

# We're only human

Illustrating the healthcare experiences of people  
with Chronic Kidney Disease and the  
professionals who support them



A DrawingOut method workshop

[www.drawingout.org](http://www.drawingout.org)

This booklet was produced as part of an Economic and Social Research Council funded Masters Dissertation project.  
The study aimed to examine experiences of health communication from both the professional and patient perspectives.

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# What is this booklet about?

## The Content

The healthcare experiences and of patients and practitioners, as told through the artwork and words of young adults with Chronic Kidney Disease, and the specialists who support them.

## The Artists

**The Patients** consisted of four young adults aged 19-27 who are currently experiencing CKD and are supported by The Can Do project.

**The Specialists** consisted of a Youth Worker, a Social Worker, a Patient Advocate and a Counsellor, who all specialise in supporting individuals experiencing CKD.

## The Workshop

The workshop, based on The DrawingOut method ([www.drawingout.org](http://www.drawingout.org)), encouraged participants to use creative methods such as drawing and collage to illustrate their experiences of health communication as patients and practitioners.

The exercises prompted a series of discussions around healthcare experiences. Although the focus of the workshop was on experiences of health communication, the DrawingOut method allows participants to put forward their own agenda and therefore other aspects of healthcare were discussed and are reported in this booklet.

## Main discussion points

- The impact of illness on quality of life, relationships and future outlook.
- Others' lack of understanding of CKD as an invisible illness.
- The positives and negatives of using healthcare services.
- Professional experiences of supporting people with CKD, and the challenges of doing so in a pressured healthcare system.

# We are young adults with Chronic Kidney Disease...

"It's like a sweet shop, except you're only allowed to choose one, so you can either have sweets that make you happy or ones that make you healthy, and I'm stuck to decide"



 HAPPY

 HEALTHY

"Transplants are hard enough as they are, but then there's the emotional impact, too"

"It's like a big grizzly bear creeping up on me, I never know when I'm going to be ill again"



"I always think, why me? Why do I have to deal with all this? None of my family have ever been in hospital, but I'm always back and forth"

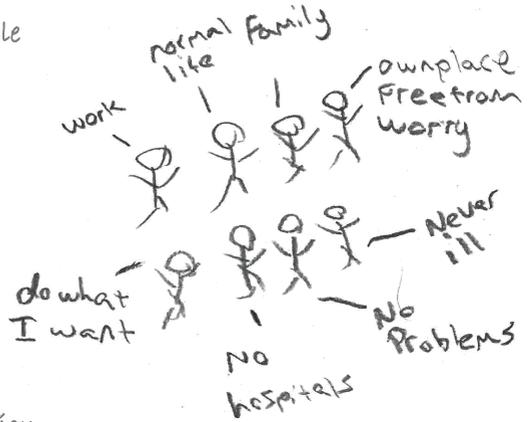
"I sometimes wish I could stop treatment, but if I choose that then everyone around me is sad because me being healthy makes everyone else happy. I tend to worry about other people rather than myself"

# Being unwell can affect our relationships with friends and family...

"You lose friends when you're ill, people don't know how to deal with it when you're going through stuff"

"My family worry that I don't look after myself properly, but it's hard"

"It'll get you down, when depression kicks in as well, and it's always when you're on your own"



"It's easy to talk about other people's issues, but when it comes to your own, you don't really want to talk about it"



"My partner's job will have to be strong enough and bring in enough money to cover us both in case I have anything that goes wrong. That's a lot of pressure on him"

"I've always wanted a family, but I think that having a child is going to be so much more difficult for me"

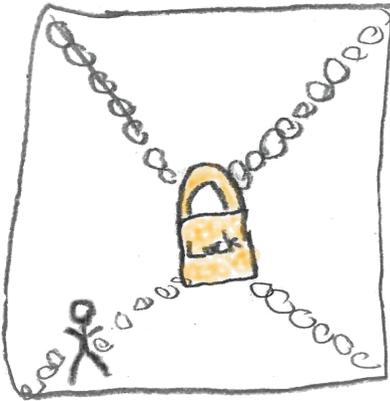
# People don't always understand CKD because its invisible...

"People don't understand it. It's not like cancer or like losing a limb or something like that, where people can tell you're ill "

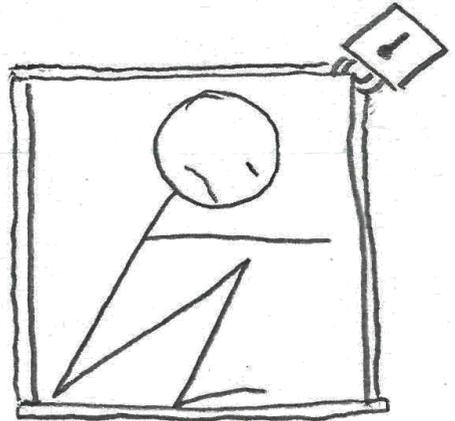


"I feel like people treat me differently when they find out I'm ill, so I don't always tell people. I feel like if they could see it they'd always treat me differently so I almost prefer it being invisible."

"People are like 'oh you look healthy'. When you're unwell, you bottle things up. I find the way I deal with it is I try and crack jokes and cheer people up. And then they're like 'he looks fine, better than ever'. The minute I'm at home on my own it's a whole different kettle of fish"

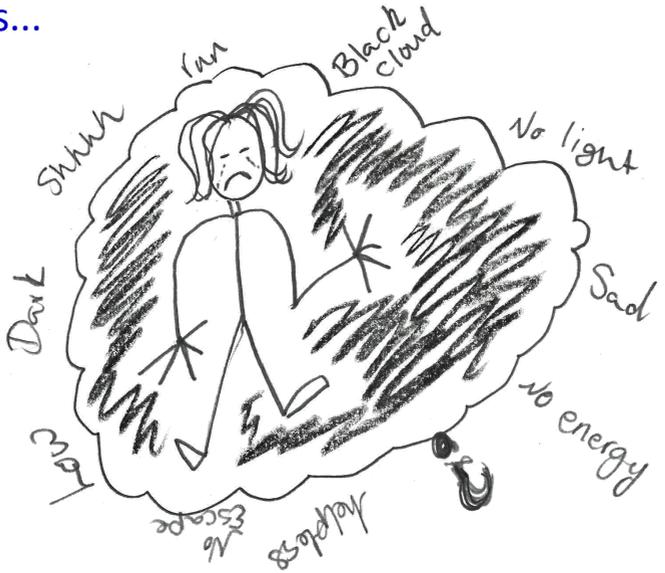


"People don't take you seriously, when you talk about dying, they say: oh, but you've got years left. They don't understand why I have my funeral planned"



# But it is very real to us...

"I've only just started to see the scary part of being ill because I shut it off for so long"



"I was told that a transplant was the most amazing thing in the world, but it took me over six months to get over that, and my parents said they see it as this amazing gift but I'm still ill and I've got to take tablets every single day"

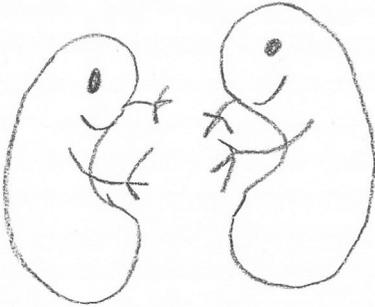
"The doctors don't take into consideration what having to take twenty tablets in the morning and twenty tablets in the night is going to do. They make you sick and they make you sad"



"It isn't fair because you go through these stages where you're like: I don't care anymore"

# There are lots of people who support us...

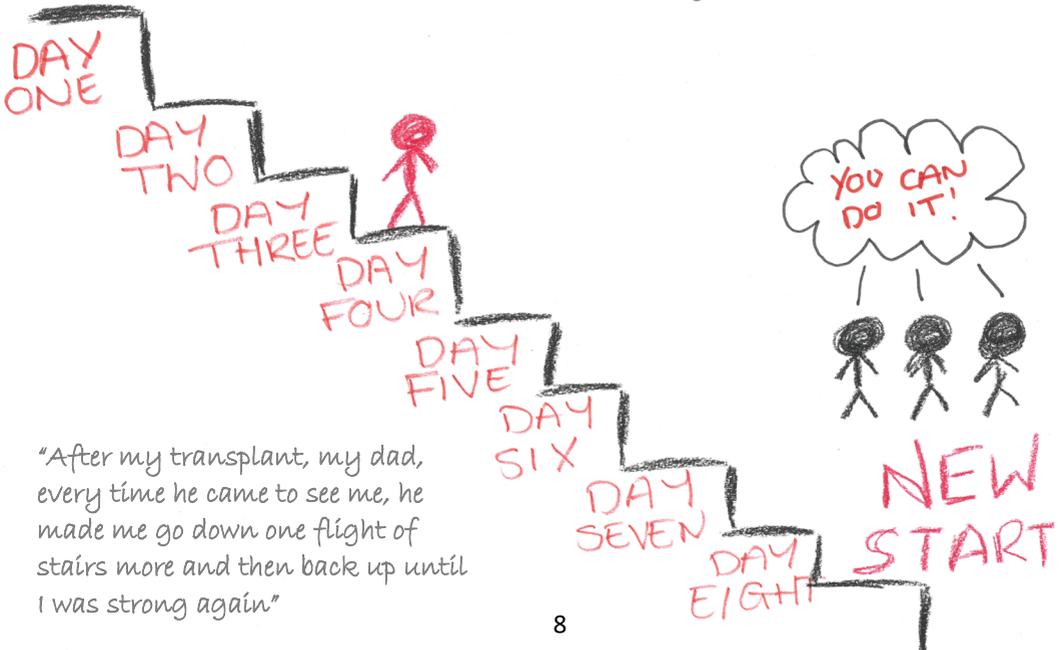
When I first started dialysis I was terrified, I couldn't look at the needles. But it got to the point where I was doing it myself, and I never thought I could do it on my own but I can!



"Someone who doesn't have a problem can't always understand. That's why it's easier to talk to people in the support group"

"Winding up our support worker makes our day better. He's a laugh"

## TRANSPLANT



"After my transplant, my dad, every time he came to see me, he made me go down one flight of stairs more and then back up until I was strong again"

# There things that we wish they knew...



I want a  
working organ  
NO complications  
NO Problems  
NO issues.

"I feel like I'm quite nasty to some professionals, but it's not because I don't like them, it's because I'm angry most of the time"

"I get told: do this, do that, take this'. But half the time I don't know why, they don't explain"

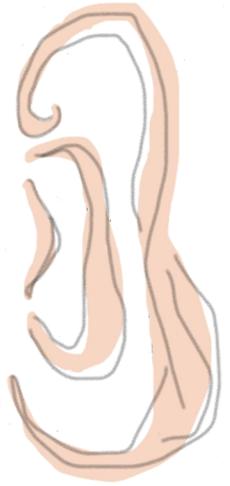
"I wish that different professionals would all talk together"

"It sometimes feels like there's no communication between GPs and specialists. It sometimes feels like GPs want nothing to do with us because we're so sick"

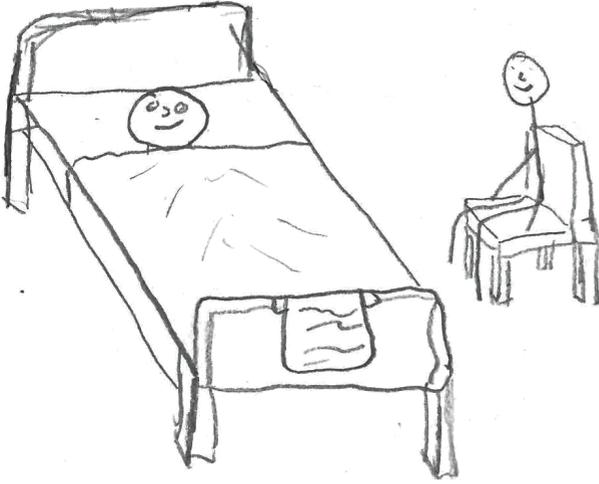
"We get a lot of mixed messages and different opinions from different professionals"

would like  
People to listen

"I think that some people think that because we're younger that we don't understand- that we don't know what we need as much, so they don't always listen to what we have to say"



# We are healthcare professionals supporting people with CKD...

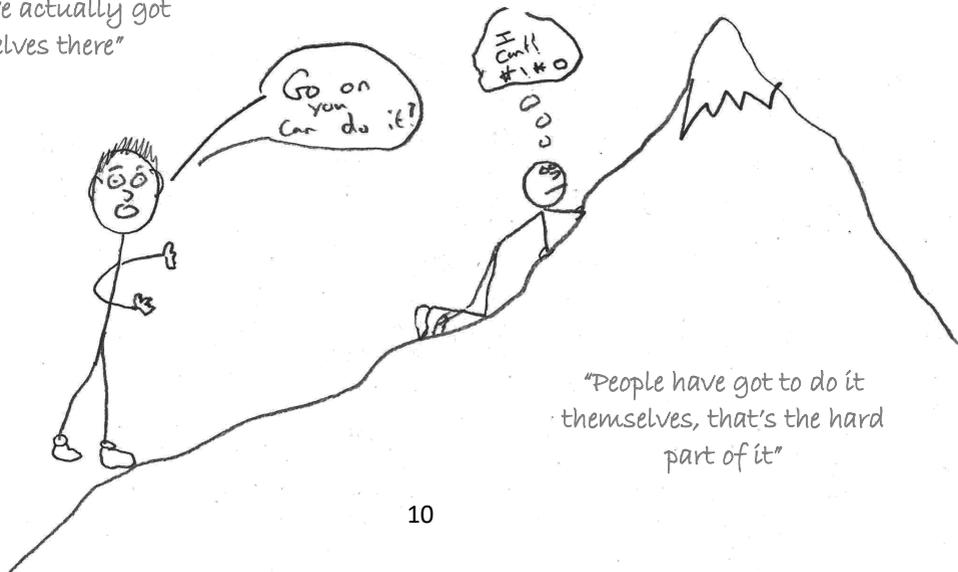


"Management work on statistics and numbers, but you can't quantify being able to help someone to be heard"

"We're expected to show evidence of progress to justify why we're working with someone. Sometimes even just building trust can take months"

"What I wish I could get my patients to understand is that they have all of the control, power, the knowledge there themselves. Sometimes we'll help people through a situation and they'll feel that we've got them to that point. They've actually got themselves there"

"With the pressure to be productive, it's easy to lose sight of the patient in there and that's the most important thing, you're working with people at the end of the day, not statistics"



"People have got to do it themselves, that's the hard part of it"

# We are not perfect, and there are times when we cannot fix things...



"Sometimes we just wish we had answers, and that's really hard at times because we wish we could just solve everything. There isn't always an answer, sadly"

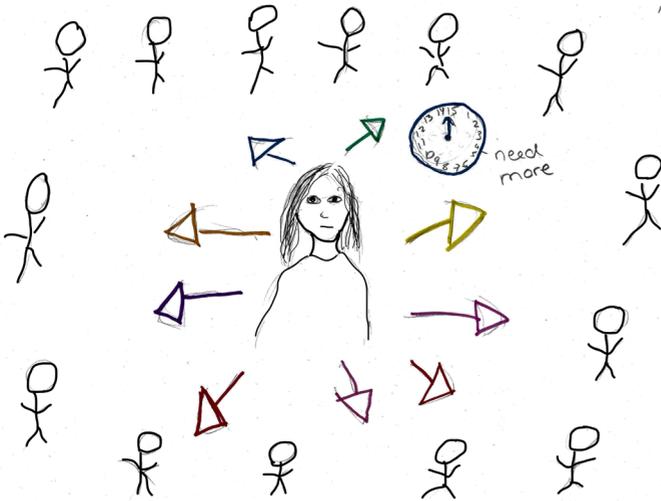


"My biggest thing is that I worry that I've caused someone more distress in a situation. There are times when you just have to be with someone and do nothing and that's what that is "



"We're always just trying to do the best we can do. Sometimes we get it really wrong and sometimes we make mistakes but everyone is just trying to do their best"

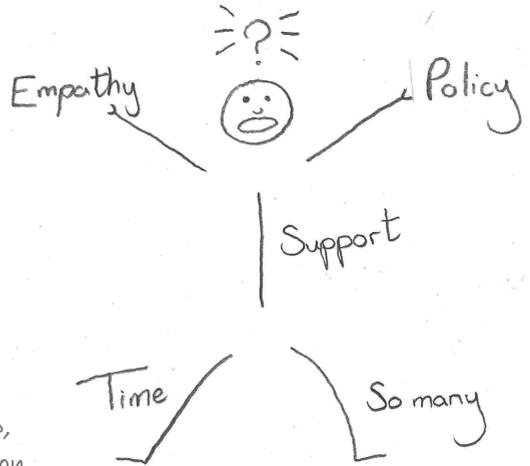
# Sometimes there aren't enough hours in the day...



"You feel like you're just splitting yourself. I've done a clock with extra time because I just feel like I need those extra hours to help everyone. I just feel helpless sometimes"

"There are so many people that I support, I feel like there's never enough time to do a good job with everyone"

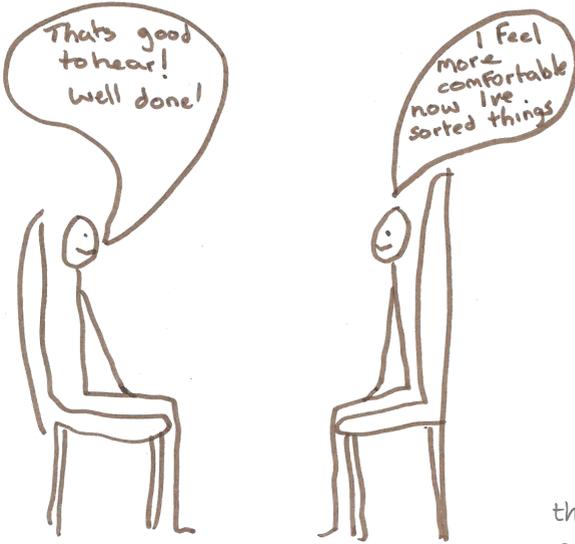
"It's about people being at the right point and right time for them to start talking about things. Very often we're thrust into a situation where it's not the right time for people and we're forced to have a conversation with them at the worst possible point"



"As someone who also lives with CKD, I used to think that having the condition would give me insight. It's actually proved to me that everyone experiences things differently, and goes through their own things. I had to learn I couldn't change the world just based on my experiences"

"It's trying to kind of get that empowerment back in people's lives"

# But we want our patients to know that we will always care...



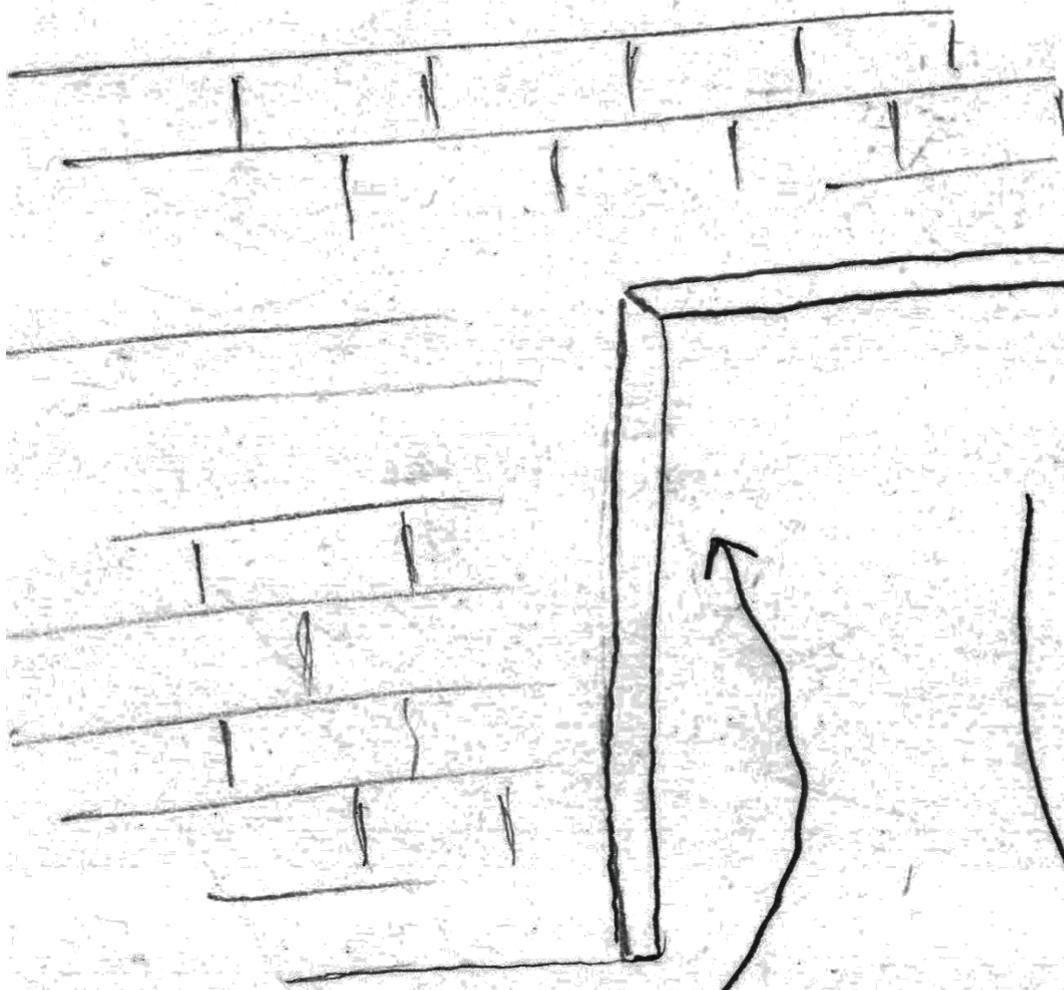
"Something I'd like the patients to know is how much we care about what happens to them. It goes beyond being a job that you do, and that when things sometimes don't go well for patients, it has an impact on us because we're only human"

"It's so difficult to see people in distress or difficulty and it's really natural to want to do something to try and change it. It's hard carrying that feeling that there isn't anything really that you can do to help sometimes"

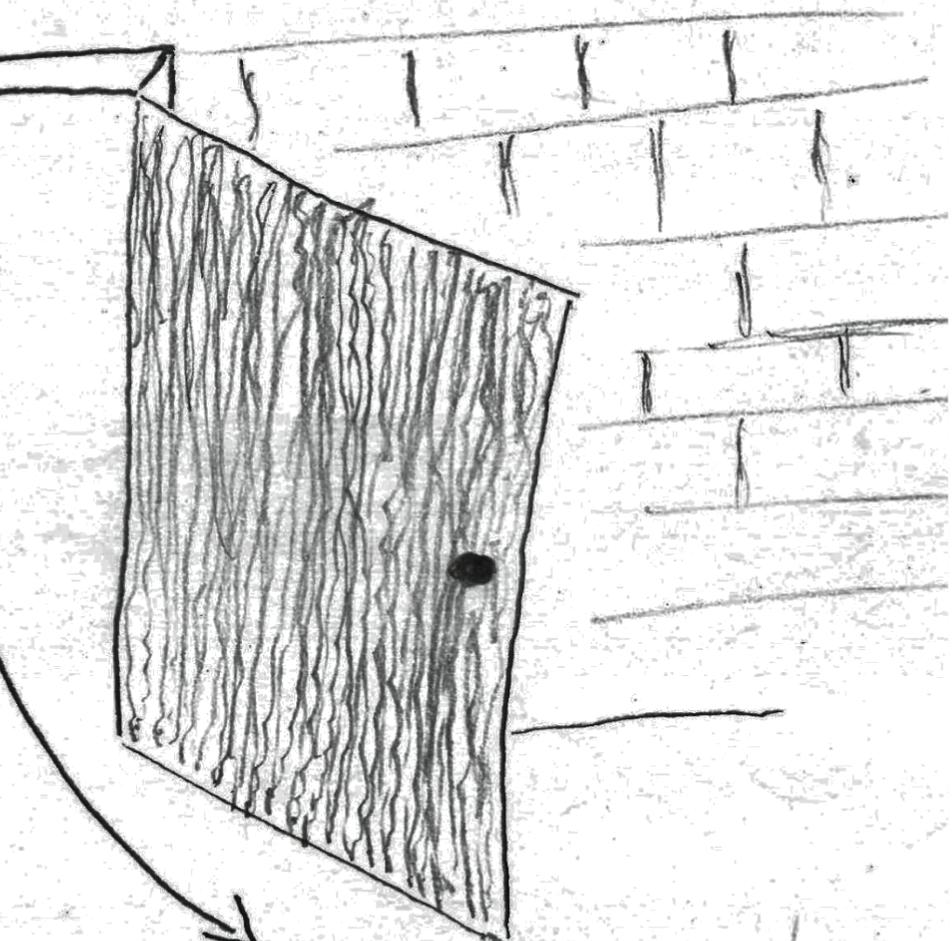
"It's part of the process of coming to terms with what's going on for you. We understand that you are going to go through different emotions and feel angry at anyone and everyone, and that's okay"

"We want that magic wand just as much as you"





Negative



Looking forward.

# Who created these drawings and spoke these words?

## The Patients

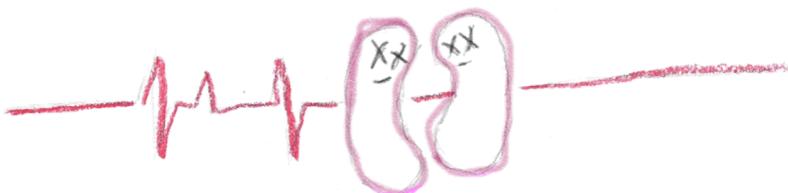
Some of these patients have had a life long diagnosis of CKD, others were diagnosed as teenagers. Their struggles are not always visible, but they are very real and have an enormous impact on daily life.

But **these people are not just a diagnosis**. They are friends. She is determined, and will always give a shoulder to cry on. He loves to party, and always wears a smile. She will always put others first. He is imaginative and full of ideas. They would like to have families of their own one day. He is a self-declared 'mummy's boy'. She loves having her nails painted. He is an expert escape artist. He is a joker and an optimist. They are looking to the future. **They can do anything.**

## The Specialists

The specialists who took part in the workshop are fighting to deliver high quality health care, in spite of the pressures of a struggling NHS.

But **they are not cogs in a machine**, they are humans beings. He is a husband, a father, and a great mate. She loves karaoke and knows all the words to 'Gold Digger'. He will literally climb mountains and jump out of planes for the people he supports. She wishes she could wave a magic wand to make everything better. They know they can't always be right, but they always try their best. **They will always care.**



## Further information and support

### Kidney Wales

<https://www.kidneywales.cymru/>

Kidney Wales is a national charity which fundraises for renal research, care and education to support clinical institutions, patients and their families

### The Can Do Project

<https://www.kidneywales.cymru/get-involved/can-do-project/>

The Can Do Project aims to support young adults with kidney disease in Wales, and emphasises the need to bring positivity to those experiencing CKD by encouraging a 'Can Do' attitude.

### Additional Links

CKD resources & Guidelines: <https://bit.ly/2k90qID>

information about shared decision making <https://bit.ly/2cYuQ72>

NICE guidelines on shared decision making <https://bit.ly/2koyJf7>

### More about DrawingOut

<https://drawingout.org/about/>

The DrawingOut method was developed by researchers at Cardiff University to enable those experiencing invisible illnesses to have their voices and experiences heard, through drawing and metaphor. For more information, or guidance on how to run your own workshop, please visit the website.

You #CanDo  
anything!

