

# COVID-19 and the UK lockdown: new challenges for the renal arts movement in Northern Ireland

The UK lockdown in March provided an opportunity for William Johnston, Northern Ireland Kidney Care UK Advocacy Officer, to further benefit from the renal arts in managing his wellbeing and health

■ mental health ■ renal arts group ■ wellbeing ■ online art

In the UK, 23 March 2020 was the beginning of the official lockdown in response to the dreadful COVID-19 pandemic that has swept the world. This date will be forever infamous in history, as it changed the dynamics of personal, home and work life forever.

New coping mechanisms were desperately sought to contend with this constant threat to health and the enforced isolation and boredom, and, to many, it was a priority to safeguard their mental health and wellbeing.

During the first lockdown, in which I had to endure shielding, my own personal choice was to concentrate on my recently rediscovered passion and dubious talent for the renal arts. As a transplant recipient and Advocacy Officer with Kidney Care UK, there was no longer the freedom to travel to renal units to assist patients, although the Zoom platform did enable me to work to an extent. However, the isolation, boredom and the onset of the dreaded feelings of depression, despair and anxiety compelled me to use this time to complete projects with the Renal Arts Group (RAG), specifically, a play that I had begun writing the previous year. To pursue this, I retreated to my decrepit wooden garden

shed, which, although nearly falling down, is weatherproof, warm and provides ample light. Most importantly, it afforded me the priceless asset of silence to concentrate on creativity, with mobile phones and dogs safely secure in the house.

## The Renal Arts Group

RAG is a collaboration between patients, carers, clinicians, academics and artists to develop a programme of research with the ultimate aim of improving the physical and psychological quality of life of those living with kidney disease.

It was formed in 2016 after a chance meeting with Dr Helen Noble (Nursing Lecturer, Queens University Belfast), where I mentioned that I had written a series of poems while on dialysis that allowed me to express my emotions and feelings and communicate better with the healthcare staff. It was written over the last 6 years of the 17 years of continuous dialysis that I endured before I received my second transplant in 2014, and examines the emotional challenges that I experienced while living life on dialysis and living in hope of a transplant. Dr Noble identified the potential of poetry and the arts to engage with patients with kidney disease and support their mental health and wellbeing, and so we set up RAG together.

## The growth of the renal arts

RAG began to develop quickly from 2016 onwards, and numerous events were held to showcase renal arts, including the

production of a chapter of my first play written while waiting for transplant.

In 2017, Dr Noble successfully secured funding for Claire Carswell, a mental health and wellbeing nurse with a psychology degree, to undertake a PhD aimed at developing and implementing an arts intervention for patients during their haemodialysis sessions. The potential benefits of renal arts for patient mental health and wellbeing were now becoming evident. In 2018, Dr Noble applied to Kidney Care UK to seed fund a part-time administrator for RAG, which led to Anna Wilson joining the group, and this has proven to be the catalyst in the exponential growth of RAG activity. It is also a great example of collaboration between national and regional kidney charities. Since Anna's appointment, several high-profile events showcasing the renal arts have been organised, again supported by national and regional charities.

The highlight event was 'The art of health and wellbeing' at the Sunflower Public House, Belfast, in November 2019 as part of the Economic and Social Research Festival of Social Science 2019. This was an evening at which patients, clinicians and academics had an opportunity to present their renal art, including poetry, art, photography and music, to a live audience, and any perceived barriers between patients and clinicians were instantly dissolved. It was an uplifting evening of fun, admiration, laughter, emotion and, ultimately, success.

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## The impact of lockdown

Despite the restrictions and challenges of lockdown, the activity of RAG continued, always with the primary objective of improving the quality of mental health and wellbeing through the arts.

Claire Carswell, now Dr Claire Carswell, completed her PhD and, along with Dr Noble, is applying for a National Institute for Health Research (NIHR) fellowship to carry out a randomised control trial with her arts intervention for haemodialysis patients across six sites. Additionally, Dr Noble, in collaboration with Dr Carswell, Anna Wilson and the Northern Health and Social Care Trust, has been awarded funding by the Economic and Social Research Council to draw up guidelines for future implementation of volunteer-led art interventions in renal units.

## Online and social media presence

During the first lockdown, a major landmark was the development of the new RAG website by Anna Wilson and the emerging social media footprint of RAG on Facebook, Twitter and Instagram.

The website has revolutionised access to renal arts activity and provides a platform to showcase research projects and patient art displays, as well as a vehicle to collaborate with other renal patient platforms such as Kidney Care UK and Kidney Beam, in which renal arts can be shared to complement the already exciting health and wellbeing interventions.

## Digital arts activities

Due to the ongoing pandemic, in-person art workshops are no longer possible, but online art activities provide an introduction to a range of art forms that patients will find engaging and enjoyable. The arts activities will include printmaking, drawing, songwriting and creative writing. Accessible by the website, the arts activities run once a month and began in October 2020.

## The starman, the superhero and the wizards

As I mentioned at the beginning of this article, lockdown compelled me to return to completing a play that I had been working on for the past year, titled, 'The



The Renal Arts Group logo

starman, the superhero and the wizards'. It is a play that was originally written to educate people about living life on dialysis and to promote organ donation. It has since evolved into investigating the daily restrictions and mental health challenges that are experienced by renal patients waiting for a transplant and how receiving a transplant can re-define new challenges.

With over 17 years on continuous dialysis, I had many operations—small and large—that left me with scars around my body: catheter insertions, necklines, fistula constructions, kidney extraction, kidney transplants, to name a few. These scars represent my physical battles. However, the hardest battles I fought during my many years on dialysis were the mental battles, and these battles also left many scars to my mental health—invisible, but still so powerful. These scars include loss, isolation, despair, anger, fear, failure, guilt and pain.

Through the play, I wanted to examine how these scars—both physical and mental—impacted life, both before and after receiving a transplant, and how these could be managed. The 'starman' in the title is the transplant recipient, as changing the 'C' in 'scar' to a 'T' spells 'star'. The 'superhero' is the donor who saved so many lives. Lastly, the 'wizards' are the medical surgeons and certain individuals or reasons that assist in managing the mental scars incurred through the renal and transplant journey.

In 2019, I initially wrote the play as a 12-minute piece intended for social media. However, the short play was picked up by the Northern Ireland Arts Council, which saw its potential and provided funding to allow renowned playwright Shannon Yee, to be a mentor for my work.

During the first lockdown in March 2020, with input from Shannon, I began writing a full-length play with a deadline for completion at the end of July 2020. After many hours cocooned in my garden shed, the script for the play has now been completed, and in mid-November will be at the stage of the first readthrough by well-known Northern Irish actors, with a view of having it performed virtually online in March 2021. However, it is hoped that, later in 2021, when the COVID-19 pandemic may have eased, the play will be performed live in a Belfast theatre.

The writing of the play during lockdown has been a godsend for my mental health and has given me a purpose and a sense of pride. I believe in the potential of renal art to be a valuable resource and asset for managing individual wellbeing and mental health, especially with how the world will have changed post-COVID-19 pandemic.

William Shakespeare may have written three of his best works (King Lear, Macbeth and Anthony and Cleopatra) during the plague in 1606—maybe William Johnston has written his best work during COVID-19 pandemic. I can only dream! **JKC**