Northern Territory Government

Renal Supportive Care Program

Palliative care for sick kidneys – a Northern Territory Renal Palliative Care initiative.

Our journey so far….

Samantha Harrington

Renal Supportive Care CNC

Top End Renal Service, NT

This presentation contains images of Aboriginal people who are now deceased.

Where did it start

- The ‘Chronic Diseases Palliative Care Pathway Project’ is funded by the Australian Government, Department of Health and Ageing.

- **Phase one** involves embedment of the Renal Palliative Care Pathway into the current systems and processes within NT Renal Services.

Our Objective

To develop a **culturally appropriate, team orientated and client focused** pathway within NT Renal Services.

Through education, support clients choosing conservative management of ESRF, and those ceasing RRT and returning to community for EOL care.

This support extends to health professionals delivering care in remote areas.

The Pathway assists to facilitate NT Renal Services to provide a continuity of care to their clients.

Our Focus

To support our clients and families to make

informed decisions

about their future healthcare, within the context of culturally significant influences.

NT Area

Land Mass: 1,420,970 Km^2
NSW: 809,444 km^2

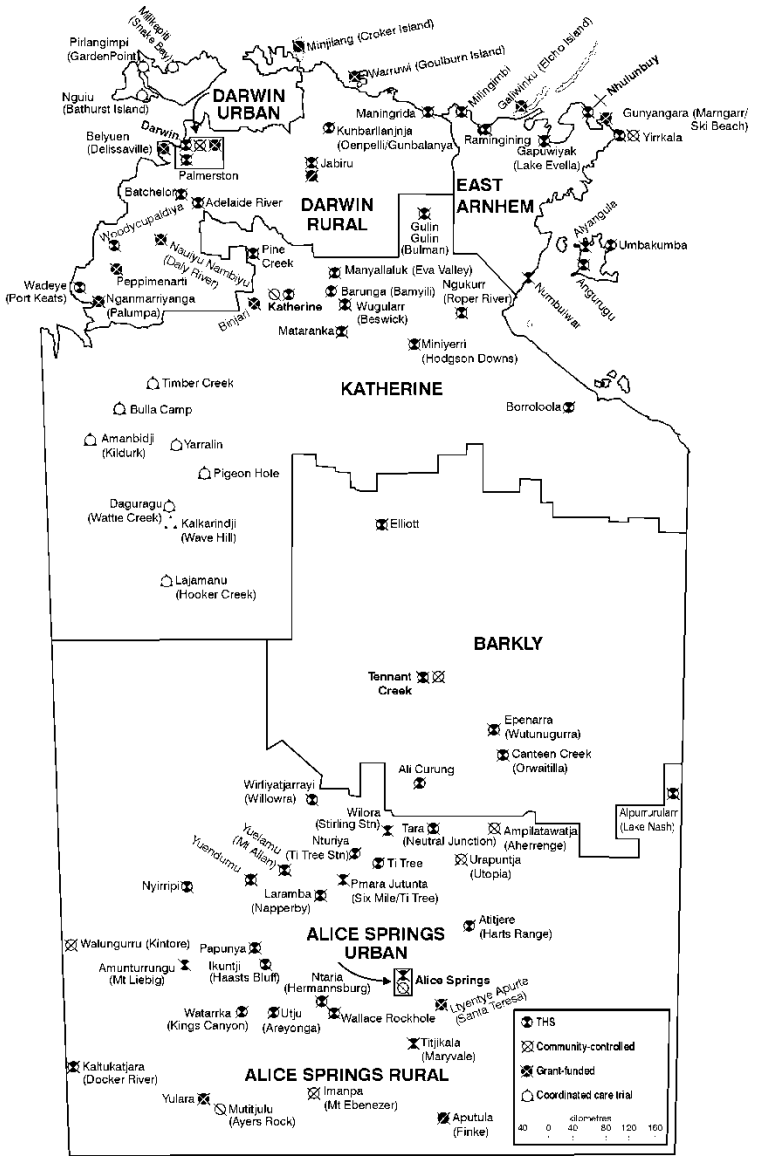
Population: 229,000
NSW: 7,439,200

Population Distribution: NT 0.17/km^2
NSW 9.12/km^2

ATSI: Represent 29% of population

ATSI: 71% live in remote areas

ATSI: 85% of all people receiving dialysis treatment in NT



Essential Components of Supportive Care Role

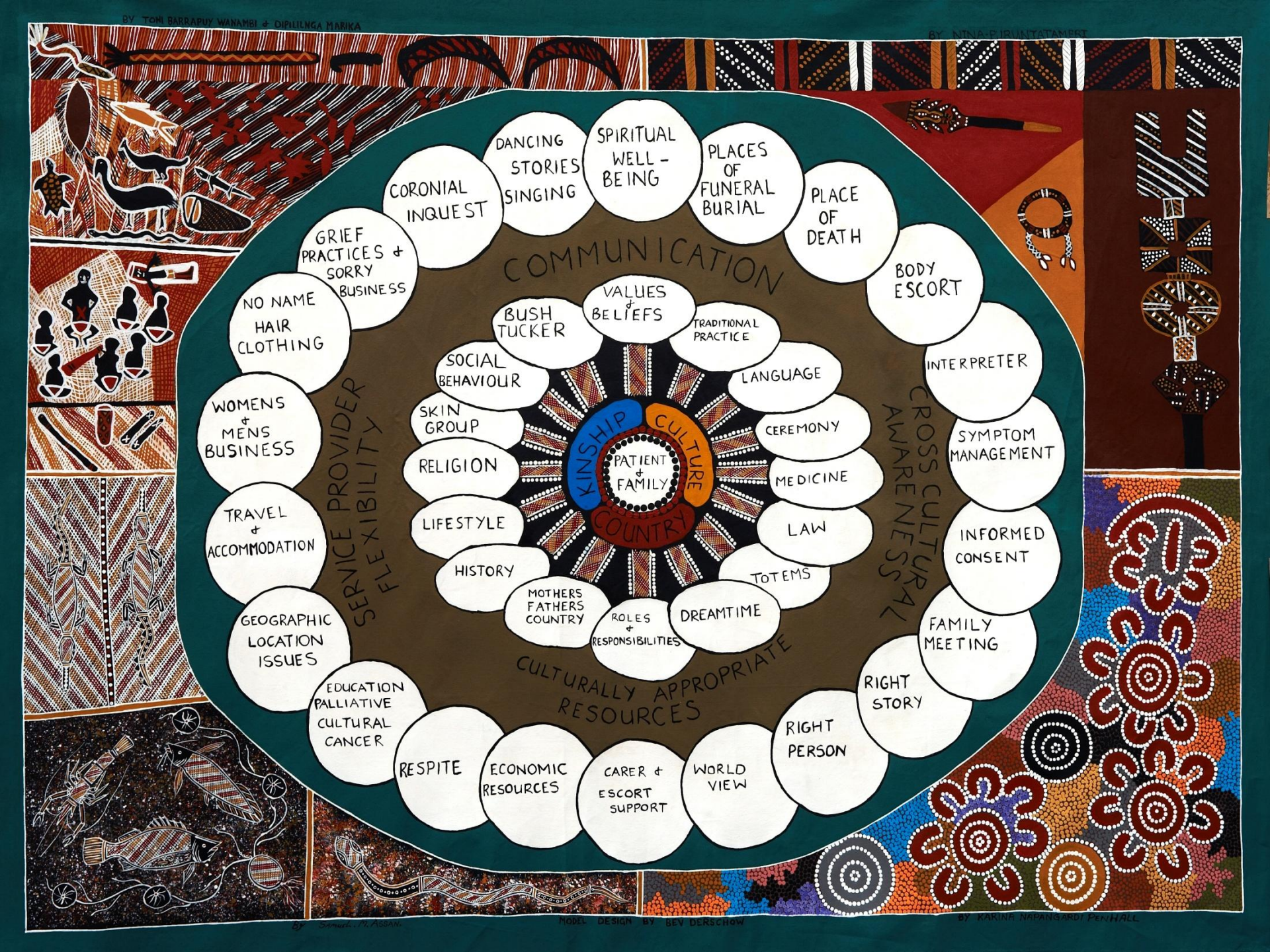
- Education and support of client, family and carers
- Education to medical and allied health staff
- Specialist Outreach clinics
- Teleconferencing
- Consultation with Remote Health Clinics
- Consultation and referral to Territory Palliative Care
- Advanced Care Planning
- Evaluation of pathway and review of death
- Bereavement Program / MMTR

Embedding this position

Building and Strengthening Partnerships

- Working collaboratively with other stakeholders
  - Territory Palliative Care
  - Chronic Disease Coordinators
  - Multiple AMS / NGO's

- Building capacity on the ground, working closely with Remote Clinics
  - Polycom links for education, family meetings, re-connecting
  - Providing resources
  - Equipment
  - Support calls
  - Visits through outreach clinics


BY TONI BARRAPUY WANAMBI & DIPILILNGA MARIKA
BY NINA PURUNTATAMERI
PATIENT & FAMILY
KINSHIP
CULTURE
COUNTRY
VALUES & BELIEFS
TRADITIONAL PRACTICE
LANGUAGE
CEREMONY
MEDICINE
LAW
TOTEMS
DREAMTIME
ROLES & RESPONSIBILITIES
MOTHERS FATHERS COUNTRY
HISTORY
LIFESTYLE
RELIGION
SKIN GROUP
SOCIAL BEHAVIOUR
BUSH TUCKER
COMMUNICATION
DANCING STORIES SINGING
SPIRITUAL WELL-BEING
PLACES OF FUNERAL BURIAL
PLACE OF DEATH
BODY ESCORT
INTERPRETER
SYMPTOM MANAGEMENT
INFORMED CONSENT
FAMILY MEETING
RIGHT STORY
RIGHT PERSON
WORLD VIEW
CARER & ESCORT SUPPORT
ECONOMIC RESOURCES
RESPITE
EDUCATION PALLIATIVE CULTURAL CANCER
GEOGRAPHIC LOCATION ISSUES
TRAVEL & ACCOMMODATION
WOMENS & MENS BUSINESS
NO NAME HAIR CLOTHING
GRIEF PRACTICES & SORRY BUSINESS
CORONIAL INQUEST
CROSS CULTURAL AWARENESS
CULTURALLY APPROPRIATE RESOURCES
SERVICE PROVIDER FLEXIBILITY
MODEL DESIGN BY BEV DERSCHOW
BY KARINA NAPANGARDI PENHALL

The Challenges

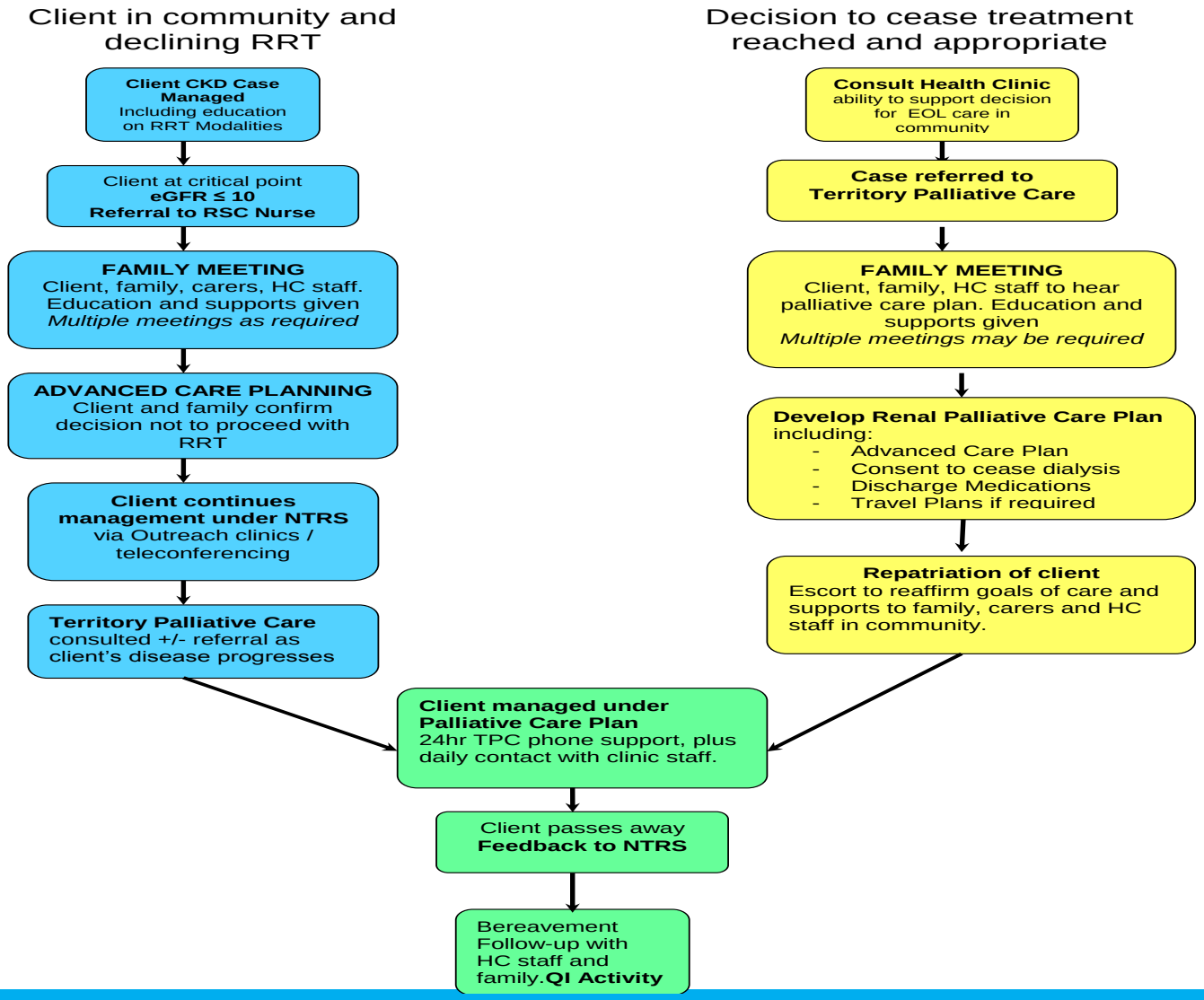
- Clients
  - Education to dispel the myths about palliative care
  - Advanced Care Planning
  - Often small windows of opportunity

- Carers
  - Education
  - Cultural approaches to dying
  - Willingness to help

- Settings
  - Supports / services available
  - Staffing at Remote Health Clinics
  - Sometimes accepting that going home is not the best plan

Supportive Care Pathway

SUPPORTIVE CARE PATHWAY - RENAL



Northern Territory Government

Client education in community

Northern Territory Government

The Barriers

Identified Barriers

- English is the second or third language in most instances
- Decision making hierarchy
- Cultural issues about death and dying (pay back, where to die)
- Small number of ATSI employees within DoH
- High turnover of Remote Area Health Clinic staff
- Medicines (Renal and Palliative Care)
- The term ‘Palliative Care’

Outcomes

- Improved coordination of care between NTRS, TPC, NGO's and primary healthcare professionals
- Improved continuity of care for renal clients
- Clients, families/carers and staff in the remote setting are better educated and supported, with increased awareness of ESRD management.
- Guidelines for referral to TPC – ensure clinical safety / governance

Northern Territory Government

Gunbalunya Community

Case Study 1 – Family Meetings

69yo Indigenous woman from Gunbalunya

- Been on RRT for 11 years
- Lives in a hostel with husband / carer
- During admission following a fall, it was identified this lady was having increasing difficulties maintaining independence with ADL's, even with husbands assistance
- After lengthy discussions with her and her husband this lady tells us her wish is to 'stop dialysis and return home to country to finish up…'

Relocation to Community

NT Government funded ‘Return to Country’ flights.

Repatriate clients ceasing active treatment, and returning to country and family to ‘finish up’,

Case Study 2 – Advanced Care Planning

67yo Indigenous female from Nhulunbuy

- Diagnosed with ESRF, declining RRT
- Previously known to Renal Services
- Very well supported by local health clinic, but family becoming distressed as symptoms begin to impact on her QOL
- The clinic request education for family, and assistance to develop an Advanced Care Plan

Ski Beach, East Arnhemland

Case Study 3 - Decision Making

42yo Indigenous male from Bathurst Island

- Commenced RRT May 2013
- Secondary diagnosis of ‘Inclusive Body Myositis’
  - Rapid progression.
  - Requiring HDx 4x/week
- Outreach visit supported day-trip home
- Large family meeting to hear the ‘right story’

Northern Territory Government

Remote Palliative Care

Northern Territory Government

MacArthur River–Borroloola

Palliative Care for People with Sick Kidneys

Northern Territory Renal Palliative Care Project

Northern Territory Renal Services

Northern Territory Government

Acknowledgements

- Sue Stewart – Chronic Disease's Project Manager
- Dr Zulfikar Jabbar – Nephrologist (NTRS)
- Dr William Majoni – Nephrologist (NTRS)
- Elaine Bowen – Clinical Nurse Manager (NTRS)
- Nicole Robert – Remote Area CNC (TPC)
- Leona Holloway – Aboriginal Liaison Officer (NTRS)

My Contact Details

Samantha Harrington

Renal Supportive Care CNC,
Top End Renal Services, NT
Ph: 08 8922 6177 pager: 0074

samantha.harrington@nt.gov.au

On-line resources

www.kidneyhealthaustralia.com.au

www.healthinfonet.ecu.edu.au

Northern Territory Government

Thank-you for listening.