Renal Supportive Care

Progress in building networks

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Barriers

- Persistent view that ‘not much literature exists’
- Many nephrologists still do not recognise the need for palliative care
- Lack of understanding (outside of nephrology) of the effects of dialysis on people
- Limited inclusion in training programmes
- Funding

Newspaper quote from The Australian

JOHN BOFFA, PUBLIC HEALTH AND MEDICAL OFFICER WITH THE CENTRAL AUSTRALIAN ABORIGINAL CONGRESS, SAID HIS ORGANISATION HAD LONG WORRIED THERE WAS **"AN ELEMENT OF COERCION INTO PEOPLE CHOOSING PALLIATIVE CARE AND THEREFORE NOT REQUIRING RENAL DIALYSIS".**

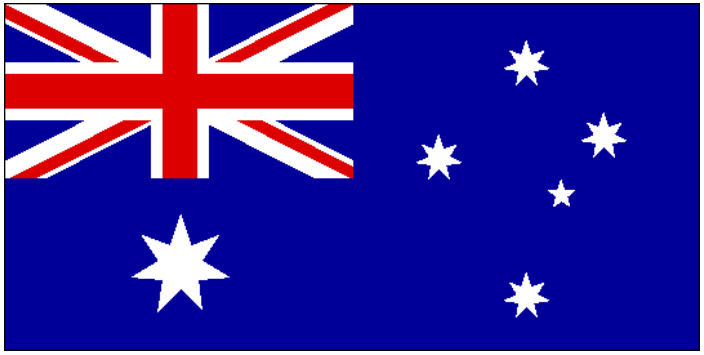
"YOU ARE FACED WITH A CHOICE OF LONG-TERM DIALYSIS IN ALICE SPRINGS, AND UNDER THAT SCENARIO (SOME) PEOPLE CHOOSE TO DIE AT HOME," DR BOFFA TOLD A HEARING YESTERDAY IN ALICE SPRINGS OF THE SENATE INQUIRY INTO PALLIATIVE CARE**. "THERE WOULD BE VERY FEW END-STAGE RENAL PATIENTS IN SYDNEY OR MELBOURNE CHOOSING PALLIATIVE CARE."**

How are we addressing these issues?

Working together – building networks

National networks

- Australia and New Zealand



ANZSN – Adelaide 2011

- Meeting of interested renal and palliative care physicians by invitation
- Face: face important in network formation (research, clinic set up, etc)
- Education identified as essential target
- Sharing of experiences
- Sharing of information
- Next meeting ANZSN Auckland 2012

SAC submission for renal registrar training

- **SAC Submission**. Supportive and non-dialysis management of end-stage kidney disease.
- **Learning objective** : Plan and manage the non-dialysis, supportive care pathway.

Knowledge

• Be able to discuss the potential benefits and problems associated with dialysis and non-dialysis pathways, taking into account the effects of the patient's age and co-morbidities as well as the social implications of different pathways.
• To be familiar with the literature supporting undertaking a conservative approach to some patients approaching ESKD, particularly the elderly with multiple co-morbidities.
• Understand that, in selected cases, it is not appropriate to initiate dialysis
• Be aware of the potential disadvantages or benefits involved with a trial of dialysis.
• Recognise the importance of different cultural approaches to palliation and death.
• Be aware of the likely trajectory towards death of a patient choosing the supportive care pathway.
• Be able to describe the symptoms of advancing end stage renal failure in a patient choosing not to dialyse and the management thereof including liaison with specialist palliative care services.
• Have a working knowledge and awareness of the legal and ethical implications of Advance Care Plans and Advanced Care Directives.

Skills

• Counsel patients about the supportive management pathway, including quality of life issues and life expectancy, in a culturally appropriate fashion.
• Recognise and manage symptoms of ESKD including fatigue, pruritis, anorexia, pain, nausea, depression and shortness of breath. Recognise the need for, and initiate the involvement of specialist palliative care input.
• Organise and manage family and multi-disciplinary team meetings to discuss prognosis and management.
• Cease or initiate appropriate medication depending on symptoms and stage of disease.
• Liaise with allied health teams in the hospital and community setting to ensure access to services for the patient and their family.

Also – as an addition to the learning objectives for
2.3.6 Plan and manage peritoneal dialysis
2.3.7 Plan and manage haemodialysis

Knowledge

• Describe the situations in which withdrawal of dialysis may be approached either by renal staff or by the patient and/or their family.
• Be able to discuss the likely prognosis following withdrawal of dialysis and the management of this scenario.

Skills

• Be able to initiate or continue discussion with patients and family about cessation of dialysis. Counsel about symptoms likely to be encountered and discuss plans for management of these conditions.
• Liaise with palliative care and allied health teams as necessary to ensure patient and family support, good control of symptoms and to allow patient to choose where they will be managed as far as possible (hospital, hospice, community).

Challenges to implementation

- Local availability of RSC training – clinic? Interested personnel?
- Inclusion in national workshops – renal trainees weekend, ANZSN update course – FB and MB will be involved in the ANZSN Update course 2012
- On-line training
- **Need for palliative care physicians training –** cross specialty training?

RSA

- Several presentations at RSA this year – different sessions
- ACP workshop 2011
- Need for an RSC focus group or network?

DNT Position Paper

- Approached to co-ordinate writing a position paper for the DNT about Renal Supportive Care
- Met with Mark Brown, Frank Brennan in Sydney to discuss approach and who to get involved (further use of network)

Areas to be covered

- Principles guiding decisions between dialysis and non-dialysis pathways
- Perspectives on issues surrounding ESKD and dialysis in the elderly and those with co-morbidities
- Use of risk calculators
- Patient information - what is available?

- Symptom management
- Models of care – including EOL pathways, ATSI and other cultural issues (awaiting a section covering Maori issues), remote and rural issues
- Areas needing research
- Guidelines available internationally
- The law
- Education – including doctors, nurses, allied health and patients and families

People involved

- From **Australia** and **New Zealand**
- Frank Brennan, Mark Brown, Su Crail, Rob Fassett, Celine Foote, Liz Josland, Ivor Katz, Robyn Langham, Rosemary Masterson, Steve May, Lisa Phipps, Cherian Sajiv, Brian Siva, Liz Stallworthy, Cameron Stewart (Law), Kat Urban, Rob Walker.

Editorial meeting

- August 17th – everyone has been emailed all sections
- Authors will be present to defend their sections
- Re-writing
- Final editing
- Submission to DNT by October

Potential uses

- **Funding**
- Discussion of present models, personnel, frequency, etc
- Use for discussion with local fundholders
- Education – How? Who? Where?

Potential uses- 2

- **Legal Decisions**
- Capacity
- Informed consent
- Refusal of treatment
- Advance care directives
- Substitute decision-makers
- Legality of withholding and withdrawing dialysis
- Is it euthanasia?

Potential uses - 3

- Review of resources available nationally and internationally
- Different formats available – DVDs, leaflets, pictures
- Possibility of forming national guidelines for Australia and New Zealand? – expansion of CARI guidelines (currently look at concept of benefit and quality of life)
- Identification of needs – cross-site research

And many other possible uses.....

Local Networks - SA Experience

- June 2010, CNARTS
- Recently merged units – QEH and RAH, main site moved to be together at RAH
- Previous good links with QEH palliative care team, RAH team more oncology focused
- Respecting Patient Choices – nursing interest ++
- No nephrologist with interest in RSC
- Non pain/palliative care doctors not allowed to prescribe long-acting analgesics

Local Networks

- Get involved – lectures, hospital grand rounds, palliative care unit
- MDT teaching – nurses, dieticians, pharmacists
- General Practitioners – country GPS
- Contact with palliative care team – formation of a clinic
- Better awareness by staff – improved management
- Possible joint training sessions for renal and pall care trainees
- SA Renal Network beginning to accept need for access to RSC pathway and use of Nurse Practitioners

International Networks

- Interested people around the world – growing
- Strong groups in UK – Fliss Murtagh, Aine Burns, Ken Farringdon.
- UK – yearly educational symposium.
- RSC prominent in renal trainee curriculum
- NSF – useful information from large scale implementation of RSC and LCP
- Dr Sara Davison (Canada) – ACP, QOL
- Drs Michael Germain, Steven Wiesbord and Lewis Cohen (USA)

International Networks

- Discussion of formation of interested parties from different countries
- Potential for research
- Need to increase profile at international meetings

Still a way to go……..