

Psychological Aspects of Living with Congenital Heart Disease: Information for Patients and Families

Prepared by:

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The document has been prepared by the authors of the following 2022 Scientific Statement from the American Heart Association. The authors, two of whom have congenital heart disease, represent psychology, psychiatry, social work, nursing, and cardiology. This document provides general information and does not provide health advice or treatment recommendations for specific individuals.

The Scientific Statement can be accessed here:

[Psychological Outcomes and Interventions for Individuals with Congenital Heart Disease: A Scientific Statement From the American Heart Association](#)



The Adult Congenital Heart Association thanks the writing group for sharing the information in this handout for patient and family supporters of ACHA.

Background

Almost 1 in 100 babies are born with congenital heart disease (CHD). This is the most common birth defect. A few decades ago, less than 25% of people born with CHD would reach adulthood. Due to improvements in both diagnosis and treatment, now over 90% reach adulthood. In the United States alone, there are over 2.4 million people living with CHD!

We know that many people with CHD are resilient and have good coping strategies. We also know that children and adults with CHD face significant medical challenges. These include hospital stays, surgeries, other medical procedures, and cardiac symptoms (like heart rhythm problems and fatigue). Therefore, it is not surprising that many also have mental health problems, such as anxiety and depression. The authors' goal with the Scientific Statement (*Psychological Outcomes and Interventions for Individuals with Congenital Heart Disease*) was to summarize information so that CHD health care professionals (HCPs) could help patients get the support and mental health services they need.

We wrote this document for patients and families. We hope patients and families use this information in many ways. First, we want this to be an easy-to-read summary. Patients and families do not have to read the whole Scientific Statement. Second, we encourage patients, family members, and clinicians to talk more about mental health. Doing so is such an important part of our overall health and well-being. We hope this will help start the conversation. Third, this summary has information about the mental health challenges of CHD that can help health care professionals (HCPs) better support patients and families. People might give this to their HCPs (including mental health clinicians) who are less familiar with CHD.

While there may be some similar experiences, every person with CHD, and every family facing CHD, is different. The challenges listed here will not affect every person living with CHD. They will also not affect all people the same way. If reading this raises any concerns or worries for you, please speak to your HCP.

In summary, many people with CHD experience mental health concerns. In this document, we describe common challenges, highlight strengths often seen in people with CHD, and explore how to get needed support. Please know you are not alone.

Emotional, social, and behavioral challenges are common

People with serious medical conditions, like CHD, have a higher risk of emotional, social, and behavioral problems. About 25% of children with CHD have problems with intense fear, worry, or sadness. These can be even more common in children with certain types of CHD. About 50% of adults with CHD will have anxiety or depression at some time in their lives. This has been linked with poorer health outcomes and higher medical costs.

People with CHD can have problems coping with uncertainty, anxiety, depression, and post-traumatic stress at any age. Some people may experience stigma (being negatively judged by others) because of their CHD or mental health concerns or both. However, no two people with CHD are the same. Everyone has different experiences and finds certain situations more stressful than others. Also, no two people have the same ways of coping with stress.

People with CHD can face challenges both related and unrelated to living with CHD. The following table shows some of the more common challenges related to CHD.

Potential CHD challenges and outcomes across the lifespan

Stage of life	Possible mental health and behavioral challenges	Possible outcomes
Infancy	<ul style="list-style-type: none"> • Hospital stays, surgeries, and other medical procedures • Exposure to scary situations or painful procedures • Being apart from caregivers and family while in hospital 	<ul style="list-style-type: none"> • Greater sensitivity to light, sound, smell, and touch • Problems with feeding, sleeping, settling, soothing, or bonding • Fear and distress • Developmental delay
Childhood	<ul style="list-style-type: none"> • Hospital stays, surgeries, and other medical procedures • Being apart from family and peers while in hospital • Less time for play • Missed days at school • Neurodevelopmental problems 	<ul style="list-style-type: none"> • Coping problems • Being less social • Learning challenges at school • Aggression or hyperactivity • Feeling different from peers • Anxiety, depression, and post-traumatic stress
Teenage years	<ul style="list-style-type: none"> • Hospital stays, surgeries, and other medical procedures • Following a healthy lifestyle (e.g., exercise and healthy eating) • Fewer chances for independence • Body image concerns • Dating • Being treated differently by friends, family, and teachers • Starting the transition from pediatric to adult care (and taking more responsibility for one's health) • New physical symptoms 	<ul style="list-style-type: none"> • Coping problems • Loneliness and social problems • Aggression, defiance, or denial • Being bothered by feeling different • Frustration due to problems with problem-solving and memory • Problems following health advice • Taking risks that might be unsafe • Anxiety, depression, and post-traumatic stress
Adulthood	<ul style="list-style-type: none"> • Hospital stays, surgeries, and other medical procedures • Following a healthy lifestyle (e.g., exercise and healthy eating) • Body image concerns • Transfer to adult health care • Moving out of family home • Dating and romantic relationships • Family planning decisions • Problems with finances, employment, or insurance • Caregiving (of other family members) • New or worsening physical symptoms • Physical and cognitive decline with age 	<ul style="list-style-type: none"> • Coping problems • Problems with relationships (family, friends, romantic partners, children) • Problems managing health care needs • Problems with college/university or work • Worry about death and dying • Anxiety, depression, and post-traumatic stress

Emotional strengths are also common

We often focus on the challenges or problems that people with CHD might face. That is because we want to make sure that more people with CHD get the emotional support and mental health care they need. However, many people with CHD say they have good quality of life. Many also say that living with CHD has helped them develop important strengths including:

- Learning how to cope with uncertainty
- Being able to adapt to new situations
- Feeling ready to face challenges
- Knowing what is most important in life
- Being kind and understanding of others
- Having a good sense of humor
- Being a good observer
- Being creative and artistic
- Feeling grateful

For people seeking mental health care, their CHD team might be able to help

Finding mental health care is not always easy. Most CHD programs do not have mental health professionals on their team... yet! We hope that our 2022 Scientific Statement will lead more CHD teams to hire mental health professionals. We know that this type of model for delivering mental health care works very well.

We think it is a good idea for people with CHD to talk about their mental health with their care team. We also know this is not easy for everyone! Some people find it a bit scary or that there is a stigma about mental health. However, the more that we 'normalize' talking about mental health, the easier it will get for us all. Also, care teams can often share advice about what has helped other people with CHD.

People with CHD face health-related challenges as well as some of the same challenges faced by people who do not have CHD. This list includes things like relationship and work stress. Community mental health professionals can help people cope with stress plus other types of mental health concerns. It is also good for everyone (with or without CHD) to know the phone numbers for local crisis/suicide hotlines, should urgent mental health concerns arise.

For people looking for support specifically related to living with CHD, here are some questions to ask their CHD team:

- Is there someone I can talk to about how I am feeling?
- Do you have a mental health professional on the team?
- Can you help me find a mental health professional?
- Will you refer me to a mental health professional?
- Does your program have a peer support group?
- Can you refer me to a patient support organization?
- Do you have other resources for mental health care?

Mental health care options

The following table presents different approaches to mental health care. A CHD team can often help patients and families to decide which option(s) are best for them.

Approaches to mental health care

Self-care strategies

- Have good sleep skills and a consistent sleep routine
- Eat a healthy diet and stay 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

Psychotherapy (talk therapy)

- There are many types of therapy. The list includes cognitive-behavioral therapy, mindfulness-based interventions, interpersonal therapy, psychodynamic therapy, and acceptance, commitment, and compassion focused therapies.
- Can be provided to individuals, couples, families, or in group settings.

Pharmacotherapy (medications)

- Patients or their prescribing mental health professional should discuss medications (e.g., for depression, anxiety, or sleep problems) with the CHD team to make sure these medicines are safe for one's heart.
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People might find a 'licensed' (or 'registered') mental health professional by talking with their medical team, friends, or family. Others search the internet. We think it is helpful to read a therapist's online profile to learn about their areas of clinical focus. Some health insurance companies, countries, states, or provinces have online lists of mental health professionals. We know that cost is often a concern. Not everyone has health insurance. Also, not all mental health professionals take health insurance. For people with health insurance, referral to a mental health professional might be needed.

Here is a list of types of mental health professionals:

- **Psychologists:** Non-medical doctors who specialize in mental health. They focus on therapy and/or assessment, and do not prescribe medications in most places.
- **Psychiatrists:** Medical doctors who specialize in mental health. They can prescribe and monitor medications.
- **Clinical social workers:** Social workers with extra training in psychotherapy.
- **Mental health nurses and nurse practitioners:** Some have extra training in mental health care.
- **Licensed professional counselors or couple/family therapists:** Usually have master's level training in mental health care.

We suggest that people take a summary of their CHD history (and maybe this document!) to their first appointment with a mental health professional.

Mental health is a team effort

Our main message for people with CHD who have mental health problems is to know that they are not alone. These problems are common, understandable, and treatable. People do not need to face things on their own. CHD care teams are there to help people along their journey. With support and treatment when needed, people with CHD can thrive and live their most happy and full lives.