Beyond Captured Time

A Series of Artworks and Writings by

Frank Curtis, Johanna Tanner & Philip Cullen

Created through the
Waterford Healing Arts Trust programme
in the Dialysis Unit of Waterford Regional Hospital
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Contents

Introduction 5
An Artist’s Perspective 6

Poems by Johanna Tanner
Secret 12
Greed 13
Bereavement 14
The Healing Artist 15
Renal Machine 19
Forgiveness 21
Artist in the Making 23
The Manager 24

Prose by Johanna Tanner
Caw Caw 26
Shirley 30
Renal Road 32
The Boreen 36
The Kink 38
Dialysis 41
Lourdes 45

Artist Biographies 53
Acknowledgements 56
The Renal Dialysis Unit in Waterford Regional Hospital is an 18 bed unit that accommodates 106 chronic renal dialysis patients. It provides a 24 hour service to people living in the South East of Ireland. Each client attends for approximately four hours, three times per week. Due to the restrictive nature of the clinical activity, the unit is keen to engage patients in creative experiences and in so doing transform the dialysis experience from an empty negative space to a positive productive one.

Since 2006, the Waterford Healing Arts Trust (WHAT) has delivered an arts programme in the Renal Dialysis Unit. This has been made possible by funding from the Punchestown Kidney Research Association. Patients have an opportunity to engage with trained arts facilitators Boyer Phelan and Philip Cullen. These sessions take a patient-centred approach.

In September 2008, artist Philip Cullen began working in the Renal Dialysis Unit where he met patients Johanna Tanner and Frank Curtis. Philip works creatively through a range of arts disciplines including writing and visual art. Over the last three years, Philip gently guided and encouraged Johanna to write and Frank to draw. In 2009, Frank, Johanna and Philip displayed their work in Waterford Regional Hospital in an exhibition entitled Captured Time.

This book which accompanies their second exhibition at Waterford Regional Hospital features a series of poems and stories by Johanna documenting her journey as a renal patient, drawings by Frank of the people he meets while attending the Dialysis Unit and artworks by Philip made in response to Johanna and Frank’s creative journey.

Claire Meaney
Waterford Healing Arts Trust

Brenda Ronan
Dialysis Unit
Waterford Regional Hospital
An Artist’s Perspective

‘It is in change that we find purpose...’ Heraclites

Philip Cullen

When I walked through the security doors into the Renal Unit, for the first time back in 2008, I felt anxious and excited. I had no knowledge of what might happen, who I would meet or whether anyone would even be interested in what I had to offer. I also worried that the process of dialysis might be difficult to witness.

Claire, who is the Assistant Arts Director in WHAT, walked me through the ward which is L-shaped, busy, full of machines, beds, people and a plethora of staff in a variety of coloured uniforms. It is full of windows, bright and very warm. Beside each bed was a salad-cream coloured machine festooned with tubes, buttons, screens and attachments.

Claire introduced me to Brenda, the nurse manager, who then took me on a tour of the ward. We talked to all the patients as she offered my artistic services as a way to pass the time. She explained to me that dialysis takes four hours on average, three times a week, and that it was difficult for patients to lie there for that duration, very restricted in movement. With WHAT, she had planned an art project simply to help, whoever wanted it, to pass the time.

Johanna was in the bed at the far end of the ward, writing in what looked like a book of crosswords. She was beautifully dressed, with a lovely smile and her quick agreement to undertake some artistic activity put me at ease. There began a journey that has taken us to this very day.

Brenda continued our tour and we talked to more patients. We stopped at the bed of a pleasant-mannered man. In a smooth and unruffled way he said that he had always wanted to try drawing but his only experience had been up to Inter Cert at school. With a wry smile he agreed to start next week. On that first day there were three patients who were willing to try some of the activities. The project was initially to last for a short period of time.

I have since come to the dialysis unit almost every week for two and a half years.

In the beginning the renal dialysis machine was as significant as the person. I would warily eye it as if it were some benevolent beast that might be dangerous if awoken. This complex apparatus takes the place of a vital organ; it is a life-giving wonderful thing. I was terrified of tripping over a cable or tube. Brenda suggested I sit at the opposite side of the bed, safely out of the way of the medical process. Over time though, I began to see the person far more than the machine that they were attached to.

Despite the chronic condition of patients, the unit is often a place of warmth and fun. I know that no working environment or hospital ward is perfect. There are always stresses, strains, sadness and loss but I have found it to be a place of warmth, care and at times full of tremendous hilarity. A light snack is served in the middle of the dialysing process, often by Nora. Skilled as I am with language and working with people, I am no match for her. Vanquished in a storm of craic, innuendo and drama I can often only hopelessly smile and pray for the storm to pass. I am like a rag in a gale, while various patients and even staff stir the pot for greater effect. Some patients have told me that they love the fun she and others bring, that it makes the heavy burden of time pass more agreeably.

I worked with other patients over the years and had many enjoyable experiences. They told me stories about their lives, the disease and their creative desires. Unfortunately time was limited, my hours fixed and patients had to leave due to timetabling and taxi filling requirements.

I believe in the power of creativity, that each of us is creative and our limits are unknown. When I spotted talent in Frank and Johanna I encouraged it and pushed them to develop. Frank’s first drawings were attractive but naive. He was a very willing student and methodically practiced for hours each dialysis night. We looked at tone, line-drawing, negative space, perspective, texture and different styles. He expressed a desire to draw people. I showed him the basics of portrait drawing. Then I and others watched in amazement as his works developed in complexity, skill and accuracy. Each week I offered feedback and suggestions upon how to improve. He was hungry for correction and
Brenda made the working environment welcome, insisting that the art project was important and valuable. Staff members on the unit have always been kind and helpful. Without the structure of agency, management, artist, willing participants and a supportive ward, a project of this kind cannot happen.

As an artist, I often seek beauty in the far away landscapes of the world, or in my own mind. A man once said to me “Seek the extraordinary within the ordinary”. My friend and mentor Trevor Scott quoted from a philosopher saying that “true art is a balance between the head, the heart and the hand”. I was once told that “success in life is in helping others to stand in your shoes and in you attempting to stand in theirs”.

With these three principles underpinning my approach I urged Johanna and Frank to record what was around them. I asked them to observe the staff and patients, to help those of us who do not know what it is like to be a renal patient to understand, to help us to stand in their shoes. We three began to look for the extraordinary within the ordinary.

I mined Johanna’s philosophy as expressed in her language, for themes, and in Frank’s love of portraits and his desire to capture accurately the person he is drawing. I supported him to undertake ‘Drawing on the Right Side of the Brain’, a book by Betty Edwards full of exercises to increase one’s basic art skills. I continued providing feedback and tips on the portraits of staff and patients.

I supported Johanna to move from poetry into prose, into telling her story, into helping us to stand in her shoes. “But who would want to listen?” she asked. I assured her that there were many of us who wanted to hear what she had to say.

I chose to paint Johanna and Frank in acrylic, from low-resolution mobile phone photographs. I outlined the shapes in black because dialysis is an intense environment, a place of life and death, where machines, nurses and doctors replace the function of a vital organ. I filmed the dialysis process and created music for the short video entitled ‘Flow.’ I have carved two small abstract shapes in Cork marble to represent kidneys.

My artwork Between Time and Space represents a theological acceptance of suffering. This came from a series of discussions initiated
The Renal Unit is an extreme place. Within this environment comes humour, wisdom, patience, acceptance (or not), as well as a variety of difficulties, strong emotions, depression and despair. People sleep, read, chat or watch TV while their blood is removed from their bodies, cleansed of toxins and returned.

Beyond Captured Time is art, love, metaphor and an expression of life. It is the summation of countless hours of effort, thought, experience, risk, discussion and endeavour. I sought the extraordinary within the ordinary and found more than I could ever have imagined.

Blood swirling, foaming
Through tubes and valves
A bitter tang sometimes
Clatter noise all around
Mechanical and human
A strange symbiosis
Noisily attendant
At each disinterested bed
Words written, spoken, read
Create a dizzying crowd
A sudden calm
Quiet murmurs and beeps
Nurses soft-footed and spoken
Gentle machines
Sometimes the sun casts an orange light
Into this mechanical monk’s church
And we are all blessed

Philip Cullen, April 6th, 2011
Secret

More wounding
Than the surgeon’s
Knife
That pierced her chest
More sickening
Than the cancer
That drained her health

Targeted and isolated
A secret
Not to be revealed
Until the curtains
Close

An aged hand
Did sign away
Trust
In ebbing sands of time must
Cease its play
To an empty shell
Of forgotten grace

As the sword
Of the spirit divides
Truth presides
Startled and surprised
The hope of solstice
Light
Of long and shortest
Time
Moon beams
The starlit night
Revealing the concealing
Darkness
Of the hidden.

Greed

Need that leads
To greed
Impatient its path
Opportunity its field
Would fain to have
Appropriate apace
At any price

Greed beyond need
The avarice eye
Beams
Charting a course
Of unending seeking
Selflessness did bleed
Through the wound exceed
No conscience
To impede
Bereavement

Numbness banks the lids
Of unshed tears
Of dull and stricken eyes
Staring into nothingness
Reflect the incomprehensible
The intellect carving through
The reality presented
In the loss acknowledged

Wandering around
In a fog of pain
And confusion
The time-line cycle
Of negotiating emotions

Alone with denial
Anger in tow
Bargaining to ransom
Depression may show
Gift of acceptance
Not afforded to all
Happiness in abeyance

Gradual process
Towards longed for peace
When hope regains
Its place
Stabilized to a new
Lifestyle
Immortalize good memories
Love’s last gift to us.

The Healing Artist

A man with a purpose
Sanded in an alien world
People with machines
Attached to them
Alarms sounding
For prompt attention.

What ailment brought
Them here
Though the body is imprisoned
The mind roams free
To create and integrate
A talent to unearth
In time to liberate.

Relinquished is the busy life
The copious cares that abound
Balance within has
Ceased its rhythm
Time to accept patiently
One’s disabled self
Unshed tears glisten.

He held the lantern
That illuminated
A path in need of clearance
Of doubt and delay
To find the time
To listen to the voice within
To hear what this soul
Has to say
Let the pen move and
Find its way.

In gentleness and forbearance
The Healing Artist (continued)

In gentleness and forbearance

In the fruit field
Of profound listening
Of appreciative, true
And honest words
The treasured gifts
Of his mind unwound
Through the sharing
Of creative thinking.

Words danced again
And had their form
Choose to immerge
As one awoken
Imagination and recall
Twilight memories
Once dormant, now healed
Arose to march and trod
The halls of history.
Renal Machine

Beside my bed
This rigid robot stands,
Awaiting our connection
To bring it to life
And give me back mine.

Visual screen of health displayed
External workings of machine.
Internal workings of the body
Profile and pressures read.
Warning lights shine,
Musical alarms; its voice.

Join together vein and artery
No access to life if
Bloods not mixed at fistula point.
Arm extended on scar site,
Needles remain injected.
A necklace of clear and red tubing
Pulsate to heartbeat rhythm.

To a bee-buzzing sound
Two wheels, one turning
Blood pump pulling
Haemo lines carrying ruby liquid,
From its host
And back again
Purified,
Beleaguered bubbles carried safe
To entrapment chambers.

One arm, steel stand,
Holding liquid saline.
Beneath it, clasped, the dialyser;
The machine’s kidney.
Its snow white solution
Forgiveness

Choosing to forgive
An act of the will
Made apart from
The person who hurt us,
It doesn’t depend whether
They repent, need or deserve it.

It’s a gift of obedience
Forgive us our trespasses
As we forgive those
Who trespass against us
Mercy received
Mercy extended
Love conquering
For the same measure
That is meted out
It shall be measured
To you again
Total forgiveness.

Renal Machine (continued)

Its snow white solution

Now pink in reaction,
Extracting what’s harmful,
Keeping what’s needful.

Four hours finished,
A cleansing mournful sound
In sympathy with its co-dependant,
Flushing, rinsing, expelling
What absent kidneys once performed,
A memory.

Man’s mechanistic gift for life’s extension
Mirror a mercy and redemption.
Loss and gain now of new meaning
From womb to ancient years
Life’s days are counted
By eternal creator’s will.
With inventor Kolf
We live them to fulfil.
Artist in the Making

With stoic patients
He held the pencil,
The imprint of carbon
On sheets blank of impression
He formed a profile.

A mind slowly
Transfigured
By each stroke
Accomplished
To see with the heart
His essences
Was found.

Observing and concentrating
Erasing and adding
Sketching alone
Portraits of people
He has grown to love.
The Manager

Seeing the need
she is there
aware
of undiminished
constancy.
The prudence of
restraining lips
she listens
when words are
many
transgressions are
not lacking
offering to do
the smallest thing
for the glory of God
a golden heart
distributes
him.

Brenda – Frank Curtis / Pencil on paper, 36 x 27cm / 2011
and used to hard work, and white-haired Sally was taller and stronger. My father gripped the handles of the plough while holding the reins from both horses. Every now and again, he would look behind to check if the line was deep and straight enough. What he saw were masses of crows, pecking unearthed worms and grubs. Overhead the shrill sounds of circulating seagulls and the intrepid crows cawing in delight, waiting to alight and partake. He would stop after some hours working to have the tea and sandwiches we brought to him and to give the horse’s water, grass and a rest. The nearest crows got the crusts. They remained long after the seagulls had left. To protect the seeds when planted, a scarecrow was placed in the middle of the field. We all contributed to make it as realistic as possible with old clothes, a hat, a dried out mop underneath and a cloth bagged face with facial features inscribed by marker. It worked for a while until the seeds became plants. Then one day we went out to see a raven placidly perched on the reduced and weather-beaten scarecrow. He was observing the terrain. The largest of the family of crows, measuring three feet from beak to feet, ravens form groups as juveniles, pairing off to become lifelong monogamous pairs. Another alighted on the other shoulder - it was time to take down the scarecrow. It had lost its scare.

The autumn field was often black with numerous crows and their many cousins – ravens, rooks, grey-backs, gathering for the harvest feast, the remnants of a bumper crop of barley and oats. They ate late into the evening. On one particular morning I recall, the hens were enjoying morning grain and offal scraps, scattered on the farm yard. The crows alighted on the telegraph wire. It wobbled as each crow joined the line up, all awaiting the opportunistic dive to scoop the prized morsels. A successful crow flew away with a large beak-full of bread. The murderous group followed to prize the bread from him. A tug of war ensued with the victor relegated to carrier. Undaunted he returned to his vantage point and tried again. This time taking no chances, he picked a smaller piece which he promptly swallowed. Edging their way forward, I was amused by their ungainly walk, their bodies moving in union with each step. Then they hopped to the target, a quick scan about in jerky neck turns, they secured the snack and flapped away. Their wing revolutions seemed slower than other birds. The wide black fan like feathers made swishing sounds that one could hear in the silence.

Caw Caw

‘Caw caw’, the familiar and welcoming sound of the crow, interrupts my solitary ramble, and brings to my mind many scenes held in my memory. I stop to watch the sideways dance he makes towards a meal spotted from on high. He keeps a wary eye fixed on me while eagerly devouring the feast, as yet undiscovered by the other crows. Raucous calls announce the arrival of more crows to partake in the unexpected meal. Excitedly they peck at the ‘fast food’ while smaller birds hang about the periphery awaiting their turn. A deeper caw, a thicker beak, a bigger body, more ruffled feathers denotes the elder crow that struts forth, confident that it’s safe to peck with so many of its kind. There is always one, a brave young crow that boldly hops forward in defiance seeking to take the remaining bit from one above his rank. He hastily retreats but not before he receives a sound peck to the head. With everything consumed they depart, all too soon for the eager observer.

Since childhood, crows have always held a fascination for me. When I was about ten years old, I resolved to catch one of these comical and interesting birds. Living on a farm, I had ample opportunity so I devised a plan. Knowing that I would easily fit into one of the empty barrels which often stored grain, I concealed myself within. I placed a sack over the opening with some bread in it to operate as my bait, while I hid underneath the sack in still and quiet anticipation. Eventually after what seemed like an age, I noticed the sack sagging a little. The recognisable indentations of bird feet meant it was time to move. I sprang up with youthful energy and grabbed its feet and held the startled creature in my grasp. I knew by its shrill cries that I had indeed caught my crow. The trapped bird struggled to pull away as I revealed my face to him. I was forced to hold him at a slight distance from me as he responded to my delight in a pecking mode. I held his wings to prevent his flight and stroked his shiny feathers with breathless excitement. His keen dark eyes locked onto mine in stunned observation, as I looked back at him in admiration.

A pair of horses, Cob and Sally led my father’s plough, straining forward with each step to break the ground. Cob was brown haired and low sized...
An unusual dark coloured fox moved niftily across the field. A murderous group of crows followed him close behind, clearly agitated as they flew above its head determinedly until it disappeared into the forest.
The noise was different to the cumulative one when they collected for their council in early spring before nesting began, when trees were claimed and lifelong partners too. The collective chorus sounded like a heavy discussion, instinctive and learnt behaviour was passed on from generation to generation.
The injured crow lay on his side after being hit by a car. One wing looked decidedly out of place. He made a vain effort to get up, flapping his good wing, which made him look even more pitiful. The desperate situation noted by his companion crows saw them circulating low overhead, swooping near him and landing on a nearby fence to observe and caw in helpless distress and sympathy.
This was my second chance to acquire a crow, this time to see if I could help. Approaching gingerly while the other crows flew away, he instinctively tried to move from my outreaching hands. How light he felt when I lifted him – I used my youthful experience in handling him. At home the family encircled the injured bird to give their operative opinions on the best procedure to fix him; a piece of stick was attached to his broken bone. The wing was immobilised and he was put into a makeshift cage with some water and crumbs, he wasn’t interested. As the weeks went by, he became our favourite pet, his fear lessening. We tempted him with still wriggling worms for protein, which vanished only when we weren’t looking. He became more alert as he healed, pecking at the cage demanding food. But he remained silent. One day, we brought him outside for fresh air; he sharply looked around, his beak raised to see no welcoming party. In a short time, a row of silent crows lined the telegraph wire and watched. Throwing out some bread, they eventually flew down, the noise and flapping of both wings and the long awaited caw. Our patient made a din in the cage, nearly knocking it over. He was wild and belonged to the wild; it was nearing time to set him free. We picked a day shortly after. Outside we opened the door of the cage, nothing happened. We waited encouraging him as if he could understand. Finally he hopped to the opening and didn’t waste time in ascending. We waved goodbye and wondered if we would ever see him again.
From time to time after that, seeing a lone crow on the overhead wire, head focussed downwards on the yard while swaying and balancing in the breeze, we wondered if it was him.
Major Hanlon’s private estate, near where my husband grew up, was a paradise for crows. The Major was owner of the Old Mill nearby. Numerous, tall, majestic trees surrounded by a nine-foot high wall provided a permanent address for these social birds. Here they congregated en masse in raucous discourse for the well known crow’s council. As they settled down, any latecomers were met with a resumed cacophony of sound, as if in simultaneous complaint and welcome for the late arrival.
The pale blue and spotted brown of the crow’s egg is a prize beyond all for the collector. The neighbouring children would gaze in awe as the more adventurous amongst them would attempt to scale the forbidding trees. It is an unwritten rule to only take one from the nest and leave without any sign of disturbance. This delicate object is carried in the mouth in order to navigate down the branches with both hands from such heights. With flushed face and wide eyes the child reveals the coveted egg. He then later exhibits it along with a variety of other birds’ eggs, all identified with labels.
The estate changed hands in time and was bought by a religious order. The new inhabitants worked in harmony with nature. Life of nature was uninterrupted in its cycles of peace until it was sold to a food factory and the crows’ palace was felled to make way for ‘progress’ and financial pursuits. The untouched beauty had no place in the plans of progress. The spirit of the estate had flown with the evicted birds; all that remained was the concrete coldness of the mechanistic action of the factory – no thought for amiable co-existence. The crows, a barometer for our changing times, retreated to less ideal areas.
I first met Shirley in the surgical ward two days before I had to undergo surgery. It seemed she was well known by everybody there. This lady was a live wire, agile in spirit, but got around by wheelchair; she gravitated towards my bed and inquired curiously as to what I was in for.

‘Partial or total loss of my remaining kidney,’ I said. Her expression registered the most sincere kind of acknowledgement. As it turned out she had no kidneys.

From Shirley I would receive a map of my future living; her insight gave a perspective on how to sustain life without kidneys. She talked at length about her wonderful husband, of his help and understanding. Her account would later mirror the strength of support I was to receive from my own husband Richard.

After telling her about my condition and the surgery ahead, she said ‘my thoughts and hope are for you. You will have life after this, with changes of course, but without your kidneys there will be no life. You are very brave with your lovely smile, I will be praying for you... all the very best Johanna’.

I was deeply moved by our encounter and I thanked her, assuring her that I would keep her in my prayers also.

‘You keep praying all the way,’ she said. She gave me a hug. ‘We are like sisters now, there for one another.’

Shirley was an encyclopaedic guide to any renal problem you might think of. I was left in no doubt about the effect of potassium on the heart or the phosphate levels on the bones and their food sources. We talked about adjusting to dialysis and the renal diet and she gave me my first introduction to the measurements of fluids. I would have to reduce my fluid intake by 600ml, including sauces, and avoid salt and potassium – they’re potentially lethal and the build up of them in the body can cause heart attacks. I would have to boil potatoes twice, bring the first water to the boil, empty it out and then refill again, covering well over the potatoes with hot water, and finish boiling. No steaming, no frying, no crisps. I’d have to monitor my intake of dairy products - the phosphates contained in them would attack my bones.

Shirley was trying to prepare me for what I would eventually hear in a more detailed way from a renal dietician. There was an incredible amount to take in. Habits and preferred tastes of a life time would have to change.

Explaining to Shirley how I had looked after my mother for the past eight years, she said that there way is no way I could take care of anybody, I would have to rest.

‘I usually feel tired for about two hours after dialysis. There is certain weariness in the tiredness, rest is the only answer,’ she told me.

I also mentioned the pain at the back the neck which can get severe. She recognised this immediately as a kidney headache, the tiredness and fatigue and being pale was a result of kidney disease. She was a godsend. So many of my apprehensions were dealt with and I could process my acceptance of the inevitable. She wheeled around the ward with a kind word for every one, shared a joke if there was an opening, and then wheeled herself out for fresh air ... and a smoke.
much in my mind. This visit dispelled any illusion I grimly held on to. His delivery was again kind but forthright. ‘If there is only a quarter of your kidney left, it will not be enough to sustain you for long. You may get some years with support from the kidney unit in Waterford. With these monthly blood tests and monitoring the functionality of the organ, we will find out whether it is maintaining itself or becomes sluggish or goes into decline. Also, there is no consideration for a donor kidney until after three or four years when medical doctors are absolutely sure that there is no cancer in the body.’

This was indeed dismal news on my prognosis. After six months of continual bad news, I wondered if I would ever hear good news again. Physical pain is easier to endure than when vain hope is extinguished.

A nurse co-ordinator who liaises between the patient and the surgeon brought me up to date on how I was preparing for the major operation and all the procedures carried out so far, including blood tests done by a haematologist in relation to kidney function. My hopes again rose like a graph when she said, ‘it wasn’t too bad, better than expected.’ It was a lot better than the word ‘sluggish’ given in the early stages of diagnosis. I

The Operation

It was the 28th of May and all of nature was flowering in celebration of the coming summer. I was preparing for the months ahead too, but in a different way, in the cross of acceptance.

I arrived in hospital two days before my impending partial nephrectomy. As I was already down to one kidney, all that remained for me was a slim hope of saving the main part of the second one. These days of preparation were filled with a series of visits, from the hospital chaplain to the surgical, medical and renal teams. Preparatory procedures were carried out, from blood tests to angiograms, whereby a needle with a fine tube attached was inserted into my femoral artery. A dye was injected which in turn travelled around the vascular system. The organ of focus was my right kidney. The dye showed how the blood vessels and veins were working. In the case of disease and areas that were blocked, impaired function was shown and this informed the surgeon on how to proceed, and whether or not ‘partial’ should become ‘radical’.

On the eve of the proposed surgery the Consultant Surgeon called early at 7.40am during his doctors’ rounds. His purpose was informative. He again told me that cancer cells have invaded the surrounding tissue of the tumour – ‘the kidney will have to come out!’ His very dark brown eyes never left my gaze as he made sure that I understood the reality of my situation. I assured him I did. Looking back it seems that I was given a little information at a time, just so as to allow the tune of each new rendition of the surgeon’s recital to be justly appreciated.

The registrar of the surgeon who admitted me informed me that with kidney disease there would be poor amounts of iron in my system, causing loss of haemoglobin and low energy. Four units of blood were ordered there and then. We chatted on the importance of the human side of medicine, which together with medical knowledge aids diagnosis. He said in his country of India, medical schools place equal importance on medicine and the humanities.

Later in the day, during the pre-op, a medical Consultant came and introduced himself. I was mildly surprised as I was focusing totally on the surgery ahead. The hope of a partial removal of kidney was still very

Renal Road

by Johanna Tanner
asked the nurse about the nature of the surgery - 'the opening will be above the waist front to back', she told me, 'sutures will close the wound and will be removed after ten days. Restrict movement for eight weeks after, including lifting anything stressful after surgery. The surgeon will tell you the results, or a member of his team. Diet will be given depending on the outcome of the surgery'.

Another member of the surgical team came late morning. He told me cannula number two will be inserted during the operation into the subclavian artery and jugular vein to facilitate probable haemo dialysis. ‘You will be under when the cannula will be put in and may spend the night in post operative care.’

The Surgeon called at 8.00am. Viewing results of the scan, he was not hopeful for success of this operation. He said he was putting in a dialysis shunt in case of necessity. He informed me that haemorrhage and leakage and the complex area of the tumour made him cautious about the outcome.

A flood of good wishes, prayers and candles, enough for a runway, were a constant source of strength from family and friends. The renal nurse co-ordinator prepared me for the inevitable. She said that the surgeon said that there were few cases that gave him sleepless nights and this was one of them. I told her that I felt for him giving me the bad news.

The decision to remove my whole kidney was taken after the MRI on the eve of the operation. The radiographer said that the tumour had grown bigger and was an aggressive renal type and also the cancer had invaded the renal veins. This enabled them to make the final decision. In reflection, I’m glad I had embraced both options, and now, the inevitable outcome beforehand. Before he left, he pressed my arm and there was a change, though brief, in the look of those lovely dark brown eyes from professional scrutiny to one of compassion.

Now I had to process all the information I had received up to date. ‘No, not dialysis,’ I protested internally. It would mean the end of life as I knew it. Freedoms, little and great that one takes for granted, would be curbed.

No need to consider how one eats. Now I’m attached to an alien machine taking liberties with my blood. This would involve three days a week out of my home to keep my date with my mechanical kidney. I grappled with the sense of isolation I was experiencing, the uncertainty of the future and the constant feeling of illness.

I questioned who would look after my mother now, who needed daily care. The attention she needed had increased in the eight years I was caring for her. My volunteer work at the wheelchair shop once I recovered was at least allowed and that left me feeling normal for a moment.

I remember also a nurse friend of ours in her fifties who was on dialysis for less than one year who un-expectantly died. Would I have a similar fate, how would it affect my family and their willingness to accommodate changes? I now had to negotiate the psychological feelings of being useless or a burden to my family after an active life. Would I even play music again? My instruments had felt too heavy to lift for some time. Did I want life to continue? Instinctively, affirmative! I would embrace life in all its difficulties and diversities with the help of God.

On the operating day, I was on standby for theatre, as a bed in ICU was necessary post-operation and the team had to be sure that one was available. My call came at around 12.30pm, pre-med was already given. I realised that I needed ‘to go’, as I prepared to leave for theatre. It dawned on me that this would the last time I would take part in this natural ritual. With a sinking feeling I realised nature’s organ for the filtering and the balance of minerals in body would cease. I felt the internal tears of loss as the last drops of urine fell from my body. I allowed the familiar liquid sound to fill my ears for the last time.

About four hours later, I woke up in ICU and was told that the operation went well. All the cancer was removed, and also the thrombus of cancer in the renal veins. My sister Mary on holiday from Spain, where she lives, and my nephew Jordan sat in vigil holding my hand all night. During the many emergencies undergone that night, I was aware of their presence and strength as I battled through each crisis. I spent two days in ICU living in the half light. With constant, excellent care and pain-control, I returned to a single room to see a single tall sunflower staring down on me from my daughter Siobhan. To me it was symbolic of joy and of the confidence my family had in my recovery. After settling in, a fellow renal patient named Shirley who had befriended me came to see me. She said ‘you are very brave and things will get better for you Johanna, you will see. All the best and I will be thinking of you always’. The impact of her personality, her joy and her positive approach to life, despite its challenges, has remained with me ever since.
The entrance to our house is by way of a boreen that cuts through a farm, and then a forest as it glides downwards toward home. The road is an ancient one that had been pock marked with pot-holes which I often compared to ‘craters on the moon’. I would walk up to the top of the boreen to be collected by the taxi for dialysis just to avoid the chance of damage being done to their cars, and hence their livelihood. This situation was resolved one year later when divine providence took a hand in the form of the co-operation between County Council, the Forestry and ourselves to lay a new road of tarmac transforming the old boreen into an exemplary smooth surface.

As I make my way along the newly laid boreen, I recall the first time I walked to meet the taxi. It had been an autumn evening and as I avoided the water-logged holes a light mist had descended revealing cobwebs laced through the fur bushes. Fir trees on one side cast shadows as the light of the evening sun shone through them. How vivid too is the shadow of the cancer that shaded my life back then, and the un-ending question; was it gone or would it return again?

On the sunny side of the boreen, I remember, a robin perched on the handmade post-box fashioned by my husband Richard. I stopped briefly to observe it, a blink-less stare held mine for a time, then chirped and flew to another site. I pondered at its freedom as it flew away. I decided to check the post. Once again my gratitude surfaced as I handled the get well cards, Mass bouquets and letters of well wishing and encouragement.

Our two dogs, Peepaw and Ragnar, had run on ahead expecting the usual forest walk. The grey cat Mow followed behind, complaining of my leaving and perhaps of the rough surface also. All were confused when I entered a strange car awaiting me, and seemed unsure as I ordered them home. I met Ann, my driver, for the first time, a lady with a kind smiling face. So began a special friendship that would extend to her lovely family.

Now, returning to the present, the scent of pines assails my nostrils. I sigh and thank God for being able to walk this boreen safely and without careful watching. I am able to meet my future, whatever it might bring - at least I have some future after all of the surgeries. The rough road, for me, has become smooth in time.
The Kink

Life at the time was surreal living from procedure to procedure. My only association with the world of everyday activity was through hospital windows, my mobile phone, letters read and re-read and warm, sustaining visitors.

Having experienced ‘lines’ put into my neck in the subclavian jugular and later in the femoral artery going to theatre for a realignment of the catheter with the ‘kink’, was just another variety of experience in the vascular access which is the life line to the machine for dialysis patients.

The procedure involved putting a wire through the bend to straighten it and allow the blood to flow through. Since the organ of the heart is a pump, it caused a negative energy in the vein pressure level of the catheter in my neck. These were the early days of dialysis and being attached to a machine did the work of my absent kidneys. Other functions were compensated by tablets and injections. Overhearing the nurses talking on my behalf they said ‘she is only managing 200 in venous pressure but she will need 300 for good dialyses’. Being quite prepared to accept anything to put me right, I still hoped the kink straightening would be successful.

The line with the kink lasted for two days only. Then I had to have a femoral line inserted. Usually a short emergency procedure, on this occasion it was long and protracted. I was conscious of staying very still as I asked the angels to guide the surgeon in his difficult task. Success followed. As I offered my petition, we talked about our respective faiths. I was delighted at the revealing of shared faith of another persuasion. ‘Our faith’ he said ‘is sometimes all we have’. Though lost in a fog of unknowing and pain, this is what I remember most – a man with a sensitive spirit.

So the kink that occurred in Dublin was now a case to be resolved by removal. In the middle of it all, I received a text from my son Victor. ‘Hey Mom’ it went, ‘having more surgery today!? A Christmas turkey gets carved less than you do!’ The normality of humour is like a tonic, and its affect of a smile can carry on it the will from deep throughout.

As nausea returned, the associated kidney pain pitched in the back of my neck persisted. I longed for a resolve of feeling this unwell. It came through a very good Consultant who identified my struggles. His explanation and proposal to establish a constant regular cleansing of my system, ‘which you have not yet had’, renewed hope in me that things could return to some degree of normality.

One more line procedure made these reassurances a reality. The kink in my neck line couldn’t be straightened, so it was removed.

Once again in theatre, the surgeon’s calm and precise explanation considerably lessened my trepidation. The feeling of pressing and pulling conjured up images in my mind’s eye of a trapeze artist taking a leap, as he jerked out the bent line and put in a new one!!
Dialysis

During the following month of recovery, the radical incision which removed my second kidney healed. Subsequent to this I went through a gambit of experiences in the search of a successful site dialysis. The jugular and the femoral were probed and finally vascular access was found in the subclavian artery.

These vascular accesses provide a lifeline for dialysis patients, and it is this lifeline that one accepts, no matter how it is thrown.

The unknown fears I carried about dialysis, and the deeper feelings of disruption it caused, certainly lessened as time moved along in a three dimensional way. Moments of what I had been prepared for, and advised about, were to be met by what I experienced in the actual events. What I wasn’t prepared for was the sickness that constantly plagued my being. My body was in shock, trying to adjust to survival without the vital work kidneys do for the health of our bodies. It protested everyday in every way it could. Headaches pitched at the back of my neck which intensified as time went on, together with retching.

The first time on dialysis almost passed as any other procedure. It was a connection of a jugular line to the machine by two lines of plastic tubing, expelling toxins and normalising bloods took three and a half hours of dialysis time. This reduced the constant sickness I experienced. Creatinine and urea levels, which were high, halved after dialysis. My haemoglobin was low but I was not to receive any more transfusions, just an iron infusion instead.

One day on a Consultant’s round, a knight in medical armour arrived. Listening to my complaints on how ill I felt and my dread of dialysis, he explained that as I had not yet established a regular and constant cleansing of my system, time was needed for things to settle and they would. ‘In order to establish a regular pattern of good dialysis which you have not yet had with all the interventions you have undergone, we will reassess you,’ he said. He spoke at length about my options; he infused hope back into me that things would eventually regulate to some normality.

This I desired more than anything. Subsequent treatments lasting four hours became a successful turning point in my recovery.

It was our Wedding Anniversary and Richard my husband texted me to
Getting used to dialysis bit by bit, with the professionalism, kindness and concern of the medical staff was a wonder. It is easy to say of this work that it’s more of a vocation than just another job. So much goodness of their person is invested even if just practically applied when doing the mechanical aspects of care. Getting to know the medical staff became such a big part of my renal experience and made it infinitely better to process and endure.

The unit I attend at Waterford Regional Hospital cares for eighteen patients. There are now seventeen hundred renal dialysis patients nationally.

My more immediate challenge it seemed was trying to remember the names of each nurse and not mix them up. Finding out the meaning of the names helped me to recall them, until each name became as familiar as the person.

After about one year as a renal patient, it was decided that a fistula was to be put in my forearm to facilitate a new vascular site for dialysis. This would mean the neck line would be discontinued. Of course being on the receiving end of such a procedure is unpleasant. Under local anaesthetic, a surgeon worked on the arm. The memory of probing, cutting, sewing and an additional injection when pain started to resurrect, is a one I would rather forget. I did however marvel at the skill of the surgeon in uniting my artery and vein while avoiding vital nerves.

About three months later after healing had taken place, the first attempt at a fistula dialysis was possible.

A cream which contains lidocaine and prilocaine contains a numbing effect and is put on the arm one hour before dialysis. It took me a long time to even become slightly de-sensitised to the piercing of the entry site where the two needles are situated and remain until dialysis is complete, one needle for arterial and the other venal flow.

The physiological impact was variable at each stage. There were feelings of guilt as to the effect this was having on my family. I was no longer available in the same way as a mother and a wife. The care for my own mother had to cease also. I just prayed for things to work out in God’s providential care for everyone, and then decided to trust and remain positive.
Lourdes

A journey of joy, a pilgrimage of fulfilment, I had forgotten how powerful a shrine it really is. It was a Franciscan organised pilgrimage. Long years of experience were provided for our benefit. I was constantly amazed at their efficiency. We didn’t have to deal with our ticket, we never even saw them. All was taken care of with the added love and spiritual ease that comes from their spirituality.

The previous years booking had been cancelled as the date for my next operation was given - this time on my lung. It wasn’t my time and I was appeased when Brother Isadore had someone to take my place. In another way it was good timing for me and I had people praying in this powerful healing grotto for the success of my life saving surgery.

Later I discovered my that own family thought I wouldn’t make it. This came as great shock just when their support was needed the most. A cold wind drifted through me and I felt the severity of their response in the negative. It invaded my dreams and my unconscious and made it a challenge to remain positive during my recovery. Immediately cushioned by my husband and children, I navigated this mine field of confused thoughts, and drifted towards happier memories.

During this time I received spiritual council from Brother Isadore who brought humour and humanity to all our exchanges. Philip Cullen artist and an every day luminary always seemed to say what I needed to hear at a time when I was immersed in a feeling of sharp rejection. I encountered great kindness and empathy with those I shared in the unit.

Unable to eat much at the time and eating the wrong foods affected my blood balance with excessive potassium and phosphates that kidneys normally process. This was addressed quickly. It was a time of grieving and I went through all its stages. Forgiveness brought freedom and peace to my soul, as once again I reluctantly took up my pen to write poetry. The advice from my artistic daughter Maria was that ‘this is the best time to write!’ The healing artist Philip Cullen’s many talents came to the fore as he bore with my variable processing of thoughts and sporadic writing. My reluctant hand didn’t want to imprint on blank pages incidents best forgotten. Yet, sharing may help other patients to see that help and support is there in all its facets through these great people.
At one stage Philip suggested that I see a renal councillor. I was aware that I had already received the very best counselling from him but I was glad that the service was an option. The healing from a family rupture had begun, and I realised once again that love is unconditional. Appreciating the visits from my caring and humorous brother Nicholas, life, though altered continued. Acceptance was now my goal, the heart of mercy.

Now I was in Lourdes at the shrine of great healing as only our heavenly mother knows how to give to each person. Each day brought its own joy and blessings that seemed countless. Meeting fellow pilgrims and sharing was a varied and rich experience. Walking slowly in queue to enter the grotto for the first time in twenty years gave me time to absorb the quiet prayerful atmosphere. The roughness of the granite cave was smoothed like glass from the countless pilgrims’ hands that reached out to touch the rock where Our Lady appeared to St Bernadette. The theme of the pilgrimage was the reverence in blessing one’s self with the sign of the cross, as St Bernadette learned from the visions she witnessed.

Candles are a familiar sight in the grotto; with some so enormous it takes two men to carry them. These are usually at the request of a diocese county or country. The healing waters are obtained through a wall of faucets to drink and bring home, and the baths are part of this healing opportunity.

At the baths, French and English volunteers helped us to curtained cubicles where we waited, stripped and given blue gowns. Eventually ‘next’ was announced and I was received by two gentle French ladies who invited me to recite my own prayers before I descended the three steps into breathtakingly, cold water. They asked me ‘do you wish to be submerged Madame’? I nodded and, taking hold of my arms, I was propelled backwards by the two women. I gasped involuntarily at the impact of the freezing water on my body, which amused the helpers. They encouraged me towards where a small plastic statue of the Madonna was placed. One is invited to kiss it and pray in thanksgiving for blessings received. The experience was so emotional, so permeated with gratitude that any previous reluctance when viewing this particular image of Our Lady was swept away in the joy of the moment.

Like magnets on the first day Liz, Nora and I were drawn to the grotto where we joined the queue of the pilgrims. Their lips moving in silent prayer, their hands raised and touching the shrine rock as they walked through and around it.

When we emerged again, Liz said ‘I feel uplifted, I feel different as if something has happened.’

‘So you have received an anointing?’ I replied.

‘What does that mean? Liz asked.

‘Probably it was a grace or a blessing to prepare you for more to come during this pilgrimage.’

And indeed more blessings came to Liz from the Heavenly Mother.

It was a pilgrimage like no other for the three of us. On another occasion Br. Isadore brought us to the lift of the great Pope John Paul II (who is to be beatified in May) used on his visit to Lourdes. It was a special moment, and we again shared it.

We recounted the countless good deeds exercised in Lourdes by Nora, a catering member of the renal staff. Like an angel, she could turn up anywhere. Liz, Lil and I were brought by Br Isadore to dialysis in Bartres where St Bernadette once lived. A special unit was built there to accommodate renal pilgrims. We were just after having our tea, coffee and croissants when to our surprise and delight, in comes Nora gowned and capped and wearing a mask to visit us. Sweat on her brow she had walked ten kilometres to see us. She had been given the permission see us and afforded refreshments that Br Isadore found frankly amazing. On another occasion, Nora went to the healing Mass which we could not attend due to dialysis. She asked the celebrating Priest for a special spiritual gift for me, and he consented. This was just like Nora. After the baths she was the one who brought my chariot back to our headquarters when there was no one to bring me, and, when attending a procession, she waited for Liz at a time when she wasn’t feeling well. Such goodness thrived in an atmosphere of good will and in all the volunteers who helped there. Our Matron of the pilgrimage Grace, who as a person mirrored the nature of her name. Grace was a resourceful lady and keen organiser who anticipated and accommodated the needs of each person as they arose.

My room mate Maria was a delightful person and I was blessed to have time with her and get to know with joy and ease the impression of her person. We accompanied one another wherever we wanted to go. One of the days before we returned to our lodgings, I was anxious to get some rosary beads so we found a good shop a distance into the town. While browsing, I noticed four toy cats curled in baskets on the second shelf and
I thought to myself how my grandchild Iona would have loved picking out the one that looked most like her pet cat. The owner of the shop came over to help me decide.

‘You like madam?’

‘Yes,’ I said and I turned the little cat over to see its price. Nine euros it cost. Immediately I remembered my reason for being there.

‘I must get rosary beads and some medals first,’ I said.

Very happy with my purchases I thanked the lady in the shop and left.

Maria then asked me ‘did you change your mind about the cat’.

‘No,’ I said. ‘I had just roughly enough for the rosary beads and medal.’

‘But what is that circular package in your bag then?’ Maria asked.

I couldn’t believe it - it was the cat.

‘Let’s be charitable and leave her to God,’ said Maria, as I tried to come to terms with the thought that the lady had sold me the cat when I couldn’t afford it.

Later that night in bed, I thanked Our Lady for all the blessings of the day. I asked her about the cat incident. Then it came to me to add up all I had bought in the shop, only to realise the cat was a gift. I repeated to myself ‘the cat was a gift’. I couldn’t wait to tell Maria the next morning. In thanksgiving to Our lady I asked her to bless the generosity of the giver’s heart.

The annual gathering of the pilgrims for the collective photograph was another occasion of the unexpected. Br. Isadore said to me, ‘there is someone I want you to meet, follow me’. After introducing me to a gentleman who was both a doctor and a poet, he took off and left me with the stranger, despite my feeble protests. Sharing my thoughts with Dr. Brady, he was amused when I resolved with conviction that ‘there are no strangers in the land of Mary!’ A generous person, as all the volunteers are, he gifted Liz, Maria and myself with his poetry books drawn from his medical experiences, his fatherhood and his empathy with pilgrims.

One day he asked me if I would read at the International Mass for pilgrims in the Basilica. ‘Don’t worry about the fact that there will be twelve thousand people there, just read to one!’ he said. I swallowed a spit that wasn’t there, took a deep breath and said ‘yes’.

The next day was Sunday and the day of the Mass. Each reader was given a helper and Dr. Brady was mine. Finally, when the microphone was placed in front of me I read calmly. It was a great privilege and once again I felt grateful for Br Isadore’s surprising intentions.

Since these ceremonies are so highly organised, and each category of pilgrim is recognised by wheelchair or chariot, he devised a plan to leave me in a chariot easily identified especially to overcome any confusion. Dr. Brady pulled the vehicle into the basilica with Maria following as a helper. As it was a circular building, seating was arranged in blocks of ten seats. One hundred and twenty concelebrating Priests were seated at the right side of the altar. A red carpet led from the tabernacle to the altar. The Bishops led the procession of the concelebrating Priests. I was wheeled to the front of the next block of seats. Presently a German lady joined me in a wheelchair. I looked to greet her but she didn’t respond and she looked very severe. Taken back, I decided to greet and pray to my guardian Angel.
When the time came during the Mass to extend the Sign of Peace, I reached out to her in reassurance that she was not alone and she responded with a smile.

The readings of the Mass were done in all the languages of those present. Dr Brady read the English epistle. The prayers of the faithful were next and were also recited in each language. I was to read the English one. A signal was given to Dr Brady to get ready. This meant pulling the chariot onto the red carpet in front of the Priests who were at this stage seated. There was a difficulty in straightening the chariot as directed by the organisers. Perfectly capable of standing up to read, I had to remain where I was and undergo this mortifying helpless feeling with outward appearance of placidity and dignity. Finally a Priest came to help Dr Brady until such time as a Lourdes helper finally took over. I was placed precisely where they were satisfied. I was relieved that Dr Brady had got some help.

I was not informed when I was expected to read but just heard a Priest say to Dr Brady that he would give him a signal when to put the microphone under my mouth. In the meantime I thought about the one person I had to read to. I observed that the around Basilica large pictures of saints were hung. Then I spotted the one nearest the altar and my line of vision, it was St Irene. Providence to the rescue and my daughter Irene, whose name means ‘messenger of peace’, was to be ‘the one’ who I would read to. The signal was given and I read with confidence and clarity, mindful of the privilege it was to take part in this unique Mass of healing.

As the whole ceremony was visually recorded, screens were placed throughout the arena. Brother Isadora said he couldn’t believe his eyes when he glanced up recognising the voice. It was yet another confirmation I was meant to be here this year. The German lady and her helper shook hands warmly when it was over, and we were back to where we had started. The presence of Maria was also a bonus as she was always willing and full of joy. Relief was palpable afterwards.

At the time of Holy Communion, the perfect order and direction of the Priests as they made their way down to this large auditorium, reminded me of missionaries throughout the centuries making their way to unknown territories, just to spread the good news and nourish the souls of mankind.

There was one Orthodox Priest who wore white vestments along with white and gold head attire. The Mass was also concelebrated with the Roman Catholic Priests, who wore cream vestments. I had a brief thought that I would receive Holy Communion from him, but he was directed down to the basilica pews. In the mean time, the choir sang and filled the atmosphere with celestial sounds at this reflective part of the Mass. Time passed and it seemed the only people who had not received were the German lady and I. Then to my amazement I noticed the white vestments of the smiling Orthodox Priest coming towards us, and received the host. It was a little wish, and for whatever reason, but even that was granted. In thanks giving and praise, I prayed.

The gifted Fr Edmund, who sings with a powerful baritone voice, held the position last year as Director of Pilgrimages. Forty years he worked under this title and during a Mass which I was unable to attend a surprise was presented with an award from the Bishop of Lourdes bestowing on him the Freedom of the City an award rarely given. Next day in the middle of his thank you speech and final Mass as Director the probable next Director came up to him and whispered to him to thank the nurses and the doctors. As he returned to his seat Fr Edmund wryly said ‘the new broom’ to the amusement of all as he had already thanked everybody.

I had something to do before I left Lourdes. Returning to the grotto, I sat and watched for a short queue as I found standing for a long time to be tiring. My chance came on the Sunday. Having observed the spot directly under the Lourdes statue of our Lady I leaned forward and my forehead touched the cold hard rock. With eyes closed it brought to mind the different members of my family and friends. I prayed for their health, their spiritual wellbeing and protection especially in their travels. Also I prayed for my fellow renal patients, the staff members that looked after us individually and my benefactors in the Franciscan Order. Finally I put a spiritual question and request and remained quietly eyes closed in peaceful contemplation. The sudden impact of a drop of water landing on the left side of my back where once my kidney was shook me out of my reverie. In an instant, this spoke volumes. To me it was symbolic of an answer I had hoped for. I left the grotto feeling like someone who has received something and had been listened to. I straightened up, looked up at the image and smiling I thanked her for what? I wasn’t sure, time would tell. Some weeks later my faith was answered far beyond my expectations.
Philip Cullen was born in the late sixties in England. His parents returned to Ireland shortly afterwards to live on the family farm in rural Kilkenny. He is the eldest of his parent's four children.

He developed a love of hurling, art and music from a young age. He played hurling for Thomastown, Bennetsbridge and the Kilkenny minor team (1985 and 1986).

After an unhappy stint in UCD studying French, History of Art and Archaeology, he left Dublin to study art in WIT and then the Crawford College of Art and Design. He graduated in Fine Art, specialising in sculpture.

After college he worked in an antiquarian bookshop in Cork, wrote a satirical novel which failed to impress any publisher, painted watercolours and continued learning the guitar.

In 1995 he left Ireland for Australia and travelled there for almost two years. He worked as a cook, farmhand, bulk wheat handler, house painter, market researcher and finally in financial desperation as a busker in Darwin.

Upon his return to Ireland in 1997 he set up a studio and home on the farm he grew up on. He became a developmental community artist and has worked in the participatory arts field since then.

He has taken part in many of the national arts festivals, exhibited in Ireland, Luxembourg and Belgium, and been commissioned by public and private bodies. He is a prolific artist and enjoys working in a variety of media including stone, paint, sound and metal.

He is currently studying classical guitar with Maurice Daly, creating a large public commission for Enniscorthy Town council and supporting a group of older men to voice issues in a Shadow Puppet Theatre project in partnership between Respond! and Get Vocal/Age and Opportunity.

www.philipcullen.ie
Johanna Tanner

Johanna Tanner was born in the fifties in Dungarvan, Co. Waterford. She grew up on a farm run by the Augustinian Order, with two sisters and two brothers. Coming from a musical family, her father played the mouth organ and her mother taught the children to play music. She later studied music with the Mercy nuns. The family played in the Fleadh Ceoil for seven years, often appearing in the local pub The Pyke. At thirteen, Johanna was the youngest performer in an adult Céilí Band in Ireland. She went on to become a professional musician playing piano for the Ballycoe Céilí Band.

After working for almost a decade in England, Johanna returned to Ireland and toured the country with the Ballycoe Quartet. The band made some television and radio appearances on programmes such as Ceoilte Gael and Céilí House.

Johanna met her future husband, Richard, in Cork. They are married with five children whom she calls her ‘flowers’.

Johanna went on to develop an interest in art and began restoring and painting religious statues. She took part in the restoration of thirteen statues that went to Russia in the eighties.

As a patient in the Dialysis Unit of Waterford Regional Hospital, Johanna met the artist Philip Cullen in September 2008. Philip works for the Waterford Healing Arts Trust as an arts facilitator on a project funded by the Punchestown Kidney Research Fund.

With Philip’s gentle encouragement Johanna began writing poetry. The rest is history.

Frank Curtis

Born and raised in Loughnageer, Foulksmills, Co Wexford. Frank is the second child of parents Jim and Agnes. Together with his eight siblings, Mary, Deirdre, Una, Edel, Colette, Seamus, Donal and Emer, he was raised on the family farm in south west Wexford. Frank always had a keen interest in farming and his ambitions were realised when he took over the farm as a young adult.

Frank married his wife Mary in 1988. They have three children of which they are very proud. Sarah, 22 is in her final year of nursing studies at WIT. James, 19 is following in his father’s footsteps and is completing his farming studies in Kildalton Agricultural College. Paul, 17 is currently studying for his Leaving Cert, and also helps out on the farm.

Having been diagnosed with polycystic kidney disease, Frank subsequently began dialysis in June 2008. At the dialysis unit he was introduced to artist Philip Cullen who encouraged him to participate in the Waterford Healing Arts Trust’s arts programme. Frank had no prior artistic training or any sense of his own creative ability up to this point. In September 2008, with Philip’s guidance and Frank’s willingness to embrace this new challenge, a hidden talent for sketching portraits was discovered. Just under a year later in August 2009, he displayed his work in.

‘Sketching portraits gives me a positive focus during dialysis sessions and I thoroughly enjoy the sense of achievement’. Out of adversity comes opportunity certainly holds true for this artist.
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Above: Flow – Philip Cullen / Acrylic on canvas, 27 x 36cm / 2011
The Cover features a detail from this painting.
Back cover: Flow 2 – Philip Cullen / Acrylic on canvas, 36 x 27cm / 2011
Since September 2008, artist Philip Cullen has been working creatively with patients Johanna Tanner and Frank Curtis as part of the Waterford Healing Arts Trust programme in the Renal Dialysis Unit in Waterford Regional Hospital.

This book features a series of poems and stories by Johanna documenting her journey as a renal patient, drawings by Frank of the people he meets while attending the Dialysis Unit and artworks by Philip made in response to Johanna and Frank’s creative journey.

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