# Living with Locked-in-Syndrome

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#### **Stroke**

*Stroke* is an abrupt loss in brain function caused by lack of or severe decrease in blood supply (ischemic stroke) or leakage of blood in the brain (hemorrhagic stroke). Stroke covers a diverse range of vascular diseases that are related to the blood vessels that supply blood for the brain.

### Stroke types:

Depending on the type of the stroke and the particular blood vessels, stroke can affect the brain differently and in turn results in different symptoms. In the most common type of stroke, called ischemia, which consists of about 85% of stroke cases, a blockage in blood vessel(s) occurs within the brain. The other 15% of stroke cases, in a condition called hemorrhage, are caused by a rupture in these blood vessels. In the case of a hemorrhage, a large quantity of blood gathers in the brain leading to higher pressure in the brain tissues. If this pressure does not discharge promptly, it causes permanent damage to the brain. Ischemia occurs in three categories: (i) thrombosis, which occurs when a local blockage appears in a blood vessel due to diseases that narrow the artery, (ii) embolism, when a blockage occurs due to loose clots that may originate from a distant area such as the aorta, and (iii) hypoperfusion, when ischemia occurs due to insufficient pumping of blood by the heart or low volume of blood in the body. Depending on the part of the brain that suffers from the lack of blood supply, for the amount of time that the blockage occurred in the blood vessel, the symptoms and damage to the brain can be very different. For instance, if it occurs in the sensorimotor area, the sensory and/or motor abilities of the subject in the ipsilateral part of the subject's body will be impaired. However, if it occurs in a part of the brain called the pons, which links the cerebral cortex to the spinal cord, the effects of stroke are more severe and lead to locked-in-syndrome. This usually leaves the subject with very little or no motor function in all limbs.

### **Locked-in-Syndrome:**

Locked-in-syndrome (also called brain-stem stroke) occurs when infarction damages the *pontine* region of the brain. It results in the patient acquiring quadriplegia and in 15% of cases leads to early death. Patients with locked-in-syndrome usually are totally paralyzed, except for the muscles that enable eye blinking and vertical eye movement. However, it leaves the patients' mind intact for cognitive function, whilst they cannot perform movement or speech.

## **Locked-In-Syndrome Rehabilitation (Peter Couche Case Study)**

Peter Couche, an Adelaidean businessman, while was in Singapore in 1992, experienced a brain-stem stroke leading to complete paralysis of his limbs and trunk and loss of speech. The only intact muscle movements, in his case, comprised upper eyelid movements, vertical eye movements, and his right forefinger. After being under treatment shortly in Singapore, he was taken to London and then after another 7 months of treatment in London, with no progress in recovery, finally brought back to Adelaide, and started rehabilitation sessions in the Julia Farr Centre. His only remaining movements enabled him to communicate with binary Yes/No commands and also enabled him to type using a special computer program called Word Plus, by which he wrote his life story after stroke for 13 years. Although little physical progress was achieved during the six year period in that centre, even that amount of progress was very rare at that time for patients with a similar disease. To be able to make an improvement in his muscles he began carrying out a large number of repetitions in his shoulder and neck muscles. Then he started using Pixar rehabilitation equipment, which allowed him to move his arms and feet while standing upright with the aid of the machine. Then he started using a machine called Likon that uses electrical muscle stimulation and the last thing that he found helpful was oxygen drops that he used to take to help his tender lungs that could not absorb oxygen well. Next, he decided to improve his self-image by first refusing to wear tracksuits and second by ceasing to take any medications except vitamins. In 1998, he decided to start a new life as a paralyzed person with an intact mind and move to his own home, starting a new business. He hired private carers at his own home. In 2006, he received stem cell therapy and regained some muscle movement in his fingers, limbs, and his face. Currently, he lives in Adelaide and runs the Peter Couche Foundation that is dedicated to research in stem cell therapy for stroke patients.