ASK THE EXPERT



TALKING ABOUT CONGENITAL HEART DISEASE AND MENTAL HEALTH

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Statement on Psychological Outcomes
and Interventions for Individuals with
Congenital Heart Disease







What would you suggest to parents of CHD children when it comes to building resiliency so that mental health issues can be addressed early?

I'd like to first say that I have a great deal of respect for parents and caregivers of children with CHD – I recognize how stressful their own experiences can be and would encourage them to seek support for themselves as needed.

I recommend keeping lines of communication open, so that children feel comfortable coming to their adults with any psychological or social concerns that might arise, both related and unrelated to health. It's important to avoid minimizing children's concerns or making false promises (eg, by saying things like "don't worry about it" or "I promise everything will be okay.")

Also, I recently became aware of the ISUPPORT rights-based standards for children having health care procedures (https://www.isupportchildrensrights.com). It's my understanding that these were primarily directed toward health professionals. However, I think they also provide a nice framework for parents and caregivers who wish to advocate for children's physical and psychosocial well-being in medical settings.

What are some of the factors that can contribute to mental health problems in people with CHD?

The first thing I'd say is that people with CHD face the same psychosocial challenges that people without CHD face – things like relationships, school, employment, financial stressors, discrimination, etc.

They also face CHD-specific stressors that can be chronic and/or major life events. Chronic stressors are those that happen on an ongoing or frequent basis – such as having fatigue or other physical symptoms that interfere with preferred activities, taking medications on a daily basis, or medical appointments that interfere with other things going on in a person's life. Major life events happen less frequently, but can have significant impact when they do occur – examples include surgery or another major medical procedure, cardiac device implantation, or a hospitalization. We know that negative childhood and adolescent experiences, both related and unrelated to health, can affect people throughout the rest of their lives.



Mental health support can be hard to find. Can the CHD care team help in this area, and who should parents of CHD kids, or CHD adults, speak to?

I definitely recommend speaking to one's CHD team for referral recommendations. I strongly advocate for the integration of mental health professionals within CHD teams, although that's unfortunately not common practice...yet! However, CHD teams might know of mental health professionals in the community with experience working with individuals and families affected by CHD. Primary care professionals are also often helpful referral sources.

I also believe in the collective advocacy of the voices of patients and families with CHD. I think that the more often that patients and families advocate for their mental health needs, the more likely it is that CHD programs will develop pathways for mental health care. I sense that the field of CHD is moving in the direction of accepting psychological well-being as an essential component of CHD outcomes.

The Roadmap Project

(https://www.roadmapforemotionalhealth.org), focused on the mental health of children, teens, and adults with chronic health conditions, has so many excellent resources, including a downloadable PDF on 'choosing a therapist' available <a href="https://example.com/https:

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Are there specific things CHD patients can do to reduce the likelihood of having problems with anxiety and/or depression?

There are self-care strategies that can be helpful as preventative approaches (ie, to reduce the likelihood that mental health problems arise) as well as strategies when psychological concerns arise. We include a list of examples of self-care strategies in our article for patients and families:

- Have good sleep skills and a consistent sleep routine
- Eat a healthy diet
- Stay physically active (it is good to ask one's CHD team for advice about physical activity)
- Keep a regular schedule (e.g., school, work, hobbies, volunteer work)
- Use relaxation techniques (e.g., breathing exercises, meditation)
- Pace oneself (do not overdo it on 'good days')
- Focus on strengths and what one can do
- Challenge fears by open discussion with family, friends, and medical team
- Plan pleasant activities
- Use helpful self-talk (Ask: What would I say to a good friend in this situation?)
- Connect with supportive family and friends
- Connect with others with CHD through hospital or online support groups



When looking for mental health help, are there differences in the type of specialists and what they offer? What are the most important factors to consider?

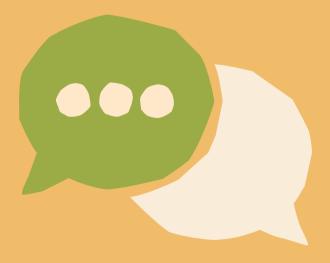
There are different types of mental health professionals. This is a list that our writing team previously prepared:

- Psychologists: non-medical doctors who specialize in mental health, focus on psychotherapy and/or neurodevelopmental/neurocognitive testing, and do not prescribe medications.
- **Psychiatrists:** medical doctors who specialize in mental health and who can prescribe and monitor medications.
- Clinical social workers: social workers with extra training in psychotherapy.
- Mental health nurses and nurse practitioners
- Licensed professional counsellors
- Couples and family therapists

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When looking for mental health treatment, it's important to consider personal preferences – whether someone prefers psychotherapy ("talk therapy") or whether one is looking for a clinician to prescribe medication. A practical factor involves access to and availability of mental health professionals. Depending upon one's country and one's personal resources, mental health care might be free within the public system, one might use health insurance to access it, or one might pay out of pocket.

Although it might not be possible to work with mental health professionals with CHD experience, I recommend working with clinicians with experience working with individuals with chronic health conditions when possible.





There's a lot of information about antidepressants and anti-anxiety medications. Can you talk a bit about when they might be appropriate for a person with CHD.

You can access the original American Heart Association article <u>HERE</u>.

A patient/family-friendly article is available <u>HERE</u>.

Thank you to Dr. Adrienne Kovacs for sharing her expertise.

Please don't forget to share!

