

Her Heart Matters

What Women Need to Know About
Heart Failure



What I Wish I'd Known

Women with Heart Failure Share Their Collective Wisdom

Eileen was only 41 years old and planning her wedding when her unexpected journey with heart failure began. In many ways, she didn't fit the stereotype of someone with heart failure — she was young, fit and her cholesterol and blood pressure were normal. But heart failure can happen at any age.

Like many other women, Eileen went through a disheartening period of misdiagnoses, all the while knowing something wasn't quite right. Her symptoms — shortness of breath, fatigue, not being able to sleep lying down and a cough — were attributed to an upper respiratory infection, then pneumonia.

Weeks later an echocardiogram — a test that shows how the heart is pumping — showed she had heart failure.

Marilyn, 42 years old when she was diagnosed, had a similar experience.

"I was told to take a pain reliever drug for my chest pain," she said.

Women say their complaints may also be dismissed as symptoms of menopause, panic attack or stress. Many people who develop heart failure are misdiagnosed early on, especially younger people. **So, early and accurate diagnosis are key.**

"You have to advocate for yourself and find the right doctor," Eileen says. "If you think something is wrong, trust your instincts."

"And with answers comes relief," says Nellie, who was 39 years old when she was diagnosed.

"I didn't understand what was happening to me — why I felt perfectly fine before getting into the shower, and then would have trouble breathing and need to lean into the wall of the shower to stabilize myself," she said. "But today I feel empowered."

Still, there is no question finding out you have heart failure is scary.

From these women's perspectives, heart failure has meant changes in day-to-day activities, more medications and medical appointments, a possible heart transplant, and the reality of a shorter life.

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"You can live
with heart
failure, but you
need to make
changes."

— Gladys
heart failure patient



Eileen



Marilyn



Nellie



Gladys

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“I thought ‘I’m going to die,’” says Gladys. “I spent a year afraid to really move or walk out of my door, but I realized you can live with heart failure, you just need to make changes.”

Changes include eating right, getting exercise, monitoring your fluid intake and weight, and following your treatment plan. “You have to be willing to accept a new normal, self-advocate, and speak up if something doesn’t feel right.”

More words of wisdom...

You can do everything right, and still end up in the hospital.

Despite your best efforts, heart failure symptoms may worsen. Heart failure can be a challenge to manage, and it’s not uncommon for women to end up in the hospital. Hospitalizations allow for testing and close monitoring and the care team may adjust your medications or recommend other treatments.

There are limits to what you are able to do.

Because of the fatigue and shortness of breath, there are physical limits to what you can do, and it generally takes longer to do things.

“It takes me two hours longer to get out of bed and dressed in the mornings,” explains Eileen.

Some women can no longer work because they don’t have the stamina. It’s an adjustment, but you find your new normal. Nellie, a perfectionist at heart says, “I’ve had to learn when good enough is good enough.”

It’s a different kind of tired.

“Women go at Mach speed, and we can usually push through it,” said Eileen. “With heart failure, no matter how hard you push, you hit a wall so much sooner.”

Marilyn, who now has a loop recorder heart monitor and an implantable cardioverter defibrillator (ICD), says she knows the feeling.

“If I do something one day – an activity or go out – I often have a hard time getting out of bed the next day or two.” It’s also meant redefining how she spends her family’s annual trip to Mexico. “I often stay in the room, sit on the balcony and watch the waves.”

But “you don’t look sick.”

This is one of the biggest challenges of living with the disease, according to the women, and other people don’t seem to fully understand how unwell you might feel.

You can and should exercise.

Many women admit they were initially afraid of doing anything that might over-exert the heart. But exercise can strengthen the heart and improve how well it pumps and lower the risk of death and hospital stays. In fact, cardiac rehabilitation programs that include exercise along with education and counseling are now covered by Medicare for people with stable heart failure.

“It’s about finding what works for you, and talking with your health care team,” said Marilyn. “I’m not able to walk at a fast pace or run, but I can go up and down stairs, do chair exercises and, when I’m able, I do housework at a faster pace. She recently completed a 5K race. “I came in last, but I finished; it was so rewarding to reach that finish line.”

Don’t let heart failure define you

“Having heart failure is not the end of the world,” says Nellie. “You are more than the diagnosis and the prognosis, and there is still life to live.”



**“Your heart may be
compromised, but
there is still a lot you
can do with the right
treatment.”**

Greetings,

On behalf of WomenHeart: The National Coalition for Women with Heart Disease, I am pleased to present this issue of “Her Heart Matters: What Women Need to Know About Heart Failure.” If you have been diagnosed with heart failure, you know what a life-changing experience that is.

Although heart failure is a common cardiac diagnosis for both women and men, women with this condition are more likely to report more significant changes to their quality of life. Often, the first symptoms of heart failure are attributed to overwork, stress and general fatigue, rather than to a serious heart condition.

It is important to remember that with proper diagnosis, medication and other therapies, heart failure doesn’t have to live up to its name. Understand your disease, seek information and make sure that you understand the therapies available to treat your condition.

Work with your doctor and your care team to make sure you feel as though you have the information and tools to manage your heart failure. Ask questions. Your heart may be compromised, but there is still a lot you can do with the right treatment.

Inside this issue, you will find important information about living with heart failure, including lessons and tips from other women to help manage this condition and how to take charge of your heart health!

Mary Norine Walsh, MD, FACC
WomenHeart Scientific Advisory Council
Medical Director, Heart Failure and Cardiac Transplantation
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Don't Let Heart Failure Define You

Heat failure means the heart no longer pumps blood to the body as well as it should. It either 1) can't fill with enough blood (diastolic) or 2) no longer has the force to squeeze enough nutrient-rich blood and oxygen to the body (systolic). Some people have both problems.

Heart failure often develops because of conditions that damage or strain the heart. For example:

- heart attack
- uncontrolled high blood pressure
- coronary artery disease
- heart valve disease
- diabetes
- certain types of chemotherapy
- alcohol or drug abuse

Some people are born with defects that can make heart failure more likely, especially at younger ages. It's also more common if you have a family history or are overweight.

Ejection Fraction Explained

Your ejection fraction is a measure of how much blood is pumped out of the heart with each contraction. Every time your heart beats, it relaxes to fill with blood and then contracts to pump it out to your body. But not all of that blood is squeezed out.

With normal heart function, between 50 and 70 percent of the total amount of blood in the ventricle is being pushed out of the heart with each beat.

Ejection fraction numbers:

41-49 percent

pumping ability is below normal

≤40 percent

pumping ability is low, raising risk of dangerous heart rhythms and sudden cardiac death

Your ejection fraction gives your doctor an idea of how compromised your heart function is, and is often used to monitor the disease. But it is only one measure of heart function.

More women than men have heart failure with a more normal or "preserved" ejection fraction. So while her heart may contract normally, it doesn't relax and fill with blood normally.

Heart failure doesn't mean your heart has stopped working, but rather that the heart isn't able to pump enough blood to meet your body's needs.

What does it feel like to have heart failure?

Heart failure can feel different depending on its severity. Common signs and symptoms include:

- shortness of breath, even during daily activities
- extreme tiredness (fatigue)
- rapid or irregular heartbeat
- feeling weak
- having trouble breathing when lying down

Because the heart isn't pumping efficiently, fluid can build in the lungs and other parts of the

body. When this happens, you might have:

- swelling of the ankles, feet, legs or abdomen
- rapid weight gain
- coughing or wheezing

Some women feel dizzy and nauseous, which could also be due to certain medications. Your medications can be adjusted to minimize any side effects.

Treatment

Treatment can help you live a longer, more active life. Your treatment will depend on how serious your heart failure is.

Treatments usually include lifestyle changes, medicines and ongoing medical care. For more advanced cases, a device or even a heart transplant may be needed.

Lifestyle changes

- eat a low-sodium diet; too much salt can make your body retain fluid, making heart failure worse
- get regular exercise (as your doctor advises)
- lose weight, if needed
- stop smoking
- restrict your fluid intake if you have been told to
- don't drink alcohol
- weigh yourself daily and notify your care team of sudden weight gain
- notify your care team of changes in your symptoms

- keep other conditions, such as diabetes or high blood pressure, under control
- ask your care team if you should have flu or pneumococcal vaccinations

Medications

Medications are used to help the body:

- 1) get rid of extra fluid
- 2) reduce the strain on the heart
- 3) manage other conditions (high blood pressure, atrial fibrillation, etc.)

For more advanced cases, a device or even a heart transplant may be needed.

Procedures or surgery

Cardiac resynchronization therapy (CRT) helps both sides of the heart pump at the same time. An implantable cardioverter defibrillator (ICD) monitors your heart rhythm and sends electrical impulses or a shock to restore a normal heart beat.

A left ventricle assist device (LVAD) helps pump blood from the heart to the rest of the body.

Heart transplant is reserved for certain people with end-stage heart failure.

Ongoing care

There are many ways your doctor might choose to monitor your condition; for example, by using imaging tests and/or special monitoring devices.

Your doctor will discuss plans for your ongoing care, including how often you will need follow up visits to help track your health.



Advice from *Others*



1. Know what is normal for your body. If you notice changes—swelling, weight gain, an odd heartbeat, or just feeling worse than usual—tell your doctor or call 9-1-1 right away.



2. Pace yourself. You may not be able to get up and go like you used to. Even simple trips to the store may be exhausting.



3. Conserve energy. Save your energy for what really matters. If you are doing an activity or going on a trip, take it easy in the days prior; opt to use a wheelchair at airports, ask for help.



4. Educate yourself. Learn all you can about your specific heart failure.



5. Find a doctor you trust. Heart failure accounts for some 11 million visits to the doctor each year. You need to feel confident in your health care providers and be able to talk openly about concerns.



6. Stick to your treatment plan. Living with heart failure means you have to actively manage your health.



7. Stay active, but don't overdo it. Many women with heart failure say that exercise is the single best thing they do for their heart – and to feel good. Ask your doctor what's right for you.



8. Ask about cardiac rehab. Cardiac rehab has been shown to lower mortality rates and decrease hospital admission, especially among women.



9. Lean on others. Take advantage of WomenHeart's free patient support services to share information, tips and get emotional and social support. Visit www.womenheart.org to learn more.



10. Watch for signs of depression. Depression is common in women with heart failure, often due to the related physical limitations and financial hurdles.



11. Take your medications as directed. Women with heart failure might take 10 or more medications, especially if they have diabetes, depression or other conditions. Make sure you understand all of your medications. For example, a diuretic or water pill helps get rid of excess fluid, but it means more trips to the bathroom.



12. Keep an eye on the scale. Sudden weight gain may mean that fluid is building up in your body because your heart failure is getting worse.



13. Be honest. Whether it's with friends, family or your partner. Give concrete examples of how your ability to do certain things has changed. Don't be shy about asking for or accepting help.

Fast Facts about Heart Failure

- Nearly 6 million Americans live with heart failure. There are 700,000 new cases each year.
- Heart failure is the main reason people 65 and older are admitted to the hospital.
- A significant number of patients with heart failure will return to the hospital soon after being seen for their heart condition. New efforts and policies are in place to help reduce hospital readmissions.
- Women and men have an equal risk of developing heart failure – about 1 in 5 people over a lifetime. Women, on average, are 5 to 10 years older than men when they are diagnosed and they tend to have more hospital stays, severe symptoms and report poorer quality of life.
- Contrary to what people might think, women can develop heart failure at any age, though it is more common as we get older. Research has focused mainly on patients with a low ejection fraction, but women are more likely to have heart failure with normal or “preserved” ejection fraction.
- Diabetes, heart valve disease and high blood pressure seem to be more strongly linked to heart failure in women than men.
- Depression is also more common in women with heart failure than men.
- About half of people diagnosed with heart failure die within 5 years. Because of this, it is important to talk to your doctor about ‘advanced’ heart failure therapies that are available at hospitals that specialize in cardiac transplantation and mechanical assist support.



Survey says...

It's time to get talking.

Based on WomenHeart's national survey of women with heart failure, the best thing you can do for yourself is to take an active role in your heart health. Be empowered. Make sure to ask about:

- ways to adjust your treatment if it isn't working for you
- how to take your medications correctly
- resources to help you cope with heart failure and/or deal with the costs of your medications and care

Getting the most from your health care visits

*W*hether it's with your primary care doctor or nurse practitioner or your cardiologist, take the time to prepare for each appointment.

- Set reminders for all of your medical appointments and tests
- Write down questions and concerns before each visit
- Keep track of your symptoms and weight
- Ask someone to go with you to offer support

Talk about:

- How you feel
- How your condition is affecting your ability to do things and if you feel depressed
- Your medications – report any side effects or other concerns
- Any financial constraints



**“WomenHeart gave me
a voice and reminded
me I have value.”**

– Eileen

WHEN TO SEEK IMMEDIATE HELP

Talk with your doctor about the warning signs that heart failure is getting worse. These may include:

- Chest pain
- Fainting
- Shortness of breath
- Rapid weight gain or swelling
- New or worsening cough



Questions to Ask Your Healthcare Team

- ☒ What type of heart failure do I have?
- ☒ What medications will I need to take and why?
- ☒ Are there side effects I should watch for?
- ☒ How will we know if treatment is working?
- ☒ How can I prevent episodes?
- ☒ What exercise is best for me?
- ☒ Can you refer me to a cardiac rehab program?
- ☒ Can other health issues make heart failure worse?
- ☒ What is my ejection fraction and what does that mean?
- ☒ Do I need my ejection fraction re-checked? How often?
- ☒ How serious is my condition? What is the outlook based on my heart function?
- ☒ How will my condition be monitored?
- ☒ At what point will I need a device or heart transplant?
- ☒ Should I see a heart failure cardiologist?
- ☒ Should I consider a clinical trial?
- ☒ Is there financial assistance?

Use the space below to write down any other questions or concerns you have:

WomenHeart

is here for YOU



WomenHeart: The National Coalition for Women with Heart Disease is the first and still only national organization providing free patient support services to women living with heart disease, and help women live healthier lives.

Through our support programs and services, women form a special bond and can freely share information and stories of hope and survival. Here are just a few programs that can help.

Local Support Networks

Led by trained patient volunteers, WomenHeart's local Support Networks meet monthly to provide women living with heart disease critical peer-to-peer support, heart health information and encouragement. WomenHeart has more than 100 community Support Networks around the country. To find an in-person WomenHeart Support Network in your area, visit www.womenheart.org.

Online Support Community

Register and become a member of our free Online Community for women with heart disease and their friends and family. Share personal stories and experiences living with heart conditions.

SisterMatch

After being diagnosed, many women experience feelings of isolation and depression. Being able to talk to someone "who's been there" can make a difference in your emotional recovery.

Through the SisterMatch program, women connect one-on-one with a *WomenHeart Champion* volunteer who can provide needed support over the phone, in person, or via email.

HeartScarves

Since HeartScarves was founded in 2005 by two female heart disease survivors, thousands of scarves have found their way to thousands of women heart patients, thanks to WomenHeart and its national volunteer corps of *WomenHeart Champions*. Each handmade red scarf offers comfort, support, and encouragement for a woman with heart disease, and becomes part of her healing journey.

"When I wrap my hand-knit scarf from WomenHeart's HeartScarves program around my neck, it reminds me of the warmth and closeness of my heart sisters."

– Manuela, *WomenHeart Champion*

Stay Up-to-Date

Register at womenheart.org today to receive a free monthly newsletter with heart health information and tips for women with heart disease.



**"Through WomenHeart,
I learned I'm not alone. I love all
the information, resources and
support."**

– Marilyn

**For more information or to find support,
visit www.womenheart.org.**

What YOU can do

Join WomenHeart to help other women with heart disease at www.womenheart.org

- Share your experiences and get support from others like you.
- Become informed and empowered about your treatment options.
- Advocate for more research — less than one in four clinical trials related to heart failure have included women.
- Tell your story to help other women.

Every woman should have access to early and accurate diagnosis and proper treatment for heart disease, including cardiac rehabilitation. Become a *WomenHeart Champion* and attend the Science and Leadership Symposium!

**For more information about heart failure
and to find support, visit:**

www.womenheart.org



202.728.7199

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WomenHeart: The National Coalition for Women with Heart Disease is the nation's only patient-centered organization serving the 42 million American women living with or at risk for heart disease – the leading cause of death in women. WomenHeart is solely devoted to advancing women's heart health through advocacy, community education, and the nation's only patient support network for women living with heart disease. WomenHeart is both a coalition and a community of thousands of members nationwide, including women heart patients and their families, physicians, and health advocates, all committed to helping women live longer, healthier lives. To receive a free online heart health action kit or to donate, visit www.womenheart.org.



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