

Leader's Guide

HEART TO HEART: WOMEN & VALVE DISEASE Conducting an Educational Workshop



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HEART TO HEART: WOMEN & VALVE DISEASE Conducting an Educational Workshop

Introduction

Purpose

This workshop is designed to provide all of the resources necessary for community leaders (health educators, community outreach coordinators, religious educators, etc.) to conduct a workshop for women on the basics of valve disease and its treatment.

Audience

The primary target audience for this workshop is women who have been diagnosed with valve disease; however, it is also suited for those who are at risk or think they may have valve disease and want to learn more. The number of participants in a given workshop will vary by site. Suggestions are made throughout this guide on how to adapt the curriculum for large or small groups.

Workshop Goals

To help women with valve disease or who are at risk to 1) understand the basics of valve disease and 2) work effectively with their health care professionals to treat their disease.

Objectives

The major objectives of this workshop are to:

- Provide educational background and engaging materials on valve disease in women.
- Offer interactive materials to help participants learn more about valve disease and their personal heart health.
- Establish a supportive environment where women can learn more and be empowered to start important conversations with their health care professionals.

Note that each section of this guide contains additional key learning objectives that outline what workshop participants should know at the conclusion of each section.



Before you conduct the workshop, you will need to do the following:

- Choose a date and time. If possible coordinate with other events that your audience may attend.
- O Secure a location. See page 4 for space requirements.
- O Promote the workshop. See page 3 for tips on getting the word out.
- **Make copies of workshop materials**. Once you have a head-count, print out the resources designed for workshop participants. See page 5 for a full list of resources.
- Download the pocket film and slide presentation. Either save to a laptop or save the files to a DVD/CD/thumbdrive.
- **Prepare a list of local resources.** This list can include support groups, heart centers, hospitals, etc. If possible, create and print a handout with this information or post the resources in the workshop room the day-of.
- Research any areas where you need additional information. Be prepared to answer questions or refer participants to additional educational materials.

Promoting the Workshop



Getting the Word Out

Consider how you will let your intended audience know about the workshop. Different promotional techniques will work in different communities, so use your own experience or the experience of others in your community to determine the best ways to bring people to the workshop. Below are some ideas to get you started:

- **Print and complete the workshop flyer.** Download and print the provided workshop flyer and fill in the date, time, location, and registration details if required (see below).
- Distribute the flyer. If appropriate, post the flyer at the workshop venue. Additionally, bring or send to organizations that have regular contact with older women such as:
 - Senior centers

Red Hat Societies

- Community bulletin boards (libraries, YMCAs, community centers, recreation centers, schools, supermarkets, etc.)
- Churches, synagogues, and other faith-based organizations
- State and/or local agencies for elders and aging
- Women's groups such as the Junior League
- American Heart Association local office
- Assisted living facilities
- Hospitals
- Medical offices and community health centers
- Advertise. Consider your audience when determining the best ways to reach them.
 - Many newspapers have a section that lists local support groups and seminars. Check the "contact us" section of your local newspaper and keep in mind that additional rates and fees may apply.
 - Find your local radio station and search on-line for the media contact person who will help you determine rates and write a script for the announcement.
 - Craigslist is an online advertisement resource where you can share community events. To get started go to <u>www.craigslist.com</u> where you will select your location, click "post to classifieds", select the type of posting, and type in your specifics. A confirmation e-mail will be sent before the posting goes public.
 - Community listservs can be great venues for getting the word out. E-mail the workshop details to the listserv moderator or if you are a member, send an e-mail for posting.
 - Social media platforms like Facebook and Twitter will allow you to create events, notify friends and followers, and spread the word.
- **Tell people.** There is no substitute for personal contact. Whenever possible, make a personal contact with those who are most likely to refer participants to the workshop.

Registering Participants

Decide whether or not you will require registration. Advance registration can help you to better plan for the workshop, but be sure to accommodate individuals who may not be able to do advance registration. Make sure you provide a registration contact name, telephone number and/or email address on your flyer, and in all advertisements and outreach.

Workshop Logistics

Timing

This workshop will last approximately 1 hour and 15 minutes.

Leader's Note: This workshop is full of information and resources. To get through all of the material you will need to manage the time well, overcoming the natural tendency to make this a support group. Assure participants that there will be time to share stories and to network at the end of the workshop.

Space Requirements and Room Set-Up

The space requirements vary depending on group size. Ideally, each participant will have a seat at a table to best enable them to take notes and participate in the writing components of the workshop. Here are some suggestions for set-up:

- If round tables are used, place tables so that no table is immediately in front of another.
- If rectangular tables are used, set them up chevron style for a larger group, or in a "U" shape for a group smaller than 15. These two set-ups are illustrated below.



• If only chairs are available, set them up in rows or in a "U" shape, and either distribute or have participants bring clip boards, notebooks, or binders for writing activities.

Materials and Equipment List

- Leader's guide
- Workshop agendas
- \bigcirc Sign-in sheet
- Patient brochures
- Patient quizzes and answers
- Evaluation forms
- Pocket film downloaded to laptop or burned to a DVD/CD/thumbdrive
- \bigcirc Slide show
- \bigcirc Watch or clock to keep track of time

- Laptop, LCD projector, and screen or blank wall OR TV and DVD player
- Table or podium (for leader)
- \bigcirc Pointer
- Flipcharts and markers OR blackboard and chalk OR whiteboard and markers
- Resource handout OR information that you prepared in advance
- Pens or pencils and paper
- Clipboards, notebooks, or binders if tables are unavailable

Depending on the length of time allotted for your workshop, you may not be able to use all of the above materials. Also, remember that the first eight items can be downloaded from the Alliance for Aging Research website at <u>www.agingresearch.org/valve_disease</u> and printed in advance of the workshop. The pocket film and slide show can also be found on the Alliance website.

After the Workshop

In addition to distributing the evaluation forms for participants at the end of the workshop, please take a few moments to fill out the leader's evaluation form and return all forms to the Alliance. Your feedback will help us better support you and other workshop leaders in the future and we thank you in advance for taking the time. To return them to the Alliance you have a number of options:

- Scan and e-mail the forms to info@agingresearch.org.
- Fax the forms to 202-955-8394.
- Consolidate the feedback into an e-mail and send to info@agingresearch.org.
- Mail the forms to 1700 K St., NW, Suite 740, Washington, DC 20006.

If none of the above are available to you, please call the Alliance at 202-293-2856 and we will mail you pre-paid postage.

Workshop Agenda

) Time	Topic	Learning Objectives	Activities & Notes
:00	Welcome & Introductions (10 minutes)	 Go over logistics. Meet participants. Understand what will be covered during the workshop. 	 Leader introduces the workshop, describes what will be covered, and points out necessary logistical information. If the group is less than 15 people, participants introduce themselves.
:10	Valve Disease in Women Overview (3 minutes)	 Recognize the prevalence of valve disease in women and its increase with age. 	 Leader presents statistics on valve disease and helps participants understand its prevalence. Leader gives a brief overview to set the stage for the rest of the workshop.
:13	How It Works: The Amazing Heart (3 minutes—not including the Mayo Clinic video)	 Describe the basics of how the heart works and its anatomy—including the 4 chambers and 4 valves. 	 Leader shows and describes the anatomy and function of the heart. If there is time, participants view the Mayo Clinic video on how the heart works.
:16	Valve Damage: Types of Disease (6 minutes)	 Understand the different types of valve disease. Know which types are the most prevalent in women. 	 Leader asks if anyone can name a type of valve disease and then describes the different types of damage that can occur. Participants who have valve disease share what type they have.
:22	Causes & Risk Factors: How You Get It (3 minutes)	 Understand what causes valve disease. Know who is at increased risk. 	 Leader talks about the most common causes and risk factors.
:25	Symptoms: How to Know if You Have It 4 minutes)	 Identify the symptoms of valve disease. Know when to talk to a health care professional 	 Leader emphasizes how important early detection is. Participants call out their thoughts on valve disease symptoms. Leader goes over the list of symptoms.

() Time	Topic	Learning Objectives	Activities & Notes
:29	Seeing a Professional: Getting it Diagnosed (6 minutes)	 Learn about the different tests used to diagnose valve disease and what they involve. Know that heart diseases and conditions are too often misdiagnosed in women. 	 Leader goes through the various tests and tells what they are for and the basics of what is involved with each test. Participants ask questions about the various tests.
:35	Going Forward: What if You Have It? (5 minutes)	 Understand what the presence and absence of symptoms can mean. Know that there are successful treatment options. 	 Leader covers the prognosis and the need for treatment of valve disease. Participants share stories about delays in treatment that they have experienced.
:40	Getting Treatment: Different Options (5 minutes)	 Understand that valve repair or replacement is often the only effective treatment. Know that there are minimally invasive options for those at high surgical risk. Understand risks and outcomes. 	 Leader discusses the usual course of treatment. Participants learn about valve replacement surgery and less-invasive procedures, as well as the different valve types.
:45	Life After Repair or Replacement: Now What? (3 minutes)	 Anticipate what recovery will entail. Prepare for the future. 	 Go over recovery times, rehabilitation, and transitioning back into daily life. Discuss potential side effects of repair/replacement procedures or surgeries
:48	What Have We Learned? (12 minutes)	 Review what was learned during the workshop. 	 Watch pocket film. Review concepts shared. Participants take the quiz to assess how much they've learned.
1:00	Wrap-Up & Evaluations (15 minutes)	 Receive additional resources and give feedback on the workshop. 	 Share the brochures and refer to additional resources. Pass out evaluations. Continue any unfinished discussion.
1:15	Adjourn		

Workshop Script

The following learning objectives and suggested script are designed to make it easier for you to cover a lot of material in a short amount of time. However, you should also do some background research in advance to make sure you're comfortable with the material. Keep in mind that while it's important to script your talking points when discussing medical information, you should also be sure to make the script your own.

Welcome and Introductions

Objectives:

- Go over logistics.
- Meet participants.
- Understand what will be covered during the workshop.

WELCOME participants to the workshop and introduce yourself. If there are fewer than 15 people, you may want to have them introduce themselves to the group. Be mindful of time and limit this to about 7 minutes.

POINT OUT logistical information such as the agenda, location of the restrooms and fire exits, etc.

Leader's Note: Arrive at least 30 minutes before the start time to familiarize yourself with the room and facilities, specifically:

- Lighting and light switches/adjustment
- Temperature controls
- Arrangement of participant chairs and/or tables
- Location of leader table or podium
- Audio-visual equipment
- Location of the fire exits and restrooms

ASK how many people have valve disease, or a loved one with valve disease. Keep this number and these people in mind for later discussions.

Valve Disease in Women Overview



• Recognize the prevalence of valve disease in women and its increase with age.

SHOW SLIDE # 1

SAY: • Here are some statistics on valve disease that show how prevalent, or common it is, and how it becomes more common with age.

DISCUSS the statistics and what they mean. Consider the average age of the participants and point out what this means statistically. For instance, if they are all between the ages of 65 and 75 this means that statistically, 1 in every 13 of them are likely to have valve disease at some point during that ten year period.



- **SAY:** There are many types of valve disease and all involve damage to one of the heart's four valves. Mild valve disease is not serious, but severe disease can lead to major complications including disability, loss of independence, and even death.
 - Valve problems can be there at birth. This is called a congenital abnormality. Or they can develop from damage later in life which occurs more commonly.
 - Fortunately, valve disease can usually be successfully treated with valve repair or replacement in patients of all ages.
 - The key to successful treatment and outcomes is talking to your health care professional if you have valve disease, or think you may have it.

How It Works: The Amazing Heart

SHOW SLIDE # 2

Objectives:

• Describe the basics of the how the heart works and its anatomy—including the 4 chambers and 4 valves.

Leader's Note: If you have time and would like to download a video of how the heart works, a helpful video is available through the Mayo Clinic (search for it on the Mayo Clinic YouTube channel). They give more detail than is necessary for this point in the workshop so you may only want to show a portion to conserve time.

POINT OUT the different chambers and valves as you talk about them.

- - **SAY:** Your heart is a powerful organ that is responsible for circulating blood throughout your body.
 - The heart's four chambers—the right atrium, right ventricle, left atrium, and left ventricle work together to pump blood to your lungs to receive oxygen and then out to your body to deliver it.
 - Between each chamber is a valve. There are four valves in the heart—the tricuspid valve, pulmonary valve, mitral valve, and aortic valve.
 - The valves are thin leaflets of tissue that keep the blood moving in only one direction and with the right amount of force. These valves keep the blood from leaking backwards when the heart squeezes by only opening one way and sealing tightly when the heart chamber pumps the blood forward.
 - Because your heart is responsible for pumping blood to your body, when it is diseased or damaged it not only impacts your heart's ability to function but can also affect your overall health and lead to death.

Valve Damage: Types of Disease

Objectives:

- Understand the different types of valve disease.
- Know which types are the most prevalent in women.

ASK if anyone can name a type of valve disease.

Leader's Note: While you do not need to list all the types of valve disease, if you ask for participants to name types you will want to refer to this list to confirm or correct:				
 Aortic stenosis Aortic insufficiency Bicuspid aortic valve and aortopathy 	 Mitral stenosis Mitral regurgitation Mitral valve prolapse Tricuspid stenosis 	 Tricuspid regurgitation Pulmonic stenosis Pulmonic regurgitation Mixed value disease 		

- Tricuspid stenosis
- Mixed valve disease
- **SAY:** Most value diseases involve a damaged value that can't open or close properly—sometimes both. Because of this, the usually organized blood flow through the heart and to the body is disrupted.
 - There are two main types of damage.

SHOW SLIDE # 3

SAY: • Regurgitation is when a valve doesn't close all the way and allows blood to leak backwards. You may also hear this type of valve damage referred to as an insufficient or leaky valve.

SHOW SLIDE #4

- SAY: • Stenosis is when a valve doesn't open all the way, so not enough blood can flow through. You may also hear this type of valve damage referred to as a sticky, narrowed, blocked or stiff valve.
 - Each of the four valves can have regurgitation, stenosis, or both. The valves that most commonly experience damage though are the aortic valve and the mitral valve.
 - The most common types of valve disease are:
 - Aortic regurgitation, which is also called aortic insufficiency. This type of valve disease occurs in around 8% of women.
 - Aortic stenosis. This type of valve disease affects 1 in 4 women over the age of 65.
 - Mitral regurgitation is also called mitral insufficiency and may affect 2 to 3 percent of women. • A relatively common type of mitral regurgitation that you may have heard of is "mitral valve pro-lapse". It is usually diagnosed in young women, becoming less common with age. Most cases don't need treatment.

ASK the participants who have valve disease, or a loved one with valve disease, what type they have. Let them know that there will be other chances to share more about their stories at other points throughout the workshop.

Causes & Risk Factors: How You Get It

Objectives:

- Understand what causes valve disease.
- Know who is at increased risk.

SHOW SLIDE # 5

SA

- **SAY:** People can be born with valve defects or damage. This is called a congenital abnormality. An example is a bicuspid valve that has two leaflets instead of the normal three. Around 1 to 2 percent of people are born with a bicuspid valve which is more vulnerable to damage and other problems that can lead to disease.
 - The other types of damage develop later in life. Some of the different types of damage include:
 - Calcification. This is where calcium deposits form on the valve and narrow the opening. The most common risk factor for calcification is age.
 - Other diseases of the heart or circulatory system can lead to valve problems. For example, heart attacks can scar the heart muscle and make the valves open and close improperly.
 An enlarged heart from heart disease can stretch the valve and keep it from closing all the way. High blood pressure can also lead to damage.
 - Although rare in the U.S., strep throat that is left untreated can progress into rheumatic fever, which can damage heart valves later in life. This is most common in African Americans and women. Staph infections can also cause valve damage.

Symptoms: How to Know if You Have It

Objectives:

- Identify the symptoms of valve disease.
- Know when to talk to a health care professional.
- g s
 - **SAY:** Most types of valve disease are equally common in men and women. However, for all types, women are less likely than men to have their disease diagnosed. This means they have it, but they don't know it. This is especially problematic since early detection of valve disease is critical in reducing complications and saving lives.
 - Knowing the symptoms of valve disease, listening to your body, talking to your health care professional, and making sure you're being heard are all important pieces in proper treatment of valve disease.
 - So we need to know the symptoms.

ASK for participants to call out symptoms.

SHOW SLIDE # 6

- **SAY:** When valve damage reduces blood flow, the heart has to work harder to get oxygen to the body and this can cause a number of symptoms including:
 - Shortness of breath
 - Severe fatigue
 - Nausea
 - Pressure or weight in the chest, especially after having been active or exposed to cold air
 - Sudden weight loss
 - Feeling lightheaded or too weak to perform normal activities
 - Feeling that the heart is beating irregularly or skipping beats
 - Swelling in the ankles, feet, or belly
 - Also, an infection of a valve can cause fever, chills, night sweats, paleness, and weakness.
 - Some people will only experience these symptoms during activity and as the disease worsens, they will begin to experience them at rest.
 - Others with valve disease won't experience any symptoms. For these people, it will be the detection of a heart murmur (a noise made by blood flowing through the abnormal valve) by their health care professional that leads to a diagnosis. This makes seeing a health care professional for symptoms AND regular check-ups important. Be sure to ask your health care professional to listen for a murmur. If one is detected, further evaluation should occur.

ASK the participants who have/had valve disease to share what symptoms they experienced. If this is a large group, instead of opening it up for discussion, you may want to ask the question of a few individuals.



Seeing a Professional: Getting it Diagnosed

Objectives:

Learn about the different tests used to diagnose valve disease and what they involve.Know that heart diseases and conditions are too often misdiagnosed in women.

• As we just discussed, a person might go to their health care professional complaining of symptoms, or the health care professional might notice a heart murmur with their stethoscope during a routine exam. In either case, the primary health care professional or a cardiologist will do further testing to diagnose valve disease and determine how severe it is.

SHOW SLIDE # 7

SAY: • Listening for a murmur is as simple as using a stethoscope.

PLAY the two heart sounds available on the slide.

SHOW SLIDE #8

- **SAY:** The most common test used for diagnosis of valve disease is the echocardiogram (abbreviated—echo) which uses sound waves to create a moving picture of the heart as it beats. The echo can show the size and shape of the heart, how well it's pumping, and whether a valve is too narrow or allowing blood to flow backwards.
 - To do the echo, a transducer that sends the sound waves is placed on the surface of the chest. A transesophageal echo, or TEE, may be needed to get a better image. This involves a transducer on a thin tube that is guided down the throat and into the esophagus.

SHOW SLIDE # 9

- **SAY:** An electrocardiogram, or EKG/ECG, measures the heart's electrical patterns and can reveal an irregular heartbeat, signs of a previous heart attack, and enlargement of the chambers from damage.
 - During an EKG small electrodes are placed on your chest, arms, and legs and hooked to a machine that tracks the electrical activity.

SHOW SLIDE # 10

- **SAY:** A chest x-ray can be used to look for fluid in or around the lungs or enlargement of the heart.
 - During this test an x-ray machine takes a picture of your chest.

SHOW SLIDE # 11

- **SAY:** A stress test can show if exercise causes symptoms to develop or if the valve changes from the exertion.
 - The test is usually done by performing an echocardiogram or electrocardiogram while the patient is exercising, or immediately afterwards.

SHOW SLIDE # 12

- **SAY:** A cardiac catheterization can give additional information on the blood flow feeding the heart muscle itself and the pressures inside the heart, which may change with valve disease.
 - This is done by inserting a long, flexible catheter into a blood vessel, and threading it to the heart.
 - If you think you may have valve disease, the most important thing is seeing your health care professional as soon as possible.
 - And don't ever be afraid to get a second opinion if you don't feel like you're getting the answers you need. Research has shown that women experiencing heart disease symptoms are often misdiagnosed as having anxiety and don't get the treatment they need.

ASK if participants have any questions about the diagnostic tests.

Leader's Note: Be sure to do research on the various diagnostic tests in advance so you are prepared to answer questions. If you don't know the answer, refer them to medical sites like Mayo Clinic and Cleveland Clinic for more information.

Going Forward: What if You Have It?

Objectives:

- Understand what the presence and absence of symptoms can mean.
- Know that there are successful treatment options.
- **SAY:** Depending on the type of valve disease, the damaged valve may prevent adequate blood flow to the body and make the heart work harder than it should.
 - This can lead to an enlarged and damaged heart, arrhythmias (an abnormal heart rhythm), congestive heart failure, stroke, other heart disease, and even death.
 - Unsurprisingly, valve disease can significantly impact quality of life and make everyday activities increasingly difficult.
 - When it comes to treatment, some types of valve disease, like mild mitral valve prolapse, typically don't need to be treated but should be checked regularly to be sure it does not progress to severe mitral regurgitation.
 - Other types may be mild enough that they only require monitoring to see if the disease progresses. If this is the case, monitoring should be regular to prevent damage to the heart and body as the disease worsens.
 - Other types inevitably need treatment. With aortic stenosis, the average life expectancy once symptoms develop is less than three years. And with mitral valve disease, symptoms usually signal heart failure.
 - Thankfully repair and replacement procedures and surgery are available and have very high success rates. In most cases, they improve quality of life and add many health years.
 - However, it's important to note that in general, women have a worse prognosis (or likely outcome) than men with valve disease. This is often because women are more likely to ignore their symptoms and delay seeing their health care professional. This means that when it comes to valve repair or replacement, women often fair worse because they're getting treatment at a later stage in the disease.
 - This is why it's vital that women trust their bodies and see a health care professional if it seems like something is wrong.

DISCUSS AND SHARE stories of situations where participants put off seeing their health care professional, ignored their symptoms, or had their symptoms dismissed by their health care professional. Do your best to limit the time but encourage the story sharing. If you need to, delay the sharing of some stories to the end of the workshop.

Getting Treatment: Different Options

Objectives:

- Understand that valve repair or replacement is often the only effective treatment.
- Know that there are minimally invasive options for those at high surgical risk.
- Understand risks and outcomes.
- **SAY:** If no treatment is necessary yet, monitoring with an echocardiogram, every 6 to 12 months is typically recommended.
 - There are some medications that can help relieve or lessen symptoms.
 - There are also medications that can help reduce the heart's workload and prevent clots.
 - However, there are NOT any drugs that keep the disease from getting worse, that undo damage that has already been done, or that cure valve disease.
 - In most cases, the only effective way to treat the disease is to repair or replace the valve.
 - If possible, the valve will be repaired since this provides the best longevity and fewest long term risks. A regurgitatant or leaky mitral valve can almost always be repaired, while a stenotic or sticky valve usually needs to be replaced.

SHOW SLIDE # 13

SAY: • While most valve replacements involve open heart surgery, there are now minimally invasive procedures for people who are at high risk for surgical complications. Surgical valve replacement is still the preferred treatment for most types of valve disease but minimally invasive procedures are a good alternative for those with diseases and conditions that make them poor candidates for surgery.

SHOW SLIDE # 14

- **SAY:** Defective valves can be replaced with mechanical or bioprosthetic valves. Bioprosthetic valves are made of tissue from animals or humans.
 - Tissue and mechanical valves have different risks.
 - Mechanical valves do not wear out but they require the patient to take lifelong blood thinning drugs to prevent blood clots.
 - Tissue valves do not require blood thinners but eventually fail if the person lives long enough.
 - The best choice for each patient depends on their medical history and personal preferences.
- **SAY:** For most patients the risk of complications and death from surgery is very low—the survival rate for valve surgery is around 97% and above.
 - The success rate is also very high and in most cases relieves symptoms, restores quality of life, and lengthens lives.
 - Keep in mind that while the risk of surgical complications does rise with age, age alone is not a reason to avoid valve repair or replacement. Unless a person has serious diseases or conditions that could complicate surgery, they are most likely a good candidate—no matter what their age.



Life After Repair or Replacement: Now What?



What Have We Learned?

Objectives:

Review what was learned during the workshop.

PLAY the pocket film on valve disease to give a review to participants.

PASS OUT the quiz for participants to test their knowledge. Give them around 5 minutes to complete it and then pass on the answer sheet for discussion and to take with them.

Wrap-Up & Evaluations



SHARE the patient brochures.

POINT OUT the resources section and share the local resources that you identified.

ENCOURAGE anyone who has valve disease to share their story on the Alliance website. All participants can go to the Alliance site to learn more.



ASK participants to fill out evaluations and to return them to you once finished.

If you have additional time and you feel like there are still questions, stories to be shared, etc. allow for more conversation and networking.

Adjourn





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