



The
Roadmap
Project

Psychological Aspects of Living with A Chronic Condition: Information for Patients and Families

People with serious medical conditions, have a higher risk of emotional, social, and behavioral problems. People with chronic conditions 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 chronic condition or mental health concerns or both. However, no two people with a chronic condition 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 chronic conditions can face challenges both related and unrelated to living with the chronic condition.

This document was initially developed for patients and families living with congenital heart disease and their families as a companion piece to the to the American Heart Association Scientific Statement on Psychological Outcomes and Interventions for Individuals with Congenital Health Disease. We have deleted much of the background specific to congenital heart disease and are sharing this as we believe that many aspects are applicable to those living with chronic conditions.

The authors note that your organization is welcome to use and modify this document to meet your needs and those of your patients and families. Attribution to the authors and its context is appreciated.

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The document has been adapted from the publication 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 n Association](#)

Potential challenges and outcomes across the lifespan for those with chronic conditions

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 chronic conditions might face. That is because we want to make sure that more people with chronic conditions get the emotional support and mental health care they need. However, many people with chronic conditions say they have good quality of life. Many also say that living with chronic conditions 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 clinical team might be able to help

Finding mental health care is not always easy. Most chronic care programs do not have mental health professionals on their team... yet! We hope that our 2022 Scientific Statement will lead more congenital heart disease 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 chronic conditions 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 chronic conditions.

People with chronic conditions face health-related challenges as well as some of the same challenges faced by people who do not have chronic conditions. 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 chronic conditions) 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 chronic conditions, here are some questions to ask their clinical 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 clinical 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 care 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 the same condition through hospital or online support groups
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- 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.
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- Pharmacotherapy (medications)**
- Patients or their prescribing mental health professional should discuss medications (e.g., for depression, anxiety, or sleep problems) with the care team to make sure these medicines are safe for one's condition.
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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 medical 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 chronic conditions 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. Clinical care teams are there to help people along their journey. With support and treatment when needed, people with chronic conditions can thrive and live their most happy and full lives.