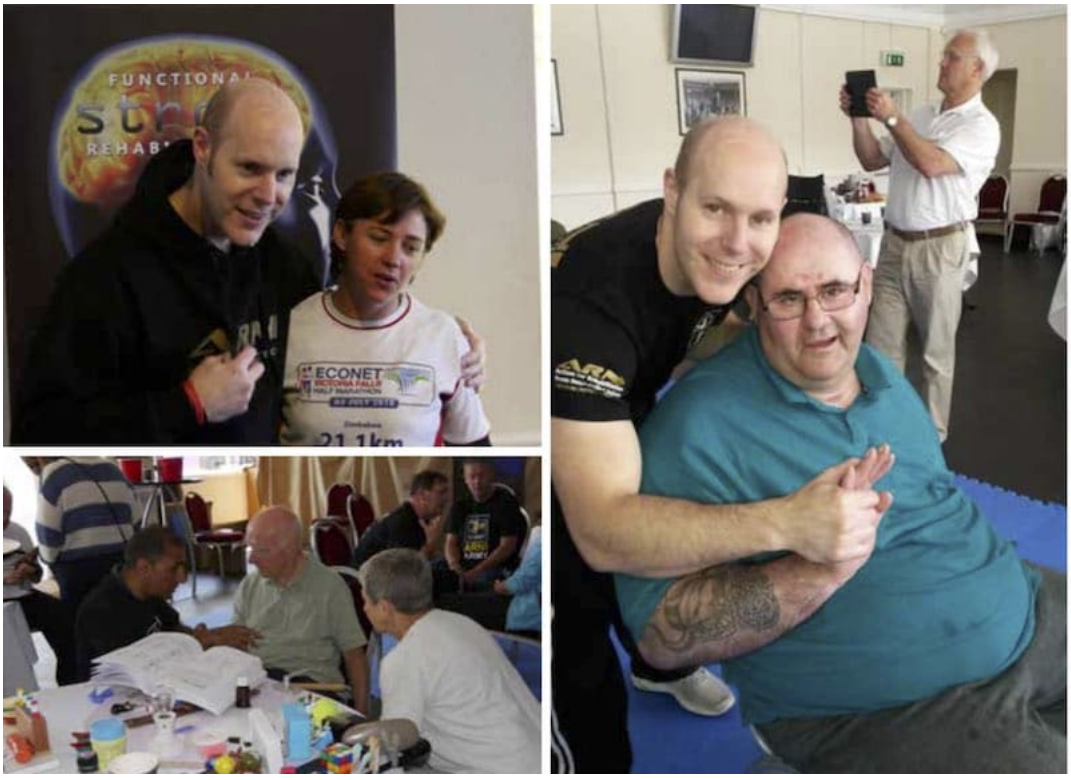
INSIGHT

Why the Arni way is up

Published 3 years ago on
By **Andrew Mernin**



Dr Tom Balchin's mission to help UK stroke survivors was forged in tragedy. In late 1996, his twin brother Alex died aged 21 after falling from a building during a night out in London.

Three months later Tom suffered a serious subarachnoid haemorrhage stroke, which he believes may indeed have been triggered by the stress of losing his sibling.

"I wasn't coping very well before the stroke and there was a lot of grief I just couldn't get out," he says.

He was initially paralysed down his left side and weighed just nine stone when he left hospital in a wheelchair six months later. His journey to independence taught him a lot about what really works in rehab; and shaped the ARNI Institute, which has helped thousands of stroke survivors since Tom founded it in 2002.

"I wanted to get out of hospital as soon as I could and I just went for it. I got hardcore about it! At home, I remember hauling myself upstairs on my behind, step by step, to prove that I didn't need a stairlift.

"I used combinations of all sorts of exercises I found for myself, including piano finger playing exercises – but the best thing in those early days was to try to get back to my DJ decks, put my paretic hand on the platter and try and move it back and forward, beat matching. I even turned the decks backwards initially, before my fingertips were able to grip into the grooves of a record, and made special surfaces for records which assisted my fingers and thumb to move where I wanted them to go.

"The headphone was held on the side of my brain which had suffered the stroke. I progressed to being able to control the cross-fader, equalisers and samplers, take records out of and back into sleeves with my good arm and hand. It was intensive... at least four hours per day, for a number of years. The other big thing was that I was evaluating my performance in relation to my action control each time by recording what I was doing. I made some terrible tapes.

"I would encourage anyone with spasticity in their upper limbs to consider this kind, or any kind, of intensive dosage of fun 'hobby'- type training. It's very hard for patients to find the right thing to do, but anything they can do to ramp up the number of hours of rehabilitation, the better.

"Back then there was nobody around to tell you not to do something, which was good, in a way. I had to innovate. Over the last 18 years or so, I've seen patients time and time again being told not to move for fear of doing bad movement. But in most areas, particularly lower limb rehab, this is wrong and out-of-date."

ARNI – or Action for Rehabilitation from Neurological Injury – works with stroke survivors "stuck in limbo" after their therapy programme ends.

Via a network of specialist instructors and therapists across the UK, they learn ARNI's functional "retraining" strategies aimed at enabling them to take charge of their own recovery.

It offers intensive one-to-one sessions in the home, some group classes and training manuals and DVDs which encourage stroke survivors to continually work on their rehabilitation. Classes are paid for by the client, although often at a reduced rate.

Balchin, however, has always been a volunteer in his own charity and has never taken any payment for his input. The programme is designed to speed clients from the stage where an NHS therapist becomes unavailable, to making recommended activities part of their daily life as they work towards more independence.

Its therapists and professional instructors meet the standards of the Stroke-Specific Education Framework. Clinical Commissioning Groups and charitable and local authorities

provide community- based ARNI training for stroke survivors, which has been positively received.

The approach is now the adopted model for combined rehab and exercise after stroke for a number of UK areas.

“My big mission when I launched ARNI in 2002 was to get one ARNI qualified, appropriately insured and DBS-checked trainer within five miles of every stroke survivor who needed help, wherever that was in the country. I now have about 120 trainers on the books and am almost there. We haven’t quite got to everyone yet, but we’re getting there.”

Stroke survivors on the ARNI programme are matched with personal trainers and physical therapists; their focus is on helping people with partial paralysis to make as full a recovery as possible.

Results are achieved through various activities, including education in exercise principles after stroke and the establishment of an independent home-based exercise programme.

ARNI also develops skills in goal setting, functional problem solving and self- monitoring. It is a personalised programme, with substantial one-to-one training to ensure individual tailoring of activities, feedback and progression, and encouragement to work “at the edge of personal capacity”.

The approach has become increasingly well evidenced since 2007. In one small study, reported at the World Stroke Congress, involving 24 stroke survivors at the ARNI stroke gym at Chaul End Centre in Luton in 2011/12, participants reported improved mobility, range of movement, fatigue and confidence. Service audit data reported 24 ambulance call-outs for fallers during the year preceding intervention.

In the year of the intervention there were zero call outs, with an ambulance service saving of £7,200. This particular statistic was mirrored the following year.

Further savings of £5,482 came from the reduction in care packages, nursing input, catheter care, respite care, appliance support and medications.

Another small-scale study in 2014, supported by the NHS and the charity Different Strokes, revealed that all participants showed ARNI-powered improvements over a span of clinical measures.

A number of bigger randomised controlled trials have been undertaken, including one supported by Stroke Association, entitled ‘Retrain’. This was conducted by the University of Exeter and published in 2017.

It involved 45 patients and showed that ARNI is feasible, acceptable and safe. It also showed that key techniques involved in it could successfully support patients with one-sided loss, including those with multiple comorbidities (eg with lower limb amputation).

This year, an upper limb research study is taking place at Brighton and Sussex Medical School, looking at the efficacy of use of ARNI upper limb task training by patients and families in the clinic.

The ARNI programme involves task-specific functional movement training, development of physical management strategies, stroke- specific resistance training with adjuncts such as technology and pharmacological inputs recommended as appropriate. It was borne out of Balchin’s own rehab experience. He credits part of his success to an “innovative” physio who, in the early days after his stroke, taught him the importance of regaining self-reliance as quickly as possible.

Martial arts were also hugely influential. Despite the remnants of partial paralysis on one side, he powered through the coloured belt classes of aikido, karate, taekwondo and hapkido in the years after his stroke.

He also learned Teukgong Moosool, the official martial art of South Korea's special forces. In 2008, he was awarded the grade of 3rd Dan by Grand Master Lee (8th Dan), Head Grand Master of the International Teukgong Moosool Federation.

Balchin also became a serious power-lifter and strength athlete, regularly working with non-stroke trainees. He added strength training into the mix from the initiation of his project for stroke survivors, at a time when the majority of UK therapists were not introducing it for fear that it would exacerbate tone.

> It was difficult to find the evidence for strength training for stroke in the very early days, he says, but eventually did, academically justifying his project and implementing it successfully.
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> He honed his mental strength and capacity after his stroke too. He went back to university to finish his first degree and then taught for two years in a primary school.
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> He then went on to complete a masters degree and Phd and spent three years as a research fellow/lecturer in gifted education at Brunel University, London. Following that, he worked as an MA course leader in gifted education at Reading University.

He says: "Through my training, I regained nearly all my functional movement, and continued to perfect it twenty years later using ARNI-developed techniques.

"I still train all the time as it's the only way to stave off limitations from stroke; and I'm still dealing with drop foot.

"The biggest weapon you already have on your side is definitely neuroplasticity. I learned that from Professor Nick Ward who runs the UK's first specialist upper limb clinic. A very early supporter of ARNI, he helps me run the ARNI functional rehabilitation course for therapists and trainers."

In the case of stroke, brain plasticity could allow certain lost functions, such as speech and language, to re-emerge as the result of intensive rehab. The ARNI system contains techniques designed to prime the body for task-related practice.

Often, therapists help stroke survivors to get to their feet and walk again after brain injury and many achieve great successes in the very short time they have to work with them in the acute/chronic stages.

However, ARNI works with many stroke survivors who find it hard to move on from sticks, orthotics and other aids to functional movement. Many feel they could achieve better function in their weaker hand, for example, if given a chance to do so by an ARNI instructor.

The benefits of rigorous training beyond the standard allocation of post-stroke therapy sessions are wide ranging, according to ARNI. They include balance and posture correction, improved timing, better flexibility and greater muscular, tendon and ligament strength.

These in turn can boost self-sufficiency, confidence, self-esteem and productivity in employment or hobbies. In ARNI's case, clients are encouraged to work "on the edges" of their current ability to stimulate maximum neuroplasticity. Instructors teach progressively more advanced exercises.

A core part of the ARNI approach is to teach clients how to cope with falls; the most dangerous part of the balance problems caused by stroke.

Trainees (many of whom have the functional use of just one arm) learn how to get down to, and up from, the floor without any kind of external support to pull themselves up with.

They also learn other innovative strategies such as turning, step and ramp navigation and emergency action techniques. Balchin also teaches what he calls “gait-tactics”.

Upper limb retraining is a large part of the syllabus, with no coping or compensation allowed for the patients in this area: they are taught creative stretches to access, and then extend time, on discreet and progressive tasks, with spasticity decline being a focus.

“You have to develop strategies that are workable for the individual. You can give them the tools they need but clients need to be able to personalise them. Also, a key to good recoveries that I worked out straight away is that you can’t tell people they can’t do things. That’s absolutely critical.”

Balchin believes the rise of ARNI is timely, given current trends in UK healthcare. He points to the “sad fact” that effective rehab is generally unavailable from the NHS once sufficient movement to simply get around has been achieved.

At the same time, neurophysio and occupational therapy services are stretched, he says, while he believes stroke classes that promote active task-related functional movement and resistance training are non-existent.

“Most physical after-stroke classes that do exist are fitness-focused and many attendees report that these are, in conclusion, unable to provide them with the specific and custom tools they need to rehabilitate functional limitations or effectively cope with the rigours of their daily lives.

“This is especially the case if extra problems persist such as epilepsy, aphasia or fatigue. Most report that they need external help to guide balance control or spasticity decline for example, but that their essential cardio fitness can, in the end, be done better at home.” Meanwhile, global research findings have backed up the ARNI way for years, he believes.

Home visits and outpatient exercise programmes have been shown to improve gait speed. Research into ARNI techniques show that in a number of activities, performance is retained and built upon.

Balchin cites the example of the Dutch researchers Kollen, Kwakkel & Lindeman who, in 2006, reviewed all available published, clinical stroke rehabilitation trials, of which at the time there were 735.

They selected 151 studies including 123 randomised controlled trials and 28 controlled clinical trials. The rest did not meet the inclusion criteria as they lacked quality or statistical validity.

They wrote: “Traditional treatment approaches induce improvements that are confined to impairment level only and do not generalise to a functional improvement level”.

In contrast, they stated that: “More recently developed treatment strategies that incorporate compensation strategies with a strong emphasis on functional training, may hold the key to optimal stroke rehabilitation.”

In summing up their findings, they reported that “intensity and task-specific exercise therapy are important components of such an approach”.

Balchin says: “There is a good range of interventions with strong evidence of both efficacy and effectiveness now. Cochrane reviews have found that electromechanical gait training,

treadmill training, circuit training, physical fitness training, repetitive task training, CIMT, mirror therapy and FES are also effective.

“You’ll notice that all of these interventions require that you DO something. So many stroke survivors do what is essentially a homeopathic dose of what is required to recover well.”

The delivery of ARNI’s services usually relies on the goodwill of others. While individuals pay for one-to-one sessions, the session costs are low – around £45 to £55 an hour.

The charity’s overheads are partly covered by physios paying to become qualified trainers and serious rehab training sessions at ARNI’s headquarters in Lingfield, Surrey.

The charity also gives full bursaries to students and runs a trainer sponsorship programme which enables any organisation, family or carer to sponsor an instructor through the ARNI qualification. The course fee is partly paid back by the instructor in the form of free lessons to the survivor. The charity also often gives away helpful material such as copies of The Stroke Survivor Manual and its stroke survivor DVD set.

“It’s a fact that a lot of stroke survivors just don’t know what to do when their clinical physio ends because they haven’t been set up properly to do better. What they probably need is an evidence-based, innovative and personalised programme of training strategies, a low-cost means of trainer or therapy support as they do it and to be guided to access helpful local community services or other specialist services.

“It’s really important that survivors are guided to autonomous retraining efforts if possible, in order that they may fulfil goals and thrive rather than decline, become dependent on others or just re-enter the care pathway.

“This is really hard to achieve, but one by one, over the years, ARNI has helped a vast amount of people. I’m proud of this and of the way that, by its sincere efforts, ARNI has gained the trust and support of professionals in neurorehabilitation over the years.”

Balchin describes the charity as his life’s works and passion. “Stroke has driven me to get better, and it continues to drive me to make the effort to help people affected by stroke to do better,” he says.

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I revisited the document where I wrote about the significance of music in my life and career choices, and I realised I did not really deepened the concept of meaning *per se* (maybe I will not here either...). At the time I did not know better, psychodynamically speaking, or perhaps, I was just not ready to see the bigger picture but also the detail within it.