#### Family support

Dr Sue Brown Consultant Clinical Psychologist on behalf of the psychosocial team

#### **Psychosocial team**

Katherine Barlow, clinical psychologist 0.6 wte

Sue Brown, consultant clinical psychologist 0.6 wte in cardiology

Catherine Hankinson, clinical psychologist specialising in neuropsychology 0 .12 wte

Vacant post - recruitment in progress 0.3 wte

Social workers, Rise Shemilt, Kerry Walker, Julie Eardley

Rainbow trust – family support worker

Psychosocial care of people experiencing extreme enduring uncertainty, fear, loss and distress



# Early needs

- History of the heart failure condition
  Sudden onset/congenital
- Impact of shock and grief
- Initial psychological trauma care
- Relocation/disorientation
- Lack of usual support
- Practical issues finance, accommodation, other sibs, PR, safeguarding

# **Typical reactions**

- Lack of self care
- Difficulty processing information
- Shock
- Disbelief
- Guilt
- Fear/terror
- 'switched off'
- Relief
- Gratitude

# Who provides this?

- PICU/ward team
- Chaplains
- Social workers
- Claire McGraith VAD nurse
- Transplant coordinators
- Transplant nurses
- psychologists

# Mandatory psychosocial care?

- 'normalised' psychological and social work involvement
- Parental choice
- Indirect care
- Even the most resilient and adaptive families will struggle
- We can't deal with all mental health issues of all of the family

### **Psychological therapies**

- Counselling- 'bearing witness'
- Cognitive behaviour therapy CBT
- Acceptance and commitment therapy ACT
- Systemic/family therapy
- Indirect shared understanding of mental health impact/systemic challenges

### The wait.....

- Uncertainty
- Constant threat of loss of child
- Impact on relationships
- Feeling torn
- Parallels with pandemic self refection
- Will my child get a transplant
- Where has that heart come from?
- Will they survive the transplant?
- will they suffer morbidity e.g. stroke?
- How can we/they ever have a normal life?

Later reactions during admission – could be a year in hospital!

- Anger
- Unfairness
- Envy/bitterness
- Loss of hope
- Anxiety and panic attacks
- Depression
- Signs of mental health decline –eg withdrawal

# **Evolving picture**

- VAD
- Sepsis
- Organ failure
- Neurological events
- No offers
- Parallel planning

# After transplant

- Time to process
- PTSD
- Parenting/resuming normal life
- Picking up the pieces of life eg work, siblings, friendships
- Living with 'on going' threat
- Education, work, finances, travel, relationships, re-evaluating goals and beliefs

### Do you want to know more?

- Please approach us directly for teaching and training topics but also for case consultation
  Contact details
- Clinical psychology 0191 213 8248
- Social work 0191 244 8443
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