Should I Take Mavacamten for Obstructive Hypertrophic Cardiomyopathy? (Non-Surgery)

A decision aid to discuss options with your doctor

This decision aid is for you if:

- Your doctor says you have obstructive hypertrophic cardiomyopathy (oHCM).
- Your doctor has offered mavacamten to help with your oHCM.
- Your oHCM is causing symptoms that are affecting your quality of life.

What is oHCM?

- oHCM is a genetic heart condition where the muscles between your heart chambers are naturally thicker.
- With each heartbeat, the additional muscle mass blocks (or obstructs) blood flow out of the heart.
- There is currently no cure for oHCM, but symptoms can be managed with medications and sometimes a procedure.
- oHCM can cause tiredness, chest pain, shortness of breath, lightheadedness or dizziness, leg swelling, and reduces your ability to be active.
- These symptoms can decrease your quality of life.

What is mavacamten (brand name: CAMZYOS®)?

- Mavacamten is a medication for oHCM. Mavacamten works by relaxing the heart muscle and relieves the obstruction. This results in more blood being able to leave the heart.
- The potential pros and cons of taking mavacamten for oHCM are listed on **page 2**. It is important to understand that mavacamten does not prevent or delay death.
- Mavacamten is a capsule taken by mouth once a day.
- In Canada, this medication costs around $22,500 per year, but your insurance may cover some or all of this cost.

What are your options?

Take mavacamten	⟷	Decline mavacamten
		+discuss other options with your doctor

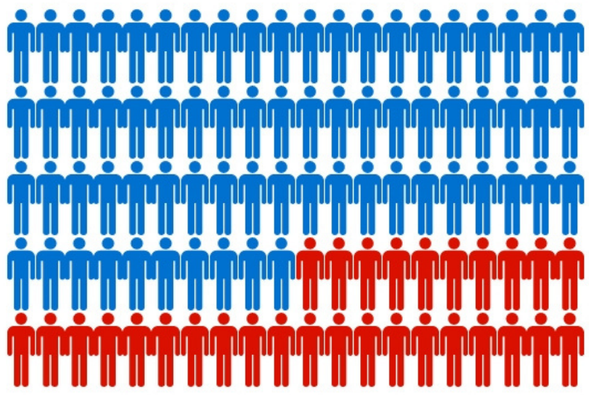
Working through these 4 steps will help you consider the different options

Step 1: What are the benefits and harms of each option? **(Pages 2)**
Step 2: What matters most to you? **(Page 3)**
Step 3: What else do you need to prepare to make a decision? **(Pages 3 and 4)**
Step 4: What are the next steps? **(Page 4)**

Step 1: What are the benefits and harms of each option?

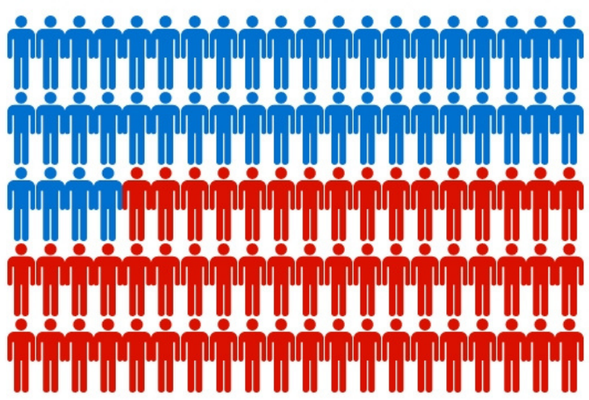
Take mavacamten	Decline mavacamten

Symptom improvement



70 out of 100 people like you will have noticeable improvements in quality of life due to fewer symptoms

30 out of 100 people like you will NOT have noticeable improvements in quality of life due to fewer symptoms

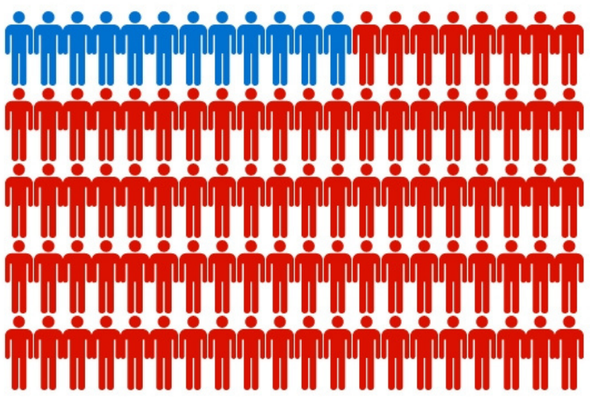


44 out of 100 people like you will have noticeable improvements in quality of life due to fewer symptoms

56 out of 100 people like you will NOT have noticeable improvements in quality of life due to fewer symptoms

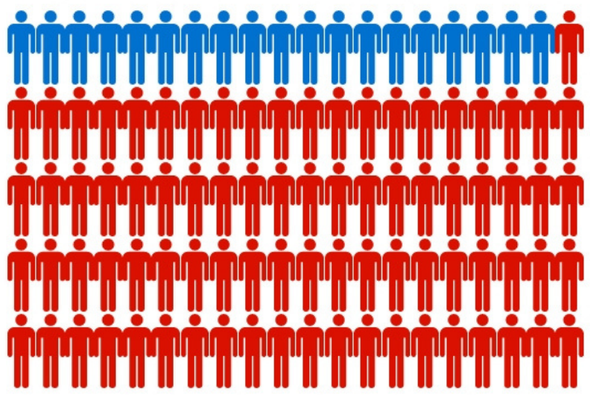
Another way to interpret this: if 100 people like yourself took mavacamten, 26 more would have noticeable improvements in quality of life.

Side effects



12 out of 100 people like you will not experience side effects

88 out of 100 people like you will experience 1 or more side effects



19 out of 100 people like you will not experience side effects

81 out of 100 people like you will experience 1 or more side effects

The 2 most common side-effects of mavacamten are dizziness and headache.

Required monitoring

- Mavacamten can reduce the squeezing function of the heart (called the ejection fraction).
- After starting mavacamten, we will monitor your heart function with frequent echos (short for echocardiograms).
- For example, you may get an echo every month for the first 3 months after starting mavacamten.
- If you decide not to take mavacamten, you are still required to do echos around once a year, as part of your routine heart check-up.

Costs

Without insurance, mavacamten costs about $22,500/year.

You can check how much mavacamten will cost you by following these steps:

1. Call your insurance company regarding coverage and the cost of mavacamten with your plan.
2. Talk to your healthcare team about any support programs to help with the cost of mavacamten.
3. Write it down: mavacamten will cost me $ _____ per year.

Step 2: What matters most to you?

Circle how much each reason matters to you on a scale from 0 to 5.
0 = **NOT** important to you. **5**= **VERY** important to you.

How important is it to you to...

improve your symptoms?	0	1	2	3	4	5
avoid spending money on mavacamten?	0	1	2	3	4	5
avoid the need to repeat echos?	0	1	2	3	4	5
avoid side effects like dizziness and headaches?	0	1	2	3	4	5
avoid taking one extra pill once a day?	0	1	2	3	4	5

Think about which option has the reasons that are most important to you. Check ☑ one.

☐ Take mavacamten ☐ Decline mavacamten ☐ I am not sure

Step 3: What else do you need to make a decision?

Find out how well this decision aid has helped you learn about mavacamten.	**Taking mavacamten**	**Not taking mavacamten**	**Both are the same**	**Not sure**
Which option has the highest chance in improving symptoms?	☐	☐	☐	☐
Which option will increase the chance of side effects like headache and dizziness?	☐	☐	☐	☐
Which option requires less echo monitoring?	☐	☐	☐	☐
Which option will be the least expensive?	☐	☐	☐	☐

Step 3 answers: Question 1 - taking mavacamten. Question 2 - taking mavacamten. Question 3 - not taking mavacamten. Question 4 – not taking mavacamten.

Find out how comfortable you feel about deciding	**YES**	**NO**	
Do you feel SURE about the best choice for you?	☐	☐	**If you answered 'No' to any of these, please discuss with your healthcare provider.**
Do you know the benefits and harms of each option?	☐	☐	
Are you clear about which benefits and risks matter most to you?	☐	☐	
Do you have enough support and advice to make a choice?	☐	☐	

(The SURE Test © O'Connor & Légaré, 2008)

Step 4: What are the next steps?

Check ☑ what you want to do next

☐ I have decided to take mavacamten.
☐ I have decided not to take mavacamten.
☐ I need to discuss further with my specialist and family.
☐ I need to know more about my options.
☐ Others, please specify _____

This information is not intended to replace the advice of a healthcare provider

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Benefits and harms data are taken from: the VALOR-HCM trial (PubMed identifiers: 35798455), and the EXPLORER-HCM trial (Pubmed identifiers: 32871100).

My notes: