CareSearch nurses[HUB] news

November 2016 www.caresearch.com.au

CASE STORY

Mary, a 35 year old woman with advanced breast cancer was referred to the Palliative Care service based at the Royal Darwin Hospital. Mary lived on a remote community in East Arnhem Land with her husband and 3 children, aged 9, 12 and 15. She was diagnosed with breast cancer 3 years ago and at the time commenced chemotherapy.

In November Mary was evacuated from her remote community via the Aerial Medical Service to the Royal Darwin Hospital with increasing chest pain and dyspnea. Mary had her sister Betty present as an escort and support person. Mary's skills in speaking and understanding English were limited. Her first language was the North East Arnhem Land language Yolgnu Matha which she spoke at home with her family. Betty appeared to have a better grasp of English and often acted as an interpreter for her.

At the time Mary claimed to be comfortable but she clearly looked to be in pain, wincing at times when moving around. She was able to walk and transfer with assistance. Mary underwent a CT scan which showed a 6 cm mass in her left breast with left upper lobe lung and local lymph node metastases. A bone scan revealed metastatic spread to T 6 - 8 spine and 3rd and 4th right ribs. Mary's disease had clearly progressed.

According to Betty, she had been taking Paracetamol on an ad hoc basis for some time now. Betty said that her sister was often in pain, mainly at night and had not slept properly for some time. Betty also reported that her sister was afraid of taking 'strong medicine' for pain and would rather take something that she was familiar with.

Mary was transferred to the Hospice at the Royal Darwin Hospital and started on Morphine for her pain and dyspnea. The Morphine was explained to Mary and she was initially reluctant to take this 'strong medicine'. However she eventually agreed as her symptoms got worse. Her pain and breathlessness improved after 24 hours.

Mary was offered further chemotherapy treatment but she stated that she wanted to discuss the issues with her family at home. It was important that the family hear the story themselves.

A teleconference was arranged and an interpreter was booked. The teleconference included family and clinic staff back at her community as well as Palliative Care team members, Mary and Betty.

During the teleconference Mary's prognosis, disease progress and treatment options were carefully explained to the family. It was stated that the treatment would not eliminate the disease but would possibly slow down the progress. Mary and her family decided that she did not want to have any more chemotherapy treatment.

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She said that she was homesick and wanted to return home to be with her family. Seeing family members on the screen of the teleconference made her even more homesick. It was agreed that arrangements be made for Mary to travel home as soon as possible.

During the teleconference a plan of care was discussed. The family stated that it was crucial that Mary 'finish up' on her country with family present. It was agreed that when Mary deteriorated she would be managed by the clinic nurses and visiting doctor on the community and that she would not be evacuated to Darwin.

It was stated that the Palliative Care after hours on call service could be used by the clinic staff and family for advice and reassurance. Family members who would care for Mary at home were also identified. It was agreed that the community clinic staff would visit each day to monitor Mary's progress. Equipment needs were identified and arrangements were made to have that sent out to the community.

It was important to everyone involved that all parties hear the one story and agree to the plan of care.

Due to her dyspnea and increasing immobility it was agreed that Mary would not be able to travel by a commercial flight and a medical plane was booked. There is often a waiting time for medical flights as they will take the patient home for end of life care when the plane is travelling to evacuate someone from the same area.

Two days passed and Mary's condition continued to deteriorate. On day 3 a plane was available to take Mary and Betty home. Mary made it home and passed away peacefully surrounded by family and community members 2 weeks later.

At one stage a family member who had not been present at the teleconference wanted to have Mary evacuated to Darwin when she deteriorated. This created an argument within the family. The family members who had been present at the meeting mentioned the agreed upon care plan and consequently over rode the person that wanted Mary sent back to Darwin.

The clinic staff had utilised the on call service a few times mainly to get reassurance around doses and frequency of medications for Mary.

Members of the Palliative Care team visited the community 2 weeks later and spoke to the family and clinic staff. The family stated that they appreciated the support given for Mary.

What Happens Now (No right or wrong answers here – just food for thought)

- Consider how you would advocate for someone like Mary and her wish to 'finish up' on her country
- Consider how teams can work collaboratively to achieve a client's wishes
- How often would a case conference be helpful in planning care? Consider how you could facilitate one for a patient in your care

Author: Simon Murphy / Clinical Nurse Manager Hospice and Palliative Care / Territory Palliative Care | Top End Health Service

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What are your immediate thoughts?

Discuss it among the team: use it for in-service education, to reflect on how your service practices, or just to consider palliative care in a different context or setting.

CareSearch has resources that could be of help. Some of these are highlighted here:

- There is information that may be of relevance and interest to Aboriginal and Torres Strait Islander Peoples, families and community, and to the health professionals who are looking after them. This includes:
    - Aboriginal Health Workers and Practitioners
    - Related Program and Project Information
    - Indigenous Australian Organisations
- The Clinical Evidence pages include a section on: Advance Care Planning, which includes pages on surrogate decision makers and medico-legal aspects. There are also symptom management pages that include Breathing and Dyspnoea
- There is a Rural and Remote and Aboriginal and Torres Strait Islander Review Collection as well as one on Dyspnoea
- There are also PubMed Topic Searches on Dyspnoea, Rural and Remote Health and Aboriginal and Torres Strait Islander Health
- In the nurses hub there are relevant resources: Rural and Remote and Aboriginal and Torres Strait Islander People
- In the Residential Aged Care (RAC) Hub there is information on case conferencing
- In the GP Hub there is a page on Planning for a Home Death that you can refer your GP colleagues to.

Coming soon! CareSearch are currently developing a suite of resources in relation to Aboriginal and Torres Strait Islander People which we will be releasing in the coming months. Look out for this exciting new initiative!

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