

**Living kidney donation
network meeting
Supporting patients and
their families**

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Sudden increase in demand for our services

- Calls to the charity – up by one third
- Calls for advocacy services – up by one third
- Calls for counselling – up one third...growing demand at the moment
- Rapid need for information and support while we all moved to work from home
- Hardship grants up (holiday grant requests down)
- Many of us at Kidney Care UK are also clinically extremely vulnerable

Building a community information resource

- Early phase in particular jointly written with medical colleagues, especially from the RA
- Invaluable input from transplant, pharmacy, patient information group colleagues
- Heroic out of hours work
- Updated daily at first, now 2 or 3 times a week for the last 12 months
- Pressure points e.g. when lockdown and shielding rules were brought in, and then changed, and then changed again – including at weekends. Now it's vaccination.
- Information is a vital tool in a pandemic

Covid-19

Information

- Website – nearly 635,000 hits to the Covid-19 page since March 2020 with an average 5 minutes dwell time
- Thank you for supporting this (it's on NHS Choices, NICE guidance &c)
- Separate transplant section
- Great patient & professional feedback
- So many queries from people with one kidney

Education

- Webinars x 5, 1500+ people, 1 on dialysis, 1 on transplantation, 3 on vaccination incl 1 w BAME focus
- Answered questions and changed minds
- Next one just announced 'Lifting lockdown'

Covid-19

- Insights
 - Patient experience surveys x 3 over the year
 - Mental, physical and financial health
 - Bringing patients & policymakers together for insight meetings

- Lack of transplants
 - Sadness
 - Anxiety
 - Some understanding and some anger with life and communications



Kidney Care UK Covid-19 patient survey

- 'Worried Sick'
- **May/June 2020 - 1211 participants, published July 2020**
- 4/10 people reported a mental health impact
- Nearly 7/10 reported disruption to care
 - e.g. 35% had surgery/appointments cancelled & 26% had not had their checkups
- 25% reported worries about getting food
- Some family members chose to co-shield
- Confusion over government advice & whether to shield
 - 13% didn't know they were advised to shield
 - 18% had verbal confirmation but received nothing in writing & weren't able to access government support such as food boxes, employment support
- www.kidneycareuk.org/coronavirus created in March 2020

Outcomes

- ✚ Dialysis and CKD5 explicitly on the government 'clinically extremely vulnerable' list so people could recognise themselves and get the shielding protection they needed
- ✚ NHS England outpatient services transformation group
- ✚ Health question on transplantation (oral) and lots of written questions including some on vaccination incl on JCVI
- ✚ Ability to campaign for access to vaccination for those on dialysis
- ✚ Greater recognition of kidney issues with media and policymakers
- ✚ Impactful joint working with much larger national charities re e.g. employment

So what?

- Providing evidence for policymakers, renal services and Trusts
- Commissioners, please use these experiences to rebuild/restart
- Use this opportunity to reshape virtual/face to face consultations/access to blood tests – do they work for patients and families and what about those who don't use the internet?
- Increase patient comms – check for clarity
- Look at your local unit feedback too – ask
- Look out for unintended consequences e.g. transport, food
- Reflect and learn together

Key messages

- 100% of patients wanted timely, clear advice on Covid-19 and need support and protection
- Fear and anxiety continues to be very high – please don't ignore it
- Inequalities highlighted – let's engage with those affected
- Continued need to monitor, update, support and advocate for patients and families (with your help!)
- www.kidneycareuk.org/coronavirus



Thank you – Kidney Care UK policy team



Amjid Ali, Partner, BAME inclusion lead



Andrew Cromwell, Policy Officer



Sam Sharp, Senior Policy Officer

[Our next event Tues 30th March at 5.30 All welcome
https://www.kidneycareuk.org/news-and-campaigns/news/question-time-covid-19-and-ckd-lifting-lockdown-webinar-on-zoom/](https://www.kidneycareuk.org/news-and-campaigns/news/question-time-covid-19-and-ckd-lifting-lockdown-webinar-on-zoom/)