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.

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.

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

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

SARAH AND HER FAMILY RETURN HOME

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

ACCESSING MEDICATION/ENTERAL FEEDING SUPPLIES

Regular 1.5 hour drive to Hughenden Multipurpose Health Service.

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 family stay at Ronald McDonald House in Townsville.

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

An initiative of PalliativeCare QUEENSLAND PALLIATIVECAREQLD.ORG.AU

Supported by phn NORTHERN QUEENSLAND An Australian Government Initiative | 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.

Joe's journey

Flinders LGA – Colorectal Cancer

Joe is a 76-year-old retired butcher, who lives with his wife in Hughenden. They have a large supportive family and have been very active in the community for more than 50 years.
Joe has several comorbidities, and after being diagnosed with adenocarcinoma of the bowel (colorectal cancer), the specialist has told him that surgery would not be possible and that he could receive some treatment to slow down the process.

An initiative of PalliativeCare QUEENSLAND
PALLIATIVECAREQLD.ORG.AU

Supported by
phn NORTHERN QUEENSLAND An Australian Government Initiative
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.

COLONOSCOPY

Joe drives 4 hours & plans to stay overnight in a hotel but receives a cancer diagnosis from the gastroenterologist. He remains in Townsville for further imaging so the specialist can advise on treatment options.

CANCER COUNCIL QUEENSLAND 13 11 20

The cancer care nurses refer John & his wife to the Cancer Council hotline to access accommodation and some counselling support.

PRIMARY CARE

Joe drives 1 hour to Richmond to see the General Practitioner (GP). The Hughenden GP has been on leave for 2 weeks & there is no replacement.

HOME CARE

Flinders Shire Council Community Care increase in-home care as Joe's needs increase. When Joe has admissions to the MPHS, Community Care, the GP and Hughenden MPHS work with Joe's family to ensure they have the required support at home.

SPECIALIST PALLIATIVE CARE

The oncologist refers to Specialist Palliative Care Rural Telehealth Service (SPaRTa) who meet Joe at the Day Unit and then provide ongoing telehealth with the GP and Hughenden MPHS. Joe's wishes are documented.

SPECIALIST CARE AT TOWNSVILLE UNIVERSITY HOSPITAL (TUH):

Over the following year, Joe has multiple hospital admissions, oncology day unit appointments and other outpatient appointments with surgeons, medical oncologists, radiation oncologists, infectious disease specialists, radiation therapists, dietitians, social workers and physiotherapists.

When Joe returns home, between treatments he is referred to visiting allied health clincians and tele-chemotherapy at Hughenden Multi Purpose Health Service (MPHS) is considered.

TRANSITION TO SYMPTOM CONTROL

Oncology Nurse Navigator talks to Joe & his wife about the benefits of palliative care as the oncology treatments are focused on symptom control.

JOE'S FUNCTION DECLINES

Charters Towers Hospital Allied Health Team visit. Medical Aids Subsidy Scheme fund aids.

DYING AT HOME

The Hughenden MPHS aged care coordinator supports Joe's family and friends to care for him at home with the help of regular telehealth with SPaRTa.

Joe returns home with MPHS nurses assisting family with cares.
Joe dies 2 days later.

HOSPITAL-BASED AMBULANCE

Joe is transferred to Hughenden MPHS several times so his family can have some respite and medications can be optimised.

Key Themes:

- Hughenden is a one doctor town
- Rural workforce shortages
- Patient Travel Subsidy Scheme
- 400km from tertiary hospital
- Use of Retrieval Services Queensland
- Visiting allied health services
- Medical Aids Subsidy Scheme

Potential issues/barriers:

- Travel to Townsville HHS for biopsy/imaging that can't be done in Hughenden
- Travel & accommodation required
- Where is his preferred place of care?
- His wife's capability of caring for him
- Letters from treating team to GP may take several days (posted, not emailed)
- GP not always available for shared-consults with specialist teams