

End of Life Care in Renal Disease

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Aim to cover..

- Background of end stage renal failure population
- Registry data (SRR)
- Our unit outcomes
- How to know when someone is better off without dialysis
- What to expect if you don't dialyse / stop dialysing
- Symptom control / managing death

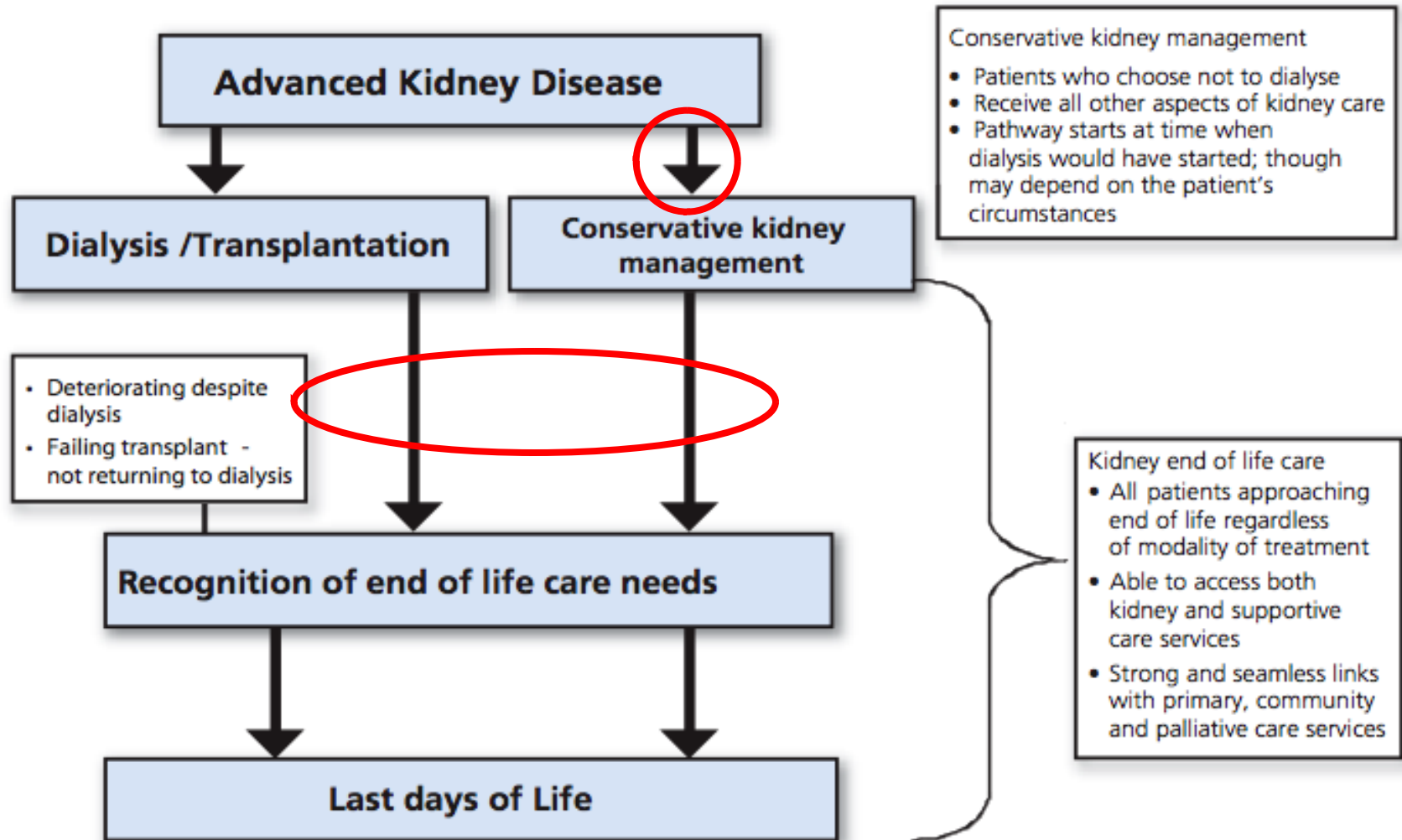
Factoids (1)

- RRT = all forms of dialysis + transplantation
- Since 1960 17,337 patients have started RRT in Scotland (until Dec 2016)
- 106 per million people start RRT in 2016
- 250 per million people start RRT age >65
- Median age 2016 was 61 years
- 5026 prevalent patients 2016 – rising due to better life expectancy + 57% have Tx

Factoids (2)

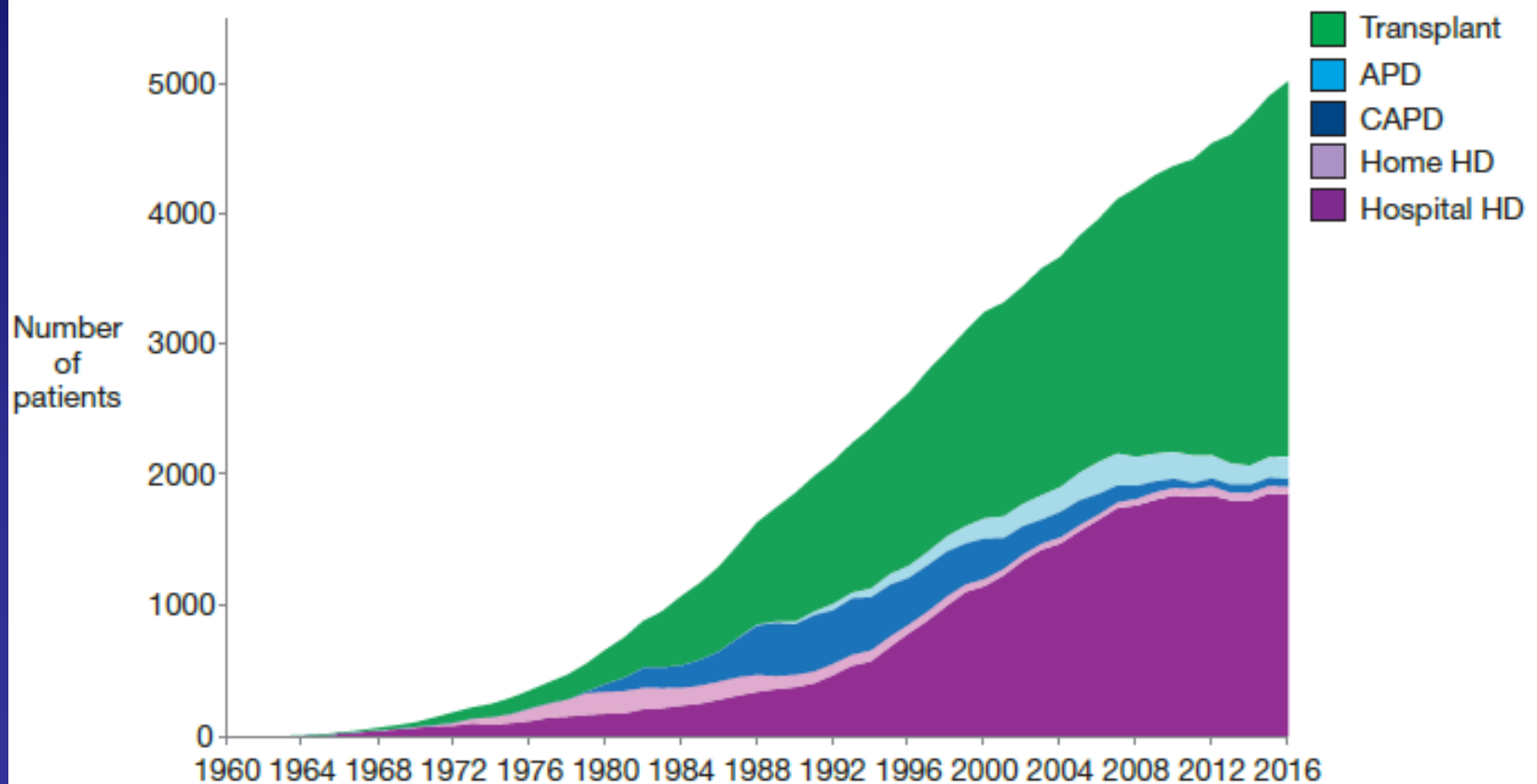
- Age + PRD + SD predict survival on RRT
- Overall survive on RRT 43% at 5 years
- Outcomes for diabetes worse
- 27% aged >75 die from withdrawal of dialysis. SMART audit data suggests 33% withdrawal contributes to death.
- 65% RRT patients die in hospital
- Overall dialysis population is becoming frailer

Figure 2: End of life care in Advanced Kidney Disease



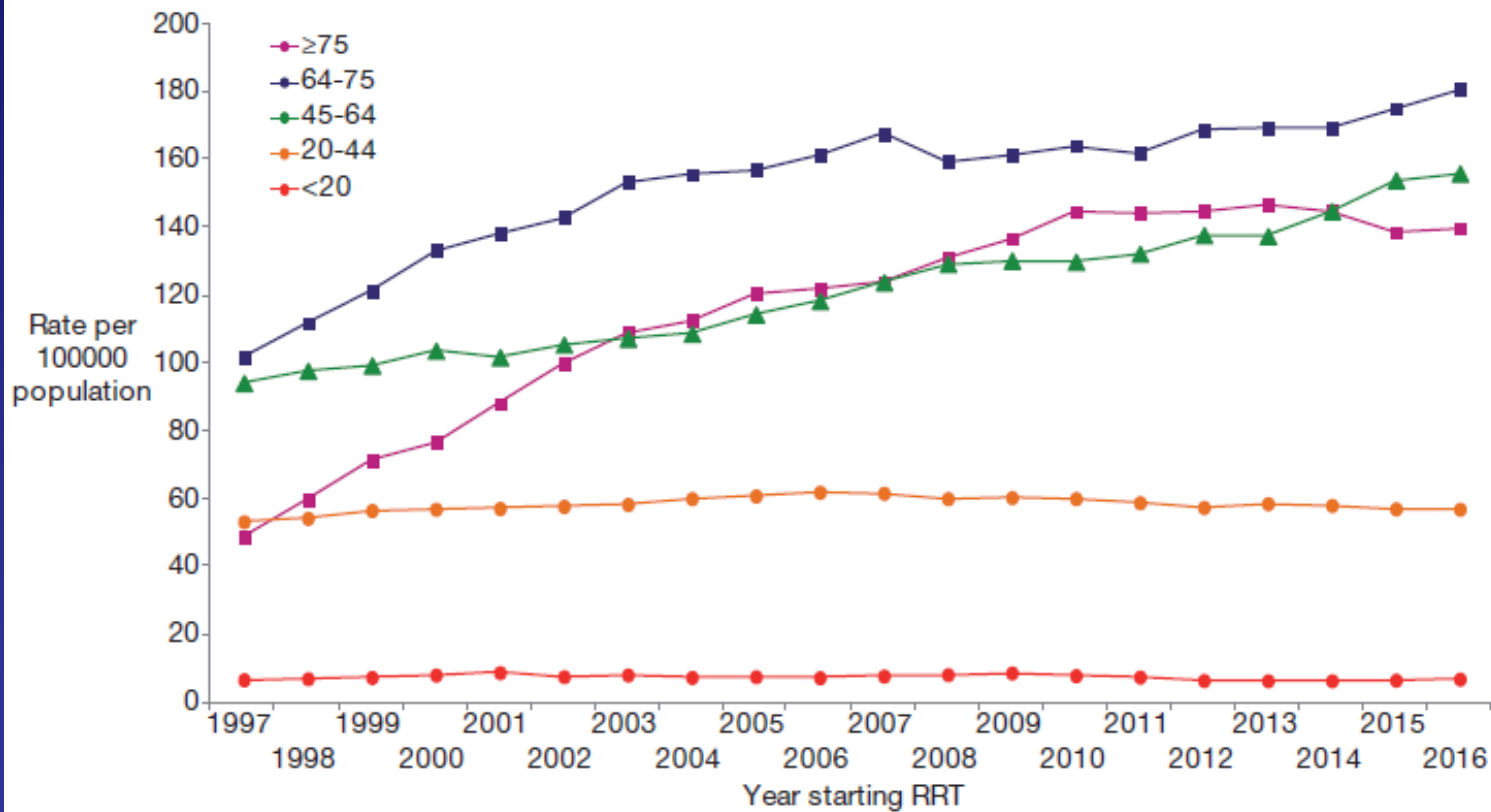


B1.1 Prevalent patients every year between 1960-2016



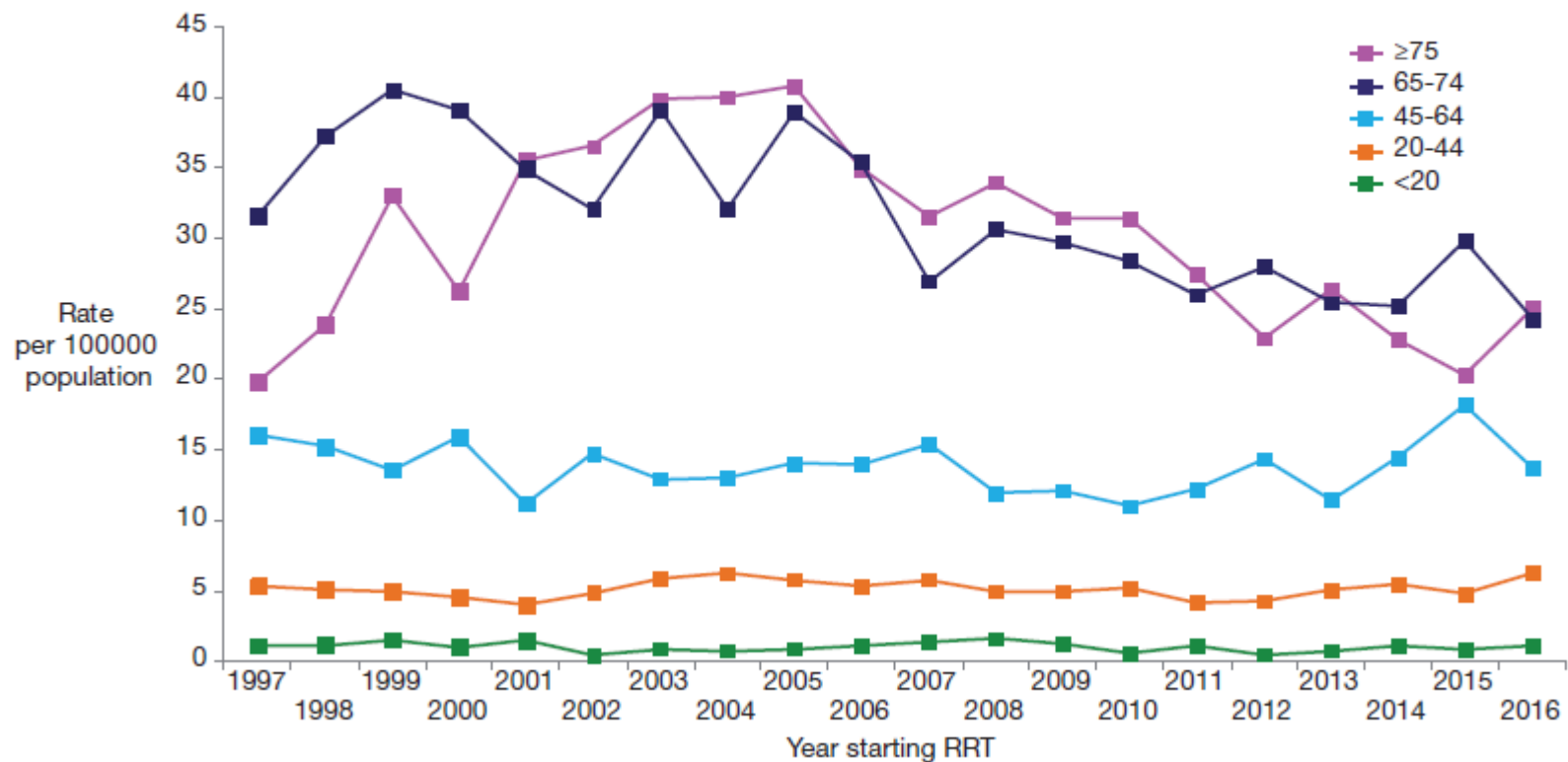


B1.5 Age specific prevalent RRT population 1997-2016 per 100000 population



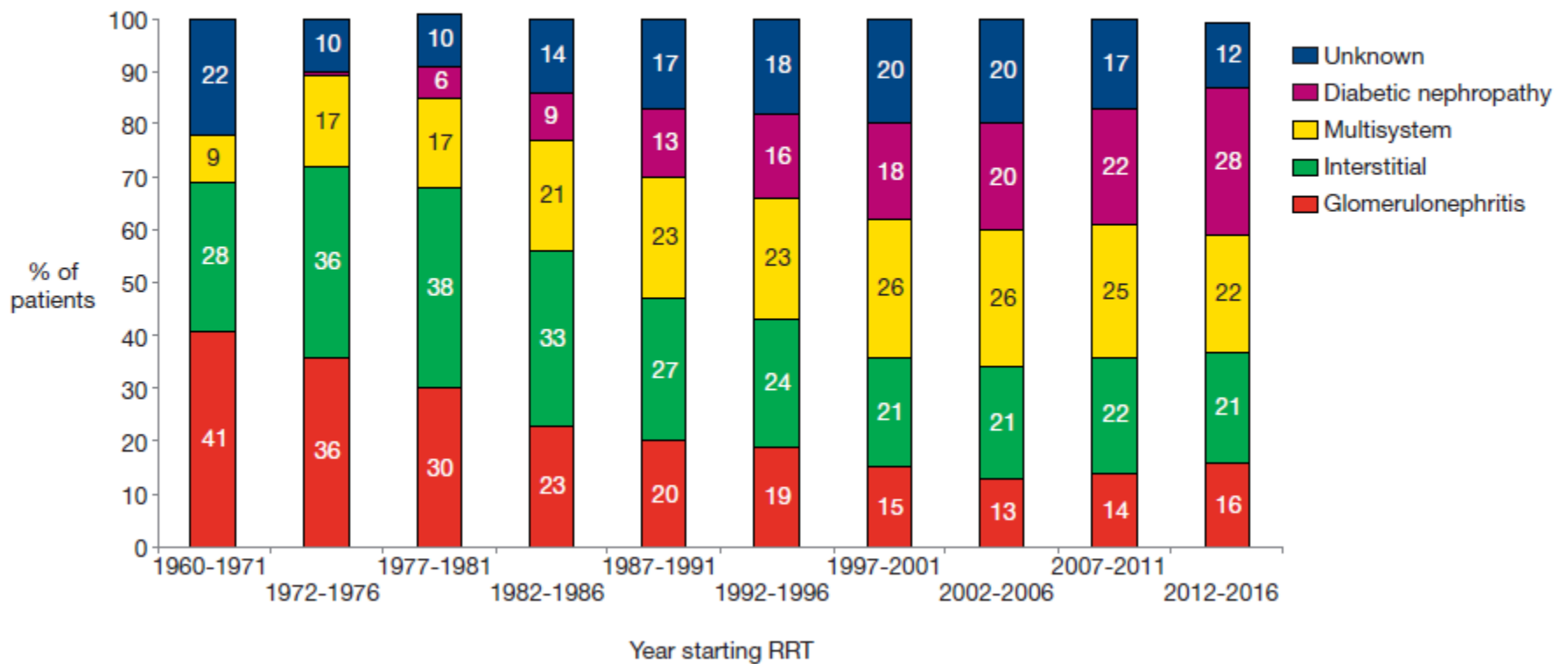


A2.2 Age specific incident RRT population 1997 to 2016 per 100000 population





A4.1 Percentage of patients in each diagnosis group starting RRT 1960-2016



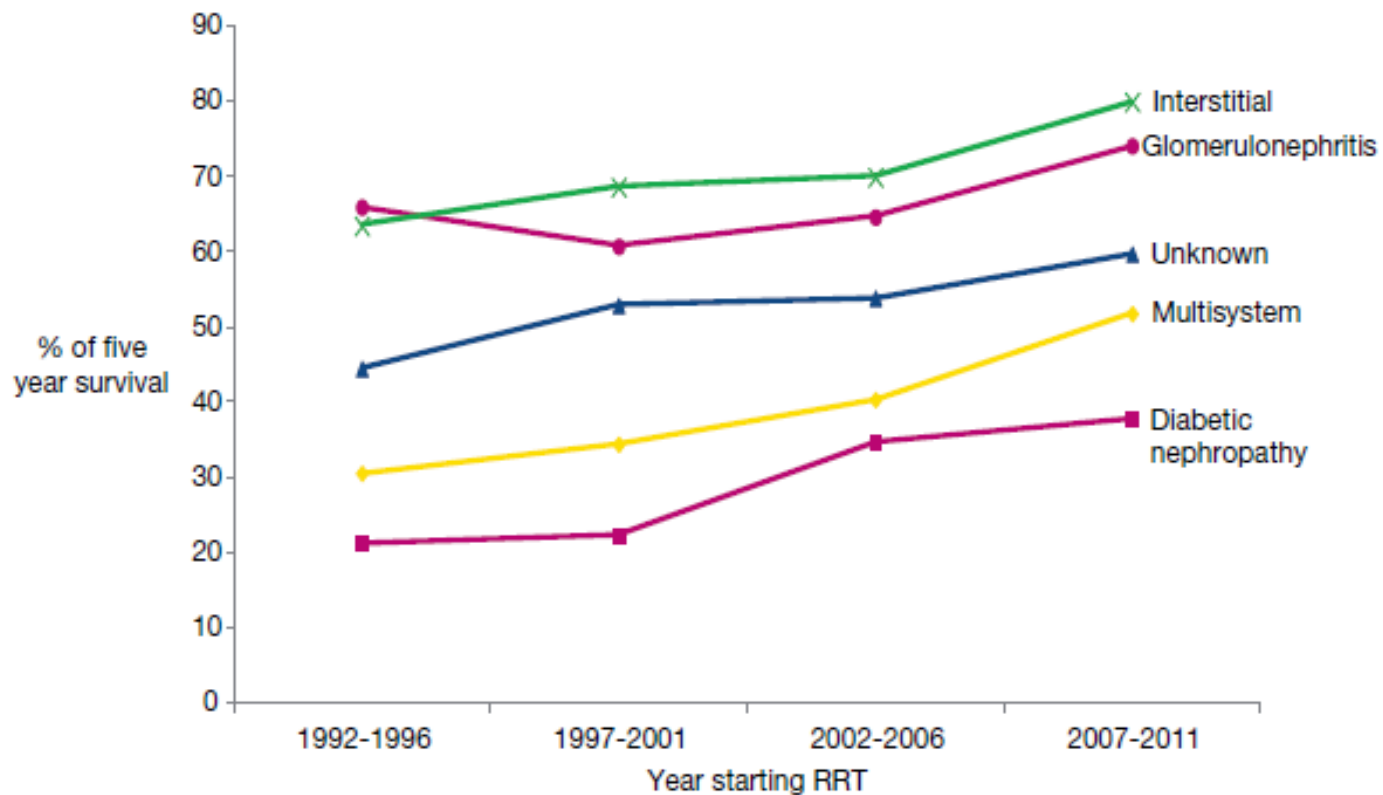


C1.1 Proportion of patients starting RRT 1996 - 2015 surviving at one, two, five and ten years by age and primary renal diagnosis group

Age group (years)	Diagnosis group	1 year survival			2 year survival			5 year survival			10 year survival		
		Number starting RRT (1996-2015)	n	%	Number starting RRT (1996-2014)	n	%	Number starting RRT (1996-2011)	n	%	Number starting RRT (1996-2006)	n	%
≥75	Unknown	680	439	65	663	298	45	582	95	16	401	8	2
	Diabetic nephropathy	291	188	65	280	132	47	223	27	12	140	2	1
	Multisystem	794	468	59	751	307	41	653	73	11	431	2	0
	Interstitial	280	199	71	269	142	53	237	52	22	159	3	2
	Glomerulonephritis	218	138	63	205	93	45	165	27	16	110	6	5
	All Diagnoses	2263	1432	63	2168	972	45	1860	274	15	1241	21	2
65-74	Unknown	579	430	74	556	331	60	500	155	31	382	27	7
	Diabetic nephropathy	635	468	74	594	333	56	481	94	20	321	6	2
	Multisystem	973	611	63	919	431	47	796	159	20	585	21	4
	Interstitial	438	362	83	413	288	70	342	134	39	240	26	11
	Glomerulonephritis	331	275	83	305	209	69	254	97	38	179	21	12
	All Diagnoses	2956	2146	73	2787	1592	57	2373	639	27	1707	101	6
45-64	Unknown	412	345	84	384	279	73	331	178	54	239	71	30
	Diabetic nephropathy	1000	845	85	907	635	70	708	224	32	470	50	11
	Multisystem	704	533	76	656	424	65	564	237	42	403	85	21
	Interstitial	939	873	93	873	762	87	713	520	73	486	244	50
	Glomerulonephritis	584	540	92	539	464	86	449	302	67	296	132	45



C2.1 Trend in 5 year survival from starting RRT 1992-2011 for patients aged 45-64 for each primary renal diagnosis group

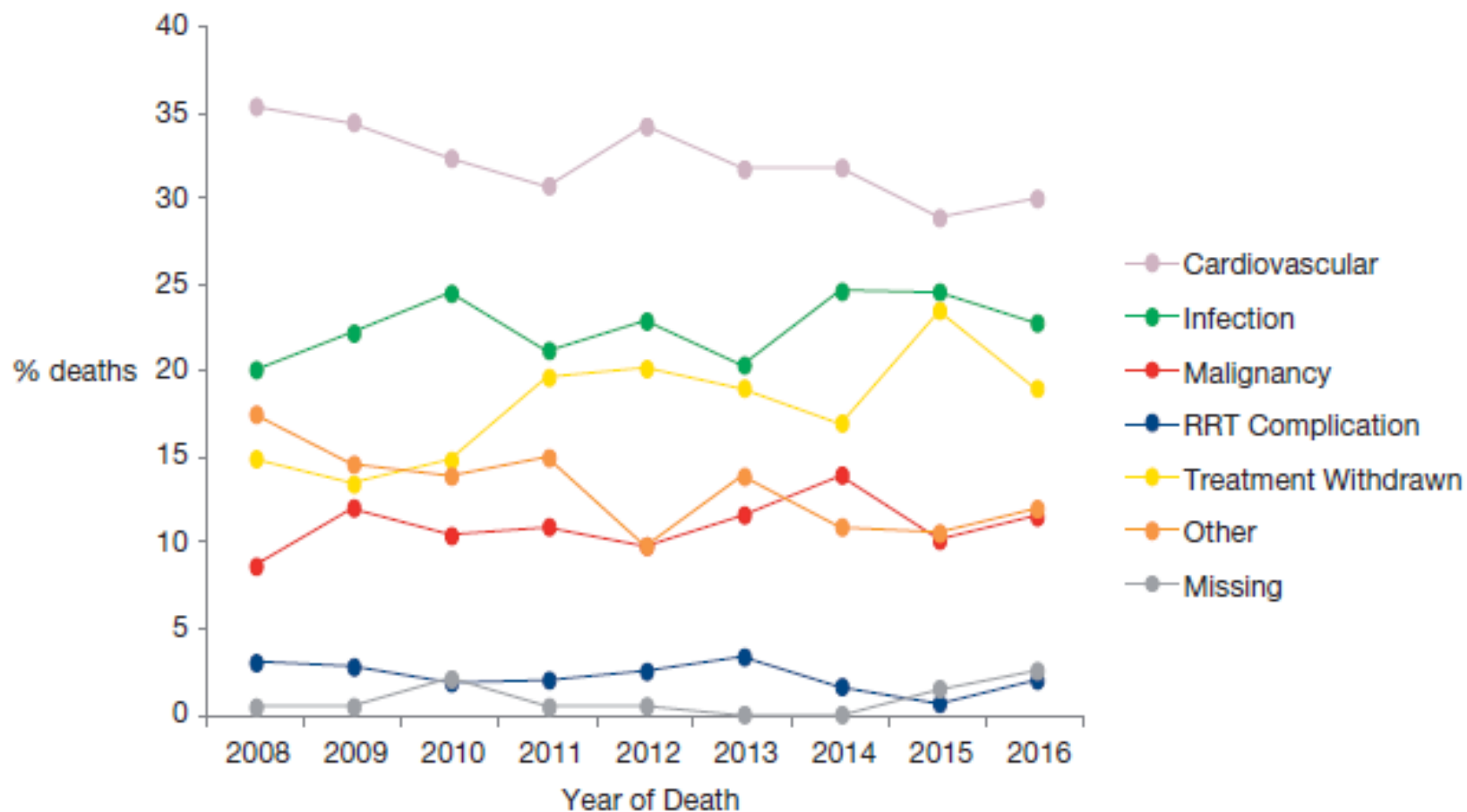


Age	Life expectancy males	Life expectancy females
85	5.5	6.4
75	10.5	12.2
65	17.3	19.7
55	25.3	28.2
45	34.1	37.4

Source: National Records of Scotland (NRS) life expectancy tables

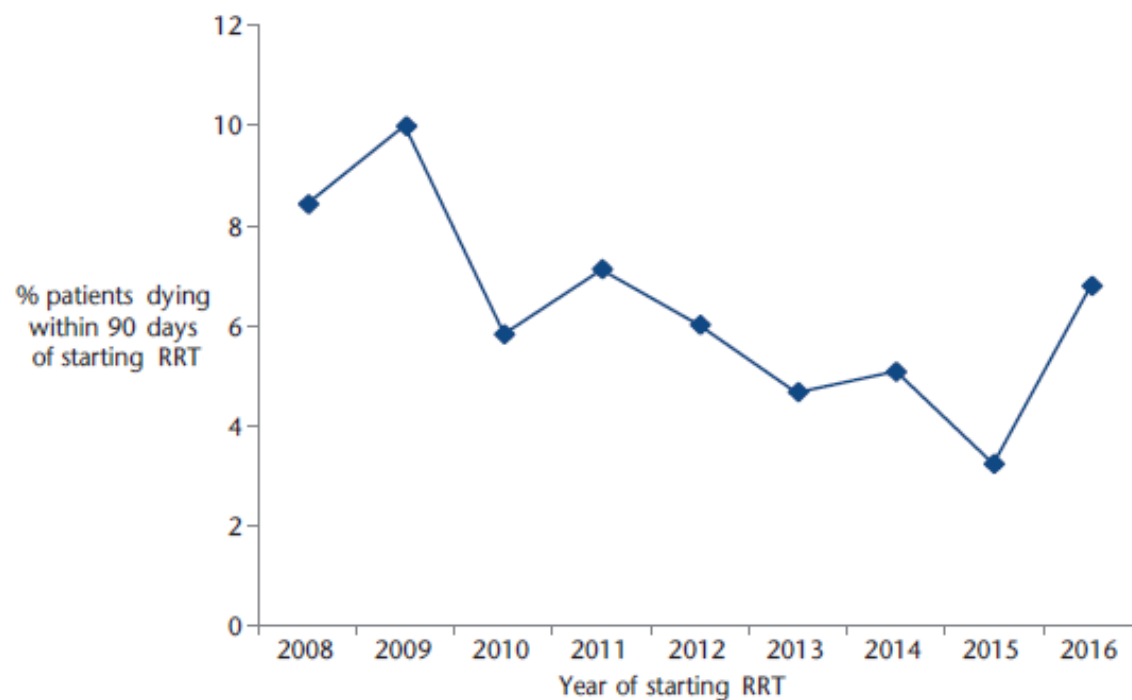


D3 Trends in cause of death group by year 2008-2016





E5 Proportion of patients who died within 90 days of starting RRT 2008-2016

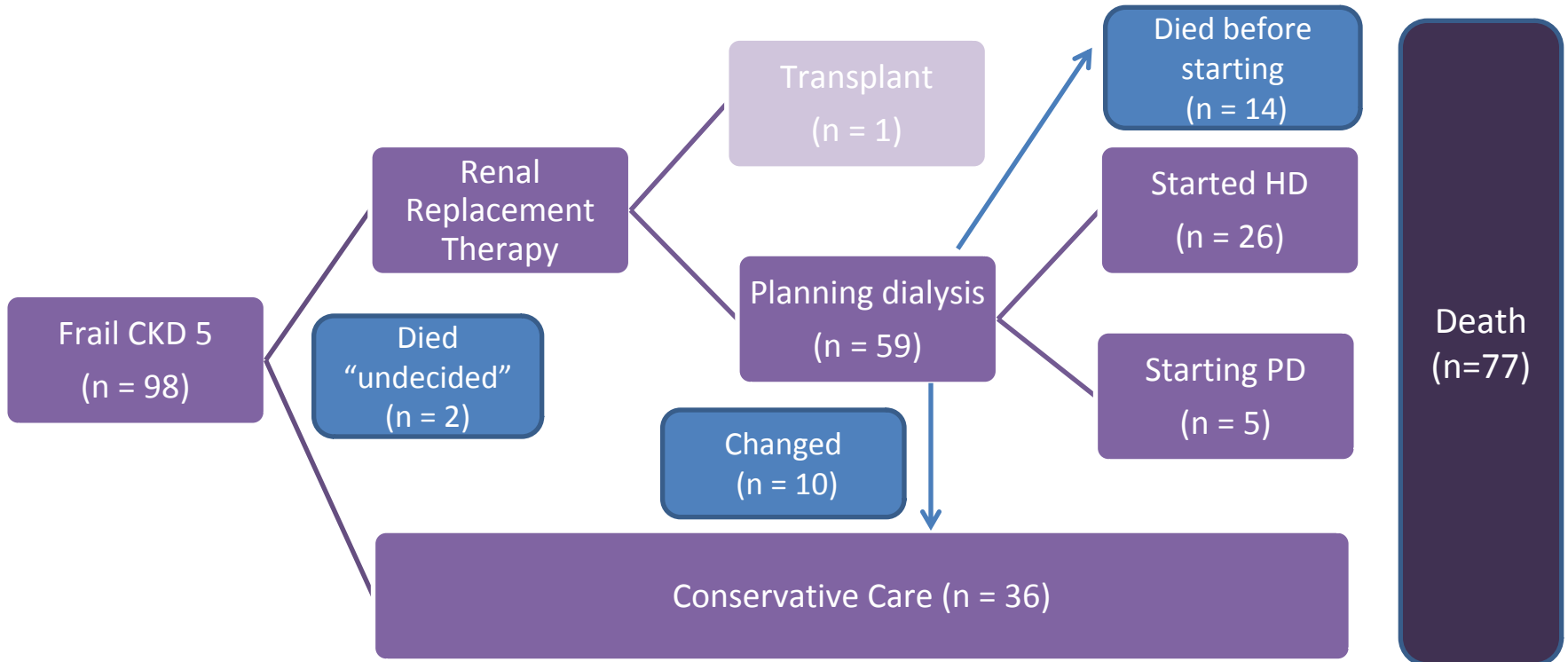




K3 Location of patient death 2008-2012

Location	Number of patients	Percentage of patients
Usual place of residence	483	22.2
Hospital	1500	69.0
Hospice	43	2.0
Community hospital	47	2.2
Place of death unknown	26	1.2
Data missing	73	3.4
Total	2172	100





Demographics

	CC choice n=36	RRT choice n=59	Received RRT n=31	Died before RRT/changed n=28
Mean age	78.2	76.9	76.6	77.3
Charleston comorbidity	8	8	7	8
% PPSV2	60 (n=26)	75 (n=36)	85 (n=24)	60 (n=12)
% Diabetes	47	51	40	61

Survival

- Survival advantage of 5 months from eGFR 15 for those who started RRT (21 vs 16m)
- 34% of RRT patients died within 1 year of starting dialysis

Vascular Access

- 39 fistulae created in 33 people
 - 17 (43%) were used
 - Fistula complication/failure to mature
 - Changed to conservative care
 - Died before starting dialysis
- 30 tunnelled lines in 20 patients – all used
 - 10 episodes of line sepsis (33%)
- 4 PD catheters for 4 patients – no complications

Emergency admissions in last 6 months of life

	RRT	No RRT
Emergency admissions last 6m	3.4	1.5
Renal admissions	2.3	0.3
Mean number of days in hospital	58.3	22.9

Quality of Death

	Conservative care (n = 32)	RRT received (n = 19)	Died before RRT (n = 14)	RRT then CC (n = 10)
DNAR	75%	73.7%	14.3%	100%
End of life planning	62.5%	42.1%	7.1%	50%
Cause of death	9 unknown 5 ESRD alone 6 ESRD +other 10 infection 3 malignancy 7 CV disease	9 withdrawal of dialysis 6 CV disease 5 infection	5 unknown 3 ESRD +other 5 CV disease 4 sepsis/infection	1 unknown 6 ESRD alone 3 ESRD + other 2 malignancy

RRT Summary

- RRT population is getting older & more co-morbid
- Small survival advantage for some
- Median survival < 2 years
- RRT requires intervention
- RRT population spend more time in hospital
- RRT population likely to die in hospital

Big impact on quality of life

Dialysis is not great if you are old & frail, but is it better than the alternative?

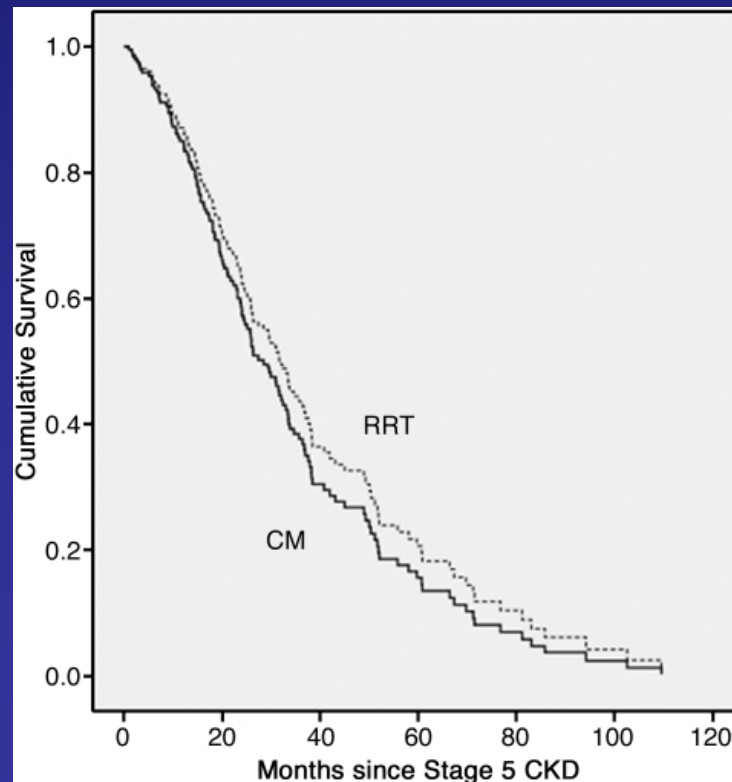
“Dialysis....damned if you do, dead if you don’t”

Will patients live longer on dialysis?

- UK, n=38, consecutive patients from clinic
- >75yrs + high co-morbidity
- 19 conservative vs. 19 RRT
- After one year:
 - RRT – more admissions (14 vs 5, p=0.008)
 - RRT – more infection (8 vs 0, p=0.003)
 - RRT – more deaths (7 vs 2, p=0.12)

Will patients live longer on dialysis?

- UK, n=844, 155 CM
- >75yrs + high co-morbidity – 4 months survival benefit

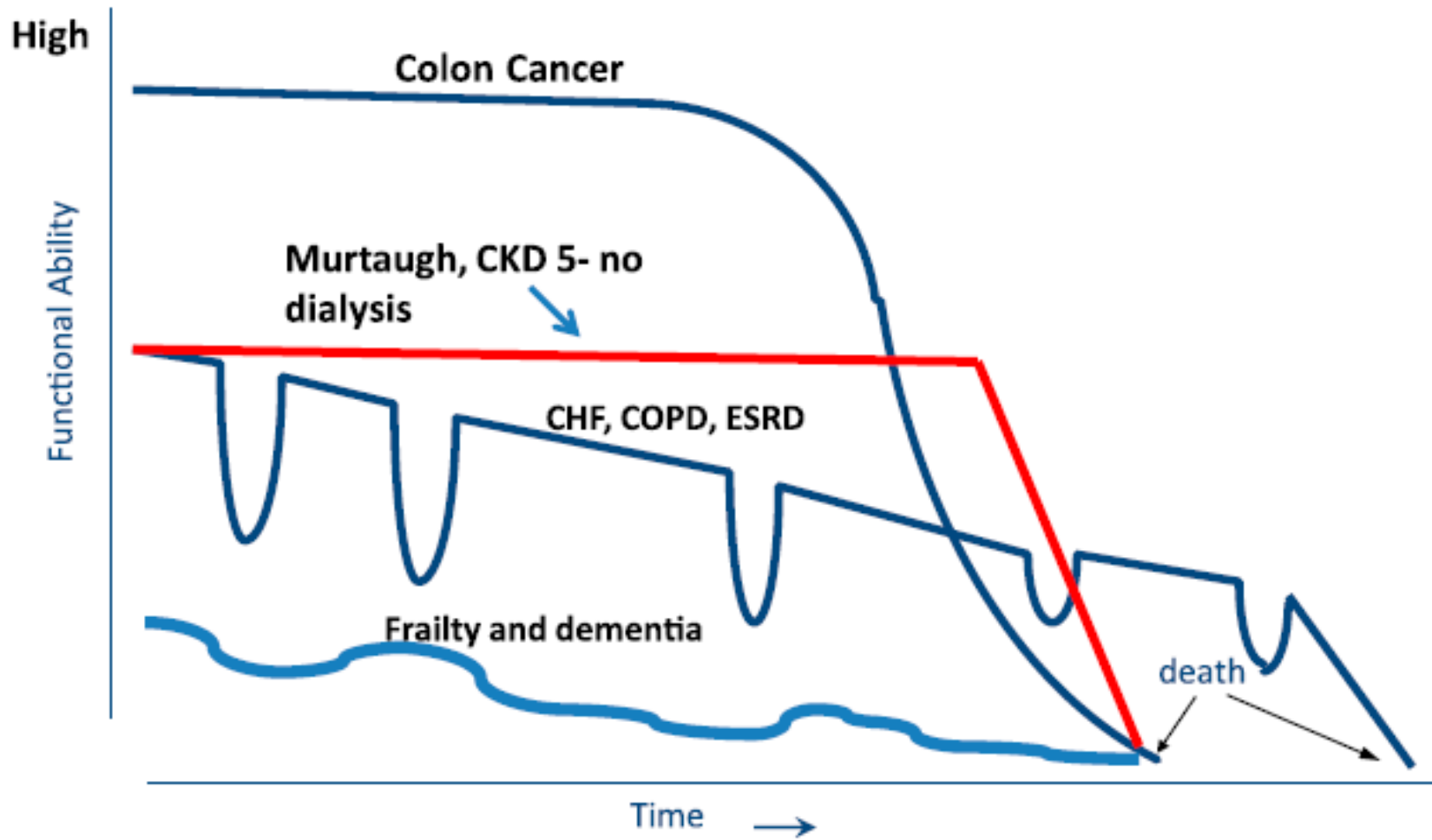


Will patients live longer on dialysis?

- UK, n=441, >70yrs – 172 CC vs 269 RRT
- Survival advantage lost:
 - >80yrs
 - Poor functional status
 - High co-morbidity
- RRT group:
 - more admissions
 - Less EOL planning
 - Die in hospital vs home

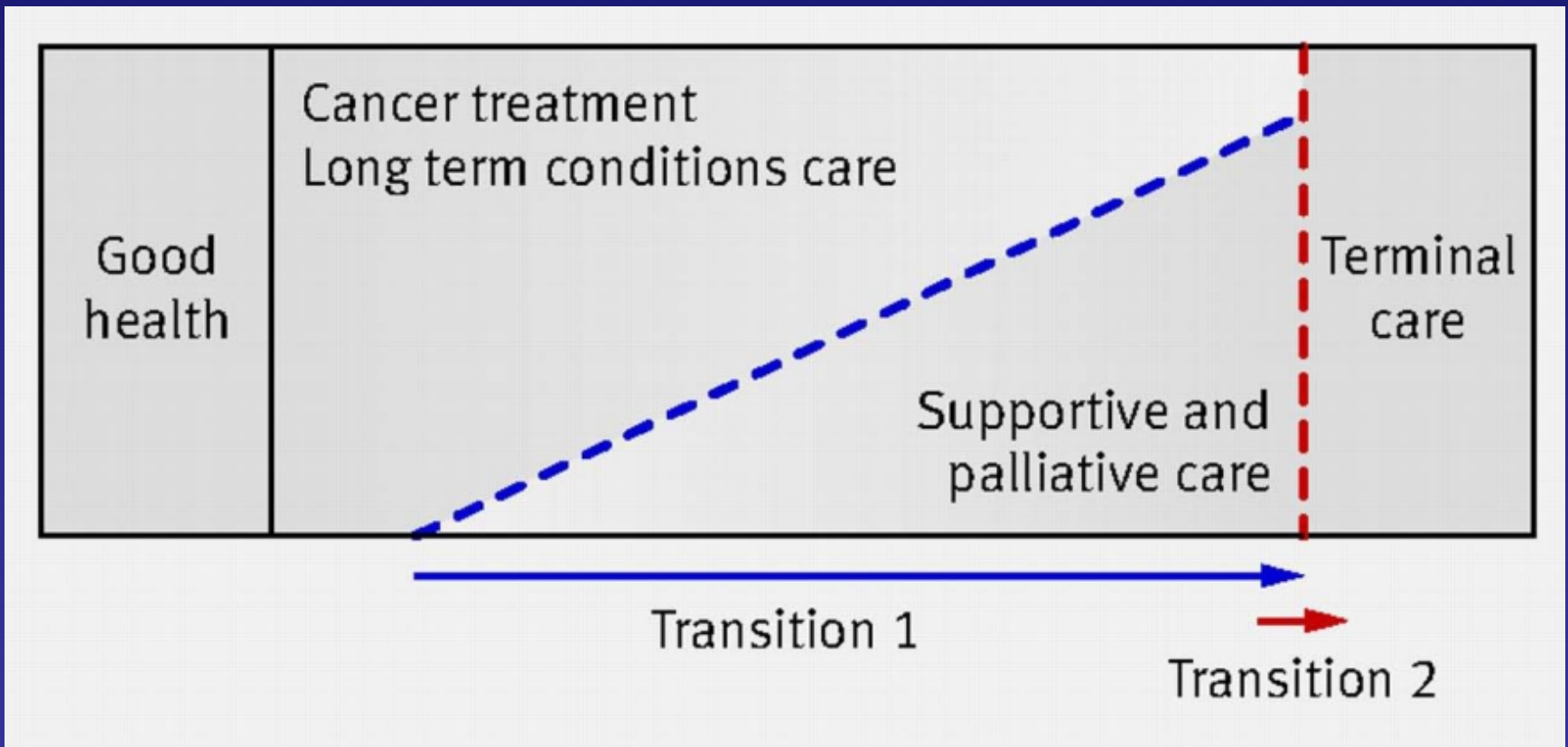
Is Dialysis Really Better Than The Alternative?

- Dialysis prolongs life for the majority of people
- BUT it may not do so for frail people:
 - poor functional status
 - nursing homes
 - not passing the ‘surprise question’
 - high co-morbidity – DM, PVD, dementia
 - >75yrs
- Cannot predict survival benefit for an individual
- Decision to have dialysis remains patient choice



Palliative care ≠ terminal care

....treatment that strives to improve quality of life and relieve suffering for patients with life-threatening illness and their families.



Supportive & Palliative Care

- Slow CKD progression
- Treat CKD consequences
- Clinical Frailty Score
- Holistic Assessment
 - Social
 - Spiritual
 - Financial
 - Symptoms
- Anticipatory Care Planning
- Plan for uncertainty
 - Contacts
 - Sick rules
 - Just in case drugs

Treat CKD Progression

- Disease specific treatments
- Slow progression of CKD:
 1. BP
 2. Proteinuria
 3. Acidosis
 4. (Glycaemic control)
 5. Lifestyle – activity & weight loss

Treat CKD Consequences

- Anaemia
- Acidosis
- Fluid status / BP
- Bone disease
- Hyperkalaemia
- Symptom management
- (Fertility / sexual health)
- (RRT planning = Tx vs other)

Clinical Frailty Score

- Simple, validated in ESRF
- Predicts poor outcome at onset of HD
- Predicts choosing CC or death prior to dialysis at RRT education stage
- Recently adopted this score
 - 3 monthly in RDU
 - CKD 5 group

Holistic Assessment

- Specific meeting with CNS
- Family / carers present
- Knowledge of linked services
- Signpost to appropriate services
- Build a relationship / trust
- Begin ACP – GP register, DNACPR etc
- Deliver education & information
- Provide point of contact

Guiding Principals for Therapy

- Stop unnecessary drugs as health declines
- Don't treat things that won't improve QOL
- Ask about symptoms
- Ask about exacerbating factors
 - Anxiety, social circumstances, nocturia
- Can use some drugs usually contraindicated at end of life
 - NSAIDs
- Proactive care prevents admissions eg infection
- Start low & titrate up doses

Symptom Management

High symptom burden from CKD & co-morbidities:

- **dialysis patients** - >50% experienced symptoms (59 studies reviewed)
- **CKD5 managed conservatively** - >33% experienced symptoms, similar to advanced cancer population
- **Last month life** - >50% physical + psychological distress, more than cancer cohort

1. Murtagh et al Adv Chronic Kidney Dis. 2007 Jan;14(1):82-99.
2. Murtagh et al J Palliat Med. 2007 Dec;10(6):1266-76.
3. www.britishrenal.org/OLDBRSCONTENT/.../O38_Murtagh.doc
4. Noble et al J Renal Care 2010 Mar 36(1):9-15

Symptom control in patients with chronic kidney disease/ renal impairment

Introduction

- This guideline covers modifications to standard symptom control that are recommended in patients with chronic kidney disease or acute renal impairment.
- Renal impairment is common in patients with diabetes, cardiovascular disease or cancer (from disease or treatment eg. chemotherapy, obstructive uropathy, myeloma).
- Symptom control is complicated by delayed drug clearance, dialysis effects and renal toxicity associated with commonly used medication (eg. NSAIDs).
- 50% of dialysis patients have pain. Depression and other symptoms are common.

Assessment

Chronic kidney disease (CKD)		
CKD stage 1	Normal renal function	
CKD stage 2	Mild impairment (eGFR 60-89 ml/min)	Asymptomatic
CKD stage 3a	Moderate impairment (eGFR 45-59 ml/min)	Asymptomatic
CKD stage 3b	Moderate impairment (eGFR 30-44 ml/min)	Anaemia, fatigue, muscle cramps
CKD stage 4	Severe impairment (eGFR 15-29 ml/min)	In addition: anorexia, nausea, insomnia, neuropathy, gout
CKD stage 5	End stage renal disease (eGFR < 15 ml/min)	In addition: itch, headache, cognitive impairment, death

- Pain is common and associated with many of the complications of advanced CKD.
- Look for multiple types of pain and/or other symptoms due to:
 - renal disease (polycystic kidneys, liver cysts, amyloid).
 - co-morbidity (diabetes, vascular disease, angina).
 - dialysis (abdominal pain in peritoneal dialysis, headache, fistula problems).
 - other pathology (cancer, osteoarthritis).
- Pain in patients with chronic kidney disease:
 - Musculoskeletal pain.
 - Muscle spasm, cramps, restless leg syndrome.
 - Osteoporosis.
 - Renal osteodystrophy.
 - Osteomyelitis, disc infection.
 - Carpal tunnel syndrome.
 - Neuropathic pain – renal or diabetic peripheral neuropathy.
 - Ischaemic pain – peripheral vascular disease, vasculitis.
 - Calciphylaxis – complex pain caused by tissue ischaemia due to calcification of small vessels/ subcutaneous tissue.
- Identify chronic pain (needs regular analgesia) and any intermittent/ episodic pain as this often needs managed separately with short acting analgesics/ non-drug measures. (see: Pain management, Pain assessment)
- Some drugs will be cleared by dialysis; an extra dose during or after dialysis may be needed.
- Patients are often on multiple drugs with a high risk of interactions/side effects.

Management

- Much of the advice in the palliative care guidelines is applicable to patients with renal disease. See table for renal prescribing advice.
- There is another renal palliative care guideline: Last days of life (renal).
- Choice and dose of opioids depends on the degree of renal impairment.
- Mild renal impairment; use lower starting doses of renally excreted opioids (codeine, dihydrocodeine, morphine, diamorphine, oxycodone) and slower titration.
- Stages 3-5 chronic kidney disease; use a modified WHO analgesic ladder (see page 2).

Renal Disease in the Last Days of Life

Introduction

This guideline applies to patients with stage 4 to 5 acute or chronic kidney disease (eGFR <30ml/min) whether receiving dialysis or not.

Plan end-of-life care in advance if a patient is likely to stop dialysis soon. Median survival after renal dialysis withdrawal is 9 days, but some patients with residual renal function may live much longer and need continuing care. If they pass urine they are likely to live longer than if they have minimal urine output.

Other relevant guidelines include: [Last days of life](#), [Subcutaneous medication](#), [Alfentanil](#) and [Fentanyl](#).

Assessment

Diagnosis of the terminal phase can be difficult. Potentially reversible causes of deterioration include [hypercalcaemia](#), infection, and opioid toxicity. Clinical signs include:

- bed-bound and drowsy or semicomatose
- only able to take sips of fluid or having difficulty swallowing tablets
- poor tolerance of renal replacement therapy
- background of deterioration.

Management

Plan and document care of the patient and family; consider using an individualised care plan or checklist.

- Discuss prognosis (patient is dying), goals of care (maintaining comfort), and preferred place of death with patient and family, as appropriate.
- Clarify resuscitation status; check DNACPR form has been completed. (See [national policy](#))
- Reassure the patient and family that full supportive care will continue.
- Stop unnecessary investigations and monitoring (blood pressure, pulse, temperature).
- Discontinue medication not needed for symptom control, and review daily.
- Prescribe [anticipatory medications](#) for symptom control ('Just in case' box in community).

Some patients may still benefit from oral diuretics, adjuvant analgesics and bicarbonate.

- If able to swallow, consider liquid formulations. Otherwise use the subcutaneous (SC) or rectal route.
- Offer oral fluids, maintaining any fluid restriction; review the patient's requirement for clinically assisted hydration in order to maintain comfort.
- Comfort nursing care (pressure relieving mattress, reposition for comfort only), eye care, [mouth care](#) (sips of fluid, oral gel), bladder and bowel care.

Patients with ESRF have a high symptom burden

Uraemic Symptoms

lack of energy, 76%
pruritus, 74%
drowsiness, 65%
dyspnea, 61%
oedema, 58%
pain, 53% - type?
dry mouth, 50%
muscle cramps, 50%
restless legs, 48%
lack of appetite, 47%
poor concentration, 44%
dry skin, 42%
sleep disturbance, 41%
constipation, 35%

Co-Morbidities

Diabetic neuropathy
PVD
Musculoskeletal

Dialysis

Recovery time
Hypotension
Nausea
Cramp
Headache
Access related

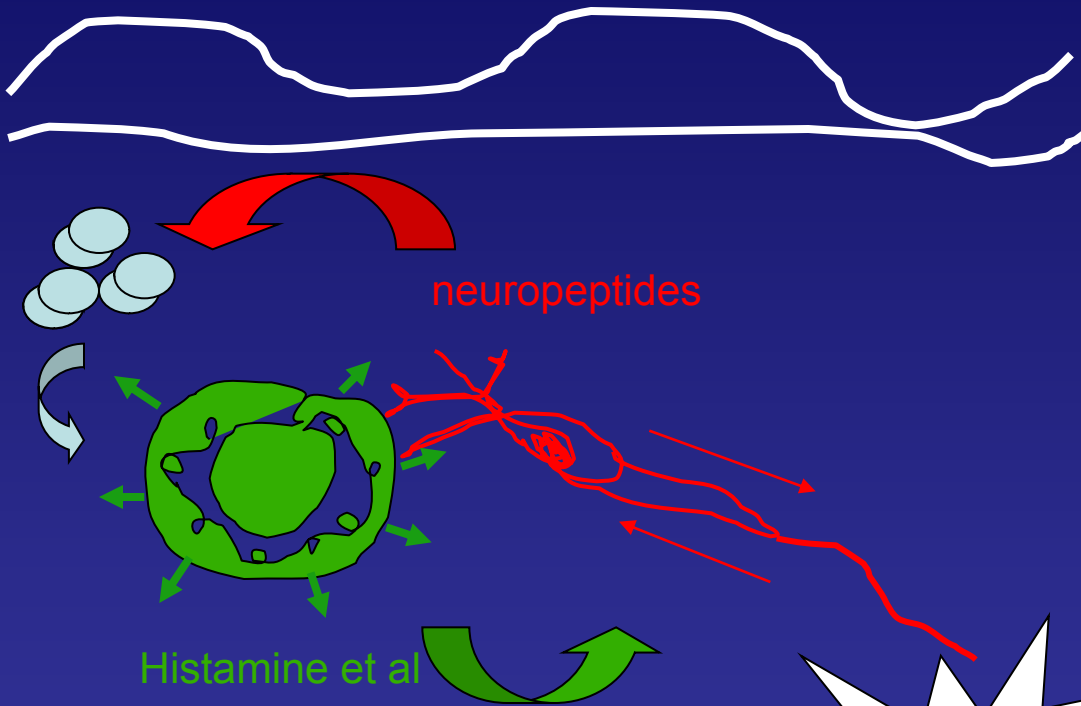
Primary Renal Condition

SLE
Vasculitis
Myeloma
APCKD

Modified Pain Ladder

- Paracetamol
- NSAIDs
 - residual function
 - GI bleeding
- Opiate
 - Sensitivity varies so warn carers re accumulation – jerking, drowsy
 - Buprenorphine patch good as low dose
 - Avoid long acting preps in CKD4/5
 - Fentanyl + alfentanil better than morphine
 - Co-prescribe laxatives & anti-emetics
- Midazolam / diazepam if agitated
- Gabapentin if neuropathic
 - 100-200mg nocte or 200-300mg alt days CKD5
 - Probably better than amitriptyline, carbamazepine
- Calciphylaxis especially problematic

Itch



- Superimposed conditions
- Other eg TFT, amyloid etc

- Transplantation – cure
- Better dialysis
- Control anaemia
- Control bone disease

• Antihistamines don't work

- **Emoillents**
- Menthol / **capsaicin**

• Steroids

• **UV**

• **GLA/eve primrose**

• (Naltrexone – opiate Ag)

• Nalfurafine – uopiate Ag

• **Gabapentin**

• Ondansetron

• **Thalidamide**

Uraemia
Xerosis
Anaemia
Hyperparathyroidism (Ca, P, PTH)
B2 microglobulin

Opioid
Receptors

Restless Legs

- Clonazepam
- Dopamine Agonists eg Madopar
- Gabapentin

Nausea

1. Review diet eg regular supplements
2. Stop phosphate binders / oral iron?
3. Treat constipation
 - Metoclopramide / Domperidone
 - Gastric stasis common
 - before breakfast / meals
 - Can be good for hiccups (baclofen also)
 - Cyclizine
 - Levomepromazine (watch BP)
 - Haloperidol (also agitation, delirium)

Breathlessness

- Correct anaemia
- Correct acidosis
- Treat anxiety – midazolam/lorazepam
- Improve fluid overload – salt/water/diuretics
- Consider cardiac / respiratory disease
- Opiates – oramorph, sc forms
- Hyoscine for secretions

Depression

- SSRIs – eg citalopram, sertraline
- TCAs if resistant
- Psychological therapies
- Talking – identify fears

End of Life Medication

- Refer to Renal Palliative Care – Last Days of Life document (SERPR)
- Work together
 - GP / district nurses
 - Open line of contact
 - Family may need renal unit contact
 - Link with palliative care teams as needed

Diagnosing Dying

- Not good at this
- Crisis prone & higher rates of sudden death
- Allows futile treatments not to be pursued
- Allows transition to terminal care
- Allows focus on QOL / symptoms / spiritual / psychosocial issues
- Better outcomes for bereaved
- Families need an alternative narrative

Case 1 – Dialysis withdrawal

- Age 76, male, HD May 2006 - July 2013 (7 yrs)
- IHD/MIs, PVD, AAA, BP, COPD
- Catheter & recurrent UTIs
- 7 admissions last 6 months life – reducing QOL
- Patient requested withdrawal
- Planning with GP / family / Palliative Care (email/phone)
- DNACPR in place
- Medication plan
- District nurses & palliative CNS activated
- Access to guidelines & specialist if needed
- Died at home 7 days later (preferred place)

Case 2 – Dialysis withdrawal

- Age 75yr, male, HD April 2012 – Nov 2013 (1.5yrs)
- IHD(MI), RAS, PVD, Renal Cell Ca
- 4 admissions
- 7 reviews with family – 2 man transport, wheelchair, leg pain, frail, initial improvement in symptoms then progressive decline + PVD symptoms + long recovery time post HD
- Reluctance to engage in ACP
- Final admission – pain+, amputation, last HD 14 days prior to death

Stopping Dialysis – discussion points

- What will happen to me?
- How long have I got?
 - 12 days average
 - HD vs PD
 - May feel better initially then coma
 - Fluid overload – opiates/midazolam vs UF
 - Renal Unit attachment
 - Access to specialist advice
 - Mode of death – coma vs K

Case 3 – Conservative Care

- Age 77 yrs, female, 1st review 2002 – 2012 (10yrs, 2yrs from CKD5)
- DM, COPD, BP, gout
- 2 admissions last year of life
- Daughter RRT due to DN
- Sustained wish for conservative care
- Attended CC clinic – tired (IV iron,ESA), cramp (quinine), intermittent confusion, eGFR 7
- 16 remote contacts with renal unit & family / GP – advice re fluid, agitation, nausea, pain (alfentanil+midazolam+levomepromazine SC)
- Family support
- Died at home (preferred place) from ESRF

Conservative Care – discussion points

- Crisis points can trigger admission
- Crisis points can trigger dialysis
- More likely to have residual renal function
- May die from an unrelated cause
- Often low symptom burden until late
- Can decline rapidly – family/GP need access to help when needed
- May survive a long time

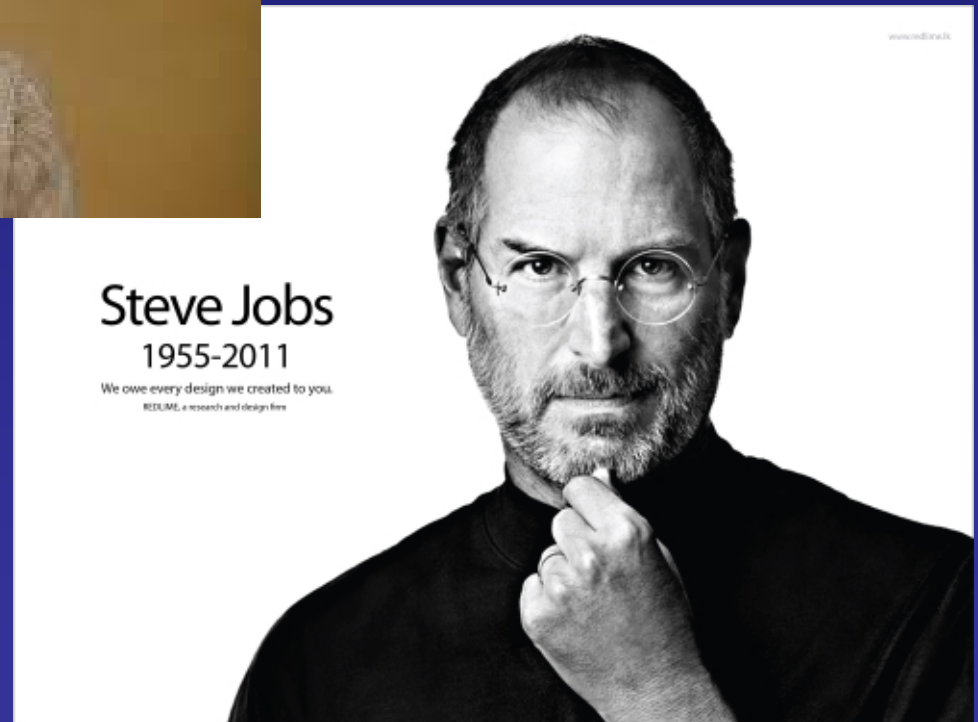
Case 4 – Early death on dialysis

- Age 77yrs, RRT April 2013 – Aug 2013 (4mo)
- Cirrhosis, IHD (MI+LVF), COPD
- Keen for HD – started with AVF
- 7 admissions post HD start – chest sepsis, IHD, c.diff, inguinal hernia
- Wished to continue HD + CPR 2 weeks prior to death
- GP + family decided to stop HD – died at home 5 days later

Why is ACP so hard?

- Failure to recognise decline on part of doctor or patient – “surprise question”
- Communication is difficult
- Denial is a coping strategy
- Easier to offer intervention
- Faster to offer intervention

Death remains an unpopular choice



Summary

- ESRF population is becoming older with higher co-morbidity
- Low awareness of poor prognosis in ESRF
- High symptom burden - similar to cancer
- Illness trajectory is variable - timely ACP is important – ‘plan for uncertainty’
- Unplanned admissions are common – hospital death or dialysis
- Renal adjustment for drugs
- Good communication between primary & secondary care is essential

Thank You!

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