

# Mary's journey

## Bwgcolman (Palm Island) – First Nations – Cancer of Unknown Primary

Mary is a 60 year old proud Aboriginal woman, who has family connections in Bwgcolman, Townsville & the Atherton Tablelands. She enjoys watching her family play sport, as well as fishing & cooking. After noticing Mary had lost weight & started walking with a limp, a health worker encouraged Mary to have an annual health check.



### PRIMARY CARE – PALM ISLAND COMMUNITY COMPANY (PICC)

Mary has her health check with the female doctor, who has always been good with women's business.

### INVESTIGATIONS – JOYCE PALMER HEALTH SERVICE (JPHS)

Mary's blood test shows raised tumour markers, while the X-ray of Mary's pelvis reveals a tumour.

### CHEMOTHERAPY - TUH

Mary stays with her niece when in Townsville for chemotherapy or scans. The TUH Indigenous Health Liaison Officers (IHLO) & JPHS health workers support Mary & her family.

### HEALTH LITERACY / CULTURAL SUPPORT – PICC & JPHS

The health workers & nurses help Mary organise travel to Townsville. They explain the situation many times to help Mary's shocked family understand.

### DIAGNOSIS / SPECIALIST CARE – TOWNSVILLE UNIVERSITY HOSPITAL (TUH)

After biopsies & many scans, the multi-disciplinary cancer care team at TUH diagnose Mary with cancer of unknown primary with bone metastases in Mary's hip and spine.

### DECLINING FUNCTION

Mary's family don't understand why Mary isn't getting better after the chemotherapy. The physiotherapist & nurses provide education, training & equipment.

### PAIN MANAGEMENT AT HOME – SPECIALIST PALLIATIVE CARE

JPHS organise telehealth appointments with the specialist palliative care service at TUH. Mary is very worried about having medications in the house & how to keep the children safe.

### BEREAVEMENT

25 members of Mary's family gather at the hospital in her last days. After Mary dies, the nurses assist the family to bath & dress Mary. While the council helps plan Mary's burial.

### FINAL HOSPITAL ADMISSION

Mary is showing signs of a spinal cord compression & her pain medications need close monitoring. JPHS nurses & health workers spend many hours preparing Mary's family for her death.

#### Key Themes:

- Common end of life medications & 2 syringe drivers available at Joyce Palmer Health Service
- For some families, use & storage of controlled drugs in the home is a concern, due to drug misuse & dependency within the community
- Health literacy & support for planning healthcare
- Culturally appropriate health and bereavement services
- Timing & access to advance care planning & specialist palliative care
- Experienced health professionals often need to be strong advocates for patient wishes

#### Potential issues/barriers:

- Staff shortages – use of agency nurses, adequate medical staffing for patients to be transferred back to JPHS
- Medical teams often keen to transfer people to Townsville
- Limited residential aged care
- Healthcare professionals understanding of eldership
- Late diagnosis due to reluctance to go to Townsville for investigations
- No culturally appropriate pain assessment tools available



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# Samuel's journey

## Bwgcorman (Palm Island) – First Nations – Kidney Disease and Diabetes

Samuel is a 58 year old man who has family on Palm Island and in Townsville. He likes to stay on Bwgcorman country, as he often runs into trouble with family, finances & alcohol when in Townsville. Samuel's father, like Samuel, required renal dialysis three times a week, for the last 7 years of his life. Samuel is very worried about his own son, who was recently diagnosed with diabetes.



**DIALYSIS – JOYCE PALMER HEALTH SERVICE (JPHS)**



### SPECIALIST CARE

The renal team from Townsville University Hospital (TUH) visit JPHS every month. Samuel is not eligible for a kidney transplant due to his poor overall health.

### VISITING SERVICES & PALM ISLAND COMMUNITY COMPANY

Non-government allied health providers work with JPHS doctors, nurses & health workers to complete a NDIS application for equipment & ongoing support services as Samuel's health & function decline.

### PSYCHOLOGICAL SUPPORT

The multi-disciplinary team refer Samuel to a counsellor, but he misses the appointments. Samuel gets support from his friends at dialysis, the junior football club and church.

### SORRY BUSINESS

While in Townsville for sorry business, Samuel is admitted to TUH with alcohol intoxication and a wound infection. He is admitted to the Intensive Care Unit (ICU) with sepsis.

### SUBSTITUTE DECISION MAKERS

The ICU doctors have difficulty identifying Samuel's substitute decision maker and establishing Samuel's wishes. The renal team assist, as they have known Samuel for many years.

### FAMILY CONFLICT

In Samuel's final days at TUH, the indigenous health liaison officers (IHLO) organise a visiting roster, as there is conflict between his Bwgcorman-based and Townsville-based family. John dies in the ICU at TUH.

### BEREAVEMENT

In the months following Samuel's death, many of his friends miss dialysis. Several of Samuel's family members struggle to go to school or work. Some start drinking and smoking more.

The team & other patients know Samuel well. They often share stories about family & talk about the footy results.

#### Key Themes:

- NDIS is the main funding source (younger population living with chronic disease)
- Four chairs available for dialysis at JPHS. Temporary chair swap arrangement available if someone living on Palm Island needs to travel to Townsville
- Culturally appropriate health and bereavement services
- Complex family dynamics
- Impact of serious diagnosis on wider family (e.g. school attendance, employment participation etc)
- Choice of escort for healthcare in Townsville

#### Potential issues/barriers:

- Impact of complex grief on health choices & advance care planning
- Multiple generations of families dying from diabetes & renal failure. Often the family is still grieving when the next family member is diagnosed or starts dialysis
- Visiting services ability to find patients & the need for health worker support
- Drug & alcohol dependence



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