

# Jayden's journey

## Townsville – First Nations – Squamous Cell Carcinoma Oesophageal

Jayden is a 62-year-old proud Aboriginal and Torres Strait Islander man who has family connections in Townsville and Mer (Murray Island). He lives with his wife and two of his four children in Townsville. Jayden works full time at the Townsville City Council.

Jayden developed difficulty swallowing with some associated pain, which he noticed getting slightly worse over a 6-month period. Jayden developed a persistent cough and, one day after coughing up some bright red blood at work, went to his doctor.



### PRIMARY CARE



Jayden has missed his last 3 annual health checks with the General Practitioner (GP) because he has been busy with work and coaching his son's footy team. The GP performs a thorough health check and refers Jayden for an urgent endoscopy.

### INVESTIGATIONS



Jayden has an endoscopy at Townsville University Hospital (TUH). After this, Jayden is advised by his gastroenterologist that they have found a large tumour which was biopsied and sent for testing.



### SPECIALIST CANCER CARE

Jayden receives care from the multi-disciplinary team who specialises in gastrointestinal cancers at TUH. After his outpatient appointment, the Indigenous Health Liaison Officer (IHLO) sees Jayden is shocked and unsure what having advanced oesophageal cancer means.

The IHLO supports Jayden and his family through multiple appointments with dietitians and medical oncologists. Jayden starts palliative chemotherapy.



### IMPACT ON FAMILY LIFE

The IHLO and social worker assist Jayden when he starts chemotherapy at the oncology day unit and needs to stop working. Jayden doesn't want to do a My Aged Care application but would like some support from the Cancer Council Queensland for advice regarding financial planning. Jayden goes to footy and fishing but he often sits there and doesn't talk to anyone.

### SAD NEWS (SORRY BUSINESS)

The nurses are worried when Jayden misses his chemotherapy at the day unit. When Jayden returns the next week, he tells the IHLO there has been sad news and he has been on Murray Island with his family.

### EMERGENCY CARE

Jayden is taken to the Emergency Department and admitted to the inpatient Oncology ward with neutropenia. It is during this admission that the IHLO discovers that some of Jayden's family think he is going to get better because he is receiving chemotherapy. The IHLO organises a referral for Jayden to assess Integrated Team Care funding on discharge to assist with transport and support during medical appointments.

### PALLIATIVE CARE CONSULT



The IHLO makes sure Jayden's wife and brother are there when the palliative care team see him for the first time in hospital. Jayden's brother will act as a spokesperson and shares relevant information with the extended family.



### SPECIALIST PALLIATIVE CARE

Palliative chemotherapy is no longer providing symptom relief. Jayden is eating and drinking less. His difficulty swallowing means, he misses medication regularly. Jayden is admitted to the Palliative Care Centre for the first time. He is overwhelmed by the number of new doctors, nurses, dietitians, pharmacists, speech pathologists, occupational therapists (OT) and physiotherapists he meets.



### PALLIATIVE CARE AT HOME





Between hospital admissions, the contracted nursing service visit Jayden at home to help his personal cares and medications. This was difficult at the start as the team didn't talk to Jayden about how he would like to approach men's business. The palliative care doctor, OT and physiotherapist also do home visits.








### MOURNING PERIOD

During Jayden's last stay in the Palliative Care Centre, the IHLO works with the multi-disciplinary team to accommodate Jayden's large family. A priest visits to perform a blessing. Following Jayden's death, the family organise a traditional burial.

#### Key Themes:

-  Late diagnosis
-  Aboriginal & Torres Strait Islander people are eligible for My Aged Care from 55 years
-  Importance of Sorry Business
-  Curative vs palliative intent treatments
-  Spiritual and Emotional Healing

#### Potential issues/barriers:

-  Health literacy - words such as oncologist, tumour & biopsy explained
-  Cultural awareness of service providers
-  Financial stressors
-  Dysphagia management
-  Multiple disciplinary teams (ED, oncology, palliative care)



An initiative of  
**PalliativeCare**  
QUEENSLAND  
PALLIATIVECAREQLD.ORG.AU

Supported by



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.