

Shared decision-making
for people with heart
valve disease:

A patient guide





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- Victoria Delgado, University Hospital Germans Trias i Pujol, Spain
- Ruggero De Paulis, European Hospital, UniCamillus University, Italy
- María Cecilia Salvador González, Asociación Española de Portadores de Válvulas Cardíacas y Anticoagulados, Spain
- Sandra Lauck, St Paul’s Hospital, The University of British Columbia, Canada
- Patrick Myers, European Association for Cardio-Thoracic Surgery, Lausanne University Hospital, Switzerland
- Jens Näumann, Initiative Herzklappe, Germany
- Bernard Prendergast, St Thomas’ Hospital and Cleveland Clinic London, UK
- Katja Teichert, Meine Herzklappe, Austria
- Wil Woan, Heart Valve Voice, the Global Heart Hub Heart Valve Disease Patient Council, UK

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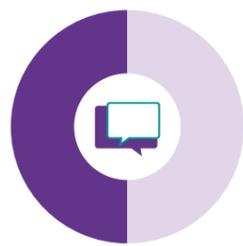
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Who is this guide for and what does it cover?

This guide aims to support people with heart valve disease in participating in decision-making about their care. People who are diagnosed with heart valve disease are often confronted with a wide range of treatment options. The most recent ESC/EACTS Guidelines for the management of valvular heart disease (Box 1), published in 2021, state that ‘the patient and their family should be thoroughly informed and assisted in their decision on the best treatment option.’¹ Shared decision-making goes beyond educating a person about their illness. It involves doctors and patients working together to choose the most suitable treatment, based on the patient’s preferences and goals as well as clinical evidence and the doctor’s expertise.²⁻⁴

Shared decision-making in heart valve disease has proven benefits. It has been shown to improve patient satisfaction, quality of life and other outcomes meaningful to individuals, but too often it does not take place.



A recent survey of people with heart valve disease in Austria and Germany found that only about half of respondents had been involved in discussions about different treatment options.⁵

This guide seeks to empower people with heart valve disease to express their goals and treatment preferences to their care team. It does not seek to replicate or replace established clinical guidelines for the management of valvular heart disease.

Box 1. What are the ESC/EACTS guidelines?

The 2021 ESC/EACTS Guidelines for the management of valvular heart disease have been developed by clinical experts, primarily from the two main medical societies in Europe involved in the management of heart valve disease: the European Society of Cardiology (ESC) and the European Association for Cardio-Thoracic Surgery (EACTS).

Guidelines represent the scientific consensus on what treatments and interventions are in the patient’s best interest. While guidelines are not a strict protocol for each treatment decision or person, they are nonetheless an important and influential document that doctors and patients should be aware of.

The ESC/EACTS guidelines provide recommendations for care, which are based on available scientific evidence and medical knowledge. These recommendations are not mandatory – they cannot anticipate the unique needs, wishes and circumstances of every person. Rather, the final decision about which treatment strategy to choose for each person depends on their characteristics and preferences, and should be made jointly by the treating doctors and the person themselves (and a carer, if appropriate).

Shared decision-making:

When and how you can be involved in decisions about your care

Being diagnosed with heart valve disease

What do the guidelines say?

If a doctor suspects a heart murmur, they should refer you for further investigation, ideally to a heart valve clinic where you can receive specialist care.

To confirm the diagnosis of heart valve disease, an echocardiogram should be performed by specialist imaging staff who are trained in echocardiography. Further tests, such as an exercise stress test, might be needed to confirm a diagnosis of heart valve disease.⁶

What is specialist heart valve care?

Every person with heart valve disease should ideally receive care from a team of professionals with specialist knowledge in heart valve disease. The team, often referred to as a heart team, typically includes: heart surgeons; cardiologists trained in interventions for structural heart disease, imaging and heart failure; anaesthesiologists; and specialist nurses.¹ They each contribute their expertise to make the optimal treatment recommendation for an individual patient. Together, they can help weigh the risks and benefits of the different procedures and discuss them with patients. They should then make a joint decision with the patient about the choice of treatment.

What are my opportunities to participate in decisions about my care?

- Once you are diagnosed with heart valve disease, **your doctor should provide you with information materials about your diagnosis.** This will allow you to learn about your condition and ask any questions the materials do not answer.
- Many people who are diagnosed with heart valve disease will eventually need a valve replacement or repair. **Informing yourself about the possible options early will mean you are prepared** when it comes to making a decision on different treatment options.
- If your symptoms get worse while waiting for a referral to confirm your diagnosis, **speak to your referring doctor** and let them know – you may need to receive further investigation sooner.



‘Watchful waiting’: the period before treatment

What do the guidelines say?

If you have been diagnosed with heart valve disease, you may not immediately require treatment. During this ‘watchful waiting’ period, doctors or nurses who are experienced in the management of heart valve disease will have regular appointments with you to keep track of your health and note any changes in the state of your heart valves and heart muscle. The length of this close monitoring varies from person to person, and it will last until you require a valve repair or replacement. At this point, it’s time to make a decision about the type of treatment.¹

In some cases, the heart surgeons and cardiologists in your care team may suggest an immediate valve repair or replacement, even if you don’t have any symptoms. This could prevent you from experiencing cardiovascular problems in the future, and might be considered if you are at low risk of complications from surgery.¹

Making a choice about treatment

What do the guidelines say?

When the time comes for your valve to be repaired or replaced, a range of options will be available (*Table 1*).

Your team of doctors should carefully evaluate and weigh the risks and benefits of each approach for you, and explain them to you. Guidelines clearly state that treatment recommendations should be discussed with you as a patient so that you and your care team can make an informed treatment choice together.

What are my opportunities to participate in decisions about my care?

- **Make sure you closely monitor any changes in your symptoms**, and attend regular check-ups with your doctor. The doctor can assess whether the condition of your heart valves has worsened, even if the changes were unnoticeable to you.
- **Think carefully about your personal life goals and any worries you may have about the procedure.** Be sure to talk about this with your doctors, so they can consider your perspective when recommending a type of valve repair or replacement and the exact timing. It may be important, for example, to consider how any planned activities might fit in with recovery times after the procedure. Your care team should also address any concerns and fears you may have.
- **Connect with your local patient organisation.** It might be useful to get in touch with a patient organisation, which can offer support and point you to information and resources.



Table 1. Options for valve repair and replacement

Heart valve repair		
Surgical techniques		
It may be possible to repair heart valves instead of replacing them. The repair requires open heart surgery and aims to fix defects in the heart valve. Repairing a heart valve can often bring better results than replacing it. ⁷		
Heart valve replacement		
Surgical techniques	Catheter-based approach	
A surgical valve replacement is usually performed by open heart surgery. Minimally invasive techniques with smaller incisions are also increasingly available.	This involves a thin tube (catheter) being inserted through a blood vessel, giving access to the heart valve. A new biological valve can then be inserted without removing the original one.	
<p>Mechanical valve replacement</p> <p>Mechanical valves are made of carbon or metal and are very durable – they can last a lifetime. This means it is less likely that you will need a second valve replacement.</p> <p>With a mechanical valve, you will need to take blood-thinning medication every day for the rest of your life to reduce the risk of blood clots forming in the valve.</p> <p>Mechanical valves may increase the risk of bleeding.¹</p> <p>Mechanical valves make a clicking sound that some patients may be able to hear.</p>	<p>Bioprosthetic/biological valve replacement</p> <p>Biological valves are made of animal tissue that is strong and flexible enough to last 10–20 years. They usually don’t require high doses of long-term blood-thinning medication.¹</p> <p>This means there is a higher chance you may need another operation than with a mechanical valve, but the risk of bleeding is lower.⁸ This might be important if some of your daily activities, such as your job or hobbies, increase your risk of bleeding.</p>	<p>Catheter-based approaches are typically recommended when surgery is not appropriate. An example is transcatheter aortic valve implantation (TAVI), recommended for people over the age of 75 who have a higher risk associated with surgery.¹ A valve replaced with a TAVI procedure can last up to eight years (and perhaps longer) in this group of people.</p> <p>Complications, such as the need for a pacemaker implantation and problems with the valve leaking, are more likely with TAVI than with surgery.¹</p>

‘For a variety of reasons, a valve sometimes needs to be replaced more than once and it is important to be prepared that this might happen. As a congenital heart disease patient, this has been the case for me, with my first valve replacement taking place several decades ago. It is great to see that there has been so much progress: today, several less invasive surgical procedures are available and the recovery is much better than 40 years ago.’

María Cecilia Salvador González, patient advocate

What are my opportunities to participate in decisions about my care?

- **Ask whether you will have the opportunity to discuss your preferences** for a valve repair or replacement with a member of your heart team, such as a nurse. They can share your preferences with the treating heart surgeon and cardiologist, and answer any questions you may have.
- **Write down any questions in preparation** for this conversation in advance. Try to define your goals and preferences for the life you want to live after the valve procedure (you can use the guiding questions from the [shared decision-making checklist](#)).
- **Many people find it helpful to bring a family member, close friend and/or carer** to the appointment to discuss their treatment. They can make notes and help ask questions, as the amount of information shared can sometimes feel overwhelming.
- **If you are still unsure about the treatment choice** after you’ve had your conversation, it’s fine to request another appointment or ask for a second opinion from another heart team

‘Initially, the diagnosis of heart valve disease was a shock for me, with many uncertainties, emerging fears and unanswered questions. And as a patient, it often doesn’t seem like you can have an open discussion with your doctor. In my opinion, two things are therefore important when it comes to the conversation with your doctor. First, come prepared, by writing down any questions you may have before the meeting, and ask follow-up questions if anything is unclear. Second, bring someone with you to the consultation – they can provide emotional support, take in additional information and talk it through with you afterwards.’

Jens Näumann, patient advocate

The shared decision-making checklist

How can you prepare for the conversation about the choice of valve repair or replacement?

Think ahead and ask yourself what is important to you.

This will help your doctors consider the range of options and optimal choices for your treatment.

You may wish to ask yourself:

- What does my **lifestyle** look like now? Am I physically active? Do I work full time and am I the sole earner? What are my hobbies and things I like to do in my spare time? What does my weekly/monthly routine involve, and how flexible can I be with my commitments and interests?
- Do I have major **plans** or events coming up in the next 12 months for work, travel, family life (for example, starting a family), religious or cultural activities, or other interests?
- What kind of personal **commitment** am I willing to make to achieve the best possible outcome for the chosen treatment? What adjustments are easier to make and what would seriously reduce my quality of life? For example, would I find it easy to take daily medication for the rest of my life, or might that be difficult in reality?

‘With one of my patients, we decided together to move his mitral valve repair forward by a couple of months as he was planning to move to another country. It made him feel at ease to have had the procedure before settling into a new country, and he hasn’t had any issues since.’

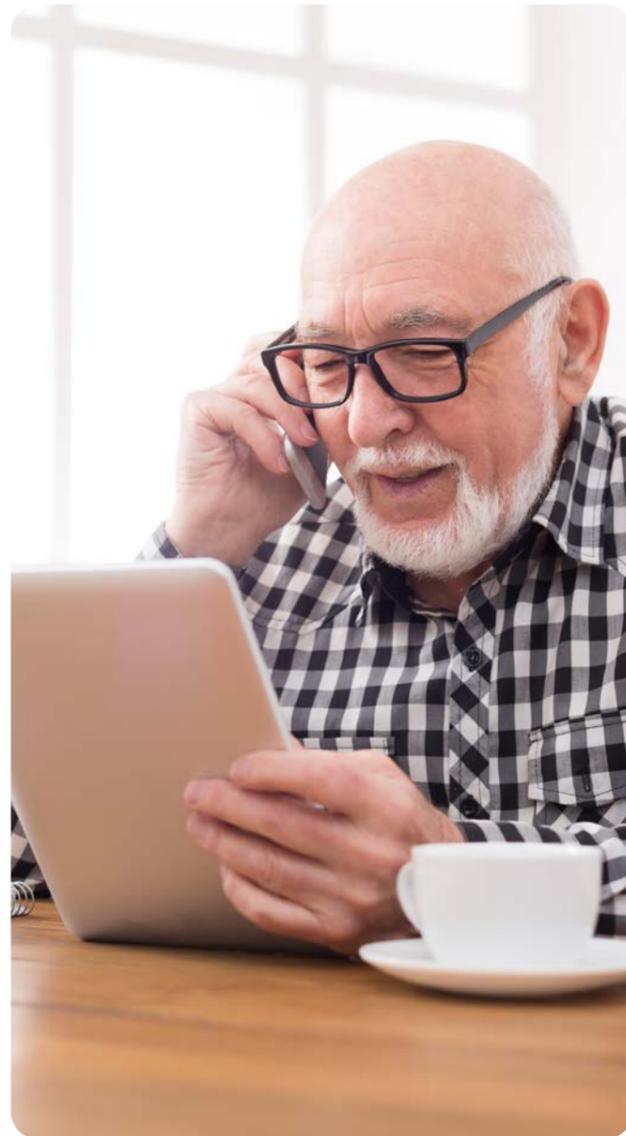
Victoria Delgado, cardiologist

Prepare questions that you may want to ask during the meeting with the heart team.

These could include:

- What are the different **options** for a valve replacement or repair (i.e. bioprosthetic/ biological or mechanical valves, or catheter-based interventions) and what advantages and disadvantages might they have for me? What are the risks if I do nothing?
- What is the likely **impact** of the different options on my daily life? What precautions might I need to take, and what will I have to do to stay well (e.g. daily medication)?
- How long might it take me to **recover** from each type of treatment? How long will I have to stay in hospital? What might my recovery time depend on?
- How might the **timing** of the procedure impact on my daily life and planned activities, including time to recover?
- How long does each method of replacement/repair **last**? What would it mean for me if the valve needs to be replaced again in the future?

Your doctors cannot predict the future, but they can give you helpful answers based on what they know about you, evidence from clinical research and their experiences with other patients.



Are the doctors involving you in decision-making?

Many people find it difficult to think of everything when speaking with their doctors, as choosing a treatment option is an important decision with consequences for health and wellbeing. You may want to reflect on your conversation later, when some time has passed. It may be helpful to ask yourself the following questions:

- Were the different treatment choices and their risks and benefits **explained** to me? Did doctors offer me useful materials that helped explain the different options?
- Was I given **time to think** about my preferences, lifestyle and life goals, and how they may be influenced by each type of treatment?
- Was I able to share any worries and ask **questions**? Did the doctors listen to my preferences and goals? Was I given time to think about my choice?

If, on reflection, you don't feel comfortable about the discussion you have had – or the choices that you or others have made about your treatment – you should raise this as soon as possible with your doctors or ask friends and relatives for support.



References

1. Vahanian A, Beyersdorf F, Praz F, *et al.* 2021. 2021 ESC/EACTS Guidelines for the management of valvular heart disease: Developed by the Task Force for the management of valvular heart disease of the European Society of Cardiology (ESC) and the European Association for Cardio-Thoracic Surgery (EACTS). *Eur Heart J*: 10.1093/eurheartj/ehab395
2. Lindeboom JJ, Coylewright M, Etnel JRG, *et al.* 2021. Shared Decision Making in the Heart Team: Current Team Attitudes and Review. *Struct Heart* 5(2): 163–67
3. Coylewright M, O'Neill E, Sherman A, *et al.* 2020. The Learning Curve for Shared Decision-making in Symptomatic Aortic Stenosis. *JAMA Cardiol* 5(4): 442–48
4. Lauck SB, Lewis KB, Borregaard B, *et al.* 2021. What Is the Right Decision for Me?; Integrating Patient Perspectives Through Shared Decision-Making for Valvular Heart Disease Therapy. *Can J Cardiol* 37(7): 1054–63
5. Näumann J, Teichert K. 2021. Patient Journey Herzklappen-erkrankungen. Erfassung des Ist-Zustands in Deutschland und Österreich. Available from: https://www.meineherzklappe.at/wp-content/uploads/2021/11/Patient-Journey-HerzklappenpatientInnen_Endversion.pptx [Accessed 30/11/21]
6. Wait S, Krishnaswamy P, Borregaard B, *et al.* 2020. *Heart valve disease: working together to create a better patient journey*. London: The Health Policy Partnership and The Global Heart Hub
7. Jung JC, Jang MJ, Hwang HY. 2019. Meta-Analysis Comparing Mitral Valve Repair Versus Replacement for Degenerative Mitral Regurgitation Across All Ages. *Am J Cardiol* 123(3): 446–53
8. Glaser N, Jackson V, Holzmann MJ, *et al.* 2015. Aortic valve replacement with mechanical vs. biological prostheses in patients aged 50–69 years. *Eur Heart J* 37(34): 2658–67

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