

Queerying Graphic Medicine

# On the Aesthetic Education of Caregivers

The Specificities of Form and Genre  
in Comics about Dementia Care

Graphic Medicine 2019, 12 July, Brighton, UK



# Project Personnel

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Canada

**Ruhina Rana**, Douglas College,  
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**Peter Wilkins**, Douglas College,  
Canada

**Simon Grennan**, University of  
Chester



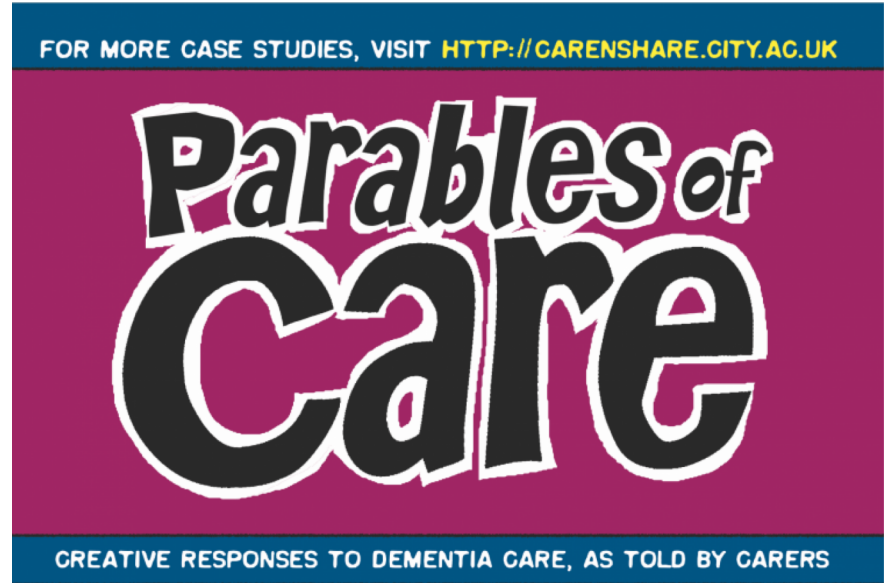
# Querying Dementia: The Parables of Care Project

Dr Ernesto Priego

Centre for Human-Computer  
Interaction Design

City, University of London

@ernestopriego



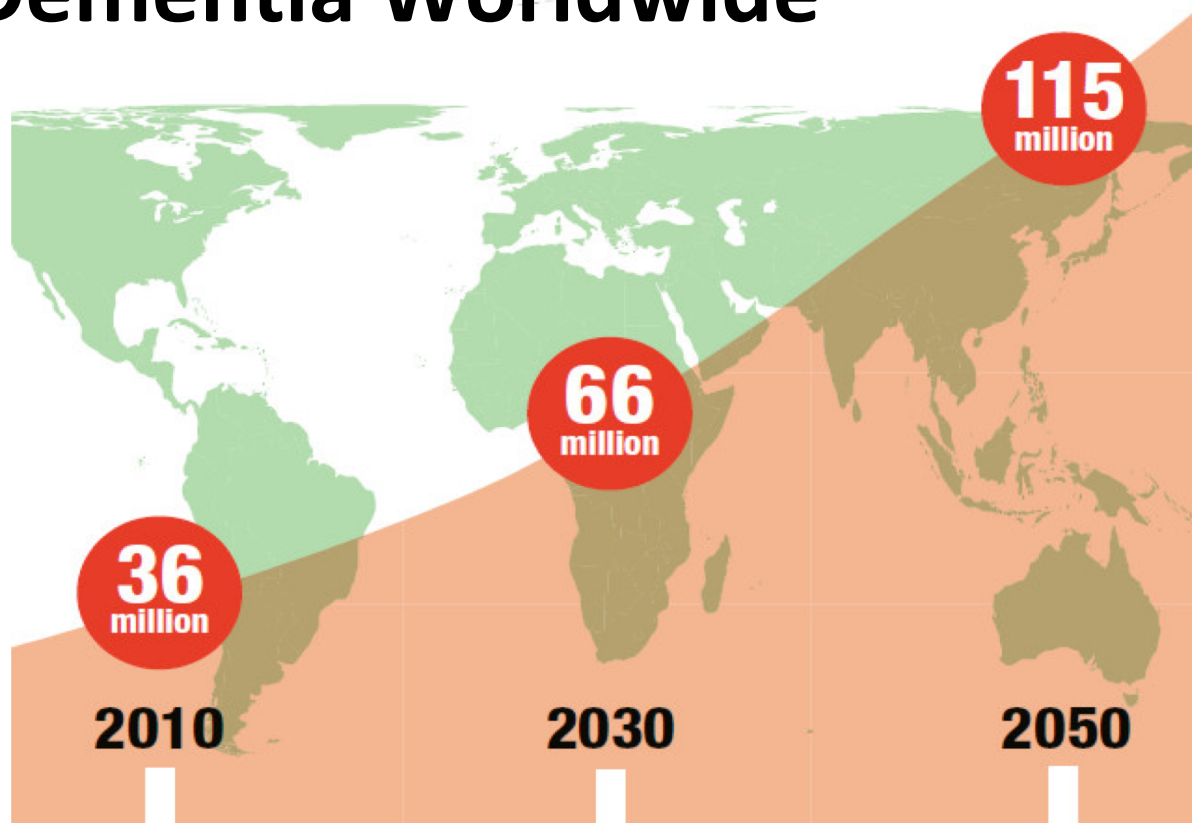
# What is Dementia?

“The term 'dementia' describes a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes.”



(Source: Alzheimer's Society)

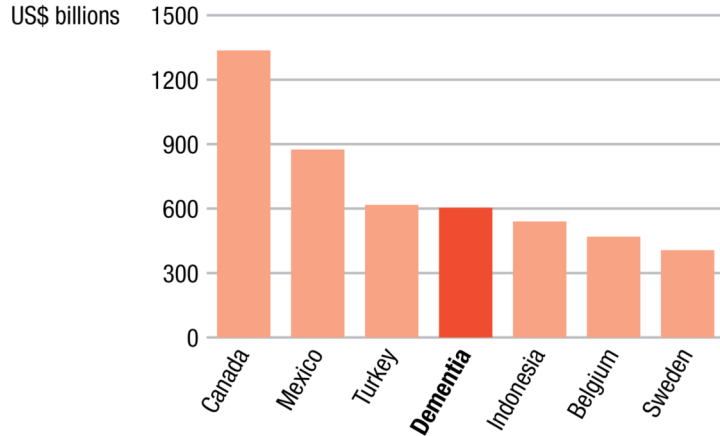
# Dementia Worldwide



(Source: Dr. Jacob Roy Kuriakose, Alzheimer's Disease International)

# Dementia Worldwide

Cost of dementia compared to national economies

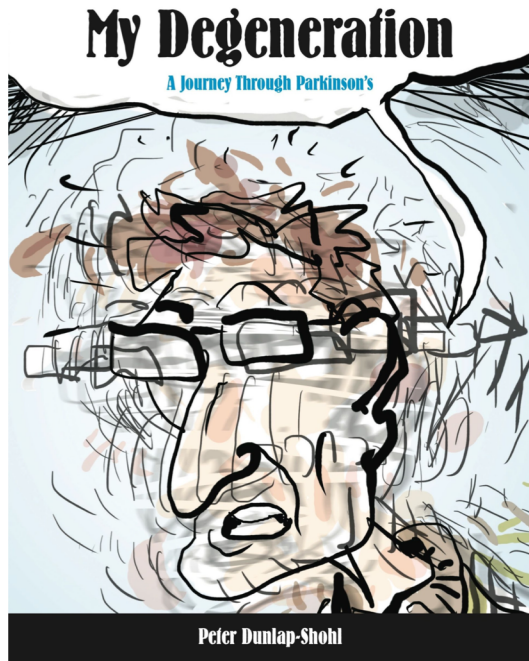


**US\$604 billion in 2010**

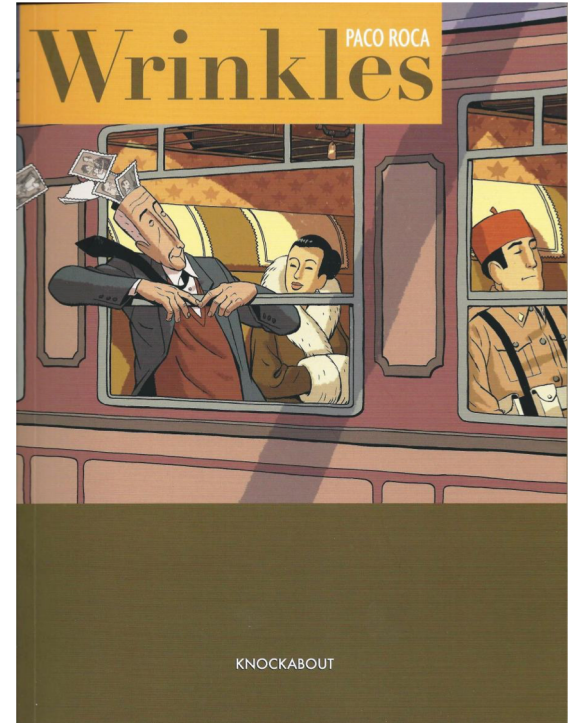
- Includes direct medical costs, direct non-medical costs and costs of informal (family) care

(Source: Dr. Jacob Roy Kuriakose, Alzheimer's Disease International)

# Background

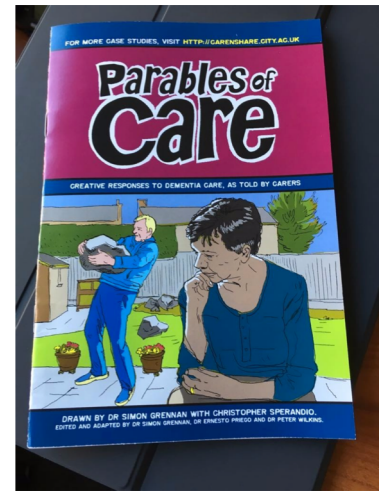


<http://memories.sutueatsflies.com/>



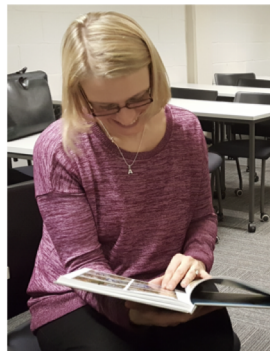
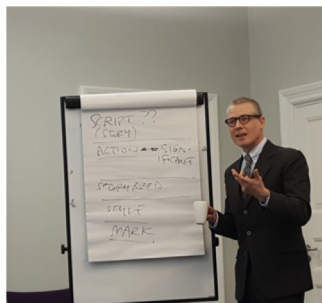
# 16-Page Comic!

- ***Parables of Care*** explores the potential of comics to enhance the impact of dementia care research.
- ***Parables of Care*** was edited and adapted by Dr Simon Grennan (University of Chester) Dr Ernesto Priego (City, University of London) and Dr Peter Wilkins (Douglas College).
- ***Parables of Care*** was drawn by [Dr Simon Grennan](#) [with Christopher Sperandio](#).
- Translations! German, Spanish...





# Connected Projects – User-Centred Design Methods



# Adapting Cases from City's Care N Share App



CITY UNIVERSITY  
LONDON

The Suffolk Brokerage



CareNShare

sharing best practice across the older adult care sector

## In which work setting might this situation be found?

(Choose as many as needed)

- |  |                                       |
|--|---------------------------------------|
| <input type="checkbox"/> Residential/nursing home                  | <input type="checkbox"/> Acute care   |
| <input type="checkbox"/> Live-in care                              | <input type="checkbox"/> Day services |
| <input type="checkbox"/> Domiciliary/hourly care/sheltered housing | <input type="checkbox"/> Other        |

## What is your role?

- |   |  |
|---|--|
| <input type="checkbox"/> Carer/senior carer | <input type="checkbox"/> Housekeeping/Domestic staff   |
| <input type="checkbox"/> Manager            | <input type="checkbox"/> GP                            |
| <input type="checkbox"/> Activities staff   | <input type="checkbox"/> Specialist (eg OP/PT/SALT/SW) |
| <input type="checkbox"/> Catering/kitchen   | <input type="checkbox"/> Other                         |

Enter a suitable name/title for this case

## Please describe the situation

How did this situation make you feel?

carenshare.city.ac.uk/casedetails.php

CareNShare


Back to other matched good care practices

Reflect on how the different people experienced the situation below, and use their care plan to create a care plan for your current situation. You can also use the creative guidance at the bottom of the page to help you.

Alarmed by reflections

Create PDF

The Situation



When my husband James who is living with dementia, saw his reflection in television screens and window glass, he would interpret this as other people. He would get out of his chair, point, wave his arms, glare and shout "Go, gone away!" But if you shout at your reflection what does it do - it shouts back, James would race over to the windows and, still shouting, bang on the glass. I would try and comfort him, saying "there's nobody there" and "there's nothing to worry about," but often he could not be consoled. This case is adapted from And Still The Music Plays by Graham Stokes, pages 66-70

How Different People Experience The Situation

- How the staff member(s) felt
- How the older person might be feeling

Care Plan / Action Plans: Good Practice Examples

- The Environment

So the carers in this case...

- tried to eliminate the chances of this happening by encouraging the resident to be in one of two rooms - a small, cosy lounge and the resident's bedroom - both of which they removed mirrors and TVs from, and kept the curtains drawn when dark. How could you implement this good practice in your care work?

And more generally, have you considered...

- how the older person's personality affects their wants and needs?
- which activities match the older person's interests?

Other considerations

For more learning, these external links might be useful...

- SCIE dementia friendly environments
- Kings Fund: Developing supportive design for people with dementia

Comments

(Contributed comments are moderated by our team before being made public. Click [here](#) to learn more.)

Add comment



End

<http://carenshare.city.ac.uk/>



# Parables

- Ambiguity – General Applicability

- Analogy with many situations



# Yonkoma as form

## Plan A: Funny Faces



**KAPOW!**



More on our public impact at

<https://blogs.city.ac.uk/parablesofcare/readers-on-parables-of-care/>

# Co-designing for Aphasia

## Poetry as Form – Insights from a Sibling Project

Dr Abi Roper

INCA Project, Centre for Human-  
Computer Interaction Design

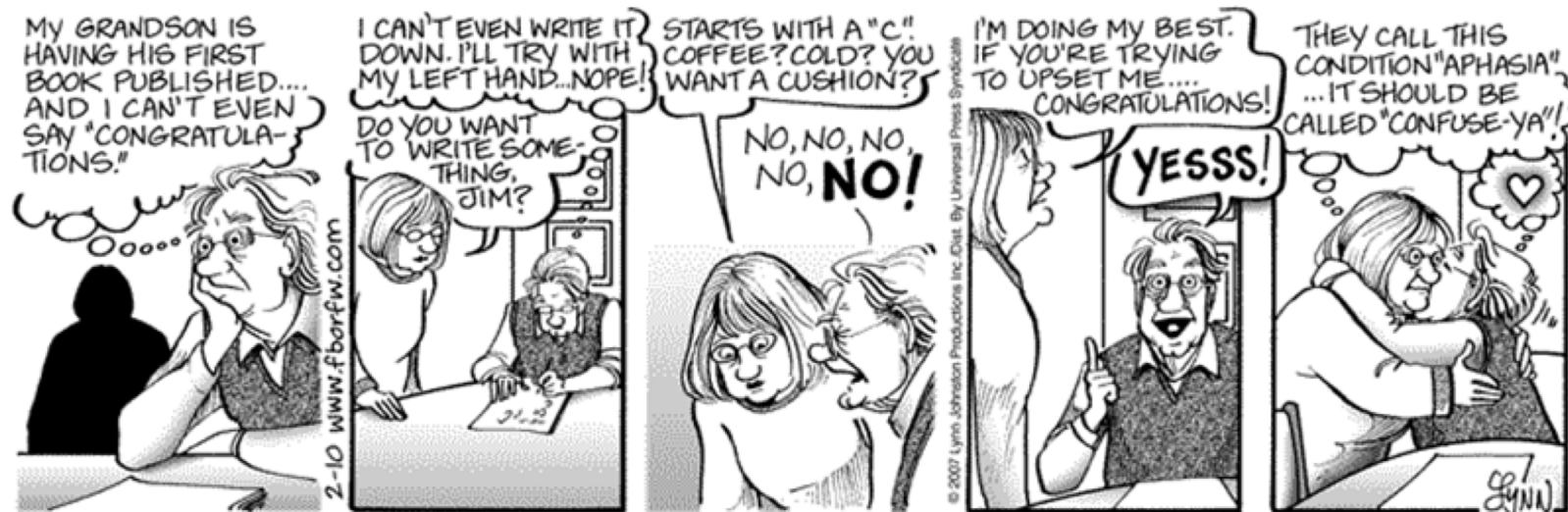
City, University of London

@abracabadger

@incaproject

soundless town with veils of  
white lace  
i shall silk in a space

# Aphasia



Grandpa Jim. From the storyline "Jim's Stroke"

Image reproduced with permission of Lynn Johnston and Entercom Canada Inc

Available at: [https://fborfw.com/stripe\\_fix/saturday-february-10-2007/](https://fborfw.com/stripe_fix/saturday-february-10-2007/)

# Aphasia





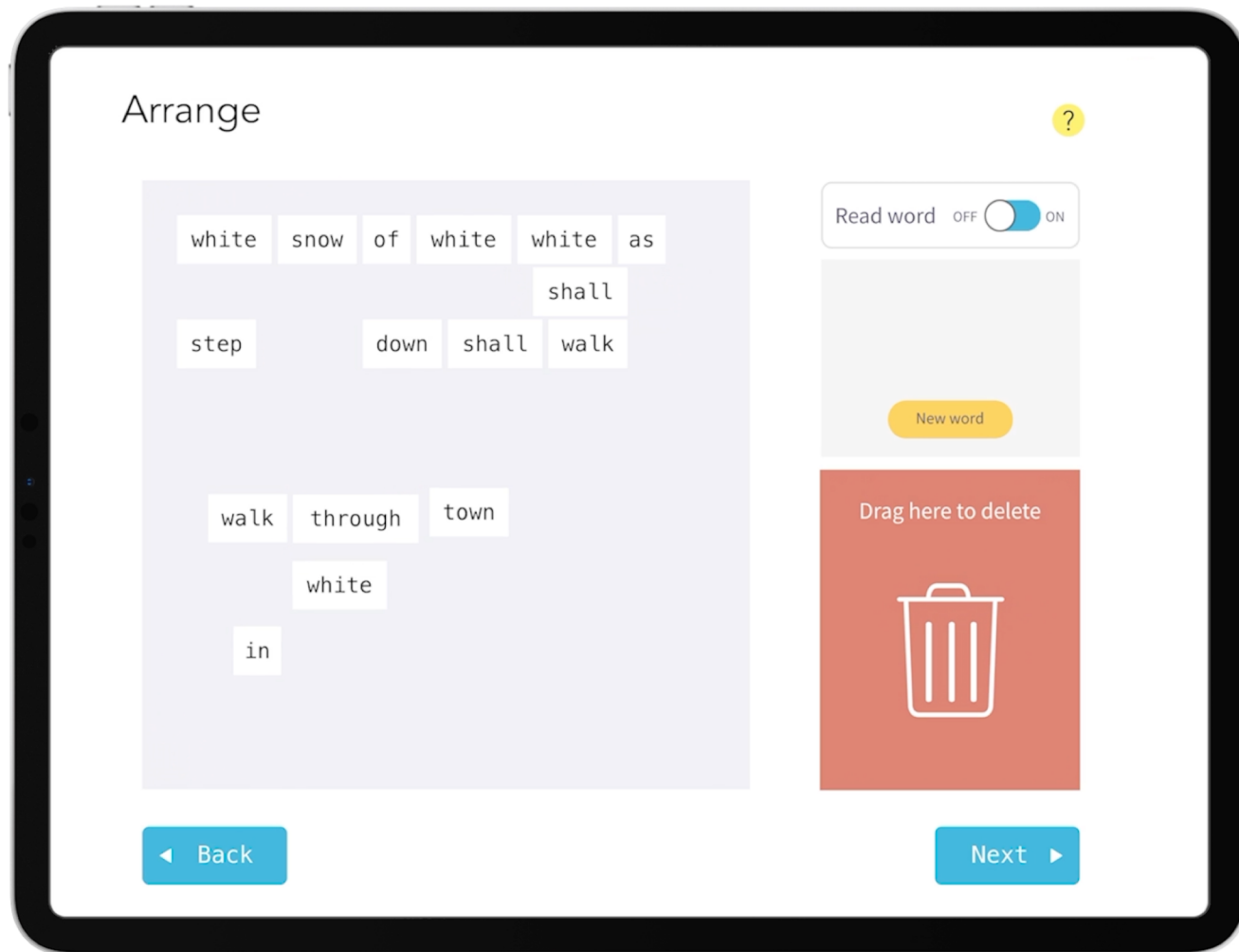


Aphasia

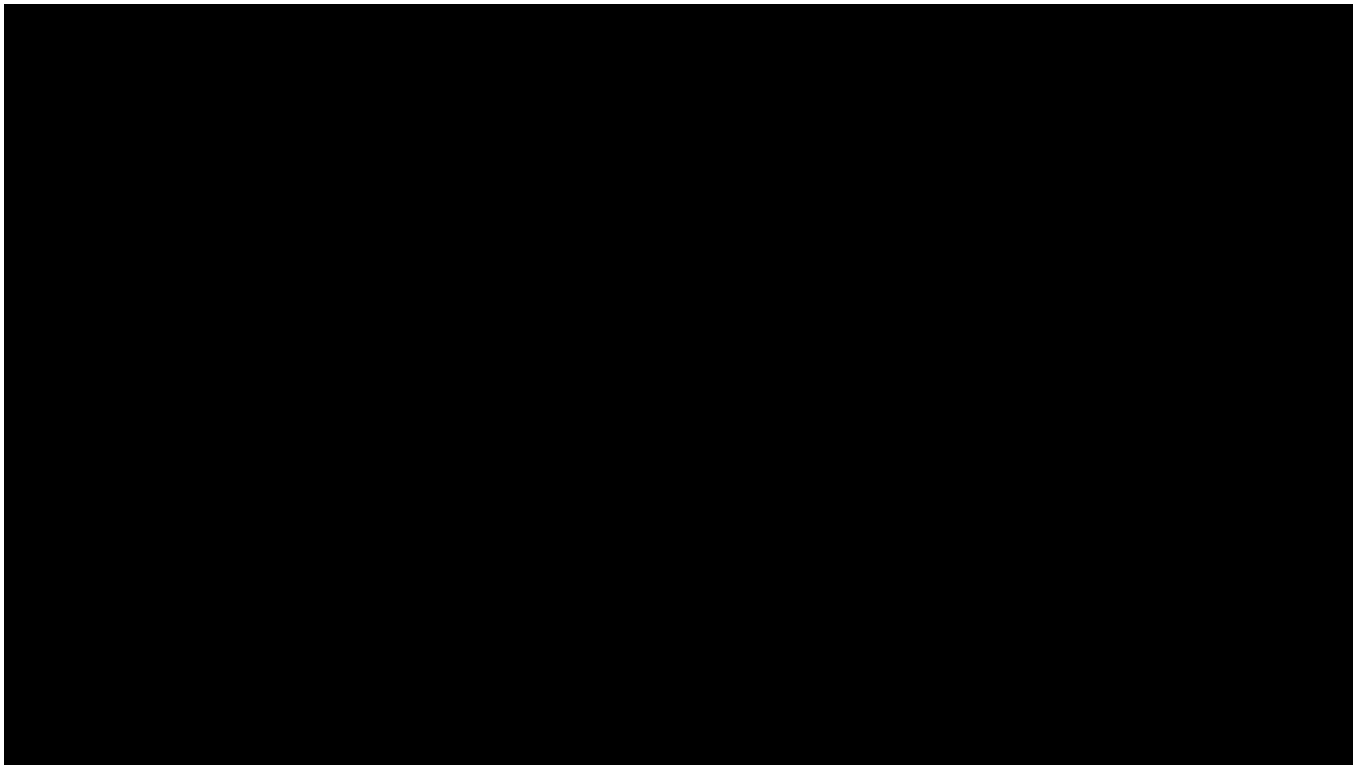
Co-Design



# MakeWrite App







Aphasia  
Re-Connect

# Comics and Health Literacy; The Douglas College Dementia Comics Project

Marie-Pier Caron  
Nursing Faculty  
Douglas Project, Canada  
@mpcmpc



Art by Melissa Martins



**21**

Around **50 million**  
people have  
dementia worldwide



Nearly **10 million**  
new cases every  
year – one every 3  
seconds

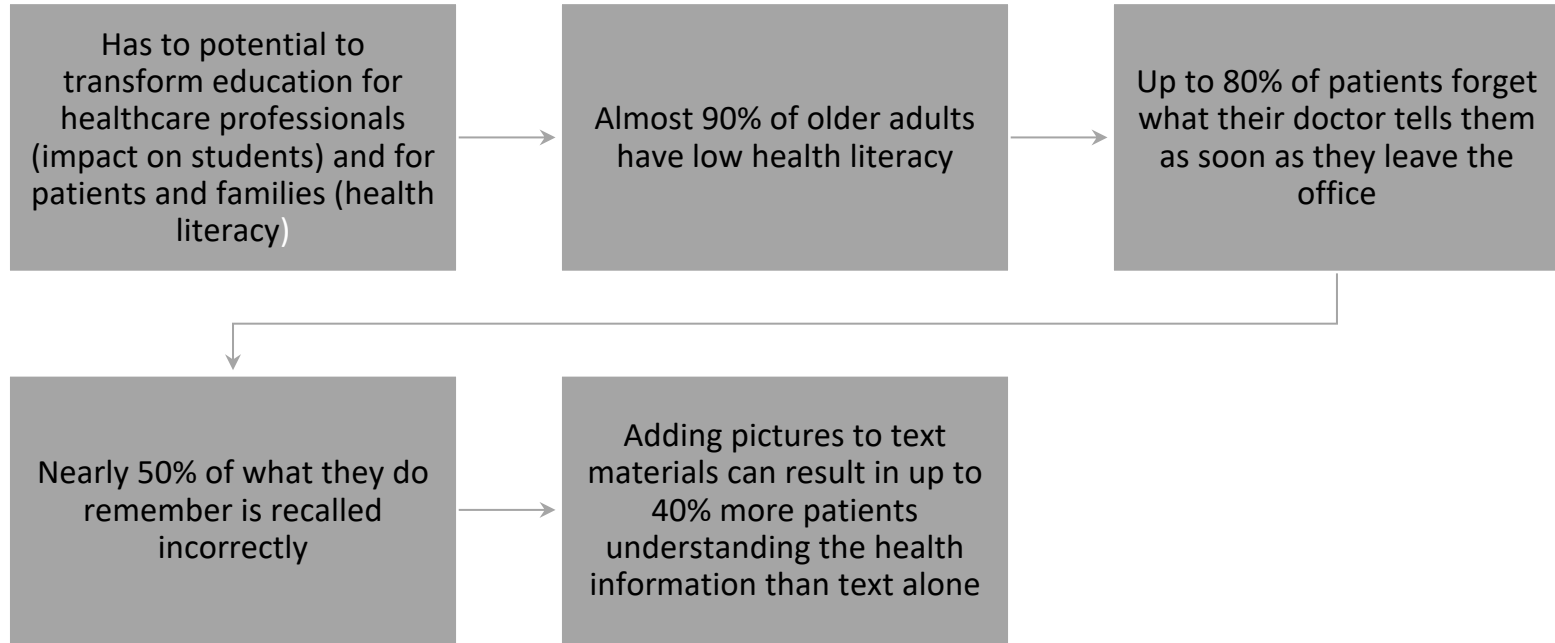


Dementia cost: **\$818 billion** - The majority  
of care is provided  
by family carers.

My Mom is Not Alone!

# WHO – Global Action Plan on the Public Health Response to Dementia

- Enhance dementia research and interventions
- Influence government policy-making
- Improve service delivery and risk reduction
  - Parables of Care is used in our nursing curriculum – **training tool**
- Build our capacity by:
  - Participating in training programmes on dementia, including programmes aimed at **identifying and reducing carer stress and burnout.**



## Graphic Medicine in Nursing Education

In the US, 60% of all Alzheimer's caregivers are women

At the age of 65, women have a 1 in 6 chance of developing Alzheimer's, compared to a 1 in 11 chance for men

In Australia, nearly 2/3 of all dementia-related deaths were women; in the US, 2/3 of those living with the disease are women

In England and Wales as well as in Australia, dementia has become the leading cause of death for women

## Gender and Dementia

# **Emotional Labour of Care; The Douglas College Dementia Comics Project**

Ruhina Rana  
Nursing Faculty  
Douglas Project, Canada



Art by Melissa Martins



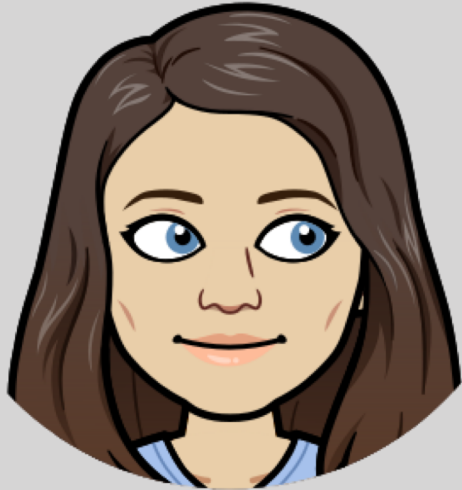
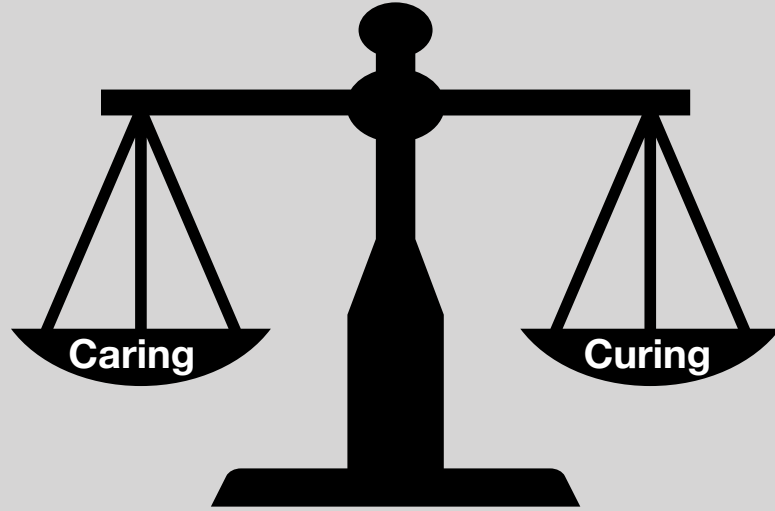
# Graphic Healthcare?

**Nurses in Canada prefer “Graphic Healthcare” over “Graphic Medicine” because as nurses we are separate and distinct from medicine**



Avatar created by Bitmoji

# Nursing vs Medicine



It's all about the  
relationship!

# Why this is Graphic Art Important in Dementia Care?

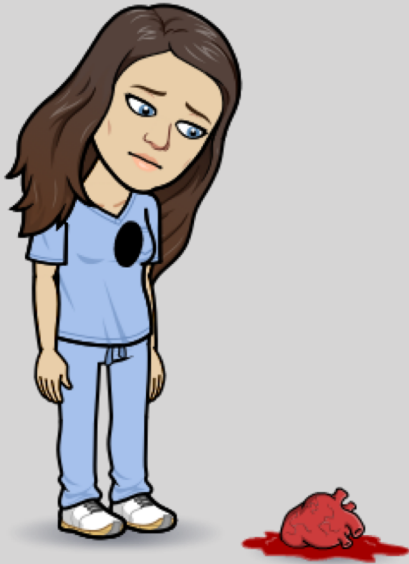
Development of shared language & experiences to regain control over dementia, rather than it overwhelming and controlling us



# Emotional Labour of Caregiving

**Caring for someone with  
Dementia can take an emotional  
toll.**

**How do we prepare healthcare  
providers and family members for  
this?**



# Transforming Healthcare & Education



- **Sharing narratives through art so that the affective domain can be explored in-depth.**
- **Not a how-to manual, rather a way to share the emotional labour of caring for people with dementia.**
- **The outcome is to ensure that caregivers understand the complex experience of dementia care and to know they are not alone.**

# **From Parables to Tragedy: Genre and Dementia. The Douglas College Dementia Comics Project**

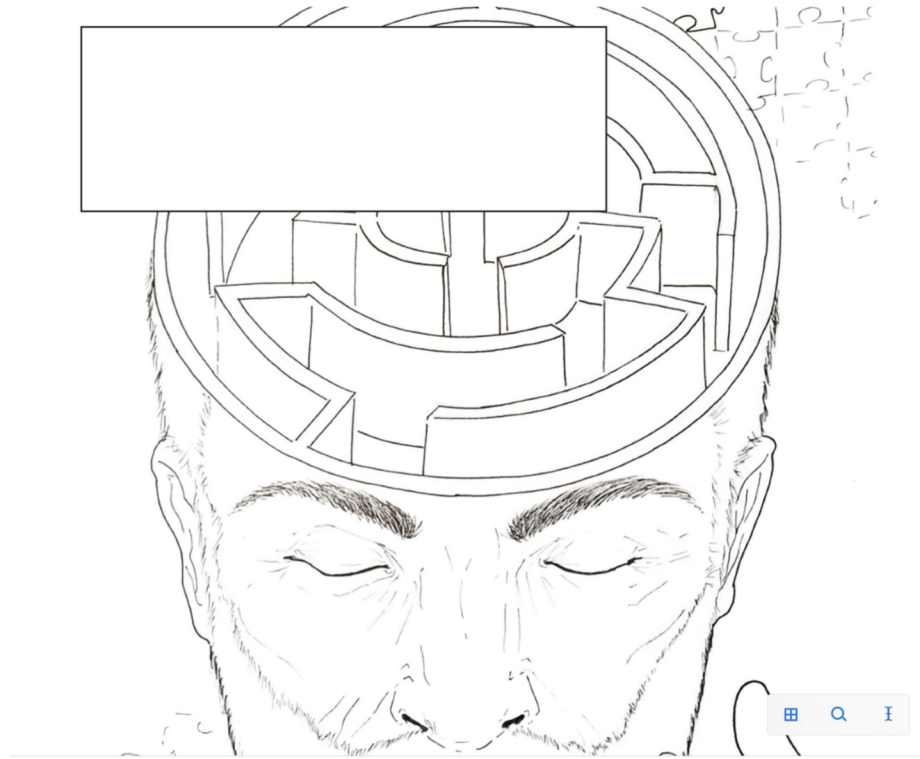
Dr Peter Wilkins  
Douglas Project, Canada



Art by Melissa Martins

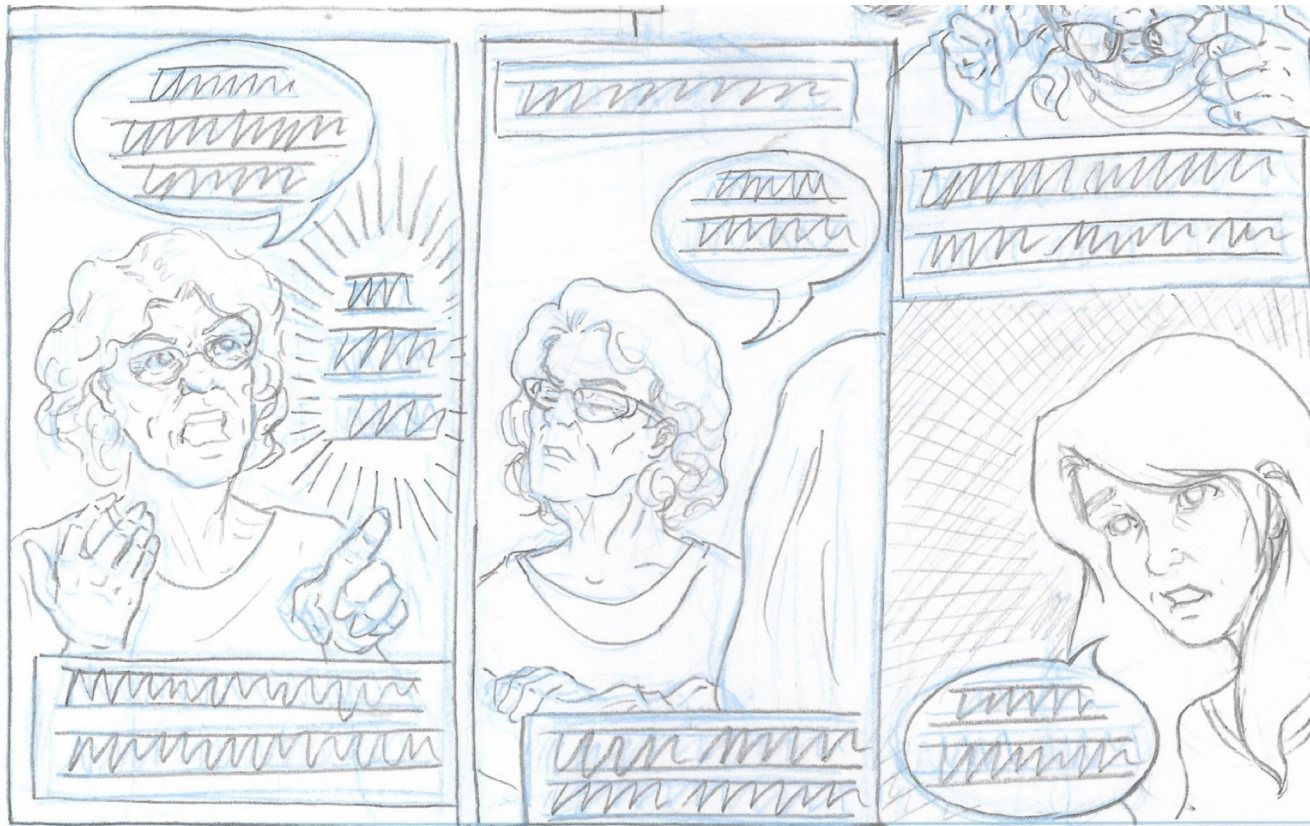


# Greek Tragedy



Prologue/Epilogue



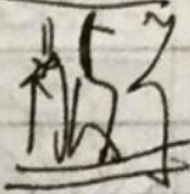


Episodes

WHEN FAMILY VISITS FOR  
THE HOLIDAYS THEY ASK LOTS  
OF QUESTIONS |

IS SHE  
EATING?

WHAT  
DID  
THE  
DOCTOR  
SAY?



\*CHORUS



Chorus



# From Why Comics? to What Comics?



Sketches from an interview from the Douglas College Dementia Comics Project. Art by Peter Wilkins

# Panel Discussion!