Let’s talk about...

Appealing for a kidney on social media if you or someone you know needs a transplant

Social media has a huge impact on how we live our life – whether we like it or not!

Some people who are waiting for a kidney transplant have chosen to use their social media accounts to tell the world about their need. This is something that you could do too. It is rare to find a donor in this way but there are cases where it has happened successfully.

If you are thinking about doing this, here are some things to consider before you begin:

• Before posting any kind of appeal please speak to your Living Donor Coordinator and tell them of your plans. They can help you find the right words and ensure that you have the correct contact details. It also helps the team to prepare for any increase in enquiries.

• Think carefully about what detail you want to go into about your personal circumstances and your illness – once something has been posted over the internet it will always be there. Be particularly careful if you are talking about anyone else in your family and seek their permission first before sharing information about them.

• Do you want to share your story publicly or just amongst family and friends?

• Be aware of internet trolls – not everyone’s comments will be supportive and some may even be hurtful. Think about how you would cope with this.

• Individual members of the transplant team should never be named in person. Please discuss with them the most appropriate contact details for the team to include in your appeal.

• We suggest that you never post your own contact details. Remember you may get 10s, 100s, 1,000s or no ‘Likes’ or responses - this does not mean you will or will not find a donor. The team has a process for selecting the most likely donor(s) from those stepping forwards and only those people will be assessed.
• Ask any potential donor to contact your Living Donor Coordinator directly, as discussed with your team. You cannot do this for them. The donor assessment process can be long and involves many hospital appointments and tests. It is important that the donor is not put under any pressure and that they receive all the correct information from the team so they can understand the process and risks and decide if it is something they really want to do. Even if they want to donate, not everyone is suitable.

• Donating a kidney is major surgery and donors are expected to take at least six weeks off work to recover depending on their work and lifestyle

Above all, remember to seek advice from the Living Donor Co-ordinator in your transplant centre before you get started and be realistic about your expectations.

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