



Palliative Care for Renal Clients Living in a Remote Setting

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Renal Aboriginal Liaison Officer**

“You white fellas gotta stop being afraid to talk to aboriginal people about death and dying. Our people are dying all the time, every where”

A Message from a wise project officer

“It’s not about saving money or freeing up dialysis machines...it’s about giving chronic kidney disease clients a choice of conservative-palliation as a treatment choice”

Project Objectives

- **Examine barriers** to renal clients choosing treatment options, including remaining at home and returning home to community when palliative
- Determine the most **appropriate stage** in renal deterioration where palliative care options are integrated into treatment choices.
- Identify and establish client and carer **needs** when palliative and living in a remote setting.

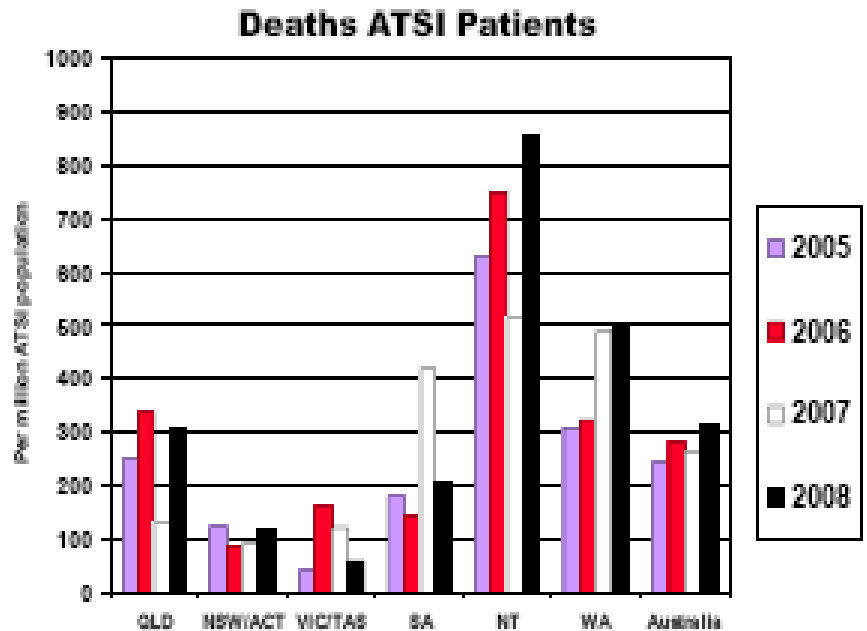
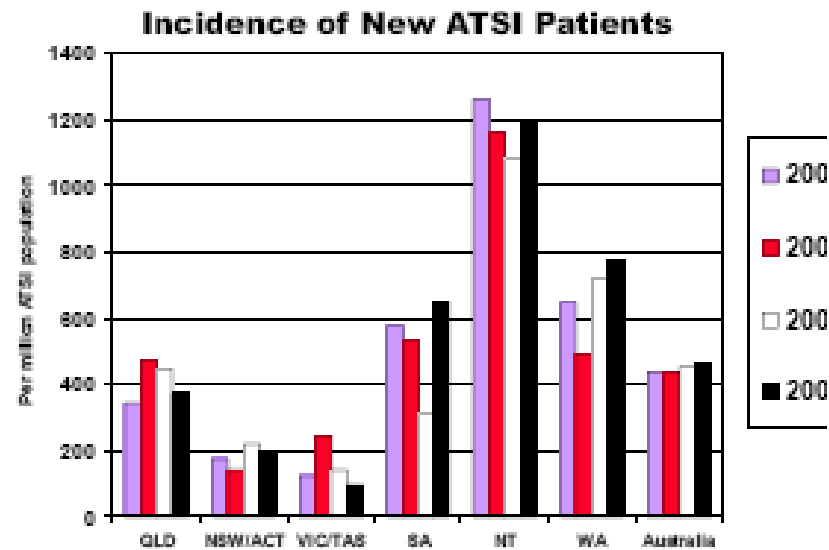
Project Objectives

- Develop a **culturally appropriate** client focused pathway within renal services to enable renal clients to choose the palliative care option.
- Once a palliation pathway and model of care is developed it will be **scoped to transfer** this model to other speciality services such as cardiac and COAD.

The Elephant in the Room



Figure 12.11



Lets talk about the silos

- Acute Renal Services



- Chronic Disease Network



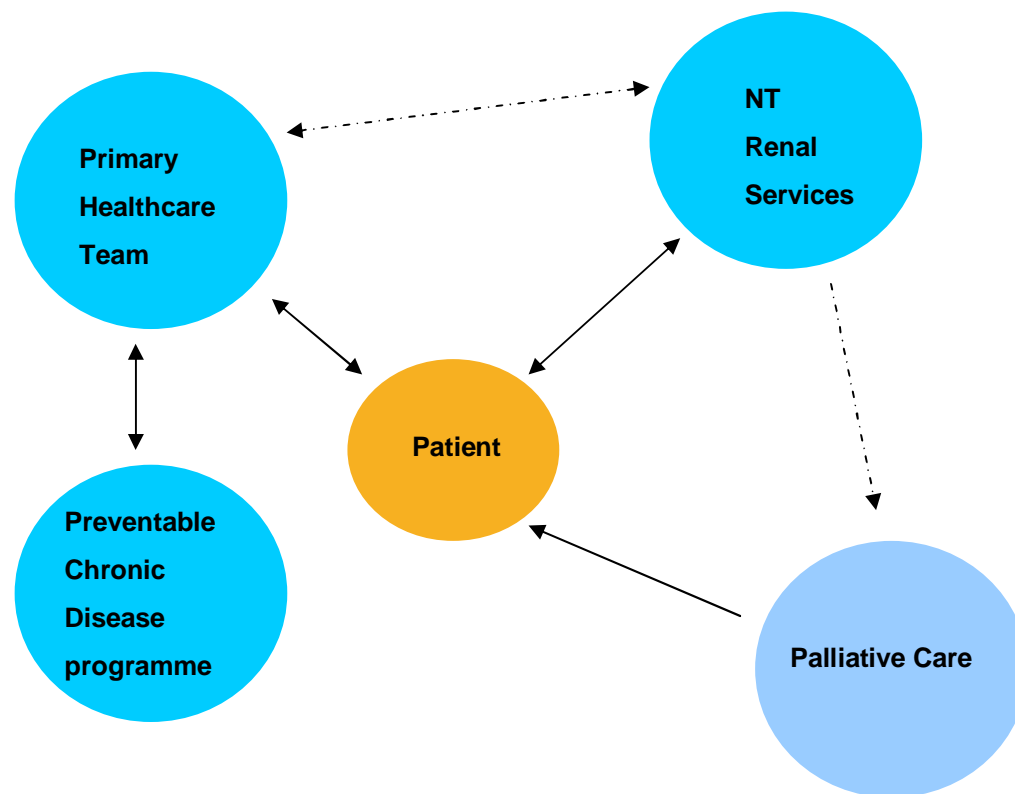
- Palliative Care



The Long Road Ahead



Service articulation at start



Lack of understanding of service roles and clarity of responsibility

LAJAMANU ROAD

UNSEALED SECTION

WEIGHT LIMIT

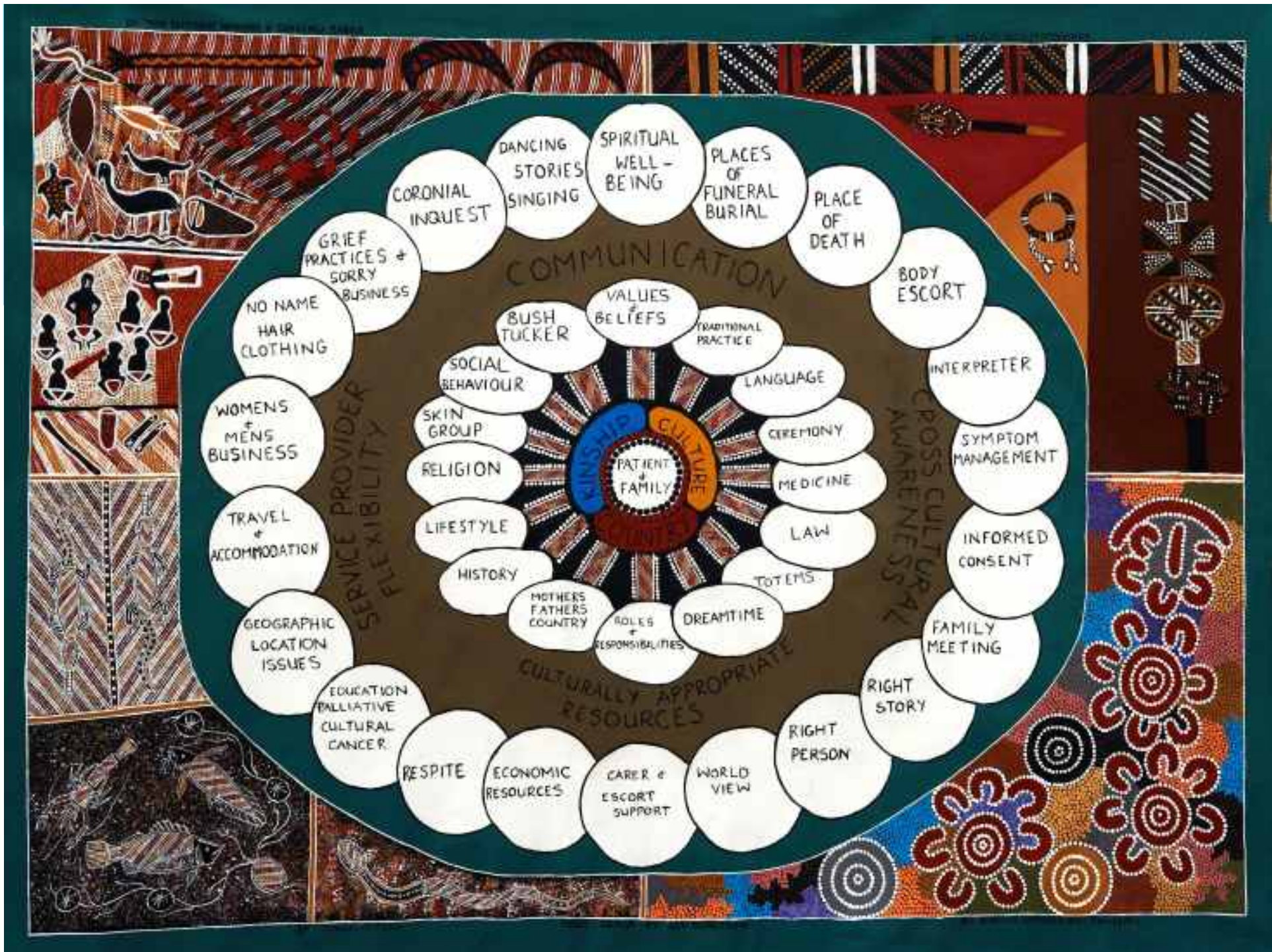
No. OF AXLES

ROAD INFORMATION 1800 246 199



What was

- No Palliative Care Story for renal clients
- Lack of resources to assist renal and remote health staff and clients to understand the palliative care pathways
- Little or no education of aboriginal interpreters in regard to palliative care and renal disease
- Health care workers seeking more education in Palliative Care and Chronic Kidney Disease
- Late referral of Renal Clients to Territory Palliative Care
- No Advance Care directive
- No Renal Care Plan



Consultation with Renal Services

- Client Options at End of Life –Understanding they have a choice
- Understanding of the holistic palliative care approach
- Referral to Palliative Care
- Loosing control if client referred to Palliative Care
- Client & Family meetings when discussing end of life issues
- Discharge planning when client withdraws from dialysis

Consultation with Remote Communities





Identified Barriers to Palliation of Renal Clients in the NT and beyond our borders

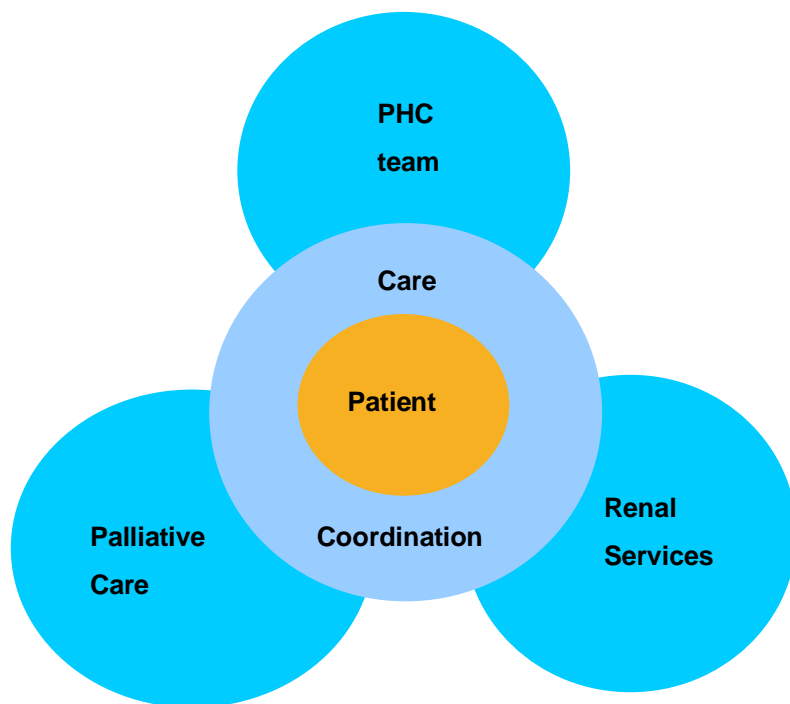
- Pay back if the client passes away in their care in the Community.
- If Client dies in family home, family can not live there for a period of time.
- Some people think the medicines that they get from palliative care are going to finish them up sooner.
- Providing respite care in remote communities
- Availability of medical equipment for clients in remote communities
- Transport of renal clients at cessation of dialysis back to their country to finish up – No PATS
- A place to finish up in Alice Springs
- Limited use of aboriginal interpreters when educating clients about kidney disease and treatment options
- Information to health staff and aboriginal people about kidney disease and Palliative Care

Improving delivery of services

- **Clarifying** the roles and responsibilities of each area
- **Case Conferencing – Everyone hears the same story**
Renal, Remote Health Clinics and Palliative Care

Renal Palliative Care Plan

Information to remote health staff – Symptom and symptom management, equipment, medications, social issues etc



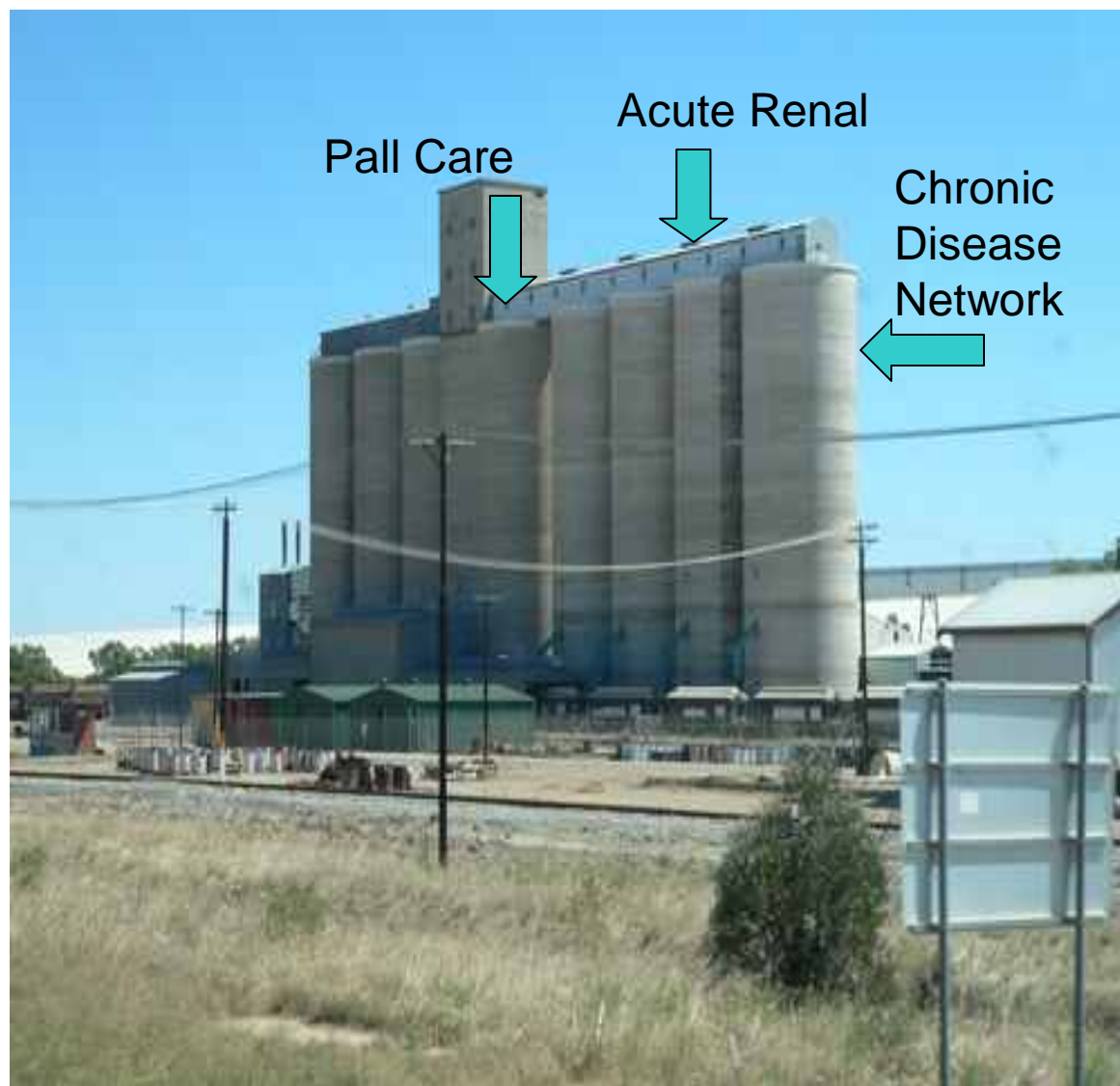
“There has been a huge increase in the awareness between the palliative care and renal teams of each others roles as well as the potential for development of those roles.

This has lead to a greater understanding and collaboration between the two teams. This has happened in a relatively short space of time”

Palliative care nurse

Providing services closer to home

Breaking down the solitary silo approach to care delivery for ESRF clients and those that withdraw from dialysis



Outcomes of Referral to Palliative Care

Estimated number of patients/families carers to be assisted in the Top End

Top End	2006	2007	2008	2009	As at April 2010	Total
Total Referral	5	21	41	33	5	105
Hospital Death	1	6	8	5	0	20
Home Death	2	2	11	6	2	23
Hospice Death	0	9	9	12	0	30
Nursing home Death	1	2	5	0	0	8
On going referral (Alive)	1	0	3	3	3	10
Discharged from TPC	0	2	5	7	0	14
Indigenous	4	14	29	23	5	75
Indigenous %	80%	67%	71%	70%	100%	71%

When do we start to talk about it?



Palliative Care for People with Sick Kidneys

Northern Territory Renal Palliative Care Project



Northern Territory
Renal Services

Renal Palliative Care Plan

- Renal Palliative Care Plan back to community
- Information to Health Centre Staff
 - Symptoms and symptom management
 - Medications,
 - Equipment
 - Involvement of other services
 - Specialist Palliative Care contacts
 - Social Issues
 - Information and education package for family so that they can be educated before patient returns home.
 - Tool for Renal Case Conferencing

Advanced Care Planning

- Change in Legislation not due until 2011
- DHF Acute Care End Of Life & Decision making policies due out in Sept/Oct 2010: 3 policies will be linked
 - End of Life & Decision Making
 - DNR
 - Advanced Care Plans
- These documents will be available on PROMPT and will present with detailed instructions which will be inseparable
- Available through ATLAS
- Network policy including all 5 NT Hospitals
- Education programs for Remote Health and Aged Care
- NTRS form a working group to investigate and implement ACP's within Renal Services

Family Meeting Policy and Proforma

- Development of a family meeting policy and proforma has been developed.
- Will be integrated into the DHF End of Life Framework
- Encouragement of trial of the policy and proforma within NTRS was unsuccessful

Bereavement

- Patient at commencement of dialysis
 - Family
 - Country
 - Religion

- Patient at renal unit on dialysis transfers to Hospital very sick and “finishes up”
 - Relationship between patient, staff and other patients
 - Information back to staff and other patients
 - “how did it go?”**
- Follow up with family and CHC “was it a good death?”
- What went well? What could have gone better?
- Can we do it better?



INDUCTION COURSE

Renal Health Care Course for Interpreters

Month Year

**Making a difference, by working
together to understand each other**



Ongoing Education

- 3 Day Renal Palliative Care workshop conducted by PCD Program, Chronic Conditions Strategy Unit.
- At Induction to NTRS, identify staff that should undertake a PEPA (Program of Experience in the Palliative Approach) placement at TPC.
- Through the PEPA Program continue with Placements from other health services visit to Renal Units at 7A and or Nightcliff Renal Unit
- Education to Aboriginal Interpreters “What do the words really mean?”
- Increase aboriginal professional involvement in all palliative pathway processes through
 - Increase participation in case conferencing and family meetings
 - Participation in PEPA program and other educational & professional development opportunities
 - Promoting professional interpreter training
 - Support for improved cultural safety
 - Provide access to de-briefing and counselling as needed



Palliative Care Pathway – Renal

Figure 1

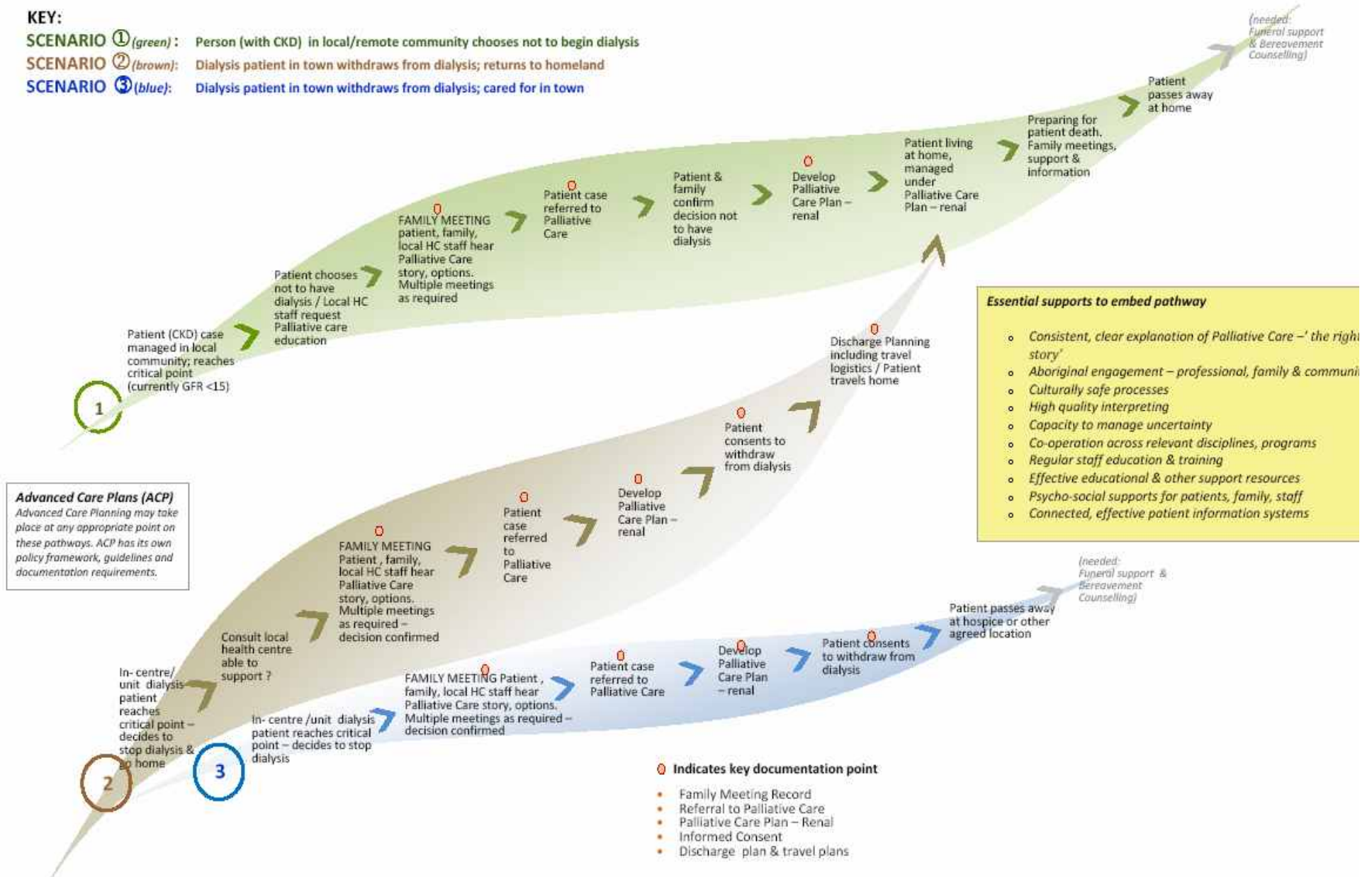
Based on work done under the *Palliative Care for Renal Patients Living at Home Project*
An Initiative of the Australian Government Department of Health & Ageing, June 2010)

KEY:

SCENARIO ① (green): Person (with CKD) in local/remote community chooses not to begin dialysis

SCENARIO ② (brown): Dialysis patient in town withdraws from dialysis; returns to homeland

SCENARIO ③ (blue): Dialysis patient in town withdraws from dialysis; cared for in town



Palliative Care for People with a Chronic Disease Living at Home

Phase 1 – Finalisation and system embedment of renal palliative care pathway within NT Renal Services

2 Renal Palliative Care Coordination Positions – 1 in Top End and CA

- Client & family consultation & education
- Education to NTRS staff
- Development and implementation of Advanced Care Plans into NTRS
- Consultation & agreement with remote health clinics and Services
- Initiation of renal pall care plans including symptoms & symptom management to remote health clinics
- Evaluation of palliation pathway and review of quality of death
- Development of a bereavement program to NT Renal Services

Thank you very much for
listening.

Any further information please feel free to contact.

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