

Marie Brett & Kevin O'Shanahan



E EGRESS S

'tis the head, 'tis a curse



E.gress | A film exploring the twilight world of dementia

Produced by Marie Brett and Kevin O'Shanahan

National Tour 2015 - 2016

Dublin | The Irish Museum of Modern Art

Nov 3rd - Dec 13th

Cork | Alzheimer Society of Ireland (mobile cinema)

Feb 11th

Sligo | The Model

March 3rd - April 28th

Waterford | Alzheimer Society of Ireland (mobile cinema)

April 14th

Limerick | 69 O'Connell Street Arts & Culture Centre

May 12th

Kilkenny | Butler Gallery

May 26th

Dublin | The Irish Museum of Modern Art

July 14th

A powerful affecting film

STRANGE BEAUTY & EERINESS

E.gress connects at a very deep level

Open ended & undetermined

Open ended & undetermined

A very challenging piece

A very challenging piece

Honoring the human condition

Risky, Edgy, Scary

Extremely worthwhile

Extremely worthwhile

HONOURING THE HUMAN CONDITION

A very powerful and moving work

E.gress captures some of the essences, challenges and losses associated with Dementia

OPENED DOORS

A move beyond a preoccupation with the symptoms of dementia

A move beyond a preoccupation with the symptoms of dementia

Good to see it from the inside out

As a carer it is so helpful

Good insight into the Alzheimer's life

As a carer it is so helpful

Reaches into the subjective reality of the person who remains behind the disease

As a carer it is so helpful



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E.gress | A film exploring the twilight world of dementia

Marie Brett

E.gress is a soulful and stirring artwork that maps a twilight world of loss and change, exploring how individuals diagnosed with dementia find new ways to adjust to a changing world. This multi-layered film, a portrait of living moments on life's edge, invites us to contemplate loss, love and life itself.

E.gress was produced by artist Marie Brett and musician Kevin O'Shanahan following an intensive collaboration with the Alzheimer Society of Ireland. Families, carers and individuals diagnosed with dementia contributed to a regional project led by the artists who captured personal experiences of dementia through photography, video and sound recording.

Dementia is a condition that causes damage to brain cells which affects memory, thinking, language and an ability to perform everyday tasks. An aim for the artwork was to publicly re-imagine this individual and collective dementia experience, and it's been said that E.gress has both extended and challenged current arts thinking within Ireland, and contributed to the field of dialogical aesthetics.

Marie Brett is visual artist who creates art that responds to culturally shunned and tricky subjects, often related to ideas of loss and human suffering. Her artworks recurrent enquiry into contemporary social and cultural questions is underpinned by a frame of dialogical aesthetics. Her approach to collaboration with community and place, to inform and influence the making of new work, has gained international interest. Brett's artwork slows time. She uses a minimal aesthetic opening up new contemplative space which balance intimacy and vulnerability. She holds a Visual Arts BA and a Masters Degree from London University Goldsmith's College.

Kevin O'Shanahan is a musician. His practice has a focus on percussion and following many years playing drums with recording and touring experience, he founded Music Alive with fellow musician Caoimhe Conlon, an organization specializing in music based activities within mental health settings. O'Shanahan is a qualified psychiatric nurse and the Arts & Mental Health Co ordinator with West Cork Mental Health Services.



DISTANCE

Seán O Sullivan

As I write, I am looking back and forth between the words and a photograph of a woman superimposed onto a grey background. She is dressed in a blue knit jumper, and wears four pieces of dull-coloured gold jewellery. Her face carries the subtle specks of red that come with age and those distinct, dark wrinkles that mark the areas where her expressions must have taken shape so many millions of times.

Marie Brett and Kevin O'Shanahan's E.gress records and responds to the experiences of a group of people affected by Alzheimer's disease. The project contains a collection of interviews, portraits and scenes—all crossing between the strangely significant and intensely personal moments that make themselves a part of dementia. And knowing this, I keep looking at the woman's portrait, trying to find a trace of her character and her feelings, wondering what she thinks of being seen in this photograph. Her eyes are such a dark blue that they are barely separable from black; her head is cocked and she peers right into the camera lens, back to me, with a look half-made of intensity and half of distance.

At the beginning of the E.gress interviews, there is a brief and hypnotic sequence of music: a violin and cello refraining over one another, harmonising against a few intermittent electronic notes. Hearing this is a signal to prepare for the intimacy of the scenes to follow—for how delicate they are. The score fades into a story told by a daughter, explaining that although her mother can recall things that happened years ago, she has trouble with what happened five minutes ago and might spend a day explaining the same memory over and again. She says that her mother still thinks everything is normal.

There are small segments of music that divide the junctures between each monologue, and in the next story, a man talks about how he needed to give up driving. But, in the years that he could drive, he travelled to theatres in different towns and cities, and had seen a few shows in London's West End. He talks about this comfortably enough before pausing to remember the name of a singer—the story stops there. The pause continues for the next few minutes, and he spends the time trying to force the singer's name up to the surface. It's a difficult wait. The memory never makes an appearance, so he mentions again that since he became sick he hasn't been able to travel, and that he misses it terribly.



The music fades in to end the interview. It swells up to a brief and simple tune played on the violin. The stories recorded for E.gress are poignant, and distressing in many places, so it is a relief that hear the music keeps rising up over the words to soften their effect.

Part of what is so distressing about listening to these interviews is the way the stories seem so familiar and ordinary in their tone, but then stop cold when certain basic information is mentioned: the name of a hometown or a university for example. The damage that dementia causes is not limited to removing those memories of life, it also simplifies the mind's facility for language, slowly taking away words that used to exist inside. It's a terrible thought to arrive at, the idea that a disease not only takes memories, but also the capacity to think. In its ordinary use, thinking helps us to move our emotions out from their abstract beginnings and into concrete, expressible words. And at the lowest moments, we use thinking to remind ourselves of our own dignity.

My own grandfather was diagnosed with Alzheimer's when he was in his late-seventies. He was a strong man: he'd left school early, and was known locally for having built a terrace of stone farm sheds near to the family home as a fourteen year old—they still stand today. It was difficult to see his mind betraying him. In the beginning, our small, daily interactions with him became flatter and simpler. He lost his passion for going through old photographs. As the losses progressed, he began to imagine his food was poisoned. We visited often, and I'd catch myself hoping that one of those days would coincide with a moment where he would become lucid enough to have an ordinary chat of the kind we'd lost. You feel selfish for wanting those things, but you want them nonetheless.

The music appears again to close out the recording; it's a short song, where a man repeatedly sings the words 'going home'. Music is one of those rare pleasures that can invade a mood without any invitation, and the act of listening to it is still pleasurable even when the tune escapes memory. The song ends on this note—going home.

At the end, there is no one moment to certify the loss. Instead there are years of tiny erasures, one after the other. Alzheimer's robs life of its ending—it robs the part where you get to say goodbye.

DISTANCE | POSCRIPT | SCRIPT

Seán O'Sullivan opened E.gress at the Crawford Art Gallery in Cork, on October 24th 2013. This text is drawn from an audio recording of the event.

I wanted to begin by talking in the frame of reference that I drew up in my own essay for the catalogue. What I really want to say is that the difficulty and the pain that is highlighted in some of the documentary material that forms 'E.gress', it is just very powerfully affecting, it is very strong, and in a lot of ways, it is very hard to watch.

I think Alzheimer's disease, has its own special kind of violence on the mind; it takes away something very special in a person. And what is so difficult about it, is the inability to describe that experience for somebody who suffers it. It is just for us to try to characterise that and see it from the outside is very, very difficult.

I think one of the really important things about this film, aesthetically speaking, is because it is not trying to make some representation or grand gesture in any sense. Instead what you are seeing is just recollections and recordings and scenes and talking, by people who have this disease, who are just talking about how they feel. And that is a very significant thing and actually it is a very hard thing to do because it is in its own way so emotional, it implicates so many people who in their family life and their friendships have relationships to people who suffer from this.

And it (the artwork) requires a great amount of latitude in everybody's mind to try to understand what the feelings that are being expressed actually represent. What they make up in their totality. That is, for me what is so hard to watch.

It is actually a very sophisticated aesthetic that happens in this film because between all of this difficulty that I have just described, there is some very beautiful and very expressive visuals and music that forms an interplay. What is played off against the emotional, is quite soft and quite moving movements of cello and violin that kind of rub up against each other but also push against the film. They change how what you see and the words you hear, how they are characterised; what that all means. And without that, without that music, it is almost too damning, it is almost too much.

I think it is very important to try to get an understanding of what the pain that we are seeing, or what the difficulty that we are seeing means, when you try to understand it against the context of art, and against the context of representing emotions; representing feelings. But also representing facts and ideas and the people who are at the centre of this.

I wrote in the essay about my own grandfather and how we had felt seeing him suffer with Alzheimer's, this was about 10 years ago. I must say, I found it really difficult to talk about; I really did. And the thing that really struck me, is that there actually is nothing to say. It is just there. And in my memory, one of the final times that we met when he was lucid; he talked about the feeling of what it was like to have his eyes kind of failing him, they were closing a lot and he couldn't quite get control over this and it stayed with me really, it has stayed with me my entire life. He just said this is the worst thing, there is nothing like this. And that is really what is at stake in this artwork, that is the kind of thing that you are talking about.

There was another version, an earlier version, where a man talked about his experience of being able to travel to London when he was younger and all the different things he was interested in and how that had very slowly been taken out of his life. I was really struck by the fact that he didn't really want to set the blame or say why it had happened. It was just, it couldn't be done anymore, going somewhere, that time was kind of over.

I don't mean to be saying that it is an artwork that emphasises any feeling of hopelessness. I don't think that is what is at play. I think what is happening is much more subtle. You are just hearing people talk and that is quite powerful in its own way. Just hearing them talk about what the sense of this is and how it makes itself manifest, what they feel. I guess a lot of people have the reaction that it was quite distressing to do that; but talking, in its own way, is very powerful. It makes concrete some things that really we have extraordinarily difficult times navigating.

It is particularly important when you feel like you have been shut out of being able to understand your own feelings around this illness, and I know definitely if you are somebody who has seen Alzheimers in your own family, one of the feelings that really takes over is that the most important person is the person who is suffering and that is true, but you get to thinking so much that this is the case, that you sort of stop being able to make interpretations of it yourself. You stop being able to describe your own feelings.

One of the other things I thought was very powerful in the documents that led up to the production of this film was a daughter talking about her mother and just saying that she might tell a story and think that this was a very good story, a normal story, just the kind of conversation that anybody would have and then tell it again. And tell it again and tell it again. And this might happen 10 times. I remember that very distinctly. You feel like you are being very patient but you are not quite sure where the realisation sits with the person who is telling it, do they know they have told it before, did they have a vague recollection of having maybe mentioned it but they can't remember? - and there is a certain politeness that almost become unethical around it. You try to not push people too hard; you can end up treating them like they don't deserve to even be interacted with. That is very difficult and I think that is really brought up in this film. Particularly around the way that Marie and Kevin worked where there is this very direct approach of just going and discussing things. Just discussing and just recording that, and having that be the form of work, that is, I guess the most aesthetically appropriate, the most conceptually rigorous, the most right way of documenting this. And it is very, very powerful for that, and I think it has a certain kind of strength for that. And I must say I really applaud Marie and Kevin for that.

There was a question earlier where we wondered – somebody wondered, why it was so distressing to watch this film; why you get feelings of distress when you watch it. I have been thinking about that since it was asked and I think there is something quite strange that goes on. Maybe when you meet somebody who suffers from Alzheimers, you wouldn't imagine yourself seeing them having Alzheimers, you would see them as a whole person. And oddly enough I think the distress in some way of seeing these interviews, in the sensory mental space of film, means not only do you see the whole person being interviewed, but you also see yourself. And that I think is where the distress comes from; it is not just about seeing the person, it is seeing yourself reflected back.

*Seán O Sullivan is a writer and curator based in Dublin.
He is the Visual Arts Advisor to the Arts Council*

'The artwork is a tangible snapshot of a moment ... it honours the human condition in a different space and place. We're looking at the resonance of a person, what's deep inside at the core'

Jon Hinchliffe, Alzheimer Society of Ireland

'VERY POWERFUL AND GOOD INSIGHT INTO THE ALZHEIMER'S LIFE'

Family member

'A very powerfully affecting film; in particular the interplay and counter-posing of visuals and sound is so integral to the aesthetic sophistication of E.gress'

Seán O'Sullivan, curator/writer

'On the one hand risky, edgy. The artwork's disquieting, to watch and I have seen it many times; in a positive way, it's scary and about a collective but it is also in my professional and personal opinion extremely worthwhile'

Jon Hinchliffe, Alzheimer Society of Ireland

'Thank you, as a carer it is so helpful, and good to see it from the inside out. Your work is so professional and so moving. Humanity oozes from the screen'

Family member

'E.gress connects at a very deep level'

Jo Calnan, Alzheimer Society of Ireland

'A very challenging piece'

*Helen O'Donoghue, Senior Curator,
Irish Museum of Modern Art*

'STRANGE BEAUTY & EERINESS...OPEN ENDED & UNDETERMINED'

Julie Murphy, HSE South Community Work Department

'Good to see it from the inside out ... So professional and moving'

Carer

'This is a very powerful and moving work. It succeeds in creating a space for those who engage with it; to bring their own experience to it and to make their own meanings. The image I have is one of oscillation, where each person involved moves back and forth to create this powerful, moving and crucially open – ended piece'

Ann Davoren, Director, West Cork Arts Centre

'REACHES INTO THE SUBJECTIVE REALITY OF THE PERSON WHO REMAINS BEHIND THE DISEASE'

Jo Calnan, Alzheimer Society of Ireland

'An absolutely incredible collaboration; the idea of collaborating on such a work is hugely ambitious (and it is deeply emotional at a number of levels)'

Thomas Mc Carthy, novelist / poet

'It makes concrete some things that really we have extraordinarily difficult times navigating'

Seán O'Sullivan, curator/writer

'A wonderful piece of work. I feel in a short clip of eleven odd minutes, E.gress manages to capture some of the essences, challenges and losses associated with Dementia'

Mark Tyrrell, School of Nursing, University College Cork

'Somebody wondered why you get feelings of distress when you watch this film? ... When you see these interviews in this sensory and mental space of film, not only do you see the whole person being interviewed, but you also see yourself; and that is where I think the distress comes from ... seeing the person and seeing yourself reflected back ...'

Seán O' Sullivan, curator/writer

DANCE DANCING ON THE EDGE OF RISK OF RISK

Julie Murphy

“He wanted to limit me to his own investigation of who I was....”

Sheridan Hay

E.gress is not about people with dementia. This project does not present any statements or offer any opinions about what it is like to live with this condition either as the person who has it or as the one in a caring role. And so in this sense it cannot be said to be an instructive project – it does not seek to teach any lessons. E.gress rather is a collaborative arts project with people with dementia. It involves the creation of a space whereby those experiencing dementia are seen and heard. It creatively presents the transformative impression made upon artists by the people with dementia that they collaborated with – and invites the viewer to respond. What emerges through this response is open ended and undetermined and this is what makes the work exciting and adventurous. It is a work continually in the process of being created through the response of the viewer. In this way the field of meaning of dementia is open to ongoing proliferation; diffuse and unbound by certainties. It seems to me that this is a way of approaching dementia that is novel, expansive and potentially liberating not only for those connected with the experience of the condition but for the wider society also in which people with dementia live and belong.

Unlike more established evidenced based modes of enquiry into dementia – (including the bio-medical discourses of neurophysiology, psychiatry and geriatrics and the social scientific discourses of sociology, social psychology and ethnology) – E.gress does not involve proposing explanations or advancing hypotheses on the condition of dementia. Undoubtedly all of these domains of discursive enquiry generate very valuable knowledge that expands the range of understanding of the genesis, treatment, care and social dimensions of the condition¹. What interests me in the context of E.gress however is the question of whether within all of these analytical fields – (which almost always involve people who do not have dementia writing about those who do) – those with dementia become structurally positioned as ‘the other’ assigned to a passive role with regard to the knowledge that is generated and produced about their otherness?



The French cultural theorist Michel de Certeau had a particular ethical and epistemological interest in the construction of otherness through written discourses (scriptural practices) and the relations of power and disempowerment generated by and sustained through these practices². Essentially his view was that analytical writing is an act of power that captures and paralyses the experience that it seeks to explain. The raw, messy, inchoate stuff of lived experience is contained literally and metaphorically in written discourse and the vitality of lived experience of some people is erased and supplanted through the containing written account of more powerful others. This is a dynamic that occurs not only in analytical writing but within the structure of any relationship where one person is 'authorised' to inscribe the experience of another, whatever the medium of inscription might be.

De Certeau's quest in his work was not to eradicate inscription but rather to cultivate spaces where the author and the one inscribed could form an encounter that would lead not to a captured content but rather an altered understanding of both. This entails a radical shift in the practice of relationship between those enquiring and those enquired about from one of active-passive to one of reciprocal engagement.

As someone involved in an advisory capacity on E.gress I had a worry at the outset that the project might carry within it an implicit (thought not intentional) impetus towards inscription ... a desire to capture someone else's experience of dementia. Historically there have been many arts practices where the viewed subject is passive and determined under the all powerful gaze of the viewer artist³. Given that personally and professionally the value of safeguarding space for every individual to hold autonomy, dignity and self-determination is important to me (no matter how restrictive their health might be) I would have found it difficult to collaborate with this kind of approach.

However, having talked at length with the artists Kevin and Marie and listened to their approach and the details of how they practice, I realise that E.gress demonstrates a very different kind of arts practice and mode of enquiry; one that is oriented towards reciprocal relationship, partiality of perspective and the necessity of movement by both artist and subject in the space of encounter. In another essay in this catalogue Sheelagh Broderick has written about 'something happening' for the people who participated in this project. Something happened also for the artists... their encounter with people with dementia moved and changed them (a change further deepened by their connection with family members and carers) and so rather than being in the all powerful position of authorising meaning they found themselves within a space where meanings emerged

(egressed) through the relationship formed between them and the people with dementia that they encountered.

From the outset of this project both artists were adamant that this was a participatory arts project. For them this entailed an essential element of risk. It meant entering into a loose unmapped space of relationship with people with dementia without a determining expectation or assured guarantee of what would happen. It seems to me that in many ways this practice is akin to initiating a dance with an unfamiliar partner whose rhythm and step one does not know at the outset. The ensuing dance is one that takes shape in the process of both people tuning into each other and discovering (perhaps through awkward steps at first) a shared pattern of movement across the floor.

In their encounter with people with dementia Marie and Kevin began with opening a space for the person to 'present' themselves (in multiple senses of that word). In practice this meant going with the flow of the person on the day. The process of relationship wasn't subject to managed forms of communication such as diagnostic questions, or cognitive tests or leading social chat. The approach was rather one of introducing visual objects (photographs) and musical sounds and risking the space to see what would happen⁴. The response of the person became the first step and from there a dance of connection evolved between the artist and the participant.

There are two layers to E.gress . There is the process of the work as it unfolded in the encounter between the artists and the people with dementia and there is the production of the art work. In the space of the process the artists took on the role of dance partners. In the space of producing the artwork they took on the role of stage directors. The artwork involves designing an artistic frame in and through which to re-present the experience of engagement between artist and person with dementia. The relationship took place in the moment and like any moment in time cannot be repeated. However what the artwork does is evoke the impression of that relationship - creating an echo chamber in which the experience can reverberate. It is very noteworthy to me that the direct voice of those with dementia speaks in this space. In the practice of analytical writing and objectifying art it is this singular voice that gets lost – the people written about and gazed upon are silenced. The E.gress film gives space to the voices and faces of people with dementia- it cultivates a place of power through which they can move others and through this movement altered meanings and understandings of dementia can emerge/egress.

E.gress does not present a model that can be replicated. Rather it is an event that has the power to move, influence and bring about a reconfiguration of perspective in those who experience it. There is too inspiration to be drawn from the artistic practice in healthcare settings and the process of enquiry of this project: the alternating 'lead-and-follow' dance step dynamic between artist and participant; the refusal to either take over the other or efface oneself; the designing - (but not authorising the meaning) - of the work; and - through productive collaboration with families, care staff and funders - the cultivation and safeguarding of a space where the dance of engagement can happen. E.gress demonstrates how this space can be set up and maintained but there are no guidebooks for what happens when the dancers encounter each other on the stage or for when the audience encounters the work... that is the always singular, in the moment space of risk, integrity, artistic freedom and personal response.

Julie Murphy works with Westgate Foundation and previously worked with the HSE Cork South Community Work Department and Cork Arts and Health Programme. She has collaborated on a number of arts and health projects with a particular interest in developing practices of freedom. Her perspective is strongly influenced by a background in academic philosophy.



'The artwork opens up questions – like silence and how we use it, how we relate to silence. There needed to be reflective silence within the work, a companionable silence and this has been achieved'

Jon Hinchliffe, Alzheimer Society of Ireland

'THE PROFOUND AND MANIFOLD LOSS THAT COMES WITH DEMENTIA' ¹⁶

'A very powerfully affecting film; in particular the interplay and counter-posing of visuals and sound is so integral to the aesthetic sophistication of E.gress'

Seán O'Sullivan, curator/writer

'The politeness which becomes the almost de rigueur mode of responding to people with dementia – is there something deeply unethical about this – the presumption that the person cannot be responded to as a real adult anymore. This question seemed to prise a chink into closed off deeply uncomfortable territory for us all'¹⁷

'The profound and manifold loss that comes with dementia' ¹⁶

'Beautiful and very moving'

Mel Mercier, Composer / University College Cork

'SHIFTING SANDS OF POWER' ¹⁸

'The room was suspended in a silence that bore loud testimony to something portent having happened over the previous twelve minutes' ¹⁶

'Is happiness the only thing that's worthwhile capturing? – Is upset, a form of grieving, good or worthwhile too? ... What is the fundamental motive (of the artwork), for people to feel good? – or to make a deeply trusting honouring of people?. There may be beauty in this'

Jon Hinchliffe, Alzheimer Society of Ireland

'E.gress is a collaborative arts project with people with dementia. It involves the creation of a space whereby those experiencing dementia are seen and heard. It creatively presents the transformative impression made upon artists by the people with dementia that they collaborated with – and invites the viewer to respond. What emerges through this response is open ended and undetermined and this is what makes the work exciting and adventurous ...

This is a way of approaching dementia that is novel, expansive and potentially liberating not only for those connected with the experience of the condition but for the wider society also in which people with dementia live and belong'

Julie Murphy HSE South Community Work Department

'SO REAL' ¹⁹

'E.gress was carried out on a 1:1 basis consistent with the ethos of person centered care'

Dr Sheelagh Broderick

'I found myself almost heaving with strain and captivation at what I was witnessing; the starkness, strange beauty and eeriness of the work' ¹⁶

'The act of writing in the face of his own experience of his grandfather's journey into dementia was almost one of resistance against a powerful emotional sense that in the encounter with dementia "there is nothing to say". It struck me afterwards that this push to express what is almost too hard to express has a deep Beckettian resonance - that ongoing tug of war between the forces of decline and those of life that leave us feeling "I can't go on I will go on". In this light E.gress becomes part of an almost primal existential desire to speak the unspeakable' ¹⁶

THE BLANKS, LIFE AND TRAPDOORS

Marie Brett & Kevin O'Shanahan

This morning, I fell out of bed
Expecting the sun, but met the moon instead
In the front door backwards
Head after feet
By the mirror in the hall
Who do you think I should meet?
A young fellow, stone balmy they say
Who lived in both places
Sometimes night, sometimes day
Like a spailpín fánach
Wandering from here to there
Things that slip through the gaps

Lateral pathways to make connections
What the material reveals Presence and absence
Trace, visibility and evidence?
Is the work to find and record, to impartially observe as a witness, or is it
something else, something more? And if it's more - what is this more?

“The photographer both loots and preserves, denounces and consecrates. - Photographs furnish evidence and are a way of imprisoning reality, understood as recalcitrant, inaccessible; of making it stand still; or they enlarge a reality that is felt to be shrunk, hollowed out. - Perishable, remote. - One can't possess reality, one can possess (and be possessed by) images - as, according to Proust, most ambitious of voluntary prisoners, one can't possess the present but one can possess the past”⁵

The process as being on the edge in amongst ‘the grey’, the unknown, the in between. It's almost if you want something too much, the person working with you can sense it, and nothing happens; so you need to be very relaxed and at ease in your own skin

“Whether the shift from the position of the artist as producer, to the artist as a collaborator in the construction of social knowledge, not only leads towards consensual representations of other people's reality, but also redistributes agency in the production of social meaning” Proposing that artists redefine their function as context shifters rather than content providers, and that “they become more intimately involved in the production and mediation of new social knowledge”⁶

“Acceptance of chance in the process”⁷

“Simplicity is the ultimate sophistication”⁸

“Without (memory) our experience of the world would be ever transient and ever instantaneous”⁹

Healing hands: My mother delivered babies and washed the dead

Twilight/Clapsholas:

where the line between the visible and invisible worlds is thinnest

Going in the front door backwards
Approaching the individual from the side rather than the front
I cut the corners of it
To this day, I can't recall

My head is gone

“In contrast to cooperation, collaboration is driven by complex realities rather than romantic notions of a common ground or commonality. It is an ambivalent process constituted by a set of paradoxical relationships between co producers who affect each other”¹⁰

Anxiety and transference of this anxiety from artists to staff to participants prohibits the most natural encounters

Tension / how at times it can be uncomfortable working in the environment - interesting work or true reflections of an individual that may not be comfortable for families or carers = conflict or trust? Reflecting the dark and light of the individual

“A new generation of ‘relational’ artists, for whom a critique of authorship and the democratization of art are implicit rather than explicit; for whom the role of the participant predominates through dialogical process; and for whom human relations or ‘the relational’ aspect of social context is a primary point of departure. In many cases the ‘social context’ or ‘situation’ can be seen to have replaced the studio as site of process”¹¹

“The dual nature of being human, the opposing principles of light and dark. The sorrow and magic of childhood”¹²

The work is a balance of checking viability and working on the edge of what is possible - what might be possible

“Faultline between the Savannah and the City”¹³

I hadn't it too well
Amazing how it creeps up

Tá sé agam, Níl sé agam: I have it, I don't have it
You have to understand she thinks everything is normal
Day and night blurring
She's happy in her own little world

Balancing the issues of aesthetics and the art making, with ethics and the process of relation with people

The importance to avoid the challenge of over sentimentality / cliché / nostalgia and to avoid being assumptive and potentially patronizing

“Ethics is a value and is loaded with prejudices, inequalities, abuses and hierarchies”¹⁴

Connecting with the participant is crucial : verbally / physicality through body gesture / in vibe / instinctual / aided by objects

“All animal and human life lives on in us. Instinct remains after intellect”¹⁵

All the past (field recordings) and all the future (abstractions) are in the mind. The head is distracted by knowing / reason / the factual. There is an ocean of unknowable being. Distractions and blindness of the thinking mind

The known (expected) and trapdoors (unexpected)

Non linear
Residuals and echoes
Where does the impulse to censor come from?
To echo what exists or to re-imagine?
Night visiting/Ag airneán Tis the head, 'tis a curse



Forget what you had before

SOMETHING HAPPENS

Sheelagh Broderick

E.gress like other arts projects in healthcare settings is characterised by the involvement of health professionals in a process of collaboration. Families are involved too as agreement to participate in E.gress was sought from them on behalf of their loved one. E.gress thus spreads itself wide in terms of its reach prior even to project commencement. The conjunction of arts project participant, artist, health professional and family is a curious relation, borne of different expectations in an encounter that makes the artwork possible. In this essay I draw on conversations with a family member and health professional in order to unravel some of these intentions and to position them in relation to the artistic claims discussed elsewhere in the catalogue.

Recognising personhood, identity and value is at the heart of care practices in Cork, Midleton and Bandon. This care prioritises choice and autonomy for service users. Having a suite of different activities is a primary concern in best practice care that recognises that the service user 'can still do things and still has a future', especially in rural environments where access to other services is limited. The focus is clearly on the whole person, on their abilities and not their losses, with the strongly held belief that people with dementia can live fulfilling lives.

Health professionals work with the dual challenge presented by the social model and medical model of care – requiring a change of organisational and individual attitudes to displace top down structures with flexible approaches to care and decision-making. These changes make interesting and meaningful work possible. E.gress was carried out on a 1:1 basis consistent with the ethos of person centred care. Initially this relation was brokered through the health professionals who identified service users to participate in the project and then later supported the artist and the service user to establish a relation and a connection that made it possible for them to work together – 'reaching into the subjective reality of the person who remains behind the disease'.

E.gress follows on from a previous project, *Converging Lives: Portrait of a Moment*, which took place at the Bandon Alzheimer's Day Care Service (shortlisted for International Dementia Excellence Awards in 2012). From a health professional perspective, the previous experience of the artists made it easier to establish working relations - in the moment. The particular experience of participants varied with their ability to concentrate and also varied in terms of responses. Some were evidently proud of their work, while in another case work was cut short due to agitation on the part of the participant. The artwork respected the personhood of the participant through recognition that people are social beings, existing in relationships with other people and in a context through which their personhood is articulated as husband.. mother.. child. For the health professional immersed in an arts project alongside the very many other demands on time and attention, the artwork exists in the moment shared between artist and participant as a private shared reflection. The outcomes are not immediately evident even to them and will persist into the future in ways that can't be anticipated. So for example, beside all the accolades for *Converging Lives* one anecdote stands out. When a former participant passed away many months after project completion, his family chose to show the audio-visual artwork at his wake – a proud moment for him, the family and the health professional.

The fierce pride family has for their loved one sits alongside the responsibility for caring for someone with dementia - analogous I am told 'to caring for a child who will never grow up'. Speaking with a family member who cares full-time 24/7, 365 days a year, it is impossible to escape the commitment to personal dignity, and also the passion to expose the reality of dementia care to public attention. But the demands made on time by caring confines attempts at advocacy. From this family carer's perspective participation in E.gress might increase the visibility of dementia, 'the more people who know about it the better'. His Mum, he says, 'is still her own person in a lot of things; she still has self-determination in knowing what she wants'. In agreeing to allow his Mum to participate, he says it doesn't matter to him what happens in the artwork. He is 'looking for a reaction, something happening, anything is better than looking out a window'. Starkly put, these are the realities presented by dementia care. Something happening is preferable to nothing happening. There is an honesty to this that departs from social convention and academic rule.

The family member and the health professional see the participant as someone with potential to make something happen, to establish relations through which capacities can be realised. It displays a confidence in a future orientation for that person distinct from a regret for what was. Yet this is uncertain territory. In an arts project it is not possible to know in advance what that 'something happens' might be, nevertheless they honour it through their agreement and their advocacy. E.gress has had many different levels of engagement. Right now in this catalogue it is stepping out from a sheathed environment into a spotlight of critical reflection. It is too early yet to say what E.gress might do. But I can say that what it has done, is to make something happen in the lives of the arts project participants, family carers and health professionals. How they diversely describe that 'something happens' forms part of the rich legacy of the project.

Sheelagh Broderick is an artist, researcher and writer. She is a 2015 PhD graduate of the Dublin Institute of Technology Graduate School of Creative Arts & Media (GradCAM) where her practice based research concerned arts practices in healthcare settings.

'E.gress opened doors for individuals irrespective of their health status. Meaningful collaboration with the artists facilitated a move beyond a preoccupation with the symptoms of dementia by reaching into the subjective reality of the person who remains behind the disease'

Jo Calnan, Alzheimer Society of Ireland

'VERY POWERFUL & GOOD INSIGHT INTO ALZHEIMERS'

Participant's grand-daughter

'The aesthetic sophistication of E.gress and in particular the interplay and counter-posing of visuals and sound that is so integral to the work'

Seán O'Sullivan, curator / writer

'Approaching the confounding disorienting human reality of dementia from the standpoint of presence (rather than analysis)' ¹⁶

'A work hidden in a dark space evoking a dimension of human experience that is unfathomable, opaque and hard to reach' ¹⁶

'He testified to the very real experience of "ambiguous loss" that family members experience constantly and he applauded E.gress for bearing "disquieting" witness to the experience of dementia' ¹⁶

'Grief and loss and sadness are major themes within E.gress but there are counterpoints at work too - composed of presence, humanity and dignity-modulating the depletion of loss with the ongoing élan vital of change' ¹⁶

'There was profound truth in the opening image and song "going out the front door backwards captured it all", the film showing the unvarnished essence of dementia – "forgetting people's names, not recognising oneself in the mirror"' ¹⁶

'We have raised so many questions as have been answered and it is just so interesting to look at some of the key themes which arose: which were around collaboration and the nature of artistic collaboration between artists, but also with the people they are working with. With staff, with participants. And whose work is it?, the artistic challenge, the artistic merit, the ownership and authorship and also the cycle of collaboration or the nature of collaboration and the creative tension that happens at the beginning and on-going in a project. That tussle, the negotiation, the communication and then that understanding and language that has to be developed between partners before there can be a fluidity in a project. And then, the ethics and the consent and confidentiality issues. And I think, most of all, what we were touching on there was around the personhood, identity, authenticity, the absence, the presence, and the person who remains behind the disease, this is very much what the work is speaking to.' ²⁰

'The 'letting be' in the work - bearing non-interpretive witness to each person occupying their own space at that moment in the world ... rare enough and particularly important when you sense that you have been shut out of experiencing what you are going through ... this as the "most rigorous and aesthetically right way to document this experience"' ¹⁶

'A fundamental theme ... "there is a lot of negativity and failure associated with the condition [of dementia] and anything that accords dignity and recognition to the person's adulthood is really important' ¹⁶

'What struck him most in this was that although the woman didn't recognise herself in the mirror she did recognise that the face she was looking at was upset. This recognition points to a capacity in human beings which is one of the last to be lost - the ability to read facial expression. In drawing our attention to this Mark impressed on us a salutary reminder that emotional capacity and sensitivity is not lost in dementia' ¹⁶

'A key feature in the artwork is its commitment to placing the person with dementia at the very centre of the work. Connecting with the "subjective reality of the person behind the disease"' ¹⁶

'POWER IN THE COLLABORATIVE RELATIONSHIP AS NUANCED AND SUBTLE AND NOT STRAIGHTFORWARDLY POLARISED' ¹⁶

'The ambivalence of being here and not here and the simultaneity of presence and loss. For Marie the guiding thread of E.gress is the creative articulation of this ambiguity and of what it means to be in the presence of one who is and isn't with you' ¹⁶

'Testament was given to the anecdotal, unquantifiable but very real health benefits of E.gress to the people who were involved in it' ¹⁶

'Tension, unease and finding just the right holding points were intrinsic catalysts in E.gress' ¹⁶

'SHIFTING SANDS OF POWER' ¹⁷

'How is it possible to justify presenting someone in a work when that person lacks full capacity to consent to their own participation? ... In E.gress a risk was taken in good faith and in the spirit of both respecting the dignity of the people involved and honouring the responsibility to speak from a place of honesty' ¹⁶

'Respect for identity is central to this Work and anonymity would have 'effaced identity' ¹⁶

'The fading of memory as a journey of change but not one of decline' ¹⁷

'Preserving, witnessing and holding immemorially the moments of people's presence in their fading' ¹⁷

'SO REAL' ¹⁸

'I was very touched by the work – it linked to my own personal experiences with my Father' ¹⁹

'We are still here in emotion and spirit if only you could find us' ¹⁷

'A discomfiting insight : the distress we feel in viewing E.gress stems from the fact that what we see in the film is in fact a reflection of ourselves'

Seán O'Sullivan, curator / writer

'My parents died 3 and 2½ years ago. I was their full time carer. I haven't been able to cry for them in all this time until today. Thank you for allowing me to feel again' ¹⁸

DIS DISTANCE || POSTSCRIPT || SCRIPT

Seán O'Sullivan opened E.gress at the Crawford Art Gallery in Cork, on October 24th 2013. Following O'Sullivan's presentation, a discussion event took place.

The Postscript text is drawn from an audio recording of this event; edited by Marie Brett.

E.gress was exhibited at the Crawford Art Gallery, Cork from October 18th to November 9th 2013

DA DANCING ON THE EDGE OF RISK || RISK

1. For a helpful overview of studies of dementia across a range of fields see Innes, A (2009) *Dementia: A Social Science Perspective*, London, Sage Publications
2. See de Certeau, Michel (trans Tom Conley) (1997) *The Capture of Speech and other Political Writings*, Minneapolis, University of Minnesota Press and also de Certeau, Michel (trans Brian Massumi) (1986) *Heterologies: Discourse on the Other*, Manchester, Manchester University Press. Also Highmore, Ben (2006), *Michel De Certeau*, London, Continuum
3. See Berger, John (1972) *Ways of Seeing*, London, Penguin
4. This encounter could not have happened without the collaboration of families and care staff. The trust and relationship building groundwork that happened in a previous arts & health project *Converging Lives*, involving the same artists and ASI care professionals, laid down the foundation of relationships on which the space of encounter within E.gress became possible.

THE | THE BLANKS, LIFE & TRAPDOORS || ORS

5. Sontag
6. Papastergiadis
7. Cage
8. Jobs
9. Gibbons
10. Florian
11. Doherty
12. Smith
13. Moriarty
14. Burnes
15. Nietzsche
16. Julie Murphy
Drawn from two witness texts:
Launch of E.gress at West Cork Arts Centre 25th July 2013
Launch of E.gress at Crawford Art Gallery 24th October 2013
17. Marie Brett and Kevin O'Shanahan
Drawn from research and production phases of E.gress
18. Visitor's responses written in the comments book during the exhibition at the Crawford Art Gallery Cork, October 18th to November 9th 2013
19. Written in the comments book during the exhibition at the West Cork Arts Centre, 26 July 26th to August 3rd 2013
20. Ann O'Connor
O'Connor chaired the E.gress discussion event at the Crawford Art Gallery in Cork, on October 24th 2013. These quotes have been drawn from a recording of the event.
Ann O'Connor is the Arts Participation Advisor to the Arts Council

E.GRESS NATIONAL TOUR 2015-16

Principally funded by | The Arts Council

Presenting partners | Irish Museum of Modern Art, The Model, HSE South, Limerick City Gallery of Art, Butler Gallery

Supported by | The Alzheimer Society of Ireland, Create, Limerick School of Art and Design, Waterford Healing Arts Trust

With thanks to | Age and Opportunity, Arts and Health Coordinators Ireland, Cork City Arts Office, Crawford College of Art and The Office of Public Works

The Arts Council awarded a touring and dissemination of work award for E.gress to artist Marie Brett

E.GRESS COLLABORATIVE PROJECT 2013

Principally funded by | The Arts Council

Supported by | The Alzheimer Society of Ireland, HSE South, Cork City Council Arts Office, Cork County Council Arts Office, West Cork Arts Centre

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The Arts Council awarded a participatory project award for E.gress to artist Marie Brett

CONV CONVERGING LIVES: A RESEARCH PROJECT 2011-12

E.gress was informed by a research project | Converging Lives

Principally funded by | HSE South, The Arts Council

Supported by | The Alzheimer Society of Ireland

With thanks to | West Cork Arts Centre

The Arts Council awarded an AIC research award for Converging Lives, via CREATE, the national development agency for collaborative arts in Ireland, to musician Kevin O'Shanahan



Marie Brett & Kevin O'Shanahan



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'tis the head, 'tis a curse