



# Getting to the Heart of Mental Health and Wellbeing

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# Outline

- Overview of mental health
  - How CHD can affect mental health and wellbeing
  - Tips to promote mental health and wellbeing
  - Supports and resources
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# Why This Matters

<p><b>Mental health</b> (e.g., psychological distress, trauma symptoms, psychological well-being)</p>
<p><b>Physical health</b> (e.g., adherence, morbidity, mortality)</p>
<p><b>Social health</b> (e.g., relationships with family, friends, and the CHD community)</p>
<p><b>Quality of life</b> (life satisfaction as defined by the individual)</p>
<p><b>Healthcare system</b> (e.g., access, utilization, cost)</p>

**AHA SCIENTIFIC STATEMENT**

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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  
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## **Authors:**

pediatric and adult psychologists, pediatric and adult psychiatrists, social worker, pediatric and ACHD cardiologists, nurse practitioner, and individuals with CHD.

# What is mental health?

“A state of mental wellbeing that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community.”

“More than the absence of mental disorders. It exists on a continuum, which is **experienced differently from one person to the next**, with varying degrees of difficulty and distress, and potentially very different social and clinical outcomes.”

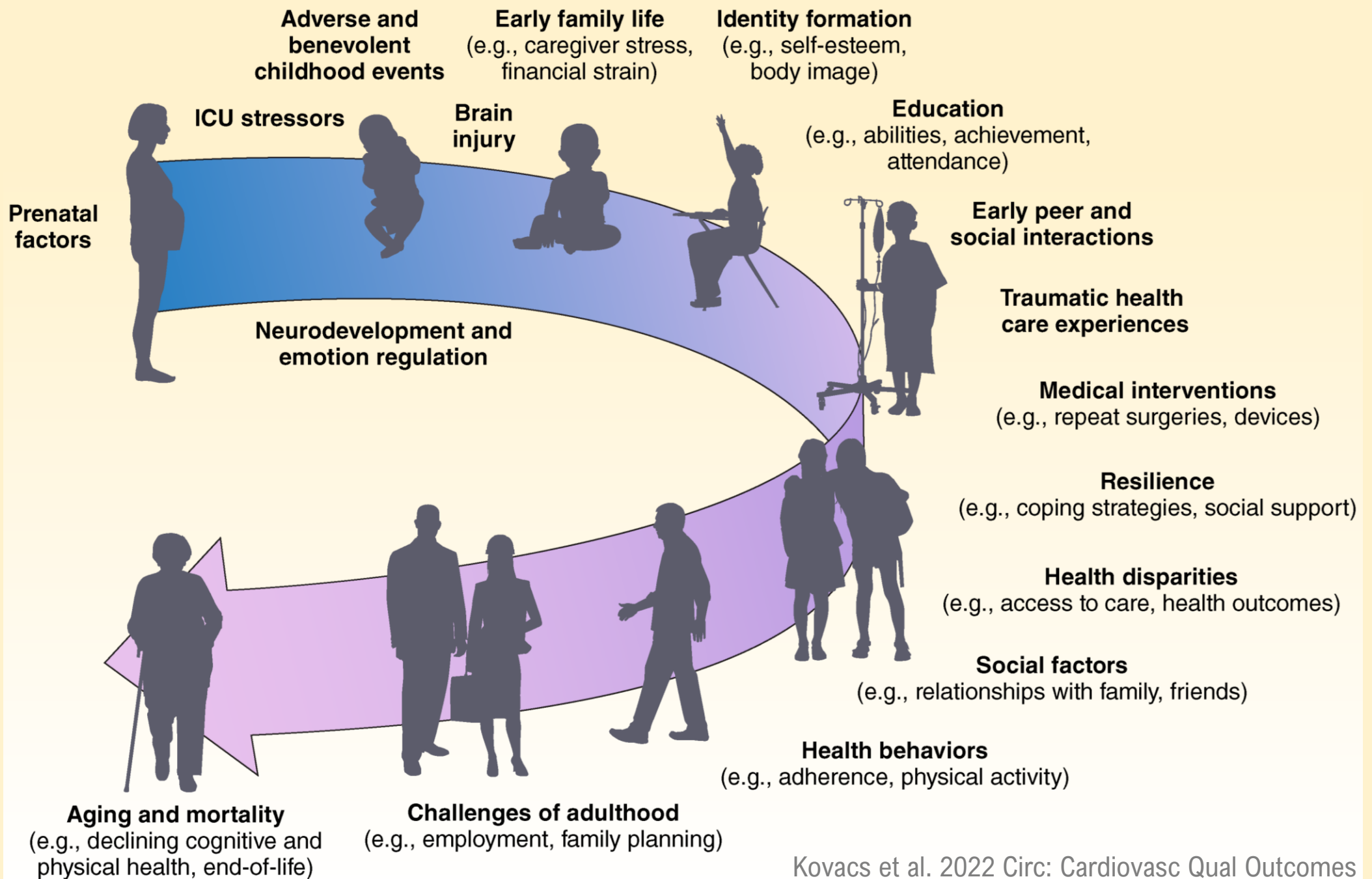
“A basic human right.”

There are many factors that can influence mental health across our lives.

No two people have the same experience.







## **Disruptions to normal life**

Hospitalizations, surgeries, medical procedures, medications, medical visits, new or worsening cardiac symptoms, being apart from family and friends.

## **Uncertainty and adversity**

Health uncertainty, traumatic experiences and memories, difficulty navigating transitions.

## **Feeling at war with the body**

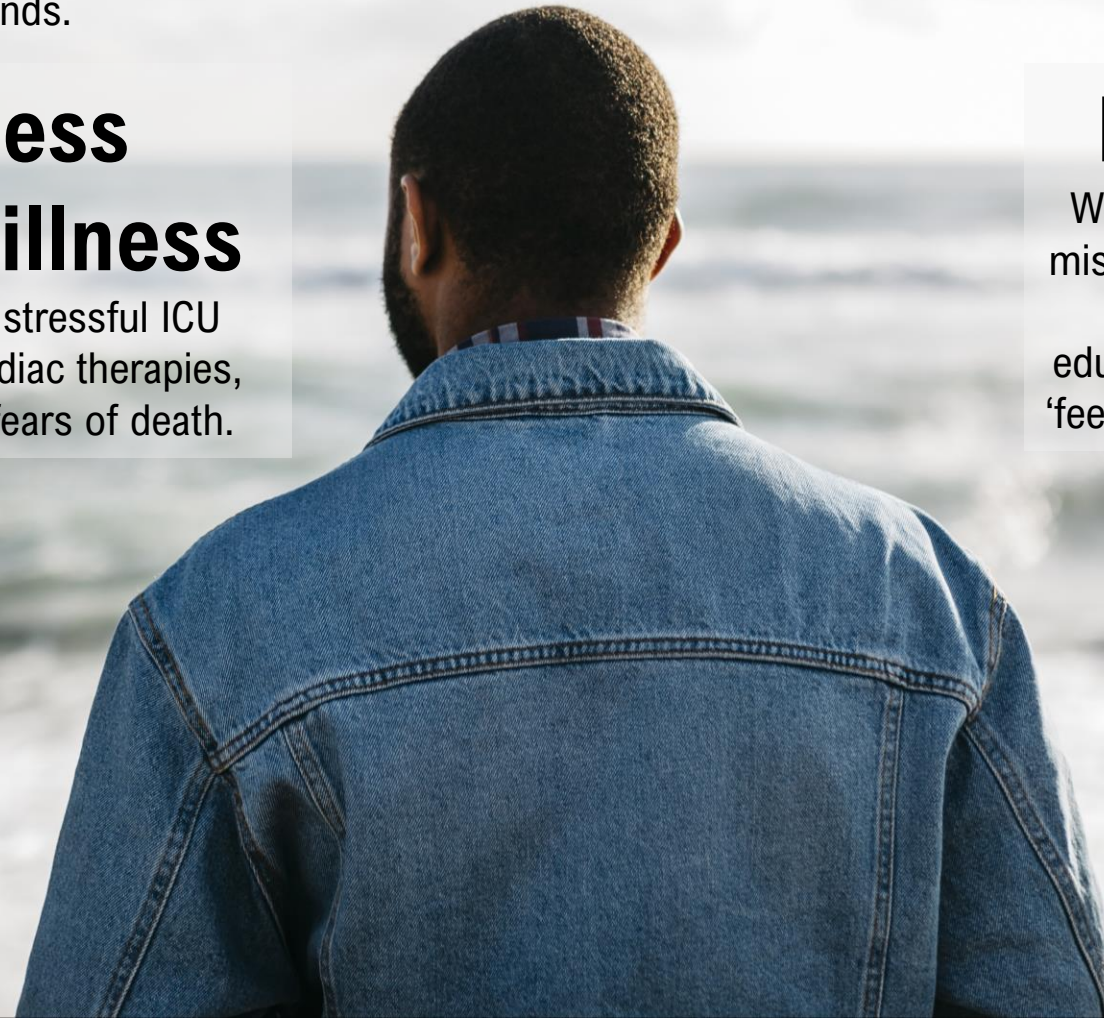
Frustration in response to fatigue, physical limitations, body image concerns, declining health status.

## **Feeling powerless during periods of illness**

Medical emergencies, complications, stressful ICU environment, ICD shock, advanced cardiac therapies, disappointment when treatments fail, fears of death.

## **Hampered goals**

Worry and overprotection from others, missed days at school, less time for play, neurodevelopmental differences, educational and occupational challenges, 'feeling different' from siblings and peers.





# Resilience

Establish one's own pace

Foster hope

Determination to thrive

Embrace the positives

Feel empowered

Value empathy

Social connections

Supportive relationships

Chong et al. 2018 Eur J Peds



# Emotional Strengths Are Also Common

Learning how to cope  
with uncertainty

Being able to adapt to  
new situations

Having a good sense  
of humor

Being creative and artistic

Being kind and  
understanding of others

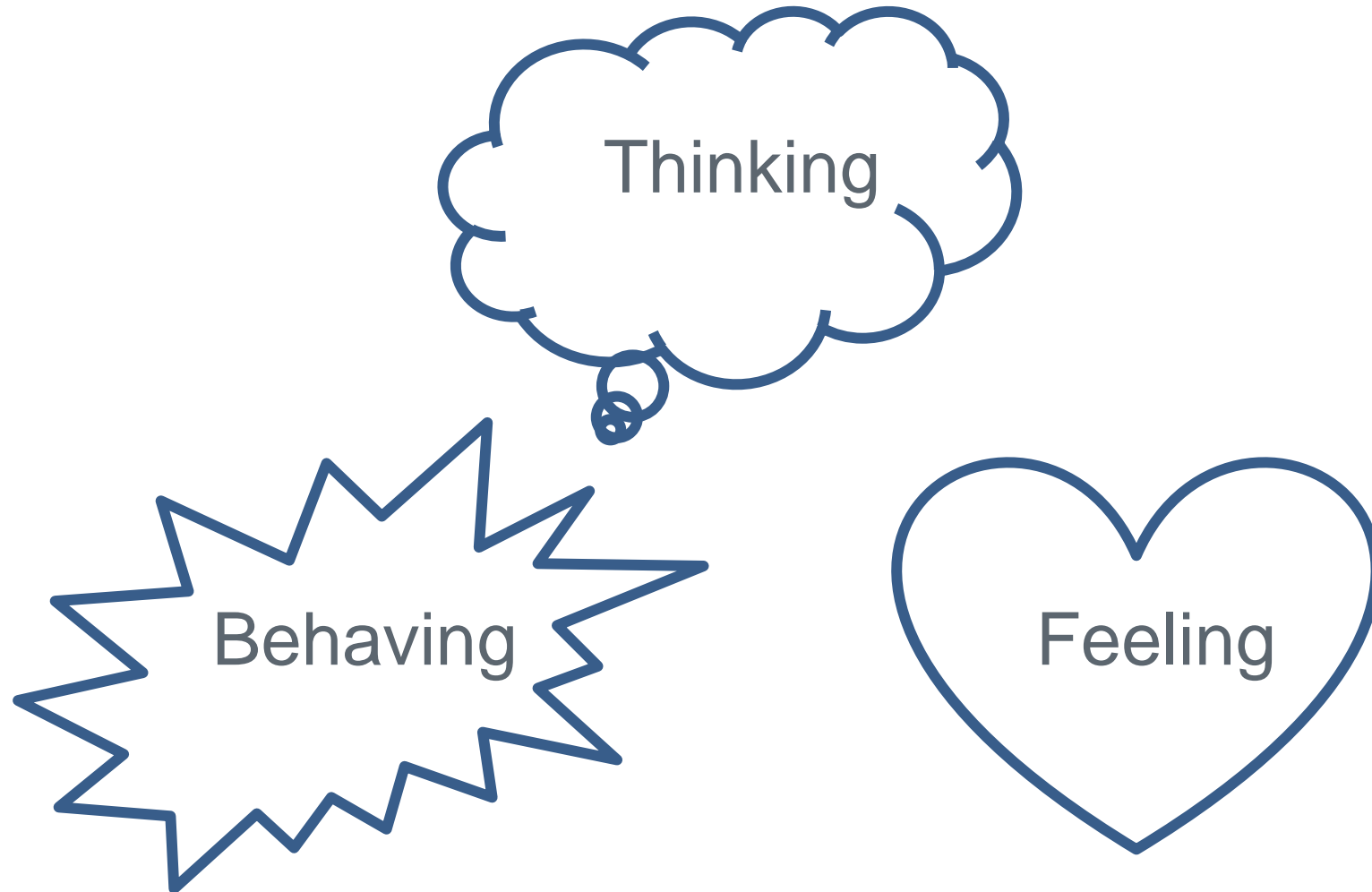
Being a good observer

Feeling grateful

Knowing what is  
important in life



# Mental Health



# Mental Health



- *It's all my fault*
- *I'll never get through this*
- *What if...?*

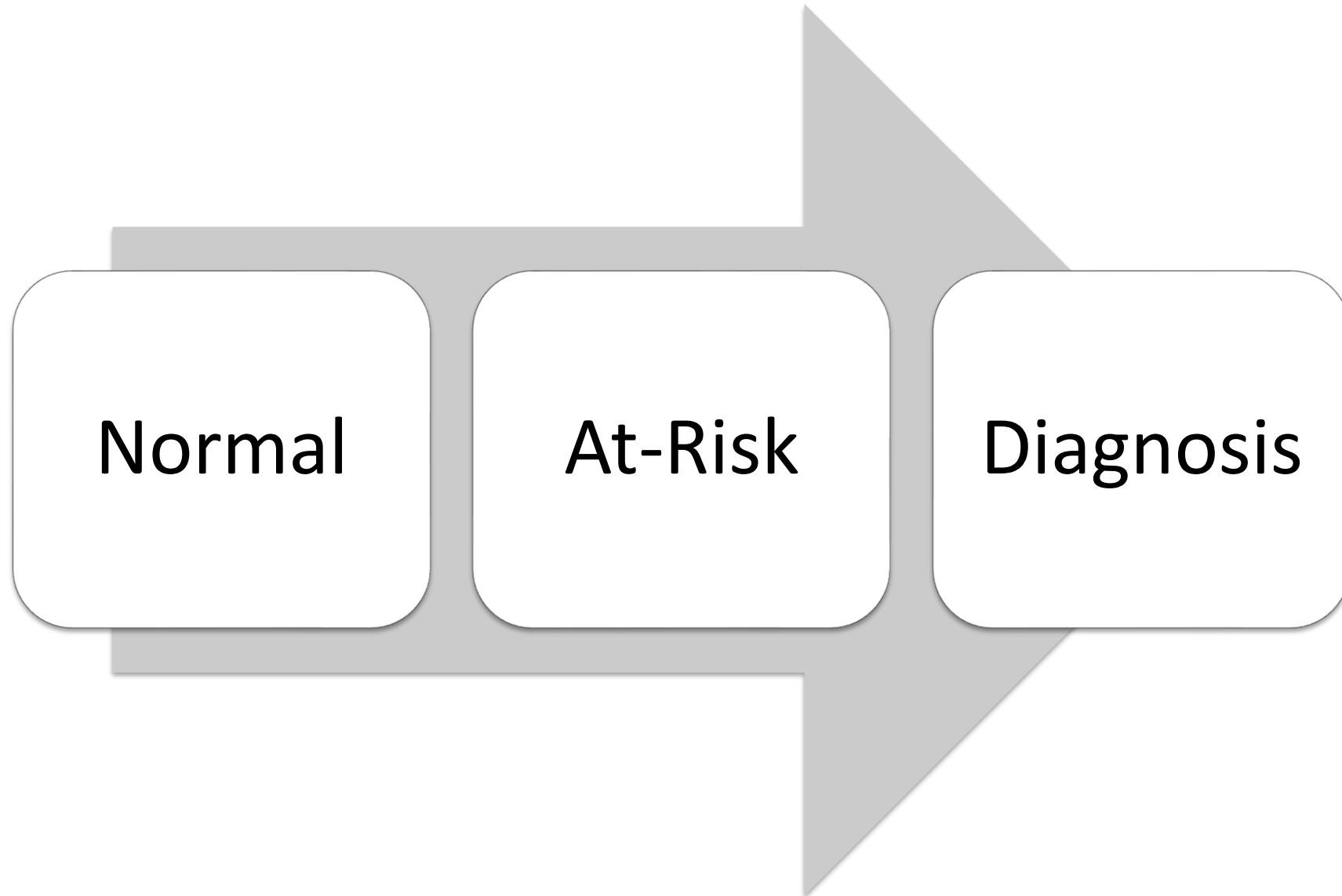


- *Avoiding*
- *Isolating*
- *Lashing out*



- *Anxious*
- *Overwhelmed*
- *Irritable*

# Spectrum of Mental Health Concerns



# Mental health concerns are common in children with CHD and their family members

- Children and adolescents with CHD have higher rates of anxiety, depression, behavioral problems, and ADHD
  - 5-7x higher in one study (Gonzalez et al., 2021, Pediatrics)
- 25-30% of children and adolescents with CHD have PTSD symptoms
- About 30% of parents of children with CHD have clinically significant mental health challenges at a single point in time



# Why increased risk?

- Children with CHD
  - Medical experiences can be scary and even traumatic
  - Unpredictable and not within their control
  - Challenges with development and learning
  - Difficulties regulating emotions and behaviors
  - Missing school and social opportunities
  - Feeling different

# Why increased risk?

- Parents/Caregivers
  - Traumatic experiences related to CHD
  - Chronic in nature
  - Unpredictable and not within their control
  - Day-to-day parenting stress
  - Strain on relationships, feeling isolated

# Why increased risk?

- Siblings
  - Family dynamics
  - Worry about sibling with CHD and/or parents
  - Separation from parents during hospitalization
  - Desire to not add stress for family

# Parent mental health is related to child mental health

- Mental health can affect parenting
  - overprotective parenting style, challenges setting limits, difficulties being present in the moment, reduced patience
- Mental health can affect family relationships





# Tips to promote mental health and wellbeing



# Normalize the emotional impact of CHD

- It is normal for CHD to affect how people think and feel
- Normalize emotional aspects of CHD
- Ask open ended questions
- Seek mental health support proactively
- Share your story

# Prioritize self-care

- Try to keep a consistent sleep routine
- Stay active
- Use relaxation techniques (e.g., breathing exercises, meditation)
- Plan enjoyable activities
- Focus on strengths and what one can do
- Self-talk: What would I say to a good friend in this situation?

# Seek support

- Peer-to-peer support
- Local chapters of Conquering CHD and Mended Little Hearts
- Online supports
- Friends, family, community members, religious leaders
- Help yourself by helping others
- Heart Camp, CHD events



# Recognize signs and symptoms

Learn about signs/symptoms of a mental health problem

- Nemours KidsHealth
- Heart & Mind Wellbeing Center at Cincinnati Children's:  
[www.cincinnatichildrens.org/heart-mind](http://www.cincinnatichildrens.org/heart-mind)
- Effectivechildtherapy.org
- WorryWiseKids.org
- Free Assessment Center (Helping Give Away Psychological Science)
- Conquering CHD – “Promoting Mental Health for Parents of Children with Cardiac Conditions”

# Talk with your child's heart care team

- Talk to doctors and nurses (PCP, cardiologist)
  - They won't know unless you tell them!
- Ask to meet with a social worker or psychologist
- Schedule an appointment with the cardiac neurodevelopment team
  - List of cardiac ND programs: [cardiacneuro.org](http://cardiacneuro.org)

# Talk with your child's heart care 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?

# Access mental health evaluation or treatment

- Learn about evidence-based therapies  
[www.effectivechildtherapy.org](http://www.effectivechildtherapy.org)
- Learn about services offered through care center
- Call insurance company for list of providers
- Ask about telehealth options

# Access mental health evaluation or treatment

- Other options
  - Psychology training clinic through local university
  - Employee Assistance Program (EAP)
  - Clinical research studies
- Online resources
  - Triple P Positive Parenting Program, Incredible Years
  - Child Anxiety Tales, Camp Cope-a-lot
  - [Healthcaretoolbox.org](http://Healthcaretoolbox.org)

# Establish an ongoing relationship

- Consider periodic check-ins or booster sessions even when no major concerns
- Use mental health supports in a proactive and preventative manner



# A Vision for the Future of Mental Health

- All children with CHD and their family members should have access to mental health services
- Preventive services
- Treatment
- Every pediatric cardiac center should have dedicated mental health professionals
- Share your story, talk to your care team
- Let's work together to make this happen!

# [Psychological Aspects of Congenital Heart Disease: Information for Patients and Families \(PDF\)](#)

