



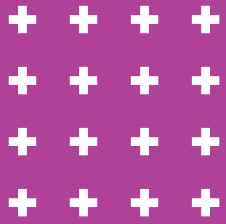
APRIL 16, 2023

Adrienne H. Kovacs, PhD, CPsych
Equilibria Psychological Health

Canadian Fontan Education Day

Psychological Health Matters





Psychological Health Matters

What do we know about the psychological health of individuals with congenital heart disease, including those with Fontan physiology?

(Recognizing that every patient has different experiences)

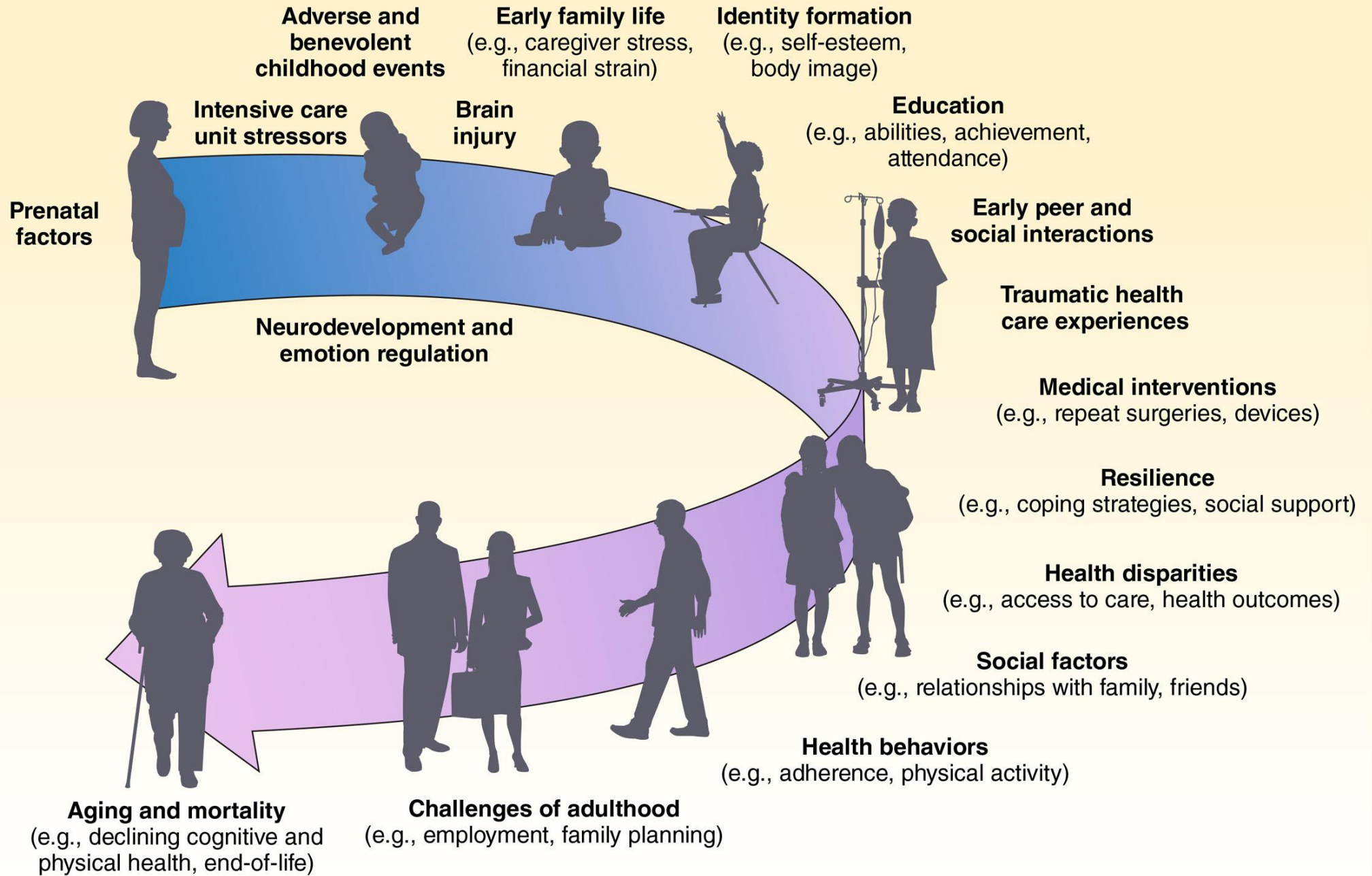
Circulation: Cardiovascular Quality and Outcomes **2022**

AHA SCIENTIFIC STATEMENT

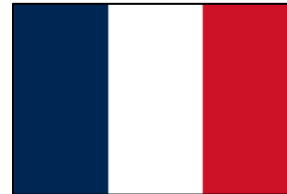
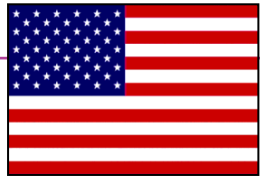
Psychological Outcomes and Interventions for Individuals With Congenital Heart Disease: A Scientific Statement From the American Heart Association

Adrienne H. Kovacs, PhD, Chair; Judith Brouillette, MD, PhD; Patricia Ibeziako, MD; Jamie L. Jackson, PhD; Nadine A. Kasparian, PhD; Yuli Y. Kim, MD; Tracy Livecchi, LCSW; Christina Sillman, MSN; Lazaros K. Kochilas, MD, MS, FAHA, Vice Chair; on behalf of the American Heart Association Council on Lifelong Congenital Heart Disease and Heart Health in the Young; and Stroke Council

Considerations across the life course



Psychological outcomes in pediatric CHD



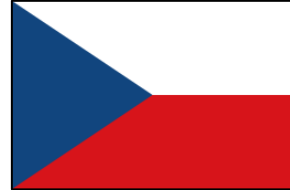
Pooled prevalence from meta-analysis of 16 studies:

Internalizing behaviour difficulties (eg, depression, anxiety): 25%

Externalizing behaviour difficulties (eg, defiance, oppositional): 15%

Lifetime prevalence of psychiatric disorder may be as high as 65% among adolescents with single ventricle CHD

Psychological outcomes in adult CHD



Self-report surveys: Elevated depressive symptoms range from 6-42% & elevated anxiety symptoms range from 34-42%

Clinical interviews: 28 – 35% meet current diagnostic criteria for a mood or anxiety disorder, with a lifetime prevalence of ~50% (exception is Netherlands)

0 – 31% of patients with psychiatric disorders receive mental health treatment

Emotional strengths are also common

Learning how to cope with uncertainty.

Being able to adapt to new situations.

Having a good sense of humour.

Being creative and artistic.

Being kind and understanding of others.

Being a good observer.

Feeling grateful.

Knowing what is important in life.

APPROACH-IS: 'Assessment of patterns of patient-reported outcomes in adults with congenital heart disease – international study'

JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY

© 2016 BY THE AMERICAN COLLEGE OF CARDIOLOGY FOUNDATION

PUBLISHED BY ELSEVIER

VOL. 67, NO. 19, 2016

ISSN 0735-1097/\$36.00

<http://dx.doi.org/10.1016/j.jacc.2016.03.477>

Quality of Life of Adults With Congenital Heart Disease in 15 Countries

Evaluating Country-Specific Characteristics

Silke Apers, PhD,^a Adrienne H. Kovacs, PhD,^b Koen Luyckx, PhD,^c Corina Thomet, MSc,^d Werner Budts, MD, PhD,^e Junko Enomoto, PhD,^f Maayke A. Sluman, MD,^g Jou-Kou Wang, MD, PhD,^h Jamie L. Jackson, PhD,ⁱ Paul Khairy, MD, PhD,^j Stephen C. Cook, MD,^k Shanthi Chidambarathanu, MD,^l Luis Alday, MD,^m Katrine Eriksen, MSc,ⁿ Mikael Dellborg, MD, PhD,^{o,p} Malin Berghammer, PhD,^o Eva Mattsson, MD, PhD,^q Andrew S. Mackie, MD,^r Samuel Menahem, MD,^s Maryanne Caruana, MD,^t Gruschen Veldtman, MD,^u Alexandra Soufi, MD,^v Anitra W. Romfh, MD,^w Kamila White, PhD,^x Edward Callus, PhD,^y Shelby Kutty, MD,^z Steffen Fieuws, PhD,^{aa} Philip Moons, PhD,^{a,o} on behalf of the APPROACH-IS consortium and ISACHD



What would you rate YOUR quality of life, on a 0-100 scale, ranging from 0 (worst imaginable) to 100 (best imaginable)?

Linear Analog Scale Quality of Life

EB estimate
quality of life
(95%CI)

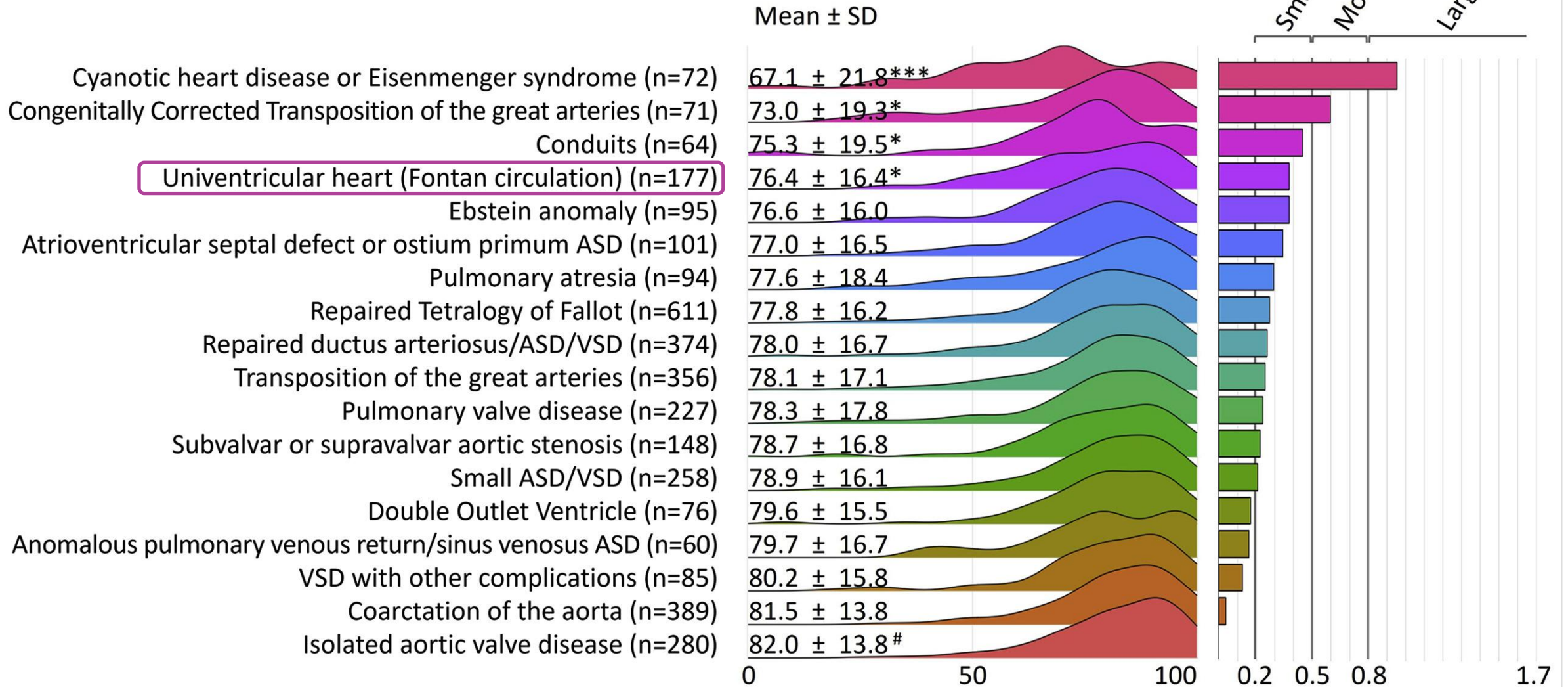
Country	0-10	11-20	21-30	31-40	41-50	51-60	61-70	71-80	81-90	91-100	
Australia	0.0%	0.0%	0.0%	3.0%	3.0%	1.5%	12.9%	20.5%	33.3%	25.8%	82.1 (79.6;84.6)
Switzerland	0.0%	0.4%	0.4%	2.2%	4.4%	6.6%	11.0%	16.9%	31.6%	26.5%	81.4 (79.5;83.2)
USA	0.1%	1.1%	1.5%	1.9%	4.8%	3.7%	10.5%	22.5%	28.2%	25.7%	80.4 (79.3;81.6)
Malta	0.0%	0.9%	0.0%	0.0%	4.3%	5.1%	11.1%	32.5%	34.2%	12.0%	80.1 (77.5;82.8)
the Netherlands	0.4%	0.0%	0.8%	0.4%	0.4%	2.4%	17.3%	37.3%	28.5%	12.4%	79.9 (78.0;81.8)
Sweden	0.9%	0.9%	1.5%	2.6%	3.1%	4.6%	12.6%	20.9%	29.2%	23.7%	79.4 (78.0;80.9)
Argentina	1.2%	0.0%	0.6%	0.0%	3.5%	6.4%	15.0%	30.1%	35.3%	8.1%	79.3 (77.1;81.6)
Italy	0.0%	0.0%	0.0%	3.2%	6.3%	3.2%	12.7%	30.2%	30.2%	14.3%	79.2 (75.9;82.5)
France	0.0%	0.0%	0.0%	2.1%	6.3%	5.3%	17.9%	25.3%	25.3%	17.9%	78.6 (75.8;81.5)
Belgium	0.0%	0.7%	1.1%	1.5%	4.4%	5.5%	16.5%	33.5%	28.3%	8.5%	77.0 (75.2;78.9)
India	1.5%	0.0%	1.0%	2.5%	6.1%	10.6%	19.2%	21.2%	17.7%	20.2%	76.9 (74.8;79.0)
Norway	0.0%	1.2%	1.2%	4.0%	5.2%	6.4%	16.8%	24.3%	23.7%	17.3%	76.9 (74.6;79.1)
Canada	0.8%	0.2%	1.4%	1.6%	4.3%	8.4%	19.9%	28.3%	23.8%	11.5%	76.1 (74.7;77.5)
Taiwan	0.0%	0.4%	1.6%	0.8%	6.8%	9.6%	18.1%	31.3%	24.9%	6.4%	75.6 (73.7;77.5)
Japan	1.6%	2.4%	4.0%	4.0%	8.3%	7.1%	15.4%	24.1%	21.3%	11.9%	71.6 (69.7;73.5)

**Median
quality of life (IQR)**
80.0 (70-90)

Total Sample

0.5%	0.7%	1.3%	1.9%	4.6%	5.8%	14.9%	25.8%	27.3%	17.4%
------	------	------	------	------	------	-------	-------	-------	-------

QOL Linear Analogue (0-100) Scale



Survey of 57 adults with Fontan circulation living in Australia or New Zealand

Open ended question:

“Your greatest concern(s) as an individual with a Fontan circulation is...”

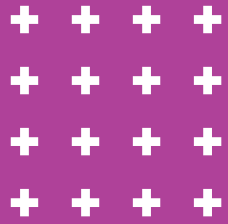
Fear of death/uncertainty around life expectancy

When will the Fontan fail?

How long do I have to be “normal”?

Uncertainty can make it difficult to make long-term plans.

Your medical team is used to getting questions about
long-term health expectations



Psychological Health Matters

Strategies for patients
(and families)
to manage psychological
challenges.

Questions to ask your medical 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/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?

Self-care strategies

- Have good sleep skills and a consistent sleep routine
- Stay active (ask for advice about physical activity)
- 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
- Avoid unnecessary avoidance
- Plan enjoyable activities
- Connect with supportive family, friends, and/or others with CHD
- Self-talk: What would I say to a good friend in this situation?

I love this book!

Healing Hearts and Minds

A Holistic Approach to Coping Well
With Congenital Heart Disease



Tracy Livecchi, LCSW Liza Morton, PhD

Types of mental health treatment

Psychotherapy (talk therapy)	Pharmacotherapy (medications)
<p>There are many different types of therapy (e.g cognitive-behavioural therapy and mindfulness-based interventions).</p> <p>For individuals, couples, families, or groups.</p> <p>Can be provided by psychologists, clinical social workers, licensed professional counselors or therapists.</p>	<p>People with CHD should discuss medications (eg, for depression, anxiety, or sleep problems) with their CHD team to make sure the medications are safe for one's heart.</p> <p>Can be prescribed by psychiatrists, family doctors, and other health professionals with prescribing privileges.</p>
<p>Not all mental health professionals in the community will be familiar with congenital heart disease.</p> <p>Consider providing a copy of your latest cardiology clinic note (and maybe even the scientific statement on psychological outcomes and interventions in congenital heart disease).</p>	



YOUR psychological
health matters.

Adrienne H. Kovacs

