

PORTRAIT OF A PROCESS-
THE VISUAL ARTS AN
MEDICINE



**DALHOUSIE
UNIVERSITY**

FACULTY OF MEDICINE
Division of Medical Education

Humanities-HEALS Program
Healing & Education through the Arts & Life-Skills

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Agenda

- Describe interactions with Art and Medicine in the field of dementia.
- Describe personal background
 - *Saving Faces & Portraits of Care*
 - *EPICS* (Experience of portraiture in a clinical setting-Emergent Themes)
- Art & Alzheimer's
 - Drawings of Pat by Norman Gilbert

- HOW ART AND MEDICINE HAVE INTERACTED AND CONTINUE TO INFORM ONE AND OTHER in the field of AD and dementia.
- AS AN ARTIST AND ARTS BASED RESEARCHER IN THE MEDICAL HUMANITIES , I WILL SITUATE MYSELF BY DESCRIBING MY OWN RESEARCH, USING THE VISUAL ART AS A MODE OF RESEARCH- DRAWING AND PAINTING PATIENTS AND CAREGIVERS.
- AND ULTIMATELY, HAVING DEDICATED MUCH OF THE LAST 20 YEARS TO LOOKING AT HOW ART AND MEDICINE HAS THE POTENTIAL TO HELP US EMBRACE ASPECTS OF OUR LIVES THAT CAN BE MOST CHALLENGING, **I RECENTLY FOUND MYSELF HAVING TO COME FROM BEHIND MY OWN EASEL TO CONFRONT THE DEATH OF MY MOTHER, PAT GILBERT, WHO WAS DIAGNOSED WITH ALZHEIMERS SIX YEARS AGO.**
- **I WAS NOT ABLE TO GET HOME IN TIME, BEFORE SHE DIED,**
- **HOWEVER, I WAS ABLE TO BUILD A PICTURE OF WHAT IT WAS LIKE THOSE LAST FEW DAYS AS MY FATHER, 90 DREW HER AS KEPT VIGIL IN THE HOSPITAL DURING THE LAST WEEK OF HER LIFE .**

I WILL PRESENT THESE DRAWINGS AND MY FATHERS REFLECTIONS ON THEM, IN MY TALK TODAY.

Disclosures

- I have nothing to disclose

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- **Kathryn Hominick**, Clinician Social Worker, Seniors' Health, Nova Scotia Health Authority.
- **Linda Bird**, Director, Programs and Services, ASNS.
- **Wendy Stewart** Associate Professor, Department of Paediatrics and Division of Medical Education Dalhousie University
- **Norman Gilbert**, Artist, Glasgow, Scotland.

ARS MORIENDI



SO

- 1)WHAT CAN THE ARTS TELL US ABOUT CARE AND CARE GIVING, DYING AND BEREAVEMENT?
- 2) AND HOW CAN PEOPLE WHO ARE DYING OR BEREAVED USE THE ARTS?
- THESE ARE IMPORTANT QUESTIONS TO ASK FOR TWO REASONS.
- FIRST, DEATH AND LOSS ARE SIGNIFICANT THEMES IN ALL THE ARTS
- SECOND, THOUGH THIS PRESENTATION IS PRIMARILY ABOUT MY OWN PERSONAL REFLECTION ON THE DRAWINGS CARRIED OUT BY MY FATHER AS HE CARED FOR MY MOTHER AT THE END OF HER LIFE RATHER THAN ABOUT END-OF-LIFE PROFESSIONAL CARE,.....
- I HOPE THE WORK PRESENTED CAN POTENTIALLY DEMONSTRATE HOW THE VISUAL ARTS CAN HELP PROFESSIONALS RE-ASSESS THE CARE THEY PROVIDE FOR PEOPLE EXPERIENCING ILLNESS, THEIR CARERS AND THOSE WHO ARE FACING THE END OF THEIR LIFE , THEIR LOVED ONES AND THOSE RECENTLY BEREAVED.
- DYING USED TO BE ACCOMPANIED BY A PRESCRIBED SET OF CUSTOMS. THE *ARS MORIENDI*-THE ART OF DYING, WAS EXTRAORDINARILY POPULAR; A 1415 MEDIEVAL LATIN TEXT
- IT WAS REPRINTED IN MORE THAN A HUNDRED EDITIONS ACROSS EUROPE. THE

GUIDE PROVIDED FAMILIES WITH PRAYERS AND QUESTIONS FOR THE DYING IN ORDER TO PUT THEM IN THE RIGHT FRAME OF MIND DURING THEIR FINAL HOURS.

- WE SEE IN THESE WOODCUTS, A DYING PERSON INHABITING TWO WORLDS-THE NATURAL WORLD HE IS ABOUT TO LEAVE WITH FRIENDS POSSESSIONS, FAMILY AND HOME AND THE SUPERNATURAL WORLD THAT ONLY HE CAN SEE WITH ANGELS AND DEMONS VYING FOR HIS SOUL.

William Utermohlem (1933-2007)



- IN THE FIELD AD AND DEMENTIA ART CAN AND HAS BEEN USED AS A TOOL FOR ANALYSIS FOR PHYSICIANS TO GAIN GREATER INSIGHT INTO THE EXPERIENCE OF THE PATIENT.
- IT CAN SERVE AS AN AID FOR THE UNDERSTANDING OF DEMENTIA, AND AS A DISCIPLINE FOR THE STUDY OF THE MIND, FOR CLINICIANS, RESEARCHERS, PATIENTS AND CARERS.

ARTIST WILLIAM UTERMÖHLEM OPENS A WINDOW TO HIS PERSONAL JOURNEY WITH **HIS** DEMENTIA.

- I AM ONLY SHOWING YOU 3 OF A SERIES OF 15 self-portraits HE CARRIED OUT DURING THE PROGRESSION OF HIS CONDITION., we feel we experience with him the anger, fear, anxiety, resignation, isolation, and sense of fragmentation of self as the disease progresses.
- HOWEVER THE ARTIST VOICE-AS IS SO OFTEN THE CASE, IS POIGNANT WITH PARADOX-
- WE MAY PERCEIVE THAT SOMEONE LIVING WITH ALZHEIMERS AS HAVING LOST SO MUCH, THAT THEY HAVE NOTHING LEFT TO GIVE,
- YET SOMETHING AS POWERFUL AS THESE IMAGES PROVES THAT NOTION

WRONG - LEAVING US TO ALSO ASK DOES DEMENTIA UNDERMINE CREATIVITY OR CHANGE ITS ENERGY?

AIR. GERIATRIC CLINIC, VETERANS



- SOME OF YOU MAY RECOGNIZE THESE IMAGES, THAT ARE PART OF A COLLECTION OF ARTWORKS CREATED BY LOCAL ARTISTS ON THE AIR PROGRAM SET UP BY Dr. KENNETH ROCKWOOD, Geriatrician, At Veterans here in HALIFAX.
- THESE ARE HANGING IN THE GERIATRIC CLINIC AT VETEREANS.
- THE RESULTANT ARTWORKS ARE A RECORD OF WHAT THE ARTSITS OBSERVED AND INTERPRETED VISUALLY, WHAT THEY WITNESSED WHILE WORKING WITH PATIENTS AND THEIR FAMILIES.
- THE PAINTINGS HAVE REPORTEDLY...
- ENANCED Clinical ambience,..... SOMETIMES PABALY DIMINISHING THE ANXIETY OF THOSE VISTING THE CLINIC
- ALLOWED ALSO ENABLED CLINICIANS TO GAIN GREATER INSIGHT INTO THE PATIENT EXPERINECE.

Artful Afternoons. Art Gallery of Nova Scotia



- *ANOTHER EXAMPLE OF ART AND MEDICINE COMPLEMENTING HAPPENS HERE IN HALIFAX.*
- *THE ARTFUL AFTERNOON WORKSHOPS ARE JOINTLY ORGANISED BY THE ALZHEIMERS SOCIETY OF NOVA SCOTIA AND THE ART GALLERY OF NOVA SCOTIA PROVIDING ARTS BASED ACTIVITIES FOR PEOPLE WITH DEMENTIA AND THEIR PARTNER IN CARE.*
- *I HAVE HAD THE PLEASURE OVER THE PAST YEAR AS A VOLUNTEER ON THIS PROGRAM TO WITNESS HOW ART CAN CREATE AND DEVELOP SHARED EXPERINECES and A SENSE OF COMMUNITY, ENHANCE CONFIDENCE, AND BE EMPOWERING*

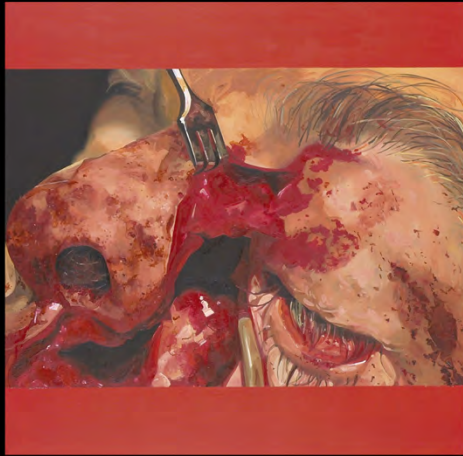


- TO SITUATE MYSELF-
- THIS IS ME PICTURED IN A PAINTING BY MY DAD ENTITLED "THE ARTIISTS FAMILY AND MARK" BEING HELD BY MY MUM.
- For the last 65 years, my father has worked on paintings in his studio, in Glasgow, Scotland. His imagery relies heavily on depictions of his family ensconced in different settings: Over the years, his pictures, more often than not, included me and my mum.



SO IT IS MAYBE OF NO SURPRISE THAT I TOO WENT TO ART SCHOOL, AND WORKED AS AN ARTIST OFTEN HAVING MY MUM AND DAD SIT FOR ME TO DO PAINT THEM.

**Saving Faces
Barts and the
London, NHS Trust**



- However, My life and working methods changed dramatically when I was commissioned by facial surgeon Professor Iain Hutchison to work on a series of his consenting patients and depict them before and after surgery and also during
- I sought a portrayal that was genuinely derived and rooted in the other and our relationship, yet still imaginative, expressive and creative. I hoped the portraits would exemplify participants holistically, demonstrating not just their physical journey, but their emotional journey too.
- AS A RESULT OF SF TOURING NORTH AMERICA, I WAS ASKED BY DR. VIRGINIA AITA AND DR. BILL LYDIATT TO COME TO THE UNIVERSITY OF NEBRASKA MEDICAL CENTER TO BE ARTIST IN RESIDENCE FOR A RESEARCH STUDY CALLED PORTRAITS OF CARE. THE PORTRAIT OF JARED IS PART OF A COLLECTION OF ONE HUNDRED PORTRAITS I MADE IN COLLABORATION AND REPRESENTING PATIENTS AND CAREGIVERS ATTENDING AND WORKING IN THE TEACHING HOSPITAL IN OMAHA, NE.

THE PROJECT SOUGHT TO USE ART, SPECIFICALLY PORTRAITURE, TO EXPLORE NOTIONS OF ILLNESS, RECOVERY, CARE AND CAREGIVING.

PORTRAITS OF CARE

The University of Nebraska Medical Center (UNMC)

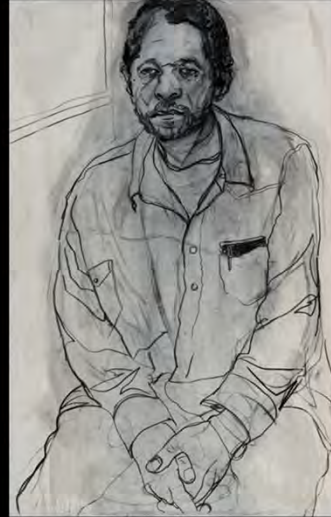
Aita VA, Lydiatt WM, Gilbert MA

Portraits of care: medical research through portraiture

Medical Humanities 2010;36:5-13.



Roger (2007)



Sebron (2007)

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- The research findings from IN BOTH THESE STUDIES focused on the effects of the resultant images on participants and viewers.
- However.... I became acutely aware of how fundamental the nature of the relationships and interactions between myself and the subjects involved in the process of making the portraits. This is what inspired the exploratory study of my doctoral research.... EPICS.

The Experience of Portraiture in a Clinical Setting

Gilbert MA, Lydiatt WM, Aita VA, *et al*
Portrait of a process: arts-based research in a head and neck cancer clinic
Medical Humanities 2016;42:57-62.

Emergent Themes

- embracing uncertainties
- developing trusting relationships
- engaging in reflective practices
- telling a story (expression)
- feeling empowered



My doctoral project sought to explore the nature and shared experiences of artistic interactions within a professional artist-sitter relationship between one artist and five patients attending the Head and Neck Cancer Clinic at UNMC.

The pictures, interviews and study transcripts were analyzed.

- **WE FOUND THESE EMERGENT THEMES PARALLELED SALIENT ASPECTS OF THE DOCTOR/PATIENT RELATIONSHIP. BUT I WOULD PROPOSE THAT THEY ARE THE BASIS OF AND APPLICABLE TO ANY COMPASSIONATE RELATIONSHIP.**
- **AND AS SUCH WAS APPLICABLE TO THE RELATIONSHIP BETWEEN MY MUM AND DAD.**



- **MY FATHER IS AN ARTIST.**
- **HE HAD DRAWN AND PAINTED MY MOTHER HUNDREDS OF TIMES OVER THE PAST 65 YEARS,**



*Woman
Climbing
into Bed,
1954*

EACH OF MY FATHER'S PAINTINGS, INCLUDING THIS ONE OF MY MOTHER FROM 1954, EMBODIES A PHASE IN HIS AND IN HER LIFE.

THE PAINTINGS BUILD ON MY DADS PRIOR EXPERIENCE OF PAINTING, HIS KNOWLEDGE AND FAMILIARITY WITH THE MATERIALS HE USES, AND HIS KNOWLEDGE OF, AND RELATIONSHIP WTH MY MUM AND THE SETTINGS IN WHICH SHE IS DEPICTED.



-over time his pictures developed into larger compositions
- The figures have neutral expressions and although the figures in his paintings are easy to perceive and are the central focus of attention, they are rendered with the same weight of line, colour and flat texture as the setting they are depicted in. It is the patterns, colours and composition that provide the emotional content as his pictures
- However these pictures still rely , fundamentally on the relationships and interactions he had with his loved ones and his environment
- This painting depicts myself when I was about 4 with my mother.



Pat,
1992

- For each compositions he would execute numerous drawings like one of my mum, as preparatory sketches towards the final compositions

Pat,
2013



- About 6 years ago, my mum was diagnosed with alzheimers and
- IN THOSE LAST YEARS MY DAD CONTINUED TO DRAW AND PAINT HER FOR MULTIPLE COMPOSITIONS. THE ALZHEIMERS IS NEVER OVERTLY REFERENCED, YET ONCE ONE IS AWARE OF THE CONTEXT OF THEIR CREATION, THEY BECOME A POWERFUL VISUAL RECORD NOT JUST OF AN ARTIST /SITTER RELATIONSHIP AND A HUSBAND AND WIFE..... BUT AS PATIENT CAREGIVER RELATIONSHIP....ONE THAT REQUIRED THAT THEY MUTUALLY SUPPORTED, COMFORTED AND CARED EACH OTHER.
- THE PAINTINGS ARE A TESTAMENT TO THE FLUID ROLES WE ARE ALL ASKED TO PLAY AT SOME POINT IN OUR LIVES WHEN WE FALL ILL AND CARE FOR THOSE WE LOVE.



Pat, 2014

- ABOUT 3 YEARS AGO, MY FATHER WAS ASKED TO ALLOW THIS PAINTING OF MY MUM TO BE PUBLISHED IN A JOURNAL TO ILLUSTRATE AN ARTICLE DESCRIBING ALZHEIMERS.
- ALTHOUGH HE HAD FOLLOWED MY CAREER CLOSELY AND WE DISCUSSED THE MEDICAL HUMANITIES OFTEN, THIS CONCEPT WAS NEVER SOMETHING THAT HE RELATED TO HIS OWN ART. AT THIS POINT, HE **HAD** TO COME TO TERMS WITH THE NOTION THAT ART CAN BE AN INSTRUMENT IN THE FIELD OF MEDICINE TO TEACH, INFORM, DESCRIBE AND RECORD AS WELL AS EVOKE AND INSPIRE.

I had already realized that art could inform medicine in abundant ways WITH ITS CAPACITY TO COMMUNICATE THE SEEABLE BEYOND THE SAYABLE.

However, when I was told my mother had had a massive stroke, that left her unable to move or to communicate, and from which she would not recover. I was still absolutely staggered to be told that as my father kept vigil during what would be the last week of her life that he had brought his sketchbook to the hospital to enable him to draw her.

.....

A week after my mum died a close friend of the family and my colleague at the University of Nebraska, Dr Regina Robbins, carried out a semi-structured interview with my dad, asking him to reflect on those last days and the drawings he created of and with my mum..

- **REFLECTING ON THE DRAWINGS AND INTERVIEW WE FOUND THAT THE 5 EMERGENT THEMES FROM MY OWN RESEARCH ARE ALSO RELEVANT TO MY DADS EXPERIENCE OF CREATING THE VISUAL NARRATIVES WITH MY MUM THAT I WILL PRESENT IN THE REMAINDER OF THIS PRESENTATION.**



THE FOLLOWING IMAGES PORTRAY MY MOTHER AS SHE LAY DYING IN HOSPITAL FOR JUST OVER A WEEK, AT THE BEGINNING OF AUGUST..

In the interview my dad initially described how he hadn't any qualms about carrying out the drawings. He just hoped that he could do it justice.

However when describing the first drawing he tentatively carried out of her hands he stated:

"Oh I was absolutely terrified that I would not be able to do it. I was completely relieved when I found that I could do it. I thought, all I need to do is to try and do it better. But I wondered under these circumstances...'would I be able to do it?' .And I was relieved to find that I could."

Reflecting on this first, cautious drawing of my mums hands, and especially the hand that she couldn't move because of the stroke, he said

"It was in the same position. Even when the nurses turned her round the other wayher hand more or less remained the same....somehow it is terribly evocative"



He and my mum were fortunate they had a private room to themselves for the whole week.

A large fraction of people with advanced Alzheimer's disease, like my mum die in hospital. In her case the care went well, she was in a private room, my dad had at least a reclining chair in which to fitfully sleep.

So the room played a large part in enabling the drawings to be done. Reflecting on the importance of the room, he stated.....

"I was fortunate that I not only had the ability to do them, but I also had a place where I could do them. There was nobody else there. I mean if she had been in a room with other people, I couldn't have done it . So that the whole thing was made possible partly by the hospital, by having a room to herself the whole week...."

embracing
uncertainties



- When describing the drawings for the first time he tends to focus on the pictorial structures, describing them in purely visual terms.
- This was the language he was comfortable with, something that he knew.
- He talked about the patterns on the sheets and her nightdress and the checks on the towel that my mums head rested on.
- This may seem odd given the nature and context of his situation.
- But to my mind, he is trying to work out and make sense of not just what he is seeing, but what he is feeling at a time when nothing seems to make sense, where the entanglement of emotions and feelings can be overwhelming. He is always striving to be able to seek some semblance of order, coherence, peace and serenity at a time of emotional upheaval and uncertainty.

engaging in reflective practices



- when asked, the reasons he gave for doing them...were numerous,
- **"because I thought it is what I do. I mean some people might have read a book, you know. It didn't enter my head to take a book. But it did enter my head to take the sketch book..... I could have put on the radio, or a television. I didn't put that on for the whole time. And....I didn't think there was anything strange about doing the drawings. It was just something I have spent my life doing . "**
- **"It actually took my mind off completely what I was doing. One of the doctors did come and saw that I was drawing, and I said 'it is alright. It just keeps me sane ."**
- **"But really when I was doing the drawings, I forgot! I was just drawing Pat again. And I had drawn her thousands of time before. I did to some extent forget. "**
- but ultimately drawing allowed him a time to reflect and to **Find solace in the familiarity of the drawing...**

It was for him normal. It seemed appropriate as he had drawn mum so many times before.

telling a story



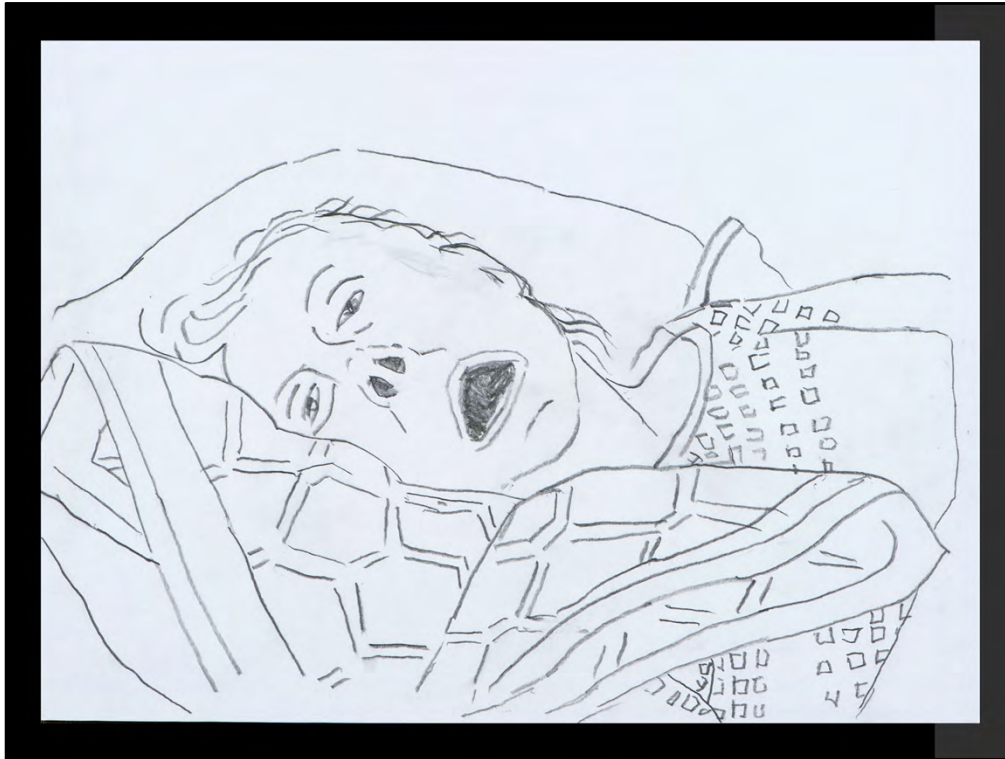
Although we knew that my mum would not recover, we were also told by doctors that she could survive in this state for weeks. At that time I was still over here in Canada. I had just been home a week or two before for the opening of an exhibition of my dad's work in Edinburgh. I had felt in my own mind when I said to my GOODBYE to my mum after that visit that it was probably for the last time. and so I felt it would be better to return for the funeral to maximize the time I could spend with my dad, helping him after,

The fact I was not there led him to consider a further reason or role for the drawings. He stated

“All the time I was doing them, Mark was the one I thought would appreciate them more than anybody else. It didn't dawn on me that really it was his line of work . And it would, some how or other, fit in with a whole lot of what he's been doing. I said to him, ‘that really I was doing them because I thought that this would be something I would be able to show him.’ He wasn't there himself so I thought well the next best thing is draw it. And I think that Mark would have liked to have been there. And couldn't , so I tried to do the next best thing. “

NARRATIVE

EXPLICITLY RECOGNIZING THE PICTURES TELL A STORY...share in the experine



- When asked how he felt about the drawings in relation to all the other pictures he had made of my mum he poignantly stated:

'I think they are separate from [THE OTHER WORK]. I can't show them to her....[I] Can't ask her what she thought of them. At one point I did say, there's no point in doing them because I can't show her them . '

Later, he pondered further their potential merit.....

I don't know if they have any SIGNIFICANCE. I don't know who would want them, I didn't do them thinking maybe I will be able to make use of this in any particular way. I had no idea what I would do with them once I did them. It was partly to give myself something to do. And partly because I knew I could do it. And partly because (doing them)it kept me sane. And I did forget the circumstances I was in while I was doing them. And that was a sort of a relief....

Not only a means of engagement, communication, reflection.....BUT also as a coping mechanism



This last quote is his account of making the final drawing of my mum.

“And at the end. I was sitting in the chair beside her, and I was covered up with the hospital blanket. And I woke up at about two o’clock in the morning, and felt her arm. And it was colder than usual. And I looked at her chest, and it was going up and down slowly. So I knew she wasn’t dead or anything. But then I looked at her mouth. Her mouth was really closed compared with what it usually was. But she was still breathing. But very slowly. And then I started counting between each breathe. And she would breath, and then I could count, one, two, three, up to ten before she would take another breath. So that there were long gaps between each breathe. And I sat doing that for about fifteen or twenty minutes. Just counting between each breathe (cont).”



-And then the last breathe, she just took a breathe and then there was a wee gurgle...and then there were no more breathes after that. And I thought I've drawn her in every position up until now, so I will need to draw her this way too . And I did. So the first thing I did after she died ...was draw her again. And then once I had done that, I opened the door and one of the [orderlys] was sitting outside the door.....And she said I will go and get the nurse. And then I came home at about three o'clock in the morning.
- Looking at the last drawing a week after doing it. He reflected.....

"Its not the best drawing I have ever done. But perhaps its got a significance that the others haven't.....I suppose for most people it would have a significance. ...that the others haven't. Perhaps people would find that it was strange that I was able to do it under the circumstances, but it wasn't a difficult decision to make. I could have just gone and called a nurse. But I thought no, I have another drawing to do."

I think you certainly can see the drawing is different, more awkward, maybe less confident. You can see in the other drawings that they become more and more resolved and 'articulate' ,. The final drawing looks as if it is the first time he has drawn her.

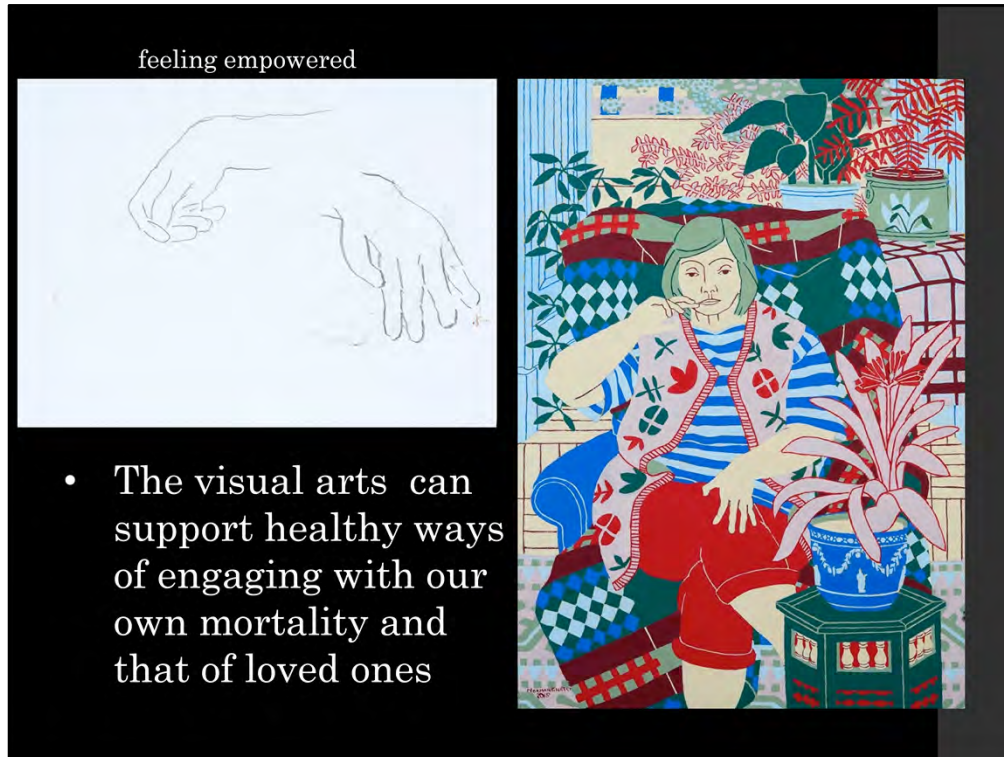
He is struggling to express and record what has happened, what he sees and also what he feels...I think you can sense that she is no longer alive. And that there is a notable difference, that there has been a shift.

...but to my mind the drawing is not 'bad' or poorer, it is remarkable, raw, honest, vulnerable, loving.He is trying to work out-make sense of what he sees of what he feels of what this means with the an urgency of looking ...like every drawing he had ever done before.....only more so.

“People talk of freshness of vision, of the intensity of seeing for the first time, but the intensity of seeing for the last time is, I believe, greater.”



- My mum had also been artist and an art teacher, having attended art school in glasgow, where she met my dad, this is her sitting drawing whlle at art school..... and she had actualy taught me art at high school and so,
- When she died, It was particularly touching and uplifting to hear from those knew my mum as an art teacher and to be told how she helped and inspired so many to articulate themselves through their art, and how she shared her belief that the arts in all their forms can help live one's life with passion, compassion and care.



- When we are confronted with images like these and images depicting illness, suffering and care we are invited to consider what we embrace and also with what we resist and find difficult to cope with. But by engaging with such experiences, we can use them as fuel to transform them into something that is positive, constructive and , even beautiful or sublime
- Finally, it might hopefully be possible that these pictures can contribute to public and professional understanding of dementia.

These pictures are a vivid description of what can happen. If they are thoughtfully presented they may be able to inform public and care provider education.

And allow us to consider the relationship between those who give and those who receive care;

They make us all more resilient by opening us up new perspectives that tell stories, encourage us to reflect on our own experiences of loss and bereavement and our own mortality.



These pictures are an intimate visual record of my father's last week with his wife of 65 years.

THANK YOU

Being able to garner the energy and motivation...in the face of negative events.
Unable to speak or communicate..he did what came naturally, he had the means and the to
turn what would have been a

He could become proactive, to work on creating their narrative one more time...bergere
quote.....and that story continues

It would last a lifetime.....a passion and and vocation that hea has been able to engage in,

always connected

Mindfull of differnet perspectives and motivations from which all phenomona can be interpreted,.....and how the pictures have already engaged multiple forms of engagement , all of which open the teller the tale and the audience up to the variations in perspective and and be able to reap the beefits from being give the gift of thees pictures as a means of reflection. By opening ourselves up to the narratives we will , ourselves absorb the stories ambiguities, diminishing the notions of a masternarrative of negativity and decline, augmenting our resilience.