

5th International LiS Webinar

8th June 2026



Join Zoom Meeting from 10am UK time;

<https://us05web.zoom.us/j/82410285324?pwd=WL6PnbNvcUgLdzCQH2Yy09Ylw289fc.1>

Meeting chat link

<https://us05web.zoom.us/jc/82410285324>

Meeting ID: 824 1028 5324

Passcode: 127759

Programme; London, UK times (BST) Please check for your local time

- 10.00 Welcome and introduction by Hosts (Shannan and Bouke)
- 10.05 Song by LiS Marie-Therese Khan (Australia); her 100 reasons why Life Is Great
- 10.10 LiS Howard Wicks (UK)
- 10.30 Prof Damien Coyle; EEG Detection of Consciousness (UK)
- 11.00 Katalin Furedy & LiS Karesz (Hungary)
- 11.30 Fernando Vidal; Legal rights and issues for LiS (Spain)
- 12.00 Feedback and Discussion of morning Presentations

12.15-13.00 45 min Lunch break;

Music composed by Dick van der Heijde

Chat with Bouke & Shannan about the LiS book

Music composed by Helen Flunder (UK)

- 13.00pm Welcome back by Hosts (Shannan and Bouke)
- 13.05 LiS Dick van der Heijde; Creating music (Netherlands)
- 13.30 Jeroen Lansbergen, Focal Meditech; Assistive devices (Netherlands)
- 14.00 James Brinton; Communication technology (USA)
- 14.30 Stefan Carmien; Communication device (USA)
- 15.00 Open Discussion with Hosts and farewell 'til next year

Presentations;

In order of appearance from 10am (UK time) Monday 8th June 2026
(times are approximate and may vary slightly on the day)

10am Introduction by **Host, Shannan Keen**; I am Shannan, the founder of these annual International LiS Webinars. I hold a BA in Psychology and Philosophy and a Masters in Neuroscience. In 2011, I founded and continue to run the Australian Register for Disorders of Consciousness (ARDoC) at the Australian Brain Foundation. In early 2023, I

launched the LiSA online Community Forum (on Facebook). In 2024, I was commissioned by Routledge to write a book about LiS. It contains chapters written by twelve people living LiS plus three professionals working in this field. It is available to purchase through Routledge or order through any book shop, or as an ebook. I'm Australian and am happily married to my husband, Max. We live part of each year in Sydney and part of each year in England.

Co-host, Bouke J van Balen; Bouke is a PhD candidate in Ethics and Philosophy at the University Medical Centre Utrecht, TU Eindhoven, and TU Delft. He researches how communication Brain Computer Interfaces (cBCIs) shape the communicative relational network between people with LIS, their loved ones, and healthcare professionals. He interviews people with LIS, their caregivers, and medical professionals to study their experiences of communication and personhood. These experiences form the basis of his philosophical analysis and ethical recommendations. Bouke lives between Amsterdam and Brussels.

[Brief resumes and biographies of today's Presenters in order of appearance.](#)

It is with pleasure that we welcome four people who are living locked-in to tell their story today.

10.00am Welcome and introduction by Shannan and Bouke, co-hosts.

10.05am Song [Marie-Therese Khan \(Australia\) who lived LiS and composed the words of this song:](#)

Waltzing With My Eyes by Johanna Rayner, **Marie-Therese Khan** and Joe Kellaway. At the age of 35, Marie-Therese Khan became locked-in. For 17 years she could move nothing but her eyelids, yet her mind was intact. She loved life and found the best things to celebrate, cheering all those around her with her positive outlook. She died in NSW, Australia in 2011 aged 52. This song was composed and written by and about her.

10.10am [LiS Howard Wickes \(UK\)](#)

Brief bio; Howard Wicks is 31, is locked-in and comes from Dartmouth, Devon in England. Howard founded and runs a charity called the Locked-in Trust.

Presentation; Howard's presentation offers a brief summary of his life, from childhood to the present day, details of his LiS charity along with his aims for the future.

10.30am [Professor Damien Coyle \(UK\) Advancing EEG-based assessment of consciousness and cognition in prolonged disorders of consciousness and LiS](#)

Brief bio; Damien Coyle is Professor of Neurotechnology, UKRI Turing AI Acceleration Fellow, Director of the Bath Institute for the Augmented Human at the University of Bath, and Professor of Neurotechnology at Ulster University. His research develops advanced artificial intelligence methods for decoding electrophysiological signals and translating them into reliable control signals for brain-computer interface (BCI) systems. His work emphasises scalable clinical translation, including multi-site trials and real-world deployment with patient populations such as spinal cord injury, stroke, disorders of consciousness, Locked-In Syndrome and post-traumatic stress disorder. He is Founder

and CEO of NeuroCONCISE Ltd, an award-winning company developing AI-enabled wearable neurotechnology platforms.

Presentation; The presentation will focus around a major UK multi-site study led by Prof Coyle and published in Communications Medicine, demonstrating how wearable electroencephalograph-based brain-computer interfaces (EEG-BCI) can detect covert awareness and support communication assessment in people with prolonged disorders of consciousness and Locked-In Syndrome. The work shows that many participants with Locked-In Syndrome could intentionally modulate brain activity during motor imagery and question-answering tasks, highlighting the potential of AI-enabled neurotechnology to improve diagnosis, consciousness assessment, and future communication pathways for patients with severe paralysis.

11.00am [Katalin Furedy and her LiS partner, Karesz \(Hungary\)](#)

Brief bio; Katalin Furedy lives in Hungary and worked previously in international studies, financial institution security and fraud prevention, a high-paced, stressful work environment. Her life partner for 23 years, Karesz, suffered a brainstem stroke on 18th April 2025, resulting in LiS. For Katalin and Karesz their relationship meant love, stability, safety, support, warmth, happiness and balance. They lived together 24/7 and, for the past five years, worked on their air conditioning repair business. By choice they had no children. Katalin was by Karesz's side in hospital every day for 7 months, arranging the best available therapy and care for him until his untimely, premature death. Close relatives and friends provide great emotional support during her ongoing, painful grieving process.

Presentation; Katalin will tell us about her life with Karesz and the experiences that they had when he had his stroke and became locked-in. She will provide us with information about the Central-European health care system's handling of LIS people, specifically in Hungary. She is telling Karesz's story as a memorial and a cautionary tale. Through this conference, Katalin also wants to connect further with the LiS community, especially medical and research professionals. She is pleased that this conference takes place annually as it enables people involved in LiS to share experiences, give and take advice and suggest areas of improvement in the field of communication.

11.30am [Fernando Vidal \(Spain\) Legal rights, communicative capacity, and lived experience in the locked-in state](#)

Brief bio: Before moving into medical anthropology, Fernando worked as intellectual historian and received, in 2021, the Carlson Award “in recognition of extraordinary scholarship in the history of the human sciences.” His two most recent academic books are 'Being Brains: Making the Cerebral Subject' and 'Performing Brains on Screen'. As Research Professor of the Catalan Institution for Research and Advanced Studies at the Medical Anthropology Research Center (Rovira i Virgili University, Spain), he coordinates, since 2018, the project “Anthropology and Phenomenology of the Locked-in Syndrome.” His own work in that context focuses on the experiential and ethical dimensions related to the locked-in state.

Presentation: This talk will present the story of two locked-in persons who were declared legally “incapacitated” because of the limitations of their capacity to communicate. It will examine the judges’ assumptions and contrast them with what the perceptions locked-in persons themselves have about their own situation with regard to communication.

12.00pm Feedback and Discussion of morning Presentations

12.15 - 13.00pm Lunch break (approx 45 minutes);

Music composed by Dick van der Heijde

Interview/chat with Bouke & Shannan about the LiS book

Music composed by Helen Flunder (UK)

Brief bio; Helen Flunder; Helen is a musician living in the UK in rural Lincolnshire. She has been playing the piano since she was 4 and still loves it. In 2013 she left primary school teaching in order to focus on her music work. Helen teaches piano and beginner accordion, and does one-off solo or joint gigs and music sessions in care homes for paid work. She writes songs and records them at home as her partner, Brendan Perkins, is a musician and recording wizard. Helen discovered LiS through Dick van Der Heijde, whose music we have just heard. Dick wrote a detailed and positive review of Helen and Brendan's joint Album which gave them a massive boost. Only afterwards did she realise that Dick was living locked-in. She could not believe someone with the immense set of hurdles of LiS had taken time and so much care, listening and responding to their album for the review. Realising the challenges that Dick faced, she reread the review and was incredibly touched that he thought that reviewing her and her partners' work was worth all that effort.

It made Helen realise, yet again, how incredible the human spirit can be, when faced with complex physical, practical and emotional hurdles that appear to stop something being feasible...some amazing humans do not let that be the end. They fight to carry on. In Helen's humble interpretation, Dick is still the same man that he was when LiS changed his life, the same but with many extra layers of 'Incredible' added to him. She also loves the way he is still creating music himself. She wrote the song we are about to hear, 'Free', thinking of him with awe, with massive respect and with the hope that it helps more people hear about and support research into LiS.

13.00pm Welcome back by Hosts (Shannan and Bouke)

13.05pm [LiS Dick van der Heijde \(Netherlands\); music composition and therapy](#)

Presentation: The making of music, and especially composing it, was, for saxophonist and keyboardist Dick van der Heijde, more than a way of life, until he was struck by Locked-In Syndrome in 1991. Dick was 28 years old at the time. In “The Locked In Muzzo” he shows who he was, how he spent more than 32 years on the sidelines, and how, thanks to the wonders of AI, he can once again play a meaningful role.

13.30pm [Jeroen Lansbergen from Focal \(Netherlands\); Assistive Devices](#)

Brief bio; Jeroen Lansbergen is technical advisor/sales consultant at Focal Meditech in Tilburg, the Netherlands. Focal Meditech is a developer, manufacturer and supplier of high-quality healthcare technology.

Presentation; Jeroen will give some information about the custom electric headrest, Papillon, that he created last year for LIS Dick van der Heijde in Kapelle, the Netherlands.

14.00pm [James Brinton \(USA\); Augmentative and Alternative Communication](#)

Brief bio; James Brinton is a licensed speech-language pathologist from Virginia, USA, specialising in augmentative and alternative communication (AAC) and assistive technology. He has over a decade of experience providing communication solutions for individuals with Locked-in Syndrome.

Presentation: James shares practical strategies for maximising communication through AAC tools, with a focus on empowering both individuals and their families. He currently serves as an AAC specialist with NuMotion Speech Solutions, where he helps match individuals with the communication devices that best fit their needs.

14.30pm [Stefan Carmien \(USA\); Communication device](#)

Brief bio: Dr. Stefan Carmien is a retired senior research fellow. He received a Ph.D. in Computer Science with a certificate in Cognitive Science from the University of Colorado. His PhD work was the design of systems for active task support for persons with cognitive disabilities and caregivers. Currently, he focuses on ubiquitous and mobile assistive technologies and context aware systems: studying the socio-technological environment, its context and the human user, deep personal configuration and end-user programming. He is a senior member of the ACM and IEEE societies, is the vice-chair of the RESNA Cognitive accessibility standard committee and a member of ISO 73-wg11. He has contributed 17 peer-reviewed articles, nine book chapters and is the author of two books.

Presentation: While there is much good work on communication with people who are locked-in there seems to be nothing on aiding them to initiate conversations. The prototype Stefan is developing to address this is based on an Arduino processor, an mp3 sound card and a 120v relay with an optical sensor mounted on an eyeglass frame. This has been produced and, in informal testing, works with no type 1 and very few type 2 errors. Stefan will be presenting a 4 minute video demonstrating the prototype.

15.00pm Shannan and Co-host Bouke chair an open discussion session for your feedback, ideas and suggestions. Close of Webinar approx 3.30pm

The day's Presentations will be recorded. The link for the recording will be sent to Registrants as soon as it is ready. The recording link will also be posted on our LiSA Community Forum on Facebook or you can email me to request the link.

New members are always warmly welcome to the [LiSA online Community Forum](https://www.facebook.com/groups/1243149376305687);
<https://www.facebook.com/groups/1243149376305687>

If you have any questions, would like further information or are interested in Presenting at the **6th International LiS Webinar, to be held on Monday 7th June 2027**, please contact the organiser; shannan@brainfoundation.org.au