

# Sarah's journey

## Flinders LGA – Inoperable Brain Tumours

Sarah is an 18 month old girl who lives with her mother, father and two older brothers on a very remote property in the Flinders Shire. One day when Sarah's mum was giving her a bath she had a prolonged seizure. Sarah's mother and oldest brother used the satellite phone to call the Royal Flying Doctors Service (RFDS) to manage the seizure using the medical chest on their property. Following admission to the Townsville University Hospital and transfer to Queensland Children's Hospital, Sarah is living with inoperable, malignant brain tumours.

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**CELC**  
 Townsville  
 CONNECTING END OF LIFE CARE

The CELC Townsville project is administered by Palliative Care Queensland and supported by funding from Northern Queensland Primary Health Network (NQPHN) through the Australian Government's PHN program.



Sarah's Mum leaves 2 sons with her husband and travels with Sarah in the RFDS plane to Townsville University Hospital.



### ROYAL FLYING DOCTORS (RFDS)

RFDS doctor takes the call from Sarah's mother. The doctor provides advice via telehealth & prescribes from the Medical Chest located on the property. RFDS organises Sarah's retrieval.

### BAD NEWS DIAGNOSIS



Brain tumours diagnosed in Paediatric Intensive Care Unit at Townsville University Hospital.

Sarah's family stay at Ronald McDonald House in Brisbane while specialists trial medications to manage Sarah's pain and seizures.



### TRANSITION TO COMFORT CARES

Queensland Children's Hospital advise there are no curative treatment options for this type of cancer. Referred to Paediatric Palliative Care Service.



### DISCHARGE PLANNING

Transferred to TUH Paediatric Oncology ward. NQ Oncology Coordinator Nurse and Social Worker are primary contacts for family.

### SARAH AND HER FAMILY RETURN HOME

Sarah's Mum & Grandmother receive training from nurses about how to care for Sarah.



### ACCESSING MEDICATION/ENTERAL FEEDING SUPPLIES

Regular 1.5 hour drive to Hughenden Multipurpose Health Service.

Sarah's family are overwhelmed with the number of services & decline further support from Cancer Council Qld or other services.

Sarah's family stay at Ronald McDonald House in Townsville.



### REGULAR TELEHEALTH

Coordinated by North Queensland Paediatric Oncology Coordinator.



### BEREAVEMENT SUPPORT

Social worker assists family to engage a funeral director & navigate best fit bereavement support services.

Sarah's family work with the hospital team to organise 'memory making' activities e.g. photos & footprints.



### SARAH'S CONDITION DETERIORATES

Sarah spends the last month of her life at the Townsville University Hospital.

#### Key Themes:

- Remote location
- Financial stresses
- Who will manage the property?
- Sibling care, support & schooling
- Overwhelming number of services involved
- Return home requires family to be trained in cares

#### Potential issues/barriers:

- Care & service coordination
- Access to resources including availability of Queensland Retrieval Services aircraft & crew, beds at each hospital & staffing within all services
- Any changes to medications or feeds will be delayed due to coordination/transport
- Access to reliable internet at home