




Art By Their Side

Artists in Residence in Service
to People at End of Life



► Foreword

This book is for those of us who are dying.

Irish Hospice Foundation's Arts and Creative Engagement programme began in November 2020 motivated by opportunity from the Creative Ireland (CI) Programme. The arts and creative engagement in all their forms help people of all ages explore and articulate loss, death, dying, and grief. They always have. CI's support enabled IHF to be intentional in this regard.

In 2022, we began a project to understand what would happen if we established Artists in Residence in support of people at the end of life in acute hospitals.

There was an open call for artists and two were selected. **Caroline Schofield**, a visual artist, was paired with **St Luke's General Hospital, Kilkenny**, and the BAFTA-winning writer and bardic poet **Kevin Toolis** was paired with **University Hospital Limerick**.

In each acute hospital, the artist and staff set out to identify and support interested patients. Both groups met online as the project developed. The project was managed and supported by

Irish Hospice Foundation's Arts and Creative Engagement staff as well as Bereavement and Healthcare teams.

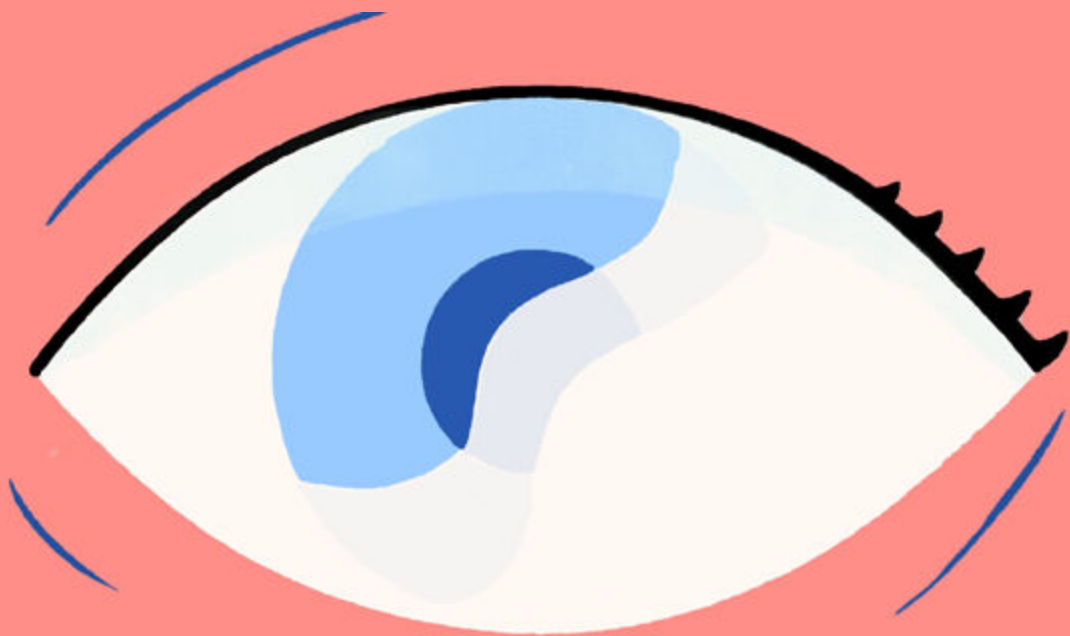
The main aim of this book is to share our learning. Specifics are removed with consideration for the individuals involved and all who contributed do so with permission. Accompanying videos and text can be seen on our website - see below. We hope to repeat and build on this programme when support can be secured.

The book is structured to present multiple voices and multiple perspectives from concentric circles of care - the professional care staff, the artist's team, and various types of support staff.

At the centre of these circles are those who were dying.

Our enduring lesson is that many voices and many disciplines need to work together in service to people at the end of life to ensure a good death. It requires creativity, courage, and compassion.

For more see www.hospicefoundation.ie/arts





Overview

Paula O'Reilly, CEO, Irish Hospice Foundation



When she died, the then An Taoiseach Enda Kenny said of Mary Redmond, Irish Hospice Foundation's founder:


"Nationally, we owe a huge debt to Mary Redmond and the Irish Hospice Foundation. Mary's vision was to make hospice care ordinary; not in its quality but in its quantum in Ireland."

At first glance, producing ordinariness seems too slight an achievement to encourage a national leader to celebrate an individual's lifetime work. But, of course, what is being said is that achieving care has become the very least that should be expected. That care at the end of life should become the normal order of things, should be part of the culture of health. That it is simply what is done.

It may be now, as it was then, a surprise to many that end-of-life care is a basic provision of hospitals, and it is important to note this is still the place where the majority of people die. But as others explain elsewhere in this book, providing care for the dying is not the ambition our hospital system was built on. They are made to

mend people. To address disease. Mostly they do this increasingly well, and with the development of new technology, new medicines. However, as a result of advancement in medicine, death has become over-medicalised. Dying and death is part of the cycle of life, and we need to ensure the person and their community are involved alongside healthcare.

What Mary Redmond recognised, and the work of Irish Hospice Foundation builds from, is that people die as they always will, and each and every one deserves comfort and kindness. We are organic beings. We feel our way as powerfully as we iron out issues. In some instances, like the end of a life, perhaps all we can ever do is feel our way.



Likewise, the people working in those places where many of us will die deserve the knowledge that end of life and hospice training brings - they are respect, relationships, and person-centredness. They may support us when we are in need, and we need to support them when we can.

Which is why we have put together this book: to share our learning from the first “Artists in Residence to People at the End of Life” project. We think creative minds change the atmosphere of health care institutions. They benefit patients, staff, and those who care for the carers. They nurture empathy and understanding. They ask questions. They bring fun and joy. These are not small things, and we value them in daily life, though they are things we are less inclined currently to measure as an output of a hospital system. Perhaps that will change in future as we build the care system for these times. Where is the hospital department that brings you a mighty dose of joy? Quietude in chaos? That supports understanding when a life changes? Enables acceptance of the inevitable?

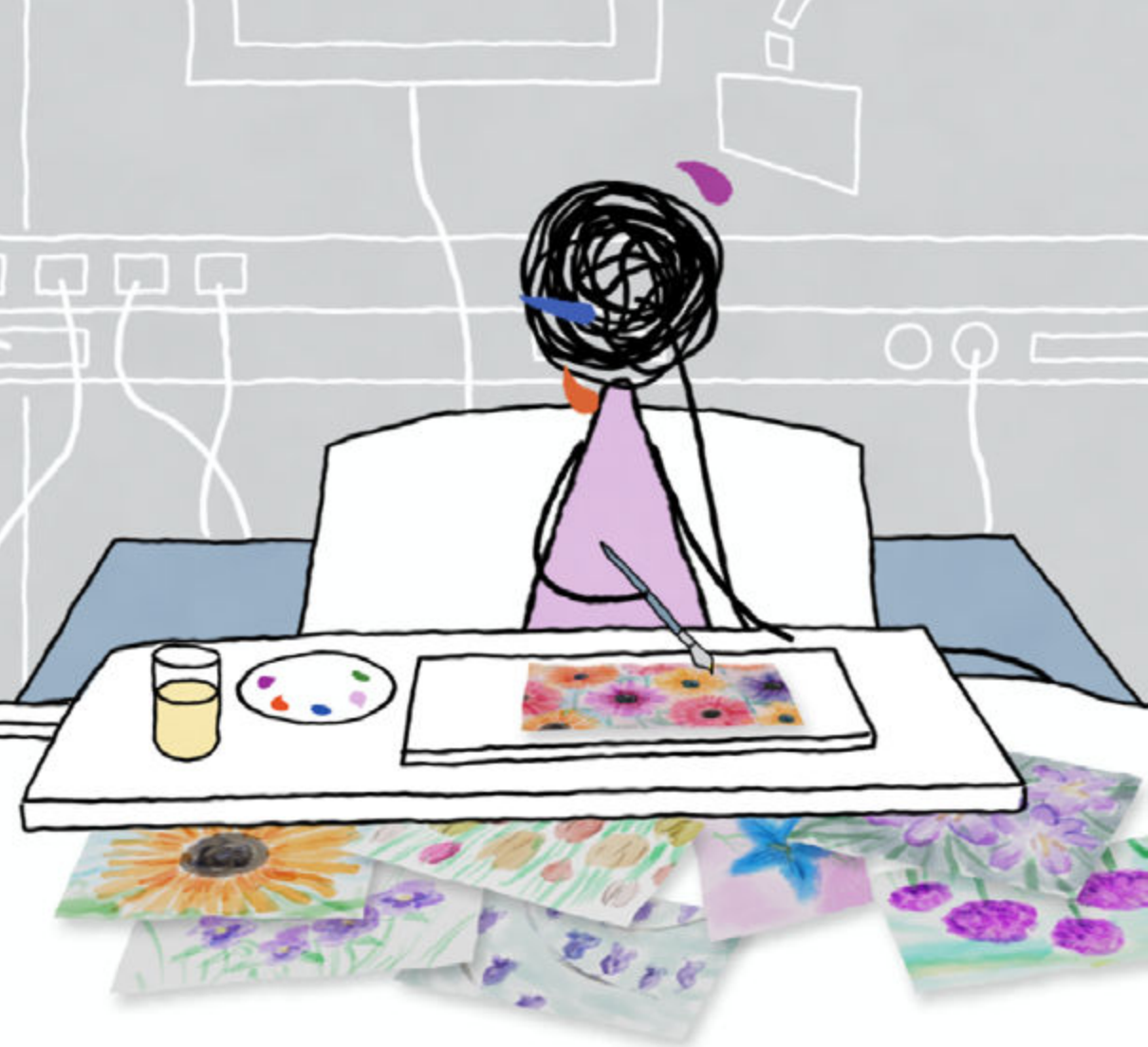
We want to express a huge public thank you to all those who went on this first foray with us into the realm of artists-in-residence programmes. They brought willingness and honesty to an adventure into the unknown. We look forward to deepening and growing all these relationships.

IHF values the impact of arts and creative engagement. It continues to be developed within the organisation to facilitate driving its core objectives towards better end-of-life and bereavement care.

One clear ambition is to make art “ordinary in its quantum” - readily available to everyone who might benefit from creativity in service to people at the end of life. Our intention is that this book plays its part in communicating the multiple and complex values of this work.







Contents

Foreword.....	i
Overview.....	iii
Introduction.....	3
St Luke's General Hospital, Kilkenny.....	6
The Visual Artist.....	7
The End-of-Life Care Coordinator.....	12
The Arts and Health Coordinator.....	16
University Hospital Limerick.....	22
The Poet.....	24
My Second Dying Skin.....	26
Accountings of the Heart.....	28
Soaring Sun.....	31
The Psychologist.....	32
Summary & Recommendations.....	40
The Reflection.....	45
Irish Hospice Foundation Resources.....	54
Thank You.....	58



▶ Introduction by Sylvia Thompson

The English word “patient” is derived from the Latin “patiens” from “patior”, which means to suffer and to bear. It’s a passive-sounding word, which conjures up the image of a sick person who not only must suffer through their illness but also must tolerate the interventions of medical experts at random times throughout the day and night.

But what would happen if patients were given a space and time apart from these daily medical routines? What would it mean to have a break from the continuous round of diagnostic tests, medical procedures, monitoring of vital signs, and sometimes overwhelming worry about your illness? What impact would such experiences have on those patients, on staff, and on family and friends visiting loved ones in hospital?

IHF believes that every person in Ireland has the right to die and grieve well, wherever the place. This includes the opportunity for creative expression – right up until the end of their life. Giving patients,

and in particular those approaching end of life, an active role in which they could creatively explore aspects of their personal identity through artistic endeavours is one way of giving people this opportunity for expression.

When the artists and hospitals were selected, we built a support system around those artists to allow them to work with individual patients in these two hospitals (St Luke’s General Hospital, Kilkenny and University Hospital Limerick). The artists were also given training and allocated a counsellor, Dr Ursula Bates B.A., M.A., D.Psych, with whom they could speak during the six-month project.

Throughout this project, it was found that offering individuals time off from their identity as a patient so that they could embrace a wider view of themselves through artistic expression can have profound and lasting tangible and intangible impacts on patients, their loved ones, and those who care for them.





St Luke's General Hospital, Kilkenny

Interviews and narrative
by Sylvia Thompson

In these short pieces, we will explore the thoughts and feelings of Visual Artist, Caroline Schofield, End-of-Life Care Coordinator, Margaret Ryan and Arts in Healthcare Programme Manager, Edel Ní Nualláin. Some staff members also give their views on the success of the project and while, for ethical reasons, we couldn't interview patients themselves, their experiences shine through in the comments of others.

► The Visual Artist Caroline Schofield

Caroline Schofield says there were “so many beautiful moments” during her time working with patients both in St Luke’s General Hospital, Kilkenny and in their homes.

Schofield’s pilot project became titled ‘Art by Your Side’ in Kilkenny. The title signals a partnership-type approach between the artist and the patient. And while patients are often now deemed in reality to be partners in their healthcare journey, creating an equal partnership between the medical professional and the ill person who relies on their expertise and care can be difficult to achieve. However, the artist and patient partnership developed through this project was open, equal, and a learning experience for both, as well as the medical staff who interacted.

Schofield says that one of the most important things about this work is not to have expectations. “It’s about process. You never know how you’re going to work with someone, but as an artist, you must trust this process,” she explains.

“It’s about the person in the room and what they want to do. It’s not a big fanfare project. It’s the small one-to-one moments that count.”

Patients were referred to Schofield by various staff members who felt the experience would benefit them. She turned up with her box of art materials for visits which lasted from 15 to 90 minutes, depending on the person. Sometimes, she needed to wear personal protective equipment for infection control.

“I had to be really flexible because I never knew what reception I would get when I went up to a ward. At the beginning, we thought we wouldn’t get enough people, but as time went on, I realised I was only reaching the tip of the iceberg,” she says. In total, Schofield worked with 25 people over 45 days during this six-month part-time project. Most of the patients she worked with in the hospital were in single rooms.







*“When you’re working with
your hands, conversations will happen.”*

Caroline Schofield

Some people were very willing to draw and paint, and one woman created so much work she had an exhibition in the hospital at the end of the six months.

Others, however, were more interested in exploring different avenues, such as listening to music. One man was a set dancer, so Schofield found old images of set dancing and played music with him in the corridor. “His feet were tapping to the music and some of the staff joined in,” she explains.

Another man she worked with loved cows. So Schofield hung lots of photographs of cows near his bed. This impromptu exhibition resulted in interesting conversations about the different breeds of cattle, with one doctor admitting that while he knew nothing about cattle, he loved dogs and showed the patient a photograph of his dog.

Schofield says another key to the success of the project was that she didn’t know the medical diagnosis or history of the people she worked with. “It doesn’t matter what someone has. I didn’t need to know this unless there was something like a speech problem or if someone couldn’t use their hand,” she says.

During the process, she got to know patients well. “In my experience, people’s pain wasn’t as bad when they were drawing.”

She also found that patients spoke quite openly to her. “When you’re working with your hands, conversations will happen. But it wasn’t my role to ride in on my white horse to sort things out. It’s about actively listening and acknowledging what you’ve heard. Sometimes, if concerns were raised, I would say that they need to talk to someone about that. It’s important for the artist not to become part of the system.”

As well as having weekly meetings with the End-of-Life Care Coordinator at the hospital, Schofield also had access to a counsellor. She found these sessions particularly valuable when she became very emotional when one man she had been working with died suddenly and unexpectedly. “I also realised when he died that I could walk out of the hospital but the staff couldn’t and how hard this could be for them.”

And will she create art herself after the project? “Yes, I will have an artistic response, but it will take time. I already have spent some time painting and drawing at the sea.”



Fiona McEvoy

Director of Nursing at St Luke's
General Hospital, Kilkenny

“Not everybody has relatives who come to visit them in hospital. A project like this takes patients away from the seriousness of their situation. It’s a great distraction and offers light discussion between staff and patients.”



► The End-of-Life Care Coordinator

Margaret Ryan

Margaret Ryan is the first End-of-Life Care Coordinator at St Luke's. Her non-clinical role is to improve the end-of-life care in the acute hospital. "End-of-life care is everybody's business. It's about the nurses, doctors, patients, and families but also about anyone who meets the patient, such as the porter," she explains.


Ryan sees 'Art by Your Side' as a valuable project that fits within a hospital environment that values kindness and compassionate culture. "The project encapsulates the theme of living for today and planning for tomorrow. Dame Cicely Saunders, the founder of the modern hospice movement, said: 'We will help you to die peacefully but to live until you die.'"

Ryan believes that this project helped staff to see the person behind the patient. "Sometimes, we are so focused on diagnosis, prognosis, and disease, we forget about the person," she says. As paintings,

drawings, and other images were hung on walls, which are usually blank spaces, it encouraged different dialogue between staff and patients.

"Creativity connects people. It makes people see that someone is interested in them. It improves communication and helps the person connect with and embrace their care," she adds.

Art facilitates memory making. "One man created wonderful art and gave pieces to staff members he liked best, and they treasure these pieces. Another woman had an exhibition in the hospital, which is a lasting legacy for her and her family," explains Ryan. She describes how the launch of this exhibition was such a moving experience for everyone who attended. "It was an absolutely amazing day to see her husband, her children, and her friends. She even took orders for more paintings on the day. This project gave her the confidence and focus to do that."




Ryan also talks about how one patient painted with his mouth because he couldn't use his hands. And another, who wasn't interested in drawing, talked about music in the few days before he died.

Most of the patients that took up the offer of being involved were in single occupancy rooms. "People can be very isolated, and Caroline was able to create conversations that took them away from their medical journeys – to have conversations that mattered to them," says Ryan. Each patient was also given an art pack when they were discharged home or to a nursing home. "People can only watch so much television and not everyone reads, so having a sketch pad there to doodle on gives them another focus," she adds.

Staff could also see the benefits to patients from participating in 'Art by Your Side'. "So many people feel isolated and lonely in hospital. Some of them have complex needs, but when you bring someone in to initiate a conversation, tell a story, make a memory, it's invaluable. Staff noticed how some patients were in a better mood and engaged with their treatment afterwards," Ryan said.

At the end of the six-month project, Ryan says that she believes it could be replicated in other acute settings. "Often, everyone is trying to mind each other when a patient is on a palliative journey, but art can enable people to talk about sensitive and difficult conversations. It can also give people an opportunity to have quality time in an acute hospital. It's like gold for patients and their families."





Emma Treacy
Clinical Nurse Manager 2 in
Geriatric Emergency Medicine

“The experience of one man stands out for me. He had challenging behaviour and was difficult to manage. But, when Caroline started working with him, his behaviour changed, and when his art was displayed in his room, it instigated conversations between him and staff that would never have happened otherwise.”





▶ The Arts and Health Coordinator

Edel Ní Nualláin

Edel is the Arts in Healthcare Programme Manager for St Luke's General Hospital in Kilkenny, Wexford General Hospital, and Cork University Hospital. She has vast experience working with patients and staff on everything from putting together art and photographic exhibitions, to hosting choirs and planning site-specific commissions. But this Irish Hospice Foundation project is the first one of its kind in which a hospital was awarded a grant for an artist to work one-to-one with patients in an acute hospital.

"I had to make sure the person selected had artist-in-healthcare training. It is very important to have the right artist who can work with people who might die during the course of the project. You need resilience as an artist for what can be a hugely emotional journey," says Ní Nualláin.

That said, the counselling sessions which were built into the project were a significant way to

safeguard the artist, according to Ní Nualláin. "The project was co-managed between myself and the End-of-Life Care Coordinator, Margaret Ryan, but while this isn't art therapy in that we weren't looking for set [therapeutic] outcomes, patient wellbeing is part of it."

Like Schofield and Ryan, Ní Nualláin was moved by the experiences of the patients. "There was one woman who had done art at school but wasn't encouraged to later in life. She did beautiful drawings, and art became a lifeline for her, creating a lovely connection with staff and giving her family and friends something else to talk about. It resulted in a huge turnaround in her wellbeing and showed us how, in the final furlong of your life, you can still have the capacity to create and leave a legacy."

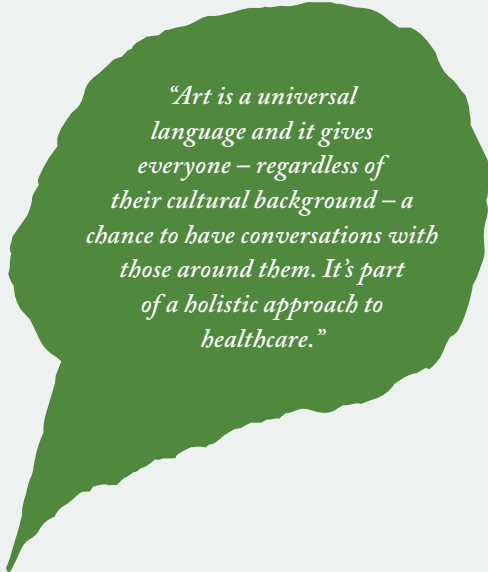
When patients are in end-of-life care, there is only so much the medical teams can do to support them. "This offers people another level of care. The creative process can help participants to transcend



their life condition. It can be magical to create something tangible and in the moment, and there are biological benefits from doing so.”

Ní Nualláin says the creative process has been found to release endorphins in the brain. “It can give people a natural high when they are feeling low. It’s like artistic morphine,” she says.

She also notes that throughout the project, the artist had to follow infection control protocols in the hospital. This meant that brushes and other art materials couldn’t be shared. However, art was allowed to be hung on the walls. This gave everyone opportunities to look at and discuss the work with staff, patients, and visitors alike.



“Art is a universal language and it gives everyone – regardless of their cultural background – a chance to have conversations with those around them. It’s part of a holistic approach to healthcare.”





Dr Rory McGovern

Consultant Geriatrician in St Luke's General Hospital

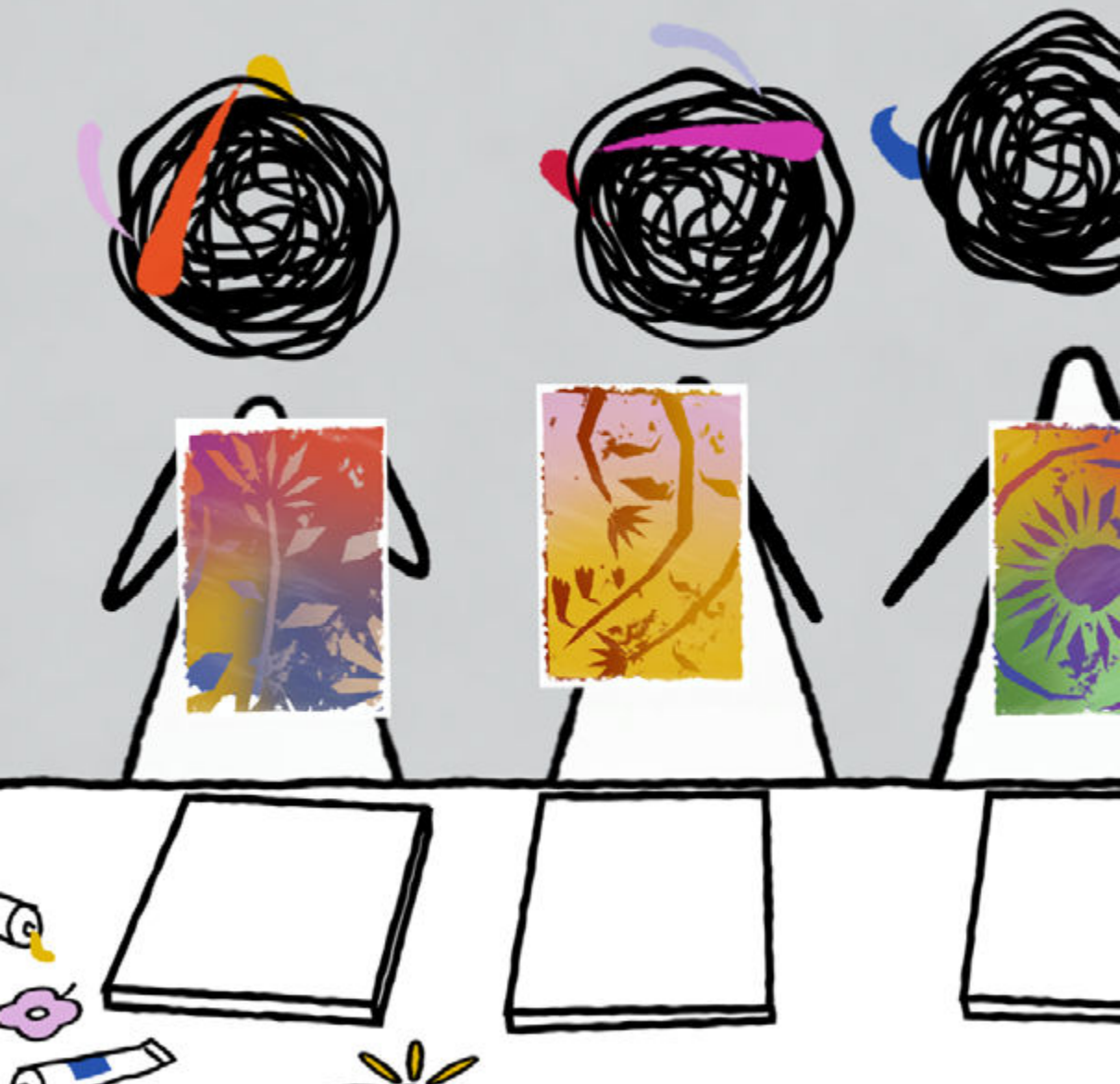
“People can become de-personalised when they come into hospital. They are at sea, out of their normal routines and comfort zone, so a project like this is an excellent way to engage them on a personal level and give them back some control over their lives.”

“Often patients won't admit to us what stresses they are under, but the artist was able to unlock something in patients to bring them into a better

psychological state. I saw how doing this work relaxed and de-stressed patients.”

“You wouldn't think that an acute hospital would be the place to do art, but maybe it's exactly where it should be done. And having patients' paintings on the walls enhanced the physical environment and gave staff other topics of conversation to have with patients and to see them beyond their role as a patient.”







University Hospital Limerick

Narrative by Dominic Campbell - Arts & Creative Engagement, Irish Hospice Foundation

Neither artist, patients, nor even hospitals are standardised. Producing programmes like this residency is often more like working from a recipe than a rule book, more about balancing opportunities and flavours, than replicating a set model. There are different cultures of behaviour even within a quality controlled closely monitored system, and different types of benefits are possible when these encounter creative behaviour.

Kevin Toolis is a wordsmith, a writer, poet, film-maker, journalist, author of 'My Father's Wake' - an analysis of death ritual. Our brief, "be in service to people at the end of life", could mean to work with the individual or understand how the systems of health engage with the dying. It could even mean both.

In this part of the book, we present poetry as a form of research. Kevin Toolis' experience of being an Artist in Residence to People at the End of Life prompted his reflections on the individual's journey and their encounter with the service of healthcare.



▶ The Poet

Kevin Toolis



*Wordsmith, writer, poet,
film-maker, journalist*





My Second Dying Skin

At first they said – sit.
Relax.
Then looking down, at the paperwork.
Paused. Consulted.
Came and went, deciding.
On the hour, the minute, to begin.
Soft. Her tone.
And then not saying, said.
“Put your clothes in the locker and change into a gown.
Don’t forget to tie the cords at the back.”

After, I wondered
Had the voice a touch of pity?
Or just, matter of fact command?
Mundane, pre-scripted, the day-routine
The way you’d speak to an anxious child. But firm:
“From here on in, you’ll be doing what you’re told.”
Would it have been better if she had said the words
out aloud?
“You need to understand, Who-Ever-You-Were,

That’s gone, stripped off, now.
Has no meaning anymore.
In here.
You and your like are ... something, ... something ... else.”
How easy, in innocence, it was, in the cubicle
Buttons unclasping, to cast away my former skin
Old clothes.
Naked flesh, feet, moments, on the tiled floor
Then rebound, recast.
The gown was grey-blue, mottled, I think
Non-descript.
The draft behind running straight up your arse.
I noticed on the walls there was no mirror for looking back
Or looking in.
My new uniform uniform
A body, now selfless, between the slips
Of my betrothal dress
When all other souls, except us damned, had yellow badges on
“Hello, my name is ...”

Back at the desk the nurse snapped on my new wedded ring
A plastic bracelet - my name and number – printed neat
Sealed in plastic.
A handcuff of my declared deficits.
No longer trustworthy, incapable.
Of the telling of the hours, the day, a history
The state of my diagnosed lumps within
The time or colour of the pills to be taken
Even the calibration
Of those last doses of radiation
And other details of trivia
The Who-I-Was, the what of That-Life-Before
Unreliable now, a mere witness
Patiently dying.

by Kevin Toolis



Accountings of the Heart

How late in time it was
Before, I began
To account my hours
The coinage of earth
Bills of lading
Debts outstanding
Weighted words, I should not,
Or could have said
The scales of doubt
Roads, I could not,
Or should have taken
Those I betrayed, befriended, loved
A counterweight of acquaintances, other lovers, friends
Balances
Sums delivered
Additions, subtractions, calculations in vain
Duties unreconciled
Promissory notes, written off
Vain investments of my heart
How I made and unmade myself
Played the part, or flailed

How late in time it was
Before, I began
To throw off the weight

The losses, the unborn children of imagination
Doors slammed, impotent rage
Names, dates and details half-remembered
Complaint
My seethings, rivals, forsworn enemies
The wastes of time
Set against the ledger of
Pastries, red wine, feasts
Songs, holidays and small victories
A soaring sun spilling joy
A trembling tide of wonder
The miracle of your soft touch

How late in time it was
Before, I began
To forget myself
A river of spent past
Tumbling waters
Narrow passages
Frailties of bone and heart
A shoal of memory
Coursing through this all too human flesh
But how late, how late in time it was
For the forgiving of myself

by Kevin Toolis





Soaring Sun

Let's not fill our hearts with sorrows
Or tears, or keening.
Forebodings
The gravestones of a thousand possibilities
Instead, hold fast to the bright joy
Of such unexpected creation
This burning love that flames from eye, to limb, to mouth, to mind
Our new born Sun
Entire, and apart
Soaring between and within
That exults the world, and skin
Our strange miracle
And smile for what is, and has come into being
Is not lost
And is not gone

by Kevin Toolis

▶ The Psychologist

Dr Ursula Bates

Background

Dr Ursula Bates B.A., M.A., D.Psych is a chartered clinical psychologist, psychoanalyst, and mindfulness teacher.

Since 1990, she has worked with cancer patients and the dying in St Vincent's University Hospital and Our Lady's Hospice Harold's Cross and Blackrock Hospice. In her role as manager of psychosocial care in the hospice, she managed complementary music and art therapy and has a personal interest in the value of art and symbolism in the care of the dying.

Staff care is central to how she understands coping with serious illness and dying. Over the course of her career, she has held de-briefing sessions for front line staff from all disciplines, and facilitated Balint groups and Schwartz Rounds, which promoted emotional development and a systemic understanding of the emotional and unconscious tensions inherent in this work.

Recently, she has contributed to the work of Irish Hospice Foundation (IHF), developing and supervising the Bereavement Support Line during the COVID-19 pandemic and teaching on the Masters in Loss and Bereavement; a collaborative programme between the Royal College of Surgeons in Ireland and IHF.

The reason & experience

The aim of having an independent supervisor was to have a space, as neutral as possible, in which the artists could reflect on how the experience was impacting on them. The artists were offered three sessions each to use as they required. They were not obliged to use the time; both choose to do so. Feedback to the organisation was by way of a report on themes raised during supervision. It was necessary to check back in with IHF Arts and Engagement office once on a boundary issue, and this was with the agreement of the artist.



Psychology theory and technique in therapy is an attempt to describe and facilitate the progressive development of thought from felt experience to highly abstract levels of language and communication. For the patient in illness, or nearing death, there is a slow body realisation of trauma, insult or injury, followed by imagery, fragments of sight, smell, hearing, brief attempts of finding meaning, finally a reaching for language to name and articulate their experience to another. Over recent years, in society, we have become more attuned to the reality and power of “naming” experiences that had long remained inarticulate and lodged in isolated and marginalised people - experiences such as child abuse, domestic violence, and gender fluidity. So, in offering the dying or bereaved a space for subjectivity, we are trying to offer an openness to imagery, language, and sharing, both in the person and in ourselves.

Art, either in visual expression or language, offers a different space that can capture the complexity

of in-between spaces when one is neither here nor there and, as Damien Freeman (2021) explores, a facilitation of emotional expression.

The following themes were explored in supervision.

Institutional “buy in”

Each artist had a liaison person within the hospital. There was considerable variation in the approach of that person. All staff needed to understand and engage with the project, even if they were a junior doctor on a placement.

Medical organisations have a strong task focus. They are designed to deliver rapid evidence-based interventions that are primarily disease-focused. On a daily basis, they observe the patient, check on vitals, and deliver planned care. If there is any change in the patient’s medical status, this activates a chain of decision - to call a doctor, increase medication, or send the patient

for further interventions. Modern medicine is increasingly specialised and sophisticated. So multiple teams are frequently involved and medications are targeted. The overall direction of care is curative and if not, then aims to delay the disease process. Fighting metaphors are a common language in medical settings. The enemy - death - is not conceded to. Therefore, the approach is to engage step by step, bunker by bunker, symptom by symptom - the illness is managed rather than the person. The emotional atmosphere is often one of vigilance, expertise, and rapid action.

This is the opposite to the subjectivity of the person, for whom being ill is a deeply personal experience. They have their own landscape of the body, their emotions, their thoughts and their struggle to make meaning of what is now happening to them. Moved, often rapidly, into a foreign environment, their bodily boundary intruded into, exposed to strange sights and sounds, they are disorientated and encouraged to be dependent. What to a nurse is a routine task, getting a needle into a vein, can be experienced as an assault on a person, but cannot be named as such.

The artists in the project experienced this in a number of ways. While being welcomed, there was a time lag in gaining access to patients. So the desire for a subjective space was there in fantasy but not in reality. Access was then interrupted frequently by the hospital routine - an assertion of priorities. There was a checking on the patient after interventions, an anxiety about “doing no harm”. An intolerance of emotional upset in relation to an intervention, as if a positive response is the only acceptable outcome. This again reflects the push to controlling symptoms, (“Do you feel better now?”) as distinct from the open acceptance that any investigation of subjectivity, whether by language or image, often has a release of effect which, while distressing immediately, is in the long run constructive.

Understanding this chasm is essential to understanding the ground on which the artist is standing when they enter an organisation. It is as if they are directed to a stony field and told to grow flowers. So staying with the image, they need to sit on a rock and think deeply about the orientation, the wind, the soil before starting to work. And all work is work. Hanging out at the nurses’ station, walking the wards,

having cups of coffee, working out small ways to engage, finding a way to carry their trade on their back, are all critically important. Accepting the nature of setting, that medical intervention will interrupt the work, that the person may wish to just engage with the materials, that a relative may wish to be present is an essential capacity. So, much more than in other settings, the artist needs to hold the work within themselves and not need to seek external validation. In looking into the eye of the other, they are more likely to see anxiety or irritation in the initial weeks of the project. This often provokes defences in the artist, a desire to have an “art space” which would support the boundaries of the work or “a neutral space” (artists suggested that the best conversations were outside the hospital).

The role of the supervisor is to have a big enough view of the dilemma, to name what is being observed and validate the difficulty of the experience. To name the conflict of the hospital, the desire to have language or art, the defences against both, the resistance to seeing death as other than a personal failure. The desires and defences of the artist, to try not to have the artist subjectively silenced or killed off.





Subjectivity of death and loss

Death has become an increasingly technical affair and is contested territory. When is its presence recognised? How do we agree that a final point is reached? Who has the authority to name that and who can communicate that to a patient or family? Both artists found that patients who were visibly frail and were referred to the project were not necessarily able to pick up a dialogue and express themselves in relation to the end of life. They had different reactions to this. One chose to sit in the space whatever it was and work with whatever arose. The other was frustrated and felt somewhat trapped in a collusion to have “a meaning – but less conversation”. In a defensive reaction, they thought that having access to the patient’s file would have helped. Supervision was explored with each artist, the places we go inside ourselves when devalued or stressed, seeking more information, seeking more contact with staff, soothing ourselves by breathing, smoking, or coffee.

Emotional reactions to the experience included: frustration, irritation, sadness, awareness of the loneliness and isolation of patients.

There is a real tension between reality of modern medicine and acceptance of death (Warriach, 2017) with limited space for consideration of the subjectivity of an individual death. There are problems of language, legal risks, patient autonomy, and a growing lack of commonly agreed societal rituals to provide a larger degree of containment of an existential experience. We are caught between our desire and love for the progress modern medicine has brought, that we can now bring children into the world and love them without fear of a premature death; we can live without fear of devastating illnesses and our awareness and fear that life is limited and that prolonging it is often prolonging our dying, so we are dying psychologically before we die. All of this was touched on by the artists.

First-hand accounts are deeply textured and personal. These accounts have pioneered societal transformation of our understanding of child sexual abuse, women's rights, minority rights, and in Ireland of the historical abuses by institutions. They are bottom-up emotional, image-based, and visceral narratives that activate our empathy and make us aware of the structures of power and

authority in which we are embedded in society. They have almost no place in standard medical literature. In eliciting such accounts, the artist is engaged in a radical activity.

Bereavement approached in a rational/abstract manner

There was the hope that engaging with the bereavement service of the hospital would offer a freer space, but this was not experienced as such. Bereavement care was also positioned within the language of the medical services as an extension of a mental health model. One artist was particularly concerned that grief was seen as an individual internal journey with limited reference to it as a socially embedded process. The one reference to social engagement in bereavement care was to sending a card to bereaved relatives - the artist's poignant reaction in supervision was "There was no space for howling."

"Did I say something out of turn?"

In such an anxious environment, the artist who is already subjectively attuned is prone to taking inwards the atmosphere of the situation and becoming too reflective. Managing boundaries is essential to holding oneself in such a situation.

To discern what belongs to the organisation, what is the patient's, what is mine, is a constant internal dialogue to-ing and fro-ing. Like mixing too many colours, the artist can walk away feeling a murky brown or grey, yet much of death and dying lies in this murky area.

Efforts to embed or infiltrate art into a hierarchical medical institution is a radical process. It elicits the desire of individual staff to affirm that they too bring their own personhood to work, but also activated their defences against that very space. There is a need to kill off the subjective self to actually engage with the work day after day, and, indeed, most are trained to keep their boundaries while working. All organisations have a public identity and an unconscious private group identity. Institutions, while espousing a public aim or mission of healing others, have also a latent aim of self-

preservation and can rapidly shut down any perceived criticism, so this needs to be known by anyone entering the space. It applies to all institutions - education, legal, and medical.

Patients are caught in the desire to believe they can overcome their illness or death and are slow to name their experience for fear of losing control and emotional containment. They take time to build trust in the process. They will, in my experience, oscillate between moments of openness and expression and periods of defence.

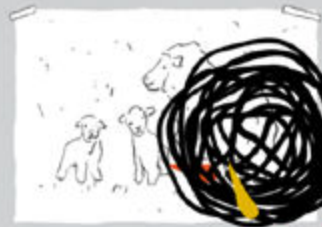
So, we need to support awareness, knowing and naming the hard dilemmas of what we desire and what we fear as human beings. It takes a steadiness of mind and heart to stand in these spaces and accept that we progress slowly towards change.



References

Damien Freeman, *Art's Emotions: Ethics, Expression and Aesthetic Experience*, McGill-Queen's University Press, 2012, 210pp

Warraich, H., 2017. *Modern death: How medicine changed the end of life*. Macmillan.



► Summary & Recommendations

Dominic Campbell, Irish Hospice Foundation, and General Hospital Team

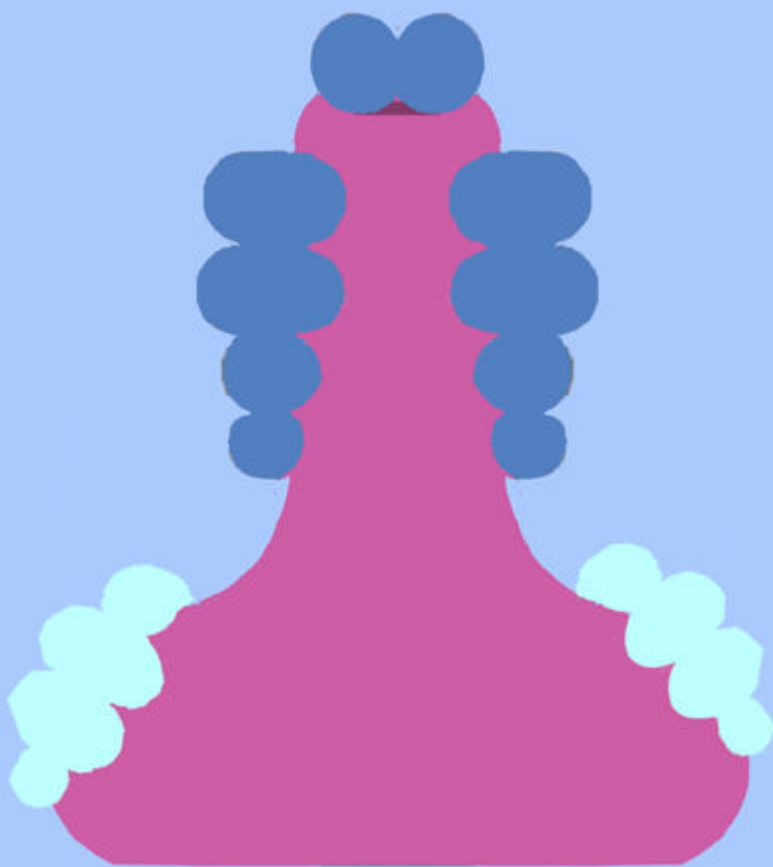
The Artists in Residence in Service to People at the End of Life was designed to bring the benefits of creative expression and its impact on the well-being of patients and staff. Through positive engagement with patients, families, and staff, the programme hopes to provide a unique outlet for self-expression and improve the health and well-being of our patients.

Both hospitals were emerging from the extreme intensity of the COVID-19 pandemic. Both Artists' first point of connection was their hospital's End-of-Life Coordinator, a position created over decades by Irish Hospice Foundation working closely with individual hospitals and the HSE. In St Luke's General Hospital, Kilkenny, an additional level of support came from an Arts in Healthcare Programme Manager. They exist in a number of Irish hospitals. Their brief varies. It might be deciding what artwork goes on the walls or supporting patient engagement. In some hospitals like

University Hospital Limerick, it's a recent development; there is an arts committee of staff representatives tasked with the development of creative practice and the role of the arts in health. In Kilkenny, the role is more established. Overall, it's an evolving system.

In Kilkenny, this extra level of support helped smooth the inevitable challenges for artists connecting into the working life of the hospital. In Limerick, by mutual agreement the programme of work ended earlier than originally projected when it was felt that it was adding an additional level of pressure to an already busy and complex working environment. All involved learnt from the programme; they value it and are seeking ways to develop it further.

For Irish Hospice Foundation, it raised unexpected questions about art form and function. Is working through visual art more valuable for people at end of life than working with language?





Are some forms of creative practice more complex than others? Is finding words for the complex sensations at end of life additionally stressful? Is this the case if you are a dying poet?

None of the people our artists encountered were simply people in a room. All had rich, diverse, fulfilling, complicated lives that brought them to

this point of encounter with these artists and the way contemporary acute health currently brings care at end of life.

This report hopes to maximise our learnings with some key recommendations for future engagement of Artists in Residence in Service to People at the End of Life.

Key Recommendations

1. Considering the complexity of the acute hospital environment and complex care delivered, reflection is required if Artists in Residence is suitable to all acute hospital environments, and time is required to identify those places that are suitable (for example, level of hospital, number of beds, etc.).
2. Define the purpose and expectations of the project to ensure everyone involved is clear on what the project aims to achieve. This would include:
 - a) clearly identifying the target audience, the desired outcomes, and any specific requirements or restrictions.
 - b) clearly defining the project scope for the hospital and artist to ensure the artist's time and resources are used effectively.
3. The selection of artist is critical to the success of the project. A cross-functional and cross-directorate interview panel could ensure the chosen artist is a good fit for the hospital and its patients by considering a range of perspectives.
4. Defining the roles and responsibilities and qualifications of the artist and relevant hospital staff from the outset would also help to ensure expectations are aligned.

5. Develop awareness training and structure for the artists that informs them of the hospital acute setting and supports them to work with patients at end of life.

6. Having a service level agreement in place would help to ensure clarity of expectations from the project from all parties. This could

include defining the project scope, the service delivered, the artist's responsibilities, and any specific deliverables. Ensuring patient safety and confidentiality and defining who is responsible for protecting patient information is important to ensure that all parties are aware of their obligations.

By considering these key learnings, we can improve the Artists in Residence to People at the End of Life Programme and ensure its success in future iterations.

▶ The Reflection

Artists in Residence to People at the End of Life

This book is for those of us who are dying.

It's important to state this so we all know what we're talking about. To bring it into the conversation, not leave it standing in the corner like an abandoned elephant. Bringing things into the centre of the conversation is what the arts are about. The arts are about many things, including death, always have been.

One way to understand them, to look at them, to understand why people make things, is that every painting, sculpture, script, poem, dance move, film, drawing, and scribble is an attempt to cheat death. To stand outside of time. To live forever.

Then again it also needs to be stated clearly that the arts are slippery.


Every time you've nailed a definition of "art", it wiggles out of being what you thought it was. Unlike sport, which is always people knocking the same ball around and around and around

forever, art evolves. It is different things to different people at different life stages. Art's benefits and joys and irritations shift. Its reasons for delivering change depending on the place and time. It changes. Just like people.

So exactly how the arts bring abandoned elephants out of their lonely corners is equally slippery. Sometimes it tempts them out with something as tasty as ice cream; sometimes its pull is heart-achingly beautiful, sometimes with humour, sometimes with charm, or sometimes with punky provocation.

The only consistent rule seems to be that, as with ice cream, over indulgence makes the attraction wear off. Whatever it was that once worked, no longer does. Think about the music you liked. But don't now. And the one that you didn't, but do now. See? Slippery.

The experience of dying is equally tricky. As we slip between this world and whatever



happens next, where we go has been a topic of conversation since topics began. The sensations felt by those left grieving equally so.

But what about the experience of approaching the end of life? The experience of reaching the end of your life and dying? Now, today, in the middle of all the contemporary life that's going on. Now, this week, or month, or maybe year. Amongst the internet and our chosen families and rich every-day diversity and same sex marriages and friends living abroad and text messages and acute hospitals and documentaries about A&E departments next to Lord of the Rings and Sunday Service or Friday Prayer. Now in this wrong season, with all the thousand things that will be left undone. The rushed exit, accident, intentional act, drama-filled or drawn out, or just a soft simple slipping away.

Dying is almost always a bit messy. It won't fit into a tidy box-like definition. Won't be told. Bends the knowledge of medical learning into strange new shapes. Hurts the head. Fries the brain. It causes conversation spoken in soft hushed voices and generates glances too strong to hold. It brings about the loss of words. Turns adults into frightened children, makes giants of the frailest child.

Dying confuses the way we think we are inside the world. It changes what the world is for us. It breaks the narrative of ourself. Sits outside of time. What can be said of dying? What do the dying want to say?

In the medical professions, a pendulum is swinging increasingly in favour of "patient voice". At its simplest, this recognises that power dynamics have an impact on health and health choices. Choices about quality of life can mean more than functional biology. Quality of life can certainly be something other than dysfunctional biology. What makes life worth living is not the same for everyone.







Over the last 80 years or so, since around the time of the Second World War, artists have been exploring “who gets to make art, what, where, when and why?”. This is one strand of thinking that led IHF to initiate this Artists in Residence in Service to People at the End of Life programme.

Vast libraries have appeared documenting the ways that some people choose to help other people make things that might help make sense of living. This programme is part of that learning. We want to know how this might apply at the end of life.

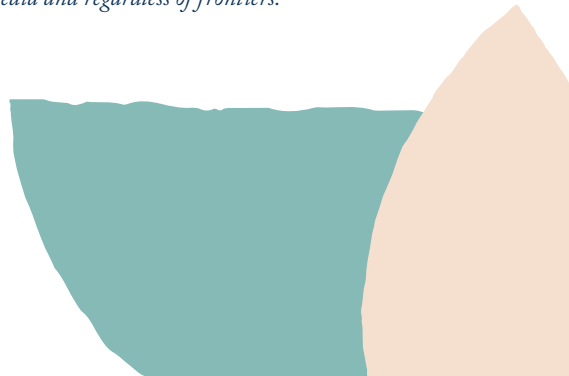
Should everyone have an invitation to create at the end of life? Or to be an audience? To look, listen, or to make? Of course, not everyone is in the same state of ill health. Not everyone wants to. But shouldn't the invitation exist to create one's own reflective moments from the unique rich experiences of a single life? And what happens when that's possible? What can others learn from the art that is made?

Another strand that informed this programme comes from the healthcare sector.

In the principles of its constitution from 1948, the World Health Organisation defined health as, *“A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”*, then went on to say, *“The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.”*

Appearing in the same year, included in The UN Declaration of Human Rights, is Article 19:

“Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.”



At IHF, we've been wondering since we were founded in 1986 about human rights and dying and care. About the right to whatever might constitute a "good" death. About your rights when you know you are dying. Or when you are dying but no longer know.

All this wondering has been in service to working out how to help. To figuring out how to bring care and support as needed. If needed. For all involved. For all dying. For everyone.

Since we founded IHF Arts and Creative Engagement programme in 2020, we've been wondering about "rights of expression" at the end of life. We've been wondering what awareness is and what "decision making capacity" in the making of art could possibly mean. We've been wondering about the nature of caring. The specific kind of caring an artist, with their specific types of slippery skills, brings for shuffling lonely elephants standing invisible in the corner of a room.

In Ireland, approximately 100 people die every day. Some of their relatives and friends will know they are dying. They get years', months' or a week's notice. For everyone else, it's the last surprise. Woops. Elephant.

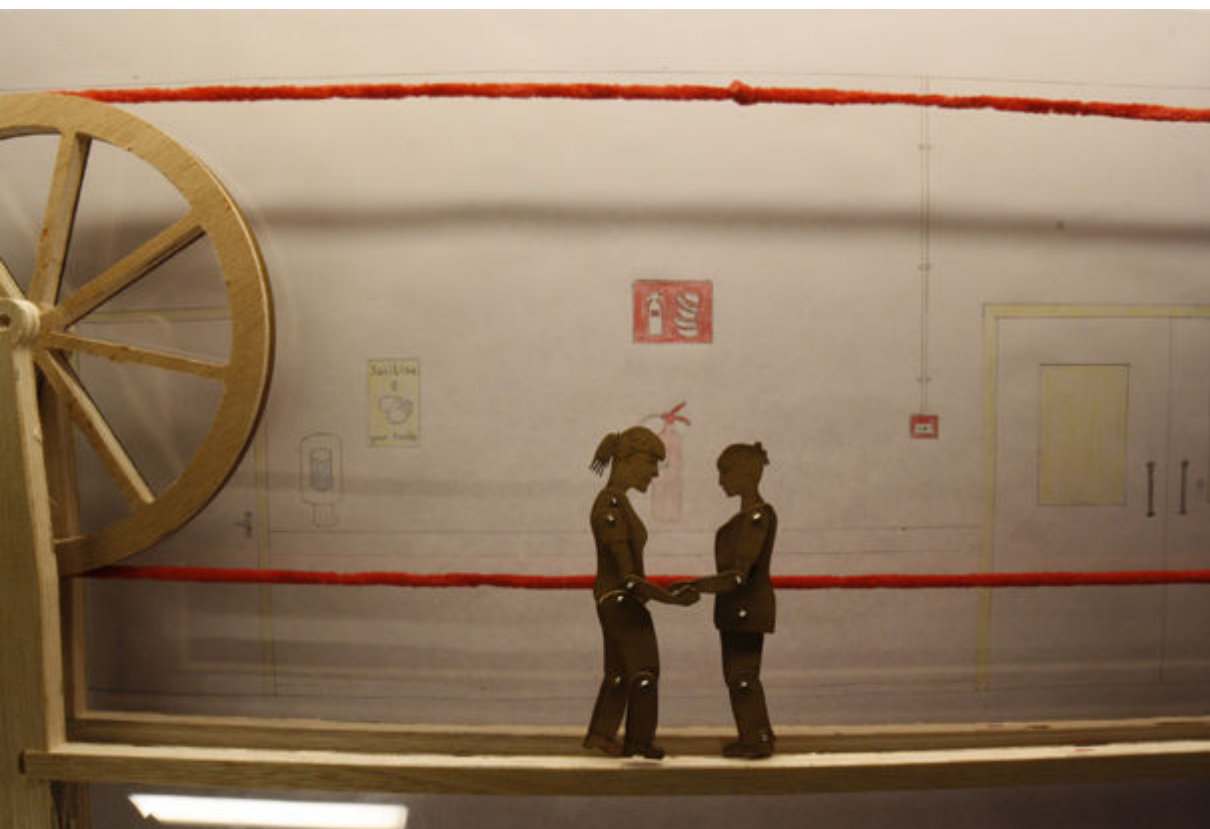
Of these people, 43% die in hospitals, technically acute hospitals, the ones with Accident & Emergency departments and crisis medicine. In Ireland, we have different types of classification of hospital, opposed to respite hospitals where people recuperate. They are all slightly different and all staffed by "Mostly Angels". And full of elephants.

One of the small elephants is that hospitals and their "Mostly Angels" are educated to fix broken people. To fix bones and cancers and failing organs. They're good at it. Lots gets fixed. Death isn't part of the formal education programme, which teaches people to fix people. It's just part of their lived experience.

A bigger elephant is that all people can't be fixed. There is no fixing dying. Can't have one without the other. No light without shade.

What happens in a "fixing" environment when "not fixing" happens? Elephants get made. Lots of elephants. Herds of invisible elephants. Difficult stuff that we can't find ways of talking about, much less find systemic responses and supports.

Into this silent shuffling herd, we sent people armed with a paintbrush and a pencil. We sent



them with a mission - “The artist is in service to people at the end of life”. It was a very clear brief. We know that art making is catalytic. It creates a thing around which small changes happen. Strategy emerges from practice.

It was a clear brief, and also complicated. It didn't say how this was going to be done. It didn't say what people at the end of life might want from an artist. It didn't give a clear itinerary because there is no clear itinerary. How can there be? It was deliberately just that little bit vague.

It did introduce the artists to the “Mostly Angels”. It did educate the artists in grief theory and collective understanding and the ever-changing learning of books. It did provide someone to talk to and safety nets and calls and a listening ear and checks and balances. It did all the professional things. It very intentionally set out to put artists into the service of people who were dying amidst a herd of elephants.

This book is ultimately about the sensation of care. Care at the end of our days. Care shared between different people with various ambitions, skills, or mandates. In the health systems that have evolved

in Ireland to date, care is communicated through several forms of language and some slipperiness. It's communicated ultimately by what we do. By the culture of care.

We bring care to people in a different way than we bring medicine.

It is primarily emotional labour. It is a thing of sensation and spirit.

Good artists look out for things. Some are attuned to spirits. They wait for tears. Laughter. Dancing. The invisible note and the felt movement. They ceaselessly ask questions. They make things across a spectrum: Is this “with”, “by”, or “for” other people?

The observations of our artists included:

All the “Mostly Angels” who work in healthcare do emotional labour. Ceaselessly. If we are to treat Care staff as humans and not pretend they're a subsection of “goddesses and gods” who are able to replace cannulas, then we need to acknowledge and support their emotional spend too.



In places or at times when the spirit is worn, we need to make extra efforts. For the “Mostly Angels” staff, this isn’t simply about a wage, it’s about how people create meaning, value, and purpose in their lives for themselves. It is about creating ways and opportunities in which they can express themselves. For those dying, it is about creating ways and opportunities to recognise the complexity of their journey, finding ways that we all might be companions. There are several roles for artists, art, and creativity here, as well as for nurturing a culture.

This book is for those of us dying. For all of us. We are all dying. We will all end up amongst the elephants.

It would be nice if when we get there, we find a person with a pencil and a paintbrush and attitude and some “Mostly Angels”; more cared for than care worn.

It would be great if playfulness could be recognised and co-exist within systematic healthcare. Playfulness to the end. Playfulness as a state of grace.

Playing with elephants to the end.



Irish Hospice Foundation Resources and Information to Support People Who Are Facing End of Life and Their Families

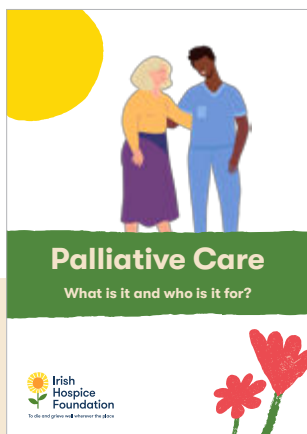
Palliative Care

Our palliative care programmes support the delivery of best practice palliative care, at all levels, and within all settings, in Ireland. Our palliative care programmes endeavour to align with the work of the National Clinical Programme for Palliative Care, whose **Model of Care**, published in 2019, aims that:

“Every person with a life-limiting or life-threatening condition can easily access a level of palliative care appropriate to their needs, regardless of care settings or diagnosis, in order to optimise quality of life”.

Many people associate palliative care only with cancer, but palliative care can be provided to any person living with a life-limiting condition. These can include heart failure, advanced respiratory disease, advancing neurological illness, chronic kidney disease and dementia. We provide information and resources for those working with patients with life-limiting conditions such as these.

Our information booklet, Palliative Care – What is it and who is it for?, for those diagnosed with life-limiting conditions provides information about palliative care that aims to make people feel comfortable and supported about their illness. Read more at hospicefoundation.ie/wp-content/uploads/2023/12/Palliative-Care-Booklet-Irish-Hospice-Foundation.pdf





Children's Palliative Care

The end-of-life care needs of children differ from those of adults. Since our beginnings, Irish Hospice Foundation have sought to ensure the needs of children and their families are met. For over a decade, we have been working in partnership with the HSE and other charities to ensure that the needs of children and their families are met and services are being delivered. Read more at hospicefoundation.ie/our-supports-services/healthcare-hub/palliative-care-programmes/childrens-palliative-care/



Nurses for Night Care

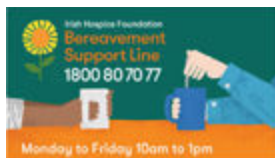
We fund the Nurses for Night Care service for people dying with illness other than cancer. Nurses for Night Care enable people with diseases like dementia, motor neurone disease, advanced respiratory disease, heart failure and end stage kidney disease to receive expert nursing care and support at night in their own homes in their final days. It also provides reassurance and respite for families and loved ones caring for someone at home. See hospicefoundation.ie/nnc



Think Ahead

A practical tool and customisable guide for advance care planning and end of life. It helps a person document their healthcare choices and personal wishes for a future time when they may not be able to make or express those decisions. Think Ahead is in full alignment with the recently commenced Assisted Decision-Making (Capacity) Act 2015. See thinkahead.ie

Irish Hospice Foundation Resources and Information to Support People Who Are Bereaved



Bereavement Support Line

A national freephone service – 1800 80 70 77, set up by Irish Hospice Foundation, in partnership with the HSE, that provides a safe space for those who have lost a loved one, friend or colleague, to talk about their loss and grief. People can also visit www.bereaved.ie for more information on coping with bereavement and finding supports.



Grief in the Workplace

We provide support, training, resources and advice to help organisations and managers to respond effectively to grief situations that can arise in the workplace. We offer a range of interactive courses which focus on coping with grief in the workplace. See www.griefatwork.ie



Local Bereavement Networks

Through our networks, which work across the country, we are committed to supporting local and national stakeholders to support best practice in the area of bereavement care in Ireland and to promote a better understanding of bereavement supports for children and adults.



Irish Childhood Bereavement Network (ICBN)

ICBN support professionals to deliver quality and accessible support to children who are bereaved. The ICBN signposts loved ones to a directory of bereavement support services. It also advocates for bereaved children and young people, and those supporting them.

See www.childhoodbereavement.ie



Education

We work with staff in a variety of settings to support and embed education and training in end-of- life and bereavement care. From our MSc in Loss & Bereavement, grief in the workplace, to our bereavement workshops, there is a wide spectrum of training to choose from.

See www.hospicefoundation.ie



▶ THANK YOU TO:

All patients, family, and Staff at University Hospital Limerick and St Luke's Hospital, Kilkenny who engaged, educated, enquired, and informed this project.

The Creative Ireland programme team without whom it would not be possible to innovate in those places where culture meets health.

Irish Hospice Foundation leadership and team, whose compassion and intelligence is the foundation from which this Programme is built.

Illustrations throughout are stills from animations inspired by the stories of this project used by permission of:

Emma Fisher and Beyond The Bark

Ivanna Davcheva

Michael Lomon www.michaellomon.com

To see the full animations go to

www.hospicefoundation.ie/arts

Designed by Stray Dog
Printed by Doggett Group
www.doggettgroup.ie



A stylized illustration at the top of the page shows a hand in shades of pink and red holding a large, light pink heart. The background is a soft, light pink gradient.

A book of resilience



To die and grieve well wherever the place



Clár Éire Ildánach
*Creative Ireland
Programme*



ISBN 978-1-3999-7877-4