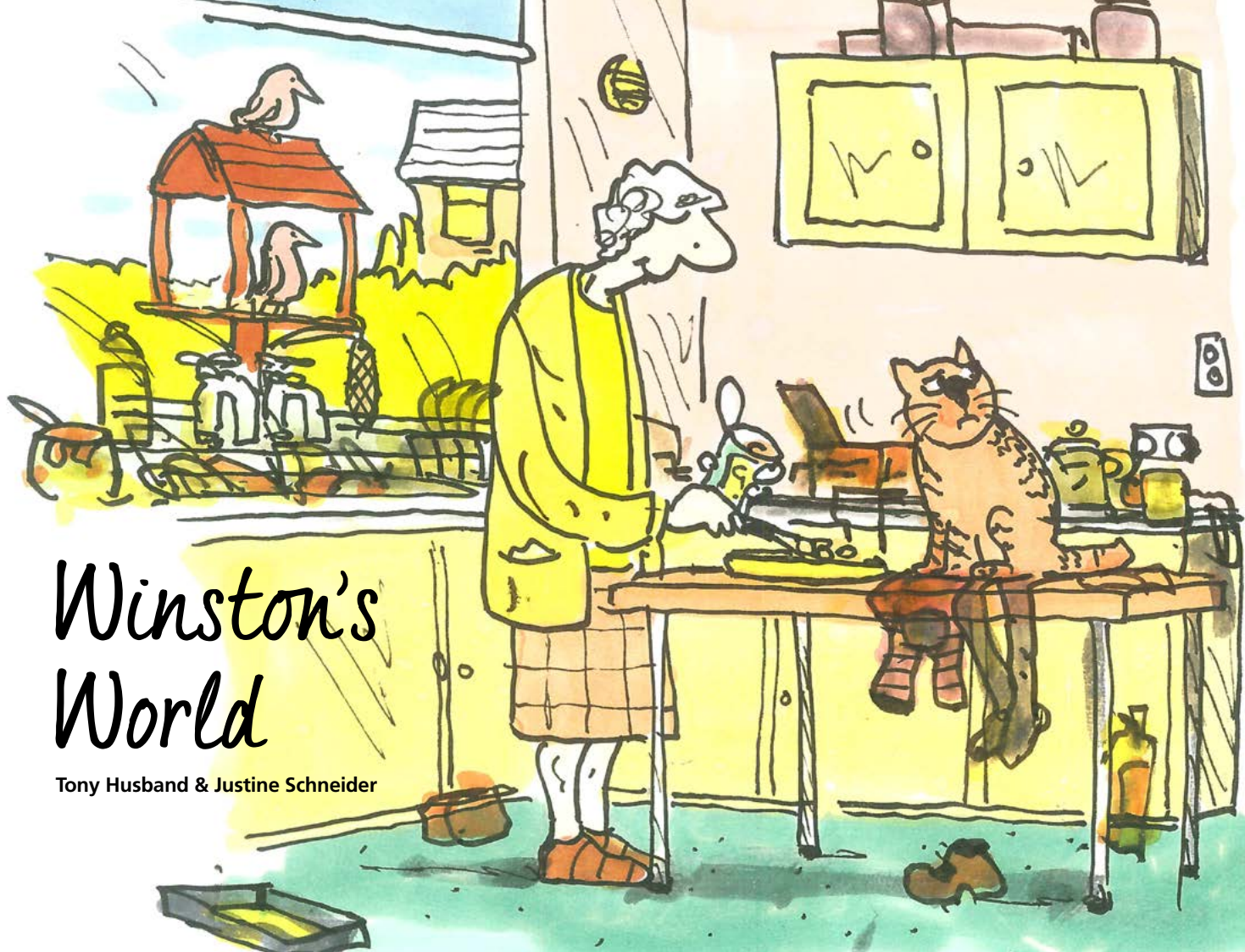




Winston's World

Tony Husband & Justine Schneider

Preface

Winston's World is based on research on home care for people with dementia. Over ten months in 2016-17, two researchers (Samantha Wilkinson and Lucy Perry-Young) worked as home carers in six households where someone with dementia required support. Two other researchers (Kristian Pollock and Justine Schneider) interviewed the workers and relatives. We had approval from the Social Care Research Ethics Committee to do this, in order to explore what 'good' home care 'looks like' for people with dementia.

We wanted to reflect the things we learned from this research without losing the sense of drama in the everyday that makes home care so fascinating. This is why we got together and developed the characters you meet in this book. Daisy, Freda, Jim, Janet, Andrew, Brutus and Winston are all fictional, but the scenarios here are typical in many ways.

The artist, Tony Husband, has demonstrated his sensitivity to dementia in the beautiful book *Take Care, Son*, so we were thrilled when he agreed to bring our characters to the page. We also took advice from home care workers and trainers about how to portray Daisy. (Note, for example, that Daisy does not always say what she is thinking!)

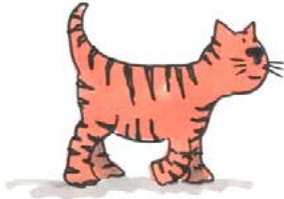
Winston's World has been written as a resource for learning about home care and about dementia care in particular. It shows a world where people are trying hard to deliver good care, but where there is still room for improvement.

Every scenario – in fact, each drawing, has been carefully developed to offer a focus for reflection and discussion. Here are a few prompts that could be used to stimulate individual reflection or small-group discussion:

- What is each character thinking?
- How does this scene relate to your experience and how do you handle similar situations?
- In an ideal world, what would Daisy do next?



Winston's World



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Meet Winston the cat...



He dreams of better days, when he was a legendary hunter of birds. Now the birds outside the kitchen window seem to mock him. To make matters worse, his person Freda sometimes torments him by holding him up to observe them. Winston takes refuge next door, chez Janet and Jim, where he knows he will always get a drink of milk - unless their son Andrew happens to there be on one of his flying visits with his awful dog, Winston's mortal enemy.

Winston's person Freda (80) worked as a legal secretary for 40 years. She was widowed before reaching retirement age. She now has mild dementia that is leaving her more confused each day. The place is cluttered with rubbish and she is forgetting to take her blood pressure pills. She has finally accepted home care under pressure from Gina her niece who lives in the Isle of Wight.

Freda's hearing is poor and she uses two hearing aids which are constantly getting misplaced.

Jim (78) and Janet (75) live next door to Freda. They have been married for nearly 50 years. Janet's dementia is more advanced than Freda's; Jim looks after her, but he is getting increasingly impatient with her. Jim's an engineer, he likes things organised and logical. He walks with difficulty and is waiting for a knee replacement.

Janet gave up her hairdressing job to raise their son, Andrew. When he left school, she found herself being a carer, first for Jim's parents and then for her own father. She then worked in a shop for a few years until she retired at 60. Soon afterwards, she and Jim went to live in Spain, returning when his knee grew too bad for him to drive and Janet's failing memory began to embarrass him in public.

Andrew (46) is a solicitor. He visits twice a month, keeping them supplied with frozen meals. His terrier Brutus loves to chase cats.

Daisy (37) is the home care worker. She is a single parent, with a girl and a boy, both in secondary school. She studied to be a nurse but never qualified, and did child-minding while the children were in primary school. Her own father lived with her until two years ago. He had vascular dementia, and was heavily dependent on her in the last six months of his life.

Daisy has decided now to get out of the house and meet more people. Home care appeals because of the flexible hours and the variety of work, and because she can use her nursing and caring skills.

Chapter 1...



Tum te tum... there you are Winston,
eat up



Tra la - te tum te tum







It's OK Freda..Im here
to help.. iM Daisy..shall we
have a cuppa?



How about a sandwich and a cuppa and we'll go in the front room. How do you like your tea?



You relax while I tidy up a bit... oh! See you've had a post card from The Isle of Wight



OK all spic and span and medication before I go

mmm shes not had the medicine for two days.. I'll let the office know



OK Freda I'll be back tomorrow at 11. Shall I put the bag in the bin?

No thank you, I'm capable of putting a bag in a bin





Ooh... Ohhh...



Miaow?..



Chapter 2...



Hello Winston.. nice to see you..
What are you after I wonder?



Drink of milk old pal?..
Ooh my knees playing up





Mornin' Daisy
Who's she?

Morning you two.. Milk and
paper as promised



Take off your clothes while I turn on the shower

I don't want a bath I tell you



Something's happened at Freda's an ambulance is outside with blue flashing lights!

Really?... Oh dear



I'll nip over Jim... Take care of Janet will you... I'll be back soon



She'll be OK she had a tumble yesterday... we're taking her in for check ups

Freda it's Daisy, how are you sweetheart?



Hope she's OK... oh hello this will
be Andrew Seeing what we
want for dinner



she tripped and lay there
all night... she managed to
crawl to the phone and rang
a relative in the Isle of White
I'm going back to Jim and
Janets now to finish there

I wonder how
long she'll be in..
I should have
insisted on taking
that bin bag
sigh





Chapter 3...







Brew's up.. Where are
you off to Janet?

Janet?



oh Janet... what 'do you fancy
wearing today?... It's lovely
and warm

Don't want
to wear anything!





Oh wow Janet you look lovely



she looks as pretty
as a picture

Tra La..How pretty
does Janet look Jim?!

Oh don't be
silly the pair of you







Chapter 4...



The hospital told me
I had, die-mentia, that
I'm do-lally

mmm.. Is that the letter they
gave you? Do you mind
if I read it?



I just had a fall that's
all. It's my diabetes, it makes
me dizzy sometimes

It's important you take
your medicines on time.
Oh, is this your new pill?



come here Winston
leave Daisy alone!

Freda if you want
I can help you organise
these papers and your pills



I'm not a baby you know
I had a responsible job

Well your Niece
has asked me to pop in
three times a week to make
sure you're OK







I can't read
without my hearing
aid

I'm writing.. I made
Freda a cup of tea and
sandwiches and gave her
her medication



Why don't you check your post.. Is there
anything else I can do for you while
I'm here? Shall I put a hot water
bottle in your bed?

oh ok then but I don't
want to keep you late those
kiddies of yours will be home
alone



oh I can't afford this
much.. We only got my
pension every month you
know

Gina your niece is taking
care of the bills.. Look it says at
the bottom, nothing to pay



I can't accept charity...
I'm sorry you'll have
to stop coming

Don't worry Freda
I'll come on Friday aye?
bye...



Tch.. I'm sure I had some napkin rings
in here.. who's taken those eye Winston?



Awe... I remember when I first
wore this...



It was the first time I'd met Joe...

Gonna Rock around the clock tonight..



Chapter 5...







Hi Jim, sorry no flowers as infection risk they say... can't stop taking my lad to football

Hi Daisy, how is Janet doing?



She's fine Jim.. settled in nicely. Anyway you'll be home tomorrow and I can take you to see her.. must dash I'm wanted sigh



Oh Winston this place is so quiet
without Janet...



It's quite nice here Daisy, isn't it Janet?
They say I can stay for lunch so I'll
get a taxi thanks Daisy

You sure
Jim.. OK, I'll
say bye
then!



mmm.. tasty grub, aye luv



Oh dear, it's getting late, better
call a cab.. sorry love..





I'll call in to see you when
I pop into Fredas I
promise

OK thank you



Hello, just left Jim so sad.. Yes
I know. On my way to the
next visit now...



Oh Winston, it's just you
and me now



Authorship Statement

The underpinning research, called Broadening Our Understanding of Good Homecare (BOUGH) was conceived and managed at the University of Nottingham, UK by Justine Schneider, with Kristian Pollock, Cheryl Travers, Tony Kelly, Kezia Scales and Nick Manning.

We collected the data for this mixed-methods study in 2016-17. The research team who initially developed characters and scenarios for Winston's World from the study data included Kristian Pollock, Lucy Perry-Young, Cheryl Travers and Nicola Turner. The drawings are the work of Tony Husband in response to a narrative written by Justine Schneider.

Disclaimer

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Tony Husband

Tony Husband is an award-winning cartoonist. His work has appeared in national and international newspapers and magazines. He has worked for Private Eye for 34 years, and has published over 50 books, including *Take Care Son*, about his Dad's dementia, and *From a Dark Place*, the story of his son's addiction to drugs. He enjoys wine and music.

www.paulhusbandphotography.com

*This book is dedicated
to all those who care.*





DAA
Nottinghamshire Dementia
Action Alliance