Ethical Considerations in Chronic Kidney Disease and Transplantation

CHILDRENS
RENAL &
UROLOGY
UNIT
QMC • NOTTINGHAM

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Helsinki May 2010

CN Syndrome

Recent advances in D & T have dramatically changed the previous pessimistic prognosis of CNF.

Paediatric Kidney Disease 1992

Everything in transplantation relates to ethics, from issues about using marginal donor grafts, using beating heart donors, patient selection – social, economic (ie insurance), psychosocial factors such as abuse and non-adherence issues

Denton Cooley 2008

Transplant Activity

2007 – 2008 UK Transplant

- 3235 organ transplants
- 911 lives were saved in the UK through heart, lung, liver or combined heart/lung, liver/pancreas, heart/kidney or liver/kidney/ pancreas transplant
- 851 living donations of kidney or a segment of liver or lung
- Non-heartbeating donors increased 36% on 2006-07
- 7655 were listed as actively waiting

Ethics
Four Principles Approach
(Beauchamp and Childress)

- Respect for autonomy
- Beneficence (do good)
- Non-maleficence (do no harm)
- Justice (the notion that patients in a similar position should be treated in a similar manner)

Ethics
The Four Quadrant Approach
(Jonsen, Siegler and Winslade)

- Indications for medical intervention
- Preferences of patient – if not competent then what is in the patient's best interest?
- Quality of life – will the proposed treatment improve the patient's quality of life
- Contextual features – do religious, cultural and legal factors have an impact on the decision?

Ethics and the Law

UN Convention on the Rights of the Child

Article 3

"In all actions concerning children whether undertaken by public or private social work institutions, courts of law, administrative authorities or legislative bodies, the **best interests** of the child shall be a primary consideration"

Article 12

"Parties shall assure to the child who is capable of forming his or her views the right to express those views freely in all matters affecting the child"

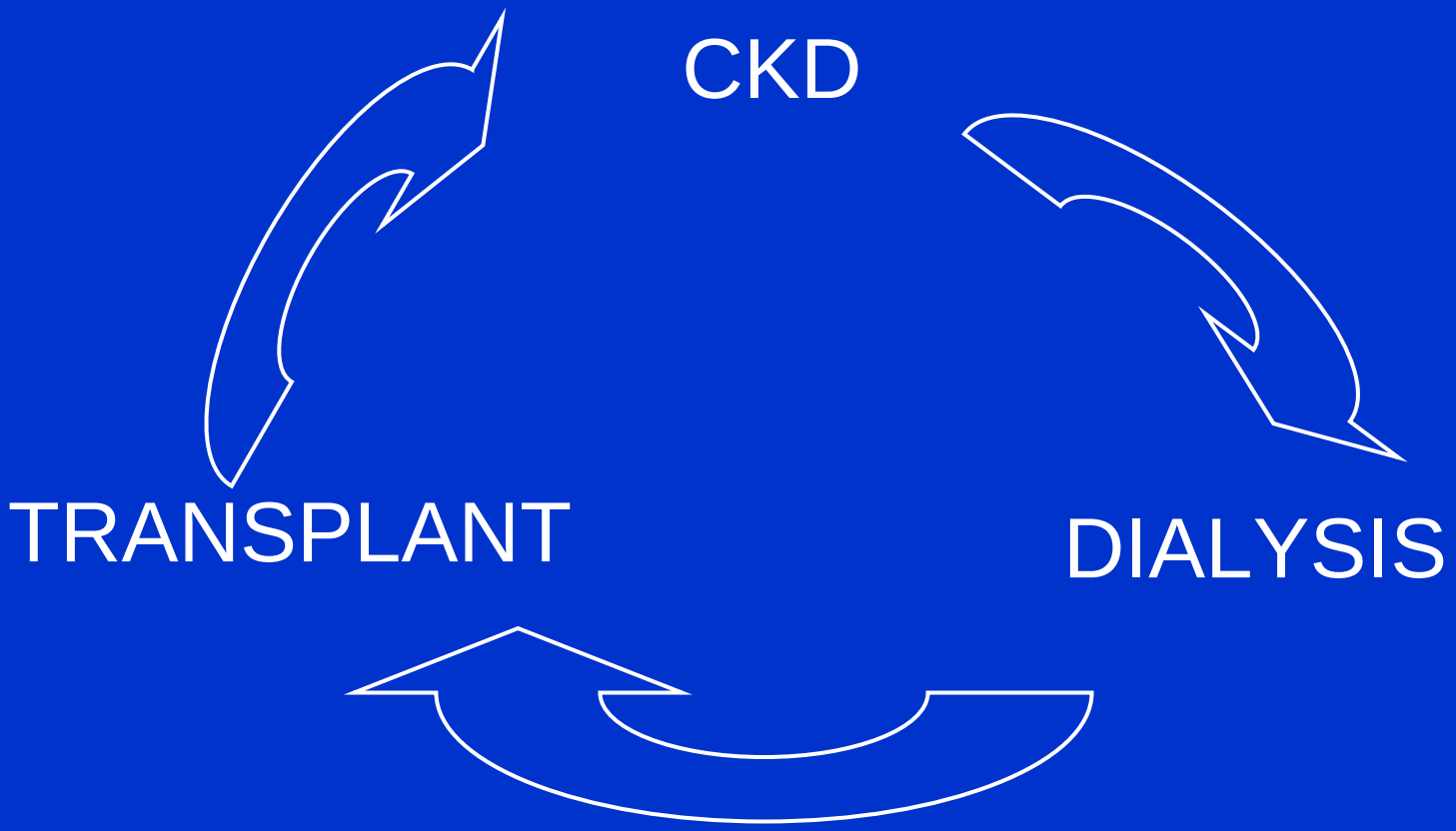
UTILITARIAN V EQUITY/JUSTICE

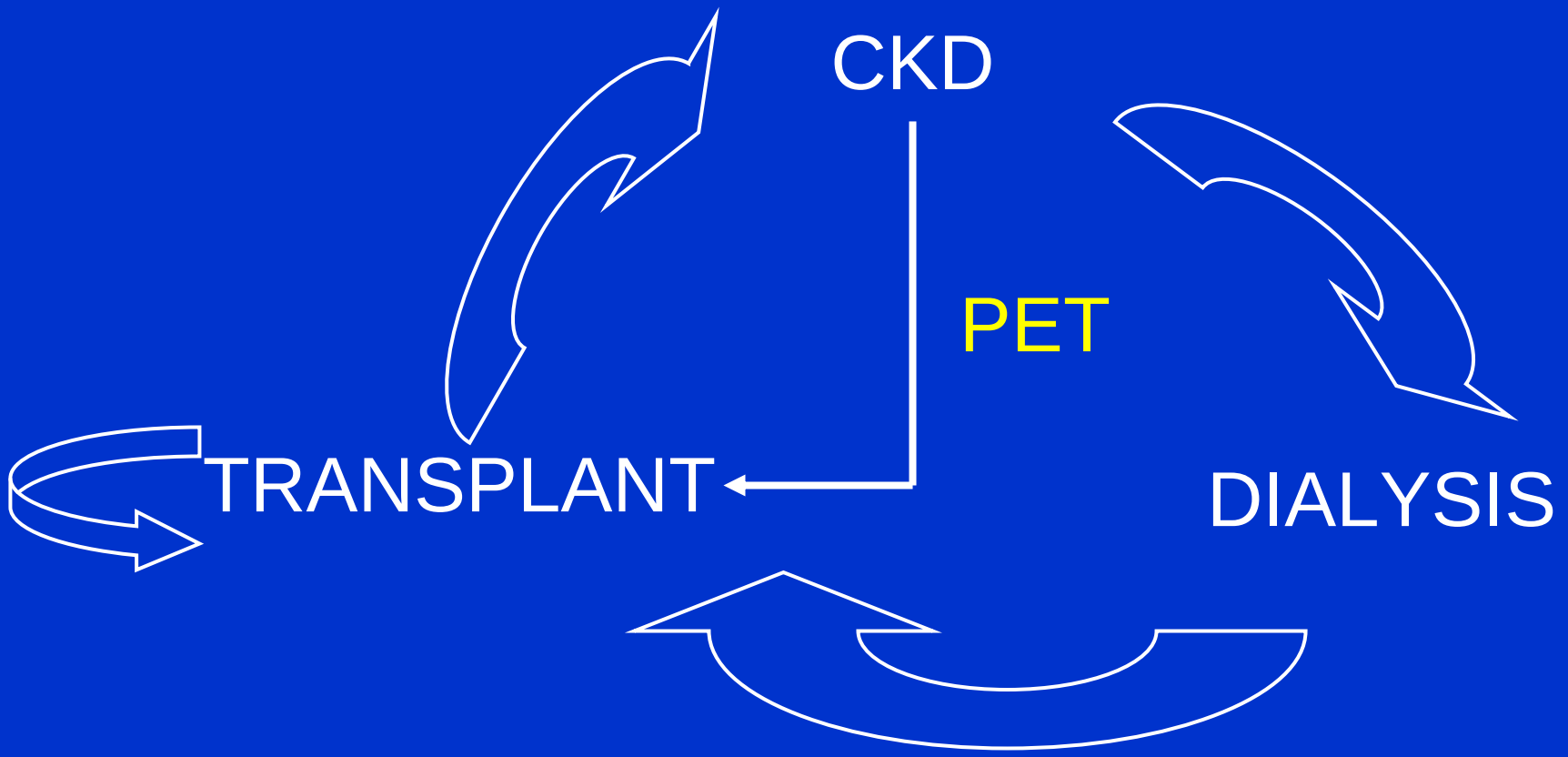
Transplanted into the recipient in whom it will survive the longest

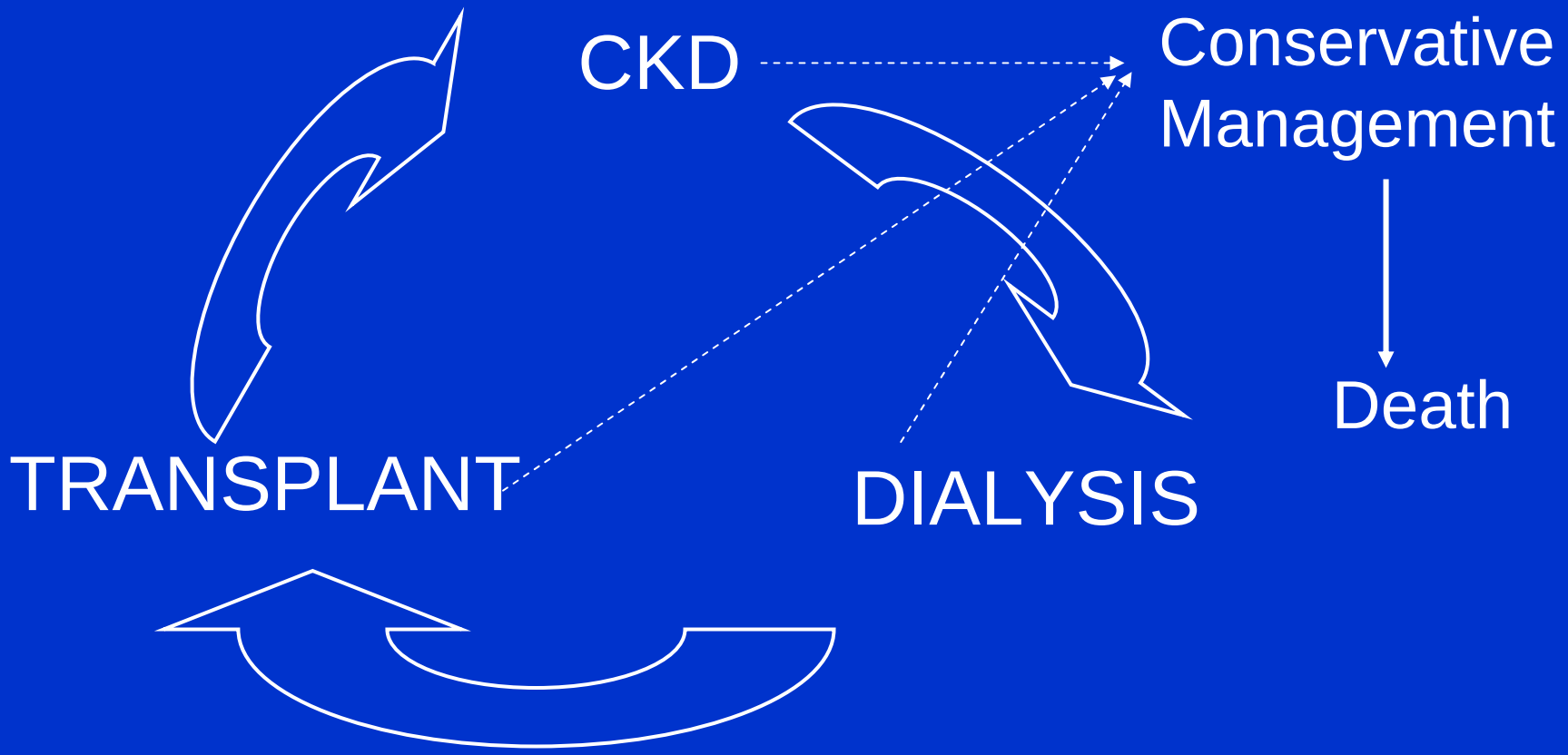
Each person who would benefit from a transplant should have comparable opportunity to receive one

Allocation of Limited Medical Resources

- Consider only ethically appropriate criteria
  - Likelihood of benefit
  - Urgency of need
  - Change in quality of life
  - Duration of benefit
  - Amount of resources required


CKD
TRANSPLANT
DIALYSIS


CKD
PET
TRANSPLANT
DIALYSIS


CKD
Conservative
Management
Death
TRANSPLANT
DIALYSIS

Ethical Dilemmas

- Should we start?
- Should we continue?
- Should we restrict?
- Should we transfer/transition?

Ethical Decisions – Guidelines for Practice

- Always act in the child's best interests
- Assemble all the available evidence
- Discuss the issues with the entire family
- Avoid second-hand or hearsay information
- Respect the opinions of everyone on the team
- Seek the wisdom of others
- Attempt a consensus whenever possible
- Consider using a clinical ethics committee if lack of consensus

Should We Start?

- Neonate with ARPKD
- Ventilated from birth
- D4 high frequency/oscillation/lung hypoplasia
- Acute renal failure with severe oliguria/ rising creatinine

Family Circumstances

- Healthy parents
- 2 year old healthy female sibling
- Father's job 'critical'
- No other family support
- Live 100 miles from tertiary unit
- Father Muslim

Janet

- 13 year old with Dandy Walker malformation
- Marked learning and communication difficulties
- Blocked shunt for hydrocephalus and severe renal impairment (CIN)

Janet

- Intolerance of medical procedures
- Behaviour difficulties
- Distance from unit
- Quality of Life

Janet

- Extensive discussions
- Conservative management ‘chosen’
- Local hospice
- Multi-agency meetings

Co-Morbidity in Paediatric Established Renal Failure Patients

868 UK patients 1996 – 2004

21.7%	comorbid condition
8.9%	developmental delay
6.5%	congenital abnormality
6%	syndromal diagnosis

Roberts Family

Christine HD (9/12) → Tx (11yr) → HD (adult unit)

Susie HD (2/12) → Tx (5 yr) → Tx (adult unit)

Eve HD (12/12) → Tx (8/12) → HD (adult unit)

Chris PET → HD (23/12) → ? Transition to adult

NOT RELISTED

Clinical Ethics Committees

Larcher V, Slowther A, Watson AR

Core competencies for clinical ethics committees.

Clin Med 2010;10:1-4

www.ethics-network.org.uk

- Act in the child’s best interests
- Build consensus with a true multi-professional team approach
- Use a clinical ethics committee if you are stuck!

You can only do your best!