

Something Happens

by Sheelagh Broderick

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The *E.gress* project 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.

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