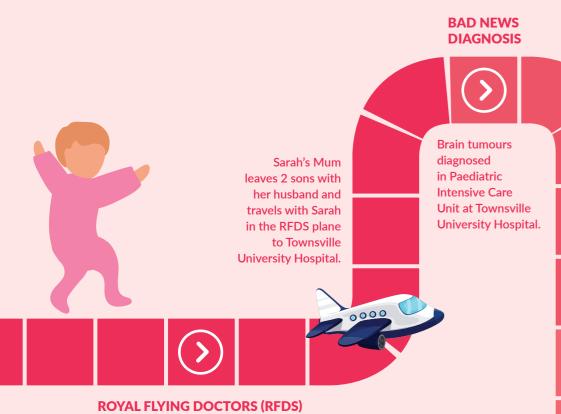
# Sarah's journey

## 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.



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

### **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

## **ACCESSING MEDICATION/ENTERAL**



Regular 1.5 hour drive to Hughenden Multipurpose Health Service.

Sarah's family are

the number of

overwhelmed with

services & decline

further support from

**Cancer Council Old** 

or other services.

Sarah's family

stay at Ronald

Townsville.

McDonald House in

#### **SARAH AND HER FAMILY RETURN HOME**

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

**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.

# **FEEDING SUPPLIES**

#### **REGULAR TELEHEALTH**

Coordinated by North Queensland **Paediatric Oncology** Coordinator.



An initiative of

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.

#### **BEREAVEMENT SUPPORT**

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



phn NORTHERN QUEENSLAND

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.

### 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

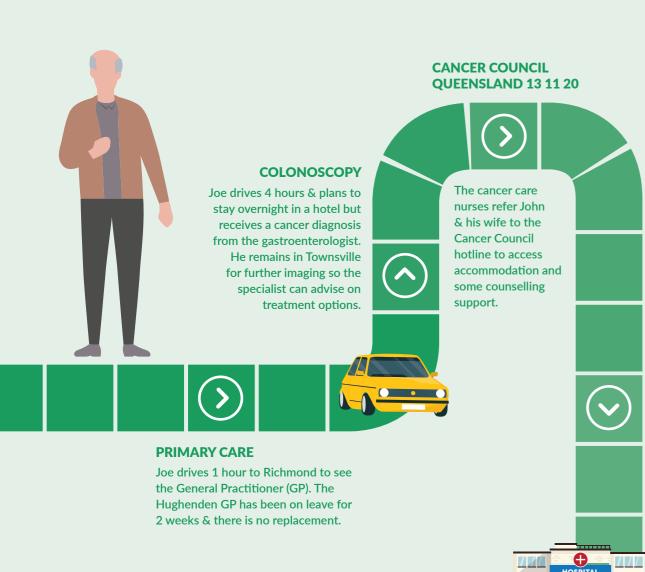


# Joe's journey

## 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.



#### **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

# 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.





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

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

### 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.



#### **HOSPITAL-BASED AMBULANCE**

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

### 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

# SPECIALIST CARE AT TOWNSVILLE UNIVERSITY HOSPITAL (TUH):

**HOME CARE** 

Flinders Shire Council Community

Hughenden MPHS work with Joe's

Care increase in-home care as

has admissions to the MPHS,

Community Care, the GP and

family to ensure they have the

required support at home.

Joe's needs increase. When Joe

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.