

Article

The “A Graceful Death Exhibition”: Portraits and Words from the End of Life

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Abstract: This article discusses the lack of knowledge and awareness that hampers end of life experiences, for both the dying and those left behind. It draws on personal experiences, and explores working creatively with dying people, using observations, painting and writing to communicate ideas. Asking the dying to tell us and show us what it is like is very successful in raising awareness, and the article concludes that less separation within our communities from the dying would normalise the process and lessen the fear.

Keywords: palliative care; dying; art; portraits; soul midwife; creative expression; compassionate community; end of life education; end of life experience

Until someone I loved died, I had no idea how such a thing as death could happen. In 2007 my partner, Steve, was diagnosed with liver cancer despite having been in remission for a year from bowel cancer. After his diagnosis it took him just three months to fold up, diminish and fade away, until one morning in November 2007 he died, and I had to face a whole life ahead without him. Nothing had prepared me for this to happen, nothing had prepared me for the effects of grief afterwards, and for a long while I felt that the world, and I, had spiralled out of control. I did not believe that someone you loved could die. I did not know that dying looked like this, I did not understand that the bereaved needed to have conversations about the process and I did not know, even if I had wanted to, what vocabulary to use to address what I was going through. Part of me could not believe it was happening. At no point before the very end did anyone tell me that Steve was going to die. I would not have believed them if they had, I had no experience of the end of life and did not know what was normal and what was not. I was not only ignorant, I was lost, slightly mad and out of my depth.

As a professional artist, I began to paint Steve as he did his dying. In a bid to understand what was happening, I tried to capture him in paint, detailing his decline and concentrating on the details that showed how the cancer had affected his body. If he was jaundiced, I painted him yellow. If he was thin, I painted all the bones that were showing through his skin exactly as they were and if he was confused, I painted the look in his eyes to show his distress. I could not do anything about Steve's dying, except watch and record. This dying was something only he could do. Painting him became my way of journeying with him, it became a way of honouring the process by paying attention to what was happening, and capturing the details exactly as they were; showing the skeletal thinness of his face, arms and chest against the distended stomach and swollen feet and ankles. On the day of Steve's death, I sat with him so that I would remember how he looked in death, and how it felt to be with a body that no longer held life, and how that body that no longer held life was my Steve. The painting of Steve on the morning he died is very beautiful but took many versions over many months to be able to capture the beauty. The finished image is only of his head, jaundiced, elegant, sunken and thin within a large golden halo, harking back to the Renaissance images of the Christ deposed. Surrounding the halo is a deep rich dark French ultramarine blue, contrasting and illuminating the yellow of the face and the golden yellow of the halo. I painted the glint of light reflecting from the ointment on Steve's mouth, showing the care the nurses took that he was comfortable until the end, and I painted the glint of light in his half closed and sunken eyes. These spots of light gave me great comfort, as if there was physical light in the darkness.

In Figure 1, the two paintings show Steve's reaction when I entered his hospital room too quickly, not giving him time to compose his face. The first image shows his vulnerability, his head tilted backwards, his eyes wide, and his face open. The second image shows him within seconds, composed, and guarded, ready for facing the day ahead.



Figure 1. The real man and the guarded man diptych.

In Figure 2, the Last Bath with Ducks, Steve can no longer cope with the water on his skin. He is distant, uncomfortable, jaundiced and thin. I have taken pains to paint all of the bones showing through his skin, it felt important to show how he could be so thin and ill, but still here and still Steve. I used to put the plastic ducks in his bath as a joke which he loved. But here, he can no longer see them.

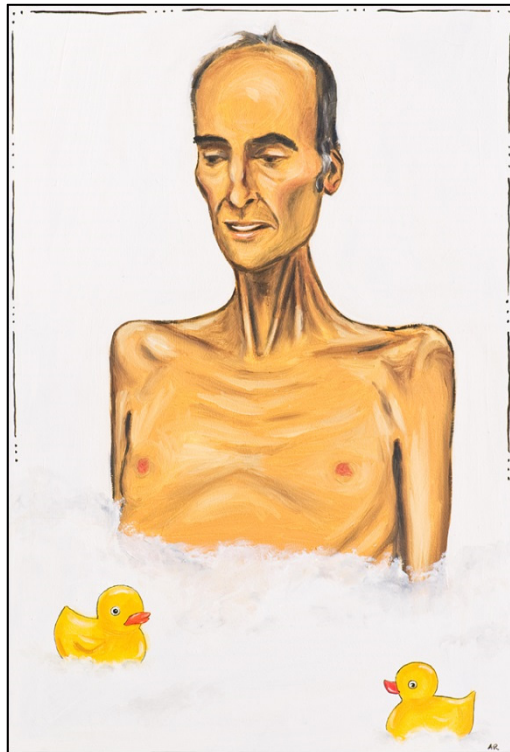


Figure 2. Last bath with ducks.

Figure 3 shows is the morning that Steve died. It took many attempts to capture this stark and elegant beauty. Note the gleam of light on the ointment on his lips to protect his mouth, and the glint of light in his sunken eyes. These gleams of light give me great comfort.



Figure 3. Steve as the Christ Head.

I spent the next two years in my studio going over and over all of the images and photos that I had taken of his illness and death, producing enough paintings to hold a first and very tentative exhibition in my house in November 2009. Instead of coming to see the paintings and sympathising with me, many

visitors identified the images I had painted with their own experiences, and I realised that not only was I was not the only person to have been bereaved, but that everyone was carrying around a story, an experience, of the end of life, with nowhere to express or place it.

The A Graceful Death exhibition began its journey from that showing in my house. I began to paint other people facing the end of life, and over the next six years I met, painted and interviewed many ordinary people facing their own death. It was an extraordinary experience. When someone is actively dying, there is not much time. There can be so much unsaid, there is so much that has not been done, and the process of dying is relentless. It can take all one's energy to communicate just a little. Often, one does not know what to say or where to begin. I ask my sitters two questions. Who are you? And what do you want to say? In only one case where I was asked to come to paint and interview, was the person too ill when I arrived, either to know that I was there, or to speak to me. This is the painting of Peter and Anne Snell, Figure 4. Peter was very close to death when I arrived at the hospice, and as his wife Anne was lost in her vigil with him, sitting with him day and night quietly talking to him, I painted the two of them as if they were one person. There are very few words to this painting, Anne did not know what to say, and so we left it that the image would speak for the experience. Before I arrived, Peter had asked for me to come, to make something of his death to help other people. He was in the last stages of his dying when I arrived at his bedside, and all I could do was sit and watch, take photographs and be silent. In the painting you can see his vulnerability in the curve of the back of his head, like a baby. His arms and hands are thin and veined, and on his left hand is the most important thing to him, his wedding ring symbolising his marriage to Anne, both of whom found real happiness, each with their second marriage, with each other.



Figure 4. Peter and Anne Snell.

Peter was too ill to see me when I arrived to sit with him to discuss painting him. I painted him and his wife Anne, it seemed impossible to separate them. Anne is quietly whispering to Peter. Note Peter's vulnerability in the curve of the back of his head, like a baby. Note too, his veined arms and hands, and the wedding ring on his left hand.

Working with art gave me permission to ask questions of my sitters. We have a project together. I am to produce a portrait and an interview, they are to allow us to see their image and to tell us their story. It is vital for me to understand who I am sitting with, and what was going on for the sitter right now. It is also vital that my sitters want to talk to me, and trust me. As with the paintings of Steve, I want to capture the present reality. This is who they are, today, looking like this, and not how they were in the past when they were well and not actively dying. It is vital to honour my sitter in their present moment, in their illness, and to listen to what they say. Sometimes, things were said that were painful. Sometimes everyone laughed and reminisced. When I went to interview and talk with Caroline Soar in her hospice in Figure 5, the whole corridor echoed with the laughter and jollity in her room. She was a larger than life, amusing, much loved lady, most of the time spent with her was full of laughter and discussion. Sometimes with my sitters, because I was listening so quietly and asking for the truth, there were terrible tears and pain. During one of my conversations with Julia Wilson who had Motor Neurone Disease about her painting and what she wanted to say, Julia cried so hard and loudly that her family were very concerned. She asked them to leave her to cry, telling them with difficulty due to her illness, that she had to cry and needed to be left to do so. We were tearful too, witnessing Julia's pain. In Julia's portrait, you can see her gentle face and eyes, and how her arms are lifeless and wasted. Her hands were lovely, but you can see that they are no longer able to move and have been placed in position for the day by her husband. She had a tube in her stomach for her food, and I placed some forget me not flowers on the arm of her chair, next to the names of her husband and two children.



Figure 5. Caroline Soar.

Caroline, Figure 5, was a friend, and used to advise me on the exhibition. We did not expect her to become a part of it. I have painted her large and colourful, with her beautiful big blue eyes and red bandana. Caroline was such a big personality and such a fun and clever lady.

I form a relationship with my sitters that can be intense and truthful. I witnessed these people, normal people like all of us, doing a normal thing called dying, and it felt quite extra ordinary.

The process of being painted from life requires stillness and a level of concentration from my sitters that I feel would be too hard for them to maintain. Painting a portrait takes a long time, and that is

something that we do not have. Talking can be exhausting too, and for someone who is ill, I have to be aware of when to leave. It is less intrusive for me to do the artwork somewhere else and so I take photographs and use them to create the paintings later in my studio. This suits my sitters; they feel they are not required to perform in any way, and though they have agreed to become part of the exhibition, they are nervous of the process. They do not know what to expect, most have not had their portrait painted before. It makes them more nervous than the talking. When they understand that I will take photos to use later, there is relief, and they relax into the visit. They are, however, very curious about how I will present them. We discuss what ideas I have for the finished painting during the first visit, and I explain that once I start painting, it usually goes its own way, and I am often surprised at what I end up with. The finished paintings are realistic, and I aim not only to show the physical condition of the subject exactly as I see it (jaundiced, muscles wasted, hair loss, wheelchair), but what I feel is the essence of the person from the meetings I have had with them. Mike Hardy, Figure 6, painted with his Motor Neurone Disease in his wheelchair, had an engaging smile and a wicked sense of humour, which I wanted to show as part of who he was, apart from his deteriorating muscles and wasted limbs.



Figure 6. Mike Hardy.

Mike was a deputy head master. He taught me that if you spend time with someone who cannot speak except for a computer, time is quite literally what you must take. It took him ages to type out a sentence, but, he said, all the things he wanted to say were talking away in his head. He was physically unable to move due to Motor Neurone Disease, but his mind was unaffected. Mike died in May 2015, his illness having lasted for twelve years.

Stuart had lost his wife Sue to a very well planned and determined suicide a year before he came to the studio to discuss Sue joining the *A Graceful Death* exhibition. He was in a terrible state when we met, and nothing could give him comfort from the fact that he did not know that Sue was planning her own death so carefully and methodically. I based the painting for Stuart and Sue on two small paintings of the Duke and Duchess of Urbino painted between 1465 and 1472 by Italian Renaissance artist Piero

della Francesca, now in the Uffizi in Florence. The two small profiles of a husband and wife, together in marriage but inhabiting separate paintings, facing each other and finished in exquisite detail was the inspiration for the telling of Stuart and Sue's story.

In Figure 7, Stuart and Sue are also painted in profile, facing each other as do the Duke and Duchess, together in marriage but on two separate canvases, against a bright blue sky representing Tanzania, where Sue grew up. Around the edges of both paintings are colourful, pretty cottage garden flowers such as poppies and foxgloves, symbolising Sue's love of gardening. I added three very small canvases to be displayed between Stuart and Sue, still with the bright blue sky and with the colourful flowers. On the first are three extracts from Sue's diary up to the day of her death, "...If life is sacred, then we shouldn't have to drag it around like a dead thing all our lives". The second is her suicide note, "...I have taken 40 mg of diazepam to decrease my anxiety, and some more (crushed) to depress my breathing and decrease my likelihood of convulsions. Some Tramadol simply because it makes me dizzy; around 6 units of alcohol and 30 mg zopiclone. The helium is self-evident. There is no cry for help here; I do not intend to be found; I intend to die." The third is the most poignant letter written for Stuart on their wedding day ten years previously, "...when we are done, and they see the pages of our life, bound and nestling together, I want them to turn to each other and say: 'Theirs was a good book—such characters; what a story'".



Figure 7. Stuart and Sue.

The painting shows Stuart looking at Sue over extracts from Sue's diary before her suicide, her suicide note, and a letter to Stuart from their wedding day.

The effect of the five finished paintings together is very powerful. It is significant for me that the only photograph of Sue that I received from Stuart showed her in profile, in her garden the day before her suicide. Try as I might, I could not make out Sue's face or features. It was as if the person in the photograph had absented herself so totally, that there were no clear outlines left, no details to go on. It was as if Sue had already gone. Stuart's reaction to the set of paintings was profound. He was tearful, grateful, moved and determined that she should join the exhibition so that her story may do some good to someone else, somewhere, who may be either suffering as he was, or suffering as Sue was. At the top of Stuart's image are the words "All things must pass" and at the top of Sue's are the words "The brighter the light, the darker the shadow". This set of paintings moves people to tears. The feedback is always one of recognition. One mother found some solace in reading Sue's words, as her own son was struggling

with failed suicide attempts that had devastated her family. There is no answer for this mother, or for anyone visiting the exhibition, but there is a recognition that they are not alone and that, should they want to talk, during the exhibition, we will listen. During each *A Graceful Death*, there is a team available to anyone who wants to talk. We do not advise nor counsel, but we are experienced listeners and this, rather like the process of listening to the people who have been painted, is often enough. There is always tea and cake available during each exhibition too, which not only comforts visitors, but keeps us grounded in the present.

The showing of the portraits and words in the *A Graceful Death* exhibition causes powerful reactions from the public. I am frequently asked if I have permission to show these paintings. I do have permission. I am asked to explain why I would show such distressing work, and how I cope with it. These questions tend to come from people who have not yet been into the exhibition. They are fearful questions, and they assume that what is on show is abnormal and frightening. The questions also assume that it is a very miserable thing to do, to spend time with the dying and to engage with their process. I must need a good deal of cheering up. This is what I have concluded about the dying process from the people I have worked with. I want to add here that I am also a soul midwife, a compassionate end of life companion. Soul midwives aim to accompany the dying and to help create a peaceful and good death, alongside medical and psycho social professionals. We offer companionship, listening, support and we help to vigil with the dying person at the end if required. Some of the observations I make about dying draw on my experiences with people I have sat with beyond the *A Graceful Death* exhibition.

Until they are dead, the dying are very much alive. They feel ill, and weak, and are aware of what is happening, but they are not dead yet, and still find pleasure and satisfaction in such things as do we all; family, friends, good television programmes, pets, reminiscing, and bubble baths to name a few. Dying people are not that different to all of us who are not yet actively dying. They are still people, and though they are facing the end of their lives, they do not want to feel separate and alone, and do not want to feel “other”. One reason that the sitters are happy to be exhibited with the *A Graceful Death* exhibition is that they are asked to talk about what is happening to them, in order that their stories help other people. None of the paintings show anyone who is unrecognisable as a human. They want to say, with their image and words, this is how I look and this is how I am doing my dying. I am not any different to you. Here is how I am facing this end of life, here is what I say about it, and I hope that it helps you when your time comes.

The world becomes narrower and smaller towards the end of life. Whatever formed the life of someone before active dying, may be missed and mourned but often no longer plays any part in the room, or bed, in which they sit or lie. Sometimes it is hard to communicate. When words are hard to find or to say, silence is fine. Sometimes there is so much to say there is not enough time in which to say it. Each person does their dying differently, and each person retains much of who they always were until the end. Despite the narrowing of the worldly experience, many of the dying people I have worked with have found deep joy in the moment. Small things, like the colour of a flower, like the sight of a loved one, like the feeling of softness of a blanket have given them pleasure and peace. Claire Rudland, Figure 8, who I met while she was ravaged with cancer and weak from the fierceness of her treatment, told me that on the way to the hospital for one of her mammoth chemotherapy sessions, she suddenly became aware for the first time of leaves high in the trees, waving in the breeze. The intensity of her awareness of those leaves was wonderful to her. Without her cancer, she would never have noticed them. Claire,

who has since gone into remission and is still gloriously with us, tells me that she has now a new and profound awareness of the beauty of leaves in trees.



Figure 8. Claire Rudland.

I met Claire at the hospice, ravaged by her cancer and treatment. Claire did not die, and is living each day as if it is a gift. Her mission to herself is to feel everything, to experience who she is and to explore what life is left for her. Before her cancer, Claire took drugs, drank, and had no control over her life. She is a fascinating, deeply intelligent and amazing lady. This painting shows her exactly as she is now.

When I told a young man what I did, he looked thoughtful and replied that there was a lot of it (dying) around these days. I asked him if he knew of anyone who was dying, and he said no, of course not. I asked why “of course not”? He looked at me as if I was stupid. Why would he know anyone who is dying? That’s weird.

This reaction is one of the reasons for using painting and words to show that dying is just what people do. And that they look like this when they do it. And that this is what they say about it. Painting requires attention, time, and in order to complete a portrait of a dying person, I need to sit and see them, know who they are, and hear what they say. My painted portraits are realistic but are a step or two removed from a photograph and even further removed from the real thing. A painting of a dying or dead person allows the viewer a small amount of safety. They are looking at my interpretation of the image. It is not the same as having a real dying person in the room with them, time and creativity has gone into this image, and it is at a slight remove from the reality of a photograph. People like my young man who thought that knowing someone who was dying was weird probably had met someone who was dying, he was simply unaware of it. If he spent time in the A Graceful Death exhibition, he would realise that dying people are living amongst us all the time, looking like we do, and not being weird at all. If he came to the exhibition, he may be challenged to face his mortality, and at some point, he may even be grateful.

Within our current world, dying has become something that is handed over to the professionals as soon as it is on the cards. We are part of a large system that provides professional medical care,

professional psycho social care, and professional spiritual care. Dying can be part of a system that removes it from the general community. We can feel it is not our place and that we are not needed to witness dying in our communities. So we end up not knowing what it is all about, how it looks, what it feels like and most of all, what to do when it crosses our lives. We are very afraid of doing the wrong thing, and we are very afraid that we will overstep some boundary between us and them and cause all sorts of dreadful problems. Dying has left the normality of our communities and become something professionals and those who know what they are doing can deal with. I realise that there are many carers at home with a dying friend or family member, doing a truly wonderful job, often supported brilliantly. But the people I meet are as confused and out of their depth as I was with Steve. Recently I sat with a lady who was in the active stage of dying. Her son travelled from abroad to be with her, and in his distress wanted to cheer her up and to keep her spirits high so that she would recover. The lady was remarkably calm and despite her regret at leaving this life, was ready to do so. A few days before she died the son and I spoke, and I asked him what he expected would happen. He talked for a long time and eventually, he looked at me and was silent. The silence spoke for him, and it was clear that he understood that his mother would die. Even in her last days, no one had had the conversation with this young man that would help him to not only understand, but accept, the inevitable. The moment of silence with this young man was hugely sad, but also full of relief.

The A Graceful Death exhibition, both the process of working with a sitter for the exhibition and showing the exhibition to the general public, aims to bring the process of dying back to us as something unremarkable. I asked Julia with Motor Neurone Disease what she wanted to say and her reply was, "All I have left is time". This was, from Julia's point of view, exactly right. She was paralysed, had difficulty breathing and talking, was fed through a tube in her stomach, and could do nothing more than sit in her chair at home and wait. All she had left, really was time. When asked what advice she would give to us, she said we should leave all the housework, and play with our children. This is not rocket science, but is remarkably poignant coming from a wife and mother who had not long to live. Coming from Julia, we can take it very seriously. This piece of advice never fails to move people during the exhibition, possibly because it is just what we ourselves may say, and not a deeply complex and dramatic bit of end of life wisdom.

I want to return now to my experiences during Steve's death, and consider how it could have been different. Up until Steve's diagnosis, I had barely considered death and dying and had certainly not given my own death a moment's thought. Even when we knew it was liver cancer, we were in a state of denial about the prospects. When I read online what liver cancer meant, I had no way to understand what I was reading in relation to my life. What was happening to us, and I see this time and time again in the work that I do now, is that we were forced to take a crash course on end of life matters at the very time when we could not take any of it in. What if I had known more about life ending in advance, as part of my living? What if death was still a mystery, but was a familiar mystery? What if, during my lifetime so far, I had seen dying people, spoken to them, been present for at least some of their end of life journey as if it were normal, either within my family or in the community? As Steve was dying, I did not know what I was doing. As his main carer, I could not read the signs to tell me how near to death he was, and I probably did not do a very good job communicating what was happening either to him or to me, to our families and friends. I simply did not know how. Except for my amazing cousin, nobody said anything. It was my cousin who took me aside in my kitchen and explained to me exactly what was happening to

Steve a couple of weeks before he died, and told me how short his time was. She explained to me the signs of dying, and prepared me for what was to come. In short, she gave me back the power to cope and to see this thing through by simply telling me what was happening and naming the unnameable.

The dying are living among us, whether or not we are aware of it. We are all going to die. We do not know how or when we are going to do so, but it will absolutely happen. What I needed with Steve's dying, and what I aim to do now with the exhibition and the outreach and soul midwifery work that I do, is to provide someone to talk about, explain, listen and to normalise the experience before we need it and are forced to take this crash course that is so hard to deal with. It would have been so much better, it would have saved so much confusion, had I had some awareness of what dying meant and how to deal with it before Steve began his dying. As part of the A Graceful Death project, I run awareness raising events with a palliative care nurse friend and colleague. "Conversations about the end of life, finding time to think in our busy world" are held in local community areas, and are free and open to all who want to come by and talk about any aspect of end of life that they wish. Each session lasts for two hours, with tea and cake, and we are often surprised and delighted by the turn out, and by the questions and topics that are discussed. Not all of us will die from an illness that gives us time to prepare. Within our community outreach work, we hear from people about deaths from suicide, murder, still birth and miscarriage, sudden death, accidents, abortion and euthanasia. Add to this death from war and execution, and we see that these are all ways to die. So far, we have not heard from anyone in our Conversations about execution, though we have met elderly people still affected by the last world war.

Dying is private, individual and relentless and can be lonely. Not only for the person doing the dying, but for the family, friends and carers too. We need to talk about it, to take back our ability to deal with it, to stop being afraid of doing the wrong thing. We need to be prepared. It will always be fearful, it will always be a shock, but in order that we give it our best attention, we need to remember that we are mortal, and that death is not only a reality, but is inevitable and that we have only the one chance to actually die. Many of the dying that I have spent time with have found a way to accept their dying, and are not afraid. They have regrets, and would love to have done many more things in their lives, but they have accepted dying. In Figure 9 Father Dominic Rolls, a Catholic priest with cancer and the subject of the latest portrait to join the A Graceful Death exhibition, says in his contribution to the exhibition of the fear and acceptance of dying,

"Because I maintain a positive outlook on death, it doesn't mean I am not afraid of dying. I try to embrace the fear. I treat it like any other symptom. I lie down and think it through, I let emotion express itself, I don't fight it. For me fear can be manifested in anger and anxiety. Fear of dying is an active part of the process of this cancer. If you have an attitude about death, you can also have an attitude to life and living. I try to live my understanding of what is happening and accept it, but I know this is not enough to cure the cancer. I have to let go, but the anxiety about this illness sometimes makes me grab back whatever I am letting go."



Figure 9. Fr Dominic Rolls.

Fr Dominic is a Catholic parish priest in his very early fifties, and my youngest brother. In this painting, Dominic is laughing and easily identifiable as a Catholic priest with his clerical collar and black shirt and trousers. He is holding a bottle filled with chemotherapy drugs attached to a pic line going straight to his heart. After each chemo session, Dominic had to carry this with him for a further twenty four hours of treatment. It is a reminder that he looks fine, is still laughing and standing, but is very seriously unwell.

The sitters in the A Graceful Death exhibition have given us their images, their words, and their stories so that we can use their experiences of dying to think about what we will do when our time comes. Most of the people who make up the A Graceful Death exhibition are no longer alive. Some of them are still here, and we do not know for how long. Only last month, Mike Hardy who had suffered from Motor Neurone Disease for 12 years, died. His portrait shows him sitting in his wheelchair, his hands bunched and crippled as the disease progresses, and his feet turned inwards and locked at odd angles. Mike's response to what he wanted to say is written on his portrait. "I had a dry sense of humour and told outrageous lies but now I'm a gibbering wreck". Mike was deeply intelligent, and had a wonderful sense of humour and mischief. He had been a part of the exhibition for over two years. When I asked him and his wife Michele what they thought of dying, he said he didn't really think about it. He would go into the local Macmillan Unit when the time came, and that he was getting on with living. Michele didn't want to think about it, and her body language changed when I asked the question. Despite the years of very hard work caring for Mike, even though she is strong, capable and determined, the fact that he would die from this disease made Michele distressed.

I will leave you with some words from Julia Wilson, Figure 10, from her contribution to the exhibition to be shown alongside her portrait. Julia was 55 when she died. Despite her illness and the huge sadness and distress she felt very often about leaving her husband and children, she was a very positive person and liked to find the silver lining in every dark cloud.

“But it is not all doom and gloom! I am genuinely cared for, and surrounded by the warmth of all those around me. I can laugh, and when I go to the day unit near here, people can be very funny. There are lots of positives on the journey, and life goes on. It must go on. Nothing can be done about this illness. I live. Whatever that may be. I am not angry, not even when I was diagnosed. I love being together with my family and friends, I like my life and I like the people in it. Some people are afraid of upsetting me. They can avoid contact with me. But there is nothing worse than being told that you are going to die. What could be worse than that? How could anyone say anything worse than that?”

I don’t think about dying. I think about living. Everyone is inspirational, and each journey has its own challenges. I don’t have a bucket list though. Do you think I am lacking something? Julia laughs. I just want to spend time with my family. And be honest. My mother’s outlook was to play with the cards you are dealt with, and that is what I do too. I want us all to be honest.

It is good to make people aware of this illness. Someone sent me a card, it says ‘Yesterday is history, tomorrow is a mystery, and today is a gift. Use it well’. This is for everyone, not just for the terminally ill.”



Figure 10. Julia Wilson.

Julia was a mother and a wife, a gentle lady who died aged 55 after a year with Motor Neurone Disease. Her smile and warm expression are the first thing I noticed. It took a few seconds to notice that she could not move and that her arms and hands were wasted and useless. I wanted to show them, as a clue to what was happening to Julia. Her legs are swollen and paralysed and give the impression of heaviness in this painting. There is a tube into her stomach. I placed forget me not flowers next to the names of her children and husband on the arm of her chair.

The A Graceful Death exhibition now consists of 54 paintings, poetry and essays donated by members of the public. There is music especially composed by pianist Lizzie Hornby, and a film explaining the work of A Graceful Death by Neill Blume. Filmed interviews with some of the sitters by photographer Eileen Rafferty are fascinating and sometimes very moving. The exhibition travels to conferences, events, teaching establishments, and can be adapted to suit all manner of aspects of death and dying. I present talks, discussions and workshops on end of life matters within the exhibition and outside of it. For more information see www.antoniarolls.co.uk.

Conflicts of Interest

The author declares no conflict of interest.

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