

# Bringing alive a life that is ending



**Evangelo Kioussis is a film-maker who works with patients and their friends and family at Greenwich & Bexley Community Hospice, a 19-bed inpatient, day care and community service in Abbey Wood, south east London. In this interview he describes his biographical film-making project and how he feels it helps the bereaved and dying people with whom he works. One family also write about making their own film, and the hospice's head of social, psychological and spiritual care explains what he feels the projects brings to the hospice's services for its patients and their families. They were interviewed by Catherine Jackson.**

**Q: How did you come to be doing this work at Greenwich & Bexley Community Hospice?**

**Evangelo:** My wife Mika introduced me to it. She was working with Rosetta Life, an arts in health organisation that places artists in residence in hospices across the UK. She was placed at a hospice just outside London where she was making films with patients. I really admired the work she was doing and when she stopped working with the hospice, I took over her job.

My own background is in film-making, and working as a creative consultant with writers, producers and directors, primarily on scripts and developing screenplays for television and cinema.

I am currently working at Greenwich & Bexley Community Hospice. I've been there for about three years. Rosetta Life originally organised the placement but the hospice subsequently decided to contract my time on a freelance, sessional basis. I work there six days a month, based in the hospice day centre.

**Q: What does your role involve?**

**Evangelo:** I work primarily with people facing life-limiting illnesses – people with cancer, motor neurone disease, Parkinson's disease. I make biographical films with them. I have a little desk in the corner of the day centre where I sit. I have a couple of computers and scanners and I'm there all day and people come up and talk to me about what I'm doing and I show some of the films I've made with patients and tell them about the process.

If they want to make a film, I ask them to bring in a selection of their favourite photos – most people have photos from across the span of their life. I then create a digital slideshow of the photos. I then film the person telling me the stories behind the pictures. The final stage is the editing, which I do in consultation with the person.

Usually a theme emerges from the photos and stories that I can use to 'anchor' the film. It isn't just a series of photos with

a voice-over. I'm aiming to give it some dramatic structure and coherence. I will also add a bit of music to it. What comes out at the end is a digital biography of the person's life. It's much more than a simple written account or an audio recording. There's something extra about it, because it's visual. It's as though the process brings their life alive again. That, I find, is the greatest therapy.

Life is so ephemeral. For some people in here, who may be looking back and asking, 'Where did my life go?', I think the film-making process gives them something tangible – the finished digital recording – that can be shared with friends and family.

I make copies of the recording and we sometimes organise screenings for friends and family. Grandchildren in particular seem to get a lot from seeing their grandparent come to life again – in a way, it keeps them alive for their grandchildren.

**Q: You've talked about the benefits for patients in the hospice. Does the process also apply with bereaved people?**

**Evangelo:** Greenwich & Bexley Community Hospice has a service for bereaved people called Stepping Stones, which meets here twice a month. I use the same model and process with bereaved people, but with them it becomes a tribute film. Making the film can be a cathartic experience for them, I think, because it provides an opportunity to celebrate their time with the person they have lost.

I worked with one family – a husband and his three adult sons whose wife, the boys' mother, died in the hospice. The middle son is a film-maker and we collaborated on a tribute film to his mother (see page 82). The father is a musician and the other sons also have an interest in music. We spent a year putting together a one-hour film out of many hundreds of photos of their mother. We used the same process, starting with a slideshow and telling stories and then they decided they wanted to write

some music for the film. They were finding it difficult to tell the stories in words and decided they could do it better using music instead. One son wrote a rap song, the father wrote some folk songs and the younger son and I worked together on the film. He lives overseas, but we were able to use Skype to do the editing. When it was finished, last Christmas, we had a big showing at the hospice. It was really lovely, very powerful, and a very cathartic experience for them and everybody there who had lost someone.

The films are usually about five minutes long, though I have been working on an epic three-parter with one patient. People typically bring in 50–100 photos. This guy brought in 400-plus. I am always looking for threads of human connection in the narratives. If, say, the person has done a lot of travelling, I will ask who they met on their travels, the stories they shared, what that encounter meant to them – these are the things that people remember and that matter to them.

**Q: What do you think people nearing death derive from the process?**

**Evangelo:** It's about celebrating their existence, where they came from, what they did, what they are leaving behind. Sometimes the film becomes about illness and fear and the person's struggle with that, but with most people it's a light in their life – they look forward to it. Most people don't want to dwell on their illness; they find it much more compelling to celebrate what they have done and who they are.

**Q: What is the process that you see happening when people make these films?**

**Evangelo:** Our connections with other people are what validate our existence and give meaning to our lives. Our legacy is the effect we have on other people, and in particular on the people we love. The films articulate those connections – they show how much the individual meant to the people who are bereaved by their death. The films also, through the stories they tell, show how much their friends and family meant to the individual. It works both ways. It's a very affirming and positive thing.

I see the films, in their own, modest way, as part of a much wider tradition of testimonial documentaries. Perhaps the best known example is *Shoah*, the 1985 French documentary film directed by Claude Lanzmann about the Holocaust. It's the tradition of chronicling human experience so it doesn't get lost. You could say everyone's life is an epic film to them and their families. Modern technology allows me to make films in three months that ten years ago, before digital cameras were developed, would have taken much longer and required much more complex equipment and many more people. I can make the epic story of this person's life available to everyone. Technology has always driven how people tell their stories, from cave paintings to printing to photography and cinema. Digital technology is now driving a whole new style of biographical story telling.

Other artists are doing similar work but in their own artistic medium. I don't want this to be about my eye, about me as an artist making films about other people's lives and deaths. I want this to be about their eye, and using their photos ensures this – the photos are their eye, their imagery.

I think people really value the simple process of looking at old photos and bringing these memories alive. I get them to talk not just about the event but why they took the photo – it's all about that thread of connection to life, particularly for people who are literally losing control of their bodies, if they are paralysed, or deformed by their illness – especially people with motor neurone disease. It's really tough if you can't move from the neck down. The films reconnect with that spark and vitality they once had – to see that come alive again gives them their selfhood back.

It's also a very gentle way to get people to open up. A lot of people are nervous at first but if all you are doing is looking at photos and telling a story, they quickly relax.

Mothers with children in particular want to communicate how proud they are of their children.

It's a human instinct to want to tell your story – to me, it's like YouTube or Facebook – a connection to the world for those who choose to use it. There's a long tradition of vernacular history found in ordinary people's journals. Everyone wants to be a celebrity in their own movie.

It's something to say 'I was here', 'I was'. The headstone, the memorial, from ancient cave paintings to modern 3D cinema – we want to leave a mark that proclaims 'I was'.

*Evangelo can be contacted at me@evangelokioussis.com. Some of the films made with Evangelo by patients at Greenwich & Bexley Community Hospice can be found on YouTube at [www.youtube.com/evangelokioussis](http://www.youtube.com/evangelokioussis)*



*Evangelo at work with a patient*

## Who she was

**Robert Pender and his sons Thomas, Andrew and Robert, worked with Evangelo on a film about Robert's wife and the boys' mother, Marie, who died at the hospice. This is their story.**

### **Q: Why did you decide to make the film?**

There was much to talk about but words seemed pointless. Together the four of us had the skills and motives to produce something that, to us, would be unique and priceless.

### **Q: How did you hope it would help?**

Throughout the process, there was an expectancy, an excitement, that capturing and interpreting our lives as we'd lived might help combat the heavy slow sadness that pervaded our days and nights.

In our hearts and minds, a lot had remained un-said and posthumously Marie had so much to add. Conceivably we could invite her to help make those choices.

### **Q: What did your songs and music say about your life together with Marie?**

Andrew's piano instrumental was in honour of one of the ceremonial songs she had chosen and which he played at the funeral. Andrew and I performed 'Fire and Rain', as I'd often play that for her in earlier years, and Robert had written a song specifically about our loss. Other titles seemed to just epitomise all she felt and enjoyed musically.

### **Q: How did making the film help you grieve and remember?**

Inspired by love, loss and longing, there was a real sense that we were spending time with Marie again. Although her absence permeates our lives, what were we to expect from life? Or what would life now expect from us? If what we created could be used as a measure of strength, then we have demonstrated our instincts but have yet to fashion them. The DVD gives us time do so – 43 years captured forever, a panacea of sorts.

### **Q: How do you feel now, looking back at the DVD and the work with Evangelo?**

Very lucky indeed. We had a tendency to gaze into our past, retrospective thoughts to help make the present with all its sadness less real, but that just served to rob the present of its reality.

Our pain and suffering continue to be two different things. Marie endured pain; we suffer the effects, but suffering eases slightly when we form a clear and precise picture of it. The DVD helps us achieve that and, to that end, everything and everyone came together at the right time.

Greenwich & Bexley Community Hospice offered us emotional shelter and the opportunity to explore the concept of combating bereavement through creativity. It was *esprit de corps*. Evangelo instinctively and tactfully weaved a way through the many emotions we felt. He was always respectfully mindful of the person – Marie – despite the unfathomable distance – and, indeed, felt he knew the person she was when we'd completed the disc.

### **Thomas has written this last paragraph, for all of them.**

We had our first screening at Stepping Stones, as a stamp of finality to the past year while we were making the film and as thanks for Evangelo's continued assistance and consultation throughout. Watching the film for the first time all together proved the hardest. Although I had watched and re-watched it when editing it –making sure the right beats were present, their pace consistent – the significance of seeing these moments from our lives with mum amplified in magnitude on the big screen was deeply profound. Devastatingly so.

Afterwards, sharing a quiet, introspective pint with my dad, my brothers and Evangelo, we took a moment to reflect on what we each took from the film. Collectively we agreed that, while it was indeed painful to watch, its ending note was enlightening and a melancholy catharsis. For me, I was happy to have something so representative of mum that we could always look to. And to be reminded that, even though this was a battle that can never truly be won, who she was and what she stood for will never be lost.

## A different portal



### **Anthony Boland is Head of Social, Psychological and Spiritual Care at Greenwich & Bexley Community Hospice**

When people are diagnosed with a life-limiting illness, roles and identities are stripped away from them, one by one. Most of us identify ourselves by our roles in life. We get our sense of meaning and purpose from them, and when they are taken away, the question is, what is left? When a person feels that everything is stripped away, it can lead to a crisis of meaning and purpose, which we call spiritual distress. It may not be conscious, it may just be a felt sense of depression or purposelessness.

When this questioning happens people just want someone to stand alongside them. Who the person is may not matter – doctor, nurse, chaplain, counsellor – in fact, it's most often the health care assistant who helps the patient with their personal care every day who knows them best.

Greenwich & Bexley Community Hospice does not have a particular religious affiliation. We believe everyone has a spirituality. If people have had support from a particular religion all their lives, they are likely to veer naturally towards the rites and rituals of that particular faith for comfort and strength. Our chaplaincy team can support that need. But we are equally concerned to meet the spiritual needs of those people who don't have a particular religion. We want to be interested and curious about how we can best serve their needs – whether through poetry, or art, or what Evangelo is doing – or simply by respecting their need to be left alone, because some people would prefer do their suffering alone. If you ask people, do they want to see a counsellor or chaplain, they may say no, but if you begin the engagement as one human being to another, the relationship can start straight away.

One of the most powerful pieces of work that Evangelo did was with a man in his 40s whom I was seeing weekly for counselling (see the Penders' story). His wife died here, leaving him and three sons. He was distraught. Evangelo started working with him and then his sons got involved and the whole family made a DVD of his wife's life and death.

The counselling work gave way to Evangelo's work, and then he came back to see me at the end. The creation of something became hugely important and it was invaluable for the man's grief work because he really felt that in this abyss, this void, this flower of creativity was able to emerge and give him light in his darkness.

Counselling, talking therapy, is just one way to support someone. Some people prefer to make a film or do something creative. We know that sometimes men and women grieve differently and it sometimes suits men to do task-focused things.

Evangelo's work straddles the whole spectrum. He provides a different portal to people's experience. Counselling is one portal; Evangelo facilitates people to express themselves through creativity in ways that talking therapy doesn't.

I see his work as spiritual in that wide understanding of the word. It supports people to connect with a sense of meaning and purpose as they approach the end of life, to reflect on what their life has been about, what their impending death is about and means to them, perhaps through the creation of something. You can call it spiritual, psychological, pre-bereavement care – it doesn't matter. What matters is that it engages with people's experiences and sense of self in the face of death.

For me, really good spiritual care is about quality and presence and the attention we bring to the person. Evangelo attends well; people find in him a mirror of their dignity and worth, because they feel they are worthy of attention. That can have a profound healing effect. When people are having things stripped away bit by bit in their lives, they can lose awareness of their dignity, meaning and purpose.

Evangelo reminds them that that isn't true – partly by what he does but more than that. He has 'bi-focal' vision. He is working on the photographs but there is a whole other level of vision that goes into the planning and process. It goes beyond the content of the project. What's more important is that the person is doing it at all. Evangelo, through his approach and quality of attention to each person, is in effect saying to them: 'I am seeing you as a person of inviolable dignity. You have a whole life that I know nothing about. I have these snapshots of your life and through our work together I want to remind you of the greatness of who you are.' That respect holds a bigger picture of the human being – an acknowledgement of a whole history of life experiences that, up until now Evangelo has known nothing about.

For some it is the process that is important rather than the outcome. Others might want to leave something behind. Evangelo isn't attached to any end product – there are people who die before the work is finished. For the dying person and the bereaved alike, it's the process and the attentiveness and quality of presence that Evangelo brings that is meaningful, in a very spiritual way. ■



*The Penders brothers with their mother Marie*