

CAPAC

A family's perspective

Parent Info Night: Wednesday 25 June 2014

Penny Jones

What is CAPAC?

- Community Acute/Post Acute care
- Sometimes referred to as Hospital in the Home
- For CF kids, the service delivers IV antibiotics and professional physio in the home and community setting
- Service offered by the Sydney Children's Network (Randwick and Westmead)
- 7 days a week

The down-side of hospital

- Hospital stays and medical intervention are a fact of life for CF kids
- Hospital stays are long – often 14 days or more at a time to gain benefits of antibiotic treatment, sometimes multiple times a year
- Over a lifetime, that adds up to a lot of time away from normal routines
- We have an amazing team and a great facility, but we all know the problems with hospitals...

The down-side of hospital

- Cross infection
- Isolation
- Hospital food
- Addiction to electronics/zombie brain
- Sleep
- Family logistics

What's involved

- PICC line
- General anaesthetic
- Initial hospital stay of 5 days



What's involved?

- IV antibiotics delivered via Baxter infuser worn in bum bag
- Nurses visit home/school once a day to change antibiotic and check PICC line and do observations
- Physiotherapist visits home/school once a day to administer physio and do clinical assessment
- Return to SCH Medical Day Unit once during admission to check line etc.



Considerations

- Not for everyone
- Only for certain bugs
- Final call rests with clinician
- Good communication/planning required with CAPAC team
- Have school on board
- PICC line/general anaesthetic risks
- Not under constant nursing/clinicians supervision
- Risk of line coming out/infection



Life changing!

