



## **Art, disability, learning and the dance of my life**

Faith Thorley  
University of South Australia

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*I use my passion and skills as an artist to deal with my various disabilities resulting from brain tumour surgery. The ‘artvantages’ of this approach have been many: improved self-esteem and a greater sense of wellbeing, to name just two. On reflection and after revisiting the experiences of my healing journey, I now know when this journey began. Today I’ve come to recognise its beginning as the onset of my personal transformation. My aim in this paper is to explain how I believe my personal transformation happened after my brain tumour surgery and to describe the transformative learning process that followed.*

*I will support these explanations with valuable insights that I’ve gained from research in adult education and my involvement with others with disabilities. Next, I will introduce my interpretation of a phenomenon that I call ‘arts-based resistance learning’. This has been a major phase in my personal transformative journey and the subject of my current PhD inquiry. I am strongly committed to*

*my research inquiry because it is uncovering new ways of using art to enhance life, which gives me hope, and may inspire and so assist other like afflicted people, health professionals and concerned individuals.*

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My name is Faith Thorley and I am an Adelaide-born artist and art therapist with an acquired brain injury. The injury followed brain tumour surgery in 1990. I am also a student doing my PhD in Education at the University of South Australia.

My painting *The dancing irises*, reproduced here, is the inspiration for the title of this paper. I created *The dancing irises* in 1992, and now see it as an important illustration of the subject of my PhD inquiry: 'art-based resistance learning in rehabilitation'. Later in this paper I will explain how I believe this work has contributed to my rehabilitation.

This will not be just another 'survival' story. Indeed, research for my Masters back in 2000 has made me well aware of the growing genre of stories about survival. All forms of the media continue to bring us such stories, for example, the incredible saga recently of the miners in Chile, yet another example of triumph over adversity, where the human spirit seems to soar! Please do not misunderstand me. I too, am inspired by stories of survival and, because of my own journey, can empathise with the individuals concerned. I can truly appreciate the cathartic value that comes with the retelling of one's story again and again. I very much admire demonstrations of perseverance and courage. However, my motivation to write this paper and undertake my PhD research goes beyond just retelling my story for my personal therapy. My motivation for retelling and analysing my story is threefold, with each reason being interconnected with the others.

Simply put, the reasons are:

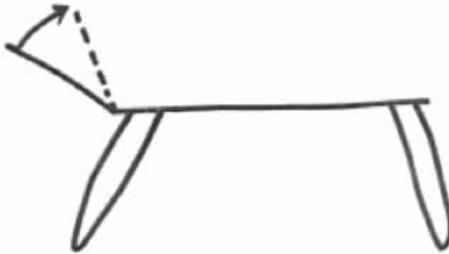
1. because I *want* to
2. because, I am *able* to do so and
3. because, I *can*.

Firstly, I *want* to retell my story to inform others and so hopefully assist people with disabilities, and their carers, health professionals, educators and concerned individuals, with the knowledge and strategies that have helped me to recover and renew my life after brain surgery. The ways that I have been doing this, in addition to my PhD thesis, include being a mentor with the Brain Injury Network of SA's (BINSAs) 'Reconnect and Transition' program for recent brain injury survivors, and conducting 'art for embracing change' workshops with various community groups.

Up to now, I've identified three explanations for my altruism in spite of being an individual recovering from a major illness. They are:

1. My experiences in intensive care after my surgery triggered off what Mezirow (1990) has described as a transformative learning process. For me, the process led from a vocation in education to one where I could use my art making as therapy for myself and at the same time assist and perhaps inspire others undergoing rehabilitation. I made a drawing of a barouche while in intensive care. I used it to 'ask' for my bed head to be adjusted and so alleviate my neck's discomfort after brain surgery. I believe this drawing, which drew a response from a nursing staff member to help me and adjust my barouche, was the trigger for my 'transformative learning'.
2. My altruism is another expression of my spiritual vocation.
3. As Arthur Frank described in his book *The wounded storyteller*, I am a storyteller on a 'narrative quest' (1995: 115). That is, I am an ill person with 'the belief that something is to be gained through the experience' of the illness and one

‘who accept[s] illness and seek[s] to use it’. According to Frank, others are tellers of the ‘chaos narrative’; ‘the sufferers’ own story’; the ‘restitution narrative’; and stories ‘about the triumph of medicine’.



Faith Thorley’s drawing of a barouche while in the Royal Adelaide Hospital’s Intensive Care Unit, post brain surgery in 1990

My second reason to retell my story is because I am now *physically able* to do so. As mentioned earlier, my acquired brain injury followed brain tumour surgery. My tumour was an epidermoid or *pearly* tumour, sited at the brain stem and had been slowly growing from birth to the size of a large orange. Because it was at the brain stem, its removal resulted in mostly motor-related disabilities such as impaired hearing and tinnitus, a paralysed vocal cord, facial palsies, impaired coordination and balance, and ongoing fatigue. Fortunately, over the years I have been able to manage many of these physiological disabilities with various therapies, technological aids and a large serve of perseverance. The psychological disabilities that resulted from the surgery have responded to a different set of strategies. More about them later.

My academic background is in education, the arts and science and because of the motor-related nature of my disabilities, I believe, the body of knowledge that I have amassed over the years has remained intact. Successful completion of an autobiographical Masters in Education in 2006 was reassuring confirmation of this, and

encourages me now towards achieving any future goals that I might set.

Thirdly, I am motivated to retell my story because I *can* now and I have the opportunity to use the vehicles of my PhD and my ongoing art making to promote my research findings. The aim of my PhD research is to delve more deeply and to describe the transformative learning process that has occurred during my rehabilitation. In particular, I am striving to create new knowledge by identifying the ways that I have used my art making to resist and overcome the oppression that I have experienced throughout my rehabilitation.

As I mentioned earlier, I believe my personal transformation and subsequent transformative learning began with the drawing of the barouche. Thereafter, art making became my vehicle of communication and connection with the outer world. I called art my 'saving grace'! On reflection, assisted by my colleagues and friends and informed by my research, I now recognise that it has been my art making that has enabled me to resist the oppression that I have experienced since my brain surgery. The oppression I have felt relates to my physical disabilities—impaired hearing and tinnitus, poor voice quality, fatigue and so on—and the psychological disabilities that have 'danced' along with them, such as low self-esteem, sense of social exclusion and sense of invisibility.

Interestingly, my supervisor Dr Peter Willis sowed the seed of 'resistance learning' when I first began my PhD. He did this when he cited a conversation between Bishop Desmond Tutu and UniSA Professor Emeritus Basil More about oppression. Bishop Tutu's response was 'we are not oppressed; we are resistant!' At the time, I did not relate to this story. I was telling myself 'I'm not feeling oppressed!' And like Desmond Tutu I had been resisting—with my art making!

Since starting my PhD research, my literature review has revealed very little about the topic of ‘resistance’ except with matters electrical, medical or related to the performance of dance. There has been some work in human resources management and in psychotherapy, mostly acknowledging its existence and noting its effects in various situations. Within the field of education there is Piaget’s related work and more recently Mike Newman with his book *Teaching defiance* (2006).

Accordingly, noting an opportunity to make a contribution to adult education and the community at large, I am aiming with my research to propose an alternate view of ‘resistance’. This view has helped me and might be of help to others undergoing rehabilitation. My proposal is an ‘art-based resistance learning’ process, whereby experiences that are oppressive and occur during rehabilitation are identified and resisted. My contention, informed by my lived experience, is that ‘art-based resistance learning’ occurs when these oppressive experiences are resisted and then positively transformed using visual art media.

Further to this, I believe my ‘art-based resistance learning’ occurs during the making of my artwork and then continues as the art is revisited. The healing and benefits of this kind of learning, I suggest, have a ‘ripple effect’ as other individuals interact with me and my artwork.

Finally, I’ll return to my painting *The dancing irises* to explain how I believe ‘art-based resistance learning’ has occurred for me in this work. My creation of this painting began in 1992 at the Ruth Tuck Art School in an eastern suburb of Adelaide. It was a still-life study of a bunch of freshly picked, delicate and fragile purple-blue irises. As I sketched them on the thick watercolour paper, I found myself interacting with their images, as I do when creating cartoons. My experience of the irises was of them as lively, animated, ‘dancing’ beings—strutting, posturing and connecting with each other and me with wispy finger-like tendrils. The choice of their bright colours and

of the radiant yellow background seemed appropriate at the time to reflect their strong, dynamic personas.

On revisiting this work, with the new knowledge that I am amassing, I now see this painting very differently. According to Winnicott, in his book *Playing and reality* (1971), a child uses his teddy bear as a 'transitional object' and so exerts control over his outer world. I contend that I too was taking control of my outer world, at this early stage in my recovery, by creating art images that were paradoxical, that is, I was creating transformed images of the irises, living through them and imbibing myself with their newly acquired strength and vitality. In hindsight I believe this was one early example of 'art-based resistance learning' where I used an 'art of paradox' to bring about learning. I have since discovered other strategies to achieve this form of learning.

To conclude, I would like to share an acronym that I have just designed that identifies the stages that I go through in my process of 'art-based resistance learning': NECTAR (food of the gods/*nectar protector*).

**N—name it** (identify the experience or disability that is oppressive, e.g. feeling of fatigue, low self-esteem)

**E—explain it** (how the oppression affects you)

**C—create it** (create an image or representation of what the oppression 'looks' like to you)

**T—tame it**, transform it (tame and transform the image or symbol into a form that is positive and life enhancing)

**A—action it** (act out the new you portrayed in your artwork)

**R—revisit it** (revisit your artwork often and revel in the new experience that you have created for yourself)

‘Art-based resistance learning’ experiences, I believe, have enabled me to rebuild my self-esteem and independence, which are steps towards renewing my life. The knowledge that has led to this insight has been gained in the dance of my life—a dance of art, disability and learning. I now wish via my PhD and art to help others learn the steps and be enlivened by their new dance!

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## About the author

**Faith Thorley** is a portrait and lyrical artist, independent art therapist and a PhD student at the University of South Australia. For her PhD Faith is researching hope-generated art-based transformative resistance learning in rehabilitation and as a life strategy for building resilience and enhancing mental wellbeing. Faith welcomes your comments and enquiries.

## Contact details

Mobile: 040 789 3042

Email: thocro01@mymail.unisa.edu.au