

Empower

Understand

Thrive



EMPOWER
MY CONGENITAL HEART



*Empowered Mind,
Empowered Heart:*

Your CHD Mental Health Toolkit



IT'S OKAY TO NOT BE OKAY!

How common are mental health conditions in CHD?

Due to repeated exposure to pain, illness, and frightening procedures, the **CHD community** is at **elevated risk** for mental health conditions.



84% experience symptoms of **trauma**

55% report severe **psychological distress**

50% suffer from **depression** or **anxiety**

30% have **post traumatic stress disorder**



Statistics Source:

www.theohhf.org/ollies-branch/

WHO TO ASK FOR MENTAL HEALTH HELP?

For Mental Health Crisis

- ◆ Call the **24-hour crisis center** at **988** or dial 911 for emergencies.
- ◆ For a **free, confidential** service that provides mental health support for anyone in crisis. *You can visit:*



Resource:

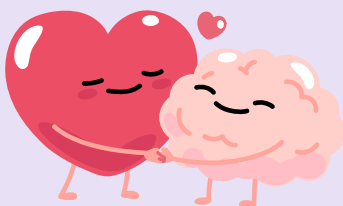
www.crisistextline.org
or text **HOME** to **741741**

For Ongoing Mental Health Care

- ◆ You can check whether you have an **employer-assistance program** (EAP) for mental health services.
- ◆ Your insurance may cover access to mental health services/ sessions with licensed mental health professionals.

If You Don't Know Where to Start

- ◆ Ask your primary care physician or your adult congenital cardiology team for help.





HOW TO USE YOUR MENTAL HEALTH TOOLBOX

Mental health is personal. What works for one person may not work for another. That's why this toolbox offers a variety of tools you can mix and match to build a support system that works for you.

What Is a Mental Health Toolbox?

This guide introduces **8 categories of support**—from self-care and stress reduction to therapy and medication.

You'll find tools you can use on your own, as well as those that are best used with a provider or other professional.

How Should I Use This Guide?

Scroll through the sections and explore tools that feel relevant or interesting to you. **Write down the tools**, apps, or strategies **you'd like to try**.

Come back anytime. Your needs might change, and so can your toolbox.



MENTAL HEALTH TOOLBOX

Below is a list of tools we put together for your toolbox:

- 1 Self-Care** 
- 2 Social Connections** 
- 3 Stress Reduction Techniques** 
- 4 Mindfulness & Meditation** 
- 5 Coping Techniques** 
- 6 Counseling / Therapy** 
- 7 Medication** 
- 8 Build Resilience** 

This is a combination of all the tools in your toolbox.

Remember: you don't need to use every tool. Even finding one or two that help can make a meaningful difference.

WHAT DO THE ICONS MEAN?



= A tool you can **try on your own**, such as journaling, grounding exercises, or helping others.



= A tool that typically involves **professional or guided support**, such as therapy, psychiatry, or acupuncture.



= This means the tool is a **mobile app** you can download and use on your smartphone or tablet.

How to Find an App

iPhone or iPad Users:

Open the App Store



Android Users:

Open the Google Play Store



Then, type the **app name** shown in this guide into the search bar and follow the instructions to download it.

What About Free vs Paid Apps?



= The app offers helpful tools in its **free version**; a good place to start.



= Some features may require a **subscription** or **one-time payment** to unlock additional tools or reports.

1 SELF-CARE



Relax

Practice ways to relax. Things like taking slow, deep breaths, imagining peaceful scenes, or gently tensing and then relaxing your muscles can help calm you down.



Enjoyment

Plan enjoyable activities. Make time for things you enjoy and that are important to you, like spending time with loved ones or being creative.



PEER EMPOWERMENT

Kieran, Patient with
Transposition of the Great Arteries

“ I live a normal life, but I have to be proactive in caring for myself to ensure the best quality of life possible. I think the anxiety associated with having my condition should not be understated. ”

1 SELF-CARE



Help Others

Doing something for someone else can make you feel happier and more connected.



Exercise

Exercise is proven to improve mental well-being and reduce stress.



Eating

Eat healthy food. Eating well can boost your mood and energy levels.

**Talk to your doctor before making major changes to your exercise or diet, especially if you have dietary restrictions.*



PEER EMPOWERMENT

Carmen Osborne, Patient with Truncus Arteriosus

“ Try not to think the worst, and communicate with your doctor and family members what you might be experiencing, good or bad. ”

1 SELF-CARE



Sleep

Get enough sleep. Good sleep can help lower your risk of feeling anxious or depressed. Some tips for better sleep include:

- ◆ Consistent sleep/wakeup time.
- ◆ Avoid screens before bed.
- ◆ Create a calming bedtime routine.
- ◆ Create a comfortable sleep environment.



Finch

Finch gamifies self-care by encouraging users to complete self-care objectives in exchange for rewards for a virtual pet bird.



Aloe Bud

Aloe Bud sends gentle nudges throughout the day, reminding users to drink water, eat, reach out to friends, and perform other self-care activities.

2 SOCIAL CONNECTIONS



Talk

Talk about how you feel. It's good to share your worries or anxieties with friends and family. Talking can make you feel less alone and might help you see things differently.



Other Ways to Connect

- ◆ Social media groups.
- ◆ Many hospitals and CHD organizations host **events** and **family camps** for individuals with CHDs.

Adult Congenital Heart Association (ACHA) Peer Support Program



bit.ly/ACHA-Peers



Progressive Adult Cardiac Experience (PACE) Program



bit.ly/PACE-Camp



2 SOCIAL CONNECTIONS



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PEER EMPOWERMENT

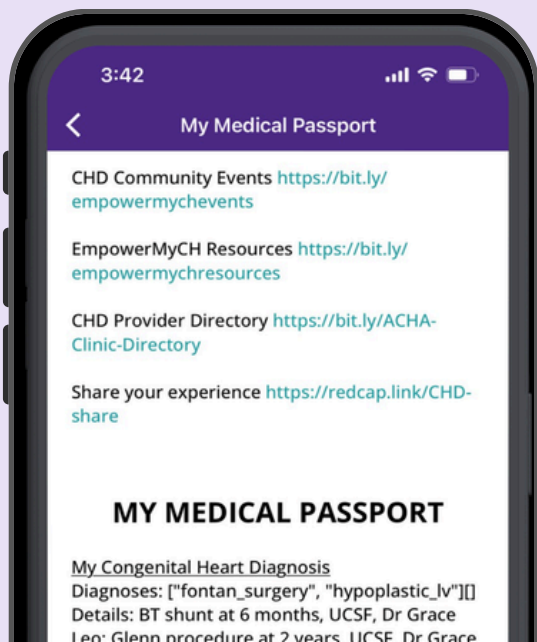
Misty, Patient with Coarctation Repair & a Mechanical Aortic Valve

“Living with CHD can be a challenge but it also offers the opportunity to educate, raise awareness and show others how life can be well lived without fear of the future despite our diagnosis.”



Community Events

Visit the **My Medical Passport** page of your EmpowerMyCH app to see what events are happening virtually and near you.



3

STRESS REDUCTION



Grounding Exercises

Try grounding exercises when you experience distressing thoughts to help you disconnect from negative thoughts and feelings and refocus. *An example could be:*

- ◆ List **5** things you can **HEAR**
- ◆ List **4** things you can **SEE**
- ◆ List **3** things you can **TOUCH**
- ◆ List **2** things you can **SMELL**
- ◆ List **1** thing you can **TASTE**

Resource:



Conquering CHD Grounding Exercise
bit.ly/ConqueringCHD-Grounding



Healing Hearts and Minds:

*A Holistic Approach to Coping Well
with Congenital Heart Disease*
bit.ly/Healing-Hearts-Minds



Journaling

Try these tips to help you get started with journaling:



- ◆ Try to write **every day**.
- ◆ Use your journal as you see fit. **You don't have to share** your journal with anyone.
- ◆ Write or draw **whatever feels right**. It's your own private place to discuss and create whatever you want to express your feelings.



PEER EMPOWERMENT

Carmen Osborne, Patient with
Truncus Arteriosus

“My mental health toolkit centers around journaling and going to church.”

4 MINDFULNESS & MEDITATION



Meditation

Meditation is the focusing or **clearing of your mind.**

The key here is to create a space for yourself where you can breathe and be aware of the moment.



There is no wrong way to meditate.

Free Guided Meditation



Guided Relaxation for Sleep
bit.ly/Calm-Guided-Sleep



A 10-minute Meditation for Stress
bit.ly/Headspace-Meditation

4 MINDFULNESS & MEDITATION



Headspace

Headspace provides mindfulness tools for everyday life, including meditations, sleepcasts, mindful movement, and focus exercises.



Calm

Calm focuses on meditation, sleep improvement, and stress reduction through guided breathing exercises, themed meditations, and "sleep stories" that help people fall asleep faster.



Insight Timer

Insight Timer provides thousands of guided meditations for free. It's praised for its high-quality content and comprehensive library of meditation resources.

5 COPING



Coping Techniques

Conquer CHD in the moment with **coping techniques** to manage stress, anxiety, or difficult situations. *Some examples include:*

- ◆ Practice **4-7-8 Breathing**: Breathe in for a count of 4, hold for a count of 7, and breathe out for a count of 8.
- ◆ Alternately **tense and relax** your body.
- ◆ Briefly rest your head on a table or desk.
- ◆ Practice position self-talk.
- ◆ Think of a place you've **felt safe**.
- ◆ Hold a stuffed animal, blanket, or pillow.
- ◆ **Count** slowly **backward** from 100.
- ◆ Give yourself a tight hug.
- ◆ Squeeze a squishy ball.
- ◆ Tell yourself **thoughts are just thoughts**.



5 COPING



Bearable   

Bearable excels at comprehensive mood and symptom tracking, allowing users to identify patterns and potential triggers. It offers robust features in the free version, making it an excellent companion for therapy or psychiatric treatment.



Daylio   

Daylio provides an intuitive interface with simple icons for tracking mood and activities. Its built-in report generator with visualization elements helps users monitor their progress over time.



Moodfit   

Moodfit, described as a "mood assistant," offers personalized mood data analysis, visualization tools, and mood-improving recommendations.

6 COUNSELING & THERAPY



Talkspace  

Talkspace connects you with **licensed therapists** via messaging, voice, and video sessions.



BetterHelp  

BetterHelp connects you with **licensed therapists** via text, phone, and video. They even covers disorders such as **PTSD**.



PEER EMPOWERMENT

Jay, Patient with CoA & Stenosis

“ Having CHD is my normal. It does not make me different, I simply function slightly different from others. ”

6 COUNSELING & THERAPY



Talk Therapy

Talk therapy involves talking about your thoughts, feelings, and behaviors to improve your mental well-being.

A counselor or therapist may recommend different types of therapy based on your individual needs. *This could include:*

- ◆ **Cognitive Behavioral Therapy (CBT)**
- ◆ **Eye Movement Desensitization & Reprocessing Therapy (EMDR)**



PEER EMPOWERMENT

Jennie, Patient with Tetralogy-Pulmonary Atresia with MAPCAs

“ I think it's important to know it's ok and valid to feel how you feel about having a CHD. Everyone's perspective, background, and history are different, so it's only natural that how we manage life with a CHD will be different too. ”

6 COUNSELING & THERAPY



Alternative Therapies

Complementary and Alternative Therapies can help you manage stress and other symptoms. Examples include **yoga, aromatherapy, meditation,** and **acupuncture.**



Creative Therapies

Arts and creative therapies use activities like **music, dance,** and **drawing** to help you express and manage your emotions and promote healing.



Support Groups

These are **group meetings** where you can connect with others who have CHD or other similar experiences.

7 MEDICATIONS

It's important to talk to a medical doctor to discuss whether medication is right for you.



Medications

Medications **can help manage** the symptoms of mental health conditions, **but they don't cure** them. The type of medication prescribed will depend on your specific situation and might include antidepressants, anti-anxiety medications, or sleep aids.



Comprehensive Support

A combination of counseling, medication, and therapy is common. Work with your doctors to determine what works best for you.



Resilience isn't a single strategy. It results from consistently using the tools that support your mental health. It grows over time as you practice self-awareness, seek support, and apply the **approaches that work best for you.**

Here, you'll find practical tips for building resilience while navigating life with CHD.



Resilience

Being Resilient: Choose thoughts and interpret life's challenges in a truthful way, and always consider the narrative that helps you become more positive, grateful, hopeful, and strong.*



Ownership

Embrace Being an Expert Patient: Proactively maintaining your general health and well-being as best as you can through self-care is essential before, during, and after any medical procedures.*



***Healing Hearts and Minds:**

A Holistic Approach to Coping Well with Congenital Heart Disease

bit.ly/Healing-Hearts-Minds



Preparation

Knowledge is Power: Studies have shown that being psychologically prepared for medical care benefits our physical, psychological, and emotional health.*



Purpose

Make Space for Meaning: Explore purpose-driven activities like volunteering, advocacy, spirituality, and connecting with others who understand life with CHD.



***Healing Hearts and Minds:**

A Holistic Approach to Coping Well with Congenital Heart Disease

bit.ly/Healing-Hearts-Minds



PEER EMPOWERMENT

Joe Valente, Patient with
Tetralogy of Fallot

#5 - Show Gratitude and Pass it on

“How do we repay all those who have given us so much? In most cases we really can't, and I don't believe that is what's expected of us. I can show them gratitude every chance I get and pass on the love that was given when the opportunity arises. My team will be proud to see me staying strong and sending out hope, love and compassion to others. We may feel as if we are a burden because we need so much from others. Sending out a drop of love, however small we may think the drop is, and watching it being received can invigorate your soul. Pass on what was given to you.”

To read all of **six of Joe's tools** in his toolbox follow the link below.



6 Rules I Live By to Lift the Weight of My Chronic Illness
bit.ly/TheMighty-Six



RECAP!

Make Your Own Toolbox

- 1 **Self-Care** 
- 2 **Social Connections** 
- 3 **Stress Reduction Techniques** 
- 4 **Mindfulness & Meditation** 
- 5 **Coping Techniques** 
- 6 **Counseling / Therapy** 
- 7 **Medication** 
- 8 **Build Resilience** 

This is a combination of all the tools in your toolbox.



Toolbox example on
The Mighty
bit.ly/TheMighty-Anxiety-Toolbox

TYPES OF MENTAL HEALTH PROFESSIONALS

Clinical Social Workers

These professionals have a Master's degree in social work and are trained to diagnose and provide counseling.

Licensed Professional Counselors

These professionals have a Master's degree in counseling or a related field and can diagnose and provide counseling.



Psychologists

These professionals hold doctoral degrees in psychology and can diagnose and provide therapy.

Psychiatrists

These professionals are **medical doctors** who can diagnose mental illnesses and **prescribe medication**.



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Dr. Julia Codrington, PhD, MA



Conquering CHD

We also referenced resources related to mental health provided by **Conquering CHD**.