



Newsletter 21 June 2023

Can you help with PhD research?

Laurie Hufton has asked if anyone can help with her research project. Her study aims to ask renal patients about their experiences of coping with their renal condition and whether ways of coping influence how much an individual's wellbeing and self-management is likely to be impacted. The study will increase understanding of how ways of adapting impact self-management and inform care in relation to this.

The research is being conducted for education purposes as part of the Doctorate in Clinical Psychology at the University of Lincoln.

Here is a link for more information.

https://unioflincoln.eu.qualtrics.com/jfe/form/SV_00FO3aRMas3E78W

Kidneycare UK Young Adult Weekend

When needed, EDKPA has provided financial support for patients to attend this event. And this year is no exception. This summary from the Kidneycare website explains more:

*"The Kidney Care UK Young Adult Kidney Group Residential Weekend is a **FREE event for young people aged 18-30 who have a kidney condition**. It's our mission to facilitate a fun and safe environment for you to be inspired, get advice, and enjoy a great weekend with others your age who truly understand you. We strive to promote the development of young people with chronic renal illness by offering a residential which will help you grow socially and in confidence, and provides knowledge to help promote independence."*

Renal dieticians' teambuilding day.

EDKPA was delighted to hear the renal dieticians (personally known to pretty much every kidney patient) were spending a day together improving their teamwork skills. We played a small part in supporting one of the practical exercises – kayaking on the Exe! It's clear from the evidence that Sharon Huish and the team were all hard at work!



Working with the hospital to improve patient experience.

EDKPA has often stepped in to help improve patient experience as a renal inpatient at Exeter or in the dialysis units. We have fitted TVs, provided exercise facilities, headphones and remotes for the TVs, snacks, etc, etc. There are many things the NHS is bound to provide for patients, but also many grey areas, where the duty is not quite so cut and dried or indeed, where severe budgetary constraints make it impossible for some things to happen just now.

We have regular meetings with senior staff at the hospital and would really like to hear from YOU, if there are little gaps needing to be fixed, which we might be able to help with. The next meeting will be during the summer, so please get in touch with any ideas you have, as soon as practical.

Please get in touch by mailing our secretary, Jean Aplin.

Our work with Citizens Advice Exeter

We pay for dedicated staff at Citizens Advice to provide help to renal patients with obtaining the various benefits to which they are entitled. The scheme works well: one patient wrote to us recently with this comment:

"I would like to say how very grateful we are for all the help we have had and are still getting from Carolyn at the CAB. She has been helping us since you contacted her last August and together, we have worked tirelessly with the DWP to get our benefits correct, we are nearly there, and we could not have done it without Carolyn's help. We wanted you to know how the help from CAB is a godsend and very much appreciated."

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