CASE STUDY

The following case study demonstrates the importance of “Returning to Country” to die for Indigenous Australians, and the role social workers play in achieving this for their patients.

Presented by Jan Newman, Senior Social Worker, Cairns Integrated Palliative Care Service, Gordonvale Hospital, Queensland.

Matt was a 57-year-old Indigenous man, originally from a remote Indigenous community in Cape York, but had lived in Cairns for many years. Matt had been living alone in a small Queensland Housing unit when he was visited by the Cairns Palliative Community Team—a Clinical Nurse and Social Worker—for an initial assessment of his needs. At that time, he was well supported in the community by the local Indigenous Medical Centre and by his individual caseworker from a Homeless Outreach Team. When the Palliative Care Service became involved, the Social Worker visited Matt at home and also liaised with his caseworker who undertook practical day-to-day issues such as taking him to the doctor and purchasing his medications. At the initial assessment the Social Worker asked Matt if he had a will (no, he didn’t) and whether he wanted to undertake this (no, he didn’t), asked if he had an EPOA (no, he didn’t) and explained what it would entail for him to complete this document (and no, he wasn’t interested in doing this). Matt was also not interested in completing an Advance Health Directive. It is acknowledged that this exercise was less than ideal as talking about these issues requires time with appropriate support to be offered in a culturally relevant way. ‘Advance care yarning’ could be explored with the person to plan about their choices so those people who provide the care know what that person wants thereby giving comfort to the person and to their family.

Matt had family in a town north of Cairns and it was difficult for them to travel to Cairns to visit Matt. Community Palliative nurses visited regularly and Matt was put on a patch for his pain as he was having trouble managing his medications. He had recurrent squamous cell carcinoma of the tongue with extensive local disease. Matt chose not to have any palliative chemotherapy. Unfortunately, he had extensive drooling of saliva and had to wipe his mouth every few minutes and it was blood stained. Matt was admitted to the Cairns Hospital and, after seeing the Palliative Care Registrar, was transferred to the Palliative Care ward of the Gordonvale Hospital (20 ks south of Cairns). When he arrived on the ward Matt was in considerable pain and distress and his jaw looked very inflamed and painful. It was hard for him to swallow his medications. Matt had dysphasia due to his tongue cancer and generally communicated by writing on paper. He also attempted to speak but it was very difficult to understand him. Sometimes he became frustrated with this. It was hoped that Matt’s symptoms could be managed and he could return home when he was stable.
After a few days he became more settled in the ward and the SW spent some time getting to know Matt. He wanted some toiletries and his reading glasses from home, and wanted his fridge cleaned out. This was arranged with his caseworker. His family were notified that he was in hospital and his sister came to visit. During these 6 weeks of this hospital admission, Matt became anxious about his Queensland Housing flat and it was evident that it was very important for him to have the security of knowing that he had his flat as he had been homeless for periods of his adult life. Social Worker contacted Queensland Housing to let them know about his hospital admission and that he hoped/planned to return.

Matt settled into the routine of the hospital and spent his time reading the paper, doing puzzles and admitted that he ‘liked being here’. He loved listening to his music and brought his CDs with him. While Matt was a very independent person, he seemed to feel some relief at having care for his wound and general well-being after attempting to manage his own care for so long. One of the joys of being a social worker for a palliative care ward is having frequent, informal opportunities to talk with patients. It is the opportunity to build a relationship with the person over time and this leads to talking about the person’s hopes, how they are feeling about what is happening for them and to talk about dying if they wish.

Matt’s condition became stable for a period and he chose to return to his unit with the support of the Community Palliative Care nursing team. He had just a few weeks at home before he was re-admitted owing to concerns about his general decline, increasing pain and the difficulty he had with managing his wound. He found it very difficult to swallow and his energy was low. During the weeks following Matt’s re-admission to the palliative ward he began talking with social worker and nurses about the possibility of his returning to his community in Cape York for his end of life. He talked about being buried there. The Social Worker and nurses made the initial contact with the health clinic in the remote town to which he was returning to discuss Matt’s health and care needs. The clinic liaised with his family who would be providing Matt with care. Arrangements were made for Matt to go back to his unit one more time to collect his ‘death clothes’ which he wanted to take with him. He also spent the day at his unit working out what he wanted to do with his belongings. The Social Worker liaised with his caseworker to contact his sister and her partner, as he wanted them to accompany him back to his community. Within a few days his sister came to the ward to see her brother. Flights were booked. His flat was closed up and Queensland Housing contacted about details. The Social Worker communicated with the clinic at his home in Cape York who contacted his family members to arrange to meet Matt when he arrived (there was no phone contact for his family). Nursing staff gave a handover with the clinic regarding his medication needs and care requirements. Matt left the care of the Palliative Ward to return to his homeland with everyone wishing him well.

There was further communication between nursing staff and the clinic regarding Matt in the following fortnight as the family were finding it very difficult to manage his care. Services and resources to support the final stage of life in the communities of the Cape are limited and this was evident in the situation regarding Matt and his family. While Matt wanted to return to country to die, the experience became challenging both for Matt and for the people who cared about him. He died just 2 weeks after returning home.

Author: Jan Newman
CareSearch Resources

There are resources within CareSearch that could help social workers (and others working with Indigenous Australians) in the care of palliative patients and their families. Some of them have been highlighted here:

- **CareSearch website**: CareSearch Aboriginal and Torres Strait Islander Resources

- **There are** Systematic Reviews **for social workers on**:
  - **general issues**
  - **regarding families**

- **The Clinical Evidence** pages provide information regarding:
  - **Advance Care Planning**:
    This includes information on communication issues, health system and medico legal considerations relating to care planning processes and documentation in advanced disease.
  - **Patient Management**:
    This section looks at common physical symptoms and psychosocial considerations in providing comprehensive care.
  - **Family and Carer Evidence**:
    This provides an overview of the evidence pertaining to carer support.
  - **Service Delivery Evidence**:
    This section reviews evidence relating to service provision and professional practice.

- **There are** PubMed Topic searches, **on many areas of interest to social workers and other allied health professionals**

- In the Allied Health Hub there are pages on:
  - **Role of social workers in palliative care**
  - **Communication in palliative care**, which includes:- A video from the Center to Advance Palliative Care (US):
    - Palliative Care and the Human Connection: Ten Steps for What To Say and Do
  - A video from the Canadian Virtual Hospice:
    - Talking with Patients and Families: Challenges and Tips.
  - **Professional Boundaries**
    From the Center to Advance Palliative Care (CAPC) Fast Facts and Concepts:
    - Professional patient boundaries in palliative care
    - Managing one's emotions as a clinician.

- In the GP Hub
  - **Information on bereavement** and **Supporting Families and Caregivers**

- In the Residential Aged Care Hub there is some excellent information on “recognising resident’s needs” for all allied health working in residential aged care.

- In the section for Patients, Carers and Families are pages on information to assist in caring for palliative family member.