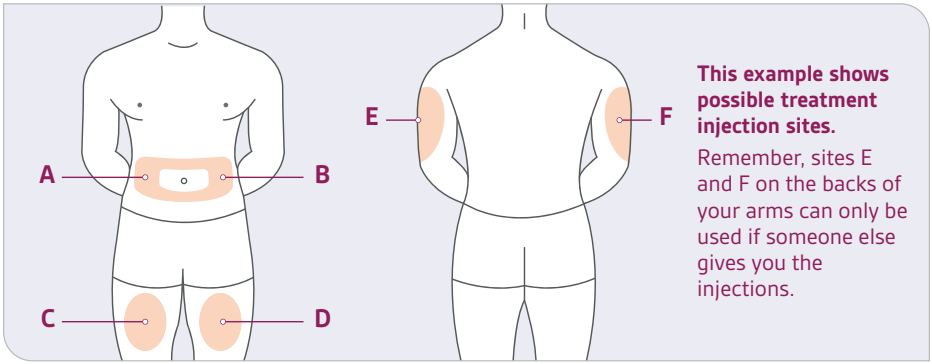
Never inject into an area that is red, tender, bruised, swollen, hard or that has scars or stretch marks.[1]

If you want to use the same injection site – for example, the same front of the thigh – make sure you inject at least 1 inch from the last injection spot.[1]



How to use the injection site tracker

Start by labeling the different injection sites with letters, so you can easily choose and record a site for each day of the week. Here's an example of how you could do this.



This example shows possible treatment injection sites.

Remember, sites E and F on the backs of your arms can only be used if someone else gives you the injections.

Each day, fill in the tracker with the letter for the site you've used. Here's an example.

	Week 1	Week 2
Day 1	A	D
Day 2	C	A
Day 3	B	C
Day 4	D	B
Day 5	A	D
Day 6	C	A
Day 7	B	C

Before each injection, check the tracker to see which site you used the day before, so that you can choose a different spot.

When you've filled in the tracker for a week or more, check if you're using all the injection sites regularly. Are there any areas you're choosing more or less often than others?

Start tracking your injection sites

Use the grids to write the letter of the site you used next to each day of the week.

Weeks 1-6

	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
Day 1						
Day 2						
Day 3						
Day 4						
Day 5						
Day 6						
Day 7						

Weeks 7-12

	Week 7	Week 8	Week 9	Week 10	Week 11	Week 12
Day 1						
Day 2						
Day 3						
Day 4						
Day 5						
Day 6						
Day 7						

Missed dose

It is important to take your medicine once daily as prescribed. However, if you realize you have missed your dose, please inject as soon as possible and then inject your next dose at your regularly scheduled time. Do not administer more than 1 dose per day. Contact your doctor for further guidance or questions.

Reflect on your achievement

When you've filled in a number of injection trackers, think back to how you felt when you started your treatment and reflect on how far you've come. Consider sharing this achievement with someone close to you to reinforce the positive feeling.

Remember to use the section at the back of this Tracking Diary to keep a note of anything that seems important. There's also space to write down questions for your healthcare team at your next appointment.

Supplies check-in

It's important to make sure you have your supplies to continue your daily injection routine. Ask yourself:

- [ ] Do I need to order more medication? I have ____ ZILBRYSQ® (zilucoplan) syringes left.
- [ ] Do I need a new sharps disposal container?
- [ ] Do I need to arrange for sharps disposal container?
- [ ] Do I need to get more injection supplies, e.g., alcohol swabs, cotton balls, bandages? Supplies will be provided by PANTHERx.

Symptom tracker

Keeping a record of your symptoms may help you get a clearer view of any changes. It's more accurate than just trying to remember.

Tracking your symptoms is part of managing your condition. It can help you feel more confident and empowered. You can share the tracker with your healthcare team so they can spot any changes in your symptoms over time and get useful insights.[2]

Tracking also helps you to think about other things that may affect your symptoms. You'll find space to note anything that may be a trigger.

The symptom tracker is based on the Myasthenia Gravis Activities of Daily Living (MG-ADL) scale[3], often used by doctors. Ask your healthcare team how often they recommend you track your symptoms. If you are concerned about any of your symptoms or you see a change in your MG-ADL scale, please talk to your healthcare team.

Turn the page to find out how to track

Make tracking a relaxed part of your day. After your self-injection, you could sit down to use the Tracking Diary and play music or a podcast in the background.

Focus on the near future

Thinking about your life with gMG in the past week, what differences would you like to have made? What words would you like to use to describe yourself in the near future?

How to use the symptom tracker

The table on the next page shows the Myasthenia Gravis Activities of Daily Living (MG-ADL) scale and explains how to score your symptoms.[3] Refer to it when you fill in your own tracker.

- Scores range from 0 (this symptom isn't affecting you) to 3 (the symptom is severe)[3]
- Simply note your score for each symptom in the final column
- Add the date you completed the tracker so you can get a sense of changes over time
- When you complete the tracker, it's often helpful to think about your symptoms over the past 7 days[4,5]
- Try to complete the tracker regularly so you and your healthcare team can see how symptoms are changing over time[3]
- Consider completing the tracker twice a month unless your doctor gives you different guidance.

Myasthenia Gravis Activities of Daily Living (MG-ADL) scale

Assist	Score = 0	Score = 1	Score = 2	Score = 3
Talking	Normal	Intermittent slurring/nasal speech	Constant slurring or nasal speech but can be understood	Difficult to understand speech
Chewing	Normal	Fatigue with solid food	Fatigue with soft food	Gastric tube
Swallowing	Normal	Rare choking episode	Frequent choking, requiring changes in diet	Gastric tube
Breathing	Normal	Shortness of breath on exertion	Shortness of breath at rest	Ventilator dependence
Impairment of ability to brush teeth or comb hair	None	Extra effort but no rest periods needed	Rest periods needed	Can't do one of these activities
Impairment of ability to rise from a chair	None	Mild, sometimes need to use arms	Moderate, always uses arms	Severe, needs assistance
Double vision	None	Occurs, but not daily	Daily but not constant	Constant
Eyelid droop	None	Occurs, but not daily	Daily but not constant	Constant

Table adapted from reference 3 - Myasthenia Gravis Activities of Daily Living profile

Sample tracker

Use the scores on the previous page to fill in your symptom tracker

This is an example of how you can record your total scores over time

My Scores		
	1	2
DATE COMPLETED	01-01 2023	15-01 2023
Talking	0	1
Chewing	2	2
Swallowing	2	1
Breathing	1	1
Impairment of ability to brush teeth or comb hair	0	0
Impairment of ability to rise from a chair	0	0
Double vision	0	0
Eyelid droop	0	0
TOTAL MG-ADL score (0-24)	5	5

What else is affecting you?

As you know, when you live with generalized myasthenia gravis (gMG), external factors such as stress and illness may make your symptoms worse.[6] We teamed up with patient groups to develop this extra tool that gives you and your healthcare team a picture of external factors that may affect you.

In the following pages, we've provided you with tables to keep a record of anything that may be affecting your symptoms. The table includes external factors known to trigger symptoms in people with gMG[6], and you can add any other factors you think may have affected you.

Fill in the table by looking at the list of external factors and checking any that apply to you.

Here's an example:

	1	2
DATE COMPLETED	01-01 2023	01-15 2023
Stress or emotional unrest	✓	
Extreme cold		✓
Extreme heat		
Illness or worsening of a condition other than gMG		
Lack of sleep or poor-quality sleep	✓	
Physical exertion		✓
Menstrual cycles		
Other factors (eating certain foods etc)		

You can use the space at the bottom of the table to write in more detail about your symptoms, if you wish.

It's sometimes easier for other people to spot symptom changes, so if you live with someone else, you could ask them to help you complete your tracker.

Track your symptoms

My Scores							
	1	2	3	4	5	6	7
DATE COMPLETED							
Talking							
Chewing							
Swallowing							
Breathing							
Impairment of ability to brush teeth or comb hair							
Impairment of ability to rise from a chair							
Double vision							
Eyelid droop							
TOTAL MG-ADL score (0-24)							

External factors

	1	2	3	4	5	6	7
DATE COMPLETED							
Stress or emotional unrest							
Extreme cold							
Extreme heat							
Illness or worsening of a condition other than gMG							
Lack of sleep or poor-quality sleep							
Physical exertion							
Menstrual cycles							
Other factors (eating certain foods, etc.)							

Use this space to make notes of any other gMG symptoms or triggers you've experienced that you would like to record:

Use this space to make notes of how gMG has affected your daily activities and required adjustments (e.g., work, social, leisure activities, mood, fatigue, general well-being, etc.)[7]:

Track your symptoms

My Scores							
	8	9	10	11	12	13	14
DATE COMPLETED							
Talking							
Chewing							
Swallowing							
Breathing							
Impairment of ability to brush teeth or comb hair							
Impairment of ability to rise from a chair							
Double vision							
Eyelid droop							
TOTAL MG-ADL score (0-24)							

External factors

	8	9	10	11	12	13	14
DATE COMPLETED							
Stress or emotional unrest							
Extreme cold							
Extreme heat							
Illness or worsening of a condition other than gMG							
Lack of sleep or poor-quality sleep							
Physical exertion							
Menstrual cycles							
Other factors (eating certain foods, etc.)							

Use this space to make notes of any other gMG symptoms or triggers you've experienced that you would like to record:

Use this space to make notes of how gMG has affected your daily activities and required adjustments (e.g., work, social, leisure activities, mood, fatigue, general well-being, etc.)[7]:

Track your symptoms

My Scores							
	15	16	17	18	19	20	21
DATE COMPLETED							
Talking							
Chewing							
Swallowing							
Breathing							
Impairment of ability to brush teeth or comb hair							
Impairment of ability to rise from a chair							
Double vision							
Eyelid droop							
TOTAL MG-ADL score (0-24)							

External factors

	15	16	17	18	19	20	21
DATE COMPLETED							
Stress or emotional unrest							
Extreme cold							
Extreme heat							
Illness or worsening of a condition other than gMG							
Lack of sleep or poor-quality sleep							
Physical exertion							
Menstrual cycles							
Other factors (eating certain foods, etc.)							

Use this space to make notes of any other gMG symptoms or triggers you've experienced that you would like to record:

Use this space to make notes of how gMG has affected your daily activities and required adjustments (e.g., work, social, leisure activities, mood, fatigue, general well-being, etc.)[7]:

Track your symptoms

My Scores							
	22	23	24	25	26	27	28
DATE COMPLETED							
Talking							
Chewing							
Swallowing							
Breathing							
Impairment of ability to brush teeth or comb hair							
Impairment of ability to rise from a chair							
Double vision							
Eyelid droop							
TOTAL MG-ADL score (0-24)							

External factors

	22	23	24	25	26	27	28
DATE COMPLETED							
Stress or emotional unrest							
Extreme cold							
Extreme heat							
Illness or worsening of a condition other than gMG							
Lack of sleep or poor-quality sleep							
Physical exertion							
Menstrual cycles							
Other factors (eating certain foods, etc.)							

Use this space to make notes of any other gMG symptoms or triggers you've experienced that you would like to record:

Use this space to make notes of how gMG has affected your daily activities and required adjustments (e.g., work, social, leisure activities, mood, fatigue, general well-being, etc.)[7]:

You've come a long way!

Use this space to reflect on how you feel when you've been taking your treatment for some time. Here are some things to get you thinking:

- What have I learned about myself?
- What do I feel proud of?
- If I could go back and talk to myself when I was about to start my new treatment, what would I say?

If you are unsure about any of the information in this document, or have other queries, please contact your healthcare team for advice or call ONWARD at 1-844-ONWARD-1 (1-844-669-2731).

Questions for my healthcare team

You can use this space to collect questions in one place before your next appointment.

If you have a lot of questions, number them in order of priority in case you don't have time to ask everything this time.

My notes

My notes

IMPORTANT SAFETY INFORMATION INCLUDING BOXED WARNING

ZILBRYSQ is a medicine that affects part of your immune system. ZILBRYSQ may lower the ability of your immune system to fight infections. ZILBRYSQ increases your chance of getting serious meningococcal infections caused by *Neisseria meningitidis* bacteria. Meningococcal infections may quickly become life-threatening or cause death if not recognized and treated early. You must complete or update your meningococcal vaccine(s) at least 2 weeks before your first dose of ZILBRYSQ. If you have not completed your meningococcal vaccines and ZILBRYSQ must be started right away, you should receive the required vaccine(s) as soon as possible. If you have not been vaccinated and ZILBRYSQ must be started right away, you should also receive antibiotics to take for as long as your healthcare provider tells you. If you had a meningococcal vaccine in the past, you might need additional vaccines before starting ZILBRYSQ. Your healthcare provider will decide if you need additional meningococcal vaccines. Meningococcal vaccines do not prevent all meningococcal infections. **Call your healthcare provider or get emergency medical care right away if you get any of these signs and symptoms of a meningococcal infection:** fever, fever and a rash, fever with high heart rate, headache with nausea or vomiting, headache and fever, headache with a stiff neck or stiff back, confusion, eyes sensitive to light, and muscle aches with flu-like symptoms.

Your healthcare provider will give you a Patient Safety Card about the risk of serious meningococcal infection. Carry it with you at all times during treatment and for 2 months after your last ZILBRYSQ dose. Your risk of meningococcal infection may continue for several weeks after your last dose of ZILBRYSQ. It is important to show this card to any healthcare provider who treats you. This will help them diagnose and treat you quickly. **ZILBRYSQ is only available through a program called the ZILBRYSQ Risk Evaluation and Mitigation Strategy (REMS).** Before you can receive ZILBRYSQ, your healthcare provider must: enroll in the ZILBRYSQ REMS program; counsel you about the risk of meningococcal infections; give you the Patient Guide, including information about the signs and symptoms of meningococcal infection; give you a **Patient Safety Card** about your risk of meningococcal infection, as discussed above; make sure that you are vaccinated against serious infections caused by meningococcal bacteria and that you receive antibiotics if you need to start ZILBRYSQ right away and you are not up to date on your vaccines.

ZILBRYSQ may also increase the risk of other types of serious infections caused by encapsulated bacteria, including *Streptococcus pneumoniae*, *Haemophilus influenzae*, and *Neisseria gonorrhoeae*. Certain people may be at risk of serious infections with gonorrhea. Talk to your healthcare provider about whether you are at risk for gonorrhea infection, about gonorrhea prevention, and about regular testing. Call your healthcare provider right away if you have new signs or symptoms of infection.

Do not use ZILBRYSQ if you have a serious meningococcal infection when you are starting ZILBRYSQ treatment.

Before you use ZILBRYSQ, tell your healthcare provider about all of your medical conditions, including if you have an infection or fever; are pregnant or plan to become pregnant; or are breastfeeding or plan to breastfeed. There is a pregnancy registry for women who use ZILBRYSQ during pregnancy. The purpose of this registry is to collect information about the health of you and your baby. If you become pregnant while taking ZILBRYSQ, you or your healthcare provider can contact UCBCares® at 1-844-599-CARE (2273) or email ucbcares@ucb.com to enroll or get more information about the registry. **Tell your healthcare provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements.

In addition to increasing your chance of getting serious meningococcal infections, ZILBRYSQ may also cause inflammation of the pancreas (pancreatitis) and other pancreatic problems. Pancreatitis and pancreatic cysts have happened in people who use ZILBRYSQ. Your healthcare provider will do blood tests to check your pancreas before you start treatment with ZILBRYSQ. **Call your healthcare provider right away** if you have pain in your stomach area (abdomen) that will not go away. Your healthcare provider will tell you if you should stop using ZILBRYSQ. The pain may be severe or felt going from your abdomen to your back. The pain may happen with or without vomiting. These may be symptoms of pancreatitis.

The most common side effects of ZILBRYSQ include injection site reactions, upper respiratory tract infections, and diarrhea.

Tell your healthcare provider about any side effect that bothers you or that does not go away. These are not all the possible side effects of ZILBRYSQ. For more information, ask your healthcare provider or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at www.fda.gov/medwatch or 1-800-FDA-1088. You may also report side effects to UCB, Inc. by calling 1-844-599-CARE [2273].

See the detailed Instructions for Use that comes with ZILBRYSQ for information on how to prepare and inject a dose of ZILBRYSQ, and how to properly throw away (dispose of) used ZILBRYSQ prefilled syringes.

ZILBRYSQ is a prescription medicine used to treat adults with a disease called generalized myasthenia gravis (gMG) who are anti-acetylcholine receptor (AChR) antibody positive. It is not known if ZILBRYSQ is safe and effective in children.

Please see the full Prescribing Information and Medication Guide for ZILBRYSQ, including the Boxed Warning regarding serious meningococcal infections. Please see the Instructions for Use for the ZILBRYSQ Single-Dose Prefilled Syringe. Talk to your healthcare provider about your condition or your treatment. For more information, go to www.ZILBRYSQ.com or call 1-844-599-2273.

References

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Inspired by **patients.**
Driven by **science.**