



Locked-In Syndrome (a paralyzing form of stroke)

Locked-in syndrome is a rare neurological disorder characterized by complete paralysis of voluntary muscles in all parts of the body except for those that control eye movement. It may result from traumatic brain injury, diseases of the circulatory system, diseases that destroy the myelin sheath surrounding nerve cells, or medication overdose. Individuals with locked-in syndrome are conscious and can think and reason, but are unable to speak or move. The disorder leaves individuals completely mute and paralyzed. Communication may be possible with blinking eye movements.

Source: National Institute of Neurological Disorders and Stroke (NINDS)

Websites

<http://abcnews.go.com/Health/story?id=2835149&page=1>

ABC News: Trapped in Your Own Body

This 2007 story profiles several people with locked in syndrome.

http://www.merckmanuals.com/professional/neurologic_disorders/coma_and_impaired_consciousness/locked-in_syndrome.html?qt=&sc=&alt=

Merck Manual for Health Care Professionals: Locked-in Syndrome

<http://www.ninds.nih.gov/disorders/lockedinsyndrome/lockedinsyndrome.htm>

NINDS: Locked-In Syndrome

http://www.strokesafe.org/resources/locked-in_syndrome.html

Stroke Awareness for Everyone (SAFE): Locked-In Syndrome

http://en.wikipedia.org/wiki/Locked-in_syndrome

Wikipedia: Locked-in syndrome

The following books and videos are available for free loan from the PRC library. For more information, please see www.paralysis.org and click *Borrow from Our Lending Library* under PRC Quick Links.

Books

- Adamson, Kate. **Kate's Journey: Triumph Over Adversity**. Sevierville, TN: Insight Publishing, 2002.
New Zealand born Adamson currently lives in Los Angeles. She has two daughters, Stephanie, 10 and Rachel, 8 years old. Since her devastating stroke in 1995, Kate has accomplished more than anyone ever imagined. She has testified on behalf of the American Heart Association, before the United States Congress for more funding for stroke and heart research. Kate is a national volunteer spokesperson for the American Stroke Association and a board member of the South Bay American Heart Association in Los Angeles.
- Adamson, Kate. **Paralyzed but not Powerless: Kate's Journey Revisited**. Redondo Beach, CA: Nosmada Press, 2007.
- Allatt, Kate and Allison Stokes. **Running Free: Breaking Out from Locked-In Syndrome**. Bedlinog, Wales: Accent Press, 2011.
- Bauby, Jean-Dominique. **The Diving Bell and the Butterfly**. New York: Vintage International, 1997.
Editor-in-chief of French Elle, Bauby suffered a stroke at the age of 43. He died ten days after the French edition of the book was published.
- Dougherty, Brittany Luciani. **God Is Laughing**. Baltimore, MD: Publish America, 2004.
- Howell, Patton and James Hall. **Locked in to Life**. Boise, ID: Tea Road Press, 2002.
Howell was a top psychiatrist when he had a near-fatal stroke.
- Klein, Bonnie Scherr. **Slow Dance: A Story of Stroke, Love and Disability**. Berkeley, CA: PageMill Press, 1998.
Canadian filmmaker Klein had a stroke in her mid-forties. Renamed *Out of the Blue* in subsequent editions.
- **The Official Patient's Sourcebook on Locked-In Syndrome: A Revised and Updated Directory for the Internet Age**. San Diego, CA: Icon Health Publications, 2004.
- Tavalaro, Julia and Richard Tayson. **Look Up for Yes**. New York: Kodansha International, 1997.
A paralyzed stroke victim tells of her years of being treated as a vegetable in a public hospital until a speech therapist taught her to communicate using her eyes.
- Vigand, Philippe and Stephane. **Only the Eyes Say Yes: A Love Story**. New York: Arcade Publishing, 1997.

Publishing executive Phillippe Vigand suffered a stroke in his early thirties. He and his wife Stephane had another child (their third) after he became paralyzed.

Videos

- **The Diving Bell and the Butterfly.** Miramax, 2008. DVD (112 minutes)
Based on Jean Dominique Bauby's book of the same name. In French with English subtitles.

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