

Children's Cardiac Nurse Specialist and Clinical Nurse Specialist in Paediatric Palliative Care: A Collaborative Approach

Poster 74: Nicola Holdback and Katie Brant

Multiple standards (1; 2) identify that young people within Specialist Children's Surgical Centre's must have access to a CCNS. Young people with complex needs must have a named CCNS and where palliation is identified, a CNSPPC. At UHL, The Rainbows Clinical Nurse Specialists in Palliative Care and the Children's Cardiac Nurse Specialists have worked collaboratively and innovatively to support the physical, social, emotional and spiritual needs of babies, children and young people with a cardiac diagnosis and palliative care needs in order to improve patient and family's journeys.

A Rainbows experience day

T is a three-year-old, antenatally diagnosed with a complex congenital cardiac defect.

After numerous admissions to hospital, T had an eight-month inpatient stay due to heart failure.

During this admission, she underwent several procedures and required an IV infusion which meant T was predominantly cubicle-bound. This significantly impacted her physical, emotional and psychological development – alongside the impact this had on her and her parent's overall wellbeing.

Supported by COMET, the CCNS and CNSPPC transferred T to Rainbows for a very memorable day!

The family were able to enjoy the sensory room, arts and crafts, soft play, Mum had a massage and for the first time were able to enjoy a meal together. This also enabled family to manage her medication and feeds in a non-clinical environment in preparation for discharge.



What this meant to the family

T had been admitted to hospital for six and a half months when we visited Rainbows for the day. It was the first time that T had left the hospital so we were anxious about how she would cope. T had been subdued in hospital and was under the psychology team.

Rainbows had asked before the visit what T's interests were and had incorporated her interests into all aspects of the visit. The messy play session and crafts arranged for T were also designed around her love of dinosaurs whilst incorporating different sensory elements, which is something Thea had been struggling with. They had taken this all into account.

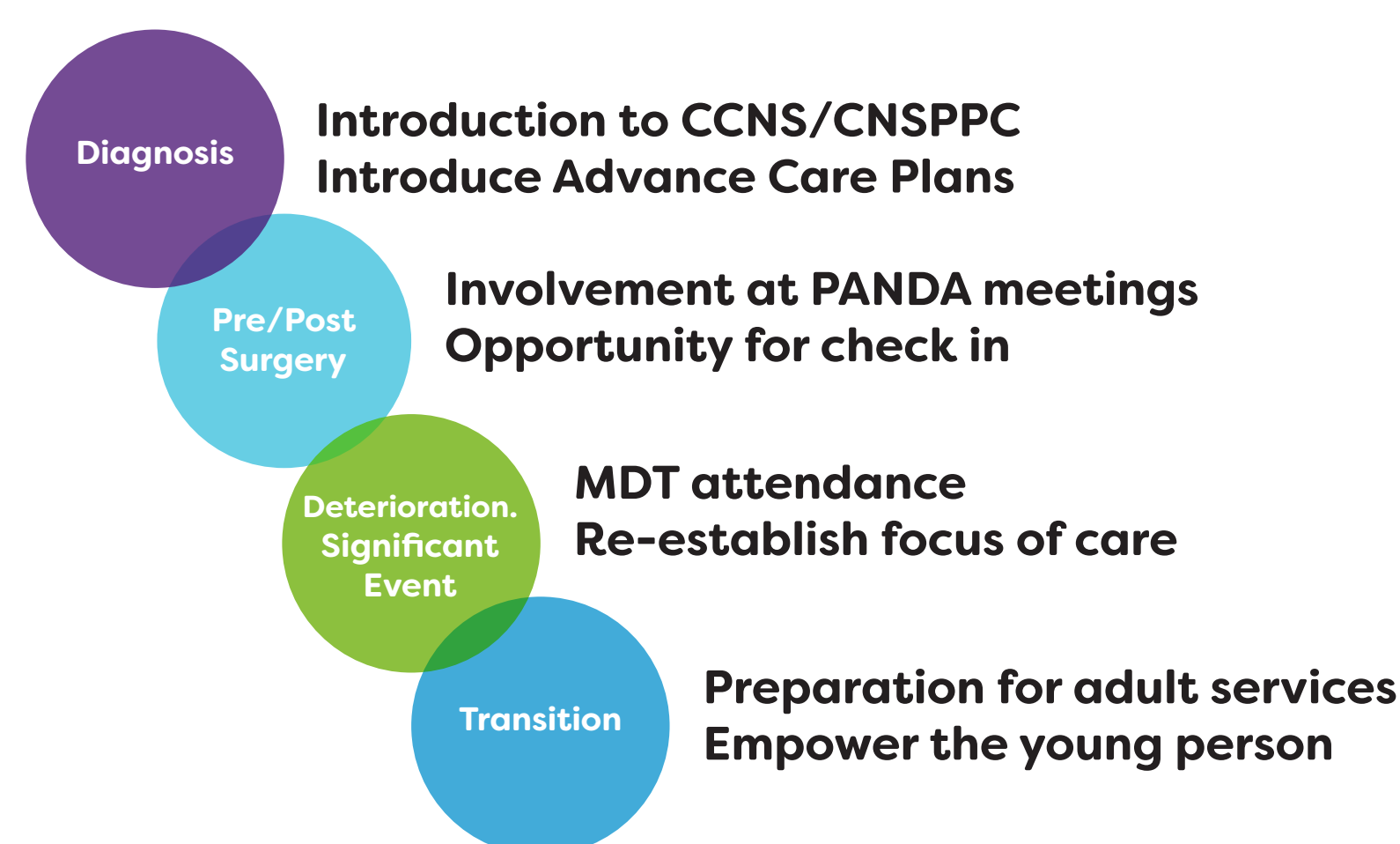
The visit gave us the opportunity to have some family time with the reassurance that T's medical needs, feeds and medication were all in hand but not in a clinical environment. We were able to sit down as a family at a table for the first time in seven months and eat lunch.

T's favourite experience was the soft playroom, her face lit up and her mood lifted. After the visit T seemed happier and not so serious. However much you try to put on a brave face when your child is ill in hospital, it is not only very hard but also tiring but when T was happier it became easier, less tiring and you can be more resilient.

The care and support that T and the family received from Rainbows during her admission, including her visit for the day and on and following discharge including play therapy at home, family fun day, respite care and support generally in negotiating family life again has been invaluable

Key collaboration points

Support is provided throughout a patients journey both in hospital and in the community, however, it is imperative to re-assess support at pivotal points of a patients journey:



Some diagnoses can be identified in the antenatal period where families are jointly supported by the Foetal CNS/CNS in Neonatal Palliative Care.

On the paediatric units, the CCNS/CNS in PPC continue to work closely to provide support to patients and their families, right through to transition. Rainbows can continue to provide support up to the age of 25years.

Our visions for the future

With excellent inter-teamwork, our aim is that individualised care can continue to be delivered to meet the holistic and complex needs of patients and their families. To date we have supported 25 patients since July 2021. Our visions for the future for all patients with a cardiac and palliative diagnosis:

- Have an identified CCNS and CNSPPC
- Have a referral to Rainbows Hospice
- Have a complete Advance Care Plan

Conclusion:

Patients have accessed palliative care throughout their inpatient stay as part of parallel planning, this collaborative approach has enabled families to access a wider variety of support. Patients have benefited from music therapy during hospital admissions, play therapy in the community, stays at Rainbows and are supported by the Family Support Team throughout their journey. For T and her family this significantly boosted their morale during a long inpatient stay and has helped them navigate the challenges of living with a complex illness.

ACKNOWLEDGEMENTS

This very special day wouldn't have been possible without the support of: the COMET Team, the Cardiac Nurse Specialist Team and the Rainbows staff. Thank you.

REFERENCES

1. NHS England. Congenital heart disease standards and specifications. [Internet]. 2016 [cited 2022 June 15]. Available from: <https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-standards-and-specifications.pdf>
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