

HOPE AND REALITY

ALS sufferer's honest memoir gives insights into fatal illness

By Vicki L. Beyer

“Your body will slowly become paralyzed and you will die. There is no cure.” Most of us cannot imagine receiving such news from our doctor. How would we react? Would we accept the news and get on with the business of dying? Would we try to give ourselves some special end to our days, fulfilling the dreams on our bucket list? Or would we just keep living our life for as long as we can?

Hiro Fujita's book, *99% Thank You: Things Even ALS Cannot Take Away*, offers his reflections on how he reacted when, just days before his 31st birthday, his doctor gave him the news that he had amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's Disease.

About 9,000 people in Japan—as well as 20,000 to 30,000 Americans—are afflicted with this chronically debilitating and ultimately fatal illness.

Fujita shocks his readers in the introduction, telling them he is actually using the movement of his eyes to write his words. At this point, three years after being diagnosed, he can move only his eyes and his left index finger. He shares with us his fear that once he loses those functions, he will be completely isolated.

A nurse, although tending to his body during a hospital visit, ignored him as a person, choosing to speak only to his companions; he observes that he has become a “thing.” How much worse it will be if he loses his ability to communicate.

Written in both English and Japanese (neither text is a literal translation of

the other), Fujita calls his book a diary, but that's not quite it. Rather, it's a memoir composed of short vignettes and observations, illustrated with apt photos from Fujita's life, including images of him in his present condition.

The book is divided into chapters that each cover a period of Fujita's life, showing us his childhood, his personality, his lifestyle prior to his diagnosis, and how he lives today. The last chapter is clearly drawn from his popular and successful blog, and has a real time feel (although, frustratingly, some entries don't seem to be in chronological sequence).

The overall style is that of candor, if not brutal honesty. We can see Fujita going through Kübler-Ross's famed stages of grief: anger, denial, bargaining, depression, and acceptance.

He tells us of the loving support of his friends and family, and his concern for his mother, who is looking after him at a time when he feels he should be looking after her. He shares his frustrations at losing various bodily functions, being hooked up to all kinds of tubes to keep him alive, and having less-than-competent nursing caregivers. He shares the sensations of two near-death experiences and tells of the helplessness he felt during the 3/11 earthquake, when he couldn't evacuate his office building without assistance, having been more vulnerable than others at a time when everyone felt vulnerable.

Yet Fujita also tells us how he continues to work as an advertising professional, even going to his office once a week. And he shares his

藤田正裕

99%
ありがとう

ALSにも奪えないもの

99% THANK YOU...

THINGS EVEN ALS CAN'T TAKE AWAY

HIRO FUJITA

ポプラ社

99% Thank You: Things Even ALS Cannot Take Away
By Hiro Fujita
¥1,500

hopes for a cure and his dreams of recovering and playing soccer again someday, notwithstanding his clear understanding of how remote such hopes and dreams truly are.

Perhaps it is this juxtaposition of hope and reality that makes Fujita's book so appealing. While Fujita sets out to raise awareness about ALS (page 15), he achieves much more, giving us insights into the lives of the handicapped, the old, the infirm: anyone incapable of doing for themselves.

We may be no closer to understanding our own potential reactions to news of our mortality, but we can understand this one man's response. It is a rare gift he has given us. •



Vicki L. Beyer is a vice president of the ACCJ.

The ACCJ Journal has one copy of this book to give away. To apply please send an email by January 31 to megan@custom-media.com. The winner will be picked at random.

Hiro Fujita's blog:

<http://blog.honeyee.com/hfujita/>

END ALS Association:

<http://end-als.com>