

EYES SPEAK

Author: Le Thanh Ha



Author's introduction words:

The book "EYES SPEAK" tells the real stories through my experiences while I was working with researchers at Human Machine Interaction Lab, Vietnam National University, Hanoi to find technology solutions to support the ALS patients in Vietnam. Starting from my wish to support my former lecturer who had ALS disease, became paralyzed and could no longer talk, I worked with the team and we developed the computer device and softwares to help ALS patients so that they are able to input Vietnamese language conveniently and speak through their eyes. The device is called BLife - My Beautiful Life.

The book recalls our journey of developing BLife device and supporting ALS patients in Vietnam to "recover their lost voices". The team faced difficulties that seem insurmountable, and obstacles during the development of the device from scratch for the usage of Vietnamese people. The journey is not full of roses but also with thorns. But finally, through our efforts, BLife device became available to the patients and they could use eyes to interact with the computer to "type", to unveil their untold stories after the time of silence and quietness due to the disease.

With the encouragements of ALS patients and colleagues, I have thoroughly collected and written the stories through my observations, ALS patient's shared notes, stories, messages, and memoirs in the hope that the readers of this book could somehow imagine the situations, thoughts, experiences and miseries that the patients have undergone. Have never thought of being a writer, given the chance to work with ALS patients through the BLife project, I feel it is my mission to help tell their stories, so that we can share the empathy and support them better.

Some ALS patients we met reported that, when they found out they had ALS, they fell into a panic state with emotional disturbances and depression, as everyday they have to witness the worsening of the disease while they could do nothing to prevent it. Some even thought of suicide and attempted it. Others sought out expensive experimental treatments on their own but that couldn't help much. Some were willing to use medicines marketed by word of mouth with the idea of "if you have a disease, you have to cure it by all means". Some relied on their faith in spirituality and developed a mindset of a higher realm of self-perception. They try to peacefully accept living with the disease and accept their final challenge of life.

Those with ALS are in a state of extreme tension between life and death, struggling and surrendering, panic and peace, etc. A healthy person could hardly feel it wholly. I hope this book will bring readers the close looks of some portraits and real stories of those poor patients to understand more about their situation. The book also aims to share and motivate any patients who are suffering from the disease. In addition, through this book, I wish to raise the community's awareness and encourage more efforts to support patients with ALS and similar diseases who are living with the disease, struggling, and waiting for a miracle.

LE THANH HA



Reviewers's recommendations about the book:

The book "EYES SPEAK" is a memoir that records the touching stories of unfortunate people who, because of ALS, have lost their voices and their movement ability. Thanks to the BLife system developed by Assoc. Prof. Le Thanh Ha and colleagues at University of Engineering and Technology, Vietnam National University, Hanoi, the patients could communicate through eye movements and "speak" with people.

Prof. Dr. Nguyen Thanh Thuy

– Chairman of the Council for Professor title of Information Technology,
Chairman of Vietnam ICT Club of Faculties, Institutes, Schools and Universities.

The truthful notes with sincere narrations of plain stories made me moved. I respect the author and his young colleagues and appreciate their real, persistent, and humane actions in developing the communication device and supporting ALS patients in Vietnam. These patients are motionless and desperate at the edges of their lives but have deep thoughts about life and death, and pathetic emotions inside.

Assoc. Prof. Dr. Luong Chi Mai

– Former Deputy Director of Institute of Information Technology,
Vietnam Academy of Science and Technology.

"Eyes speak" told touching stories of ALS patients in different stages of disease progression, who, thanks to the BLife device, were able to communicate and connect again with the world around them, hence, they could share their aspirations, thoughts, and also send out their needs of supports, ...

Doctor Nguyen Thi Dung

– Head of Rehabilitation Department, Hanoi French