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PCCS CKD QI Programme

Preparing for end stage renal disease and dialysis

Dr Katie Vinen

Consultant Nephrologist, King's College Hospital, London and Clinical Vice President, United Kingdom Kidney Association

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Dr Katie Vinen Disclosures



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- No declarations of interest



Preparing for end stage renal disease and dialysis



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- **Discuss how ESRF is classified**
- Discuss when may be appropriate to initiate dialysis and the types available
- Consider complications and risks associated with ESRF including risk of sudden cardiac death
- Early identification of end of life care and palliative care management for patients with ESRF
- Explore education strategies and SDM in ESRF
- Share resources available for patients in ESRF and on dialysis

- I have tried to give you a lot of information about how the patient may be experiencing the situation in order to help you support them



How is end stage renal disease classified?



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- Classified by glomerular filtration rate into 5 stages
- Patients with eGFR < 15 ml/min are in CKD 5
- Patients receive pre-emptive transplants with GFR between about 8 – 15 ml/min
- Patients generally start planned dialysis with GFR between 7-10 ml/min
- Patients who choose to forgo dialysis will generally die from kidney failure alone at GFR of less than 5 ml/min. Others will die at a higher GFR due to other co-morbidities
- Kidney teams often describe severity of kidney disease as “% of function remaining” as GFR very roughly equates to this

Stage of CKD	eGFR result	What it means
Stage 1	90 or higher	- Mild kidney damage - Kidneys work as well as normal
Stage 2	60-89	- Mild kidney damage - Kidneys still work well
Stage 3a	45-59	- Mild to moderate kidney damage - Kidneys don't work as well as they should
Stage 3b	30-44	- Moderate to severe damage - Kidneys don't work as well as they should
Stage 4	15-29	- Severe kidney damage - Kidneys are close to not working at all
Stage 5	less than 15	- Most severe kidney damage - Kidneys are very close to not working or have stopped working (failed)

CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate.

American Kidney Fund. Stages of kidney disease. Available from <https://www.kidneyfund.org/all-about-kidneys/stages-kidney-disease>. Accessed March 2023.



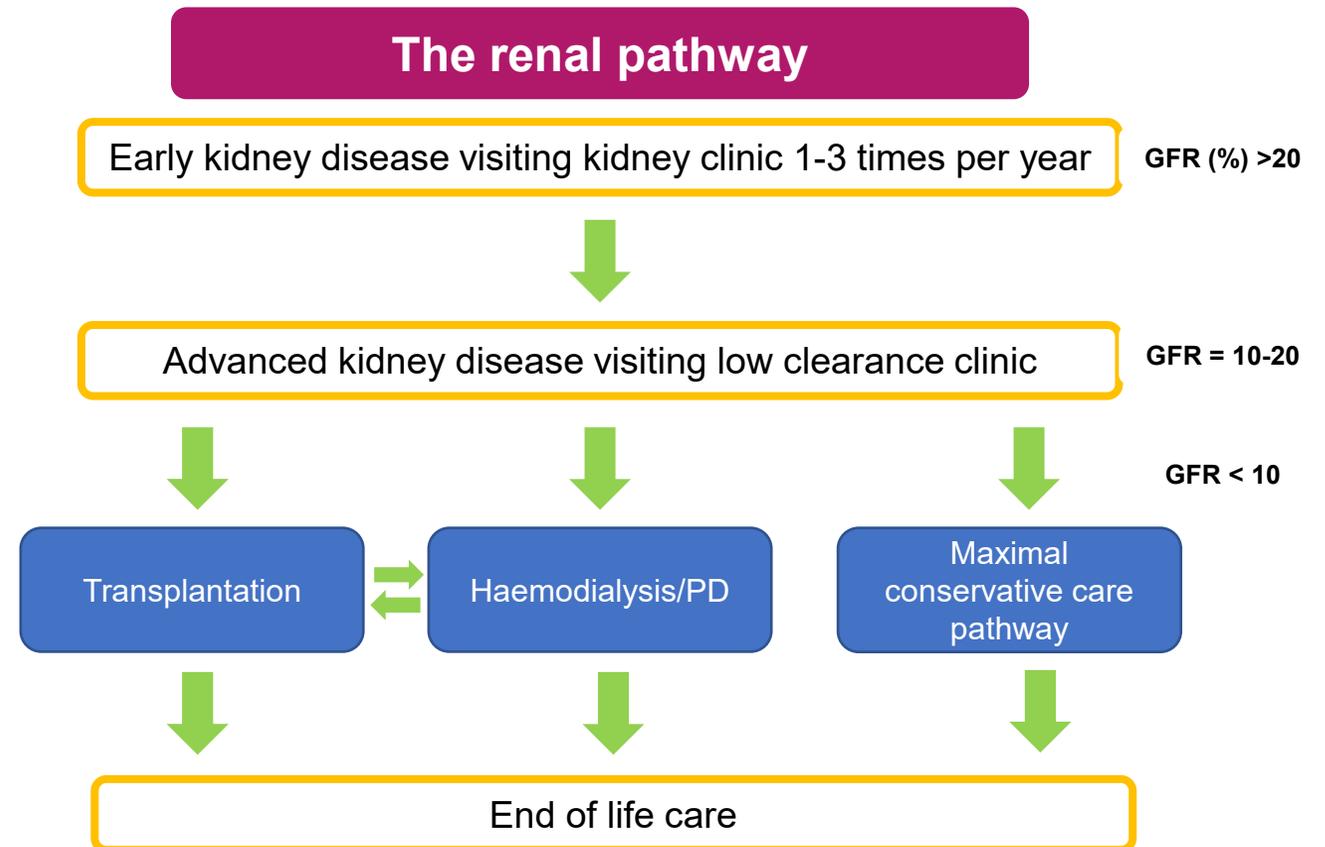
Decision making in late stage kidney disease



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- Likely to take place in an advanced kidney care or low clearance clinic (AKCC) using principles of shared decision making where possible provided by an MDT





Preparing for end stage renal disease and dialysis

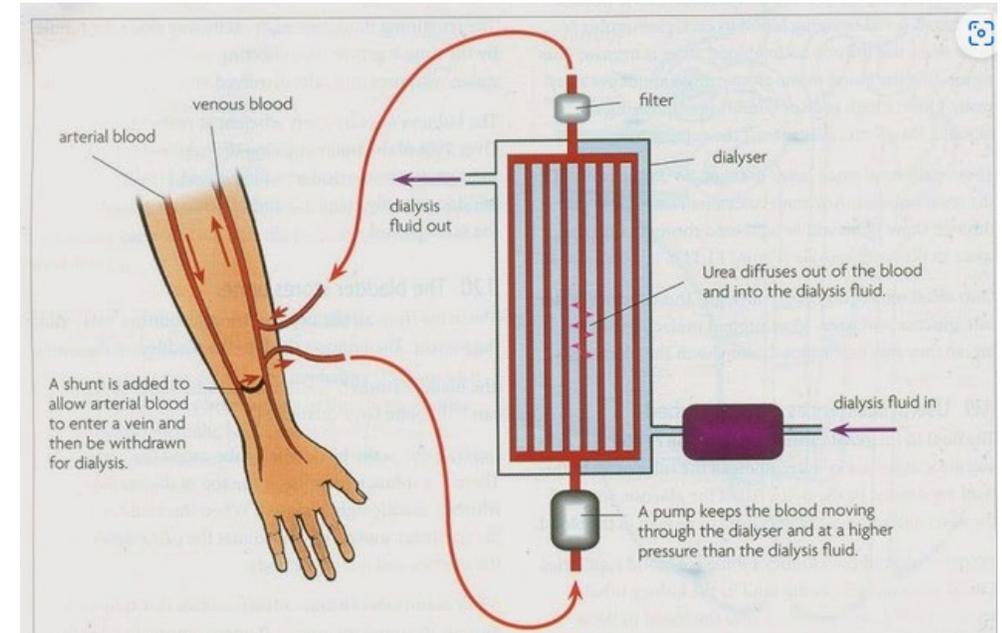


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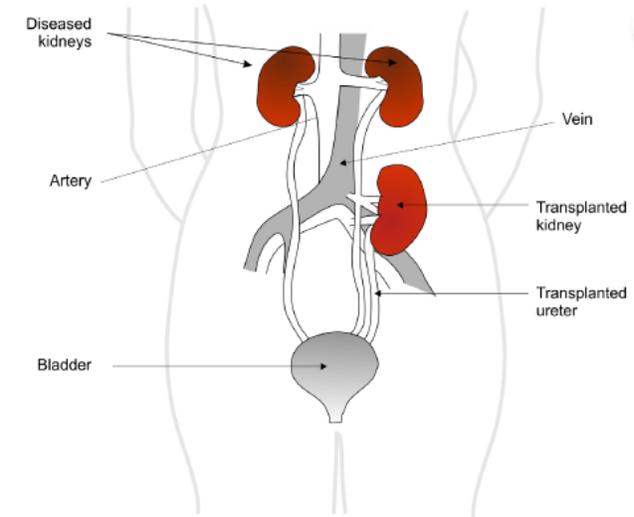
ESRF - avoiding dialysis - pre-emptive transplantation



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- Patients < 75 yrs (not absolute)
- Fit enough for significant anaesthetic
 - CVD
 - Respiratory disease
 - PVD
- No contraindications to life long immunosuppression
 - Ongoing uncontrolled infection (well controlled HIV is NOT a contraindication)
 - Ongoing malignancy or malignancy in last few years
- If possible with a live donor but still possible without
 - Live donors do NOT need to be
 - Related
 - The same gender or race
 - The same blood group



CVD, cardiovascular disease; ESRF, end-stage renal failure; HIV, human immunodeficiency virus; PVD, peripheral vascular disease.

Queensland Government. The kidney transplant operation. Available from <https://www.qld.gov.au/health/services/specialists/kidney-transplant/the-kidney-transplant-operation>. Accessed March 2023.



Indications for dialysis initiation - mixture of biochemical and symptom driven initiation



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- Uraemic symptoms (nausea, pruritis, malaise) - generally urea >35-40 mmols/litre
- Intractable persistent hyperkalaemia (K⁺ >6.5 mmols/litre consistently)
- Therapy resistant fluid overload
- Significant acidosis (bicarbonate ≤15 mmols/litre)
- Malnutrition
- Asymptomatic CKD 5 where GFR ≤7 ml/min
- Considerable variation in level of symptoms for same blood values
- Some patients “perceive” themselves to have no symptoms even at a GFR of 7 ml/min

- Mostly gentle downward trajectory - an art not a science
- Planned and ready
- Complications addressed
 - Anaemia
 - Electrolyte imbalances
 - Bone disease
 - Fluid overload
- Physically ready (fistula created, hep B vaccinations completed); active on transplant list where possible
- Psychologically ready (good education, practicalities - after major trip, after studies complete) - many patient in denial or late presenters
- Co-morbidities addressed - frailty needs assessed and addressed with realistic understanding of aims of dialysis and ideally some understanding of prognostic implications
- Differentiate renal and non-renal symptoms especially in elderly/multi-co-morbidity where benefits of dialysis more marginal
- Only renal symptoms likely to be helped by RRT



Excellent dialysis preparation... ...is multi-disciplinary



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Excellent dialysis preparation... complex, supportive, positive and ...is honest



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‘The doctors, the
nurses, they lied to
me... they said it
would be easy and
dialysis would simply
fit around my life’





Haemodialysis - “blood dialysis” - “machine that cleans your blood”



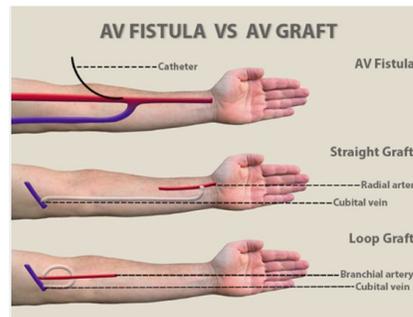
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Lots of patients/families have relatively little understanding of the complexity and time required for dialysis

Haemodialysis

Haemodialysis can be a good treatment but it is a big commitment



- Keeps you alive
- Reduces your symptoms (but may take time to recover)
- Bridges to transplant
- High level of support
- Compartmentalises treatment (in time and space)
- In centre (vast majority) - attracts majority of patients
- Semi-rigid schedules (transport 6am – 11pm)
- Fistula (needles) v less optimal dialysis line (no needles)
- Holiday travel limited
- Reduced treatment free time
- Disrupted work or study time
- Strict diet and fluids constraints
- Life extending but shorter life expectancy than peers
- Home (enough space/cleanliness, activated patients, dextrous, practical, good vision, good cognition)
- Greater flex, less travel to HD unit
- Extra sessions possible and may improve health

HD, haemodialysis.

*London Kidney Network.

Vein & Endovascular Medical Care. AV Fistula vs. AV Graft. Available from <https://www.astraveinvascular.com/av-fistula-vs-av-graft/>. Accessed March 2023.



Peritoneal dialysis, tummy dialysis - fluid being run in and out of tummy cavity to take away toxins



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Dialysis can be a good treatment but it is a big commitment *

peritoneal dialysis:

The infographic consists of six colored boxes arranged in a 2x3 grid. The top row has a yellow box (home), a green box (time), and an orange box (frequency). The bottom row has a purple box (long-term), a cyan box (operation), and a pink box (diagram). Each box contains icons and text describing a key aspect of peritoneal dialysis.

- PD can be done at home** (Yellow box)
- It can take up to 10 hours at night or 4 x a day** (Green box)
- Peritoneal dialysis is 7 day a week** (Orange box)
- Dialysis is a long term treatment** (Purple box)
- It requires an operation to insert the dialysis through the tummy** (Cyan box)
- Diagram of peritoneal dialysis** (Pink box)

Diagram of peritoneal dialysis: Shows a dialysate fluid reservoir, a catheter connected to the tummy, and waste fluid collection.

Lots of patients/families have relatively little understanding of the complexity and time required for dialysis

- Practically - mostly self-delivered
- Small abdominal operation
- 5-7 days/week commitment
- Needs space at home
- Not possible after major abdominal surgery (breached peritoneum)
- Patient delivered with training and remote support (motivation, dexterity, cognition, cleanliness, vision)
- Greater flex with work and travel
- Greater flex with food and fluid
- Greater level of control

Dialysis



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Lots of patients/families have relatively little understanding of the complexity and time required for dialysis

Haemodialysis

Haemodialysis can be a good treatment but it is a big commitment

<p>312 Journeys to and from dialysis per year</p>	<p>3-4.5 Average hours per session</p>	<p>3 Treatment sessions per week</p>
<p>Some people take several hours to recover after haemodialysis</p>	<p>Haemodialysis is a long term treatment</p>	<p>Haemodialysis involves a small operation</p>

Symptoms dialysis probably will help with

Fluid overload - feeling of breathlessness due to too much fluid

Toxic build up - nausea and vomiting

Toxic build up - itchy skin

peritoneal dialysis:

Dialysis can be a good treatment but it is a big commitment

<p>PD can be done at home</p>	<p>It can take up to 10 hours at night or 4 x a day</p>	<p>Peritoneal dialysis is 7 day a week</p>
<p>Dialysis is a long term treatment</p>	<p>It requires an operation to insert the dialysis through the tummy</p>	<p>Diagram of peritoneal dialysis</p>

*

PD, peritoneal dialysis.
*London Kidney Network.

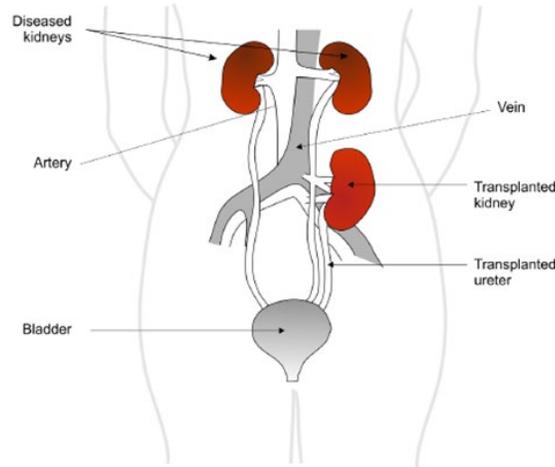


Transplantation



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- Work up
- Heart, lung, blood vessels for major surgery
- Cancer and viral screening for immunosuppression
- Operation
- Unpredictable timing - uncertainty
- 1 week hospital stay
- 3 month basic recovery
- Post transplant
- Life long immunosuppression
- Concordance vital
- Degree of uncertainty - rejection
- Uncertain transplant longevity



One size does not fit all - priorities for different patients at different stages



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- Three phases
- Aggressive - life prolonging, symptom controlling, target driven - transplant seeking - often young patients
- Stable - life prolonging, symptom relieving,
- Later/supportive - quality of life orientated, symptom orientated, may lead to RRT discontinuation - often older patients
- Symptoms may be caused by
 - Renal disease
 - Treatment
 - Other conditions



RRT, renal replacement therapy.

1. Freepik. <https://www.freepik.com/>. Accessed March 2023; 2. Shutterstock. <https://www.shutterstock.com/>. Accessed March 2023.



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- Discuss how ESRF is classified
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- **Explore education strategies and SDM in ESRF - examples throughout talk**
- Share resources available for patients in ESRF and on dialysis

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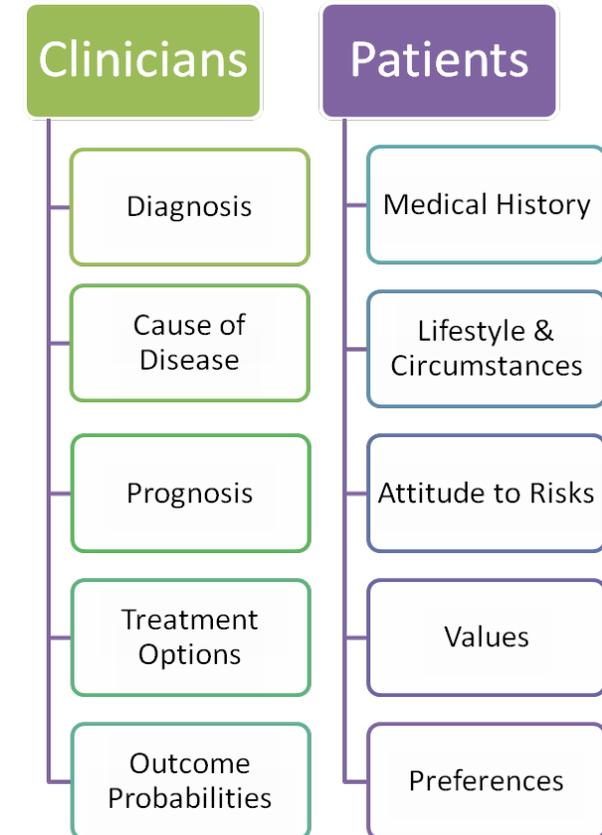
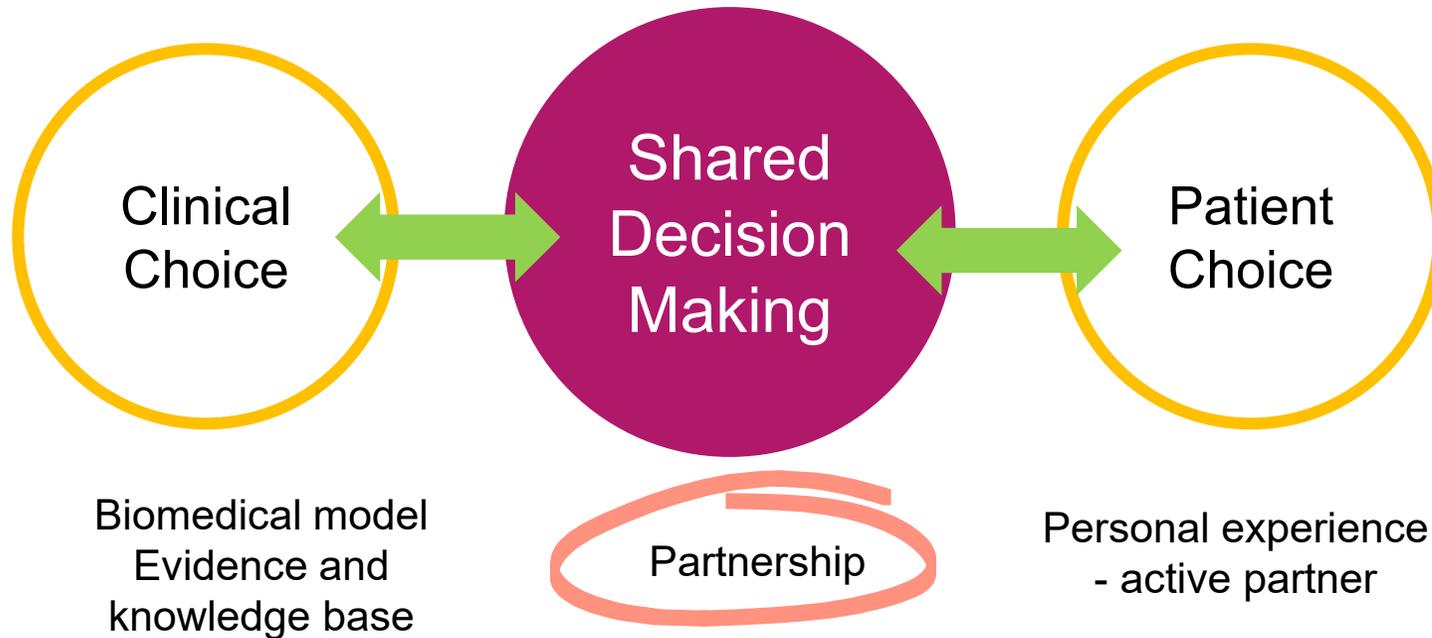


Excellent dialysis preparation... ...is a partnership



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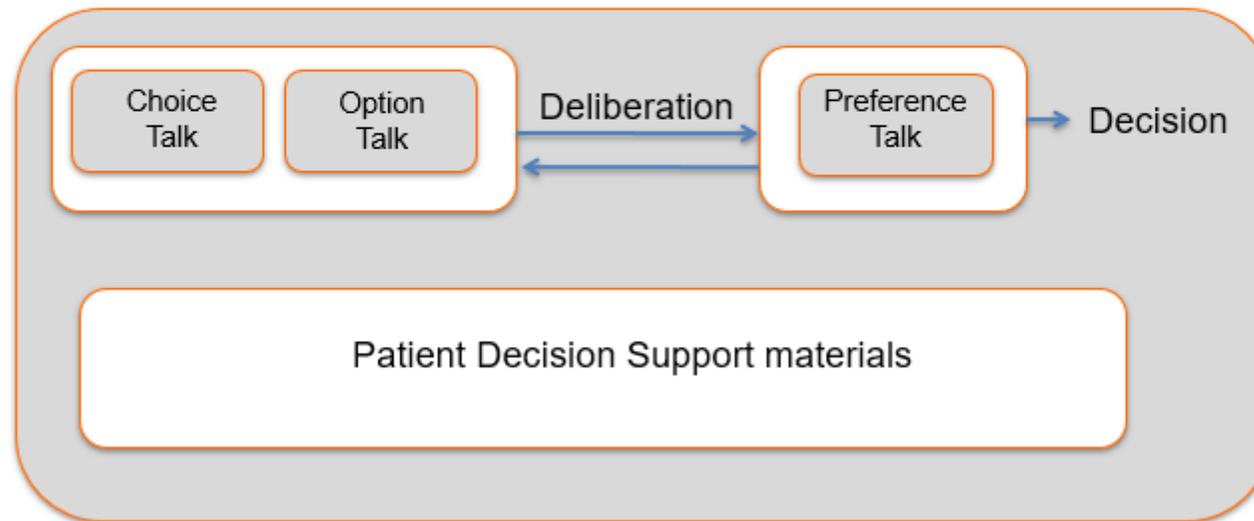
Shared decision-making



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Core Skills in SDM





Making a dialysis fistula



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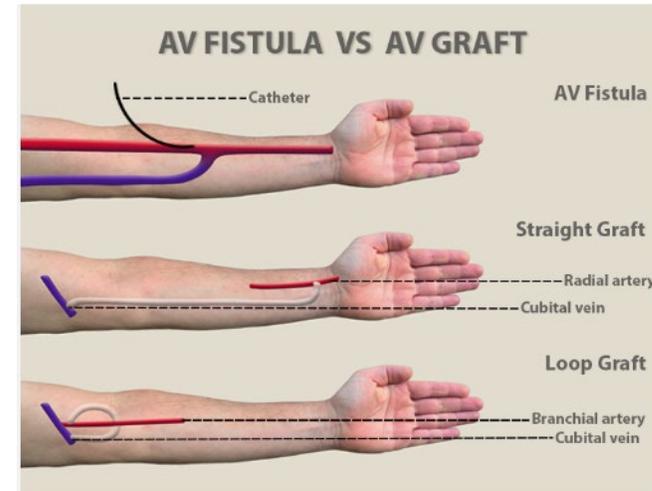
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Clinician centred Information:

- Join of artery and vein
- Radiocephalic/brachiocephalic
- Local or general anaesthetic
- Alternatives, including lines

Patient-centred information:

- What it will look like
- How much it may hurt
- How it may affect use of the arm
- What clothes can be worn
- How likely it is to fail





Key Components of SDM



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- Starts early in the treatment pathway
- Reliable, balanced, evidence-based information outlining treatment options, outcomes and uncertainties
- Decision support counselling with clinician or health coach to clarify options and preferences
- System for recording, communicating and implementing patient's preferences
- Honest
- Individualised
- Patient-centred

- More important in kidney care because:
 - Preference sensitive choices HD v PD
 - Complexity of available and non-available choices e.g. transplant
 - Uncertain evidence - RRT v MCM
 - Significant impact of ESRF on wider life over long timescale
 - Improves long term relationship between patient and clinician



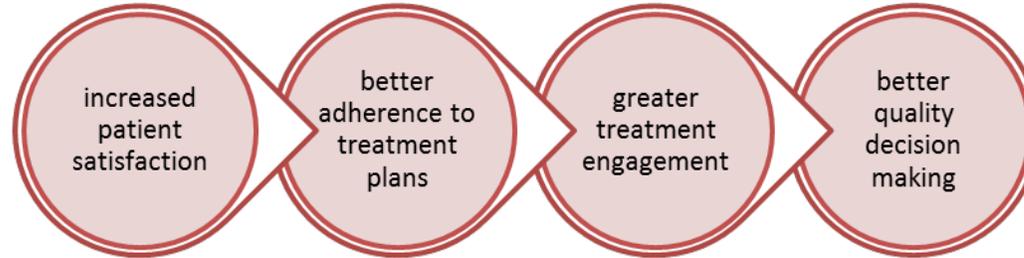


The many benefits of sharing decisions



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- Patients want it
- It improves patient knowledge
- Helps patients make healthcare choices aligned with their personal needs, values and circumstances
- Improves clinical outcomes and safety
- Helps achieve the right intervention rate and reducing unwarranted practice variation
- Reduces healthcare costs and litigation costs

POTENTIAL OBSTACLES TO SDM IN RENAL MEDICINE

- Clinicians and patients sometimes speak different languages (literally and metaphorically)
- Denial
- Uncertainty
- It's difficult for clinicians to not treat (assumption that more care = better care); difficult conversations

SDM, shared decision-making.

BHM Healthcare Solutions. Shared Decision Making Trend Ticking Upwards: Physician Prescribed Care. <https://bhmpc.com/2013/05/shared-decision-making-trend-ticking-upwards/>. Accessed March 2023.



Using dialysis decision aids - hosted on Kidney Research UK website



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	Haemodialysis (HD)		Peritoneal Dialysis (PD)	
	CHD/ HDF: Centre Haemodialysis / Haemo-diafiltration	HHD: Home Haemodialysis	CAPD: Continuous Ambulatory Peritoneal Dialysis	APD: Automated Peritoneal Dialysis
Place Of Dialysis Care	People travel to kidney centres for CHD/ HDF sessions	People have CHD sessions at home	Most people choose to have CAPD at home or work, Can be any clean place	Most people choose to have APD at home, Can be any clean place
How Dialysis Works	Attaching to a machine for 4 hours per session by the arm or leg.	Attaching to a machine for 4 hours per session by the arm or leg.	Attaching to a bag of fluid for about 45 minutes by the belly	Attaching to a machine for about 9 hours by the belly
Usual Number Of Sessions In A Week	3 times a week (day)	At least 3 times a week (day or night)	Every day	Every night
Usual Number Of Sessions In A Day	1 x 4 hour session	1 x 4 hour session	4 x 45 minute sessions	1 * 9 hour session
People Carrying Out Dialysis	Staff at the centre. Person with EKD trained for shared care.	Person with EKD trained by kidney staff.	Person with EKD trained by kidney staff.	Person with EKD trained by kidney staff.
Assisted and shared dialysis	Some people are trained to share CHD/HDF care in centres.	A carer can be trained to carry out HHD. A carer can be family, friend or health assistant (assisted HHD).	A carer can be trained to carry out CAPD. A carer can be family, friend or health assistant (assisted CAPD).	A carer can be trained to carry out APD. A carer can be family, friend or health assistant (assisted APD).

1. List the activities you do now and want to keep doing when you are on dialysis

Socialising (e.g. with friends and/or family)

Hobbies (e.g. gardening, fishing, music, knitting)

Leisure (e.g. walking, cycling, swimming, sport)

Holidays, Trips Away (e.g. locally, abroad)

Local travel (e.g. public transport, driving)

Household (e.g. cooking, washing up, housework)

Looking after others (e.g. caring for family, pets)

Relaxing (e.g. sleeping, watching TV, religion)

Self-care (e.g. toileting, bathing, dressing, hair)

Study (e.g. evening classes, writing, reading)

Work (e.g. job paid, voluntary)



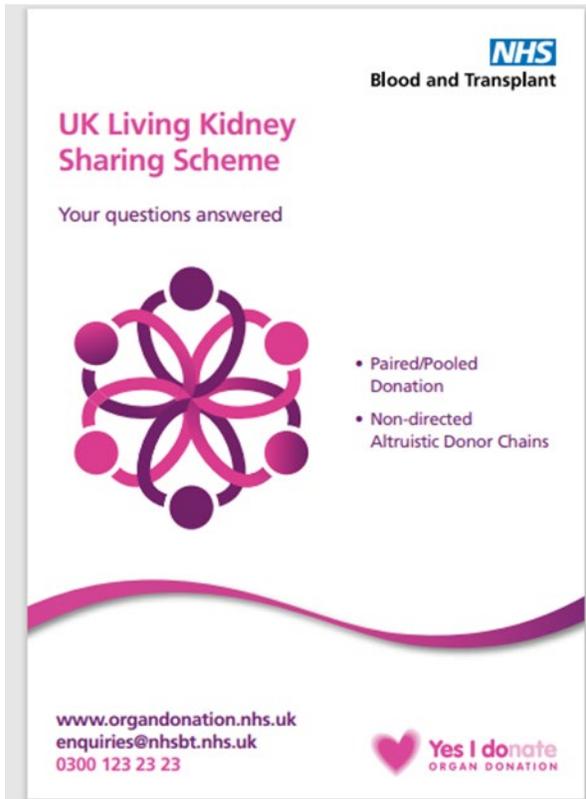
Support materials for transplantation



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Patient information leaflet



Peer support leaflet



PHONE BUDDY SCHEME

The scheme supports Black African Caribbean people living with Chronic Kidney Disease (CKD) by matching them with living donors and living donor recipients to talk about living kidney donation.



Excellent dialysis preparation... ...utilises the power of peer interventions



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'They will give you the truth but you know that is the truth because they have been through it, more than someone who has read through a book... for someone that has actually been through it and felt the pain, the grief and the happy times and the bad, you know all of it, they know because they have been there.'

'I have learnt more from the patients than I have the medical staff to be honest.'

'I didn't know what dialysis was or what it looked like but when I saw the machine, I saw someone else having it done and I thought it don't look too bad.'

'I feel like I am just repeating a cycle... I feel so worthless... she gave me hope, she gave me the confidence that I needed.'

'There was so much information... she helped make sense of it and explained a lot of it.'

'To me, the patients know more because they are on it, I am not saying they know how to do it, or what it exactly does but they know the pain part of it, like all the rest of it, all of the important bits to me, the doctors know all of the professional bits, if that makes any sense.'



Are patients satisfied with current SDM?

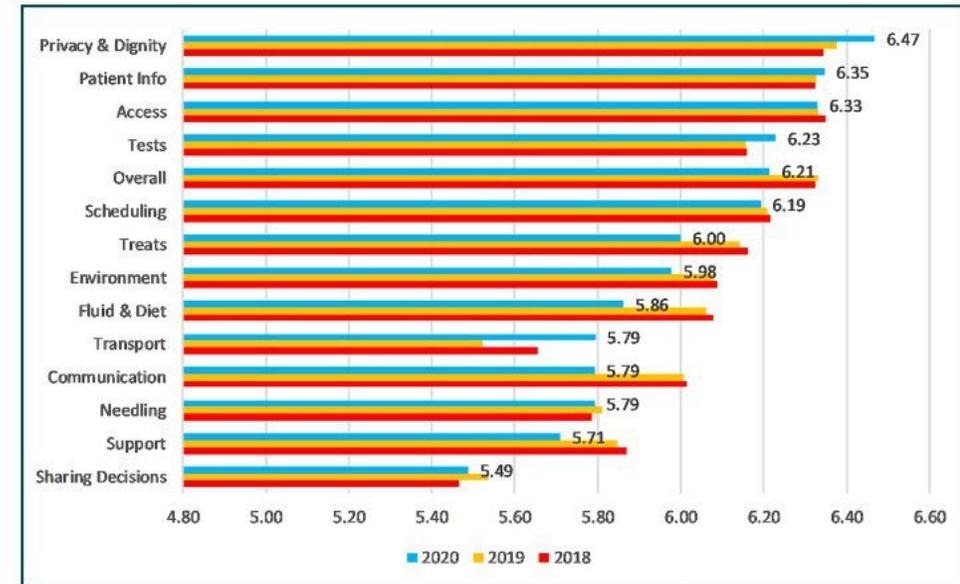
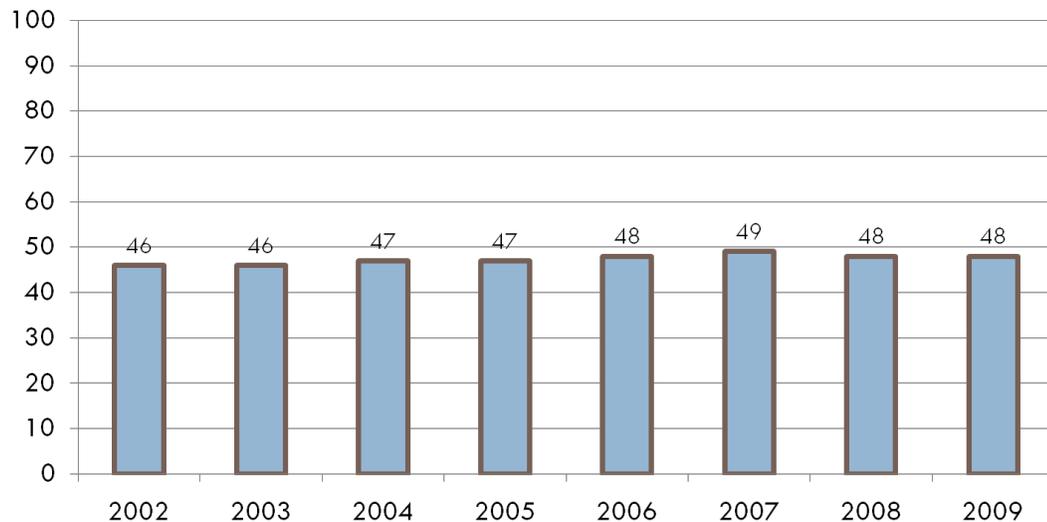


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What proportion of patients want more involvement in treatment decisions?
Source: NHS inpatient surveys¹

Patient Reported Experience of Kidney Care in the UK 2020
KCUK & RA²



Shared Decision Making – still room for improvement, but how?

KCUK, Kidney Care UK; NHS, National Health Service; SDM, shared decision-making.

1. NHS inpatient surveys; 2. Kidney Care UK. 2020 Kidney PREM results. Available from <https://www.kidneycareuk.org/news-and-campaigns/prem/>. Accessed March 2023.



Shared decision making and transplantation



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- Risks and benefits
- Option of live donor and possible benefits
- Option to transplant pre-emptively
- Realistic need to re-transplant
- BMI optimisation

- How long will I have to wait on the transplant list?
- Can I go on holiday whilst on list?
- How might I ask someone to be my live donor?
- How long will I be in hospital for?
- How big will my scar be?
- When can I go back to work?
- How can I get hold of the team urgently if I run out of tablets?
- How long will my kidney last?



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Complications and risks associated with ESRF including risk of sudden cardiac death



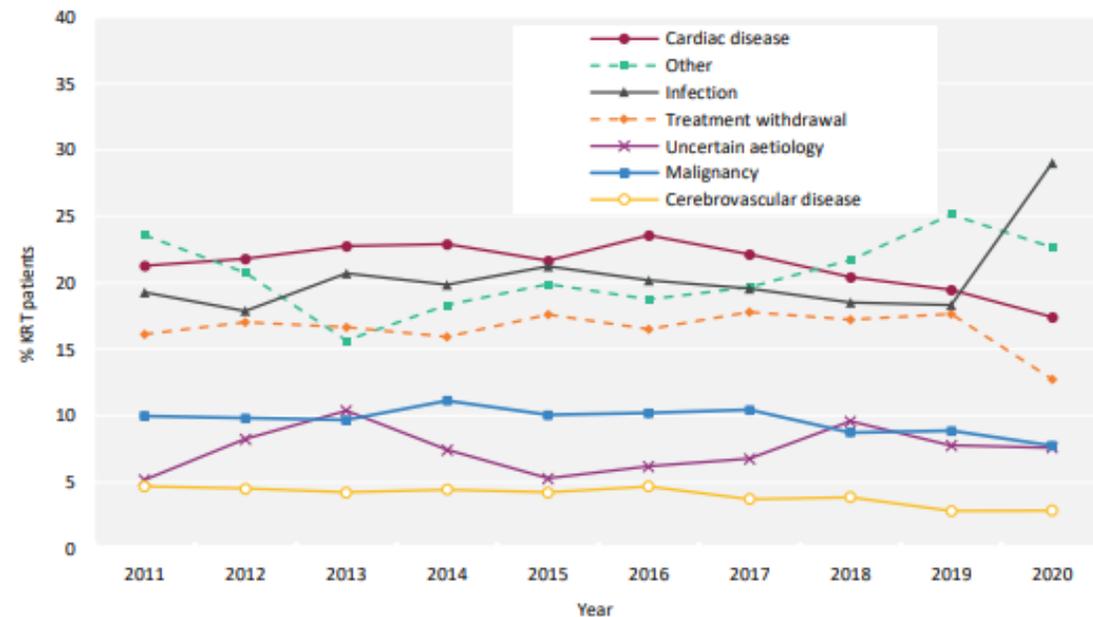
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- CVS events
- Vascular events
- Infection
- Malignancy
- Access failure

- Treatment withdrawal

Figure 3.16 Cause of death between 2011 and 2020 for adult patients prevalent to KRT at the beginning of the year

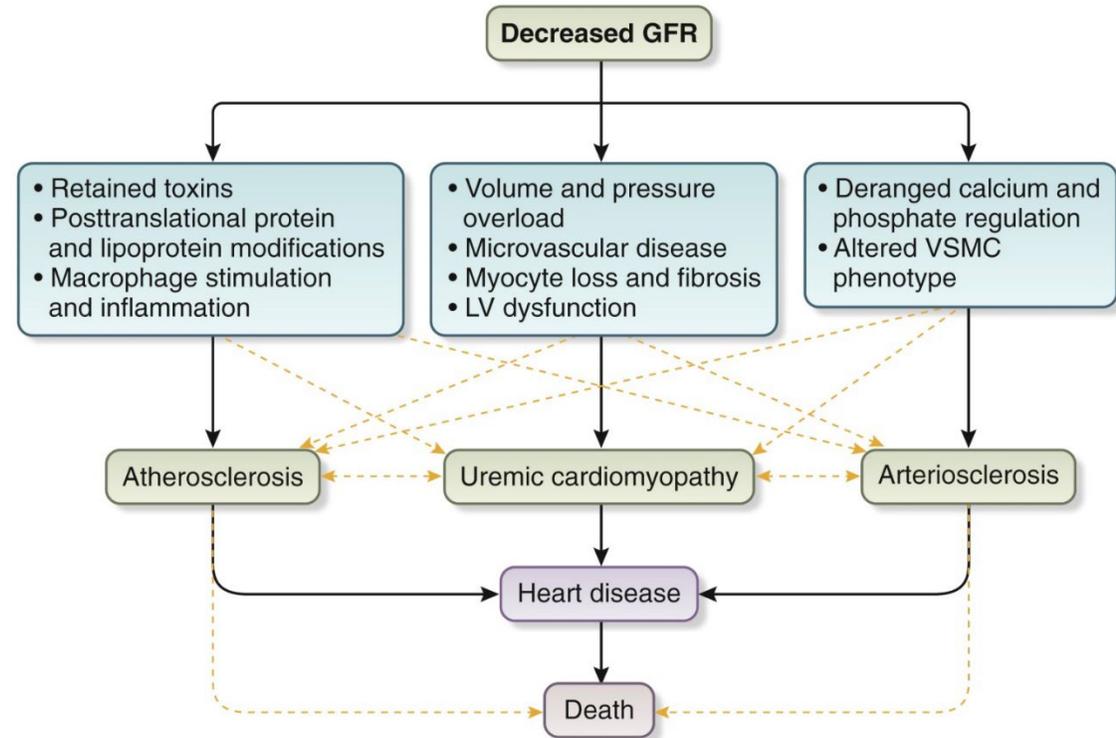
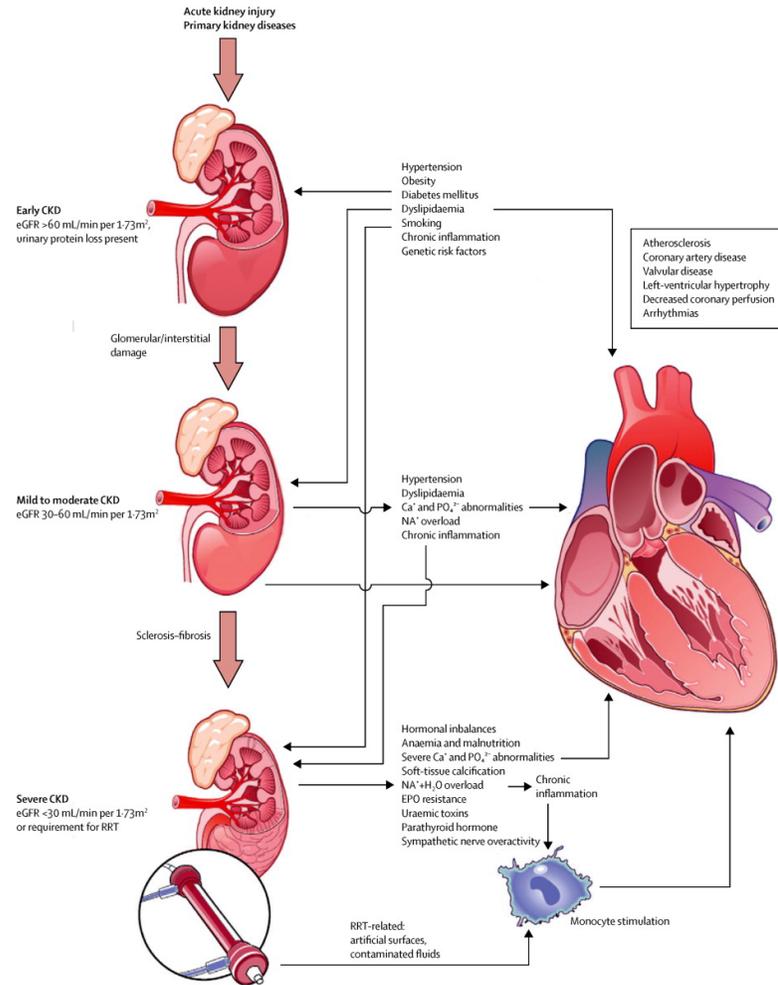


CVS, cardiovascular; ESRF, end-stage renal failure.

UKKA. 24th Annual report: Chapter 3: Adults on kidney replacement therapy (KRT) in the UK at the end of 2020. Available from https://ukkidney.org/sites/renal.org/files/24th_UKRR_ANNUAL_REPORT_PREV_Ch3_0.pdf. Accessed March 2023.



CVS effects of CKD



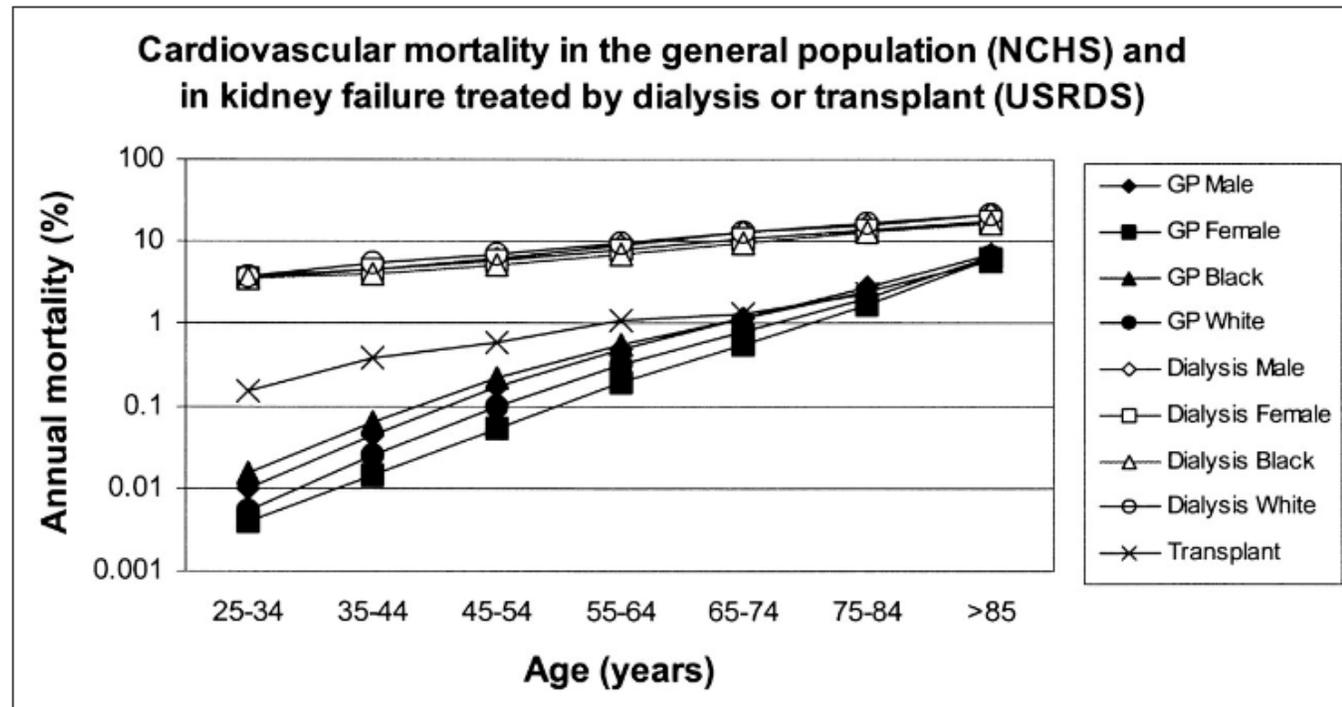


CV mortality in the general population and in kidney failure treated by dialysis or transplant



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‘The doctors, the nurses, they lied to me... they said it would be easy and dialysis would simply fit around my life’





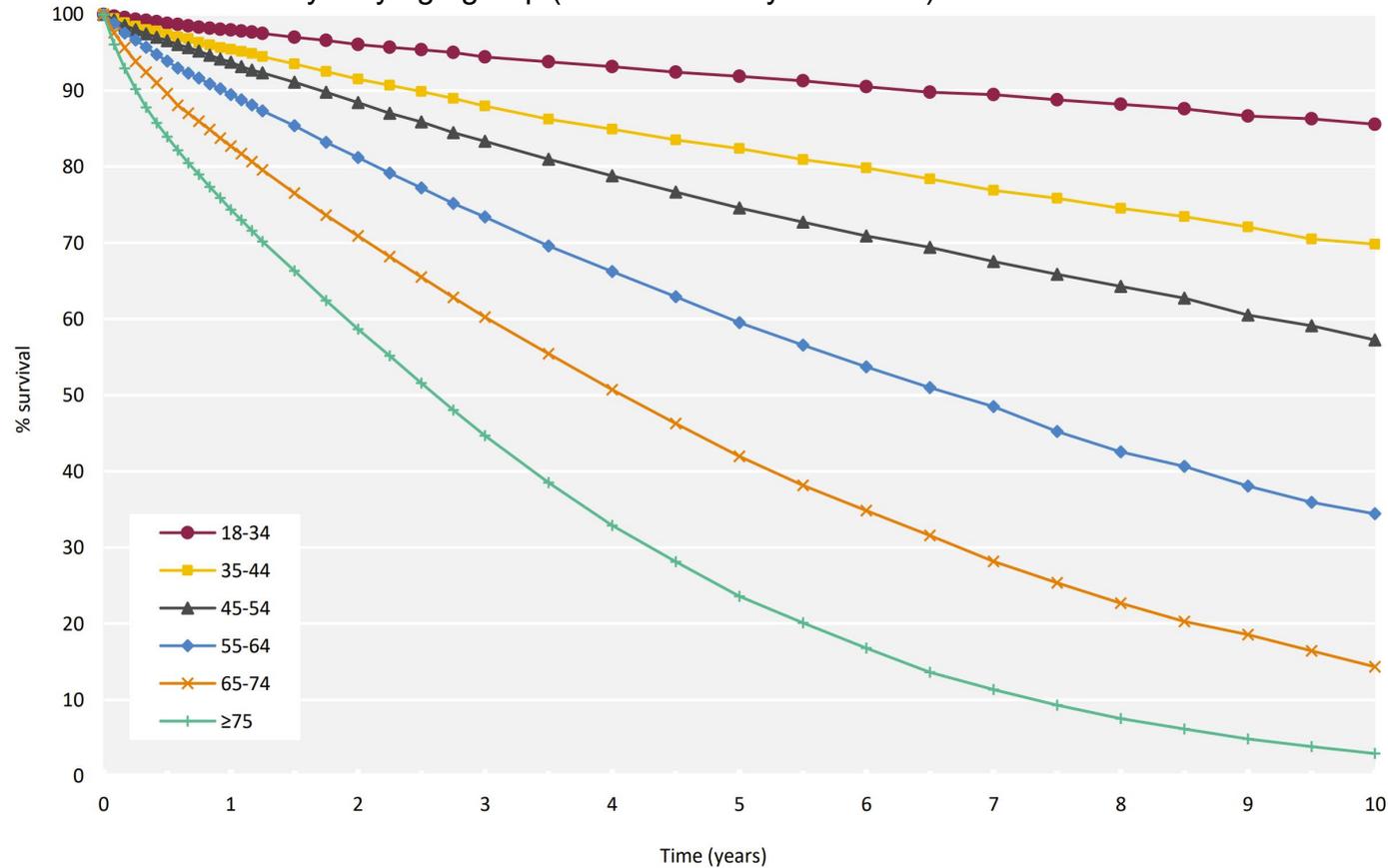
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Figure 2.21 Survival (unadjusted) of incident adult KRT patients from day 0 by age group (2010-2019 10 year cohort)





Where possible transplantation is the best option^{1,2}



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Figure 3.6 Age profile of adult patients prevalent to KRT on 31/12/2020 by KRT modality



HD, haemodialysis; KRT, kidney replacement therapy; PD, peritoneal dialysis; Tx, transplant.

1. BBC News. Covid: Third time lucky for kidney transplant siblings. Available from <https://www.bbc.co.uk/news/uk-wales-55641118>. Accessed March 2023; 2. UKKA. 24th Annual Report: Chapter 3: Adults on kidney replacement therapy (KRT) in the UK at the end of 2020. Available from https://ukkidney.org/sites/renal.org/files/24th_UKRR_ANNUAL_REPORT_PREV_Ch3_0.pdf. Accessed March 2023.



Background^{1,2}



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Patients on RRT by age - an older population with changing needs

Figure 2.4 Prevalence rates for adult patients on RRT on 31/12/2018 by age group and sex

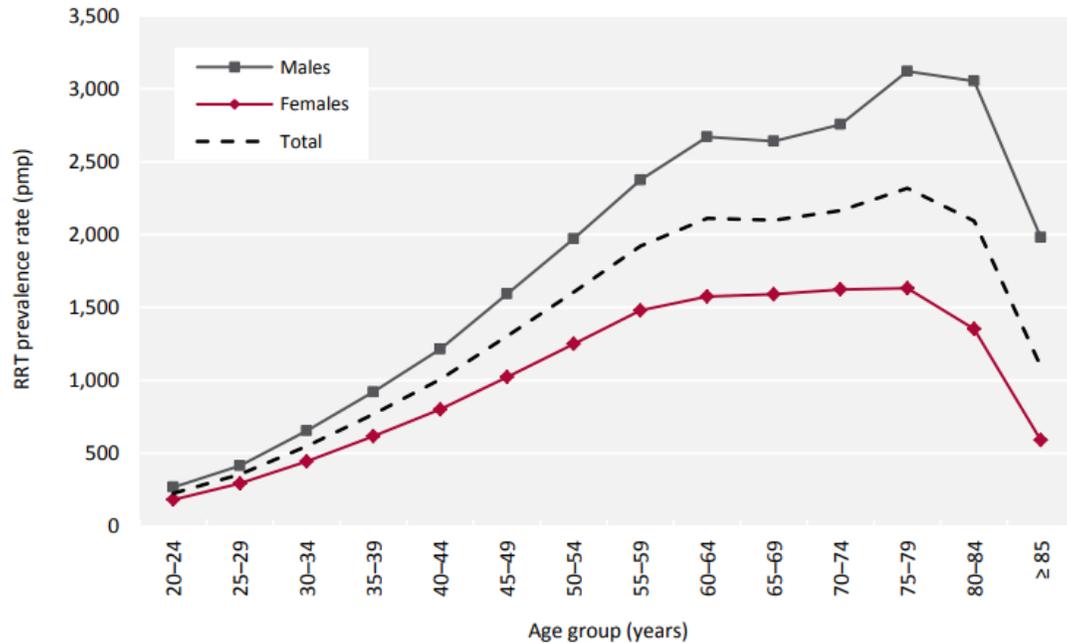
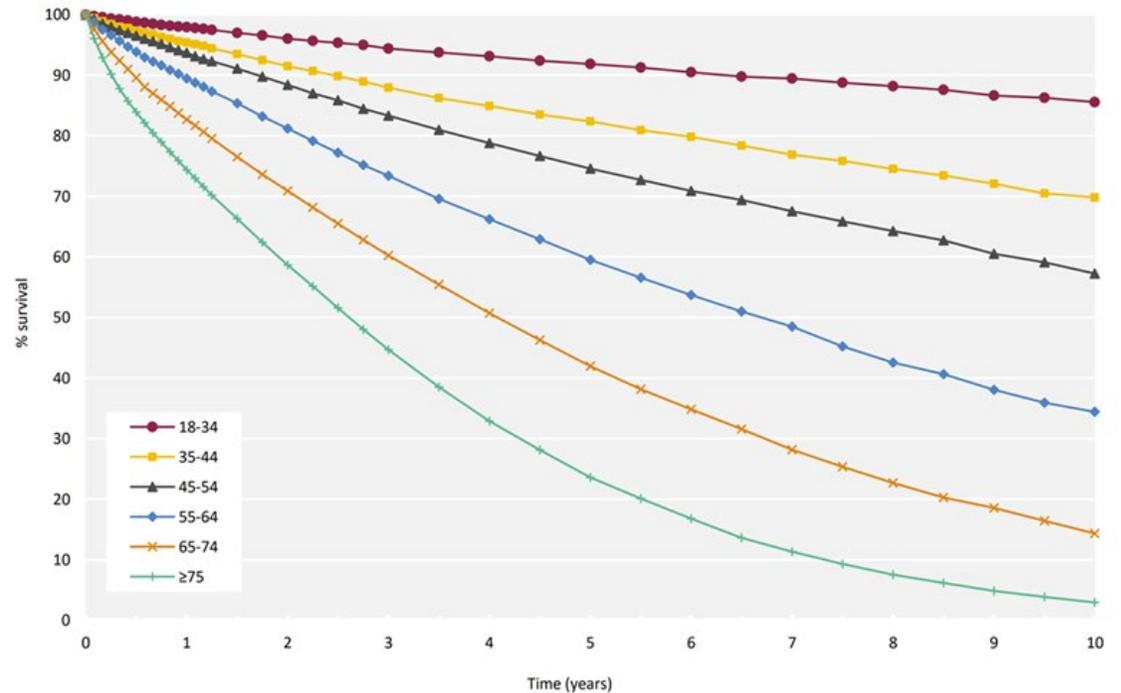


Figure 2.21 Survival (unadjusted) of incident adult KRT patients from day 0 by age group (2010-2019 10 year cohort)



KRT, kidney replacement therapy; RRT, renal replacement therapy.

1. UKKA. 22nd Annual Report: Chapter 2: Adults on renal replacement therapy (RRT) in the UK at the end of 2018. Available from

https://ukkidney.org/sites/renal.org/files/22nd_UKRR_ANNUAL_REPORT_Ch2.pdf. Accessed March 2023; 2. UKKA. 24th Annual Report: Chapter 2: Adults starting kidney replacement therapy (KRT) for end-stage kidney disease (ESKD) in the UK in 2020. Available from https://ukkidney.org/sites/renal.org/files/24th_UKRR_ANNUAL_REPORT_INC_Ch2_0.pdf. Accessed March 2023.



Background^{1,2}

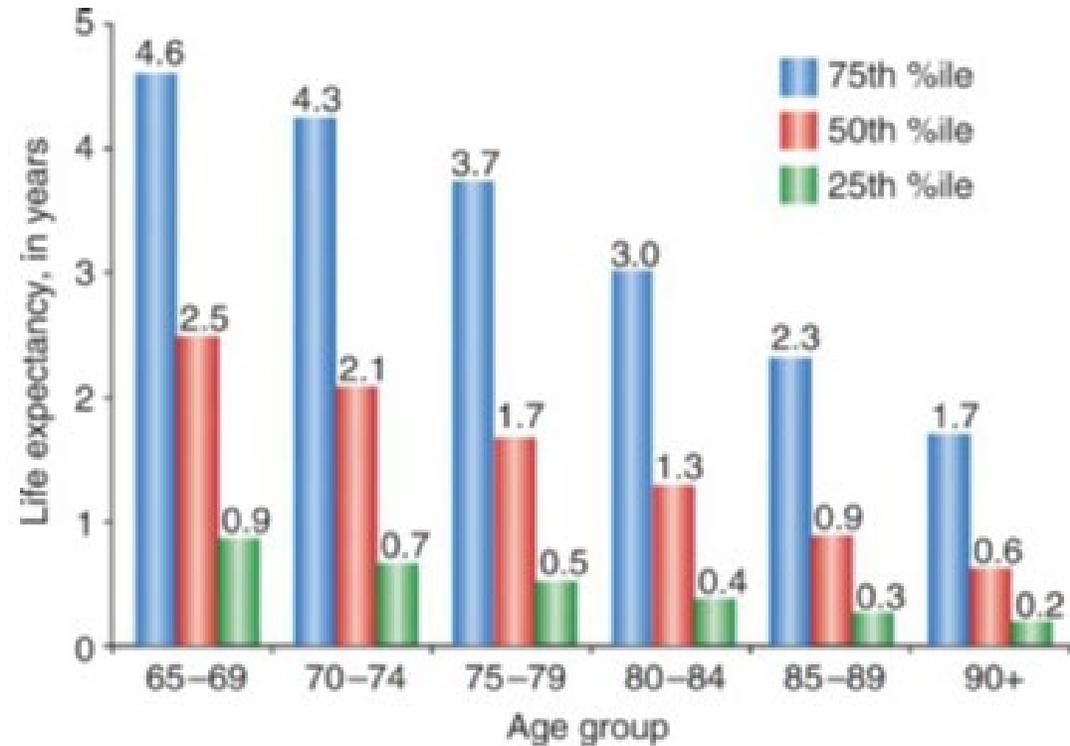
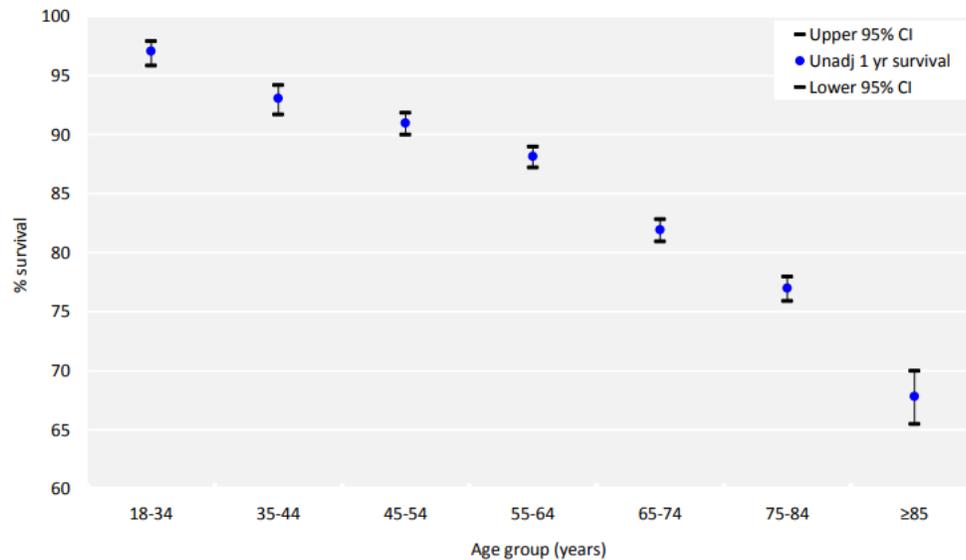


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Survival on dialysis by age

Figure 2.12 1 year survival (unadjusted) of adult patients prevalent to dialysis on 31/12/2017 by age group



CI, confidence interval.

1. UKKA. 22nd Annual Report: Chapter 2: Adults on renal replacement therapy (RRT) in the UK at the end of 2018. Available from

https://ukkidney.org/sites/renal.org/files/22nd_UKRR_ANNUAL_REPORT_Ch2.pdf. Accessed March 2023; 2. Tamura MK, et al. Kidney International 2012;82:261-269.

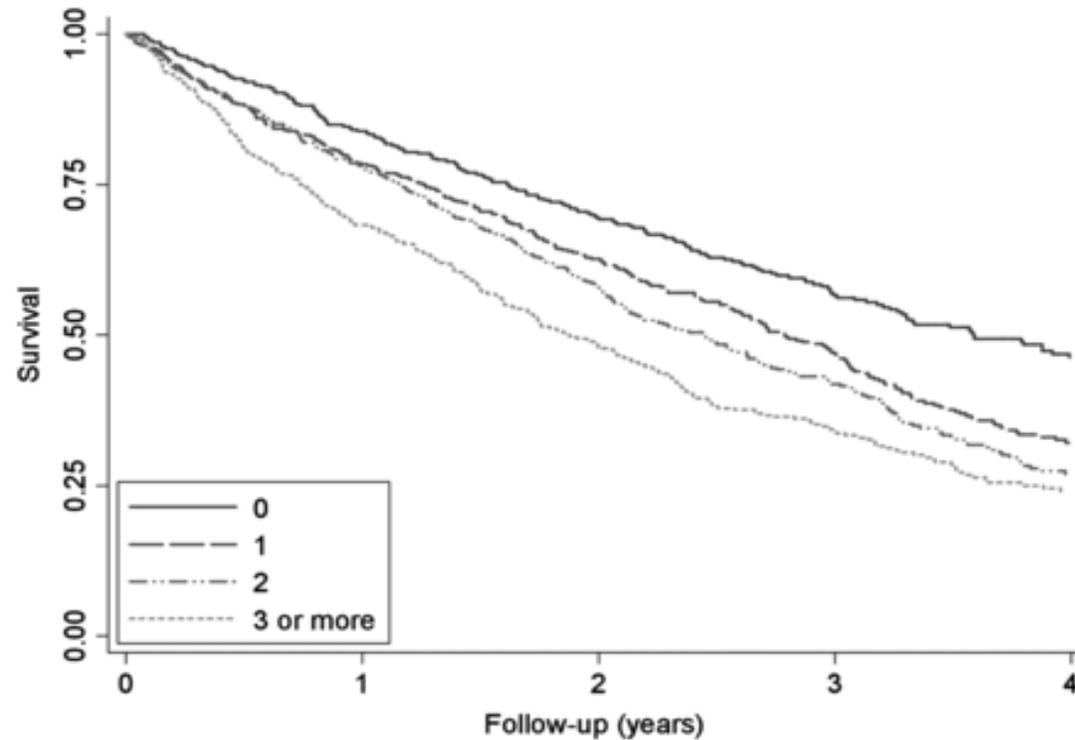


Background



Survival according to number of co-morbidities

Fig. 2. Survival of patients aged ≥ 75 years initiating dialysis in Australasia between January 2002 and December 2005.





Conservative Care - an enabling pathway that allows maximum freedom



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- Choice after honest assessment - SDM where possible - emphasise dialysis slots ARE available for those who wish to try
- Optimisation of function and priorities
 - Symptom management
 - Specialised clinic referral - falls, memory, CGA
 - Correct polypharmacy
 - Allow long periods of travel abroad
- Advance Care planning
 - Treatment escalation plans, preferred place of care
- Care of wider family after loss (including cultural/spiritual needs); information for relatives/carers
- Optimising functionality through to end of life - goals of care

				
DECISION MAKING > 15% - supporting you to make your treatment choice	STABILITY 10-15% Supporting you to achieve your goals	IMPROVING SYMPTOMS < 10%	LATER AND END OF LIFE CARE < 6%	CARE FOR YOUR LOVED ONES AFTER LOSS
Assessment	Patient and family education	Patient and family education	Patient and family education	Family support
Education	Preservation of kidney function	Preservation of kidney function	Optimisation of quality of life	Memorial events
Choice	Optimisation of physical and cognitive function	Optimisation of physical and cognitive function	Symptom control	
Shared decision making	Symptom control	Symptom control	Increasing use of network of community care	
	Introduction of advance care planning	Creation of community care network	Enactment of advance care plan	
		Creation of advance care plan	Crisis plan	
		Crisis plan		



Background



Comorbidity and survival RRT vs conservative management

Fig. 2. Kaplan–Meier survival curves comparing the dialysis and conservative groups in >75 year old patients

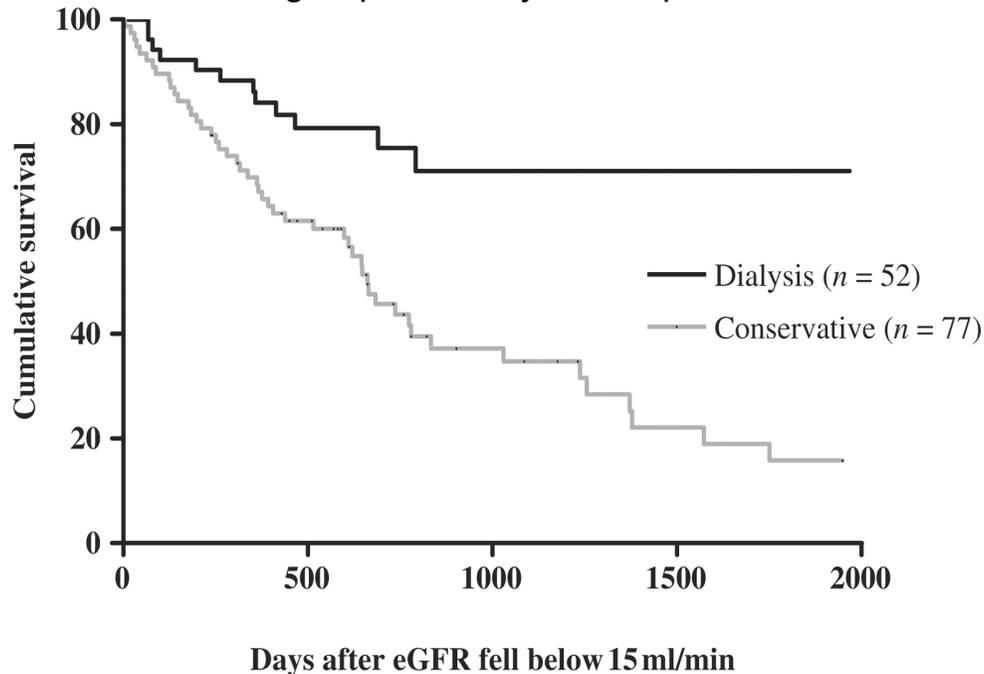
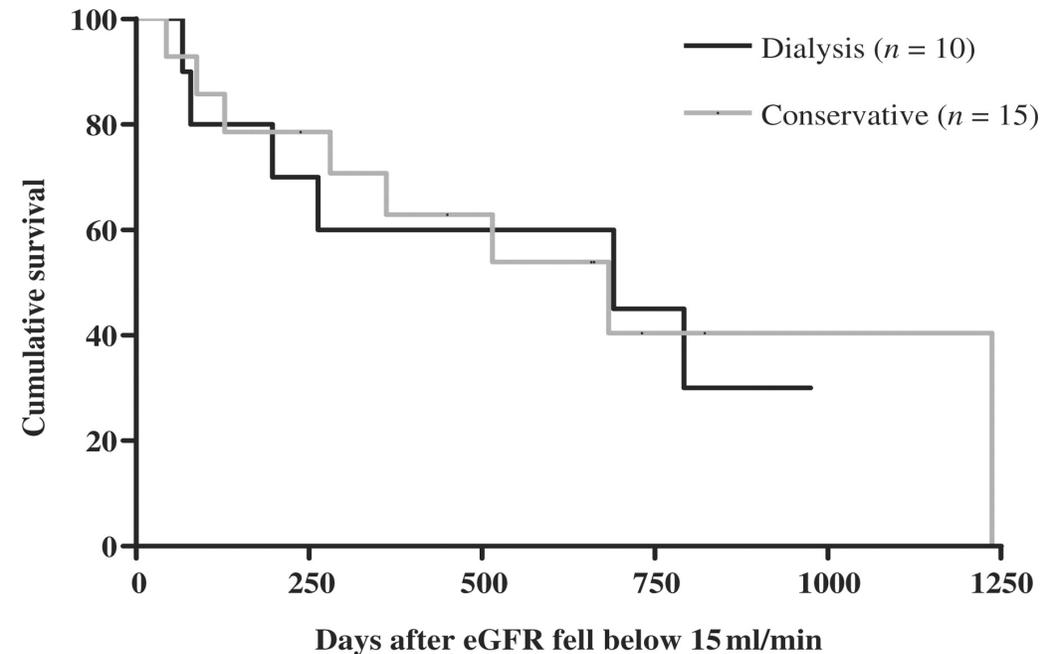


Fig. 3. Kaplan–Meier survival curves for those with high comorbidity (score = 2), comparing dialysis and conservative groups



A retrospective analysis of the survival of all over 75 years with CKD stage 5 attending dedicated multidisciplinary pre-dialysis care clinics ($n = 129$). Survival was defined as the time from estimated GFR <15 ml/min to either death or study endpoint.



SDM for the older frailer patient - clinician guidance on key issues - what does the patient/family know already?



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- What do they know about dialysis?
- Do they know anyone on dialysis?
- Do they/their family understand what dialysis actually involves?
- What are they hoping dialysis will achieve?
- Will dialysis make them live longer?
- Will dialysis make them feel better, relieve symptoms and allow them to do the things that are important to them?
- Are their symptoms actually renal related?
- How medicalised do they feel they wish to be?
- Is dialysis practical - where is their local dialysis unit?

- Will dialysis be distressing
 - Unfamiliar environment - how often do they currently leave their house
 - Exhausting
 - Take away precious time with loved ones
- Is there an alternative path
 - To care for their kidneys
 - To treat their different problems (frailty, pain, memory, etc) more effectively
- This is not rationing - this is choice
- Is the plan clearly documented and accessible to all relevant parties - patient, GP, community services?



How are decisions made?



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Information gathering

What are their values (what might they want - QOL vs. length of life - trade offs; uncertainty)

- Who are they - good social history
- What are their values/religious beliefs
- Who helps them to make decisions but also who will be doing the dialysis

What is their functional state (helps predict practicalities (or not) of dialysis and overall prognosis of patient)

- Physical - Clinical frailty score
- Cognitive - Cube/clock/MoCA

What is their likely need for renal replacement - many especially if progressing slowly will die prior to "needing" dialysis

- Are they progressing at a rate (look at rate of GFR decline per year) which suggests they will reach of GFR of 7- 8 ml/min or less in their lifetime - deciding not to decide and acknowledging may not need to decide

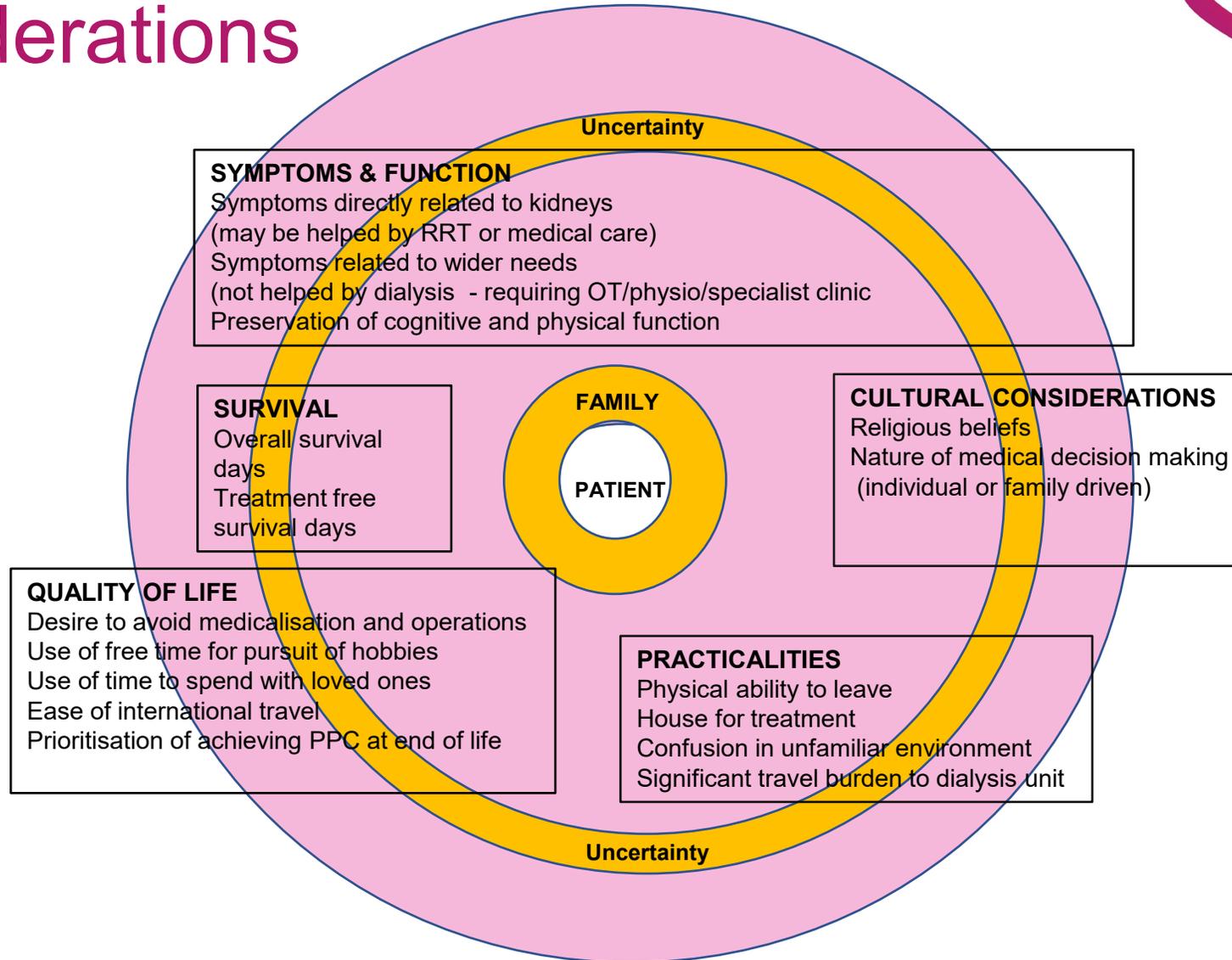


Considerations



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Screening for Frailty in CKD



- Perceived frailty is an inadequate proxy for measured frailty
- Older adults more likely to be misclassified as frail
- Need for an efficient, sensitive and discriminative outpatient frailty screening method in the CKD population
- Clinical Frailty Scale most accurate non-physical assessment frailty screening method in patients over 65
- There is also significant Frailty in patients under 65 with CKD

Clinical Frailty Scale*



1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



2 Well – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.



3 Managing Well – People whose **medical problems are well controlled**, but are **not regularly active** beyond routine walking.



4 Vulnerable – While **not dependent** on others for daily help, often **symptoms limit activities**. A common complaint is being "slowed up", and/or being tired during the day.



5 Mildly Frail – These people often have **more evident slowing**, and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.



6 Moderately Frail – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.



7 Severely Frail – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).



8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.



9. Terminally Ill - Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise evidently frail**.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.

2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

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Dialysis in the elderly



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- Many elderly patients fare badly on dialysis:
 - >3000 nursing home residents with mean age 73 years, by 12 months after dialysis start 58% had died and all but 13% had experienced a substantial and sustained decline in functional status

**'Give people the care they need
and no less, the care they want
and no more.'**

**'Just because we can,
doesn't mean we
should.'**



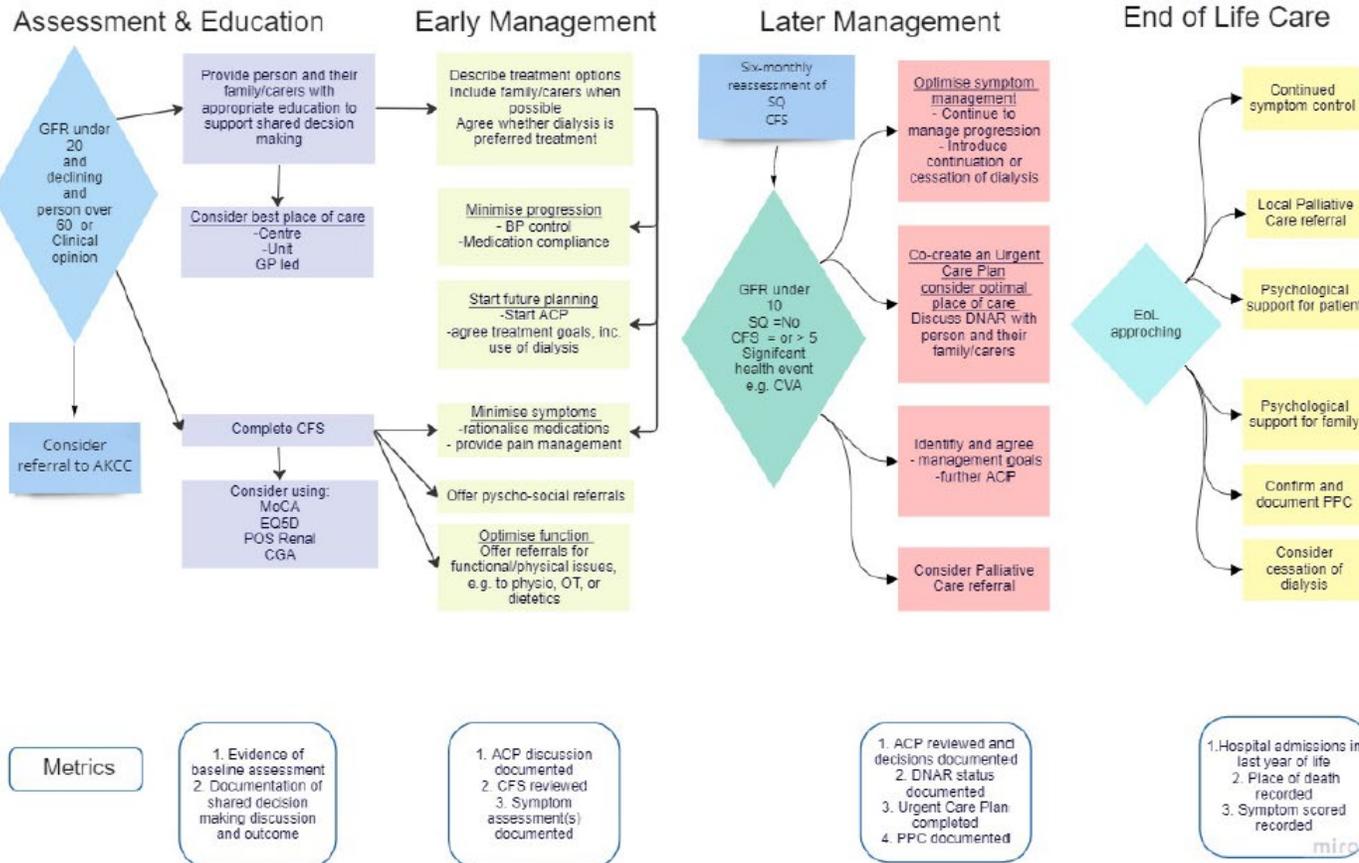
London Kidney Network Supportive Care Pathway*



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LKN Supportive Care Pathway v1.0 February 2023





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- Choice after honest assessment - SDM where possible - emphasise dialysis slots ARE available for those who wish to try
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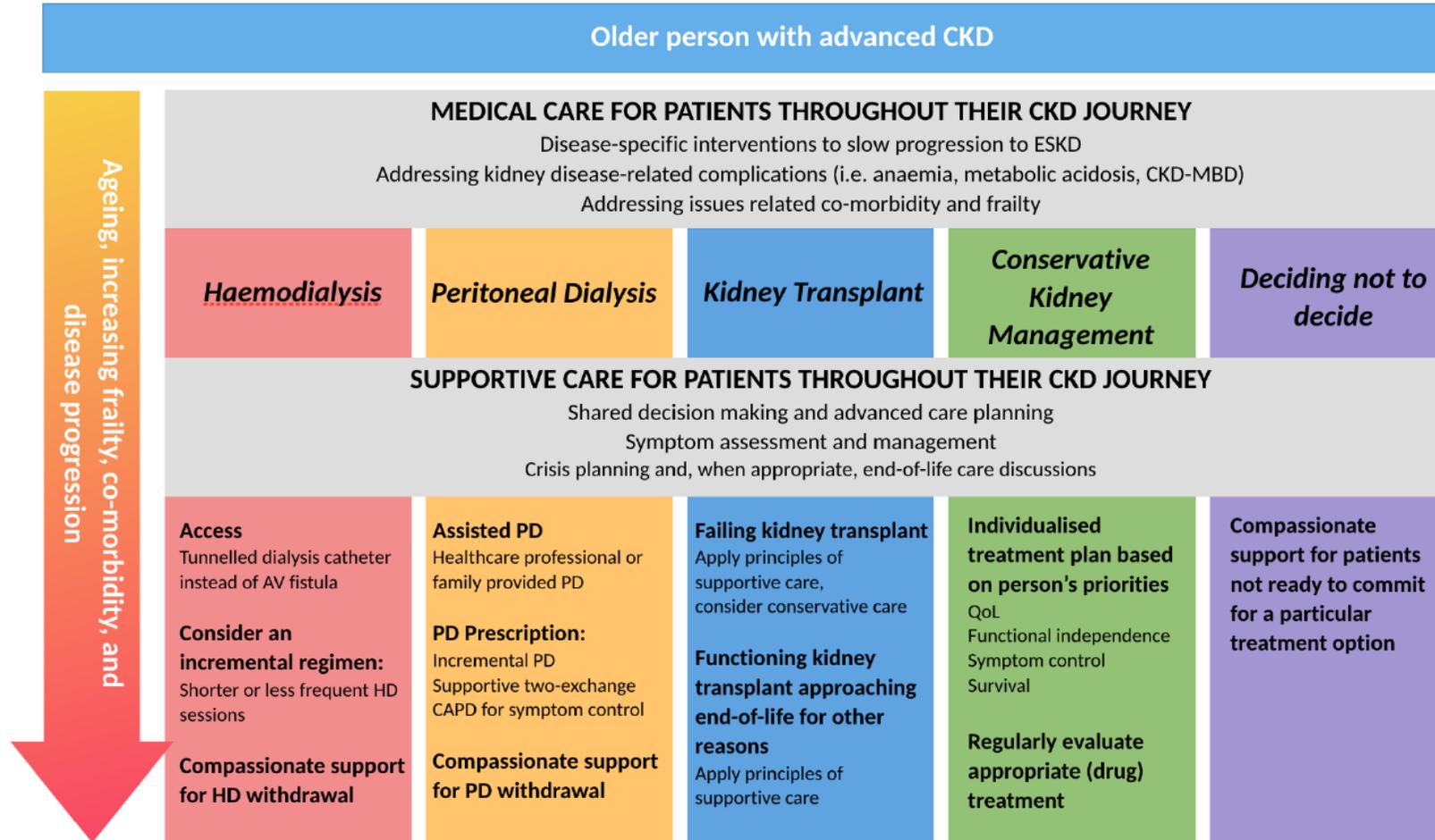


Medical and supportive care for older patients with CKD



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CAPD, continuous ambulatory peritoneal dialysis; CKD, chronic kidney disease; ESKD, end-stage kidney disease; HD, haemodialysis; MBD, mineral and bone disorder; PD, peritoneal dialysis; QoL, quality of life.

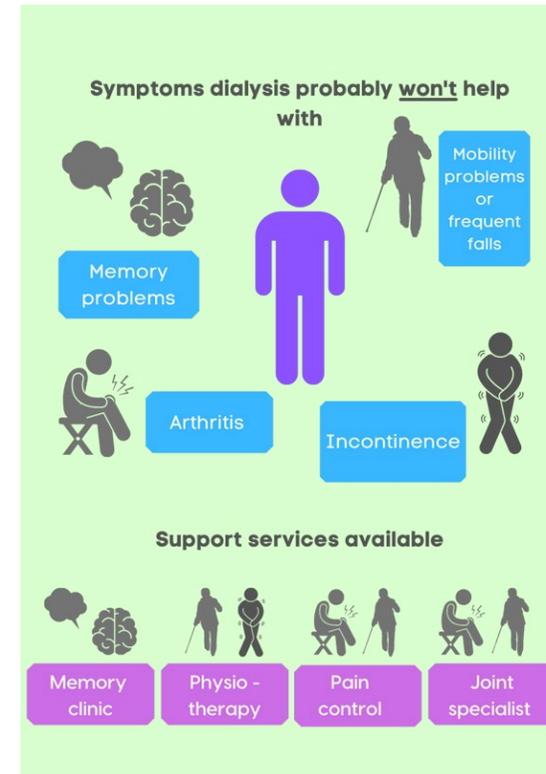
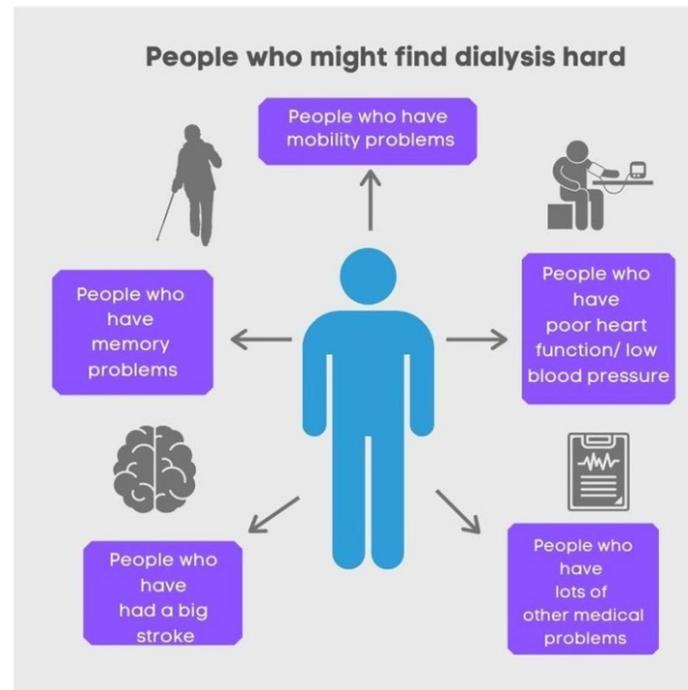
FitzGerald TJ, et al. Clinical Kidney Journal 2022;0:1-12.



Patient reassurance is important



- Some patients misunderstand what dialysis can/does not treat and fear missing out on treatment for other problems if they do not start dialysis - reassurance needed that they will receive treatment even without dialysis



*

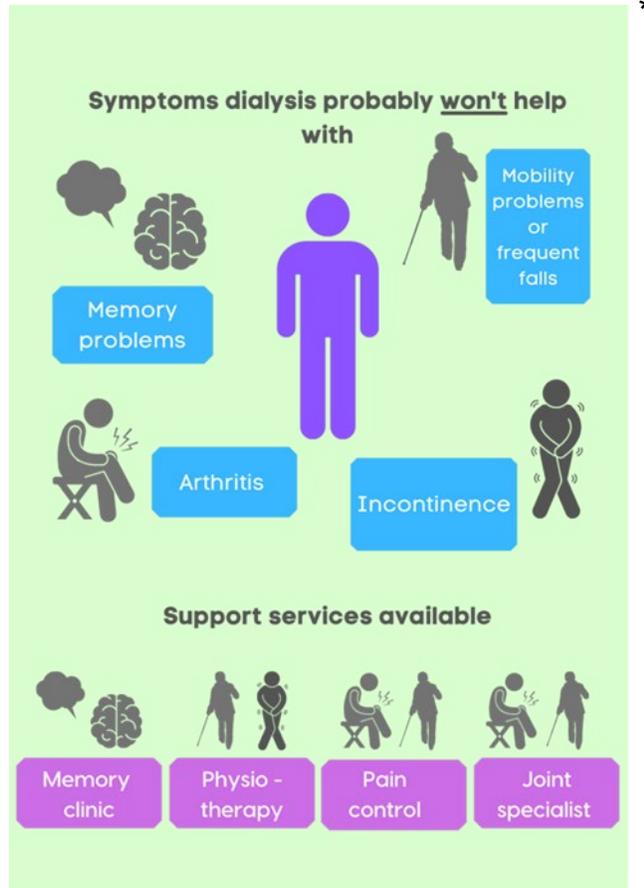


What things can I do to help symptoms not related to kidneys



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- Other specialists
- Falls clinic
- Memory clinic
- OT/PT
- Counselling
- Comprehensive geriatric assessment
- De-prescribe polypharmacy



CKD in the elderly and frail



OVERVIEW

- CKD in the context of frailty is associated with high risk of poor outcomes (AKI, CVD, fractures, dementia, harm from polypharmacy)
- However, reduced eGFR may be of less clinical significance in older or frailer patients than in the younger population
- Best management of these patients may differ from guidance for the general population, and needs to consider other factors such as independence and quality of life

Palliative Care The Renal Supportive Care team help look after patients with symptomatic Stage 5 CKD and those actively dying from it

- Please see separate guidance for advice regarding symptom control in Stage 5 CKD
- Palliative care services can provide assistance for patients dying of symptomatic Stage 5 CKD
- Consider advance care planning (DNACPR, preferred place of care and death) in a timely fashion, and ensure patient has an appropriate Coordinate My Care plan

Chronic kidney disease in the **Elderly** and **Frail**

Author: Dr Will White, Renal Department, Barts Health
Version number: 1.0 Review Date: January 2025

KEY POINTS

Stage 3 and Stage 4 CKD

- GFR reduces with age (reduction of up to 2mL/min/year after age 70 years)
- In the absence of significant proteinuria (ACR > 70 mg/mmol or PCR > 100 mg/mmol) eGFR is less predictive of progression to symptomatic kidney failure with increased age
- Guidelines for the management of CKD lack evidence for use in older, frailer patients, and may be harmful

Stage 5 CKD

- Dialysis may offer only a modest increase in lifespan for patients > 80 years or > 70 years with poor performance status and significant comorbidities, and is often associated with reduced QOL
- Conservative or symptomatic management of kidney failure may be more appropriate for these patients
- Management should consider comorbidities, function and patient priorities, with an emphasis on maintaining independence and QOL
- Advance care planning should be considered at an early stage

CKD MONITORING + REFERRAL

Monitoring

- Frequency of monitoring of renal function should be agreed with the patient - decline may be very slow and inconsequential in quality of life terms
- There is little purpose in routine blood testing of patients who are for purely symptomatic management

Referral to Nephrology

- If rapid decrease in eGFR consider:
 - obstructive uropathy (US KUB),
 - myeloma (serum protein electrophoresis + serum free light chains)
 - UTIs
- Consider nephrology referral if there is an unexplained and sustained decrease in eGFR +/- new nephrotic albuminuria (urinary ACR > 320 mg/mmol)
- Any patient being considered for dialysis should be under the care of a nephrologist
- The Renal Supportive Care team help look after patients with an eGFR < 15 who are unsuited to or who have declined dialysis (email address under Speciality Advice)

Anaemia

- Patients with refractory and symptomatic renal anaemia (Hb < 100 g/L) may benefit from treatment with intravenous iron and/or subcutaneous erythropoietin via the vCKD service
- Renal anaemia should only be diagnosed once other causes of anaemia are excluded such as iron deficiency / B12 deficiency / folate deficiency / GI bleed / haemolysis
- 6 monthly blood tests are recommended for all patients on erythropoietin and 1-2 months after starting, restarting or changing dose



CKD in the elderly and frail



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Chronic kidney disease in the **Elderly** and **Frail**

MEDICATION CAUTIONS

- Elderly are susceptible to \uparrow K⁺ with NSAIDs, ACE-Is/ARBS or spironolactone (the latter severe and persistent due to long half-life)
- Trimethoprim can cause a self-limiting \uparrow K⁺ & \uparrow creatinine by inhibiting renal tubular secretion
- Elderly are susceptible to \downarrow K⁺ & \downarrow Na⁺ with loop diuretics and thiazides
- Some β -blockers (including atenolol and bisoprolol) will accumulate in advanced CKD and can cause bradycardia / bradyarrhythmias

MANAGEMENT TIPS

- Aim systolic **blood pressure** 130-160 mmHg, diastolic 80-90 mmHg, assessing for postural drop (falls risk), in frail elderly patients
- Renal metabolism of insulin decreases with reduced eGFR leading to an increase in risk of **hypoglycemia**:
 - Avoid excessively tight glucose control: aim HbA1C 58-70 mmol/mol in frail elderly patients
- Avoid treating isolated **ankle oedema** with diuretics
- **Vitamin D deficiency** is common in elderly:
 - replace with colecalciferol (use of activated vitamin D to suppress PTH is no longer recommended in non-dialysis patients)
- There is an increased **risk of bleeding** in advanced CKD, which may outweigh the benefits of anticoagulation:
 - anticoagulation decisions (e.g. for AF) may need a MDT approach
- Elderly susceptible to **acidosis**:
 - keep serum bicarbonate > 22 mmol/L with oral sodium bicarbonate
- **Deprescribing** of medications that will not increase quality (nor realistically quantity) of life reduces pill burden and complications of polypharmacy

SPECIALITY ADVICE FOR GPs

Virtual CKD (via EMIS) or A&G (System 1)

Renal Supportive Care: bartshealth.renalsupportivecareteam@nhs.net

DIETARY ADVICE

- Elderly people with advanced CKD generally have a reduced appetite
- Strict adherence to usual renal dietary restrictions may not be necessary. It may be more appropriate to encourage "a little of what they fancy" to ensure small nourishing meals and snacks are eaten daily
- Healthy eating principles can also be relaxed and energy dense foods e.g. biscuits, cake, pastries can be encouraged
- Patients with diabetes should be guided by their diabetes team, in order to optimise their glycaemic control
- **No added salt diet** is recommended in Stage 5 CKD, the same as for the general population
- Foods can be flavoured with herbs, spices, garlic, onion, fresh ginger, lemon, vinegar and pepper instead of salt
- **Fluid restriction** is not typically required for elderly / frail patients with Stage 5 CKD. If a patient also has heart failure then fluid intake should be guided by their heart failure team
- If a patient has a healthy appetite then renal dietary advice may be applicable:
 - Low potassium diet
 - Low phosphate diet may help reduce itch
- First line low potassium, low phosphate and no added salt dietary information is available in both written & pictorial form from bartshealth.RLHrenal dietitians@nhs.net

Kidney Care UK low potassium diet sheet

https://www.kidneycareuk.org/documents/260/Lowering_your_potassium_levels.pdf

Please see the separate sheet for advice about oral nutritional supplementation

Author: Dr Will White, Renal Department, Barts Health
Version number: 1.0 Review Date: January 2025

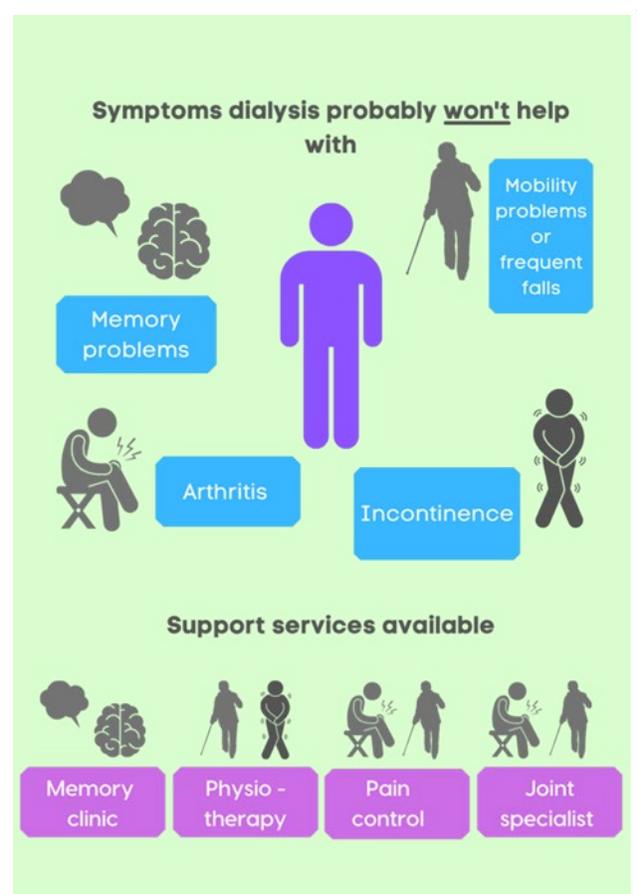


Working on dialysis and transplant units: what things can I do to help symptoms not related to kidneys



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- Other specialists
- Falls clinic
- Memory clinic
- OT/PT
- Counselling
- Comprehensive geriatric assessment
- De-prescribe polypharmacy



Supportive care on dialysis units working with our community care expert colleagues



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- For many patients this starts before they start dialysis
 - Realistic expectations of objectives and limitations of dialysis
 - Honest discussion of realistic goals of care
- Focus of optimising quality of life
 - Reducing renal symptoms
 - Ensuring referrals for other frailty syndromes
- Acknowledgement of shorter prognosis
 - Removal of prognostically unhelpful meds
 - Loosening of targets - BP, phosphate
 - Opportunities to discuss with patients and family wishes for future
 - Place of care, circumstances where would wish to stop
- Opportunities for altered dialysis regimes
 - Shorter sessions
 - Fewer sessions
- Exploration of stopping dialysis if desired
- Working with
 - Primary care
 - Hospices
 - Community services





Why and when patients on dialysis units may wish to withdraw from dialysis



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- Have reached significant milestone - e.g. anniversary achieved
- Death of significant other
- Major decline in health – e.g. after CVA
- Loss of independence
 - Needs residential care
 - No longer able to recognise family
 - No longer able to drive
- Loss of vascular access - does not wish to have further procedures
- No longer able to attend local dialysis unit due to increasingly complex medical problems - therefore would have to undertake much longer journey to medically supported unit



Withdrawing from dialysis - checklist



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- Ensure the patient understands what withdrawal means and what the consequences will be
- Try to involve the family (as long as patient allows)
- Validate their decision
- Treat depression
- Improve treatable symptoms
- Try to offer practical support if they have a sense of burden to others
- Offer a better dialysis schedule (twice weekly) or location if not currently being achieved
- Exclude external pressure



Withdrawal protocol



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Shared Decision Making Process

Withdrawal from dialysis may be raised by patient, family or team caring for the patient in the renal unit or elsewhere, in or out of hours^a.

Assessment of patient's decision-making capacity (MCA 2005) as per trust protocol and, in the absence of capacity to make this decision, best interests meeting with patient's representative or Independent Mental Capacity Advocate (IMCA).^{b, c}.

Ensure Consultant lead team (including GP where possible) patient/representative and family discussion held and documented in patient's record.



Assess and address potentially reversible factors that may influence decision making such as:

- Depression.
- Practical issues – transport.
- Complications during dialysis.
- Complex symptoms which are untreated.
- Psychosocial issues.
- Acute life threatening illness.



Withdrawal Process

1. A negotiated cool-off period to ensure considered and consistent decision (if patient's clinical condition will permit).
2. Planning meeting with patient, family and Consultant lead team including discussions around what to expect, prognosis, attempted resuscitation. Document.
3. DNAR CPR Document completed as appropriate.
4. Provide patient with dialysis withdrawal information leaflet.
5. Notify relevant community services and GP.
6. Ensure appropriate information included within electronic discharge letter if patient being discharged from hospital.
7. Establish preferred place of care; home, hospice, nursing home, hospital.
8. Complete fast track and Co-ordinate my Care register if appropriate.
9. Refer to specialist palliative care (community/hospital) as appropriate.
10. Offer spiritual, social work, psychological support to patient and family.
11. Separate Referral to Renal Psychology service as appropriate.
12. Review medications.
13. Assess current symptoms and prescribe anticipatory medicines in line with Trust guidelines <http://tw-wafr/WAFR-FAD/Applications/ClinicalGuidance/User/Details.aspx?id=3682>
14. Plan for care in line with Trust protocol for care in the last days of life. <http://tw-sharepoint/sites/GeneralPolicies/Document%20Library/End%20of%20Life%20Care%20protocol.doc>



Top messages primary care can share



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PREVENTION

- Most kidney disease is not symptomatic - this does not mean you are not ill
- Prevention of kidney disease is always better than “treatment” with dialysis and “cure” with transplantation

SPECIALIST KIDNEY CARE

- Not everyone can have a transplant but if you can it's the best treatment
- Live donors are best of all - the criteria are wide
- Dialysis can be made to fit your life - think about home options where possible

EXPERT HOLISTIC CARE

- Many older patients are living with significant kidney disease but their life will come to a close due to other co-morbidities
- Not everyone benefits from dialysis - some people don't - its not rationing - please think about the patient in front of you and manage expectations accordingly



Preparing for end stage renal disease and dialysis



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- Discuss how ESRF is classified
- Discuss when may be appropriate to initiate dialysis and the types available
- Consider complications and risks associated with ESRF including risk of sudden cardiac death
- Early identification of end of life care and palliative care management for patients with ESRF
- Explore education strategies and SDM in ESRF
- **Share resources available for patients in ESRF and on dialysis**
- I have tried to give you a lot of information about how the patient may be experiencing the situation in order to help you support them



General resources about kidney disease



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- Kidney Care UK
- National Kidney Federation
- Kidney Research UK
- NHS Blood and Transplant
- London Kidney Network: the patient information booklets containing the infographics referenced in this talk will be available via the London Kidney Network website which will go live later in Summer 2023.





Resources to help transplantation - NHS BT¹⁻³



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Expert support and resources for clinicians

Get the latest organ-specific reports, clinical guidance, procedural documents, strategic initiatives, meeting presentations and agendas from advisory and patient support groups.

» Go to the ODT clinical website

The poster features the NHS Blood and Transplant logo at the top right. The main title is 'UK Living Kidney Sharing Scheme' in pink, with the subtitle 'Your questions answered' below it. A central graphic shows a stylized flower-like shape composed of interconnected human figures. To the right of this graphic is a bulleted list: 'Paired/Pooled Donation' and 'Non-directed Altruistic Donor Chains'. At the bottom left, contact information is provided: 'www.organdonation.nhs.uk', 'enquiries@nhsbt.nhs.uk', and '0300 123 23 23'. At the bottom right is the 'Yes I donate ORGAN DONATION' logo.

GOLD programme



PHONE BUDDY SCHEME

The scheme supports Black African Caribbean people living with Chronic Kidney Disease (CKD) by matching them with living donors and living donor recipients to talk about living kidney donation.

BT, Blood and Transplant; NHS, National Health Service; ODT, Organ Donation and Transplantation; UK, United Kingdom.

1. NHS Blood and Transplant. Organ donation and transplantation: Give the gift of life after your death. Available from <https://www.nhsbt.nhs.uk/what-we-do/transplantation-services/organ-donation-and-transplantation/>. Accessed March 2023; 2. NHS Blood and Transplant. UK Living Kidney Sharing Scheme: Your questions answered. Available from <https://nhsbtbe.blob.core.windows.net/umbraco-assets-corp/15427/29800-606mv-living-kidney-sharing-olc2173-web-1.pdf>. Accessed March 2023; 3. GOLD: Gift of living donation. Introducing Our Phone Buddy Scheme. Available from <https://www.giftoflivingdonation.co.uk/gold-telephone-buddy-scheme/>. Accessed March 2023.



Helping older, frailer patients with late stage kidney disease



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- To help understand prognosis
- Known risk factors for poor prognosis (age, comorbidities, severe malnutrition, poor functional status) can be used together with the 'surprise' question to estimate prognosis



- Managing difficult conversations booklet



Table 7: Strategies and suggested language for dealing with direct confrontation

Direct confrontation	
"I think it's a bit of a shock. Something like this would probably freak them out, 'How would you like to die?' 'You mean I'm dying already? I've just started on dialysis.'" (Hussain, person with kidney failure)	
Key ideas	Strategies and suggested language
People assume the health professional has bad news about their health status if they start a conversation about future care.	Provide perspective. <i>"I can tell that this is a hard conversation to be having. Right now, you are doing well. I am bringing this up now because of the uncertainty about what is ahead, and our need to be prepared in case something unexpected happens."</i>
Conversations about the future inevitably bring up fears about dying.	Ask the person what makes them concerned. <i>"It sounds like you are pretty worried that you might be close to the end. Please tell me more."</i> Name and explore what is hard. <i>"I know that this can be scary to talk about. What are your biggest fears?"</i>
The health professional's key task is to manage anxiety, emphasising what is still possible while exploring the person's concerns and the medical realities.	Be honest and as hopeful as you can realistically be. <i>"I do think you are in a very difficult place, and your disease is worsening. I think time may be getting short. At the same time, you are still here and still very much yourself, and I would like to focus on helping you feel as well as possible so you can spend time on what matters most to you."</i>

1. touchcalc. HD Mortality Predictor. <http://touchcalc.com/calculators/sq>. Accessed March 2023; 2. Kidney Care UK. The Difficult Conversations booklet. Available from <https://www.kidneycareuk.org/health-professionals/difficult-conversations/#:~:text=advance%20care%20planning-,Difficult%20Conversations%3A%20Talking%20with%20people%20about%20kidney%20failure%2C%20end%20of,and%20frequent%20part%20of%20practice>. Accessed March 2023.



Summary



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- Renal disease is classified by GFR into five stages
- Patients generally start planned dialysis with GFR between 7-10 ml/min
- Dialysis preparation requires a comprehensive MDT
- Dialysis can be an amazing life saving treatment, but it is also burdensome and complex and it doesn't not benefit every patient
- Patients and their families can have little understanding of the complexity and time involved in dialysis
 - Patient and family education on dialysis and SDM is key
- Early identification of end of life care and palliative care management for patients with ESRF is important



Thank you



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