Janine’s journey

Magnetic Island – Stage 3 Breast Cancer

Janine is a 44-year-old woman who lives with her husband and 2 children (aged 9 and 14 years of age). Janine is an academic at James Cook University and travels over via ferry 5 days a week to attend work. On her most recent mammogram, it was found that she had several spots on her left breast that looked like tumours. Janine was sent for a biopsy of the lumps, which was sent to her family GP on Magnetic Island. She was also sent for Immuno-Histo-Chemistry test. She attended her GP and the results show that she is HER2-positive. Janine is referred by her GP to an oncologist at the Townsville University Hospital. The oncologist sends Janine for further tests, which come back as showing that the cancer has spread to the lymph nodes. She is also sent for a full body MRI and it is found that she has some spots on her spine, which are confirmed to be cancer.

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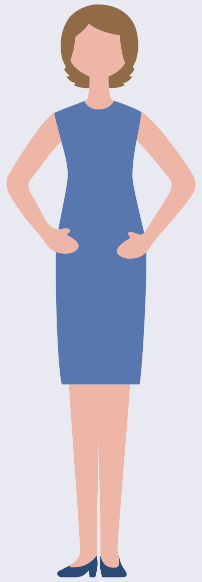


PRIMARY CARE

Janine attends a general practice in Townsville as it is easier to make appointments around work commitments.

INVESTIGATIONS

Private pathology and radiology services are a 5 minute walk from Janine’s office at the university.

SPECIALIST CANCER CARE

Janine is referred to the medical oncologist & surgeon at the Townsville University Hospital.

Janine meets a breast care nurse who becomes Janine & her families main contact throughout years of investigations, biopsies, surgery, chemotherapy & radiation.

Janine receives care in inpatient surgical & oncology wards, oncology day unit & outpatient clinics. She has appointments with many specialists, nurses, social workers, radiation therapists, pharmacists, occupational therapists & physiotherapists. Janine also participates in some clinical trials.

IMPACT ON FAMILY LIFE

Janine takes leave from work. Her husband organises income protection payments through Janine’s superannuation provider.

The family regularly stay with Janine’s parents to avoid travelling back & forth from the Island. They also help get the kids to school.

The children don’t like seeing their mum without any hair and have periods of not wanting to go to school or sports.

PEER SUPPORT

Janine’s oldest daughter looks at the Canteen website. She and her sister use the Canteen Connect App to talk to other kids who have parents with cancer.

Janine has looked at the Cancer Council & Breast Cancer network websites. Janine’s work colleagues invite her to an afternoon to raise funds for breast cancer research.

PALLIATIVE TREATMENT

The breast care nurse explains to the family that the chemotherapy and raditation is not curative and the purpose is to manage Janine’s symptoms.

The medical oncologist refers to palliative care.

SPECIALIST PALLIATIVE CARE

Janine & her husband are overwhelmed with meeting a whole new team of doctors, nurses, physiotherapists, occupational therapists, pharmacists & social workers & telling their experience over again.

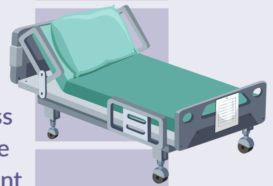
DECLINING FUNCTION

The amount Janine can do for her children decreases and, with time, this also impacts caring for herself.

The palliative care outreach nurses call regularly and organise contracted community nursing service for palliative care in the home.

The Occupational Therapist does a home visit to Janine’s house and her parent’s house. Equipment suppliers deliver aids to both homes.

Janine is spending less time at her own home now, but it is important to her kids that they are on the Island.



PALLIATIVE CARE CENTRE

Janine has several inpatient admissions. She has day leave where possible to attend events at the kids’ school if she is well enough.

Janine dies at the centre surrounded by her family.

BEREAVEMENT

The social worker, funeral home and school guidance officer all listen & provide advice to Janine’s family.

Key Themes:

- Support for children who have a parent with cancer
- Memory making and planning for children’s upbringing without Mum
- Participation in clinical trials
- Specialist coordinators – breast care nurses
- Funding sources for people aged under 65

Potential issues/barriers:

- Access to healthcare on Magnetic Island especially in an emergency
- Financial stressors
- Family’s adjustment to altered roles & lifestyle
- Fear of dying (mother and children)
- Dying on the Island not an option for many people due to service availability and costs. Transporting the body back to the mainland is very expensive

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.

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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)

Lorraine’s journey

Townsville – Residential Aged Care Facility - Dementia

Lorraine is an 80-year-old woman with advanced dementia. Lorraine moved into a Residential Aged Care Facility in Townsville 4 years ago due to her functional decline making it unsafe for her to live alone. She was previously cared for by her husband, but he has since passed away and the services available are not enough for her to remain safely at home alone. Over the last 6 months, Lorraine’s function has begun to decline more noticeably. She no longer eats and drinks adequate amounts, her ability to speak and communicate has reduced and has now started having an increasing number of falls.

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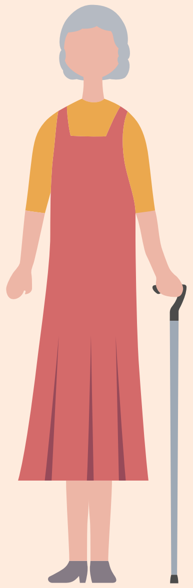

LORRAINE HAS A FALL

The personal care worker at the residential aged care facility (RACF) finds Lorraine on the ground beside her bed on a Saturday morning. The registered nurse reviews Lorraine and calls an ambulance. Lorraine doesn’t appear to be in pain. The nurse is concerned because Lorraine takes anticoagulant medication.

QUEENSLAND AMBULANCE SERVICE

The paramedics have difficulty communicating with Lorraine. They transfer her to the Townsville University Hospital (TUH) for the third time this year. She is not given any analgesia.

EMERGENCY DEPARTMENT (ED)

The junior doctor orders pathology & radiology. Lorraine isn’t talking so a history can not be taken. No analgesia is provided. Lorraine’s Next of Kin (NOK) cannot be contacted.

ED Pharmacist completes a medication history so usual medication can be commenced. The pharmacist shows the doctor The Viewer in the electronic medical file where there is a copy of Lorraine’s Advance Health Directive (AHD) and Enduring Power of Attorney (EPOA).

FRAILTY INTERVENTION TEAM (FIT)

The clinical nurse can’t find the transfer information from the RACF but gets collateral information over the phone. Following an assessment, the FIT nurse discusses pain management & the possibility of Lorraine having hypodelirium with the treating doctor.

SURGERY

Lorraine has been found to have a fractured femur. The orthopaedic surgeons recommend surgery for pain management and quality of life. Lorraine’s EPOA consents and assists the surgical doctors with making an Acute Resuscitation Plan before surgery. After the surgery, the orthogeriatricians diagnose Lorraine with dysphagia and refer to the speech pathologist.

DECLINING FUNCTION

Lorraine is not able to be rehabilitated to her pre-injury baseline and is discharged with multiple recommendations from the physiotherapist, speech pathologist and geriatricians.

RETURNS TO RACF

Lorraine returns home to the RACF. The nurse & care workers are able to hoist Lorraine to a recliner chair most days. Lorraine has limited social interactions apart from her family’s visit on the weekends and the lifestyle coordinator’s music mornings.

FAMILY

Lorraine’s son finds it very difficult to visit his mother. He previously enjoyed a cup of tea with her once a week but she can no longer hold the cup and seems to choke on her water.

GENERAL PRACTITIONER

The GP reviews Lorraine 4 days after her discharge during his weekly visit. The family ensure they are present and have a long discussion with the GP about the significant changes in Lorraine - especially her decreased oral intake and difficulty taking oral medication.

A new Advance Care Plan is established with a Statement of Choices (Form B) that outlines the ceiling of care for Lorraine including no further transfers to hospital.

SPEECH PATHOLOGY

The speech pathologist contracted by the RACF reviews Lorraine as it is important to her family that she drinks comfortably. Education is provided to the family about Lorraine’s risk of aspiration and strategies to make swallowing safer. Lorraine is prescribed thickened fluids so she no longer chokes.

FIT ED SUBSTITUTIVE CARE

Lorraine has a fever, productive cough and a new oxygen requirement, and her GP is unable to review her today. FIT visit Lorraine at the RACF and provide support to the nursing staff and the family about the signs that this may be Lorraine’s last days of life. Medications are charted to ensure she is as comfortable as possible. The FIT Doctor contacts Lorraine’s GP to advise of assessment and interventions provided.

PASTORAL CARE

The chaplain provides support to Lorraine’s daughter and assists to bring the family together. They organise a blessing.

FUNERAL HOME

The funeral director helps Lorraine’s family organise a funeral but also provides practical information about Death Certificates and bereavement.

Key Themes:

- Substitute decision makers
- Primary care in residential aged care
- Recognition of pain and delirium in advanced dementia
- Sharing medical records across the care continuum
- Contracted allied health services
- Palliative care not a core subject in aged care training.
- Role of emerging services such a Specialist Palliative Care in Aged Care (SPACE)

Potential issues/barriers:

- Family’s adjustment to deteriorating health of loved one.
- Disorientation associated with ambulance transfers and hospitalisation for people living with dementia
- Pain underrecognised in people living with dementia - Staff turnover and use of agency staff in RACFs
- Wait times for a QAS transfer from hospital back to RACF