

INTERNATIONAL WORKSHOP

**INTERPERSONAL RELATIONSHIPS EXPERIENCED BY PERSONS WITH LOCKED-IN SYNDROME**

**10 October 2024, 9:00 AM CEST – online**

Persons with locked-in syndrome (PwLIS) are unable to move their bodies voluntarily due to extensive general paralysis. As a result, they require the assistance of others for almost all activities of daily living, including in many cases with physiological functions such as breathing, swallowing, or defecation. This situation directly links the fulfillment of physiological needs and sense of comfort-discomfort of people with PwLIS to their relationships with others. Moreover, since they lack articulate speech, communicating requires various technologies, from the use of an alphabet board (which involves an expert interlocutor to transmit messages) to computers with which to generate text or a synthetic voice that others can read or hear. Yet the relational world of PwLIS is not simply reducible to their dependence on others or on technology, nor involves the lack of reciprocity the idea of dependency may suggest. Rather, it involves the cognitive and emotional complexities of all relational life - but with specificities derived from immobility, the lack of articulate speech, the reliance on technologies, and the care they require. The purpose of this workshop is to explore the experience of PwLIS from the point of view of interpersonal relationships, to better understand those specificities, to reflect on them in each individual's context, and to think about ways to ensure dignity is respected in all circumstances. The workshop will bring together LIS persons, relatives, carers and academic researchers to deepen their understanding of each other.

*This workshop, which is part of an international project to study the lived experiences of people with 'locked-in' syndrome, is organized with the support of the Support Scheme for International Joint Research Activities by Female Researchers (to Prof. Yukiko Himeno) and the Degree International Joint Research Promotion Programme (to Prof. Tatsuya Mima).*

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Zoom link: <https://ritsumeai-ac-jp.zoom.us/j/96394180035>

Meeting ID: 963 9418 0035

Registration: advance registration via online form, <https://forms.gle/UZdJ3SGr3vp4nbhr5>

**Session 1** (Chair: Yukiko Himeno, Ritsumeikan University)

9:00 – 9:05 Opening remarks

Fernando Vidal (*Catalan Institution for Research and Advanced Studies-ICREA / Medical Anthropology Research Center, Universitat Rovira i Virgili-URV*)

9:05 - 9:20 Yukiko Himeno (*Faculty of Life Sciences and the Institute of Ars Vivendi, Ritsumeikan University*)

**“Perceptions of the interpersonal relationship described by persons with locked-in syndrome”**

9:20 - 10:05 Keynote Lecture

Satoshi Onda (*President of the Japan ALS Association, President and CEO of Manmaru Shouten Co., Ltd.*)

**Interpersonal relationships with family and support team members. Considerations from a first-person perspective.”**

10:05 – 10:20 Coffee Break

**Session 2** (Chair: Fernando Vidal, ICREA/URV)

10:20 – 10:40 Ann Johnson (Personal testimony, Canada)

**“The relationship between me and my daughter”**

10:40 – 11:00 Ana Santángelo Lázaro

(*Graduate student in medical anthropology, Anthropology Department, URV*)

**“Sexuality in people with Locked-in Syndrome: a case study”**

11:10 – 11:20 Lucía Denegri Méndez

(*Graduate student in medical anthropology, Anthropology Department, URV*)

**“Still the same: personal continuity in narratives of Locked-in Syndrome”**

11:20 – 11:55 General Discussion

11:55 - 12:00 Closing remarks

Yumiko Kawaguchi

(*ALS/MND Support Center, Sakura International / Ars Vivendi, Ritsumeikan University*)