Wessex Children's and Young Adults' Palliative Care Network

SOUTHAMPTON Children's Hospital

Naomi House & Jacksplace
hospices for children and young adults

Palliative Care:
We're the Fire Department, Not the Fire

DR KATE RENTON

CONSULTANT IN PAEDIATRIC PALLIATIVE CARE

KATE.RENTON@UHS.NHS.UK

MYTHS!

What is Paediatric Palliative Care about?

Dying

Oncology

Depressing

Hospices

Niceness and Tea
(BMJ 12/11/19)

"She's our new Palliative Specialist!"

Take Home Points

Know how to introduce palliative care

Think about developing pathways involving palliative care

Work collaboratively with palliative care team locally

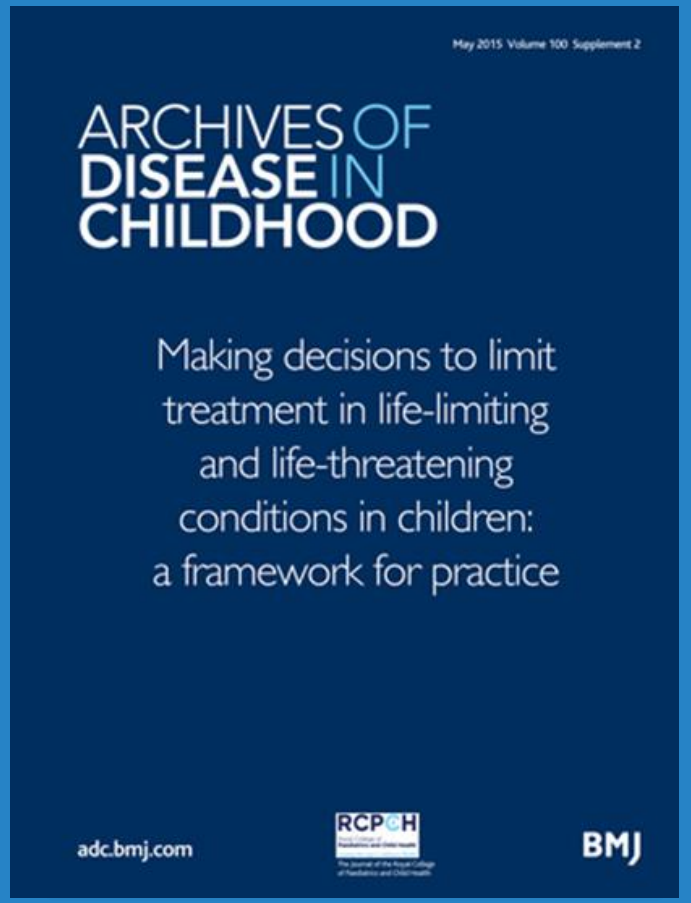
Jared Rubenstein: Palliative Care PSA We’re the fire department not the fire

What is Paediatric Palliative Care (PPC)?

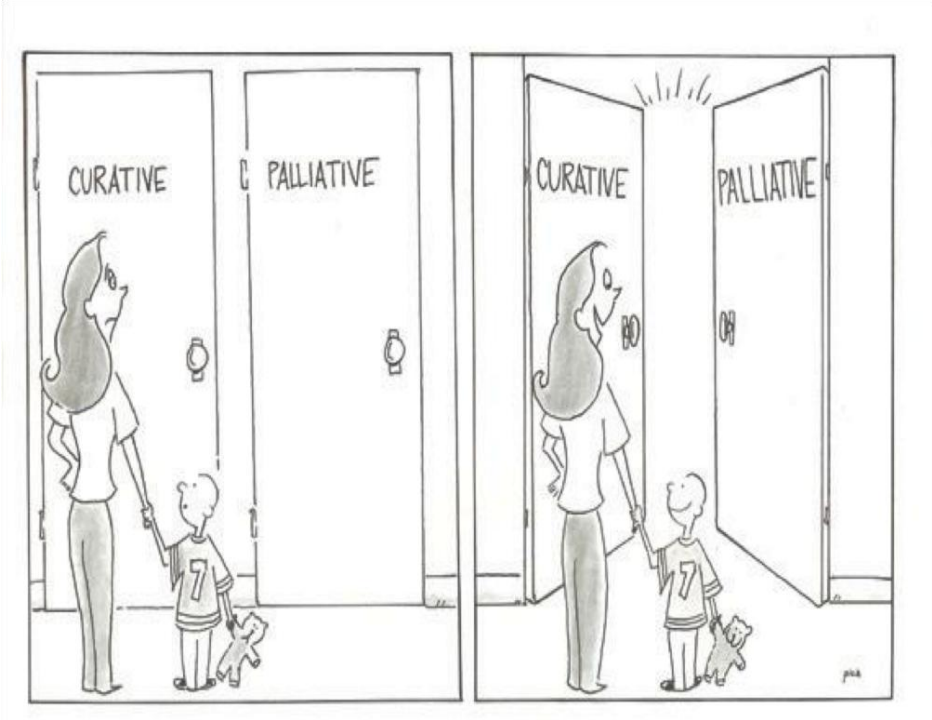
"An active and total approach to care,
from the point of diagnosis or recognition,
through the child's life, death and beyond.
It embraces physical, emotional, social and spiritual elements and focuses on
the enhancement of quality of life
for the child/young person and support for the family.
It includes the management of distressing symptoms,
provision of short breaks and care through death and bereavement."

(Together for Short Lives, 2013)

What can we do?

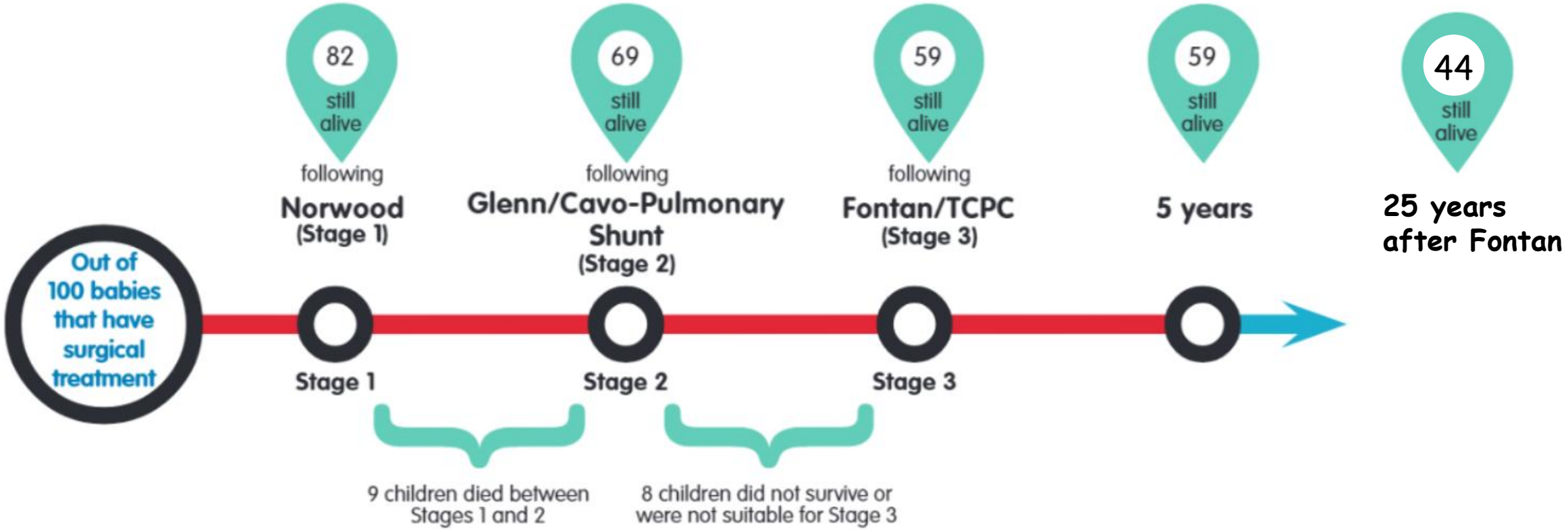


It’s not giving up



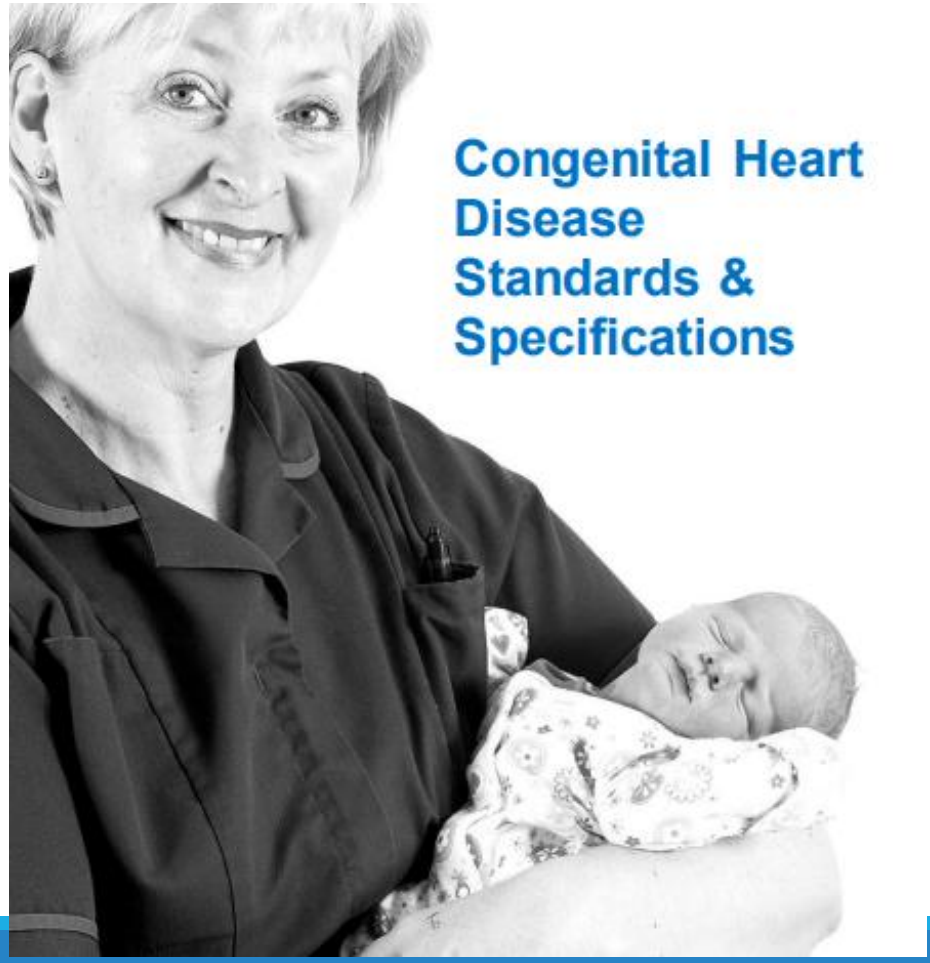
You don't have to stop curative therapy to start palliative care.
Instead, they can proceed together.
We often say that we are "hoping for the best,
but planning for the worst."

Why does it matter?



L1(L1)	Each Specialist ACHD Surgical Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the patient and partner/family or carers. This must also include bereavement follow-up and referral on for ongoing emotional support of the partner/family or carers.

Standard	Adult	Implementation timescale
Palliative Care Note: Palliative care is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.		
L1(L1)	Each Specialist ACHD Surgical Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the patient and partner/family or carers. This must also include bereavement follow-up and referral on for ongoing emotional support of the partner/family or carers.	Immediate
L2(L1)	Clinicians should use locally approved palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L1)	When a patient is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the patient and their partner/family or carers. These leads may change over time as appropriate.	Immediate
L4(L1)	The lead doctor and named nurse will work together with the palliative care team to ensure the patient and their partner/family or carers are supported up to, and beyond death.	Immediate
L5(L1)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the patient and their partner/family or carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The potential for organ and tissue donation should be discussed. The partner/family or carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate
L6(L1)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members	Immediate



Circulation:
Cardiovascular Quality and Outcomes

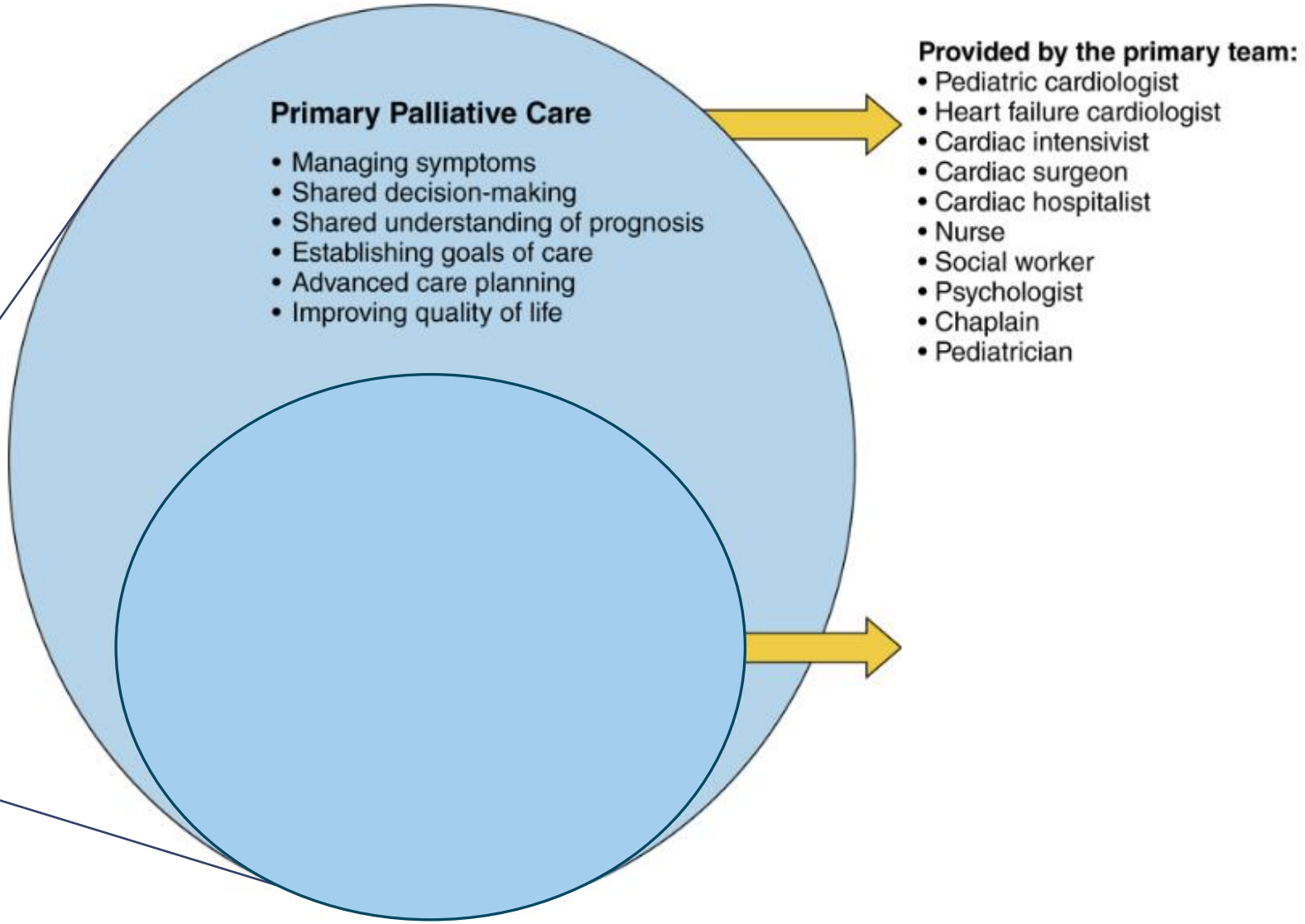
REVIEW ARTICLE | Originally Published 12 January 2023 |

Palliative Care Across the Life Span for Children With Heart Disease: A Scientific Statement From the American Heart Association

Elizabeth D. Blume, MD, Chair, Roxanne Kirsch, MD, MBE, Vice Chair, Melissa K. Cousino, PhD, Jennifer K. Walter, MD, PhD, MS, Jill M. Steiner, MD, MS, Thomas A. Miller, DO, Desiree Machado, MD, Christine Peyton, MS, PNP-AC, Emile Bacha, MD, and Emily Morell, MD on behalf of the American Heart Association Pediatric Heart Failure and Transplantation Committee of the Council on Lifelong Congenital Heart Disease and Heart Health in the Young | AUTHOR INFO & AFFILIATIONS

Circulation: Cardiovascular Quality and Outcomes • Volume 16, Number 2 • https://doi.org/10.1161/HCQ.0000000000000114

Who does PPC?



Circulation:
Cardiovascular Quality and Outcomes

CURRENT ISSUE | ARCHIVE | JOURNAL

REVIEW ARTICLE | Originally Published 12 January 2023 |

Check for updates

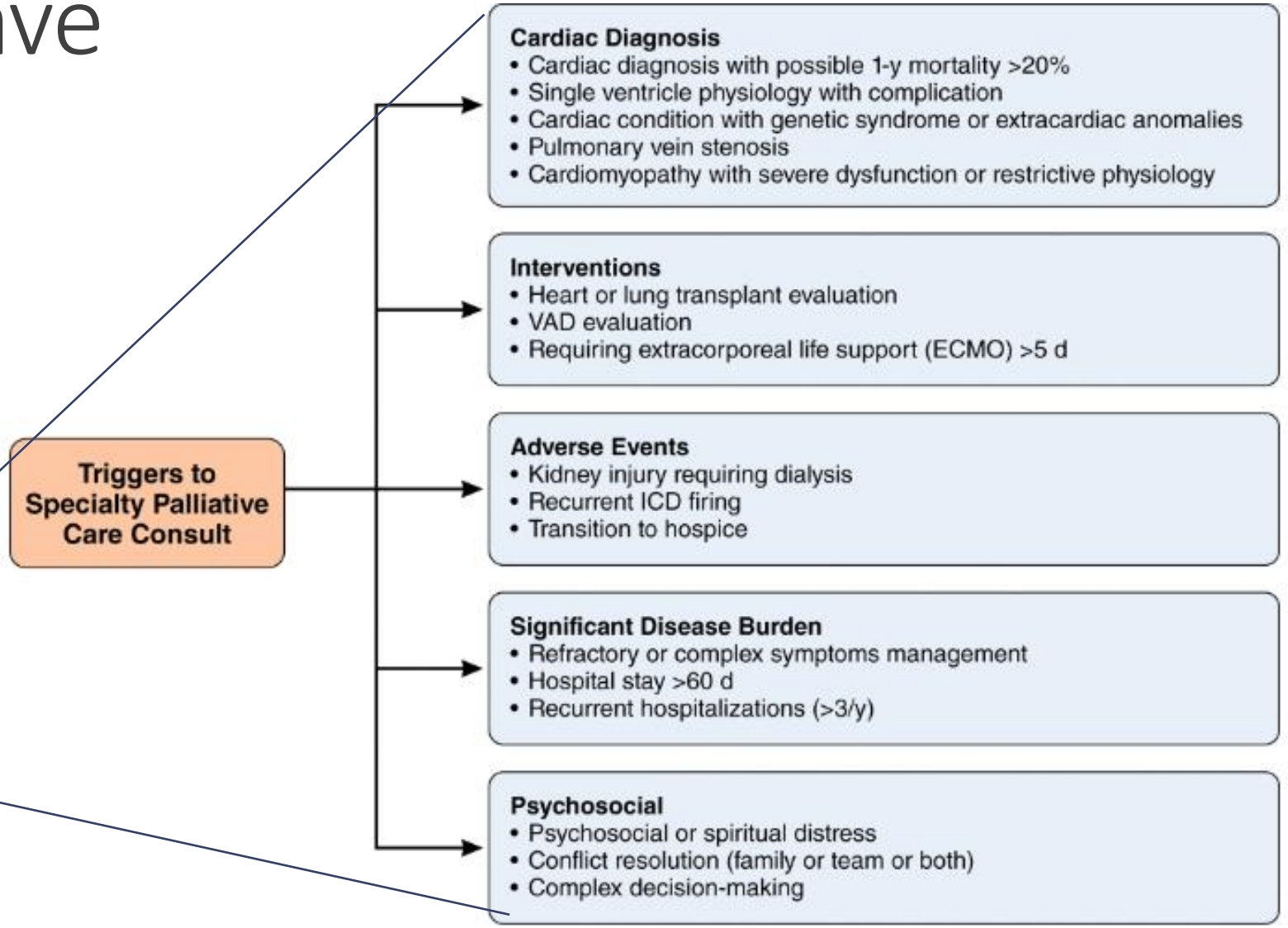
Palliative Care Across the Life Span for Children With Heart Disease: A Scientific Statement From the American Heart Association

Elizabeth D. Blume, MD, Chair, Roxanne Kirsch, MD, MBE, Vice Chair, Melissa K. Cousino, PhD, Jennifer K. Walter, MD, PhD, MS, Jill M. Steiner, MD, MS, Thomas A. Miller, DO, Desiree Machado, MD, Christine Peyton, MS, PNP-AC, Emile Bacha, MD, and Emily Morell, MD on behalf of the American Heart Association Pediatric Heart Failure and Transplantation Committee of the Council on Lifelong Congenital Heart Disease and Heart Health in the Young AUTHOR INFO & AFFILIATIONS

Circulation: Cardiovascular Quality and Outcomes • Volume 16, Number 2 • https://doi.org/10.1161/HCQ.0000000000000114

Blume, E.D. et al. (2023) 'Palliative care across the life span for children with heart disease: A scientific statement from the American Heart Association', Circulation: Cardiovascular Quality and Outcomes, 16(2).

Who should have PPC input?



Circulation: Cardiovascular Quality and Outcomes

CURRENT ISSUE | ARCHIVE | JOURNAL

REVIEW ARTICLE | Originally Published 12 January 2023 |

Check for updates

Palliative Care Across the Life Span for Children With Heart Disease: A Scientific Statement From the American Heart Association

Elizabeth D. Blume, MD, Chair, Roxanne Kirsch, MD, MBE, Vice Chair, Melissa K. Cousino, PhD, Jennifer K. Walter, MD, PhD, MS, Jill M. Steiner, MD, MS, Thomas A. Miller, DO, Desiree Machado, MD, Christine Peyton, MS, PNP-AC, Emile Bacha, MD, and Emily Morell, MD on behalf of the American Heart Association Pediatric Heart Failure and Transplantation Committee of the Council on Lifelong Congenital Heart Disease and Heart Health in the Young AUTHOR INFO & AFFILIATIONS

Circulation: Cardiovascular Quality and Outcomes • Volume 16, Number 2 • https://doi.org/10.1161/HCQ.0000000000000114

The “Wish/Worry/Wonder” framework

I wish... I worry... I wonder...

KEY IDEAS

I wish allows for aligning with the patient’s hopes.

I worry allows for being truthful while sensitive.

I wonder is a subtle way to make a recommendation.

TRY THIS STRATEGY

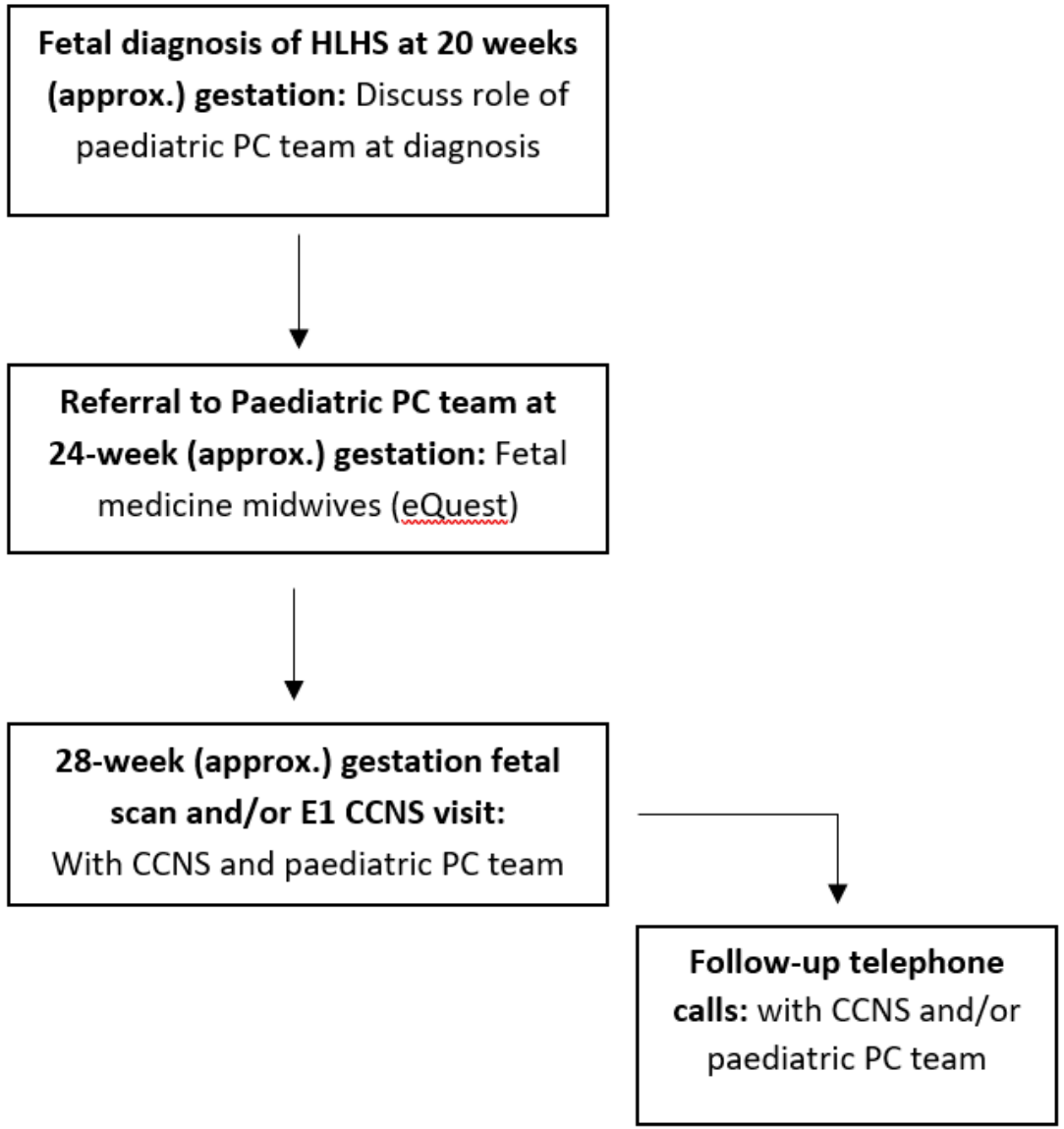
- **Align with patient hopes, acknowledge concerns, then propose a way to move forward:**

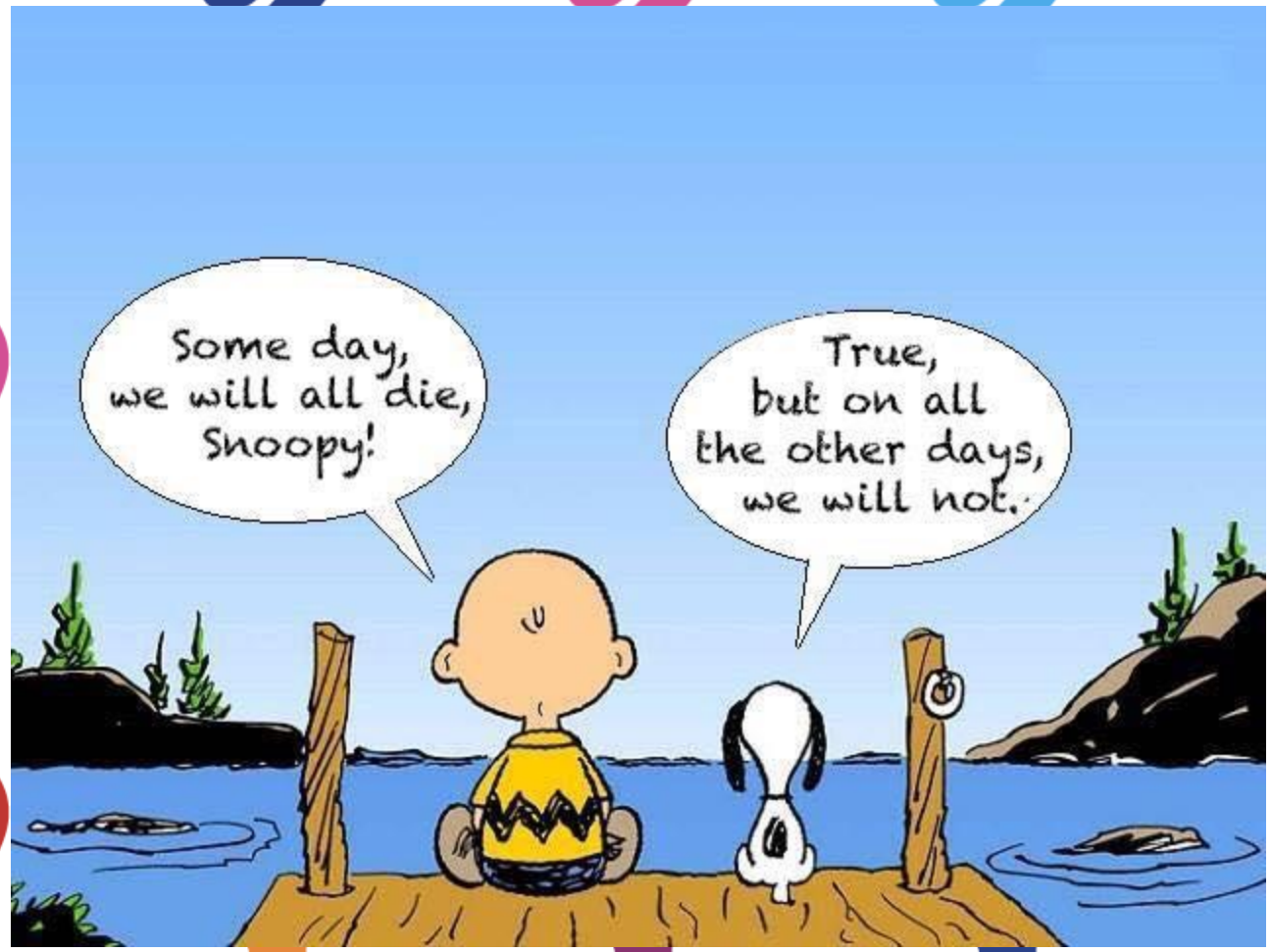
I wish *we could fix your child’s heart and I promise that I will continue to look for options that could work for her. But* ***I worry*** *that there is no curative option out there.*
I wonder *if we should think about how to manage her symptoms if we cannot make her better. In this situation we ask our colleagues who are expert in this to help. They are called the palliative care team…*

How to introduce PPC?

Patient pathways

- More debate/discussion about this later?




Some day, we will all die, Snoopy!
True, but on all the other days, we will not.

SLIDO: What are the barriers for your team in referring to palliative care?