

# Workshop 3: Adult life with a rare disease



Hosted by Rebecca together with Adela, Laura, Karin and Fanni-Laura



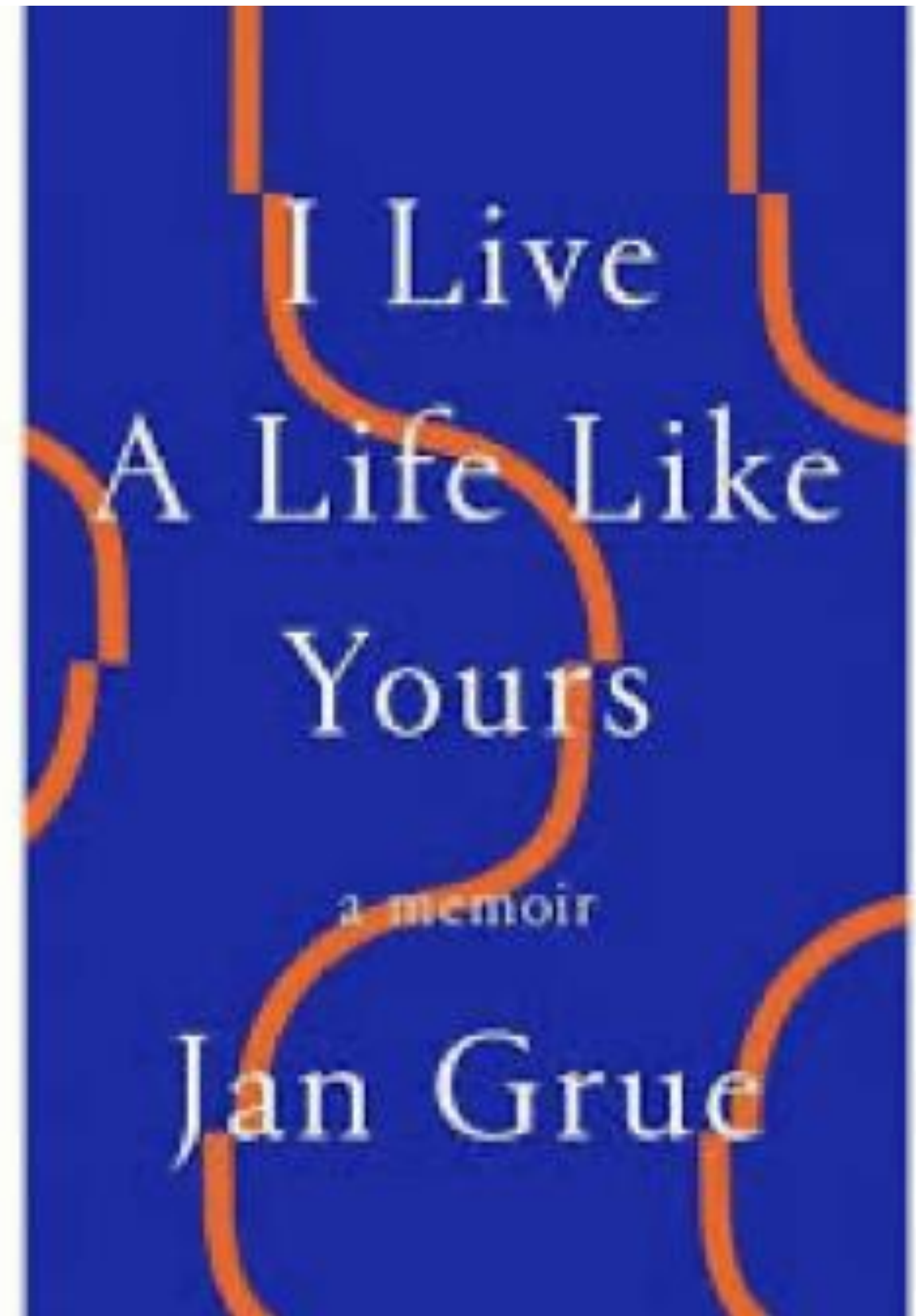
## Structure of the workshop:

- Welcome and brief introductions
- Independent Living
- Employment and housing
- Break (30 min)
- The power of sharing
- Mental health and wellbeing
- Wrap up and closing





**Break (30 min)**



What book is this?  
Find out after the break...

# Workshop 3: Adult life with a rare disease

## Part 2

“Grief,” he writes, “is the recognition that something or someone is gone forever” and this “someone” can be a self or a version of a self. In therapy, he at last admitted: “I want the same thing as everyone else. But I’m not like everyone else.” He finally allowed himself to feel sad and this sadness for what he could not have and “the body that was not” will never go away. “I dream of another world,” he writes and the closest he has come to that world is within his little family, the one “into which I was born and the one I have received as a gift... the one I have created... It is a fiction, it is an empty space in the world. Breathe in.”

*Jan Grue*



# Take home messages...?

What policy would change your life as an adult with rare disease?





# Thank you all for coming!



Disability doesn't make you exceptional, but questioning what you think you know about it does.

— Stella Young —

AZ QUOTES