



Art and Science

A new life after stroke



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Stroke Odysseys
The Place, London, UK
May 18–19, 2018

For more on **SSNAP** see
<https://www.strokeaudit.org/Home.aspx>

For more on the **Stroke Odysseys** project see
<https://strokeodysseys.org/>

For more on **Rosetta Life** see
<https://www.rosettalife.org/>

For more on **The Place** see
<https://www.theplace.org.uk/>

The upcoming tour of *Stroke Odysseys* and associated education programme is funded by the Arts Council and Wellcome Trust

Oct 5, 2018 The Point,
Eastleigh, Hampshire, UK

Oct 12, 2018 Theatre by the Lake,
Keswick, UK

Oct 18, 2018, The Mac, Belfast
International Arts Festival

Oct 25, North Wall Arts Centre,
Oxford

Nov 4, Kings College London
Nov 8, Lakeside Arts,
Nottingham

Nov 16, Circomedia, Bristol

In 1965, the American actor Patricia Neal had three intracranial aneurysms causing a near-fatal stroke. The left side of her brain was damaged, which caused paralysis on her right-side and loss of speech. In the early stages of her recovery, she spoke in jargon, replacing words with invented ones: a cigarette was an “oblogon”, a drink was a “soap driver”. Her husband, author Roald Dahl, made a crucial and pioneering decision about her rehabilitation: she would have six hours of speech therapy a day (replicating a school day), with the help of family and friends, rather than the recommended few hours per week. The documentation of his methods provided material for a book, edited by family friend Valerie Eaton Griffith. The huge popularity for his methods eventually led to the formation of The Stroke Association. With time, Neal regained her ability to talk, and her slow but remarkable recovery challenged her initial poor prognosis.

Playful, invented words became Dahl’s trademark—he spliced, chopped, and muddled-up words, with a particular fondness for spoonerisms, alliterations, and onomatopoeic creations. One of his memorable characters, the Big Friendly Giant, is a vegetarian who eats “snozzcumpers” and says things a “little squiggly”, making up words when words outwit him; such neologisms were never explicitly associated with Neal’s aphasia, but certainly shared commonalities that might have inspired him. However, if you come out of the story and into the real world, for stroke patients, language impairment is distressing. Neurological sequela from stroke are compounded by emotional difficulties resulting from loss of agency and identity. Having a stroke can divide the past and present quite dramatically, and trigger uncertainties about who the patient can be in the future.

Nick Ward from University College London’s Institute of Neurology (Queen Square, London, UK), is a specialist in neurology and neurorehabilitation, and head of a clinic that focuses on upper limb rehabilitation after stroke, a neglected area, he says. “We need people to argue the case for rehabilitation, it is in a terrible state”, Ward tells *The Lancet Neurology*. “The idea that people’s recovery will plateau at three months has driven the provision of services for so long, and being told you are not going to improve becomes a self-fulfilling prophecy.” The existence of this plateau is simply not true, he says, and he is determined to reverse this way of thinking.

Ward adds that, “currently the model we have that predicts outcome is causing people to be written off [from receiving long-term treatment].” He is referring to the Sentinel Stroke National Audit Programme (SSNAP) data that shows how patients are given an average of 16 min

of physiotherapy a day, 16 min of occupational therapy, and 13 min of speech and language therapy. “We are giving minutes when we should be giving hours”, he says. At his Queen Square clinic, he runs an intensive six month programme—“for the first 3 weeks, it is like boot camp, six hours a day, five days a week”. Ward emphasises that, to give people the best chance for the best recovery, face-to-face expert tuition is essential. Rehabilitation studies are scarce but also tend to be small-scale, and unambitious, he adds. The cost of such an extensive programme is not lost on Ward, but what he does want is to provide data so that an informed decision can be made on how rehabilitation services spend our money. “What we are doing is aspirational: [it] is what people need and deserve”, Ward concludes.

And he is not alone in his views. Lucinda Jarrett leads the arts intervention project *Stroke Odysseys*, designed by the charitable organisation Rosetta Life, for which she is creative director. Jarrett explains how the core ethos of their creative initiatives—participatory performance—encourages those limited by illness and disability to find their own self and independence, and to grow in confidence and resilience. At the same time, they can also change perceptions and tackle disability-related stigma. Out of a 4-year practice research grant that was awarded in 2014 (funded by Guy’s and St Thomas’ Charity, The Cultural Institute at Kings College London, Arts Council England, and City Bridge Trust), *Stroke Odysseys* was born. The project seeks to maximise the potential of people living with the effects of stroke by developing an arts intervention model (for community and clinical settings) that combines voice, movement, and performance to promote and improve psychological, emotional, and physical rehabilitation.

“We would discuss the aesthetics of clumsiness”, Jarrett tells *The Lancet Neurology*, “and whether we could discover a distinct aesthetics of disability where performance allows you, for example, to transform aphasia into an art of exploring abstract sound or where a paralysed leg can create a unique and distinct way of dancing. Or, whether you are always performing your disability after a stroke, can you project forwards or are you always looking at the past”.

One of the goals is self-efficacy—having the opportunity to do something you never thought you would be able to do—“pushing them further than the limits of their kinetic sphere”, Jarrett surmises. This self-efficacy is what the project can deliver, and does deliver, as it took to the stage for its premiere performance in London at the contemporary dance centre The Place.

Five people who had a stroke, two young professional dancers, and four professional musicians are all on stage

together, seated on chairs. Following the opening sequence these chairs are thrown into a pile, creating a landscape of uncertainty and chaos. Who is who, what is about to unfold, and what can the audience expect? Artistic director and choreographer Ben Duke is not even sure himself. He tells *The Lancet Neurology* about the creative process from his perspective: “it was disorientating; it shifted my sense of reality as the challenge became finding a new way of making a piece. We couldn’t use [traditional] tools such as repetition, or rely on memory in the rehearsals, and sequencing was not easy, so we created a series of games and provocations that meant we played it fresh. We learnt a lot.” The performance certainly reflects a mechanism loosely based on improvisation. Overall, it comprises a series of vignettes; however they do not feel unrelated, but appear to belong together in an odyssey shared by all of the participants on stage.

Associate artist for Rosetta Life, Orlando Gough, is the composer for *Stroke Odysseys*: “We ask for stories, and ask general questions to all the participants, but this is not an autobiographical piece. As it gradually comes together, it can, and does, change.” The musical element is often fragmented, conflicting, repetitious, but haunting and memorable. This creates a sense of being locked in to a state of regression, but simultaneously bursting with energy and excitement. The sounds rise and fall, loud then soft, fast and slow. It can be uncomfortable, but within the discomfort there is a sense of transition and transformation.

One of the actors had mild cerebral palsy and high frequency deafness from childbirth complications, and then had an unexplained stroke at age 23. He performs a sketch about scuba diving—poignant because it was the diving that indirectly led doctors to discover he had a hole in his heart, providing a connection to the cause of his stroke. Gough talks about their finding as “poetic clumsiness” and this is it. The actor’s words might not be totally decipherable, but as he adds physical gestures to describe the scuba experience, the rest of the group pick up the actions and words, and a cacophony of noise gradually finds its own rhythm, with each person adopting a part until they come together in unity. It really is a slick moment of theatrical genius in this performance.

“I was asked, if this is a therapeutic intervention why put it on stage”, Duke says, “but with a performance there is an endpoint—a goal and a direction. Our stroke ambassadors [the performers] have been trained to become advocates for life after stroke, they have been given creative skills training and psychological support, and are now resilient and independent.” Jarrett adds that “in this piece they are



Paul Neffert

venturing somewhere different; it is not only an arts and health intervention”. Risk-taking is possible on this stage unlike in a clinical environment, where it would be unethical to ask people to take risks with physical balance, for example. The two professional dancers have more of an enabling role: “it is not about showcasing their talents and techniques, they must let go of their ego and support their peers without it looking amateur and childlike”, Duke explains. They nail it. All the performers take risks at every turn but, after a standing ovation, the risks certainly pay off.

Stroke Odysseys is not a story, or a narrative, but perhaps more of a poem told with multiple voices, movement, dance, noise, lighting and projections, with instrument and song. It is an original piece of art-meets-science. Qualitative data taken from the project highlight the benefits of taking part: reducing isolation, building kinship, increasing confidence, cognitive improvements and improvements in speech, movement, and physical mastery, as well as a reduction in adverse psychological outcomes. “In other words”, one participant says, “the life you had is done, that’s it. But that doesn’t mean it’s the end of the story you know, you can have a new life.”

Stroke Odysseys also offers a lasting legacy—supporting stroke ambassadors who share their performances and experiences in clinical and in community settings, advocating for this “new life”. Hope is part of the solution and, without access to rehabilitation, hope can be forgotten. The *Stroke Odyssey* team want hope to be top of the agenda.

Jules Morgan