Dementia in underserved groups: Visual stories from the LGBTQ+ communities

Claudio Di Lorito, Ada Jusic,
and community partners

Introduction

LGBTQ+ communities experience inequity in dementia health and care services.

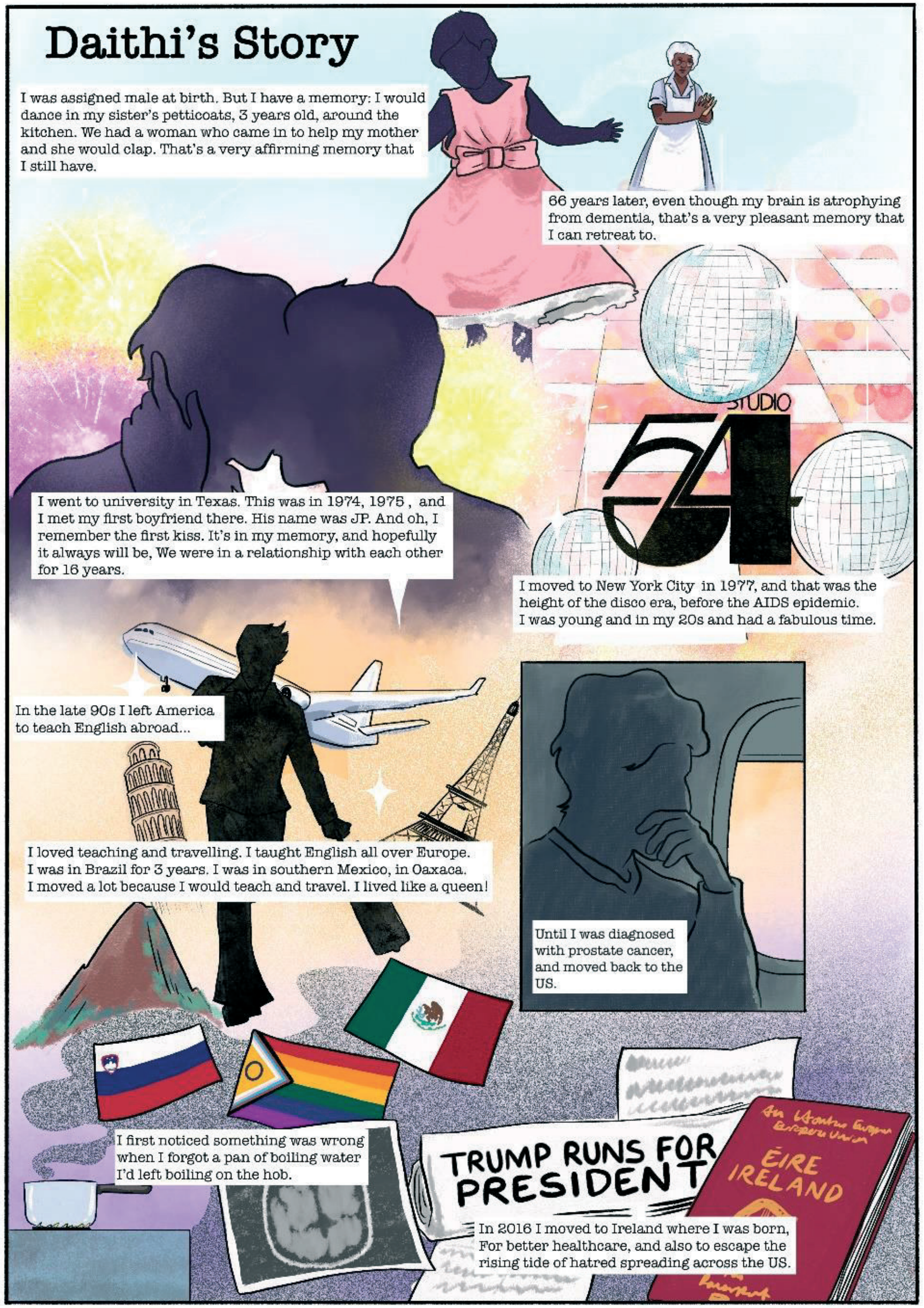
The aim of this project was to address this issue of social justice by giving voice to people from these communities.

Visual illustrations of lived-experience of dementia were co-designed by members of the LGBTQ+ communities, a visual artist and our research team at University College London.

They were showcased at community events to raise awareness (photos on the previous page).

We present the storyboards here, in the hope that people will appreciate that dementia does not discriminate and that there are unique challenges that LGBTQ+ communities experience when faced with dementia.

Daithi’s Story



I was assigned male at birth. But I have a memory: I would dance in my sister’s petticoats, 3 years old, around the kitchen. We had a woman who came in to help my mother and she would clap. That’s a very affirming memory that I still have.

66 years later, even though my brain is atrophying from dementia, that’s a very pleasant memory that I can retreat to.

I went to university in Texas. This was in 1974, 1975 , and I met my first boyfriend there. His name was JP. And oh, I remember the first kiss. It’s in my memory, and hopefully it always will be, We were in a relationship with each other for 16 years.

I moved to New York City in 1977, and that was the height of the disco era, before the AIDS epidemic. I was young and in my 20s and had a fabulous time.

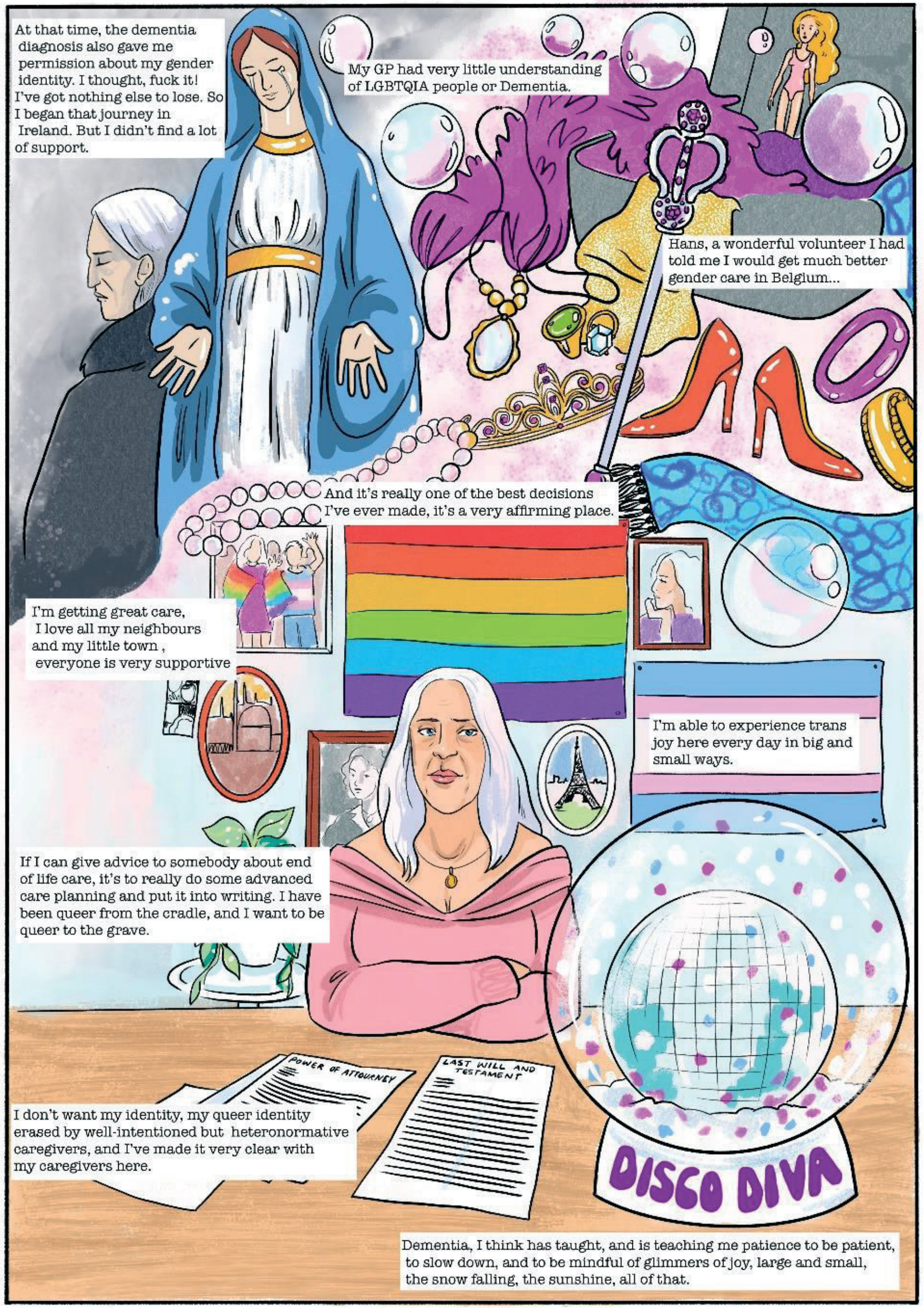
In the late 90s I left America to teach English abroad...

I loved teaching and travelling. I taught English all over Europe. I was in Brazil for 3 years. I was in southern Mexico, in Oaxaca. I moved a lot because I would teach and travel. I lived like a queen!

Until I was diagnosed with prostate cancer, and moved back to the US.

I first noticed something was wrong when I forgot a pan of boiling water I’d left boiling on the hob.

In 2016 I moved to Ireland where I was born, For better healthcare, and also to escape the rising tide of hatred spreading across the US.



At that time, the dementia diagnosis also gave me permission about my gender identity. I thought, fuck it! I’ve got nothing else to lose. So I began that journey in Ireland. But I didn’t find a lot of support.

My GP had very little understanding of LGBTQIA people or Dementia.

Hans, a wonderful volunteer I had told me I would get much better gender care in Belgium...

And it’s really one of the best decisions I’ve ever made, it’s a very affirming place.

I’m getting great care, I love all my neighbours and my little town , everyone is very supportive

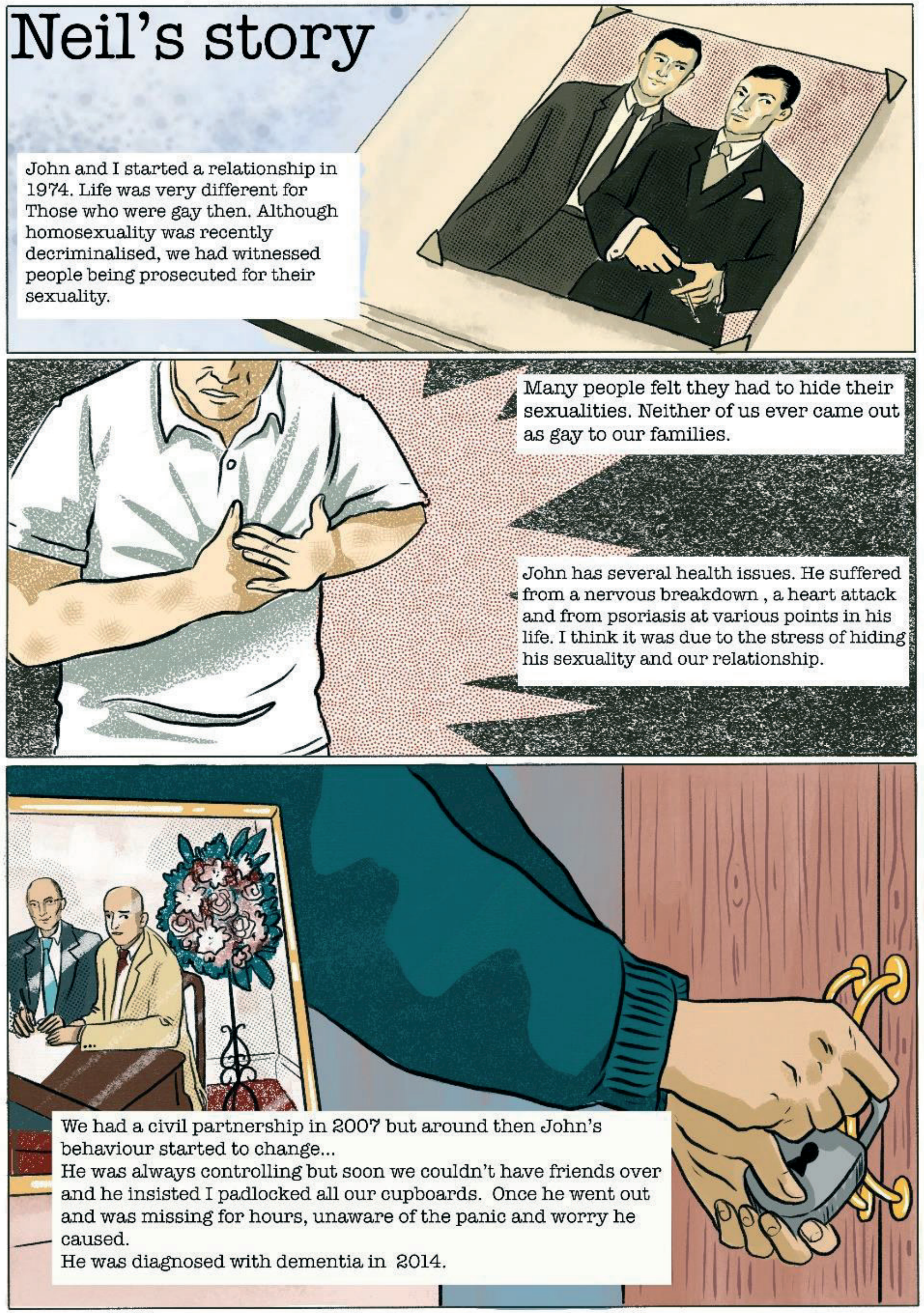
I’m able to experience trans joy here every day in big and small ways.

If I can give advice to somebody about end of life care, it’s to really do some advanced care planning and put it into writing. I have been queer from the cradle, and I want to be queer to the grave.

I don’t want my identity, my queer identity erased by well-intentioned but heteronormative caregivers, and I’ve made it very clear with my caregivers here.

Dementia, I think has taught, and is teaching me patience to be patient, to slow down, and to be mindful of glimmers of joy, large and small, the snow falling, the sunshine, all of that.

Neil’s story

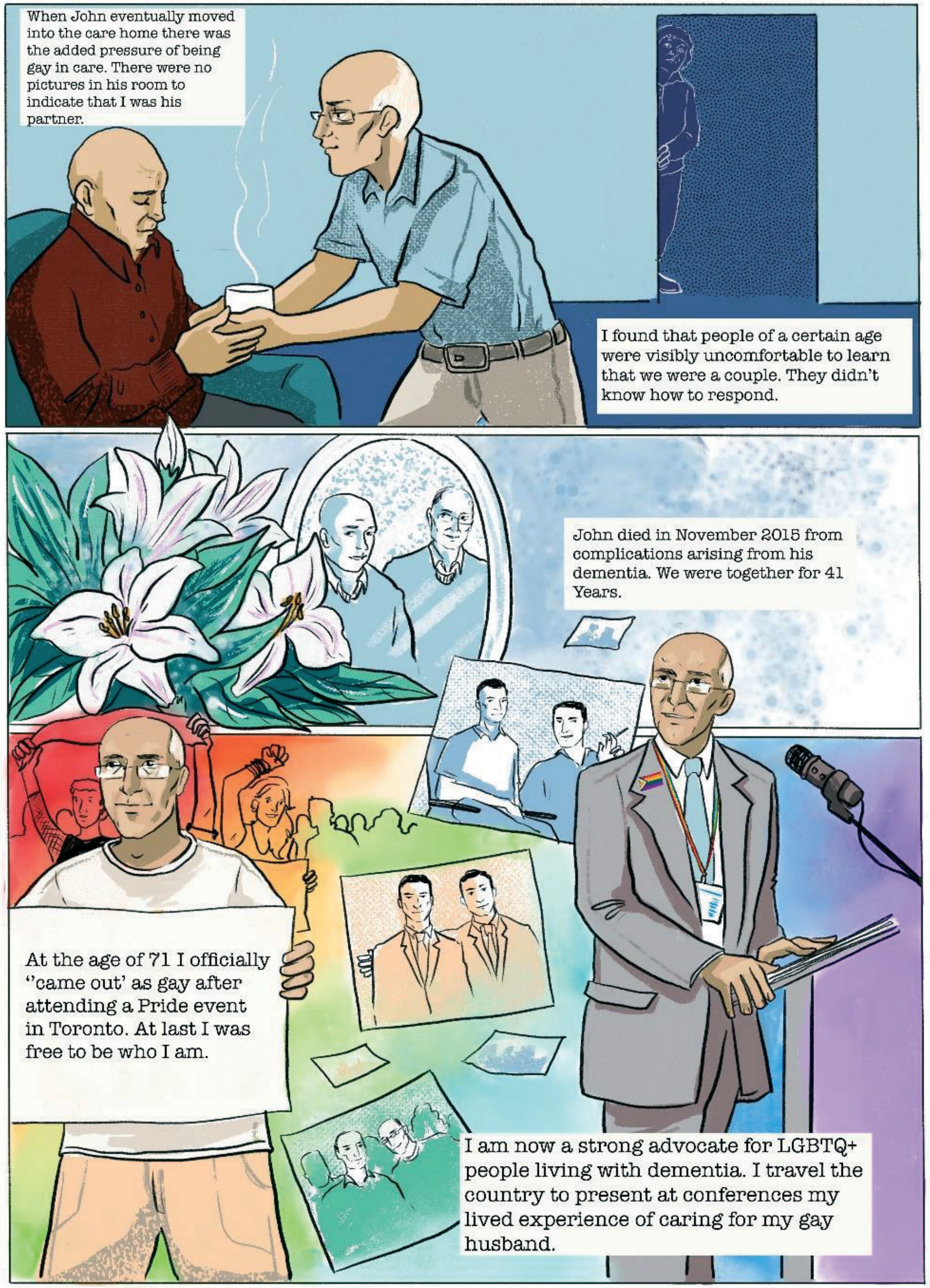


John and I started a relationship in 1974. Life was very different for Those who were gay then. Although homosexuality was recently decriminalised, we had witnessed people being prosecuted for their sexuality.

Many people felt they had to hide their sexualities. Neither of us ever came out as gay to our families.

John has several health issues. He suffered from a nervous breakdown , a heart attack and from psoriasis at various points in his life. I think it was due to the stress of hiding his sexuality and our relationship.

We had a civil partnership in 2007 but around then John’s behaviour started to change...
He was always controlling but soon we couldn’t have friends over and he insisted I padlocked all our cupboards. Once he went out and was missing for hours, unaware of the panic and worry he caused.
He was diagnosed with dementia in 2014.



When John eventually moved into the care home there was the added pressure of being gay in care. There were no pictures in his room to indicate that I was his partner.

I found that people of a certain age were visibly uncomfortable to learn that we were a couple. They didn’t know how to respond.

John died in November 2015 from complications arising from his dementia. We were together for 41 Years.

At the age of 71 I officially ‘’came out’ as gay after attending a Pride event in Toronto. At last I was free to be who I am.

I am now a strong advocate for LGBTQ+ people living with dementia. I travel the country to present at conferences my lived experience of caring for my gay husband.

Kitana's Story

I was 30 years old and I was confident and if I wanted to do something I'd just go and do it!

I stood up straight...I was in good shape and smiled.

I worked in retail and TV production, I ran a £10 million account for London 2012...

And nothing could stop me! I was just a really confident, great brained individual.

I had a breakdown caused by an abusive relationship, that's when the symptoms started.

And then suddenly from being young and free, you take half an hour to sort out pages 1-5 because you can't figure it out

Something was wrong with me, so I went for tests

My experience with the diagnosis was dreadful, I had a homophobic psychologist who ignored my issues

He said he'd never had a conversation with me, so I couldn't get my diagnosis and care plan

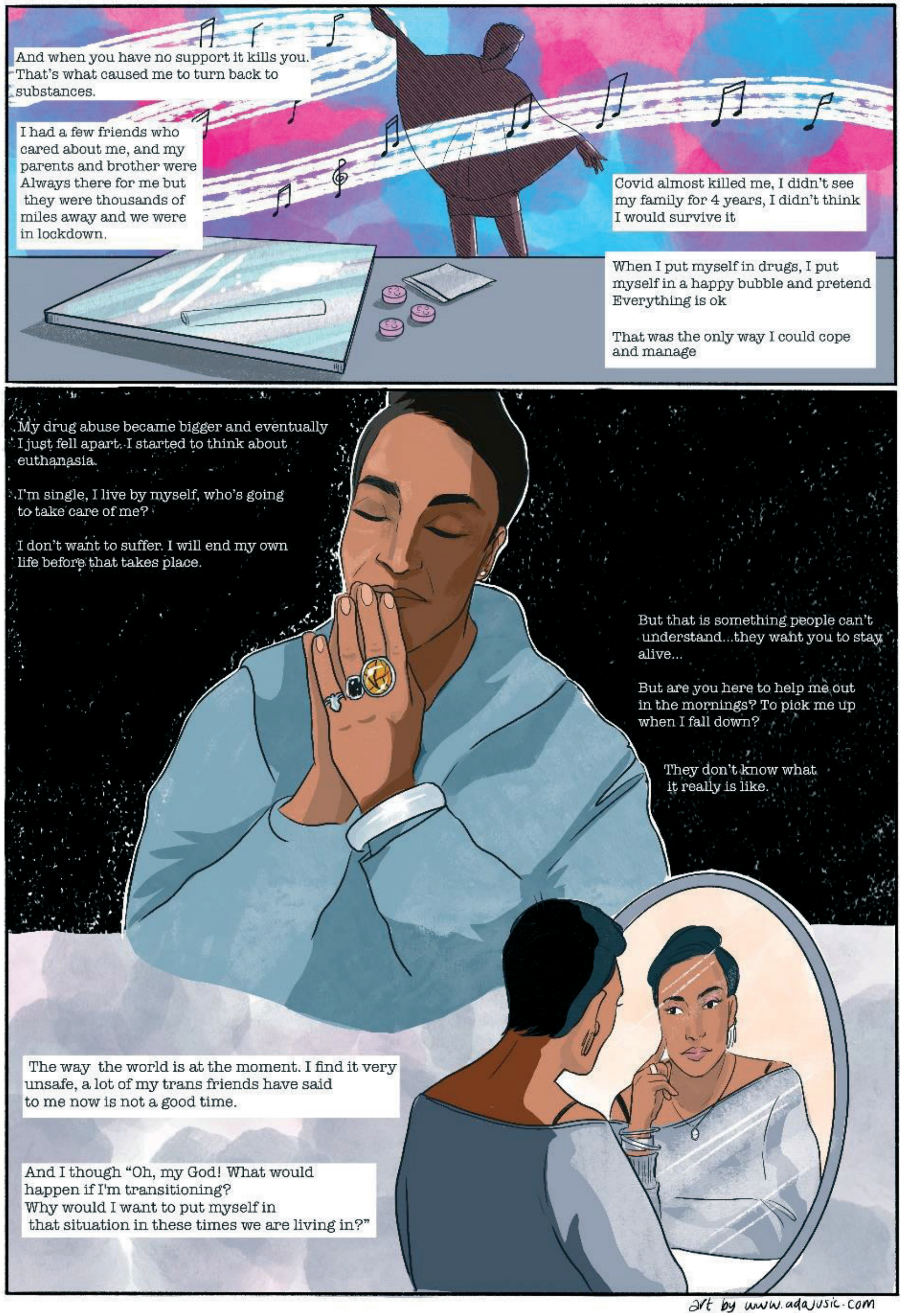
I think social isolation in our community comes from deflection

I was completely isolated because no one wants to date someone with dementia

I've learnt not to talk about dementia with my friends I only talk about it in a work aspect

It's too much for them, no one wants to think about ageing

I am the kryptonite to their Illusions.



And when you have no support it kills you. That's what caused me to turn back to substances.

I had a few friends who cared about me, and my parents and brother were Always there for me but they were thousands of miles away and we were in lockdown.

Covid almost killed me, I didn't see my family for 4 years, I didn't think I would survive it

When I put myself in drugs, I put myself in a happy bubble and pretend Everything is ok

That was the only way I could cope and manage

My drug abuse became bigger and eventually I just fell apart. I started to think about euthanasia.

I'm single, I live by myself, who's going to take care of me?

I don't want to suffer. I will end my own life before that takes place.

But that is something people can't understand...they want you to stay alive...

But are you here to help me out in the mornings? To pick me up when I fall down?

They don't know what it really is like.

The way the world is at the moment. I find it very unsafe, a lot of my trans friends have said to me now is not a good time.

And I though "Oh, my God! What would happen if I'm transitioning? Why would I want to put myself in that situation in these times we are living in?"

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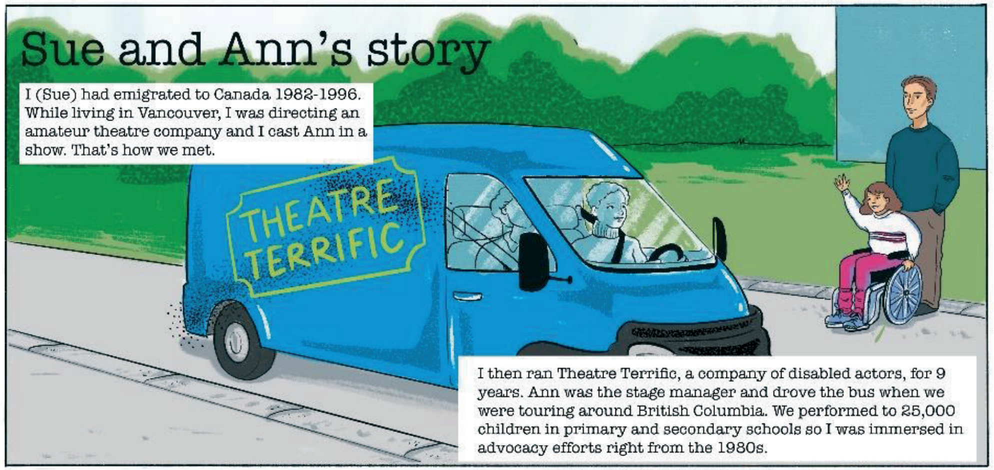
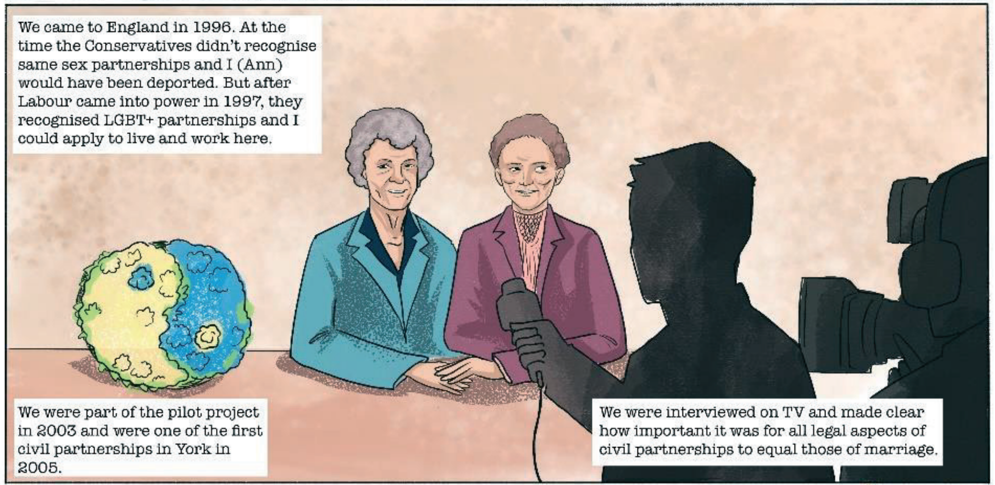
Sue and Ann's story



I (Sue) had emigrated to Canada 1982-1996. While living in Vancouver, I was directing an amateur theatre company and I cast Ann in a show. That's how we met.

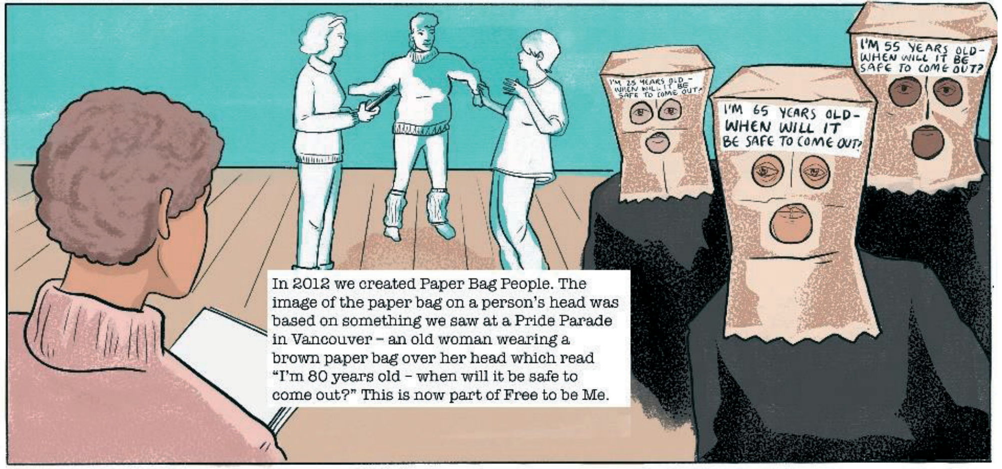
I then ran Theatre Terrific, a company of disabled actors, for 9 years. Ann was the stage manager and drove the bus when we were touring around British Columbia. We performed to 25,000 children in primary and secondary schools so I was immersed in advocacy efforts right from the 1980s.



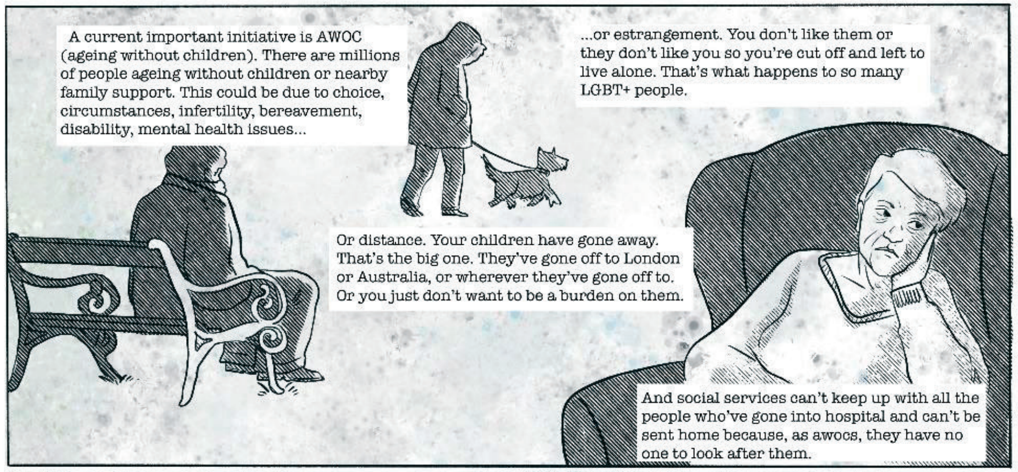
We came to England in 1996. At the time the Conservatives didn't recognise same sex partnerships and I (Ann) would have been deported. But after Labour came into power in 1997, they recognised LGBT+ partnerships and I could apply to live and work here.

We were part of the pilot project in 2003 and were one of the first civil partnerships in York in 2005.

We were interviewed on TV and made clear how important it was for all legal aspects of civil partnerships to equal those of marriage.



In 2012 we created Paper Bag People. The image of the paper bag on a person's head was based on something we saw at a Pride Parade in Vancouver – an old woman wearing a brown paper bag over her head which read "I'm 80 years old – when will it be safe to come out?" This is now part of Free to be Me.

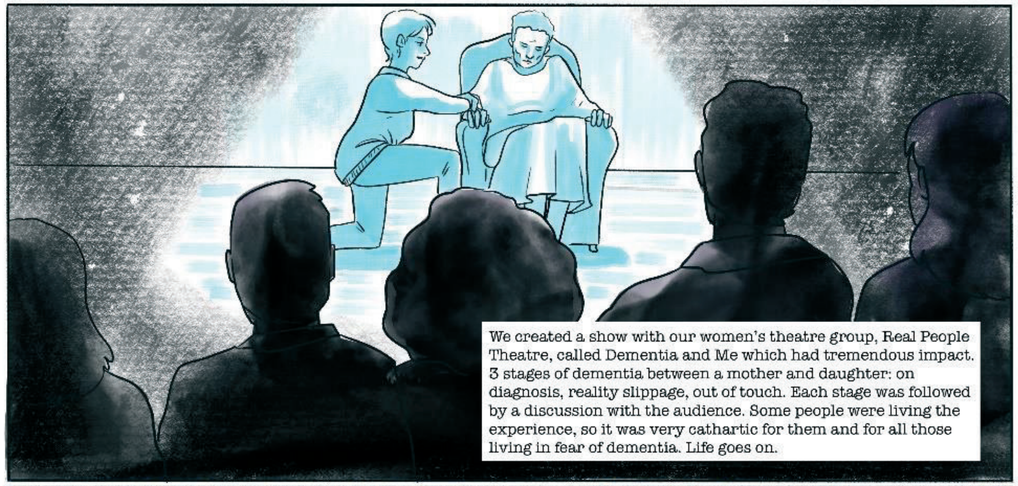


A current important initiative is AWOC (ageing without children). There are millions of people ageing without children or nearby family support. This could be due to choice, circumstances, infertility, bereavement, disability, mental health issues...

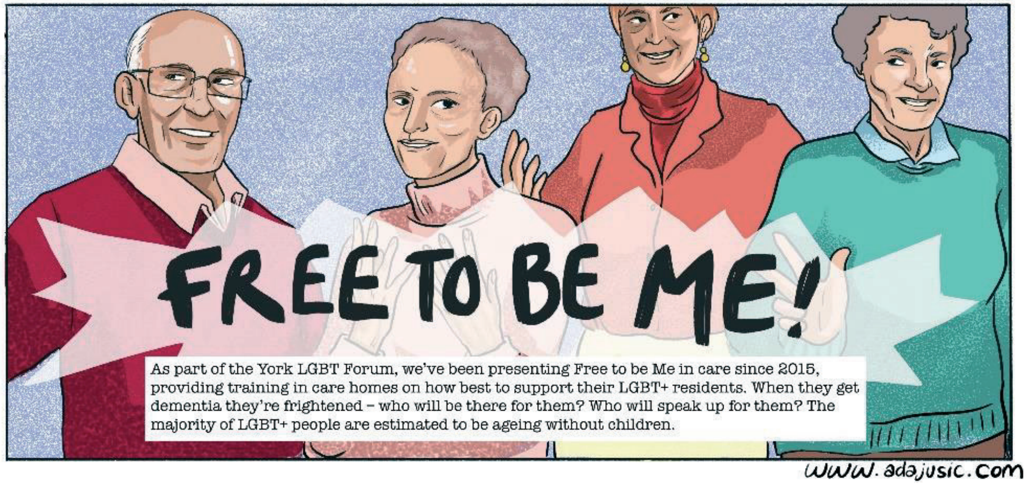
...or estrangement. You don't like them or they don't like you so you're cut off and left to live alone. That's what happens to so many LGBT+ people.

Or distance. Your children have gone away. That's the big one. They've gone off to London or Australia, or wherever they've gone off to. Or you just don't want to be a burden on them.

And social services can't keep up with all the people who've gone into hospital and can't be sent home because, as awocs, they have no one to look after them.



We created a show with our women's theatre group, Real People Theatre, called Dementia and Me which had tremendous impact. 3 stages of dementia between a mother and daughter: on diagnosis, reality slippage, out of touch. Each stage was followed by a discussion with the audience. Some people were living the experience, so it was very cathartic for them and for all those living in fear of dementia. Life goes on.



As part of the York LGBT Forum, we've been presenting Free to be Me in care since 2015, providing training in care homes on how best to support their LGBT+ residents. When they get dementia they're frightened – who will be there for them? Who will speak up for them? The majority of LGBT+ people are estimated to be ageing without children.

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Eve's Story

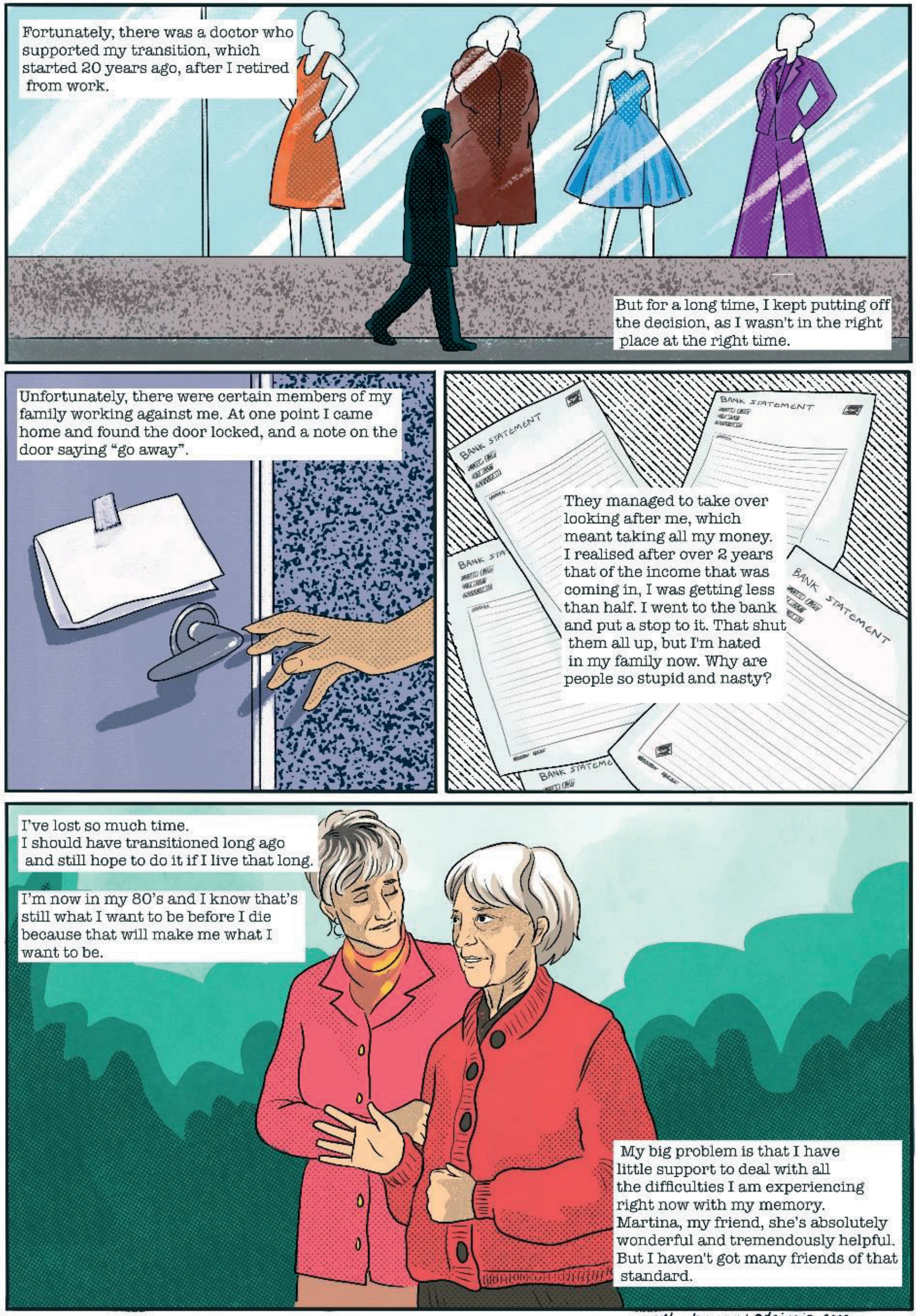
I was first concerned about what it's like being a boy at the age of 10. I was in a college, and I hated it. It was when teachers could still hit you, before it was illegal. I hated it then, and I hated being treated like that as a boy.

When I was 11 I went with a friend who had been in the war to an air show, and as we were watching this, this marvellous thing, the aircraft, it came just over my back shoulder ...

It killed 50 people. Had I been in a slightly different position, I wouldn't be here today.

It was horrifying watching people being killed. There came a dislike for men, creatures who created these bloody, great things that killed people. I just didn't want to be a man. I didn't want to do the things that killed people.

It took a long time to realise that there was an alternative.



Fortunately, there was a doctor who supported my transition, which started 20 years ago, after I retired from work.

But for a long time, I kept putting off the decision, as I wasn't in the right place at the right time.

Unfortunately, there were certain members of my family working against me. At one point I came home and found the door locked, and a note on the door saying "go away".

They managed to take over looking after me, which meant taking all my money. I realised after over 2 years that of the income that was coming in, I was getting less than half. I went to the bank and put a stop to it. That shut them all up, but I'm hated in my family now. Why are people so stupid and nasty?

I've lost so much time. I should have transitioned long ago and still hope to do it if I live that long.

I'm now in my 80's and I know that's still what I want to be before I die because that will make me what I want to be.

My big problem is that I have little support to deal with all the difficulties I am experiencing right now with my memory. Martina, my friend, she's absolutely wonderful and tremendously helpful. But I haven't got many friends of that standard.

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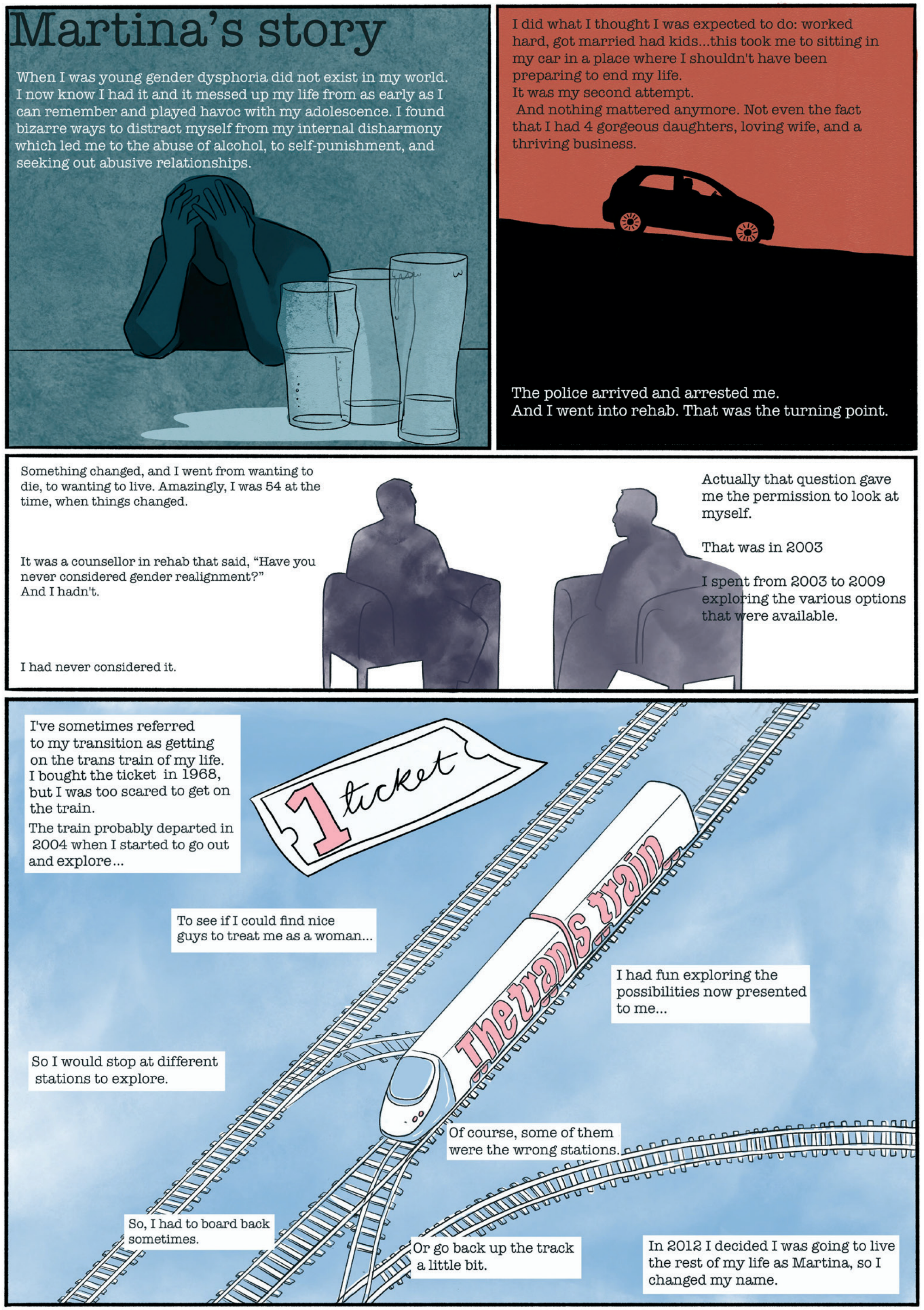
Martina's story



When I was young gender dysphoria did not exist in my world. I now know I had it and it messed up my life from as early as I can remember and played havoc with my adolescence. I found bizarre ways to distract myself from my internal disharmony which led me to the abuse of alcohol, to self-punishment, and seeking out abusive relationships.

I did what I thought I was expected to do: worked hard, got married had kids...this took me to sitting in my car in a place where I shouldn't have been preparing to end my life.
It was my second attempt.
And nothing mattered anymore. Not even the fact that I had 4 gorgeous daughters, loving wife, and a thriving business.

The police arrived and arrested me.
And I went into rehab. That was the turning point.

Something changed, and I went from wanting to die, to wanting to live. Amazingly, I was 54 at the time, when things changed.

It was a counsellor in rehab that said, "Have you never considered gender realignment?"
And I hadn't.

I had never considered it.

Actually that question gave me the permission to look at myself.

That was in 2003

I spent from 2003 to 2009 exploring the various options that were available.

I've sometimes referred to my transition as getting on the trans train of my life.
I bought the ticket in 1968, but I was too scared to get on the train.
The train probably departed in 2004 when I started to go out and explore...

To see if I could find nice guys to treat me as a woman...

I had fun exploring the possibilities now presented to me...

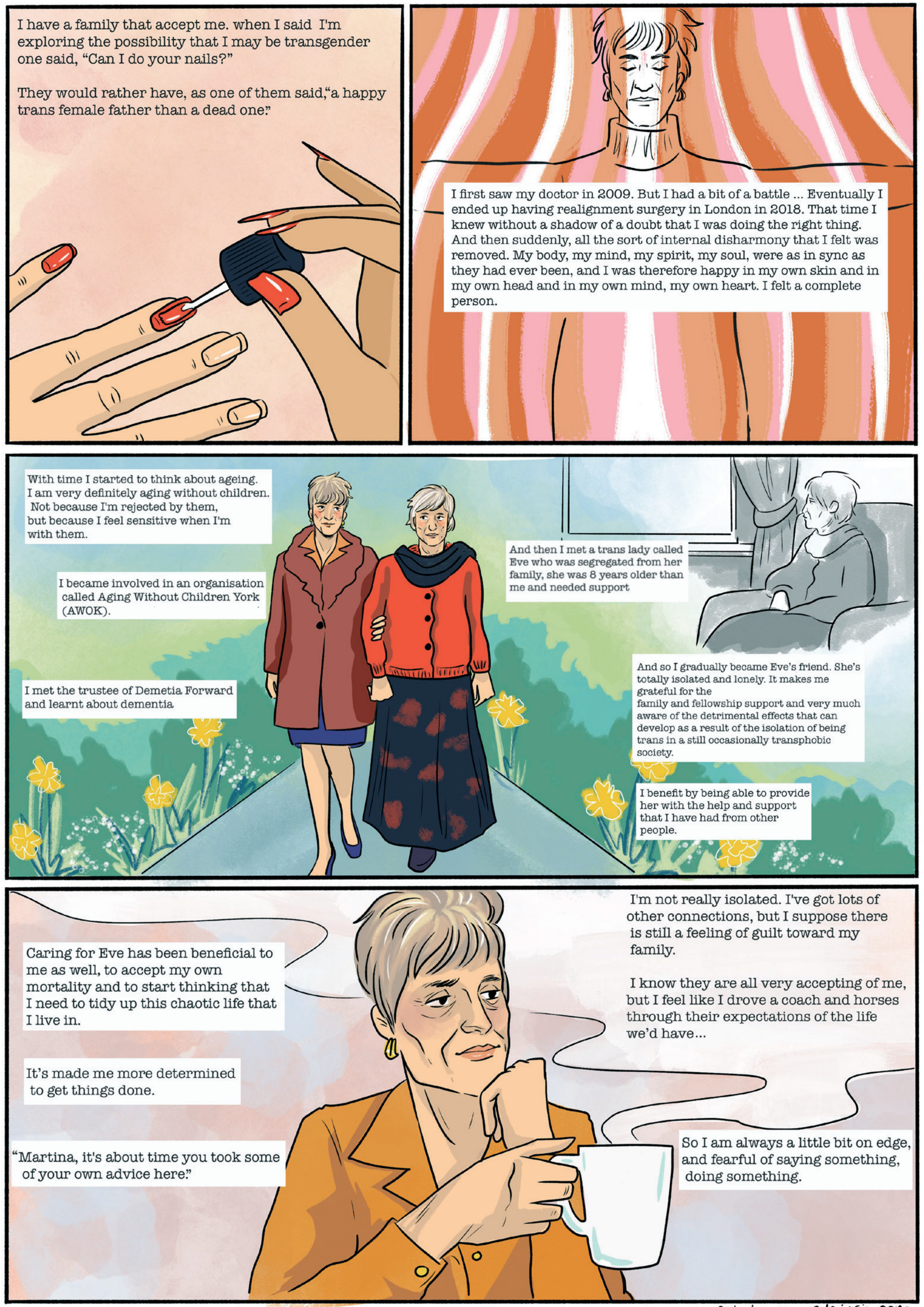
So I would stop at different stations to explore.

Of course, some of them were the wrong stations.

So, I had to board back sometimes.

Or go back up the track a little bit.

In 2012 I decided I was going to live the rest of my life as Martina, so I changed my name.



I have a family that accept me. when I said I'm exploring the possibility that I may be transgender one said, "Can I do your nails?"

They would rather have, as one of them said,"a happy trans female father than a dead one."

I first saw my doctor in 2009. But I had a bit of a battle ... Eventually I ended up having realignment surgery in London in 2018. That time I knew without a shadow of a doubt that I was doing the right thing. And then suddenly, all the sort of internal disharmony that I felt was removed. My body, my mind, my spirit, my soul, were as in sync as they had ever been, and I was therefore happy in my own skin and in my own head and in my own mind, my own heart. I felt a complete person.

With time I started to think about ageing.
I am very definitely aging without children.
Not because I'm rejected by them,
but because I feel sensitive when I'm with them.

I became involved in an organisation called Aging Without Children York (AWOK).

I met the trustee of Demetia Forward and learnt about dementia

And then I met a trans lady called Eve who was segregated from her family, she was 8 years older than me and needed support

And so I gradually became Eve's friend. She's totally isolated and lonely. It makes me grateful for the
family and fellowship support and very much aware of the detrimental effects that can develop as a result of the isolation of being trans in a still occasionally transphobic society.

I benefit by being able to provide her with the help and support that I have had from other people.

Caring for Eve has been beneficial to me as well, to accept my own mortality and to start thinking that I need to tidy up this chaotic life that I live in.

It's made me more determined to get things done.

"Martina, it's about time you took some of your own advice here."

I'm not really isolated. I've got lots of other connections, but I suppose there is still a feeling of guilt toward my family.

I know they are all very accepting of me, but I feel like I drove a coach and horses through their expectations of the life we'd have...

So I am always a little bit on edge, and fearful of saying something, doing something.

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This project was funded by the UCL Grand Challenges.

Acknowledgments: All our community partners, collaborators and Dementia UK for their partnership in this project.

For any questions, please contact: Dr Claudio Di Lorito
Senior Research Fellow
University College London
Email:
claudio.dilorito@ucl.ac.uk