



Fiona Loud

Kidney Care UK

European Kidney Health Forum
Patient Views

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www.kidneycareuk.org

Improving life for
kidney patients

Giving Total Patient Support

How we help Patients and their Families

Promote the welfare of people with kidney disease

- Providing financial assistance
- Delivering support and advice
- Holidays and respite

Educating and informing patients, the public and healthcare professionals about kidney disease

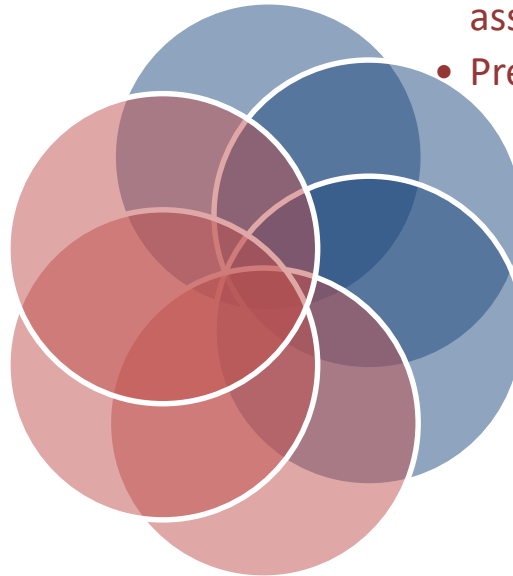
- All forms of kidney disease and associated disorders
- Prevention and early intervention

Campaigning to improve the lives and choices of kidney patients

- Informing policy and practice
- Supporting a strong kidney community

Improve the quality and access to care

- Grants to hospitals
- Funding staff
- Patient-centred research to improve quality and practice



Good kidney function is vital to a healthy life

- Moderate to severe kidney disease affects about 6% of the UK population, all stages 10%
- Kidneys can be damaged by diabetes and high blood pressure, so regular checks (blood & urine) are important
- Recent CKD audit in England & Wales of 1,000 practices shows routine checks not done well enough on people at risk
- Low awareness

<https://bit.ly/2qYYWAb> - CKD Audit

<https://bit.ly/2HmwCme> - human cost of CKD

Summary findings of patient outcomes

Patients with chronic kidney disease and moderate to severe function impairment

1. For every 100 patients, there are 38 unplanned admissions per year.
2. For every 100 patients, there are 7 AKI events occurring at time of admission per year.
3. For every 100 patients, there are 6 CV events per year.
4. For every 100 patients, there are 2 admissions to the ICU per year.
5. For every 100 patients, there are 7 deaths per year.

- Detection, prevention of deterioration and personalised info is essential
- For some people kidney disease results in kidney failure which greatly reduces quality of life, affects physical and mental health and is very expensive (£1.5bn)
- 60,000 in the UK, just under ½ on dialysis which is at least 3 times a week, 4 hours a time, for only 10% normal kidney function



- Rare disease, pre-eclampsia, & kidney cancer
- 5 years on dialysis

- One third of donations in the UK are from living donors (about 1,000 pa including altruistic donors)
- A vital option for people who do not have time to wait as they are very ill on dialysis, or children
- Numbers are falling but innovations like the living donor sharing scheme are working well
- Barriers include awareness, not knowing how to approach & concern for family members, process delays
- For me, after 5 years I received a living donation from my husband in Dec 2006

Transplant – gold standard treatment

- 2017/2018, 1,575 deceased donors – a record, but
- 4,700 have died waiting for a transplant in the last 5 years – that is 3 a day
- In the UK, 250,000 people a year die, but only 5,000-7,000 will become donors
- 4 in 10 families who could donate say no, rising to 7 in 10 from a black or Asian background

The opt-out

- “Presumed consent” means you are an organ donor unless you have opted out in life
- Soft opt-out means your family retain the right to over-ride that presumed decision
- Introduced in Wales in 2015
- Results are promising, with higher consent at 24.3 donors pmp <https://bit.ly/2qRPyyP>
- Possible in England following government announcement and consultation on how to bring it in
- National conversation is also slowly increasing numbers

Hope for patients

- Associated with higher levels of donation
- BUT for success this must go alongside:
 - More education for the public and in schools
 - Adequate resources such as operating theatres and surgeons
 - Support and honouring of donors and their families

Brexit

Reciprocal healthcare for
dialysis across the EU

Organ sharing

Research & rare diseases



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WHO WILL INHERIT YOUR GREATEST WEALTH?
BECOME AN ORGAN DONOR.

Thank you

- Early detection, support & advice for Chronic kidney disease
- Improvement of patient experience
- Opt-out
- Brexit



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