

# Unfolding Time

## Stories and Poems

by Liz McCue • Bríd Ryan • Johanna Tanner

Patients from the Renal Dialysis Unit at Waterford Regional Hospital  
Created through the Waterford Healing Arts Trust programme  
in the Renal Dialysis Unit of Waterford Regional Hospital

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## Introduction

The Renal Dialysis Unit in Waterford Regional Hospital is an eighteen-bed unit that accommodates over 90 chronic renal dialysis patients. It provides a 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 encounters 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 been working in partnership with the Renal Dialysis Unit to bring arts experiences to the bedside of patients in the unit. The visual arts programme, which is based on a patient-centred approach, is facilitated by artists Boyer Phelan and Philip Cullen, and funded by the Punchestown Kidney Research Association.

This book and accompanying CD comprise a series of poems and stories by patients from the Dialysis Unit at Waterford Regional Hospital and the publication has been funded by the Renal Dialysis Patient Fund and the Irish Kidney Association.

Artist Philip Cullen worked with the patients in a gentle manner, responding to each

individual, developing a theme and inviting patients to share their writing, with him at first, and then the wider public through this book. The writing and audio recordings reach deep into the personal lives of the patients who have imparted to us their stories and poems in an open and honest way.

The writing is beautifully accompanied by a series of photographs from the Dialysis Unit, taken by Philip Cullen.

We would like to thank Philip for working with the patients in the dialysis ward and for encouraging them to share their legacy with us.

Many thanks also to the three patients – Bríd Ryan, Liz McCue and Johanna Tanner – who have shared of themselves so generously to contribute to this book.

Claire Meaney  
Assistant Arts Director, Waterford Healing Arts Trust  
*and*

Brenda Ronan  
Clinical Nurse Manager, Renal Dialysis Unit, Waterford Regional Hospital

# An Artist's Perspective

## Philip Cullen

I have been working in the Renal Dialysis Unit at Waterford Regional Hospital for quite some time now. When I started there, I was very impressed by how the unit was run and I wasn't sure what role I could have. It was hard not to notice the blood and the machines and initially they commanded a lot of attention. I was very worried about knocking into a dialysis machine and causing some damage.

In time, I realised that art can have value for patients in ways I had never considered. Most of the people who took me up on the offer to create art had some previous interest in the area (even if their aspirations had been entirely unfulfilled). I've offered people training in drawing, watercolours, creative writing, photography, and even supported one man to learn how to use the camera on his mobile phone. These have been the most practical activities for people who are constrained in their movements, lying on their backs and unable to move the arm that is connected to the machine.

The nurse manager from the very beginning named patient welfare as the primary concern in the running of the arts programme. Creativity would be used to help patients pass the time, as dialysis can be an excruciatingly long process. The patient must lie still for four hours a day, three times a week. Patients have told me that it can be terribly boring. They can be cold because the cleansed blood is returned at a slightly lower temperature.

People have often talked about the inherent difficulties in dietary restrictions for renal patients. They are not supposed to eat bananas, chocolate, strawberries, or to drink coffee, amongst other things. Fluids must be restricted as well as foods and condiments that we all take so much for granted. Despite their size, the machines don't cleanse the blood as efficiently as even one kidney. Many patients wait and hope for a new kidney.

Art, I believe and have been told, uses a part of the brain that doesn't recognise the passing of time. This effect I noticed in myself a long time ago. Drawing or painting for what seemed to be twenty minutes could in reality be three hours. Many times, patients are surprised that so much of their treatment time has elapsed when focusing on writing, drawing or even just talking.

I have been supported to develop my own programme, which is responsive to the individual, by the management at the Waterford Healing Arts Trust and the nurse manager. This kind of autonomy has been great for multiple reasons. There are no

unreasonable or artificial goals to be reached or specific indicators for success. The sole purpose of the job is to support people to pass the time during their treatment and to maybe turn what can feel like captive time into captured time.

In this most recent project, three remarkable people have created projects in mediums of their own choice. Bríd had a desire to record her life's story; she had been given a book by her grandson through which she could write about her life in answer to guided questions. I offered to record memorable events from her life. Each week, she provided handwritten notes. I sat at her bedside with a microphone. The sound of the machines and the bustle of the ward were also captured. It was lovely to sit and listen to her voice over those weeks. The stories of an older Ireland were comforting, funny and, of course, sad at times. She pursued her goal of creating a CD with passion and dedication and created something that is valuable not only for her own family but for us all.

Liz initially tried taking photographs but admitted to having a desire to tell her life story and to see it in print. She has outlined honestly and bravely some of the anguish of kidney failure and the loss of normal life, but also her methods for staying strong, her faith in a higher power and her belief in life itself. This kind of honesty is a great personal motivator and why I find working with the Waterford Healing Arts Trust so rewarding.

Johanna has engaged in the renal dialysis project for years. Initially, she wrote beautiful, thoughtful, theological and observational poetry. This year, because her energies were devoted to her great spiritual passion and all the organising and writing that it took, we decided to focus on light-hearted haikus. She struggled with this Japanese form of poetry but eventually found a method of capturing brief instances in time and thought with an economy of language. Her final poem, which I see as a beautiful prayer, was written for the Renal Mass which is held every year in May.

Working in the Renal Dialysis Unit has been a privilege. I have met a range of people with skills, aspirations, dreams and desires who have to cope with a very difficult physical reality. I admire the nursing and care staff who manage the complicated process calmly and efficiently. There is usually friendliness, support and laughter between them and the patients. These people are bound together, sometimes for years, because unlike other conditions renal patients must come to the hospital multiple times a week and often for long periods of time. Kidney disease, its consequences and realities in the ward, is approached with valiant struggle by those I have worked with, not to mention great humour and hope. When someone donates a kidney and sets someone else free it really is a beautiful thing. Listening to the stories of life, loss and love has been an honour. Even in the midst of great personal trauma there is faith, hope and love.

Philip Cullen, September 2013

# God Loves a Trier

Liz McCue

As a child I was forever suffering from kidney infections. The doctor explained to my mother that I had a kidney disease. He called it reflux which meant that when passing water I had an abnormal backflow of urine, which travelled back up to the kidneys. This made passing urine very uncomfortable. There was a burning, stinging and constant pain. I hated going to the bathroom. If left untreated it could cause permanent kidney failure, so provided I kept taking the antibiotics when the infections started I would be okay.

I emigrated to England with my parents and finished school. I got my first job. Kidney infection was the last thing on my mind. All I thought of were boys, discos and having fun. I remember I used to feel constantly tired and would doze off at the drop of a hat. My mind was hazy – I couldn't think straight. Everything I ate or drank quickly came back up again. My poor mother was at her wits end; she was watching me slowly die. An ambulance was called that brought me to the local hospital. From there I was transported to a specialist renal unit. I was drifting in and out of consciousness. My life was slipping away.

The nephrologist told me later that if I had not gotten to the unit when I did I would have been a goner. I was in acute renal failure; my kidneys had stopped working: end stage, chronic and fatal.

The next thing I remember is waking up with a monstrous-looking machine beside me. There were tubes coming from my neck and my blood was being taken out of my body and through this machine. I started to cry. The nurse came over to soothe me and said, 'Lay still now, love. You have to do five hours of this treatment. You are on a kidney dialysis machine.'

This went on three days a week. I started to feel better in myself. I was put on a very strict diet, allowed none of the goodies I loved, such as chocolate, crisps, chips and coke. I could only drink a litre of fluids daily. I kept asking the doctor when this torture would end.





‘Well dear,’ he would say, ‘without treatment your lungs will fill with fluid and your body with toxins. You will drown in your own fluid. Hopefully we will get you a kidney transplant; if not, you will be on the machine for life.’

‘Why me?’ I wailed, and screamed at my mam. She tried to soothe me as only a mother could. For ten years, I watched my friends going out to parties and having fun as I sat at home and moaned. What was the point? I could not go boozing. I prayed for a new kidney every night.

In time, I did get a kidney. It only lasted for ten days. I spent three years on home peritoneal dialysis – a bag system carried out four times a day, seven days a week. That was great. Due to peritonitis, I had to come off that system.

I was given another transplant a few years later that was in and out in three days; another unsuccessful transplant to endure. I did try six months on haemodialysis. My mum put me on my blood machine. That did not last either; I was moved back to dialysis in hospital. My veins were getting too small and there were other problems to do with thrombosis in my leg.

Fistulas failed; the sites were non-existent for their insertion. Ten long weary years passed and I was really getting to the end of my tether with the dialysis lark.

‘I have had enough,’ I told my doctor. ‘I refuse to go on dialysis anymore.’

They always had a big powwow on Thursdays to discuss the patients. My name was top of the list. It was decided that I was to go on the European Emergency List. Because of how I was feeling, they needed to get me a new kidney ASAP. They told me to hang on in there. I was given a pager as there were no mobile phones then. Two weeks later, during my sleep, the pager started beeping rapidly. I kept it under my pillow and nearly had a seizure with the fright I got. I was excited and nervous all at once. Butterflies flew around my tummy. It was one thing to say I wanted to stop dialysis, but I didn’t really want to die. The doctors and nurses looked to me as their protégée. They had known me since I was a teenager.

‘You’re like one of those bouncy clowns,’ the professor told me. ‘You’ll sail through this operation.’

That reassured me somewhat. To me, he was godlike; I looked up to that man. He’s going to get me off my dialysis machine once and for all, I thought.

The following morning I awoke. It took me a few seconds to remember I was after having a new kidney. I felt a warm sensation coming from my bladder.

‘Oh my god, I’ve peed myself!’ I rang the bell.

The nurse popped in all smiles. ‘How are you, Lizzy?’ she enquired.

‘I think I’m after weeing the bed, nurse.’

‘Not to worry, you’ll have a tube in place for a few days till your bladder gets retrained again,’ she explained. ‘What would you like for breakfast? Try to drink as much fluid as you can, dear,’ she said. ‘Maybe two litres today and work it up from there.’

I looked at her like she was mad. After years of constant fluid restriction, plus a strict diet, it seemed so strange to be told to drink more. I found it hard to do this; I had to keep my kidney hydrated, to keep it flushed. The doctors were delighted with my progress. I was given immune-suppressive tablets to keep the antibodies from attacking the newly grafted kidney.

Life was sweet again. I had my freedom. At first, I had bloods done every day, then every third day, until eventually it was only once a week and then once a month. For thirteen happy, wonderful years my kidney lasted until reflux damaged it yet again.

I thank God for the gift of life. It was a wonderful experience, a well-deserved holiday. I have been back on dialysis nine years this week. I am waiting on my fourth kidney.

God loves a trier.



## Extracts from Bríd's Stories

### Bríd Ryan

The following extracts are taken from audio recordings of Bríd's stories which were relayed to Philip Cullen in the Renal Dialysis Unit. A CD accompanies this book and features many more memorable stories from Bríd's life.

*'When we were coming home from school we'd go in on top of the silage pit and dance around in it to press it down ...'*

*'... the combine harvester ... they came down to cut the corn for us. I gave them their dinner and took a chair out and sat down and enjoyed the rest of the evening ... it was absolutely wonderful to see it. ... Before [the harvester] we had to cut the corn, make sheaves and put them standing ... then bring it in and you'd have a threshing. You'd have twenty or thirty men to feed for the day you know, but then after the threshing there was always a can of Guinness ... and we'd steal a bucket of the stout and keep it for the night ... we'd have a sing song; that was great fun ...'*

*'Jesus I'll be shot if they hear I was singing and I haven't a note in my head hardly ...'*

*'I passed John's house on the way to school every day and I fell in love with him down there. It was a long and varied courtship ...'*

*'... Queen and John Condon were the best man and Bridesmaid ...'*

*'I was marrying into a farm, ten acres smaller than our own one and at that time that wasn't a thing to do. I thought my Uncle Patrick would read me but instead he said, "You'll never be short of a shilling because John would make money out of a stone."'*

*'When we married, my brother, Father Ned, gave us a forty-two-piece set of china; so the first time he came I thought well I'd better put this on show. I set the table and he sat in, and the cups you know were dainty little cups. He said, "Bridey, whoever gave you these you'd be right to give them back to them." I said, "You gave them to me." He liked a bigger cup.'*

*'John bought the mahogany sideboard and the first morning when I came round the corner of the stairs and saw the sideboard, I thought, God, we're going to be alright. We're moving up a bit. I think a fiver John paid ... we still have it. It's one of our treasures ... and 'tis in perfect condition even though it is a hundred years old surely ...'*

*'We went to Clery's for a three-year apprenticeship and we stayed in 47 Mountjoy Square. I had a row with Bibs Brogan one day about Dev and she hit me with an umbrella ...'*

*'I had a flat in the North Circular Road and my landlady was contrary. The night of the bombing, my bed was shifted out to the middle of the room and I didn't wake up. But the landlady came in anyway to see if I was okay. I thought she was nuts ...'*

*'We had two pet dogs in Garyroe, Bluebell and Orla ...'*

*'... we named the doll Marlene Ponsbehops ...'*

*'... you had to be able to make sure what was spent was necessary – well, the money was scarce ...'*

*'We had to get up at seven o'clock and milk the cows and get the milk to the creamery. Now 'twas a horse and dray that took the milk and some of the children would have to go with it and be back in time for 8.30 mass in Ardfinnan ...'*

*'... the officer and a group of them stood there and two other fellas came in and they said to Dada that they were taking a heifer and he said they weren't. ... Two more came anyway and they went down the field and they drove up the best heifer we had ... he tried to stop them. They took the heifer and went back over the road a little bit ... the officer gave an order to fire ... it hit him and he gave a week in hospital ...'*

*'... we couldn't take time to go up and see [my brother's new parochial house] and he only lived about six months there and then he died and we were able to go up then and give three days crying there. So that taught me a lesson – go while you can ...'*

*'I'm renowned for my apple tarts ... I put the apples in a pie dish and I cover them with a Madeira mixture and it goes down very well and there's a bit of feeding in it as well ... that and rhubarb jam is another specialty of mine ... it is associated with the home ...'*

*'... I thought if you could have an electric cooker in the country, who'd want to be in Dublin ...'*



# My Story :)

Liz McCue

Every morning, just after opening my eyes and getting to grips with my thoughts for the day ahead, I start by saying my prayers. I say them both morning and night without fail. This sets me up for the whole 24 hours.

Well, these are my thoughts on praying.

Part of my life is taken up with life-saving dialysis three mornings a week. I awake early – the alarm goes off at 5.45 a.m. The mobile phone alarm hasn't let me down once in the last five years. The driver picks me up sharpish at 6.50 a.m., bless her. She's a lovely lady. We have great chats on the way to dialysis. She picks me up most mornings but, if she's not available, her son is. I'm very grateful to them both for their conscientious work.

Now Sid, as I call my machine, takes away fluid and toxins from my body, four hours at a time on the same mornings every week. This keeps me ticking over till the next session.

The evening before, I iron my clothes and set out whatever jewellery and hair brocades I think set off my attire for the Sid session. I then make sure that my bag is packed with books, mobile phone, snacks and a can of drink for the morning ahead.

This is how I manage to cope.

Yes, some mornings I want to pull the covers over my head and go back to sleep. I call these the Shite Mornings. We all get them; anyone who says otherwise is telling porky pies!

However, without Sid my life would end very rapidly. My lungs would fill with fluid; my mind would not function and would also fail. My body would just shut down. That would not do at all. I love life. I have fun with my family and many friends. The odd day trip or shopping excursion on the bus is lovely. I visit my uncle and cousins in Dublin using the train. I do this on the two-day break from renal dialysis. Other days, I meet pals and have chats with them over tea and homemade treats.

One evening every week I attend an Angel Healing Circle. This gives me a great buzz. I go in feeling tired and drained and with a few odd aches. I leave feeling awesome. It's a spiritual group. I have made a few close friends. What goes on in there stays in there; if we want to share a few problems with each other we can. It's great knowing it won't be blabbed about. We meditate through guided tapes. Beautiful angel CDs are always playing in the background. The tables are adorned with burning candles and angel figurines in all shapes and sizes.

I have learned how to cleanse my chakras through crystal healing. We learn how to heal each other's auras, how to use the pendulum, plus our healer does the angel oracle card readings. It's done by the beautiful, healing angel Linda. It's fun.

I'm so blessed with riches in abundance. For this, I'm very grateful to God and the Universe. Most Sundays I attend Mass – if I'm up to it after the Saturday Sid session. I would like to finish now and say thank you to my family and many wonderful friends, the fantastic dialysis team (there are too many names to be mentioned), the Waterford Healing Arts Trust at Waterford Regional Hospital, and Philip, my mentor, who motivates me to write.

Faith in God above and my guardian angel spurns me on to keep fighting. I believe and trust that one day I'm going to get a successful kidney transplant. This keeps me centred and gives a sense of inner peace.

Thanks in advance, God, if you're listening up there.

From your creation,

Lizzybits  
(as I like to call myself)



## Johanna's Haikus

Johanna Tanner

Do not open your  
hand to receive and keep it  
closed when you should give

Love manifested  
believe, hope endures all things  
finds its joy in truth

The wounded body  
awakes hearts of compassion  
flowing gently, heals

The voice of silence  
solitude a companion  
meditate to keep

Rising in darkness  
he blesses the light he no  
longer sees greet him

Gratitude of heart  
produces the gift of pure joy  
even in dark moments

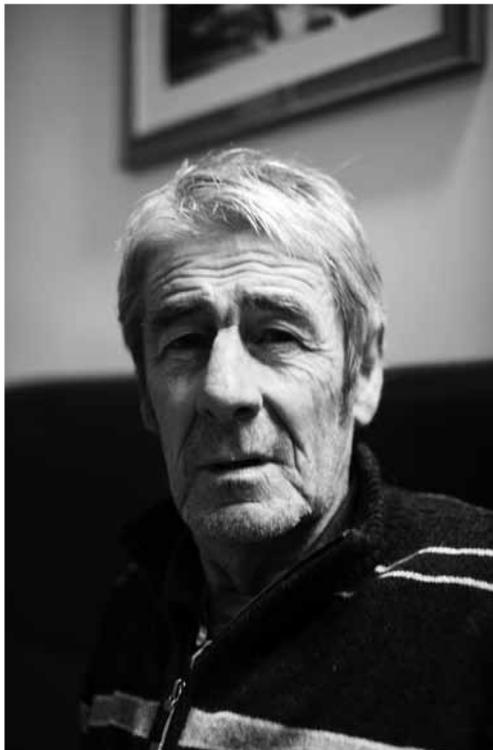
Sometimes it's better  
to explain the harshness of  
the journey ahead

Never entertain  
fear, if one twig should break  
there's another one near

Autumn strips off her  
bright colours and shows a bare  
and furrowed lean face

A few late swallows  
line up on long electric  
wire, sound their farewell

The flare of sunset  
in a saturated sky  
sees the brooding black



# Companions on Our Journey

Johanna Tanner

Sometimes, we are given to know that our days are limited.  
This is my response to this:

Sing in harmony with the will of God  
For joy to burst forth in the heart where love is born

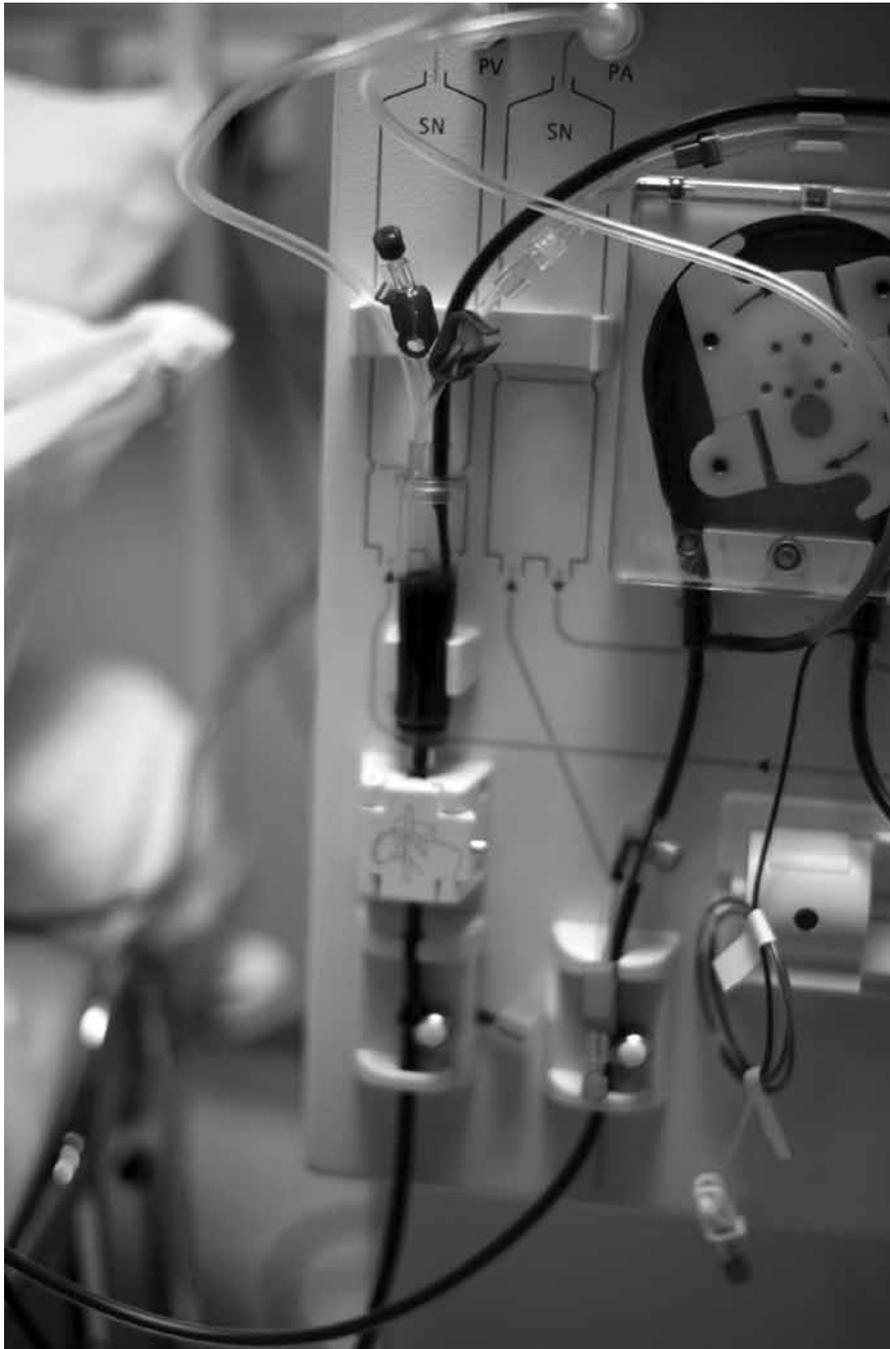
Climbing the mountain of faith  
Those peaks are steep and high; they cannot be conquered alone  
With the grace of acceptance given in a spirit of reparation,  
Refreshed in the fountains of mercy

Oh welcome companions on our journey  
In your service to others you bring the light of Christ with you  
Your living colour to our lives, to the lives of those around us

As in the Father's covenant of love,  
Sealed in a rainbow of radiant hues, our gratitude abounds

Nothing is our own  
All must be returned to him who gave  
Right to our last breath on earth, and to inhale our first in paradise  
In the sapiential breeze of the Holy Spirit  
The little bird is carried home.

Johanna Tanner  
19th May 2013  
Pentecost Sunday  
Healing/Remembrance Service



## Biography ~ Philip Cullen

Philip Cullen is an artist and participatory arts facilitator with a studio in a renovated hay barn in rural Kilkenny. He graduated from the Crawford College of Art and Design in the early nineties. After travelling and painting for a year and a half in Australia, he returned to Ireland where he worked as a Community Arts Development Officer in Kilkenny. He supported a wide variety of community groups to access the arts and develop their own skills by participating in dramas, training courses, cultural events and community exhibitions.

In 2000, he became a freelance arts facilitator and photographer and worked with groups including Travellers, disabled people, men's and women's groups, people with mental illness, young offenders, refugees, children, the elderly, and adults in night classes. As a photographer, he has contributed to *The Irish Times*, *Business & Finance*, *The Farmer's Journal* and *The Irish Examiner*.

Philip's work uses processes such as stone-carving, painting, drawing, percussion, metalwork, music and video. He has been commissioned by public and private bodies to make sculptures in hotels, Garda stations, colleges and schools. Work by Philip can be found in the foyer of Kelly's Hotel in Rosslare Harbour; the Garda Training College in Templemore; Johnswell Primary School, Kilkenny; Kildalton Agricultural College; and the EPA. His most recent Per Cent for Art commission was a large-scale stone-carving for Enniscorthy Town Council depicting scenes of the town's rich and turbulent history.

Philip has been involved in many group and solo shows in Ireland and other countries. Memorable exhibitions have taken place in the European Parliament in Brussels; the Secretariat in Luxembourg; Kilkenny, Boyle and Wexford Arts festivals; the Waterford Regional Hospital; and on the Rosslare to Fishguard Stena Line ferry.

In 2008, he was hired by the Waterford Healing Arts Trust (WHAT) to provide creative support in Waterford Regional Hospital. Since then, he has worked with patients in Oncology and Renal Dialysis, supporting them to create art including drawing, painting, creative writing and digital photography.

For three years, he collaborated with a group of older men in Waterford City for the Respond! Housing Association on an innovative shadow puppet project, looking at issues of alcoholism, poverty, loneliness and bereavement.

He is currently working on a film using footage shot over a four-year period and on a body of work involving scrap metal and found objects. A satirical novel he has been writing over a twenty-five-year period, *The Amazing Adventures of Brank Huxcrap*, has recently been self-published on Amazon.

[www.philipcullen.ie](http://www.philipcullen.ie)

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