



## TITLE:

# When a Cardiologist Says “X,” a Patient Thinks “Y”: The Importance of Shared Decision Making in the Management of Hypertrophic Cardiomyopathy

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## ABSTRACT

While once considered rare and life-threatening, hypertrophic cardiomyopathy (HCM) is now known to affect approximately 1:500 individuals in the U.S. However, since patients can be asymptomatic and undiagnosed, the prevalence of HCM may be as high as 1:200. It is the most common genetic heart disease in the U.S. and while the mortality rate is now considered low (0.5%), it remains the primary cause of sudden cardiac death (SCD) in individuals under 40 and in young athletes.

While advancements in imaging and genetic testing have led to more reliable diagnoses, it is a not uncommon for HCM patients to have been misdiagnosed or mismanaged. This discrepancy can be attributed to symptoms that are vague and intermittent as well as a lack of knowledge of the condition in the medical community.

Constructive communication between the patient, and the physician is essential in the care of HCM. A preferred approach is shared decision making (SDM), a dialogue to include the clinician’s interpretive findings, and prognostic opinions and the patient’s expressed values of what is most important to them in managing HCM.

A SDM approach is especially beneficial considering the link between HCM and SCD and the emotional and psychological toll experienced by many patients who have been misdiagnosed. It

is common for HCM patients to “awfulize” the information provided to them and misinterpret the options available to manage the condition.

Since 2005, my efforts have focused on the emotional wellbeing of HCM patients through education to national professional societies, biopharmaceutical companies, legislators, and support groups for HCM patients. The most common mental health complaint expressed is chronic anxiety, including panic attacks. Shared decision making offers a constructive patient-centered approach to ensure communication about HCM is delivered, and received, in the most accurate and sensitive manner possible.

## BIOGRAPHY

Gwen Mayes is a leading HCM patient advocate, spokesperson, and policy expert on the diagnosis and therapeutic interventions for hypertrophic cardiomyopathy. Mayes is a physician assistant and attorney with 30+ years’ experience in Washington, DC as a government relations expert representing biopharma and cardiac device companies’ interests, as a consultant to the U.S. Surgeon General, and EVP of Public Policy for the National Patient Advocate Foundation during the passage of the Affordable Care Act. More importantly, as a lifelong HCM (obstructive) patient with symptoms at birth, she provides cardiologists and other health professionals with

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the patient's perspective on how shared decision making will maximize the patient's ability to clinically, and emotionally, manage the myriad of changes that come from living with HCM. Mayes was the Project Manager of the HCMA Patient-Focused Drug Development Meeting and the lead author of the PFDD Voice of the Patient Report in 2020. She holds a BA in Biology and Pre-Medical Studies from Transylvania University; a Masters in Medical Science from Emory University; and a Juris Doctorate with honors from the University of Maryland. Ms. Mayes is currently an independent consultant.



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