

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**

[www.theohhf.org/ollies-branch/](http://www.theohhf.org/ollies-branch/)

# WHO TO ASK FOR MENTAL HEALTH HELP?

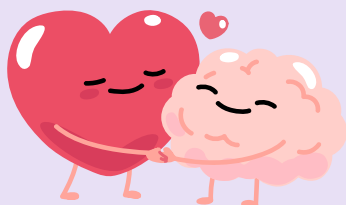
## For Mental Health Crisis

- ◆ 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:*

**[www.crisistextline.org](http://www.crisistextline.org)**  
or text **HOME** to **741741**

## For Ongoing Mental Health Care

- ◆ You can check if you have a **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 like to do and that are important to you, like spending time with loved ones or being creative.



### PEER-EMPOWERMENT

**Kieran**, *Transposition of 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. ”

**EmpowerMyCH User**

# 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**, Truncus Arteriosus

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

**EmpowerMyCH Advisor**



# 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](https://bit.ly/ACHA-Peers) 



#### Progressive Adult Cardiac Experience (PACE) Program

[bit.ly/PACE-Camp](https://bit.ly/PACE-Camp) 

## 2 SOCIAL CONNECTIONS

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### PEER-EMPOWERMENT

**Misty**, Coarctation Repair and Mechanical Aortic Valve

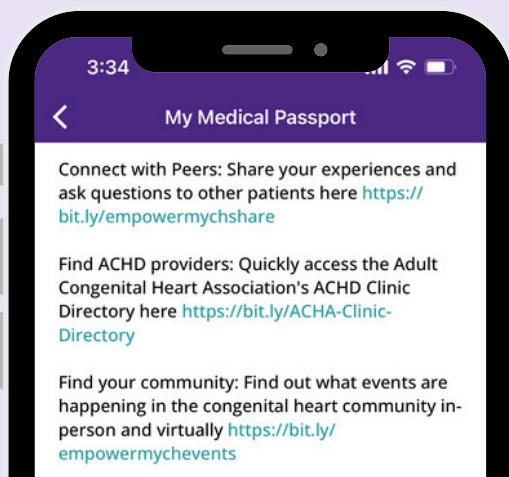
“Living with CHD can be a challenge but it also offers the opportunity to educate, raise awareness and show others how life can be well lived without fear of the future despite our diagnosis.”

**EmpowerMyCH User**



## Community Events

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





## Grounding Exercises

Try grounding exercises when you experience distressing thoughts: to help you disconnect from negative thoughts and feelings, and to 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**

*Conquering CHD Grounding Exercise:*

[bit.ly/ConqueringCHD-Grounding](https://bit.ly/ConqueringCHD-Grounding) 



### ***Healing Hearts and Minds:***

*A Holistic Approach to Coping Well  
with Congenital Heart Disease*

[bit.ly/Healing-Hearts-Minds](https://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**, *Truncus Arteriosus*

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

**EmpowerMyCH Advisor**

## 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](https://bit.ly/Calm-Guided-Sleep) 



***A 10-minute Meditation for Stress***  
[bit.ly/Headspace-Meditation](https://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
- ◆ Rest your head on a table or desk briefly
- ◆ Practice positive self-talk
- ◆ Think of a place you've **felt safe**
- ◆ Hold a stuffed animal or 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** through various communication formats, including 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, CoA and Stenosis*

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

**EmpowerMyCH User**

## 7 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 and Reprocessing Therapy (EMDR)**



#### PEER-EMPOWERMENT

*Jennie, 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.”

**EmpowerMyCH User**

## 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 things like **music**, **dancing**, and **drawing** to help you express and deal with 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 if 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.

## 8 BUILD RESILIENCE

**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 **best approaches 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 way that is truthful but always consider the narrative that helps you to 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, after any medical procedures.\*



**\* *Healing Hearts and Minds***

[bit.ly/Healing-Hearts-Minds](https://bit.ly/Healing-Hearts-Minds)

## 8 BUILD RESILIENCE



### Preparation

Knowledge is Power: Studies have shown that being psychologically prepared for medical care benefits our physical, psychological, 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  
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**[bit.ly/Healing-Hearts-Minds](https://bit.ly/Healing-Hearts-Minds)**



## 8 BUILD RESILIENCE



### PEER-EMPOWERMENT

*Joe Valente, 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](https://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.*

### ***Real-Life Toolbox on The Mighty***

#### ***Anxiety Toolbox***

**[bit.ly/TheMighty-Anxiety-Toolbox](https://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 have a doctoral degree in psychology and can diagnose and provide therapy.

## Psychiatrists

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



# ACKNOWLEDGEMENTS

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**Dr. Julia Codrington, PhD, MA**

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**Conquering CHD**