

Parallel Planning

Kath Consterdine & Jane Bryant
Family Liaison Nurses
Paediatric Critical Care

Parallel planning

A process to address expectations, change and conflict

Hoping for the best but planning for the worst

Planning in anticipation of a change in circumstances

Palliative care

A thread that weaves through the lives of all children with a life limiting/ life threatening illness or condition

Starting at diagnosis not at the end of life

It should maximise comfort, wellbeing and the quality of life of children with a life-limiting illness and that of their family and carers

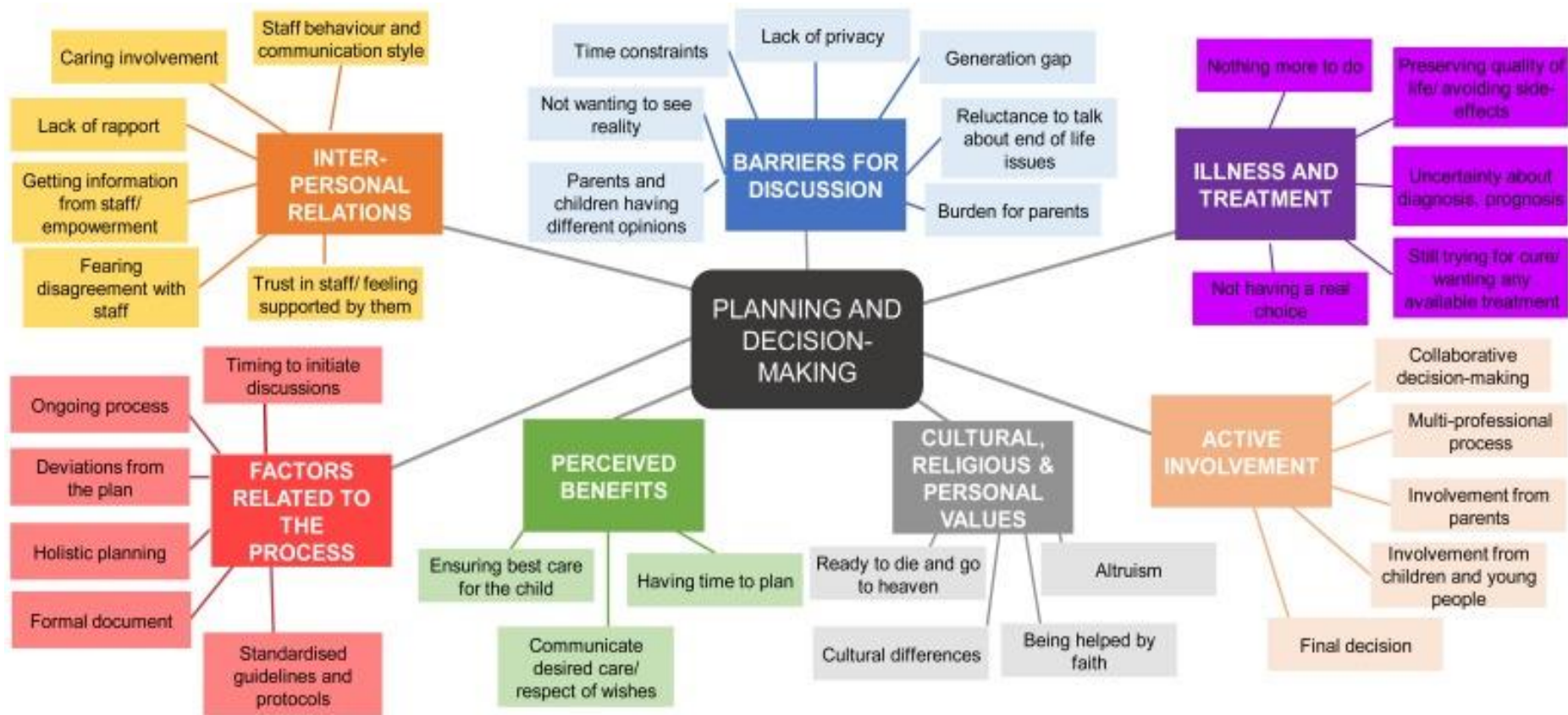
Difficult to talk about

Families : My child is going to die
 The Doctors & Nurses are giving up on my child
 Loss of hope
 My child is not worth it

Professionals: We don't have the skills to have these difficult
 conversations
 We might be wrong...is it the right time
 We might be criticised

Understanding of what we can offer the child and family

Themes from shared decision-making and advanced care planning



NG61 Standards audited in RMCH PICU (April 2016-2018)

Standard	Compliance (%)	Assurance level
Every family of a patient with a life-limiting condition has a discussion with a consultant within 48 hours of admission	80	Amber (Good)
All children with life-limiting conditions should have an Advance Care Plan in their medical records	38	Red (Poor)
If an ACP is in place, it should contain the relevant criteria as per NICE guidelines	Not measured	NA
Infants, children and young people with a life-limiting condition have a named specialist who leads and coordinates their care in ICU	29	Red (Poor)
Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it	12	Red (Poor)
Infants, children and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team	100	Green (Excellent)

ACP - Advanced care plan

- Useful for discussing and communicating information about a child's healthcare needs and the child & families wishes for future care
- Promotes informed and shared decision making
- Helps to ensure the child receives the most appropriate care, especially in an emergency
- Reduces the number of times a family have to tell and retell their story
- [Website: CYPACP.nhs.uk](http://CYPACP.nhs.uk)

Challenges in Critical Care

- Acute - No plan or documented discussions. Team who do not know child & family. Life & death decisions being rapidly made with a stranger
- Hand-held documentation not available, not accessible, and no formal record of children with ACP
- Families struggle when faced with the reality

How we contribute

- Contact wider MDT involved in child's care to build up a bigger picture of child & family
- Involvement in weekly palliative spectrum screening round – PICU/PHDU
- Enquire what if any discussions or plans are in place
- Do they have a lead Consultant DGH/Community?
- Ask parents who is involved in their care who helps and supports them

- Encourage families to have a voice in their child's care.
- If no parallel plan/ACP in place, work with family and relevant medical teams to start small discussions about the child's healthcare needs and they may be very different at discharge compared to admission.
- May be reoccurring problems which may require further admissions - How will that be managed?
- Building up network of contacts in community, DGH's, palliative care teams and hospices.