

Family Experiences of Vegetative and Minimally Conscious States

www.healthtalk.org/peoples-experiences/nerves-brain

Families share their experiences of having a relative in a long-term ‘coma’ on the award-winning website *healthtalk.org*

Research by Professor Jenny Kitzinger (Cardiff University) & Professor Celia Kitzinger (University of York), Co-Directors of the Chronic Disorders of Consciousness Research Centre (cdoc.org.uk)



We just kept saying over and over and over again “where there’s life there’s hope”.



My sister said “If God wanted to take him he would have taken him. Who are we to take the decision now?”



You’re grieving for someone that you’ve lost but you’ve kind of still got them ... and so you’re in a hideous limbo.

Find out about issues such as:

Critical care

Treatment decisions in the Intensive Care Unit

Longer term care

Rehabilitation and care centres – Recovery – A ‘Permanent’ diagnosis – Hospital re-admissions

Impact on family and friends

Hope – Grief – Impact of visiting – Impact on children – Family unity and differences – Reflections on own end of life wishes

Ongoing decisions

Resuscitation – Treatment of infections – Artificial nutrition and hydration

Death and dying

Repeated life-threatening incidents – Bereavement after severe brain injury

Endorsements

*“It is an excellent website and should be **the** resource for Health Care professionals, including managers and commissioners, because it covers all aspects and presents most of the possible points of view. It is well laid out and can be read, listened to and looked at in small bits easily.”* (Professor Derick Wade, Oxford Centre for Enablement)

“It’s an invaluable complement to the National Clinical Guidelines and will help health care professionals to deliver the guidelines in practice” (Professor Lynne Turner-Stokes, Chair of the Royal College of Physicians Guidelines Development Group)

“On this wonderful website we can hear others expressing their heartfelt thoughts and fears, and putting it so eloquently - you don’t feel so alone.” (Angela Bolton, family member)