

A Child's Identity Beyond Their Serious Illness:

Supporting children and young people to have more positive healthcare experiences

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INTRODUCTION

- Children with a serious illness or chronic condition often require regular hospital visits.
- Regular hospital visits may involve painful and distressing procedures, which can lead to poor mental health.
- Improving healthcare experiences is particularly important for children with serious chronic conditions.

Starlight is a non-profit organisation committed to improving the lives of seriously ill children and young people.

'Captains on Call' involves Captain Starlight (skilled professional performers) working in partnership with health professionals to provide positive distraction during potentially painful and distressing procedures through child-led play.



METHODS

- Captains on Call' has been rolled out at the Women's and Children's Burns Clinic and Cystic Fibrosis (CF) Clinic, as well as the Queensland Children's Hospital Retinoblastoma clinic. At each Day Clinic, Captain Starlight is present when the child arrives, providing support throughout the whole treatment journey and until they leave the Clinic.
- We used qualitative and quantitative methods to evaluate the program across all three clinics to explore the:
 - Impact on children and caregivers
 - Impact on healthcare professionals

RESULTS

	Caregivers	Children	Health Professionals
Burns Clinic	? x 18	? x 6	? x 5
CF Clinic	X 18	X 10	? 3 x 3
Retinoblastoma Clinic	? x 23	_	26



Common themes across all clinics were that 'Captains on Call':

Improves the overall healthcare experiences for the child AND siblings:
Children feel less worried and distressed about their hospital visit and procedures. It also reduces boredom for siblings, which allows caregivers to be more present for their child undergoing the procedures.

"I would say it's helped her overall improve her experience. I think having Captain Starlight preceding the radiation therapy has helped her really make a happy connection to having it. It's not a stressful or anxious thing... It's made the whole ordeal, not an ordeal."

- Caregiver, Retinoblastoma Clinic

- Provides support for caregivers: Seeing their child happy and laughing helps reduce caregivers' distress and minimise negative rumination while waiting in hospital. The extra support also meant that caregivers could relax and take a break.
- before and during
 hospital visits: Captains
 make the hospital a more
 positive place to be.
 Children feel less anxious
 about attending hospital,
 with many caregivers
 stating that their child
 looks forward to their visit
 if they know Captain
 Starlight will be there.

My daughter was looking forward to coming here, which is different from the last times. I assumed she would have associated it with feeling sick and not want to come back. But because the Captains were there, she wanted to come back and play with them."

- Caregiver, Burns Clinic

CONCLUSION

- Providing opportunities for children in hospital to build their agency through child-led play may improve their hospital experience and overall wellbeing.
- Short, and regular interactions with Captain Starlight may reduce children's and young people's anxiety before and during a hospital clinic visit whether it be for a chronic (e.g. Cystic Fibrosis) vs. more acute (e.g. serious burns) condition.
- Caregivers may benefit from seeing their child from a strengths-based lens, rather than deficit-focussed as often the case in the medical system.