About the American Lung Association

The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through research, education and advocacy. The work of the American Lung Association is focused on four strategic imperatives: to defeat lung cancer; to improve the air we breathe; to reduce the burden of lung disease on individuals and their families; and to eliminate tobacco use and tobacco-related diseases. For more information about the American Lung Association, a holder of the Better Business Bureau Wise Giving Guide Seal, or to support the work it does, call 1-800-LUNGUSA (1-800-586-4872) or visit: Lung.org.

Special thanks to Three Lakes Partners for their generous support of the Better Breathers Club Meeting Module: The Benefits of Supplemental Oxygen.
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**Materials Provided on Flash Drive:**

- Letter to the Facilitator  
- Facilitator Guide  
- PowerPoint Presentation with Key Messages  
- Educational Handouts  
- Meeting Agenda  
- Meeting Evaluation  
- Answers to Frequently Asked Questions  
- Questions about Renting and Purchasing Equipment  
- Next Step Presentation Ideas
About the Program

Acknowledgements
The American Lung Association would like to thank the Scientific and Medical Review Panel and the Better Breathers Club facilitators who took the time to review and develop this program.

Program Goal
The Better Breathers Club Meeting Module: The Benefits of Supplemental Oxygen aims to build awareness and educate Better Breathers Club members about using supplemental oxygen.

Learner Outcomes
1. Review the importance of oxygen therapy and why it is prescribed by your physician
2. Discuss the types of oxygen delivery devices
3. List ways to monitor and maintain the oxygen levels in your blood
4. Identify options for financial assistance
5. Describe opportunities to find support for yourself and how others can support you

Program Resources
Better Breathers Club Facilitator Resource Center
All elements included in this Better Breathers Club Meeting Module can also be downloaded from the online BBC Facilitator Resource Center. The BBC Facilitator Resource Center is now password protected. Log-in information is below:

Lung.org/support-and-community/better-breathers-club/bbc-facilitators-resources.html

*User Name:* bbclub
*Password:* resources
Facilitator Script

The Benefits of Supplemental Oxygen program may be delivered by following the Facilitator Script in this guide, in conjunction with the PowerPoint presentation included on the flash drive and at the BBC Facilitator Resource Center.

Flash Drive Materials

A variety of facilitator resources related to this module are included on the flash drive you received. See the Table of Contents for a list. These materials can also be downloaded from the BBC Facilitator Resource Center.

Educational handouts for your members include:

1. Using Oxygen Safely
2. Oxygen Delivery Devices and Accessories
3. Using Oxygen at Home
4. COPD Action Plan
5. How Can Oxygen Therapy Help Me?
6. Getting Started with Oxygen
7. Supporting Someone on Oxygen

Educational Videos

Brief educational videos on how to use oxygen delivery devices can be found on Lung.org/oxygen. The oxygen delivery devices covered are liquid oxygen; home oxygen concentrator; portable oxygen concentrator; and compressed oxygen gas. As you prepare for your meeting, think about opportunities to incorporate these videos into the presentation when discussing the “Oxygen Delivery Device Overview.”
Addressing Commonly Asked Questions

As you are preparing to deliver this program, it is important to remember that the topic of supplemental oxygen is very broad. You may receive questions from members about what oxygen delivery device is best, what insurance will cover or other questions that are difficult to address during the meeting. As a facilitator, you may want to provide a helpful answer but remember, it is okay to direct members back to their healthcare providers, insurance providers, the American Lung Association’s Lung HelpLine (1-800-LUNGUSA) or Lung.org/oxygen.

Members interested in comparing oxygen delivery devices should consult their physician to determine their oxygen needs. They should also contact the local oxygen supplier who is responsible for filling their oxygen needs.

Due to the number of insurance policies, guidelines and restrictions, it is important to emphasize to members the need for them to become advocates for their own health. This includes understanding insurance coverage and what they will be responsible for as a patient. They should talk with their insurance providers (Medicare, Medicaid, private and supplemental). Although this program offers a general overview of the Medicare coverage individuals using oxygen may receive, this should not be viewed as comprehensive.

Advocacy

If you have BBC members on Medicare who have had problems getting oxygen covered by insurance or getting the amount of oxygen needed, the Centers for Medicare & Medicaid Services (CMS) needs to hear from them. The American Lung Association is asking frustrated oxygen-users to share their stories by sending an email to Oxygen@Lung.org. Photos are welcome, too. The stories will be forwarded to CMS, and the Lung Association will be working to push CMS to address patients’ concerns. Thanks for helping us advocate for lung disease patients who need oxygen.

Facilitator Feedback

The American Lung Association has made every attempt to include the most up-to-date information in this program. However, the oxygen delivery device industry is fast growing, and new advancements are made all the time. Depending on the population you serve, your members’ oxygen delivery devices may be different, and we want to know if you feel we are missing important information to better serve your members. You can send your comments to BetterBreathersClub@Lung.org.
Facilitator Script: Hello, my name is [insert your name] and today we are here to talk about supplemental oxygen and the importance it can have in improving lung health.

Facilitator Script: The program goal for The Benefits of Supplemental Oxygen presentation is to build awareness and educate Better Breathers Club members about using supplemental oxygen. During the presentation, we will:

- Review the importance of oxygen therapy and why it is prescribed by your physician
• Discuss the different types of oxygen delivery devices
• List ways to monitor and maintain the oxygen levels in your blood
• Identify options for financial assistance
• Describe opportunities to find support for yourself and how others can support you

It is important to remember that this information is meant to be educational and should not replace your physician’s advice. If you have any questions about using supplemental oxygen, think you may need supplemental oxygen or have other questions about your health, these questions should be discussed with your physician.

**Facilitator Script:** The program today was developed by the American Lung Association, an organization with a long-standing history of supporting individuals with chronic lung disease and their caregivers. For more than 100 years, the Lung Association has led the fight for healthy lungs and healthy air and is America’s oldest voluntary health organization. It was founded in 1904 to fight tuberculosis, the most dreaded disease of its time.

Over the years, the Lung Association has expanded its fight to target other threats to lung health. It was among the first to tackle smoking as the nation’s leading preventable health risk and to make the connection between air pollution and lung disease.
Today, the Lung Association is funding research that unlocks the secrets of lung diseases, from asthma to lung cancer. It offers educational programs to help patients take control of their illness. And it has a network of regional offices across the country that works with thousands of volunteers at the community level to fight for healthy lungs and healthy air, right where you live. One of its areas of focus is chronic lung disease, such as chronic obstructive pulmonary disease (COPD) and pulmonary fibrosis.

**Facilitator Script:**

Oxygen is essential to all living things. Supplemental (extra) oxygen does not cure lung disease, but it is an important therapy that improves symptoms and organ function. For some people with lung disease, such as COPD or pulmonary fibrosis, the body may not be able to get enough oxygen into the bloodstream naturally, which is why supplemental oxygen is needed.

Oxygen therapy is a treatment that provides you with supplemental oxygen. It is prescribed by your physician and should be used under their direction.

It is possible, even when on adequate oxygen, that you may still feel short of breath. But using supplemental oxygen will help keep your organs and tissues healthy. Oxygen is not addictive and you will not become dependent on it. This is something everyone needs in order to live.

Quitting smoking is also very important if you are living with lung disease, and this is especially true if you are using oxygen. There are resources available through
the American Lung Association, the state’s Quitline and local resources to help you quit. You should also post “No Smoking” or “No Open Flames” signs inside and outside your home to remind people not to smoke.

Facilitator Note: For additional oxygen safety tips, share the handout “Using Oxygen Safely.”

SLIDE 5: What Is Supplemental Oxygen? (Continued)

Facilitator Script: How can supplemental oxygen help you?

Oxygen therapy can help you feel less short of breath, feel less fatigued, sleep better and increase your exercise tolerance. It can improve your quality of life and help you live longer.
Facilitator Script: How will you know if you need supplemental oxygen?

For most patients with chronic lung disease, when oxygen saturation falls below 89 percent during rest, activity or sleep, supplemental oxygen is needed and is helpful. Your physician determines this based on studies that measure the oxygen saturation in your blood while resting or during exercise, such as a six-minute walk test.

Although most often prescribed for individuals with lung disease, people with other health conditions may also find using supplemental oxygen beneficial. This includes people with severe lung disease, such as COPD, pulmonary fibrosis and pulmonary hypertension; sleep apnea; pneumonia; and recurring congestive heart failure.

For some people, oxygen levels may only be low enough to require oxygen during sleep. Your physician will know this from an overnight pulse oximeter test that is done at your home or during an overnight sleep study done in a lab. To determine if you need supplemental oxygen during activity, your physician may recommend an exercise stress test or walk test to find out if your oxygen levels change while active.

If you need to use supplemental oxygen, it is because your physician has determined, based on your symptoms and other medical tests, that your blood oxygen levels are too low. Your physician may use a pulse oximeter or arterial blood gas study to help determine your need for supplemental oxygen.

A pulse oximeter is an electronic device that measures oxygen saturation carried in your red blood cells. The pulse oximeter uses a cold light source that shines a
light through the fingertip, making the tip appear to be red. By analyzing the light from the light source that passes through the finger, the device can determine the percentage of oxygen in the red blood cells. A good number would be above 90 percent.

An arterial blood gas study is a medical test where blood is drawn through the artery and analyzed to measure the saturation and pressure of oxygen in the bloodstream, or pO2.

Facilitator Script: When you get started with oxygen, the first step is to connect with your physician. The tests we just discussed, the pulse oximeter or arterial blood gas study, will help them determine the type of device and how much oxygen is right for you.

Communication with your physician is key. Tell your physician about your needs at home and your lifestyle. You should also explain what you would like to be able to do while using oxygen as well as any concerns you have about getting started.

Your physician will provide you with a certificate of medical necessity, which says you need supplemental oxygen. You should verify that this certificate says exactly what type and amount of oxygen you will need. The certificate of medical necessity is required by Medicare and other insurance providers.
**Facilitator Script**

**Audience Engaging Question:** For anyone who is using oxygen, what are some things that you wish you would have known early on?

**NOTE:** Answers could range from more information about working with oxygen suppliers, insurance issues or discussing oxygen needs with their physician. This also may be a time where individuals share their difficulties with getting a portable oxygen concentrator covered under insurance or working with their current oxygen supplier.

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**SLIDE 8: Getting Started With Oxygen (Continued)**

**Facilitator Script:** An oxygen supplier is a durable medical equipment (DME) company that is responsible for filling your order and delivering your oxygen. The oxygen supplier is not your physician and cannot make decisions for you about your oxygen. A representative from your oxygen company will teach you how to use your oxygen when it is delivered.

Before entering into an agreement with the oxygen supplier, ask your physician to make sure the oxygen delivery device recommended by the supplier is right for you. Reviewing the oxygen delivery device with your physician is an important step. If you are unhappy with the type of oxygen delivery device provided, it is difficult to change during your contract. In addition, if you find the oxygen delivery device or current oxygen prescription is no longer effective during your contract, your physician will need to provide a new certificate of medical necessity. This should be provided to the oxygen supplier so they can fill the new order.

If you are using Medicare, Medicare is responsible for paying 80 percent of charges billed by the oxygen supplier. You, or your supplemental insurance, will be responsible for the remaining 20 percent.
The rules and regulations concerning insurance coverage for supplemental oxygen are complicated and can be hard to navigate. If you have questions or problems understanding your Medicare coverage, you can find information on Medicare.gov. Also check with your doctor’s office to see if there is someone in the practice who can advise you. If you have private insurance or Medicaid, you should consult your insurance provider to learn more about your plan’s benefits.

As you discuss the different types of oxygen delivery devices with your physician and oxygen supplier, it is important to understand the terms “liters per minute” and “flow rate” on your oxygen prescription. Understanding your oxygen flow rate is important because this will make sure you are getting enough oxygen at all times. When reviewing the types of oxygen concentrators available, it is important to remember that the settings on oxygen concentrators are not the same as the liters per minute.
Facilitator Script: Oxygen delivery devices can come in a continuous flowing oxygen unit, pulse flowing oxygen unit or both.

Continuous oxygen flows continuously into your nose through the nasal cannula or mask. Continuous flow is most often recommended if you need a higher flow rate or use oxygen while sleeping. Pulse flow delivers oxygen only when you inhale, or breathe in, which allows the concentrator and batteries to last longer.

You should discuss which method of delivery, continuous or pulse, is best for you with your physician.
Facilitator Script: In addition to talking with your physician about your oxygen prescription and lifestyle, it is important to also talk about any questions or concerns that you may have related to using supplemental oxygen. Some of the questions that you will want to consider and discuss with your physician include:

- Where you live and what type of equipment is available through your local oxygen suppliers.
- Your electrical supply and the increased cost of using an oxygen concentrator.
- Your level of activity inside and outside the home.
- Out-of-pocket costs and medical insurance restrictions.
Facilitator Script: Oxygen can be delivered from three different sources: an oxygen concentrator, liquid system and oxygen pressurized in a metal canister. In this section, we will also cover portable oxygen concentrators.

A stationary oxygen concentrator is powered by electricity and is not portable. This type of equipment is made to be used at home or at work. It concentrates oxygen in the air by removing nitrogen.

Stationary oxygen concentrators weigh around 40 pounds, making this system difficult to move around the home. You can attach up to a 50-foot hose to allow for mobility. This type of system may produce a lot of heat and should be stationed in a well-ventilated area. You should speak with your oxygen supplier representative about the best places within your home for your concentrator. This system plugs into an electrical wall outlet and will increase your home electricity bill. Since this system runs on electricity, it is important to have a backup oxygen system in place in the event of an electrical outage.

Facilitator Note: If your meeting space has internet capabilities, click on Lung.org/oxygen to view the short education videos about the oxygen delivery devices included in this presentation. To provide additional information, share the handout “Overview of Oxygen Delivery Devices and Accessories.”

Audience Engaging Question: Emergency preparedness is very important when you are on oxygen therapy. What are some things you need to do to be prepared in the event of a natural disaster or emergency?

NOTE: Answers should include telling the local fire department and electric and telephone companies that oxygen is used in the home. By doing so, if power is lost, it may be restored sooner with the knowledge that a person relies on oxygen. Participants should check if
their electric company has an Emergency Medical Equipment Notification Program. A generator is also helpful in case of an emergency where electricity is lost.

Answers should also include having a backup oxygen method, which is recommended. This could be a portable oxygen concentrator (make sure batteries are charged) or extra compressed oxygen gas tanks. Participants should know to establish a network of people they can count on in the event of an emergency. These can be friends, family or neighbors who are available when assistance is needed. A communication plan should be developed with this network.

Facilitator Script: Compressed oxygen gas is stored in steel or aluminum tanks or cylinders. Larger tanks are stationary and used at home. The smaller tanks are more portable.

Oxygen tanks run on continuous flow and need to be refilled once they run out. Your oxygen supply company will have a schedule for refills. You can also add an oxygen-conserving device to a compressed oxygen gas tank. This device will deliver oxygen by pulse flow.

There are also systems that allow you to refill your compressed oxygen gas tanks as you need them using a HomeFill, or transfill, oxygen system. This type of system is beneficial for you if you are active and may help address the fear of "running out of oxygen" since you are able to fill your own oxygen tanks. While this system has a lot of advantages, a disadvantage is that this system may be difficult to get through insurance. However, once it is in place, you no longer need to worry about routine oxygen delivery costs.
Facilitator Script: Liquid gas is made by cooling oxygen and converting it to liquid. As the oxygen warms, it turns back into a gas and is ready to use. This can be stored in a smaller volume and is more convenient than compressed oxygen gas for active people. It is also popular if you use oxygen at a higher flow rate.

With this system, oxygen is stored in a liquid form in a home reservoir that needs to be kept filled. You can use the reservoir to fill smaller containers. These smaller containers can offer longer use, even with a higher flow rate, and they do not require electricity.

On the downside, this type of system can be expensive and difficult to get in some areas.
Facilitator Script: Portable oxygen concentrators allow for increased mobility outside the home and are lightweight, ranging between 10 to 20 pounds. They can be carried over the shoulder, in a backpack or wheeled.

Most models of portable oxygen concentrators produce a maximum of three liters per minute. It is important to understand your required liters per minute. If you require more than three liters per minute, portable oxygen concentrators will not meet your needs.

Portable concentrators often come with batteries to recharge or can operate from an AC power source. Generally, portable oxygen concentrators that produce higher oxygen outputs also tend to be heavier and have a shorter battery life.

If you are interested in a portable oxygen concentrator, talk to your physician about the different options that are available to you, along with your oxygen needs and level of activity.

Questions to consider during your discussion include (but are not limited to):

- Will this portable concentrator deliver enough oxygen during rest, activity and sleep?
- Does the machine offer continuous flow or pulse flow?
- What is the weight of this portable concentrator?
- What is the battery life of the portable concentrator?
- Is this something covered by insurance?

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Facilitator Note: For additional information on this topic, share the handout “Oxygen Delivery Devices and Accessories.”

SLIDE 16: Oxygen Delivery Device Overview (Continued)

Facilitator Script: Oxygen delivery devices and supplies, such as your nasal cannula, mask, tubing or humidifier, need to be cleaned, inspected and maintained on a regular basis. The owner’s manual that comes when you receive your oxygen delivery device will provide instructions on safety and regular maintenance. You should talk to your oxygen supplier about an extra set of supplies, such as nasal cannulas, masks and tubing, to use while you are cleaning your supplies.

If you are experiencing issues with your oxygen delivery device, make sure you have a backup oxygen delivery device before you start troubleshooting it. If you have trouble breathing or worsening symptoms, contact your physician or call 911. If you suspect your device is malfunctioning, contact your oxygen supplier right away.

Facilitator Note: For general tips on cleaning and maintaining oxygen equipment, share the handout “Using Oxygen at Home.”
Facilitator Script: A pulse oximeter you use at home can help monitor the oxygen levels in your blood. These can be purchased in stores or online. Pulse oximeter readers often vary in accuracy. You can compare the accuracy of your pulse oximeter by checking it with the one used by your physician or pharmacy. It is important to note that several things that can cause a reader to vary. These include smoking, your heart rate, the ambient temperature and wearing nail polish.

While a pulse oximeter is a helpful tool for monitoring oxygen levels, you should always be aware of changes in symptoms and how you feel. And remember, even if your oxygen levels are good, you may still feel short of breath.
Facilitator Script: Pulmonary rehabilitation is a program of exercise and education designed to improve lung function, reduce the severity of symptoms and improve quality of life.

If you participate in pulmonary rehabilitation, you will learn more about your condition, symptoms and medication. You will also participate in supervised exercise, learn deep breathing techniques, learn about nutrition, and receive emotional and social support.

Pulmonary rehabilitation is done under the supervision of a respiratory therapist, physician, dietitian and exercise specialists. For most individuals, it is covered through Medicare and private insurance.

Audience Engaging Question: Can anyone share their experience participating in a pulmonary rehabilitation program?
Facilitator Script: Your body will tell you if it is not getting enough oxygen. Some warning signs that you are not getting enough oxygen include:

- Frequent headaches.
- Feeling nervous, drowsy or confused.
- Feeling agitated.
- Lips or fingernails turn blue.
- Difficulty breathing.

Call your physician immediately if you are experiencing low oxygen levels or you are experiencing worsening symptoms.

Remember, you can be short of breath even if your oxygen level is fine because of your underlying lung disease. It is not always a simple matter of increasing the flow of oxygen. If you notice that your current oxygen prescription is no longer working the way it should, it is important to talk to your physician right away.

If your pulse oximeter reading is good but you are experiencing shortness of breath, this could be a sign of an acute exacerbation or change of your disease progression. Lung diseases such as COPD and pulmonary fibrosis are progressive diseases, meaning that your disease will worsen over time. As your disease progresses, your oxygen requirements may change as well. If you begin to feel more short of breath while on your oxygen, it is important to talk to your physician so that they can repeat tests and make sure you are on an adequate flow of oxygen.
If you have COPD, using a COPD Action Plan is helpful to determine the steps to take if worsening symptoms arise. A quick relief medication may be needed to relieve symptoms and should be taken as prescribed by your physician. You can also try deep breathing exercises, such as pursed-lipped or belly breathing techniques, to help calm yourself down and increase your oxygen levels.

**Facilitator Note:** Share the handout “COPD Action Plan” with your members. For those who do not have COPD, ask about the steps they take when they recognize worsening symptoms.

**Audience Engaging Question:** Should you ever change your oxygen flow rate without talking to your physician first?

**NOTE:** The answer from your members should be no. Advise them that they should not stop or change their oxygen flow rate without discussing it with their physician first. This is to ensure they are receiving the right amount of oxygen at all times.
Facilitator Script: For a lot of people, purchasing prescription medications and medical equipment, and paying for the additional electric costs due to using an oxygen concentrator, can be a challenge. There are resources available through national, state and local organizations, but these resources can be difficult to navigate.

Financial support and assistance for medical equipment coverage and prescription medications can be found at:

- Needy Meds: needymeds.org
- Need Help Paying Bills: needhelppayingbills.com
- Aunt Bertha: auntbertha.com
- RxAssist: rxassist.org
- RxHope: rxhope.com

If you are having concerns about prescription medication costs, talk to your physician. Your physician may be aware of medication assistance programs through pharmaceutical companies.

You can also contact your local health system’s social work department to locate county-level programs for financial or community assistance. If you have a county health department or Area Agency on Aging, these organizations may be able to help with referrals. The American Lung Association’s Lung HelpLine (1-800-LUNGUSA) can also assist.
Facilitator Script: One of the most important parts of living well while using supplemental oxygen is connecting with others in your shoes. The American Lung Association has several resources to help you find the support you need.

Inspire is an online support community where you will connect with hundreds of people across the country who have shared concerns and questions and are seeking support. Learn more at Lung.org/community.

Many people find attending in-person support groups, such as Better Breathers Clubs, very beneficial. In-person social support programs often have educational sessions and provide social support.

The American Lung Association also offers the Lung HelpLine (1-800-LUNGUSA), which is staffed by caring medical professionals available to answer questions related to supplemental oxygen and lung health.

Depression and anxiety can be common in individuals with chronic lung disease. If you are having a difficult time managing your mood, talk with your physician.

Audience Engaging Question: What are ways that you find support for yourself?
Facilitator Script: As a caregiver or family member, it is not always clear how you can help someone once they are prescribed oxygen. This is a time that can be very stressful for everyone involved, not just the person prescribed oxygen.

Support from others can make living with oxygen a little bit easier. Some tips for those of you here today as a caregiver, family member or friend supporting someone on oxygen, include:

- **Invite the person out.** Oxygen doesn’t have to mean an end to life outside the home.
- **Learn how to use the equipment.** All caregivers and emergency contacts should know as much as they can about oxygen equipment and how it works.
- **Encourage independence and autonomy.**
- **Offer to help with chores and tasks,** such as cleaning or helping with meal prep and cooking.
- **Be supportive and understanding.** It may take time for someone to adjust to using oxygen. They may not want to go out in public or ask for help. Being patient and understanding will go a long way. Even if the person says no at first, continue to ask what you can do.

**Audience Engaging Question:** If there are any caregivers in the room, ask, “What are some tips that you can provide to others about being in the caregiving role?”
Facilitator Script: Today we covered a lot of information. In just a short time, we reviewed the importance of supplemental oxygen and why it is prescribed by your physician; discussed the different types of oxygen delivery devices; reviewed the ways to monitor and maintain oxygen levels in the blood; and talked about different options for financial assistance as well as opportunities to find support for yourself and others.

I wanted to share some additional handouts for you to take home and review [NOTE: You may have already shared the first four items during the course of the presentation. If so, share items 5 through 7 now as desired]:

1. Using Oxygen Safely
2. Oxygen Delivery Devices and Accessories
3. Using Oxygen Therapy at Home
4. COPD Action Plan
5. How Can Oxygen Therapy Help Me?
6. Getting Started with Oxygen
7. Supporting Someone on Oxygen

Facilitator Note: As you are preparing for the program, look at the available handouts that can accompany The Benefits of Supplemental Oxygen program on the flash drive or at the BBC Facilitator Resource Center. Print out enough of the handouts you plan to include for your members.
Facilitator Script: Before we end today's program, did anyone have any questions or comments they would like to share? If not, please take a moment to complete the “Meeting Evaluation” form. It is helpful for me, and for the American Lung Association, to have feedback on this program.

Facilitator Note: Distribute the “Meeting Evaluation” included on the flash drive or at the BBC Facilitator Resource Center. Collect them from members as they are completed.

Facilitator Script: Thank you again for joining me for today’s program. I look forward to seeing you again at our next meeting on [insert date and time]. The topic of our next session will be [insert topic].