

ambiguity, empathy and narrative co-design:

The User Experience of Reading Dementia Care Comics

Dr Simon Grennan, Dr Ernesto Priego, Dr Peter Wilkins

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Parables of Care

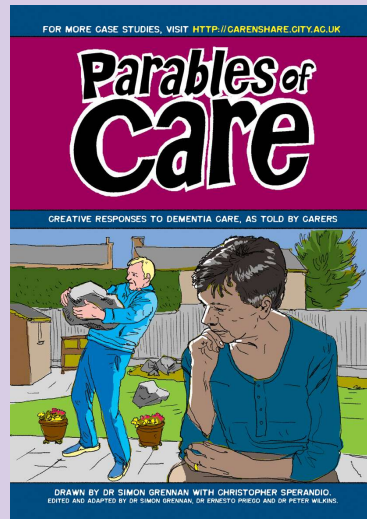
I Know how this ends

Workshop slides

Covid comic

Drawing Activity

references



FOR MORE CASE STUDIES, VISIT [HTTP://CARENSARE.CITY.AC.UK](http://carensare.city.ac.uk)

Parables of Care

CREATIVE RESPONSES TO DEMENTIA CARE, AS TOLD BY CARERS

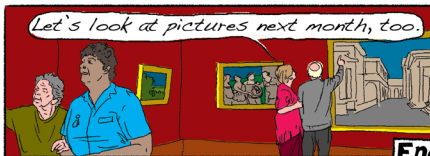
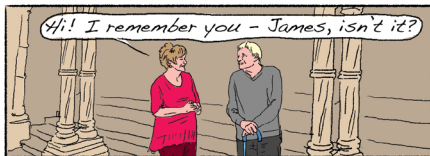


DRAWN BY DR SIMON GRENNAN WITH CHRISTOPHER SPERANDIO.
EDITED AND ADAPTED BY DR SIMON GRENNAN, DR ERNESTO PRIEGO AND DR PETER WILKINS.

Deceptive Appearance



Art Outside The Home



End

Unaccompanied

I'm gonna go out by myself. I can do that!

Well, yes, but there's a challenge...



How about this, for a plan? We'll...



I'm ready for my push back up the hill now, please.



End

At Home



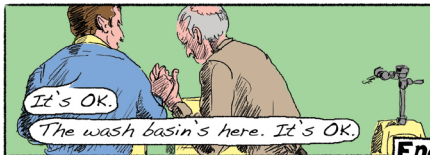
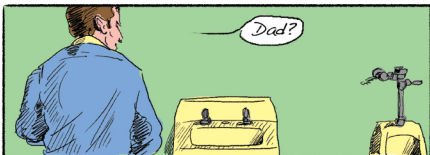
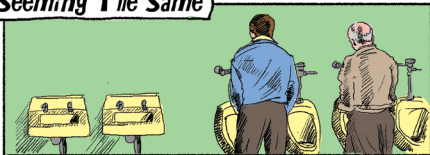
End

"Going to Work"



End

Seeming The Same



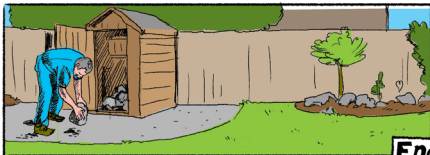
End

Moving Furniture



End

Gathering Rocks



End

G. P. S.



End

Lost Children



End

Lost Children



End

Sandra's Desk



End

A Civil Barber



Shouted at Reflections



End

FOR MORE CASE STUDIES, VISIT [HTTP://CARENSHARE.CITY.AC.UK](http://carenshare.city.ac.uk)



CREATIVE RESPONSES TO DEMENTIA CARE, AS TOLD BY CARERS

CREATIVITY, EMOTIONAL INTELLIGENCE AND COMMON SENSE ARE AMPLY SHOWN IN THESE 14 TOUCHING AND INFORMATIVE STORIES.

PARABLES OF CARE PRESENTS TRUE STORIES OF CREATIVE RESPONSES TO DEMENTIA CARE, TOLD BY CARERS, TAKEN FROM A GROUP OF OVER 100 CASE STUDIES AVAILABLE AT [HTTP://CARENSHARE.CITY.AC.UK](http://carenshare.city.ac.uk)

IT IS A PROJECT OF THE CENTRE FOR HUMAN COMPUTER INTERACTION DESIGN, CITY, UNIVERSITY OF LONDON; THE UNIVERSITY OF CHESTER, UK, AND DOUGLAS COLLEGE, VANCOUVER, CANADA.

THANKS TO NEIL MAIDEN AND ALL THE CARE'N'SHARE TEAM; DR JON BIRD, DR DYPNA O'SULLIVAN AND EVERYONE AT THE CENTRE FOR HCID, CITY, UNIVERSITY OF LONDON, UK; ANTHONY FARTHING, TAVISTOCK AND PORTMAN NHS FOUNDATION TRUST, UK; ENRIQUE DEL REY, UNIVERSITY OF OXFORD, AND EVERYONE WHO CONTRIBUTED TO THE WORKSHOPS; DR DAMON HERD, DUNDEE COMICS CREATIVE SPACE, UK; THE FACULTY OF HEALTH SCIENCES AT DOUGLAS COLLEGE, VANCOUVER, CANADA, PARTICULARLY RUHINA RANA AND MARIE-PIER CARON OF THE BACHELOR OF SCIENCE NURSING PROGRAM; NEIL GRANT AND THE CARE'N'SHARE STORY-TELLERS. DOWNLOAD THIS BOOK AT [HTTP://OPENACCESS.CITY.AC.UK](http://openaccess.city.ac.uk)

ISBN: 978-1-5272-1200-8

THE MCSE SCHOOL IMPACT FUND 2017. CITY, UNIVERSITY OF LONDON.



DRAWN BY DR SIMON GRENNAN WITH CHRISTOPHER SPERANDIO.
EDITED AND ADAPTED BY DR SIMON GRENNAN, DR ERNESTO PRIEGO AND DR PETER WILKINS 2017.

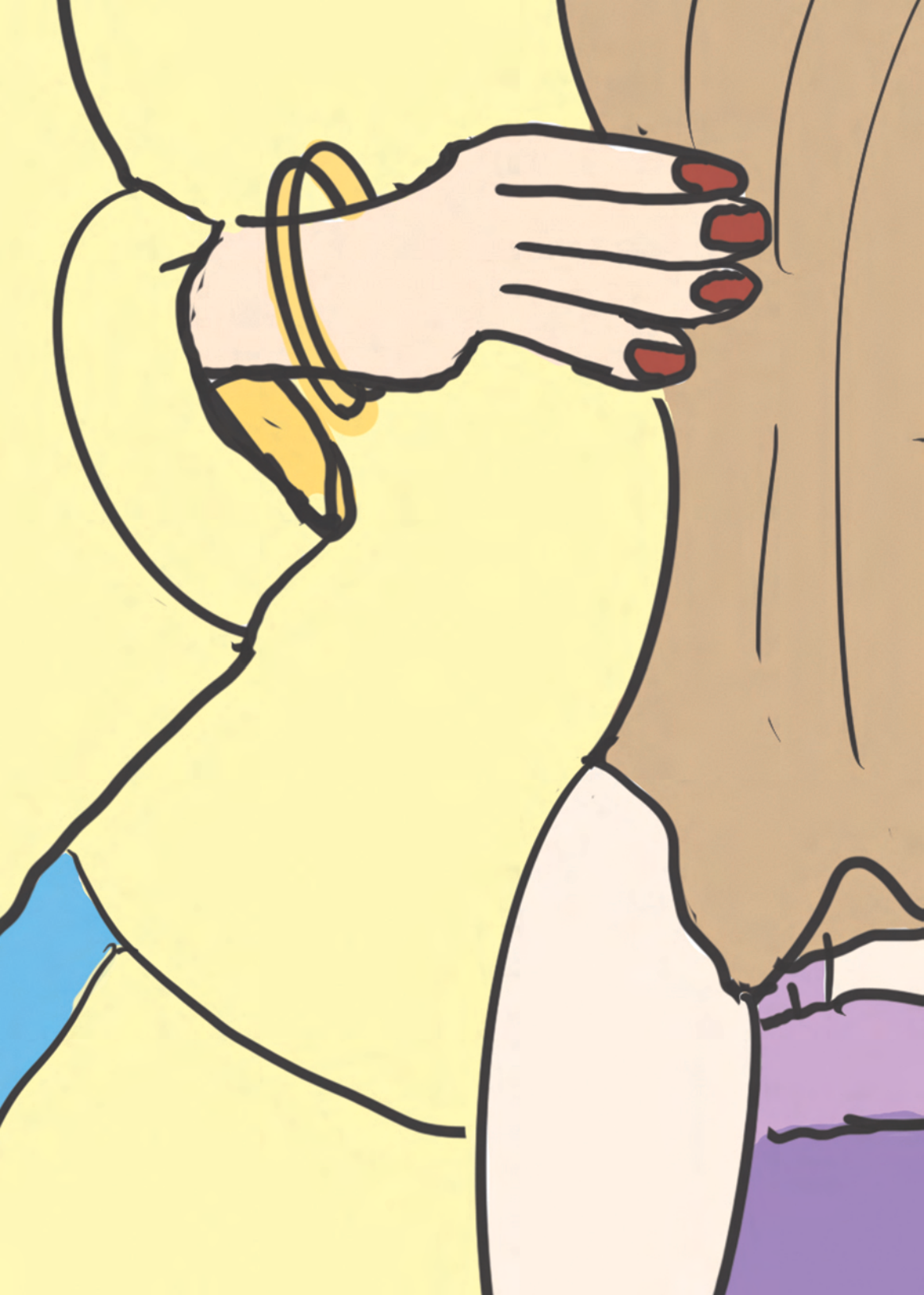
PARABLES OF CARE PRESENTS:

I KNOW HOW THIS ENDS



I KNOW HOW THIS ENDS: STORIES OF DEMENTIA CARE.

ART BY DR PETER WILKINS AND MELISSA MARTINS. STORY ADAPTED BY DR PETER WILKINS.
BOOK DESIGN BY DR SIMON GRENNAN. EDITED BY DR ERNESTO PRIEGO. 2020.



FOREWORD

I KNOW HOW THIS ENDS IS THE SECOND VOLUME IN A SERIES THAT STARTED WITH **PARABLES OF CARE: CREATIVE RESPONSES TO DEMENTIA CARE** (2017). THE PROJECT EXPLORES THE POTENTIAL OF COMICS TO ENHANCE THE IMPACT OF DEMENTIA CARE RESEARCH. THE COMICS RESULTING FROM THE PROJECT ARE AVAILABLE IN PRINTED AND DIGITAL FORM AT NO COST, AS OPEN ACCESS RESOURCES.¹

DEMENTIA IS A SYNDROME IN WHICH THERE IS DETERIORATION OF THE ABILITY TO PROCESS THOUGHT AND THEREFORE TO PERFORM EVERYDAY ACTIVITIES. IT AFFECTS MEMORY, THINKING, ORIENTATION, COMPREHENSION, CALCULATION, LEARNING CAPACITY, LANGUAGE, AND JUDGEMENT. IT MAINLY AFFECTS OLDER PEOPLE, BUT IT IS NOT A NORMAL PART OF AGEING. ACCORDING TO THE LATEST FIGURES FROM THE WORLD HEALTH ORGANIZATION, AROUND 50 MILLION PEOPLE HAVE DEMENTIA WORLDWIDE, WITH NEARLY 10 MILLION NEW CASES OCCURRING EACH YEAR. BETWEEN 5-8% OF PEOPLE AGED 60 AND OVER HAVE DEMENTIA AT ANY GIVEN TIME. BY 2030, 82 MILLION PEOPLE ARE ANTICIPATED TO HAVE DEMENTIA AND 152 MILLION BY 2050.²

I KNOW HOW THIS ENDS IS A COMIC BOOK THAT PRESENTS, IN SYNTHESISED FORM, STORIES CRAFTED FROM NARRATIVE DATA COLLECTED VIA INTERVIEWS WITH PROFESSIONAL CAREGIVERS, EDUCATORS, AND STAFF AT DOUGLAS COLLEGE IN VANCOUVER, CANADA, WHO HAVE CARED FOR RELATIVES AND PEOPLE WITH DEMENTIA IN HOSPITAL. THE COMIC IS STRUCTURED LIKE A CLASSICAL GREEK TRAGEDY – WITH A PROLOGUE, THREE EPISODES, AND AN EPILOGUE – BECAUSE THE STORIES WE WORKED WITH HAD THE ELEMENTS OF TRAGEDY: INEVITABILITY, STRATAGEMS TO AVOID FATE THAT MERELY BRING IT ON, AND CATHARSIS OF NEGATIVE EMOTIONS. THE INTENTION OF THE BOOK IS TO SHOW THE IMPORTANCE OF FEELING IN CARE-GIVING, THE PROFESSIONAL ASPECTS OF WHICH ARE SOMETIMES AT ODDS WITH THE FAMILY SYSTEMS ASPECT OF DEMENTIA.

¹ Both comics can be found and downloaded via:
City Res City Research Online, City, University of London:
<http://openaccess.city.ac.uk>
ChesterRep, University of Chester: <http://chesterrep.openrepository.com>
DOOR, Douglas College: <http://dc.arcabc.ca>
CORE, Humanities Commons: <https://hcommons.org>
To request print comics, please visit: <https://blogs.city.ac.uk/parablesofcare>

² World Health Organization, Dementia Key Facts
<https://www.who.int/news-room/fact-sheets/detail/dementia> [accessed 6 February 2020].

BOTH [PARABLES OF CARE](#) AND [I KNOW HOW THIS ENDS](#) ARE ATTEMPTS TO THINK ABOUT THE CONCEPT OF GRAPHIC MEDICINE AS DEVELOPED BY IAN WILLIAMS, MK CZERWIEC AND OTHERS.³

[I KNOW HOW THIS ENDS](#) CONTEMPLATES THE INTERSECTION OF THE REPRESENTATION OF MEDICAL PHENOMENA IN COMICS, WITH VARIOUS COMICS FORMS AND LITERARY GENRES, IN AN EFFORT TO FIND A FIT FOR STORIES ABOUT DEMENTIA. THIS WORK IS PRELIMINARY, AND WE ANTICIPATE FURTHER EXPERIMENTS AND COMMENTARY THAT FLESH OUT HOW COMICS CAN BEST DEPICT STORIES ABOUT DEMENTIA AND DEMENTIA CARE.

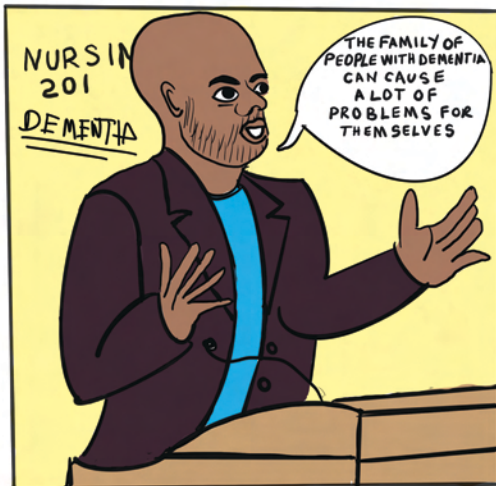
IF YOU WOULD LIKE TO SHARE YOUR FEEDBACK ON THIS COMIC, WOULD LIKE TO ORDER SOME MORE FREE COPIES OR WOULD LIKE TO FIND OUT MORE ABOUT THE PROJECT PLEASE VISIT

[HTTPS://BLOGS.CITY.AC.UK \[PARABLESOF CARE\]\(#\)](https://blogs.city.ac.uk/parablesforcare) WHERE YOU CAN GET IN TOUCH WITH US AND ACCESS MORE RESOURCES.

WE WILL BE VERY HAPPY TO HEAR FROM YOU.

3 <https://www.graphicmedicine.org/why-graphic-medicine>

PROLOGUE



EPISODE #1

THEY LOVED HER AT THE DINER



THEY DIDN'T SEE HER SHIFT OUT OF REALITY



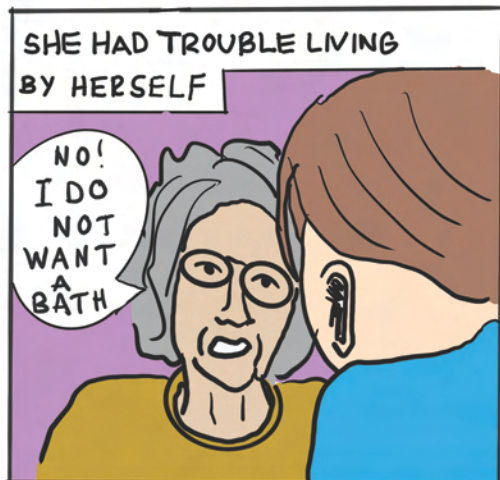
LIKE I DID



OR GET ANGRY



SHE HAD TROUBLE LIVING BY HERSELF



SHE STOPPED WASHING HERSELF AND HER CLOTHES



I GOT FRUSTRATED BECAUSE
I'D SEEN IT



I KNOW HOW THIS ENDS



WHEN FAMILY VISITED FOR HOLIDAYS,
THEY ASKED LOTS OF QUESTIONS



BUT THEY DIDN'T HELP



THEY WERE IN DENIAL



THEY STILL SAW HER AS SHE WAS



EPISODE #2

TO GET HER INTO A HOME, I HAD TO



WHEN I WAS GROWING UP, SHE TOLD ME LYING WAS THE WORST THING



BUT THIS IS BEST FOR EVERYONE



THE MORE EXPERIENCED CAREAIDES ARE RUTHLESSLY EFFICIENT



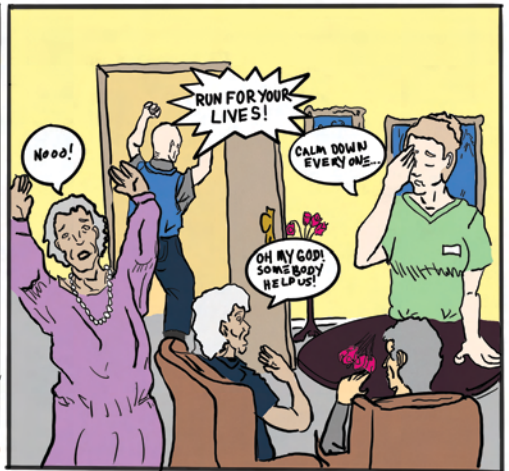
THE NEWER ONES ARE INDULGENT, EMPATHETIC AND IMAGINATIVE



I NEVER HAD SUCH PATIENCE. I WANTED HER OUT OF IT



THE CARE AIDS MADE IT ALMOST FUN



I'M NOT SURE HOW THEY STAY WELL



I'M VERY GRATEFUL TO THEM

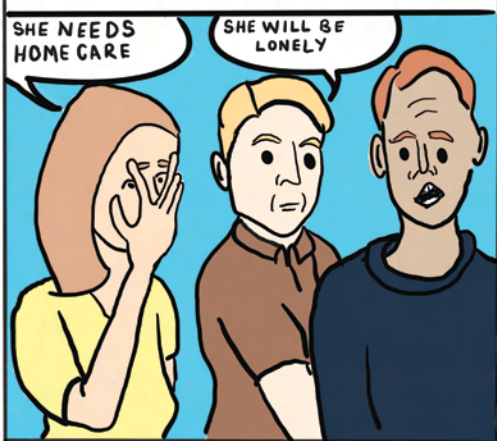


EPISODE #3

I FELT GUILTY PUTTING HER IN THE HOME



THE BROTHERS AND SISTERS DIDN'T LIKE IT



BUT IT MADE LIFE EASIER



EXCEPT ON VISITING DAY



SOMETIMES SHE DIDN'T



SOMETIMES I COULDN'T TELL



THEN ONE DAY IT WAS OVER



IT'S CHANGED THE WAY I TEACH



AND THE WAY I PRACTICE



THE STUDENTS NEED TO KNOW



WHAT THE DEMENTIA LABYRINTH IS LIKE



EPILOGUE

A FAMILY MEMBER WITH DEMENTIA
TESTS OUR OWN RATIONALITY.
WE QUESTION OURSELVES.

ARE WE
PERCEIVING
REALITY
CORRECTLY?

IT ALSO
CHALLENGES
OUR ETHICS.

TO KEEP THE
FAMILY MEMBER
SAFE WE
DECEIVE AND
RESTRAIN
A FIGURE OF
AUTHORITY IN
OUR LIVES.

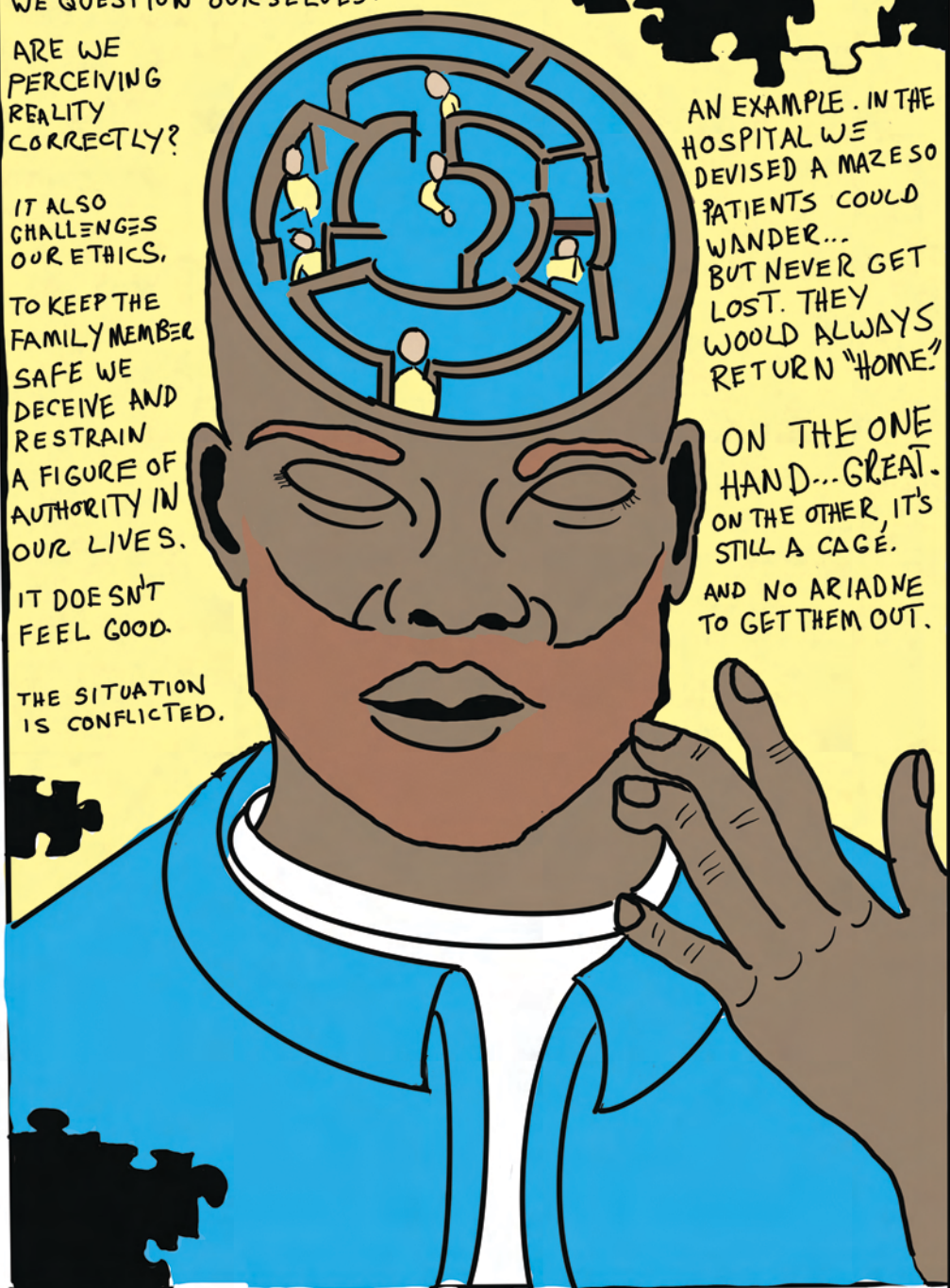
IT DOESN'T
FEEL GOOD.

THE SITUATION
IS CONFLICTED.

AN EXAMPLE. IN THE
HOSPITAL WE
DEvised A MAZE SO
PATIENTS COULD
WANDER...
BUT NEVER GET
LOST. THEY
WOULD ALWAYS
RETURN "HOME."

ON THE ONE
HAND... GREAT.
ON THE OTHER, IT'S
STILL A CAGE.

AND NO ARIADNE
TO GET THEM OUT.



I KNOW HOW THIS ENDS

**ART BY DR PETER WILKINS AND MELISSA MARTINS
STORY ADAPTED BY DR PETER WILKINS
BOOK DESIGN BY DR SIMON GRENNAN
EDITED BY DR ERNESTO PRIEGO**

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I KNOW HOW THIS ENDS WAS MADE POSSIBLE BY A RESEARCH INCENTIVE GRANT FROM DOUGLAS COLLEGE AND IS PART OF THE **PARABLES OF CARE** PROJECT, DEVELOPED BY FACULTY FROM THE CENTRE FOR HUMAN-COMPUTER INTERACTION DESIGN, CITY, UNIVERSITY OF LONDON, DOUGLAS COLLEGE AND THE UNIVERSITY OF CHESTER. **PARABLES OF CARE** PROJECT LEAD: DR ERNESTO PRIEGO.

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PARABLES OF CARE PRESENTS: I KNOW HOW THIS ENDS

AROUND 50 MILLION PEOPLE HAVE DEMENTIA WORLDWIDE. BETWEEN 5-8% OF PEOPLE AGED 60 AND OVER HAVE DEMENTIA AT ANY GIVEN TIME. BY 2030, 82 MILLION PEOPLE ARE ANTICIPATED TO HAVE DEMENTIA. **I KNOW HOW THIS ENDS** EXPLORES WAYS OF REPRESENTING DEMENTIA CARE AND DEPICTING THE STORIES OF CARE-GIVERS. IT INTERROGATES GENRE AND FORM, ATTEMPTING TO APPROACH THE EMOTIONAL COMPLEXITY OF DEMENTIA.



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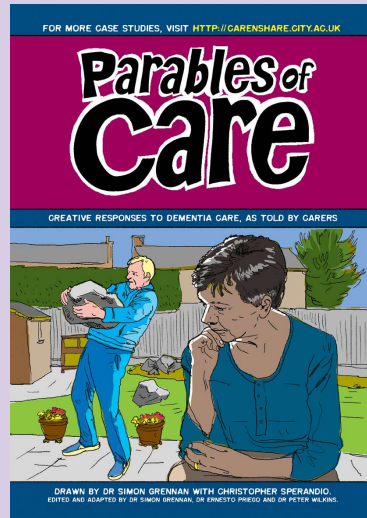
<https://blogs.city.ac.uk/parablesofcare>

ambiguity, empathy and narrative co-design: The User Experience of Reading Dementia Care Comics

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ambiguity

How do you think ambiguity is differently afforded to readers in visual and verbal media? Why is this significant?



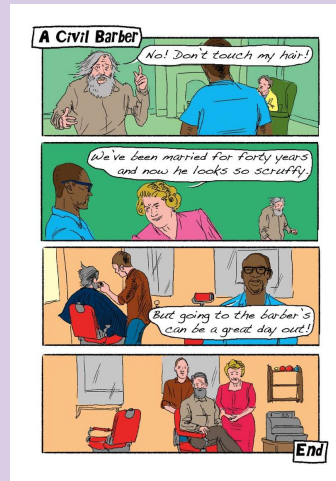
empathy

is there such a thing as too much empathy or problematic empathy when depicting illness? I.E. not enough distance?



co-design

In which ways do you think these images - or the whole comics - are the result of co-design principles?



parables

parables are stories into which many meanings can be read.
How do you think the genre can describe a reader's experience?



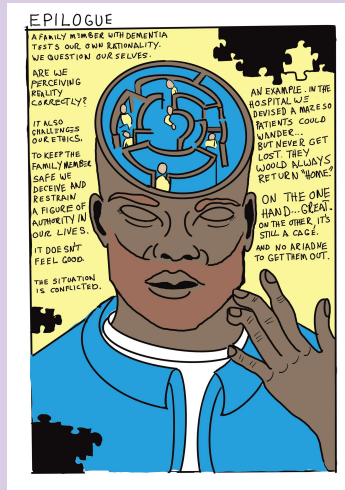
tragedy

If I say this story is a 'tragedy,' what kind of baggage comes along with the assertion? are we saying one story is like another? What does that do to the particular story?



self-reflection

What are the differences between describing our own experiences and our experience of the other's experience?
Can comics represent this question?



DRAWING ACTIVITY

Using the comics we have produced as a starting point, draw a four- or six-panel strip that depicts your own story related to dementia, Parkinson's, or other illness that you have come in contact with.

If you care to, write a paragraph explaining your motivation and process.

There are no rules other than to take your time constructing your comic and to not be critical of your drawing.

Please scan and email the result as a jpg or pdf to:
wilkinsp@douglascollege.ca by Monday, July 6, 2020.

Indicate whether you are willing to share your comic on a website or publication. We will contact you if we wish to share your comic to make sure you are happy to show it.

Grennan, S., Priego, E., Sperandio, C. and Wilkins, P. (2017) *Parables of Care. Creative Responses to Dementia Care, As Told by Carers*. UK: City, University of London, University of Chester, Douglas College. ISBN 978-1-5272-1200-8, available at <https://openaccess.city.ac.uk/id/eprint/18245/>

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