Involving People With Dementia in Clinical Trials

by

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Support & advocacy of, by & for people with dementia
Good Morning, Budapest!

(Yes, that’s me.)
The Pushme-Pullyou Phenomenon

(Dr. Doolittle, 1967)
Why I volunteer in medical research

1. I have no health insurance.

The lack of health insurance is the sixth leading cause of death in America, ahead of diabetes, respiratory disease, and AIDS.

Critical Condition (2008)
Emotional Investment

When I tried to discuss it with a social worker assigned to the clinical trial, she offered:

“I could, like, just let you vent, or discuss communication problems.”
I BELIEVE...

Clinical trials should inform volunteers about the risks of emotional investment and strategies to help deal with being studied as human subjects.
I ALSO BELIEVE...

Volunteers in clinical trials should be given easy and confidential access to psychologists or psychiatrists prior to, during, and for a brief time after the study.
...because instead of being treated like a human lab rat, we should be treated like every other human on a research team.
People with dementia can and should conduct research on ourselves.
"When the impossibility of replacing a person is realized, it allows the responsibility which a man [or woman] has for his [or her] existence and its continuance to appear in all its magnitude."

– Viktor Frankel

(Meaning comes from the pursuit of more complex things than happiness.)
So, yes, you’re welcome to explore my unique brain...

with me – all of me.
This is quality of Life.

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