

# Middle-aged congenital heart disease survivors may need special care

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For the first time, the American Heart Association has issued recommendations for healthcare providers treating people older than 40 with congenital heart disease.

"People born with congenital heart disease are living longer and fuller lives than ever before, and there are now more adults than children with congenital heart disease," said Ami Bhatt, M.D., lead author of the new scientific statement published in the American Heart Association journal *Circulation*.

"These patients often have a sense that their heart has been 'fixed' and they don't need follow-up. However, in adulthood they can develop complications from the underlying disease or the heart repairs that kept them alive as children, therefore, these adults need lifelong cardiac care," Bhatt said.

Congenital heart diseases are heart and blood vessel abnormalities present at birth.

Among issues addressed in the statement:

- Physical activity is encouraged. Exercise intolerance is common in adults with congenital heart disease, and exercise testing can help physicians create an individualized physical activity plan.
- Most adults with congenital heart disease can be sexually active. People should talk to their physicians for advice about their heart

conditions, anxiety about [sexual activity](#) or about resuming sexual activity after a new heart problem or procedure.

- Many men with congenital heart disease can take erectile dysfunction drugs as long as they're not taking nitrates and their heart condition doesn't preclude sexual activity, and should discuss this issue with their cardiologist.
- Women with congenital heart disease struggling with menopausal symptoms, such as hot flashes, and contemplating hormone replacement therapy, must consider the heightened risk of blood clots if they undergo certain congenital heart disease procedures. Vaginal estrogen therapy can be useful in those with vaginal dryness.
- Adult complications of various types of congenital heart disease and their treatment include a higher risk of heart failure, valve problems, high blood pressure in the lungs, and [abnormal heart rhythms](#).

"A seemingly simple diagnosis from childhood can sometimes have complications in adulthood, while people with more complex congenital heart issues may stay stable with age," said Bhatt, who is also director of the Adult Congenital Heart Disease Program at Massachusetts General Hospital in Boston, Mass.

People with congenital heart disease may also develop acquired heart disease and attention to controlling [heart disease risk](#) factors like overweight, diabetes, blood pressure, smoking and sedentary lifestyle is important and should not take a back seat to their congenital medical history, Bhatt said.

In addition to being followed by a cardiologist, the association recommends adults with congenital [heart disease](#) keep records of their childhood diagnoses and corrective surgeries and pass them on to their physicians.

"Patients should be proactive to ensure that their providers are well-versed in their disease, and should respectfully encourage their providers to seek expert consultation if they are not," Bhatt said.

The statement also includes guidance for clinicians treating [congenital heart disease](#) patients who may also have cancer, lung, kidney or liver disease.

"Because some of the complications that occur with aging are related to the medical procedures done early in life, we need to gather information on what happens with age and give feedback to the pediatric cardiologists and surgeons so we can find ways to improve not only longevity but the long-term quality of life for these patients," Bhatt said.

Provided by American Heart Association

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