

Outcome of a "No Dialysis Option"

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Pre dialysis / CKD education, Access, Early End of life Care Nurse

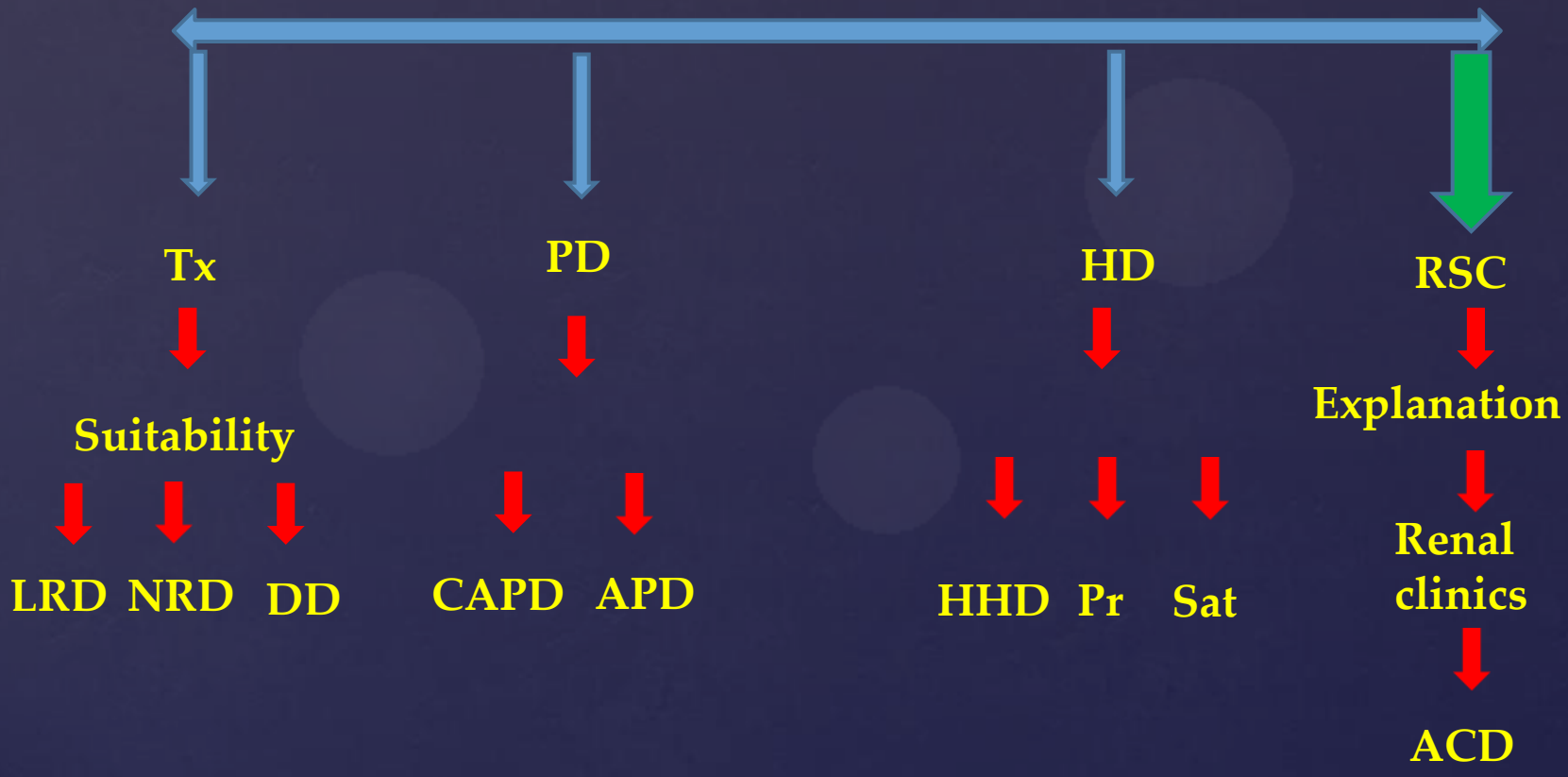
I am not a Palliative Care Nurse!

I use the Southern *Palliative Care Team*

"Having a baby takes preparation and planning.....why should dying be different"

Catherine Fox

OPTIONS


Tx
PD
HD
RSC
Suitability
LRD
NRD
DD
CAPD
APD
HHD
Pr
Sat
Explanation
Renal clinics
ACD

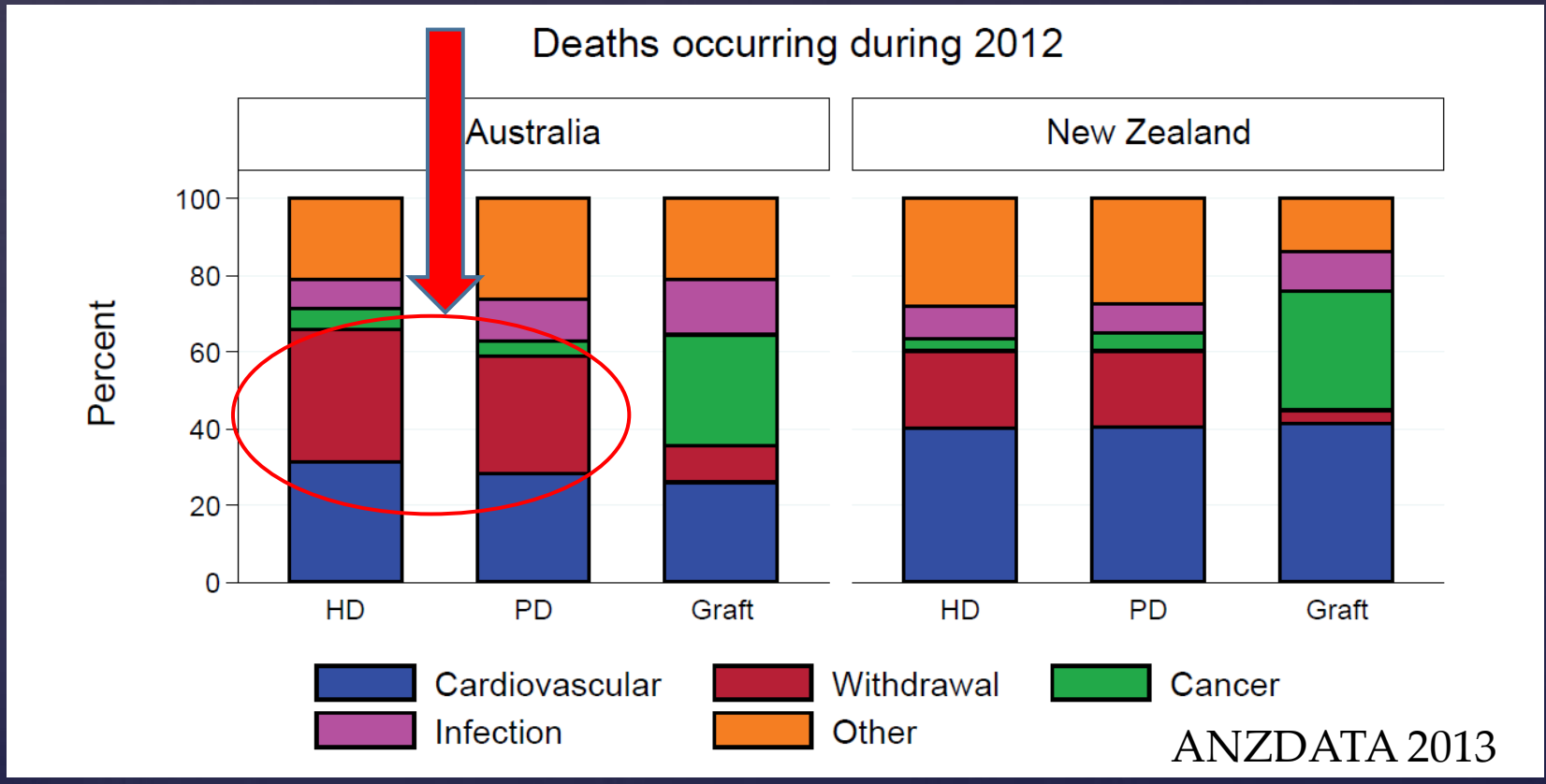
The choices

- "the discussion"
  - - One option is "No Dialysis"
  - - You have the right to refuse treatment
  - - Dialysis is an artificial procedure for preserving life
  - - In some case dialysis may not extend your life
  - - Often becomes a trade of Quality / Quantity
  - - Reinforce the preceding medical discussion (e.g "the doctor thinks I won't do well on dialysis"!)
  - - Never change tact or "send mixed messages" from something that has previously been set up.
  - Need to look them in the eye and say you are not going to do well on dialysis and may well not live longer.
  - Make sure that Advanced Care Directives are in place (regardless of option choice)

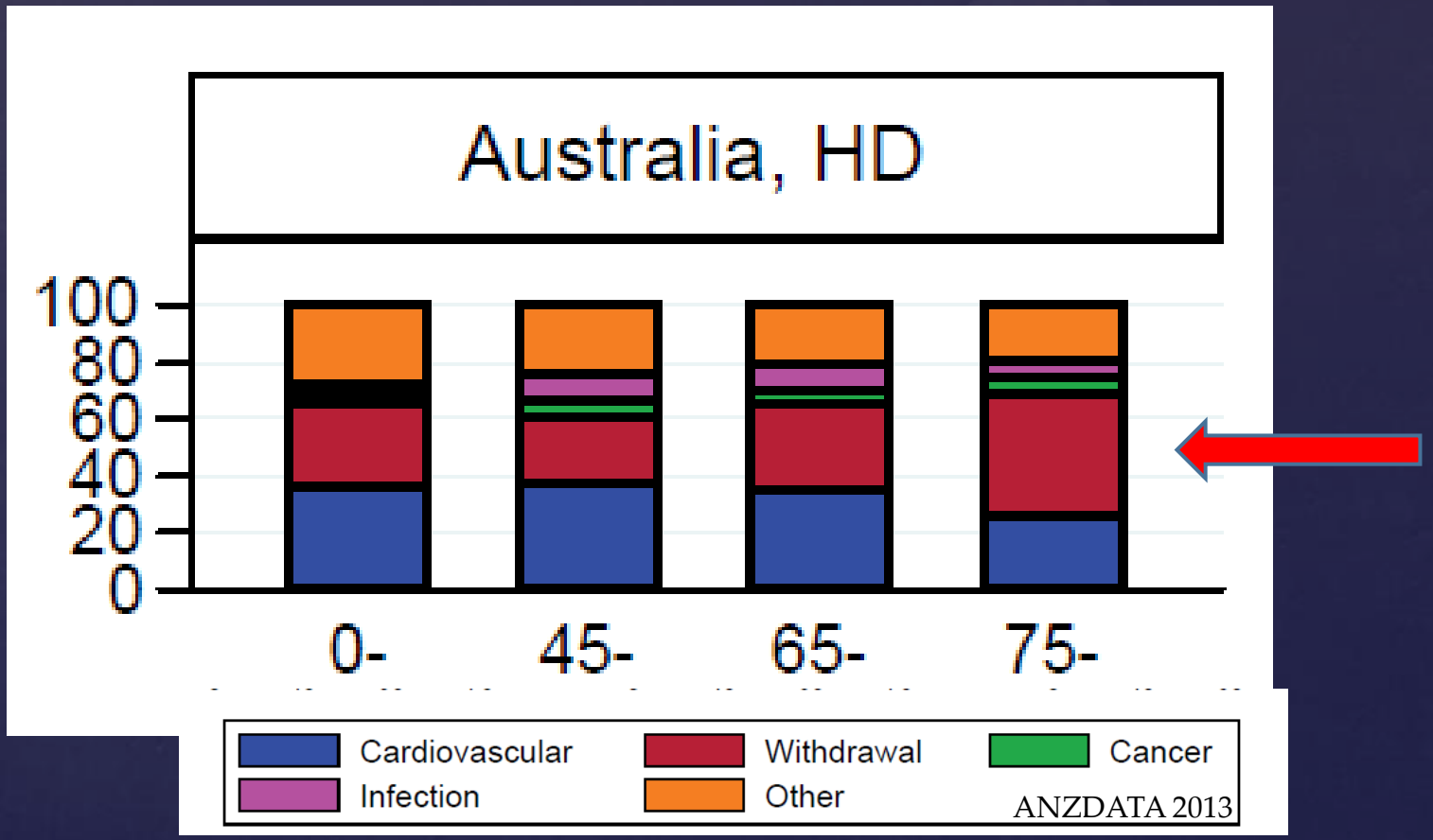
Predictors of survival

- *Factors identified with poorer survival on dialysis include:*
  - Older age
  - Comorbid conditions (Charlson index)
  - Malnutrition (Alb <25G/l)
  - Functional status (Karnofsky)
  - Late referral to a nephrologist
  - Unplanned start
    - Several studies have identified comorbidity score as a strong predictor of mortality

Death by Modality (%)



Death by Age (%)


Australia, HD
100
80
60
40
20
0
0-
45-
65-
75-
Cardiovascular
Withdrawal
Cancer
Infection
Other
ANZDATA 2013

Renal Supportive Care

- The thought of dying is usually not the problem ……..it's the road that most are frightened of.
- Explanation that…..

  - They are usually reasonable well until the end is near

  - Most can still be at home

  - Most are able to do their ADL's

  - They will get symptoms but most can be controlled well (Pall care or GP involved)

  - They will most times slowly sleep longer each day until they die.

Renal Supportive Care

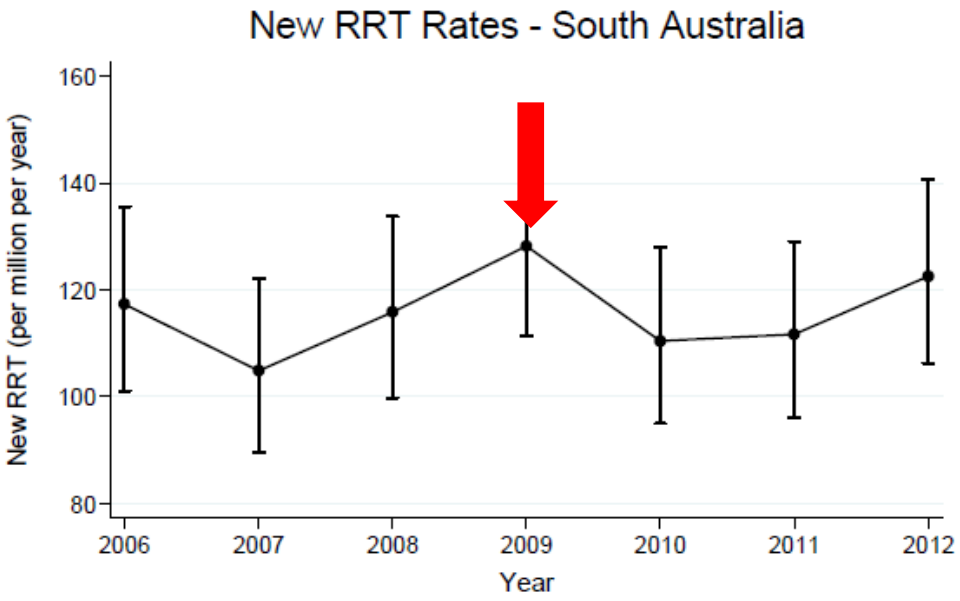
Clinics

- If you decide not to have dialysis you will stay in our clinics.
- All medical parameters are corrected where possible
- We do an "introduction to Palliative Care" – encouraged
  - Meet with Pall care team
  - Discussion about paperwork, where to die etc
  - Most time the file is then closed
  - Left with a 24 hr contact and a plan

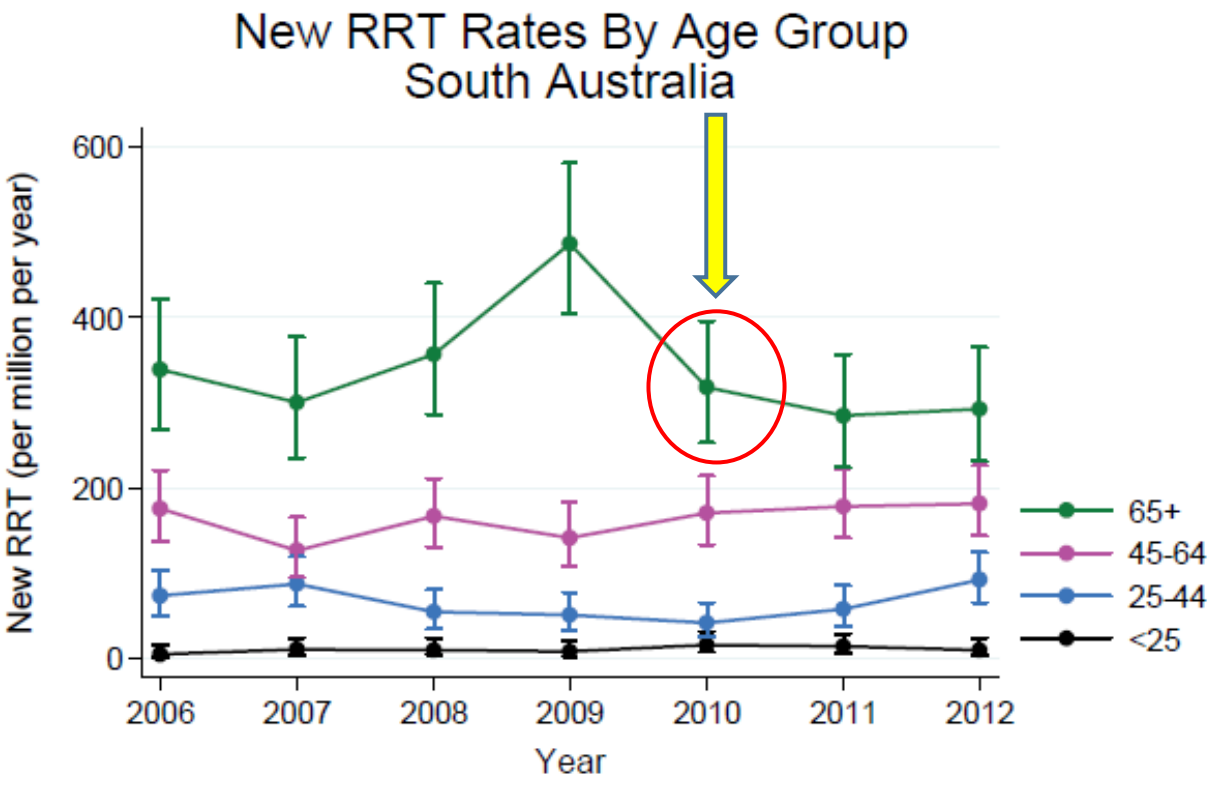
Advanced Care Directives

- Encouraged to be completed by every patient
- Needed for future changes which may occur (e.g. dementia)
- Can be used if a terminal condition occurs where the patient is unable to speak
- The addition of "7 Step Not for Resus" may occur in the future ….needs to be completed by intern or above.

Outcomes



ANZDATA 2013



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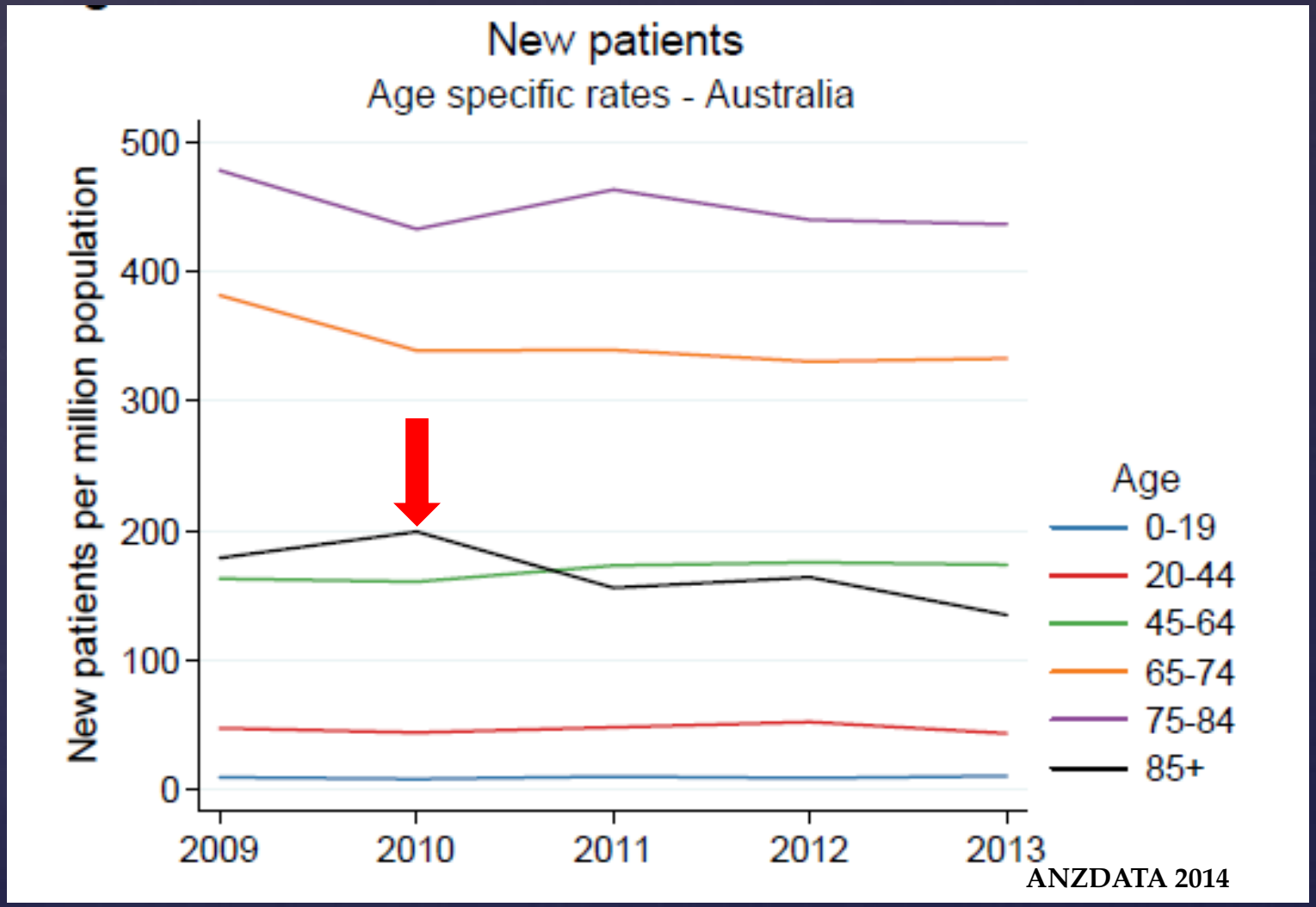
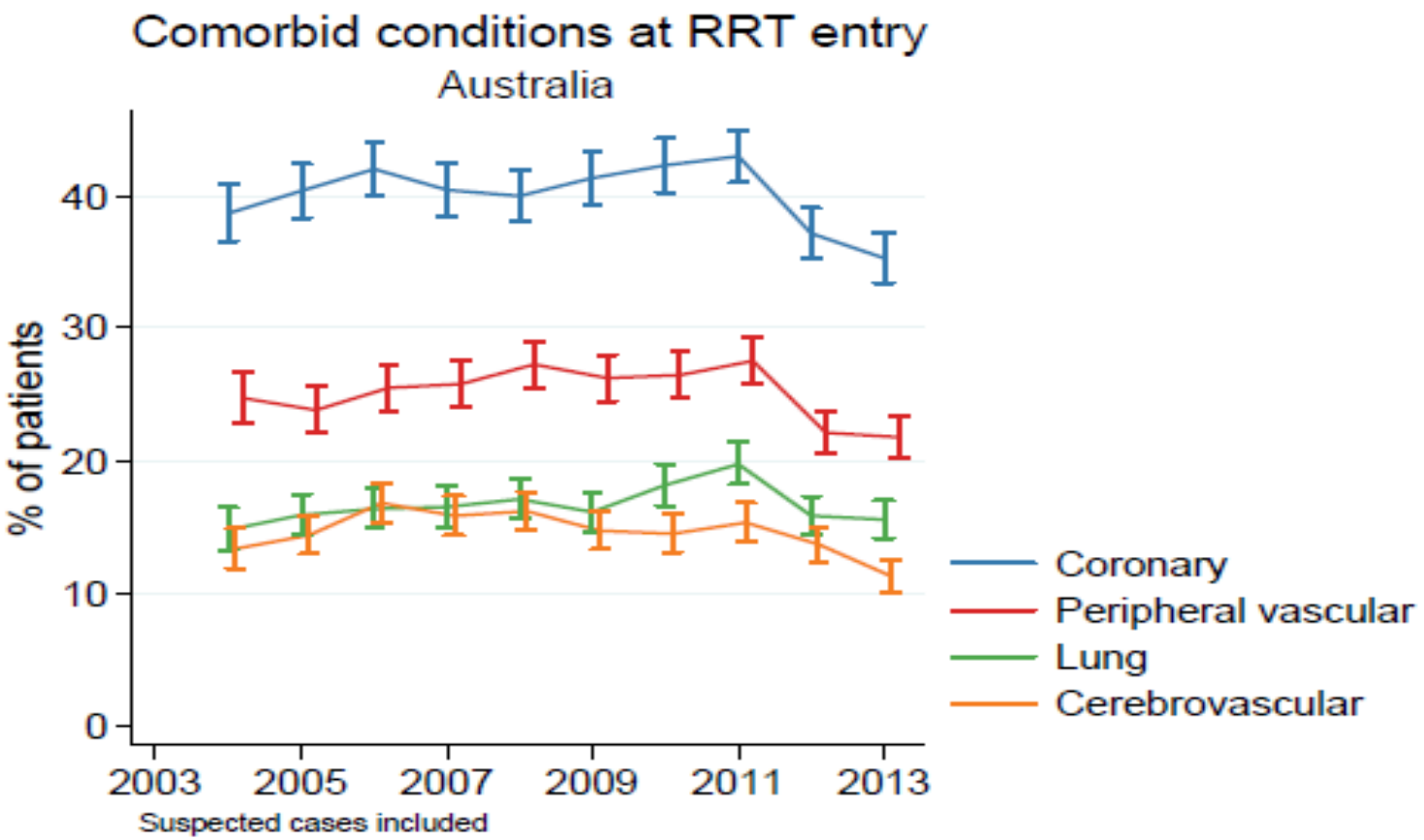


ANZDATA 2014

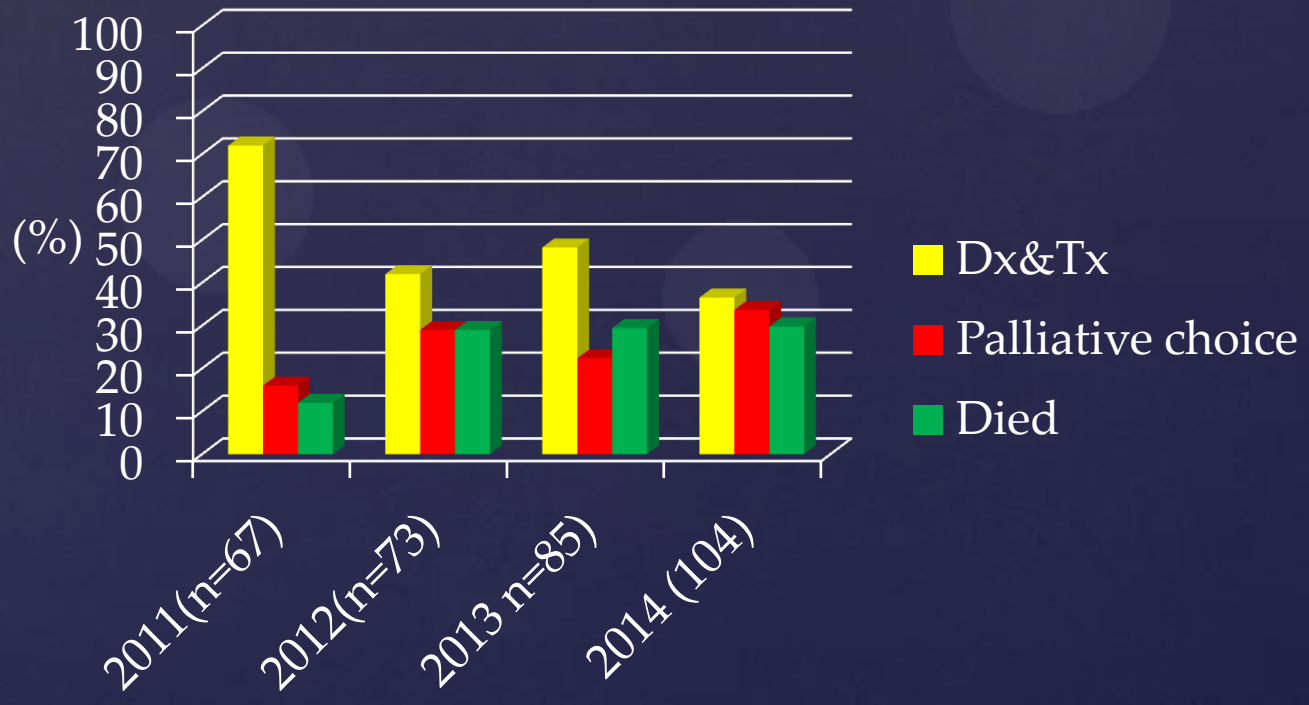


ANZDATA 2014

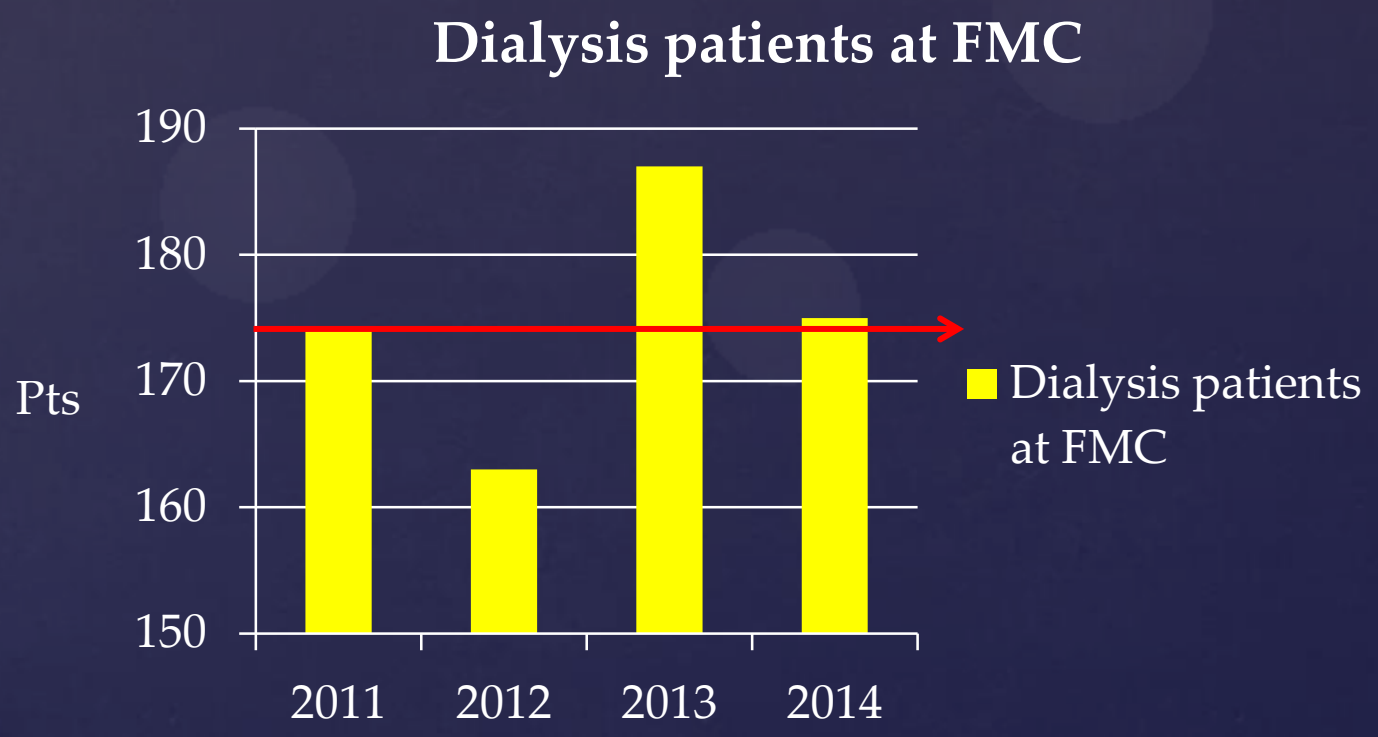
FMC - "Successful Palliation" out of hospital

- 70% of CRF patients that chose not to have dialysis where successfully palliated out of hospital over the past 4 years.
- In the past 12 months this had increased to over 90%
- Early "set up" led to early decisions and correct patient placement.

FMC - Patients lost from ESRD list eGFR <20 (%)



FMC - Renal unit number over past 4 years



Problems

- Patients living alone with no family supports – difficult ACAT
- Patients unable to make a decision
- Making sure that the ENTIRE family are "one the same page"

  -Family that live long distances
- Pall Care –
  - Limited resources
  - Hospice, assistance at home.
- Making sure other teams are aware of their decisions (Cardiac, vascular etc)

Conclusion

- It is important to give our patients a choice
- Be honest and as accurate as possible
- These decisions are difficult – many need time
- DO NOT "send mixed messages" RSC decisions – this is one of the hardest decisions in life, don't make them make it twice.
- Setting them up for the future while they are well…….Sow the seed!

Thank you for your time and attention