

Navigating a Pandemic –

Support for living donors

UK LIVING DONATION NETWORK MEETING 24 MARCH, 2021

- Pulling back on publicity
- Providing information
 - Webinars
 - Covid FAQs
- Managing expectations
- Correcting misinformation (shielding)
- Donor Forums
- Emotional support for individuals



Emotional impacts



"I'm terrified it's going to be cancelled again because of Covid. What if it's too late for [my recipient]?"

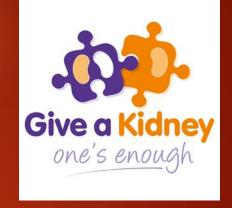
"this is probably the most frightening thing you are ever going to have to do – and to be doing it in a global pandemic is even more terrifying" "I haven't heard from them [coordinators] and not sure what to do. I know they are really busy so I don't want to bother them but I think they might have forgotten about me and I really need to know what's happening."

"I've tried to contact my team but nothing. I feel completely in limbo"

"I'm really scared and in two minds, but don't want to tell my coordinator that because I don't want them to think I'm not ready. I'm scared I'm going to say the wrong thing in front of them. I feel like I'm on trial. I just have to get on with it now I'm this far in."

"How do I tell him I don't think I can do this. I don't feel I have a choice because his life depends on me doing this."

A gap in the process?



- Emotionally more complex for directed donors?
- Experience of anticipatory or actual grief
- Fear of really being honest with care team in case of being withdrawn
- Fear and/or guilt of letting down recipient
- Processing of experience afterwards, particularly when things have gone wrong
- Declined donors
- Donor forums disclosures of abusive situations, self-harm

Could/should we do more?

Give a Kidney one's enough

- Communication is significant
- DROMS/DREMS
- For some people this is an extremely difficult process
- Mental health assessment is very different to emotional support through the process
- Could it be offered outside of care teams?
- Is there a gap that a charity like Give a Kidney could fill?



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