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 VANCOURER, 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 PARABLESOFCARE 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
THE FAMILY OF PEOPLE WITH DEMENTIA CAN CAUSE A LOT OF PROBLEMS FOR THEMSELVES.

"THERE'S A LOT OF GUILT INVOLVED."

"IT MAKES THEM DO THINGS THAT ARE NOT SMART."

"THEY THINK THEY CAN LOOK AFTER MUM AND DAD THEMSELVES?"

"THIS LEADS TO ANXIETY AND EXHAUSTION."

"IF THEY DON'T THEY FEEL UNCARING."

"NOT TO MENTION WASTING MONEY ON RENOVATIONS THAT DON'T FIT THE BILL. THE FAMILY ARE NOT EXPERTS. THEY DON'T KNOW WHAT THEY ARE IN FOR."
EPISODE #1

THEY LOVED HER AT THE DINER

THEY DIDN'T SEE REALITY HER SHIFT OUT OF
THIS IS NOT MY HOUSE

LIKE I DID OR GET ANGRY

WHERE IS GEORGE? YOU TOOK HIM AWAY!

I HATE YOU!

SHE HAD TROUBLE LIVING BY HERSELF

SHE STOPPED WASHING HERSELF AND HER CLOTHES

NO! I DO NOT WANT A BATH

SHE DOESN'T CARE
I got frustrated because I'd seen it.

I know how this ends.

Leave me alone!

When family visited for holidays, they asked lots of questions.

But they didn't help.

Is she eating? What did the doctor say?

Maybe you should take her out more. Maybe you could take her out...

They were in denial.

They still saw her as she was.

She's doing pretty well really.

She's always been like that.
TO GET HER INTO A HOME, I HAD TO LIE
WE'RE GOING TO HAVE YOUR APARTMENT PAINTED
WHEN I WAS GROWING UP, SHE TOLD ME LYING WAS THE WORST THING
PEOPLE NEED TO KNOW THEY CAN TRUST YOU

BUT THIS IS BEST FOR EVERYONE
YOU HAVE TO WATCH THEM
SHE MIGHT NOT EAT
HOW DO WE KNOW THEY WILL LOOK AFTER HER?

THE MORE EXPERIENCED CARE AIDES ARE RUTHLESSLY EFFICIENT
ALL DONE!
BUT...

THE NEWER ONES ARE INDULGENT, EMPATHETIC AND IMAGINATIVE
HOW ABOUT SOME MUSIC?
OK!

I NEVER HAD SUCH PATIENCE.
I WANTED HER OUT OF IT
MUM! I AM NOT EMILY, YOU KNOW THAT!
THE CARE AIDS MAID IT ALMOST FUN
SURE, IT'S CALM NOW, BUT...
EVERY SO OFTEN THEY THINK THEY ARE ON A CRUISE SHIP
AH, SUN DOWNING
I'M NOT SURE HOW THEY STAY WEL
THEY TEACH US HOW TO LOOK AFTER OURSELVES
I'M VERY GRATEFUL TO THEM
ARE THEY TRUSTWORTHY?
SHOULD'T SHE BE IN HER OWN HOME?
SELF CARE
RUN FOR YOUR LIVES!
OH MY GOD, SOMEBODY HELP!
CALM DOWN EVERYONE
WHAT PLACE FREAKS ME OUT
I FELT GUILTY PUTTING HER IN THE HOME

THE BROTHERS AND SISTERS DIDN’T LIKE IT

SHE NEEDS HOME CARE

SHE WILL BE LONELY

BUT IT MADE LIFE EASIER

EXCEPT ON VISITING DAY

HELEN!!

SOMETIMES SHE RECOGNIZED ME

SOMETIMES SHE DIDN’T

WHO ARE YOU?

WHAT DO YOU WANT?

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.
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

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