Living with HFpEF – a patient’s story [1]

Patient Perspectives [2]

“I count every day as a gift. I don't know how long I'll live, but as long as I'm alive I want to be active and productive”, says a determined Cynthia, who lives with a form of heart failure. Cynthia is not alone, heart failure affects approximately 26 million people worldwide¹ and this is estimated to increase by 46% by 2030².

Video of Living with Heart failure with preserved Ejection Fraction (HFpEF) | Cynthia’s story

Having heart failure means that the heart is unable to pump blood around the body as effectively as it should. Therefore, the heart cannot support the body’s need for blood and oxygen³,⁴. Heart failure does not mean that the heart has stopped working, but that it needs some support to help it work more effectively.

How Ejection Fraction affects Heart Failure

There are two types of heart failure: Heart Failure with reduced Ejection Fraction (HFrEF) and Heart Failure with preserved Ejection Fraction (HFpEF). The first, HFrEF, occurs because part of the heart loses its ability to contract normally, meaning the heart cannot pump with sufficient force to push enough blood into circulation⁵. Conversely, HFpEF occurs when part of the heart stiffens and loses its ability to relax normally. This means the heart can't properly fill with blood during the resting period between each beat⁵.

HFpEF is life-altering, and I try to make sure that I am respectful of what the disease process is doing to my body without giving myself up to the disease.

Cynthia is one of the nearly 13 million people with HFpEF¹. When she was diagnosed with HFpEF, her cardiologist described it to her as: “Your heart is small and it's hardening, it doesn't let the blood in to get out to your body. That's why you cough and have all these lung-like symptoms.”

Nearly half of all patients with heart failure have HFpEF and this is expected to increase in the developed world⁶. This increase is likely caused by the increasing prevalence of common risk factors including older age, high blood pressure, renal dysfunction and obesity⁷.
Keeping the heart of patients at the heart of everything we do

Impact of HFpEF on patients and society

The symptoms of HFpEF are often non-specific, meaning it can be confused with other conditions. Symptoms can affect daily life, worsen over time and can include shortness of breath, swollen limbs due to fluid build-up, fatigue and weakness, coughing or wheezing, nausea, and lack of appetite.

Cynthia describes HFpEF as a “chameleon disease because it can fool people… It changes its colors according to what you want to see”. This is because the symptoms can range from mild to severe and they may come and go.

Whilst her heart failure makes her very tired, cough regularly and lose her breath, she says that she won’t give into these symptoms: “You have to get up and go and move, and when you think you can't go any further, it's really important to go a little further - push yourself.”

The impact of HFpEF is broad and far reaching. People with HFpEF are frequently hospitalized and often lead shorter, more restricted lives. They may experience a lower quality of life than in many other chronic diseases. Living with HFpEF can also be difficult for patients’ support networks. In a study, caregivers of people with heart failure reported moderately poor physical and emotional health-related quality of life.

That's my hope, that people will be more open about saying, ‘Yes, I have HFpEF, and yes, we need to do something about it’.

Novartis' research into heart failure is leading to a better understanding of the disease. Regardless of the type of heart failure, we are committed to discovering new management options for all people with heart failure, including after a heart attack.

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References:


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