Little Whispers - arts in health

Using art to amplify the voices of people living with kidney disease

Barny Hole¹, Elspeth Penny² and Lucy Plumb¹

1. Bristol Renal research group, University of Bristol

2. <u>2BU Productions</u>



JO (CONT'D) Is it really worth it for the absolute misery of all these spikes and needles stuck on you.... for an extra six months or maybe a year, you know? What I saw is they wanted to put me through a messy painful procedure, for what can be a very short amount of time. I actually spoke to the doctor about this and he went up in the air.

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People with long term conditions can feel unseen and unheard. We present two projects where <u>clinician researchers and an artist</u> worked together to hear the 'Little Whispers' of those living with kidney disease.

The script on the left is from the play 'Out Like Fudge'. Fudge is a cat. Picturing inevitable kidney failure, Jo considers the idea of leaving the earth as Fudge had. She says, 'a sudden twitch and that's it, gone'. Written by Elspeth, a writer and director who specialises in using memorable, affecting art to amplify the voices of

DR NEPHROS Oh no no no, you could carry on living for years...

JO But looking at the average life expectancy, he was talking nonsense. The doctors seem to think they're the skilled person and they're talking to plebeian idiots. As I said, I've got mistrust.

Jo picks up the tea-pot again, aims for his cup and misses.

JO (CONT'D) Oh darn.

DR NEPHROS

Had you ever thought about what dying might be like or what kind of dying would be best for you?

JO

I'm horribly familiar with kidney failure as three of my cats died of it. Fudge is the one I miss the most, loudest purr I've heard. I've felt the effects, I know how nauseous and bad you can feel. Kidney failure is the commonest form of death in cats.

people living with illness, the play is largely verbatim from a set of interviews that Barny conducted for his PhD. Jo's uncertainty about whether dialysis is worth it is set against the backdrop of her inevitable death. The dialogue is unsanitised: shocking, and facetious.

DR NEPHRO I didn't know that.

DR NEPHROS failure? Like the cats?

Follow on work was interrupted by COVID-19 and a

participatory project became a return-by-post exercise. Older people, children, kidney donors and those receiving dialysis were supported with 'oldfashioned' letters and telephone calls and supplied with art packs, creating a series of 'Letters to my Kidney/s'. The results were touching and illuminating, and creations were featured in a virtual gallery.

The project is developing further, this time as 'Little Whispers'. The team has been joined by Lucy, a kidney doctor for children. An open-invitation approach to collect handwritten letters from a much wider group is underway, which will enable many more people living with kidney disease to participate and for their voices to be heard.

