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
- <u>Susan.brown98@nhs.net</u>
- Katherine.barlow1@nhs.net