CASE PRESENTATION

OVERCOMING BARRIERS A MODEL OF PAEDIATRIC PALLIATIVE CARE PROVISION UTILISING AN 'IN HOME' MODEL OF CARE

JILL CARTER
CLINICAL NURSE CONSULTANT
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AIM OF THE CASE PRESENTATION

This case presentation is delivered with the permission and the blessing from the patient's family, in the hope that 'H's' story can be shared and be helpful to other health professionals faced with a similar challenge.
To reassure all adult services you **can** do this !!

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INTRODUCING 'H'

10-year-old H was born in Thailand in refugee camp in 2014 to Burmese parents,

The middle child to an older brother 14 and younger sister 3

Arrived as refugees in Australia in 2018.(H was 4yrs old)

Settled in Geelong where there is a large community of Burmese refugees ‘Karen’ speaking.

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FAMILY BACKGROUND

- Parents NES
- Lived very simply, humble life with a strong Christian Faith, family belonged to the local church and choir
- H was a popular happy boy at school with many friends and ‘Karen’ speaking teacher assistants.
- School was an important part of his life especially playing soccer at playtimes.
- He had a love for soccer and was obsessed with the Portuguese soccer player Cristiano Ronaldo !
- Teachers and school nurses had formed a unique relationship with the family.

MEDICAL BACKGROUND

- H presented with a (pathological)fracture of the distal R femur following a simple fall from monkey bars at school 2021
- Transferred to Royal Children's Hospital(RCH) following diagnosis of **Osteosarcoma** for what then became several months of intense treatment
- Surgery – surgical resection and rotation- Van Nes rotationplasty 2022
- Followed by chemotherapy and radiotherapy 2022
- Months of living away from home, school and friends in Melbourne for chemotherapy treatment and intense prolonged rehabilitation -9months
- He was reserved , humble and stoic in his approach to his illness.

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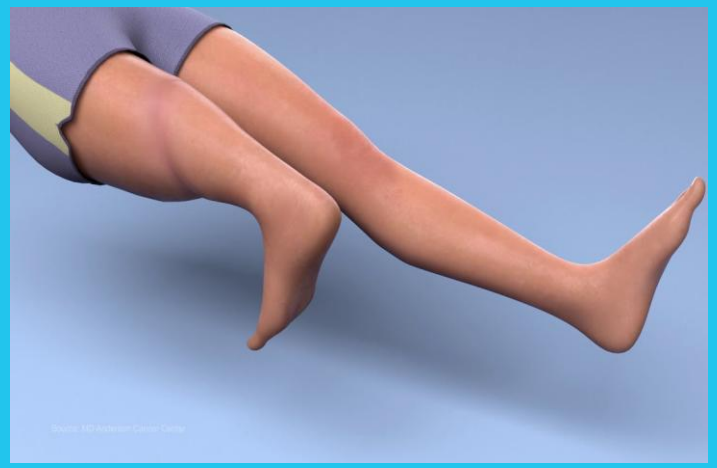
Van Nes Rotationplasty.

- This surgery is limb saving; it removes the knee joint and rotates the lower leg 180 degrees before re attaching it to the thigh.
- This turns the ankle joint into a functional "neo knee" allowing patients to use a lower leg prosthesis for high level mobility.
- The foot is pointing backwards which aids prosthetic limb fitting.
- The procedure is extraordinarily complex and requires long term rehabilitation .



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OSTEOSARCOMA

Osteosarcoma is the most common type of bone cancer. It is usually found in the ends of long bones, femur, humerus, but can develop in any bone.

More common in males than females, diagnosed in children, teens and young adults between the ages of 10 – 30 .

Most likely sites of metastases being lung, skeleton, often local invasion to surrounding bone and soft tissue.

In its aggressive and high grade form it carries a poor prognosis.

Sarcoma in children tends to grow aggressively and can be difficult to treat .

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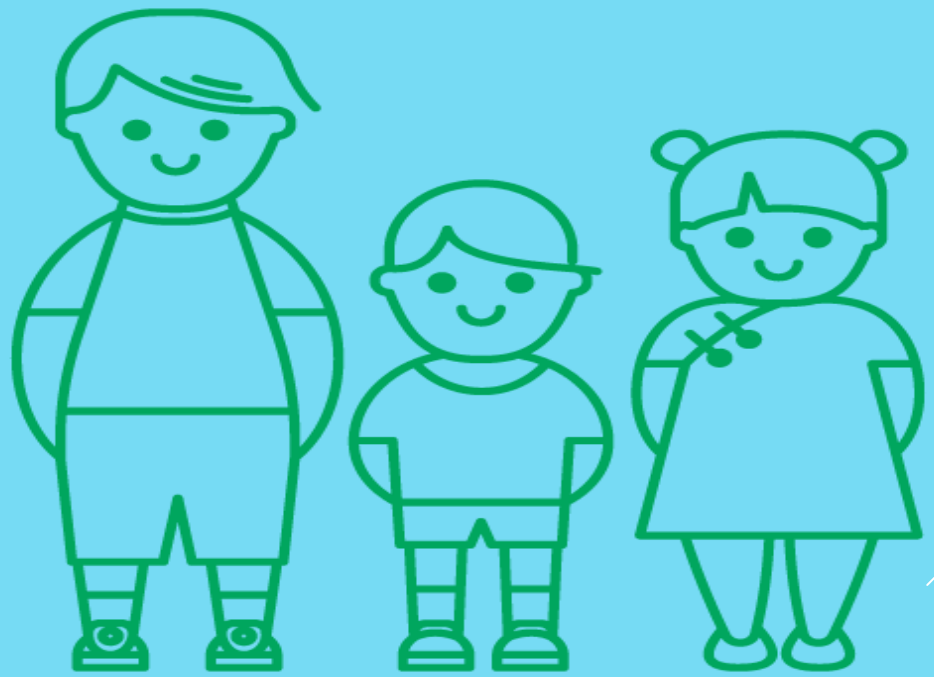
SARCOMA IN CHILDREN

Children's Cancer Institute

90 cases of sarcoma are diagnosed in children & adolescents each year in Australia.



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'H'DISEASE PROGRESSION

<2YEARS AFTER DIAGNOSIS

August 2023

- Disease progression
- Lung metastases and chest mass with a small pleural effusion present.
- No further systemic treatment available
- Referral to Community Palliative Care Service

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LOCAL SERVICES
COMMUNITY PALLIATIVE CARE

Barwon Health Geelong, Victoria provides a comprehensive

Community Palliative Care Service to over 270 patients and families (predominantly adults)covering a wide geographical area.

The service has ongoing consultancy with 24 on call.

Caring for paediatric patients as needed.

H and his family were referred to our service by

Victorian Paediatric Palliative Care Service

Children's Hospital Melbourne (VPPCS)

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WHAT HAPPENED NEXT ?

FIRST HOME VISIT

Assessed by CPC – joint visit with RCH &

Interpreter at home.

H scooting on floor after school/shy and yet curious

Stole the i pad whilst parents distracted !

Smiling happily /cheeky and denying any symptoms

Set main goal of going to school – nurse visits not to interfere with this if possible

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ONGOING SUPPORT

- 1-2 weekly visit to build rapport & trust in addition to complex symptom management and pain control
- Optimise parental education and monitor administration and supply of medications
- Permission granted by H & parents to go to school to educate and support teachers
- OT to school re toileting and access with motorised wheelchair
- Support to school teaching staff and nurses

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CHALLENGES

- Communication Interpreter
- Work arounds for call ins
- Understanding Cultural influences
- Appointments
- Social situation
- Increasing health issues disease related and non-disease related
- Changing needs requiring lots of OT/Physio input and equipment
- Home assessments

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EARLY 2024

- Further disease progression
- Thoracic spine T6 disease
- Multiple sites of disease progression
- Pathological fracture to R Humerus
- More pain in leg
- Local radiotherapy and brief stay in RCH

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DETERIORATION JULY 2024

Routine home visit led to local

hospital admission-

Spinal cord compression T6 collapse

Widespread disease

Family meetings +++ with interpreter RCH

Oncology team discussion

Decision made to discharge home

MDT involvement to make this happen

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THE PICTURE NOW

- Dramatic change for H and family
- Bed based care
- Indwelling urinary catheter
- Transdermal analgesia increased
- Daily bowel regime
- Pressure area care and skin care
- Symptom management plan including S/C route
- Explanations to H re this and availability of support medications.
- Venue of care explored at length

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FAMILY TENSION

- Differing of opinion about home V hospital
- Unresolvable /not negotiable
- Mother had to allow Father to make the decisions
- Father, withdrawn, quiet and mistrusting of health professionals
- Declined any psychosocial support offered – supportive care team both RCH and BH
- H aware of disharmony and Mum's anxiety, impending birthday

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MUMS BIRTHDAY

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PAL@HOME

- 6 'virtual' beds/in patient @home
- bed substitution model (National Weighted Activity Unit)
- Public hospital funding based on acuity.
- 24/7 support and care at home
- Rapid response to call outs
- Holistic team input
- Addition of weekly Paediatric medical consultation at home*

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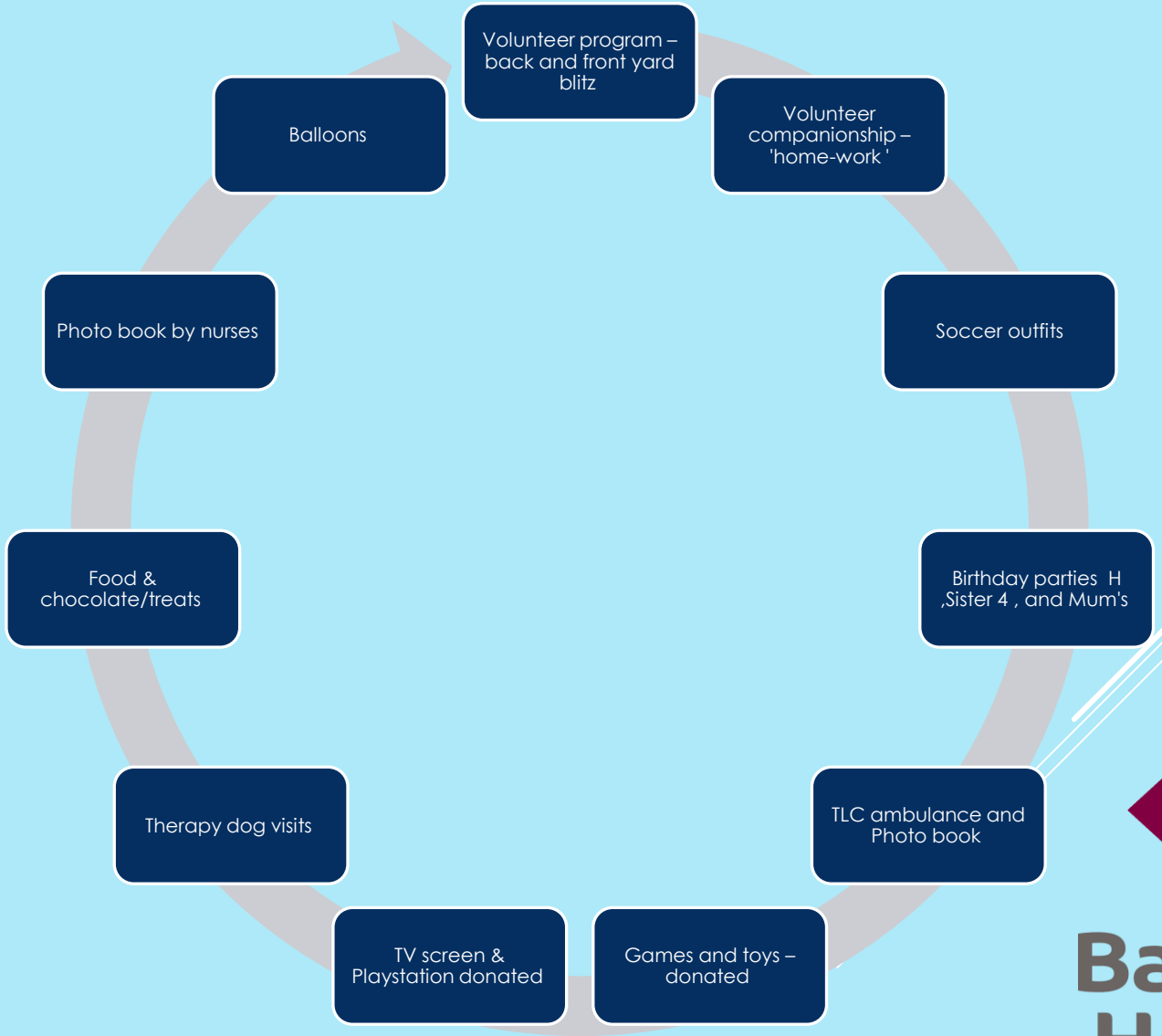
SIDE DISHES



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POKO VISITS

Transdermal patch

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SCHOOL REUNION

H had not been to school for several months

Plan to go to school to see friends and experience the reptile incursion with the aid of TLC ambulance

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DON’T ALWAYS EXPECT THE WORST!!!

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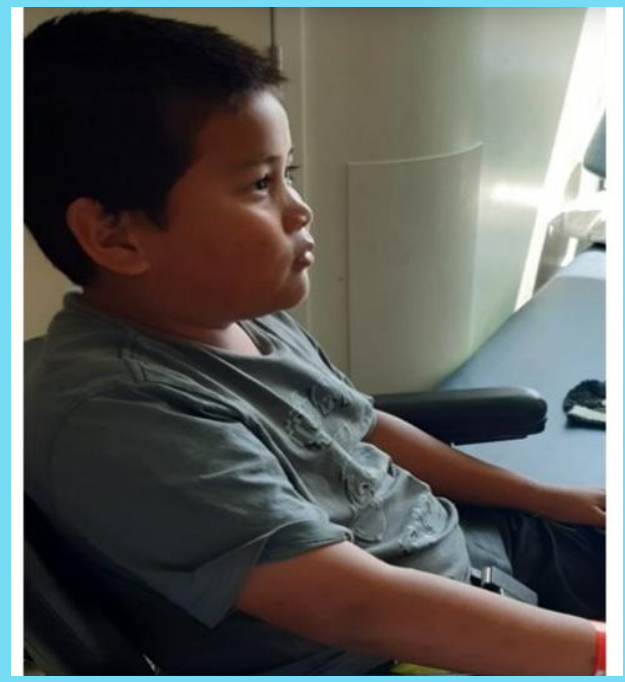
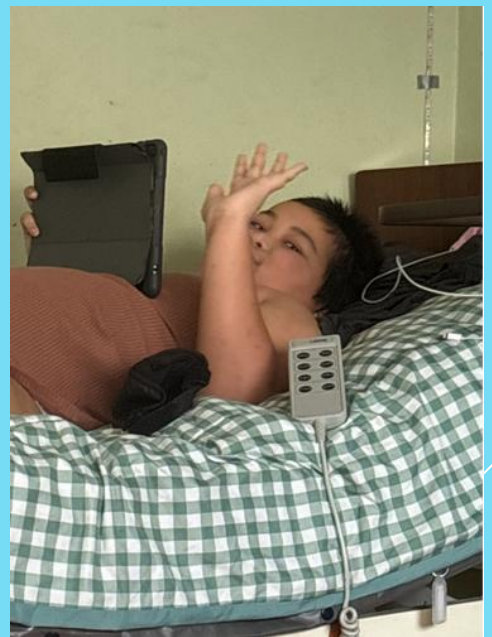
OUTCOME

- PAH cared for H for 5 months until his peaceful death in December 2024 **at home** surrounded by extended family
- This intensive level of supportive care made this possible against all the odds
- 1 hospital admission in 5 months for catheter change
- Patient and family centred
- Total of 16 months of palliative care provided
- Acknowledge the wider team for all care provided

THANK YOU





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