



**University of Dundee**

## **Drawing from our Experience**

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# DRAWING FROM OUR EXPERIENCE

## STORIES OF TRAVELLING WITH DEMENTIA



**ANDY HYDE  
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 Go Upstream

**UNIVERSE**

# **DRAWING FROM OUR EXPERIENCE**

## **STORIES OF TRAVELLING WITH DEMENTIA**

### **About ‘Drawing from Our Experience’**

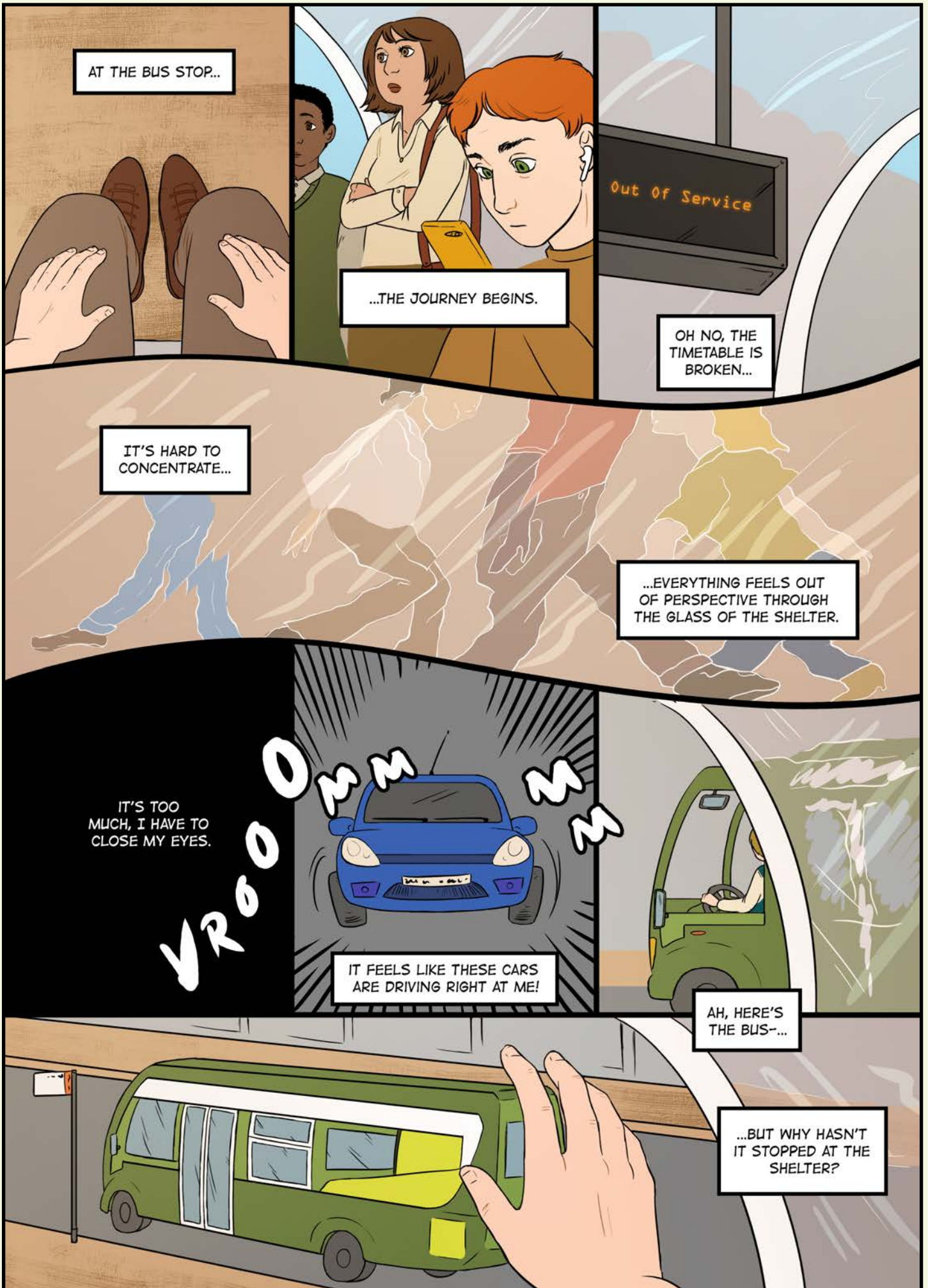
Getting out and about is essential to our wellbeing, particularly after a diagnosis of dementia. We all have a right to remain connected and active in our communities and yet many people affected by dementia describe difficult journeys and travel experiences.

Go Upstream works with people with dementia and service providers, bringing people together to create a shared understanding of travel challenges and potential solutions. This work has highlighted the emotional impact of the challenges that journeys can bring. We see that journeys aren’t just about the transport but about the plans we make, the people we meet, the services we use, the environments we travel through and the destinations we visit.

One of Go Upstream’s aims is to help service provider staff to truly understand the experience of travelling with dementia in order to support service improvement, ideally by travelling with people with dementia, gaining insights into the real challenges. But what if staff can’t be there? How do we tell stories that truly describe the experiences that some people with dementia may have?

We wondered if using the combination of artwork and text in a comic format might begin to tell these stories. If artists and people with dementia travelled and created artwork together, could we begin to more accurately describe the sights, sounds and experiences of a journey as experienced by someone living with dementia? Could we highlight the sensory impacts of dementia? Would the resulting comic be useful as a training resource, helping staff to understand the impacts of services and environments on passengers? Would the format be more accessible for people with dementia?

We started to explore these questions as part of the Drawing from Experience project funded by a Disruption Award from the Dementia Services Development Trust. After taking journeys together, artists and people living with dementia developed these stories to describe particular challenges. Of course, these can’t represent everybody’s experiences but we hope that this work can start conversations about how we can begin to design better journeys.



AT THE BUS STOP...

...THE JOURNEY BEGINS.

Out of Service

OH NO, THE TIMETABLE IS BROKEN...

IT'S HARD TO CONCENTRATE...

...EVERYTHING FEELS OUT OF PERSPECTIVE THROUGH THE GLASS OF THE SHELTER.

IT'S TOO MUCH, I HAVE TO CLOSE MY EYES.

vrooom

IT FEELS LIKE THESE CARS ARE DRIVING RIGHT AT ME!

AH, HERE'S THE BUS...

...BUT WHY HASN'T IT STOPPED AT THE SHELTER?



THE GAP BETWEEN THE PAVEMENT AND THE BUS SEEMS SO FAR. I WISH THE DRIVER WOULD PUT THE RAMP DOWN.



IS THIS THE BUS TO GET TO THE STATION?

YES. £2.60.

DO YOU GIVE CHANGE?

NO.



THERE'S NO CHANGE.

CAN YOU PLEASE TELL ME WHEN WE GET TO THE BUS STATION?

OKAY.



ALL THESE COINS LOOK THE SAME... FEELING UNDER PRESSURE, PEOPLE BEHIND ME MUST BE SO ANNOYED.

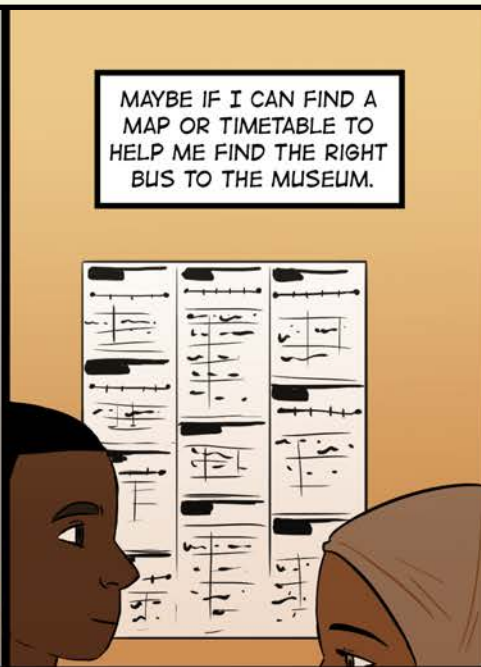


SENSORY OVERLOAD... DEEP BREATHS...

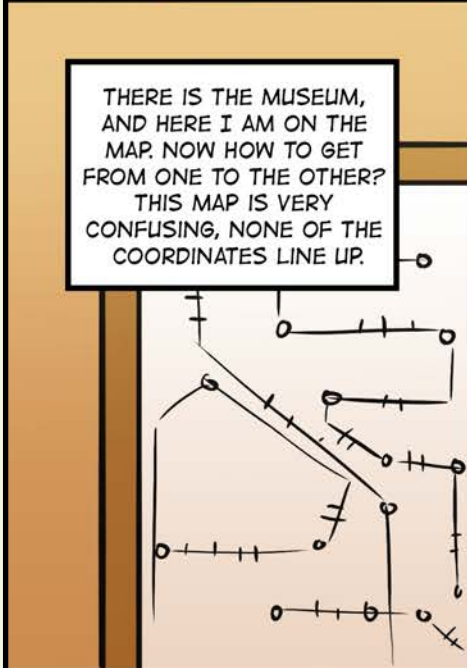
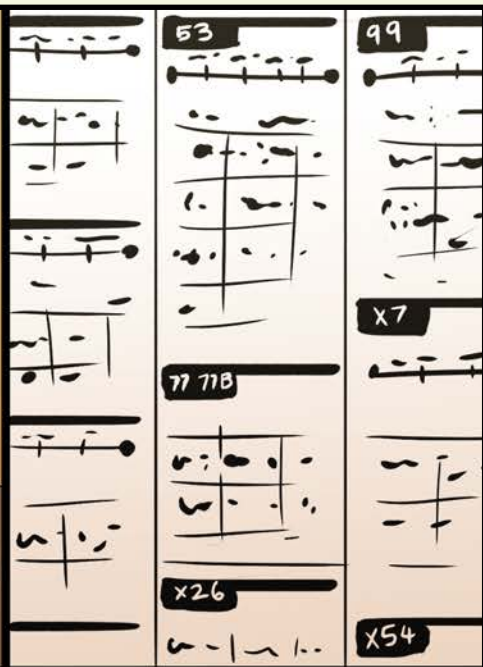
HERE.



WOW, THIS PLACE IS REALLY BUSY. THERE ARE SO MANY BUSES, WHICH IS THE RIGHT ONE?



MAYBE IF I CAN FIND A MAP OR TIMETABLE TO HELP ME FIND THE RIGHT BUS TO THE MUSEUM.



THERE IS THE MUSEUM, AND HERE I AM ON THE MAP. NOW HOW TO GET FROM ONE TO THE OTHER? THIS MAP IS VERY CONFUSING, NONE OF THE COORDINATES LINE UP.



PERHAPS IT'LL BE BEST IF I ASK FOR SOME HELP TO FIND MY BUS.



HELLO, I WAS WONDERING IF YOU COULD HELP ME? I'M LOOKING TO GET THE BUS TO THE MUSEUM.

IT'S JUST OVER THE ROAD!



IT DOESN'T FEEL SAFE TO CROSS THE ROAD.



THERE MUST BE AN EASIER WAY.

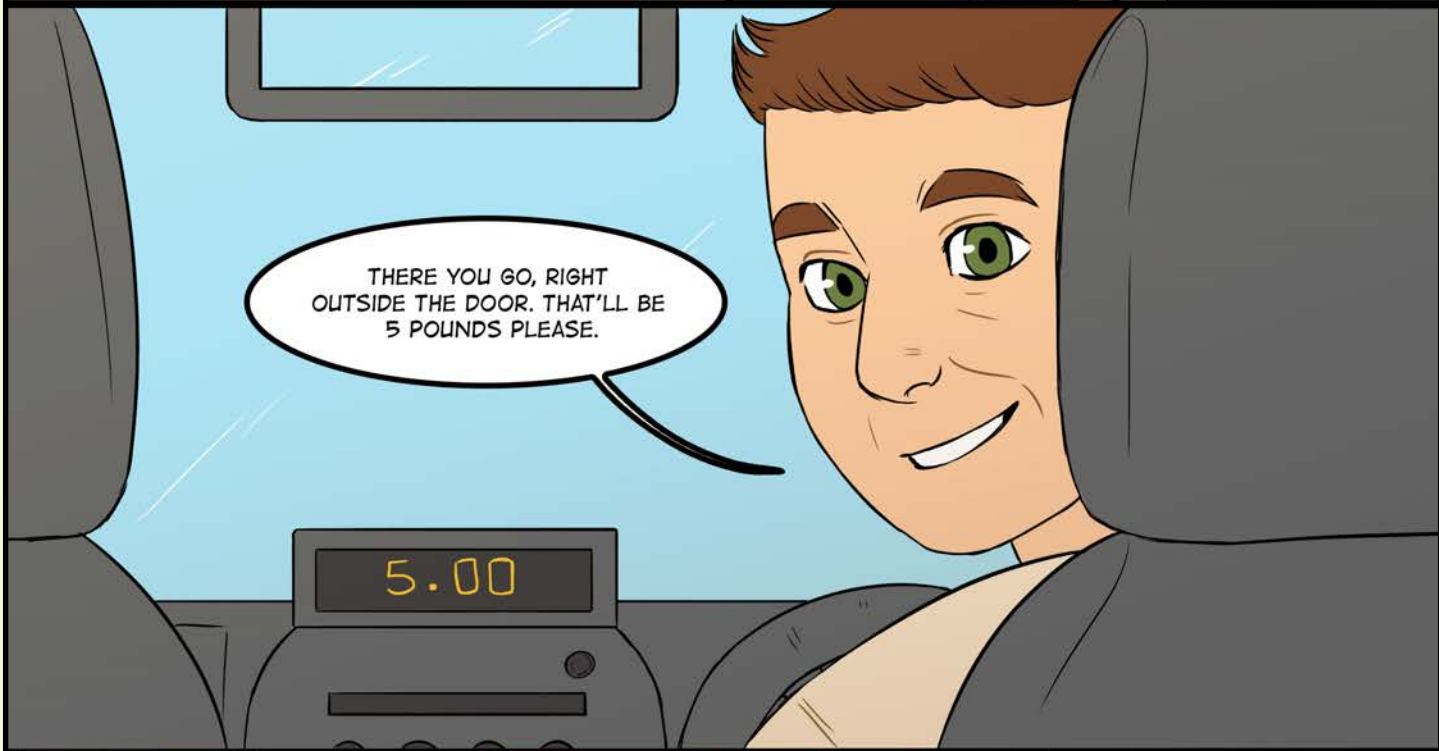


A TAXI! I FEEL COMFORTABLE WITH THAT.



HI THERE, IS IT OKAY IF I GET A TAXI TO THE MUSEUM?

SURE, THAT'S NO PROBLEM! HOP IN.



THERE YOU GO, RIGHT OUTSIDE THE DOOR. THAT'LL BE 5 POUNDS PLEASE.



NOTES ARE EASIER TO WORK WITH AND THANKFULLY THE DRIVER CAN GIVE ME CHANGE.

PHEW, HERE AT LAST!

WOW, IT'S HUGE... BUT EVERYTHING IS BLENDING INTO ONE ANOTHER, THE WATER, THE BUILDING, THE PATHWAY...

...DEEP BREATHS. I'M SURE IT WILL BE BETTER INSIDE...

IT FEELS LIKE THE PATH IS GETTING NARROWER...

WHY IS IT GETTING SO MUCH DARKER? THIS TUNNEL GOES ON FOR MILES...

THERE. IF I JUST PUSH ...


NO HANDLES

IT OPENED BY ITSELF, I FEEL OFF BALANCE

IF I CAN JUST GET OUT OF THIS DARKNESS AND INTO SOME...

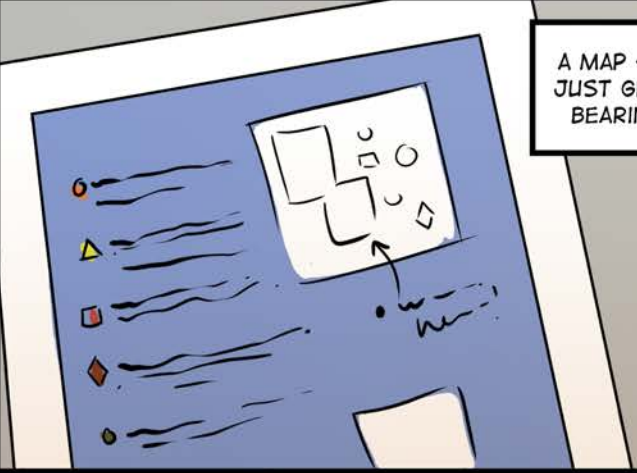


LIGHT.




MY HEAD, WHY IS IT SO BRIGHT?


EVERYTHING IS SO OPEN, WHAT A CONTRAST FROM A SECOND AGO, I FEEL SO DISORIENTATED.



A MAP - I'LL JUST GET MY BEARINGS...



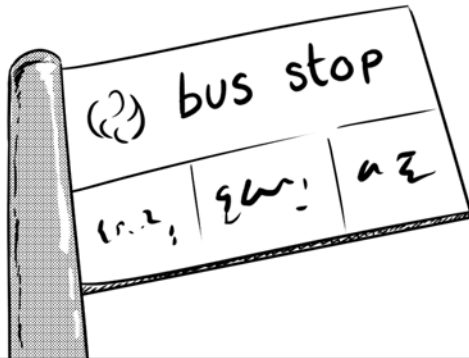
...ALTHOUGH I'M NOT REALLY SURE WHAT THIS ALL MEANS... I NEED...



...NEED ANY HELP AT ALL? SORRY, I NOTICED YOU LOOKED A LITTLE APPREHENSIVE AND JUST WANTED TO ASSURE YOU THAT I AM HERE TO PROVIDE ASSISTANCE IF YOU NEED IT.

THE END

THE START OF MY ADVENTURE.  
APPARENTLY THIS BUS TAKES ME  
STRAIGHT TO THE MUSEUM...



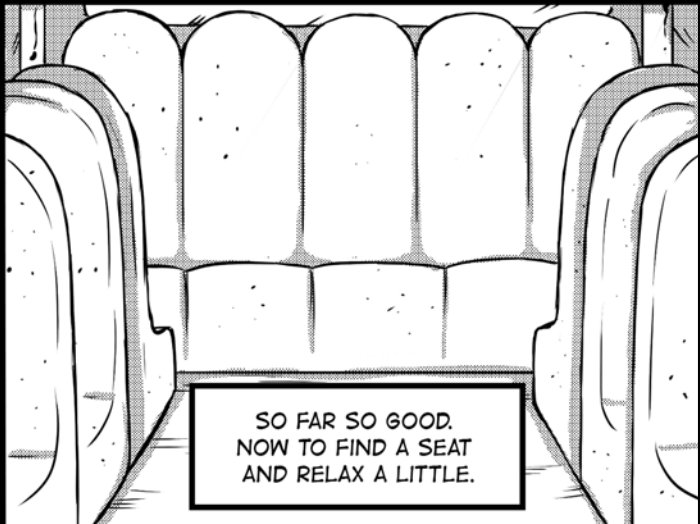
I'M LOOKING  
FORWARD TO  
THE DAY.

THE BUS DRIVER MUST  
HAVE SEEN MY STICK AND  
LOWERED THE STEP.

IT MAKES SUCH  
A DIFFERENCE.

HI, I'D LIKE TO GET TO  
THE MUSEUM. COULD YOU PLEASE  
LET ME KNOW WHEN I AM  
TO GET OFF?

OF  
COURSE.



SO FAR SO GOOD.  
NOW TO FIND A SEAT  
AND RELAX A LITTLE.

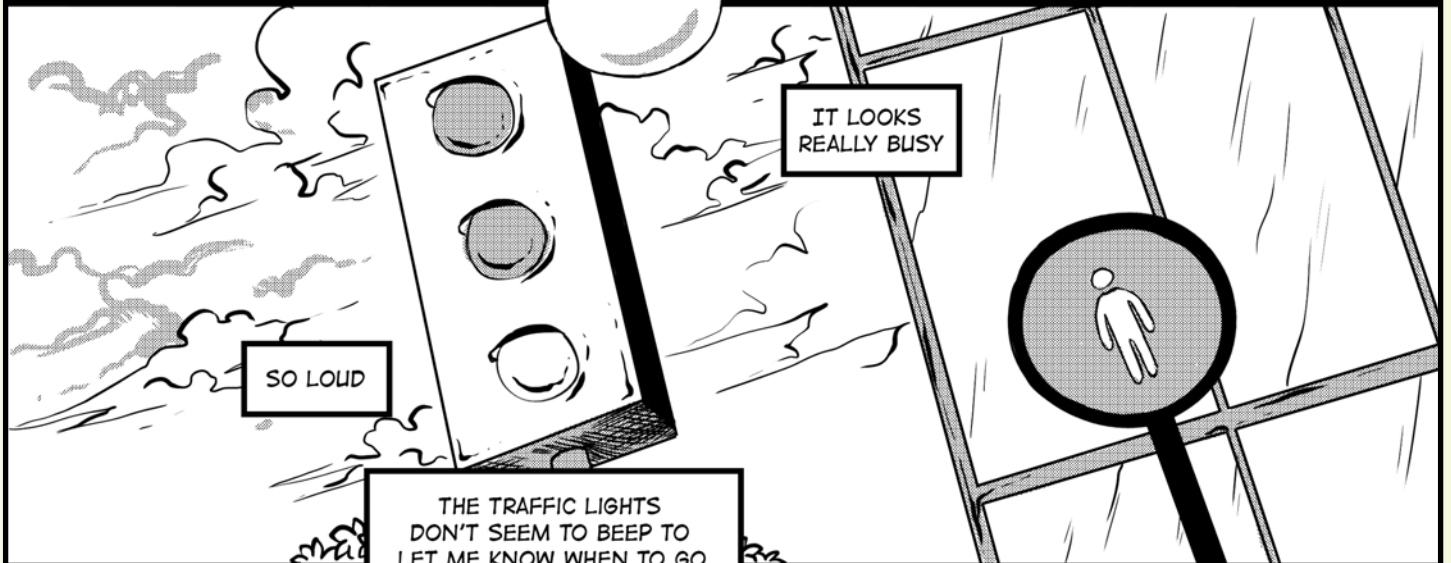
THE CITY LOOKS LOVELY...  
...AND THERE'S THE MUSEUM...

WAIT, WE WENT RIGHT  
PAST IT! DID THE DRIVER  
FORGET?



HERE WE ARE!  
THIS IS YOUR STOP,  
JUST HEAD OVER THE  
ROAD AND YOU'RE  
THERE.

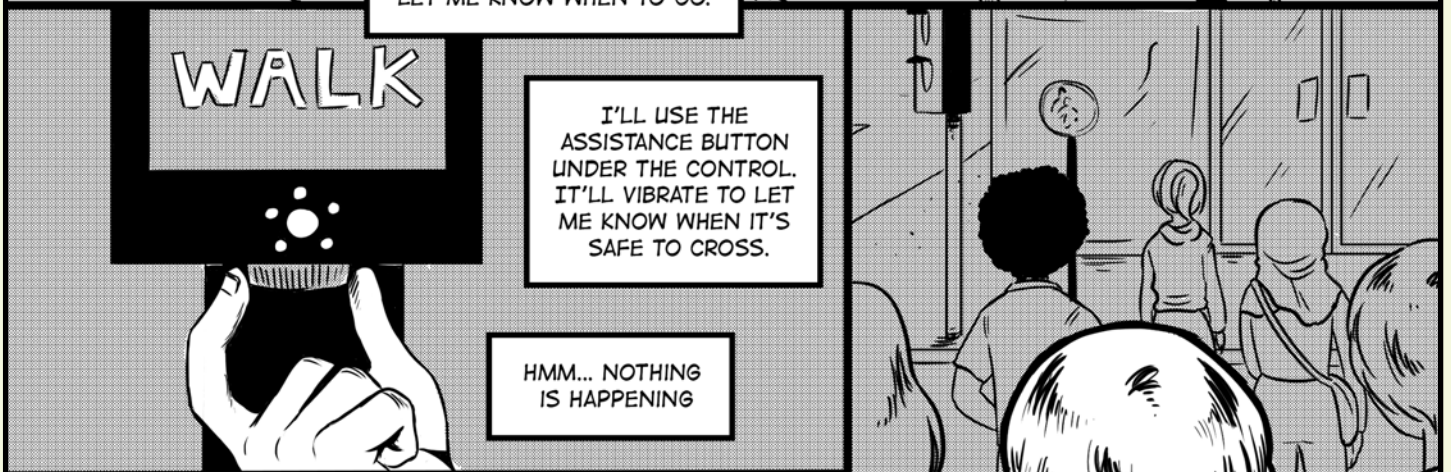
OH, THE BUS DIDN'T  
STOP WHERE I EXPECTED -  
I HAVE TO CROSS A ROAD  
TO GET TO THE MUSEUM.



SO LOUD

IT LOOKS  
REALLY BUSY

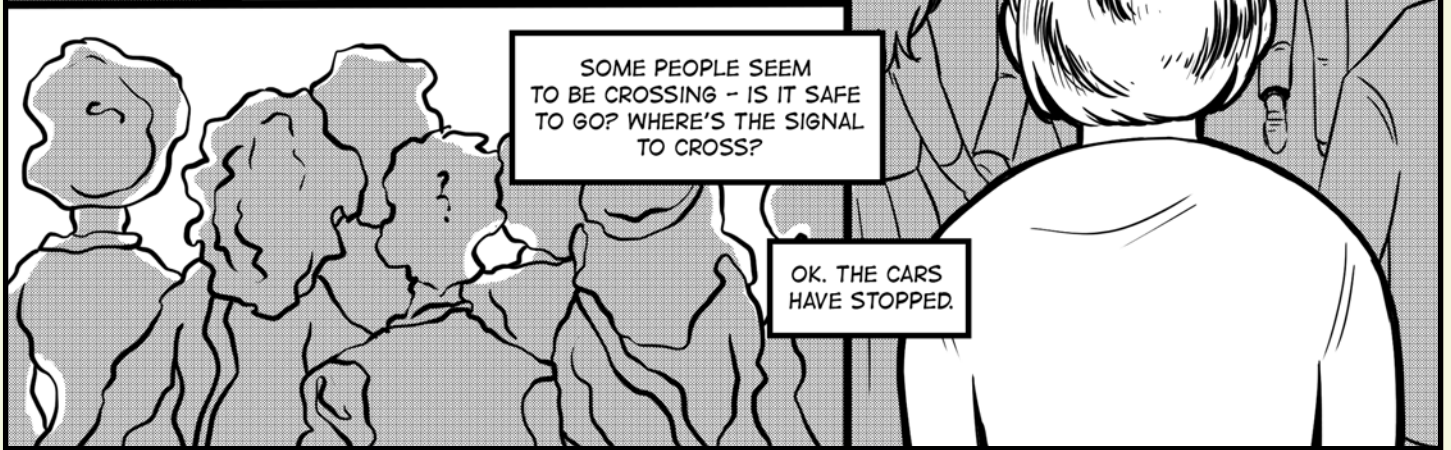
THE TRAFFIC LIGHTS  
DON'T SEEM TO BEEP TO  
LET ME KNOW WHEN TO GO.



WALK

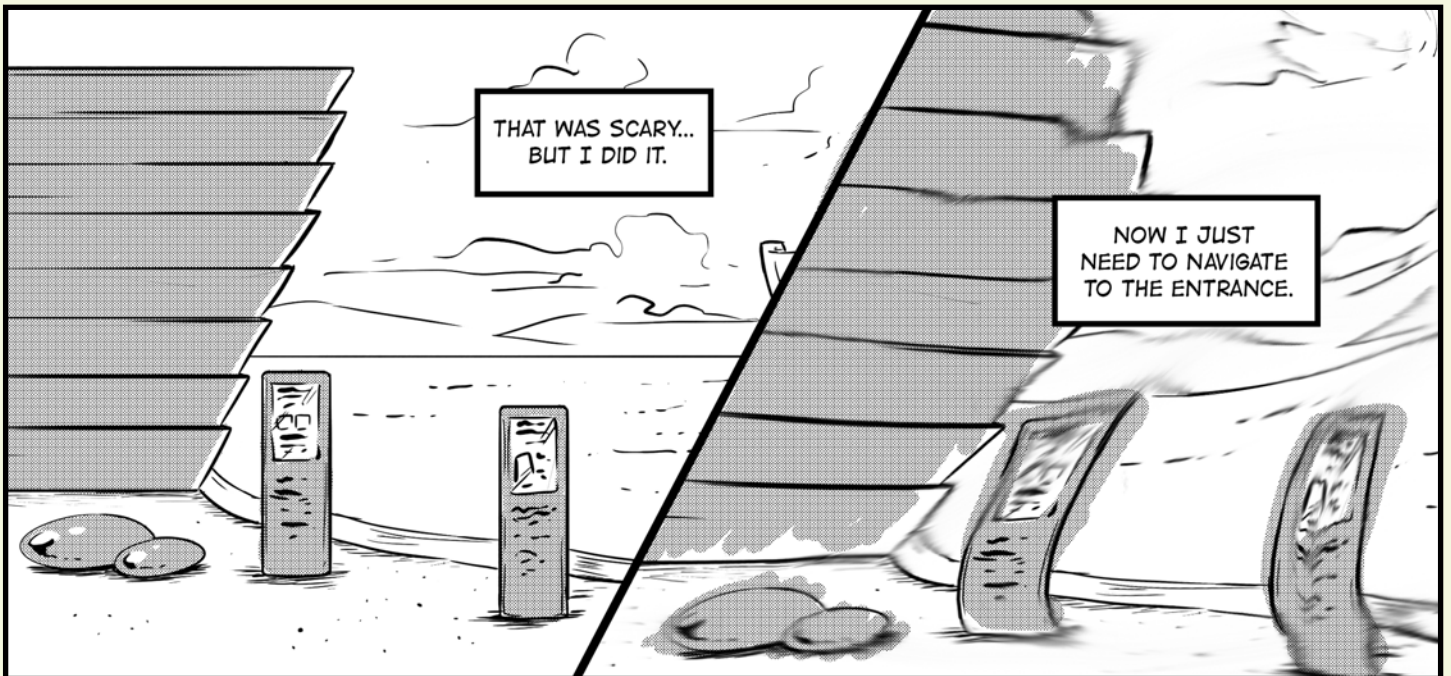
I'LL USE THE  
ASSISTANCE BUTTON  
UNDER THE CONTROL.  
IT'LL VIBRATE TO LET  
ME KNOW WHEN IT'S  
SAFE TO CROSS.

HMM... NOTHING  
IS HAPPENING



SOME PEOPLE SEEM  
TO BE CROSSING - IS IT  
SAFE TO GO? WHERE'S THE  
SIGNAL TO CROSS?

OK. THE CARS  
HAVE STOPPED.

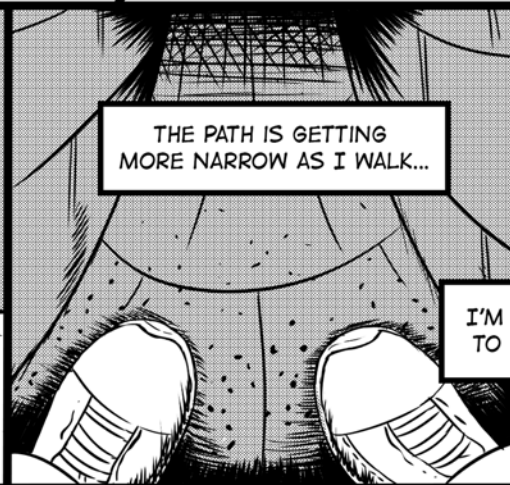


THAT WAS SCARY...  
BUT I DID IT.

NOW I JUST  
NEED TO NAVIGATE  
TO THE ENTRANCE.



IS THAT PAVEMENT  
OR WATER?



THE PATH IS GETTING  
MORE NARROW AS I WALK...

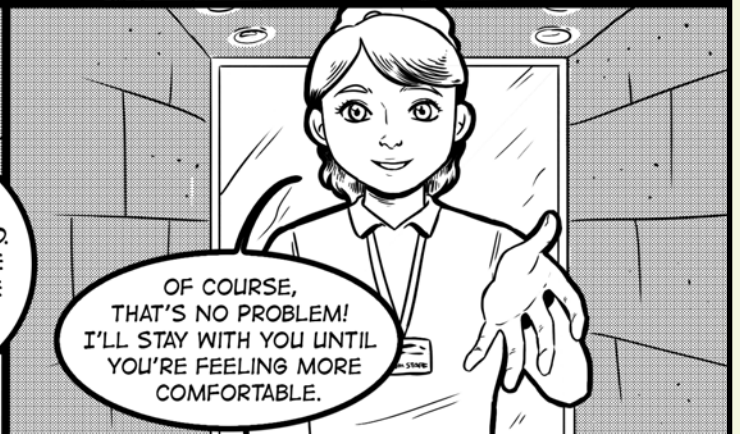


I'M SCARED I'M GOING  
TO LOSE MY BALANCE.

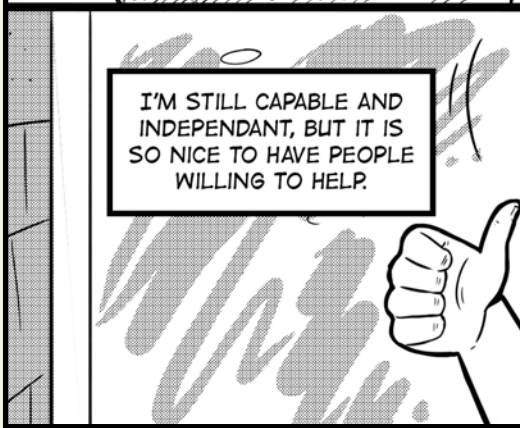


ARE YOU OKAY? YOU  
SEEMED A LITTLE FLUSTERED.

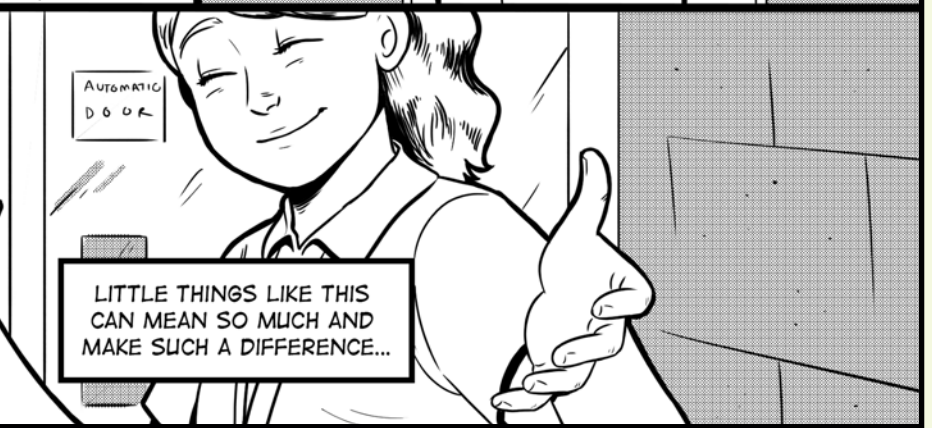
NO, I  
AM A LITTLE  
OVERWHELMED.  
WOULD YOU BE  
ABLE TO GUIDE  
ME INSIDE  
PLEASE?



OF COURSE,  
THAT'S NO PROBLEM!  
I'LL STAY WITH YOU UNTIL  
YOU'RE FEELING MORE  
COMFORTABLE.



I'M STILL CAPABLE AND  
INDEPENDANT, BUT IT IS  
SO NICE TO HAVE PEOPLE  
WILLING TO HELP.

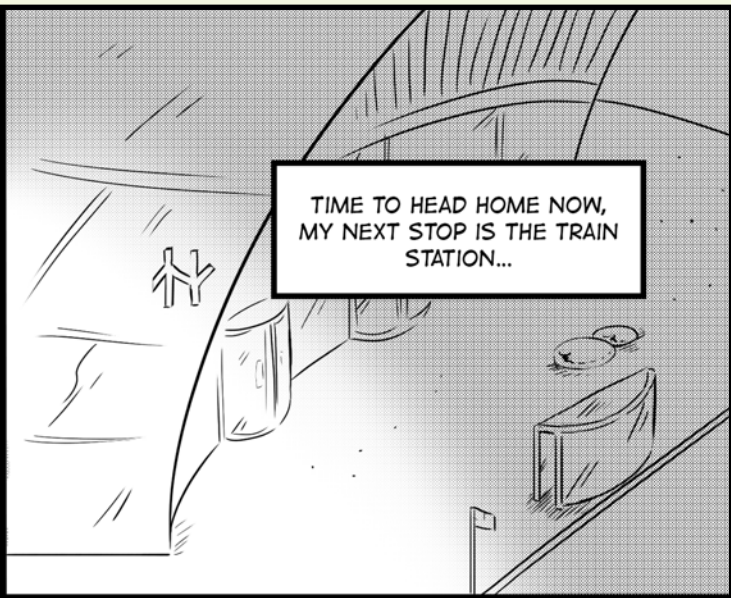


AUTOMATIC  
DOOR

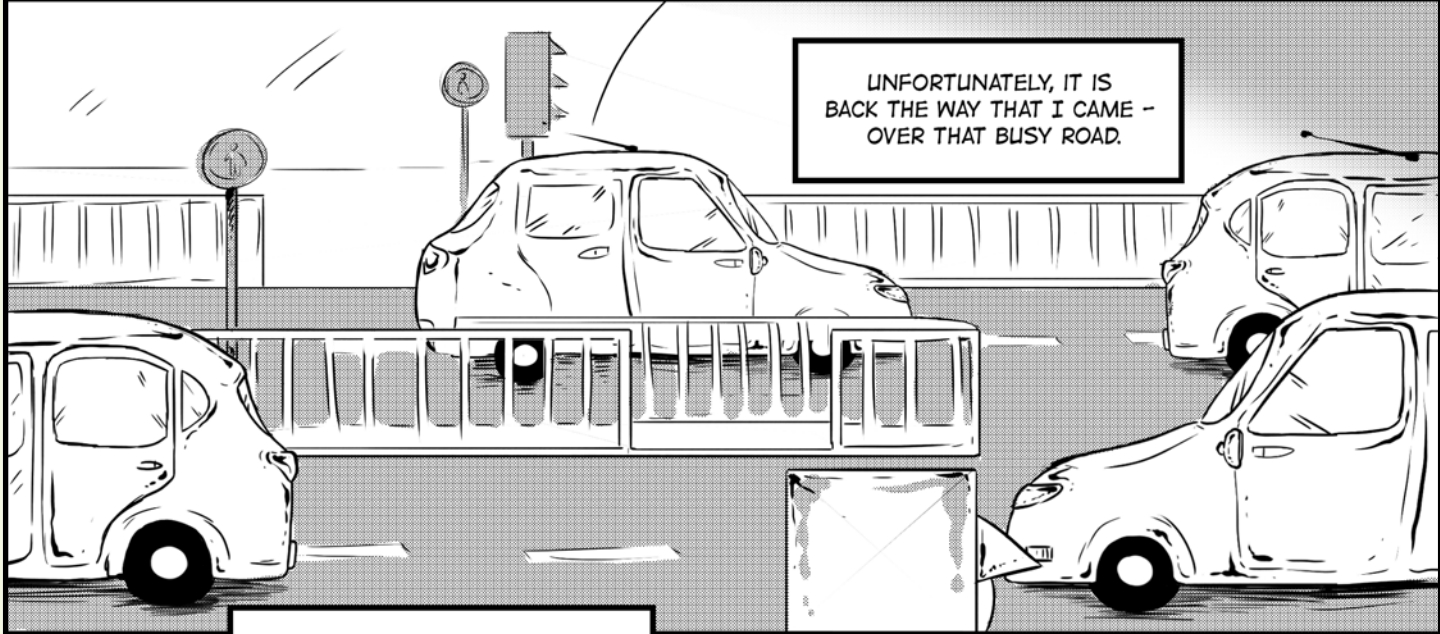
LITTLE THINGS LIKE THIS  
CAN MEAN SO MUCH AND  
MAKE SUCH A DIFFERENCE...



I'M GLAD I WENT,  
THE MUSEUM WAS REALLY  
INTERESTING. ALTHOUGH SOME  
PARTS WERE DIFFICULT FOR ME,  
EVERYONE WAS VERY KIND AND  
ACCOMODATING.



TIME TO HEAD HOME NOW,  
MY NEXT STOP IS THE TRAIN  
STATION...



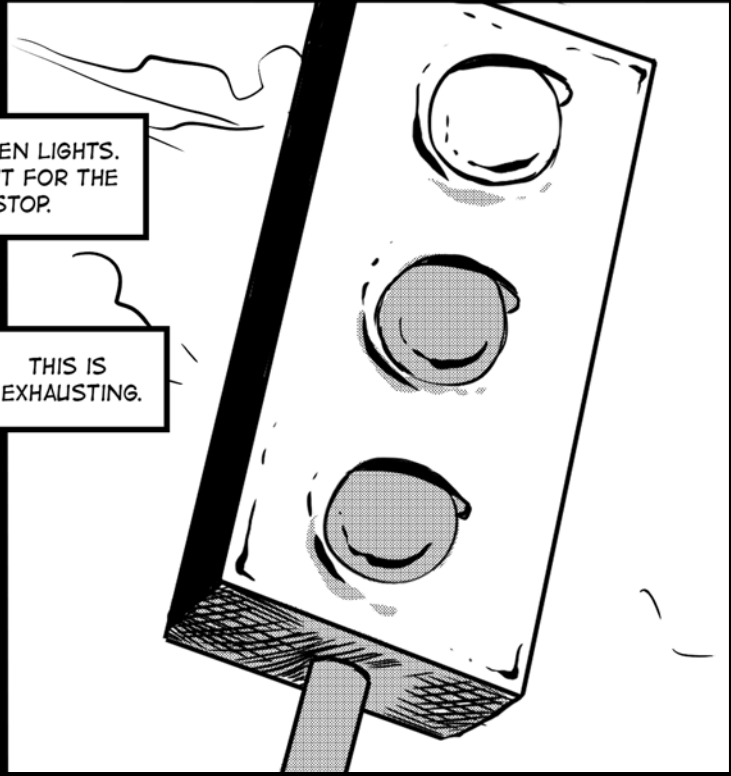
UNFORTUNATELY, IT IS  
BACK THE WAY THAT I CAME -  
OVER THAT BUSY ROAD.

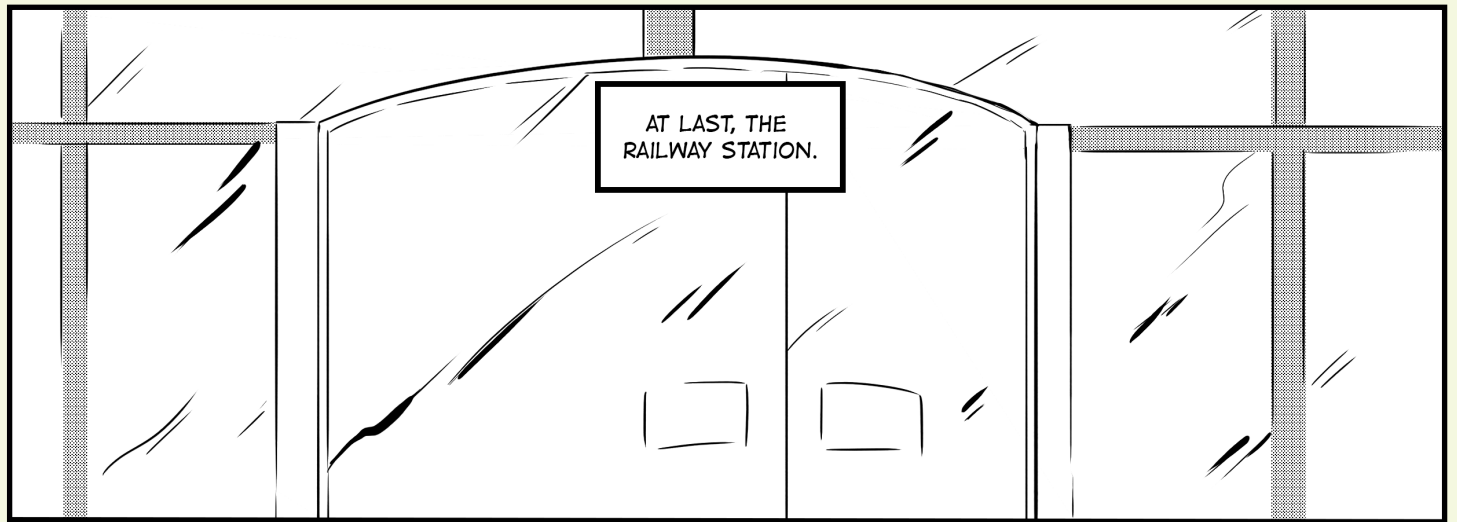


IT'S LOUD AND BUSY AGAIN.  
WHERE'S THE SIGNAL TO CROSS?

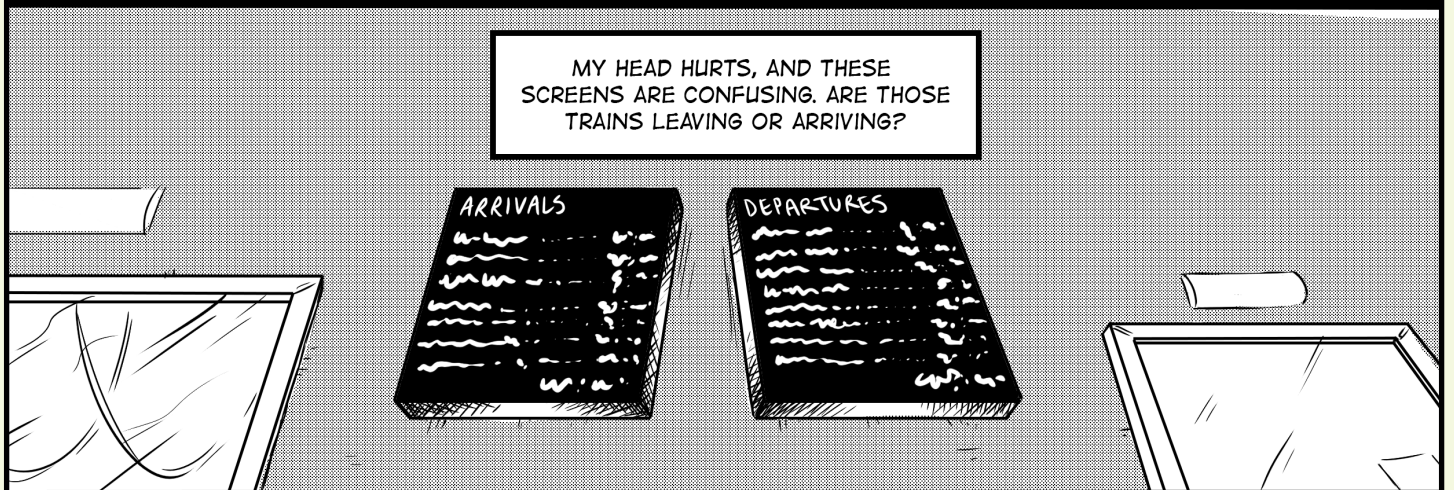
RED LIGHTS, GREEN LIGHTS.  
NO BEEPING. WAIT FOR THE  
CARS TO STOP.

THIS IS  
EXHAUSTING.





AT LAST, THE RAILWAY STATION.



MY HEAD HURTS, AND THESE SCREENS ARE CONFUSING. ARE THOSE TRAINS LEAVING OR ARRIVING?

ARRIVALS

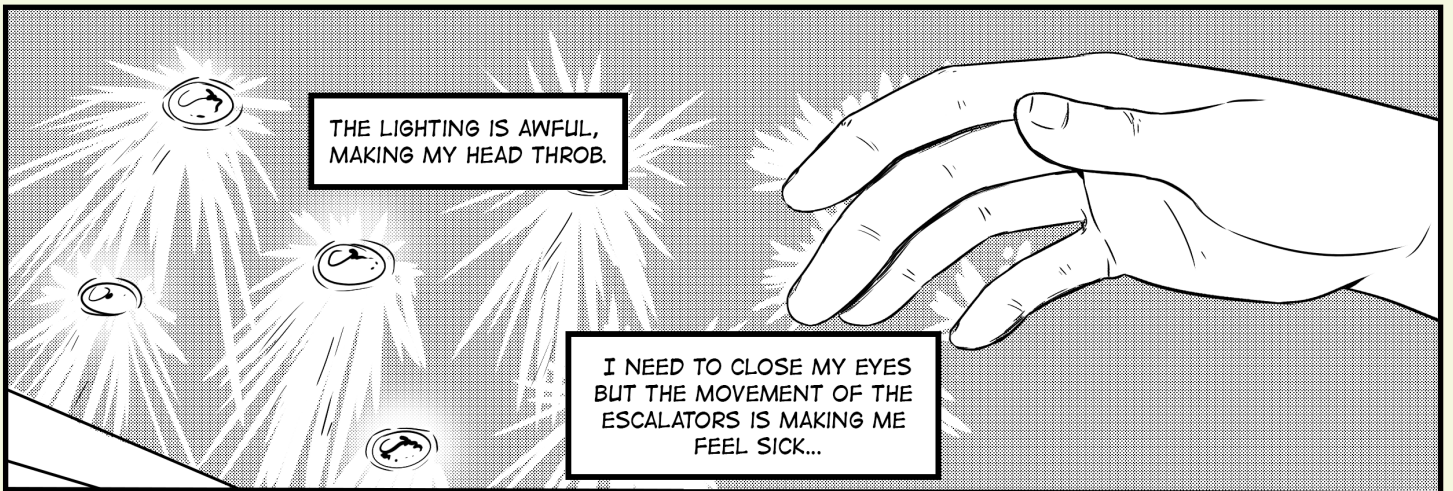
DEPARTURES



I THINK I'VE WORKED OUT THE NEXT TRAIN BUT WHERE DO I GO? NO SIGNS-



-...TO GO DOWN. OH NO, ESCALATORS...



THE LIGHTING IS AWFUL,  
MAKING MY HEAD THROB.

I NEED TO CLOSE MY EYES  
BUT THE MOVEMENT OF THE  
ESCALATORS IS MAKING ME  
FEEL SICK...

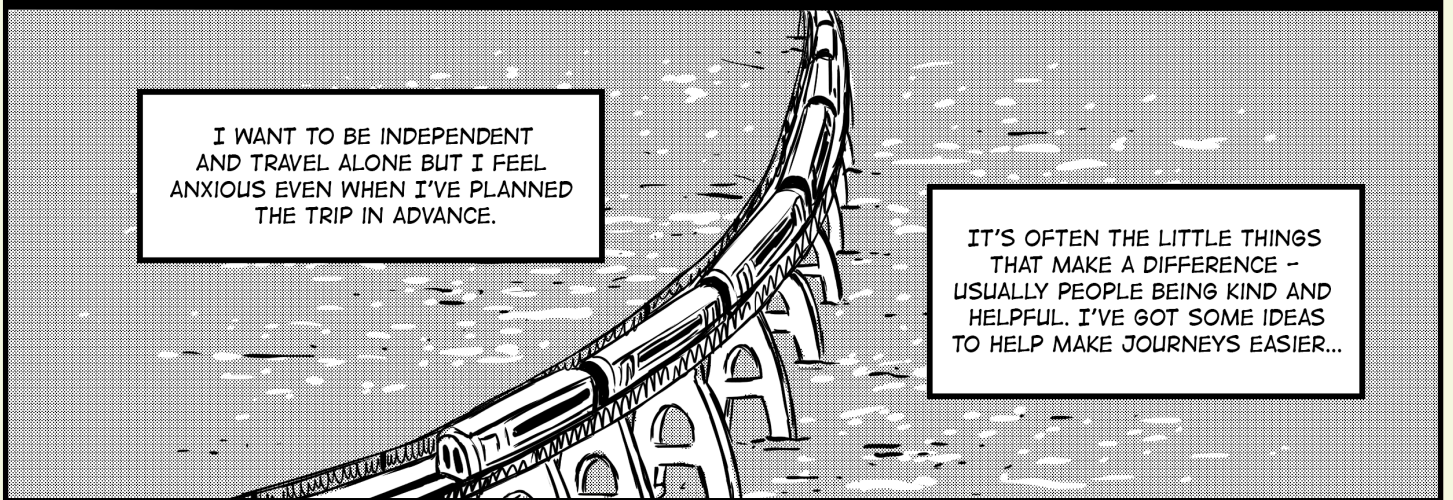


MY TRAIN SHOULD  
BE HERE ANY SECOND.  
I NEED TO HURRY.

WHERE DO I PUT  
THE TICKET?



I REALLY ENJOYED THE  
MUSEUM BUT TODAY  
WAS EXHAUSTING.



I WANT TO BE INDEPENDENT  
AND TRAVEL ALONE BUT I FEEL  
ANXIOUS EVEN WHEN I'VE PLANNED  
THE TRIP IN ADVANCE.

IT'S OFTEN THE LITTLE THINGS  
THAT MAKE A DIFFERENCE -  
USUALLY PEOPLE BEING KIND AND  
HELPFUL. I'VE GOT SOME IDEAS  
TO HELP MAKE JOURNEYS EASIER...



## What we did and Who was involved...

In late 2018 the Dementia Services Development Trust agreed to fund the development of a comic as part of its Disruption Challenge competition.

In early 2019, Andy Hyde (Go Upstream) and Phillip Vaughan (Senior Lecturer & Programme Director, Masters in Comics and Graphic Novels, University of Dundee) developed the idea further. We chose to work in Dundee because it represents the heart of Scotland's comic creativity, activity and history.

Go Upstream and The University of Dundee worked with V&A Dundee to host an initial gathering in March 2019. This attracted academics, experts in comic artwork and development, people with dementia, local city development staff and students. We used the gathering to present the project idea along with some context about the use of comics in health and wellbeing. We also did some sketching to illustrate the use of art in portraying emotion.

Following the event, Ashling Larkin and Megan Sinclair, artists and graduates of the University of Dundee Masters in Comics and Graphic Novels course met with James Mckillop, who lives with dementia, to think about how we could capture experiences and create artwork from journeys. Along with James, we were joined by Agnes Houston and Martin Robertson who also live with dementia.





## **Martin Robertson**

“I am 61, with Posterior Cortical Atrophy, (as was Terry Pratchett, hence the hat!). This means my senses (sight and hearing in particular) become easily overloaded. Bright colours, Muzak, or confusing visions such as mirrors in the wrong place throw me. My long vision is nearly non-existent so signage is confusing unless very clear, I am registered visually impaired so can relate to how those with no sight cope or not as the case maybe. I thought the comic showed my inability to cope with sensory overload very well.”



## **Agnes Houston**

“I am a dementia activist, diagnosed with younger onset Alzheimer’s Disease in 2006 at the age of 57. I campaign for best practice improving the lives of people with dementia, especially those experiencing sensory issues. I am a former Chair of the Scottish Dementia Working Group, former Vice Chair of the European Dementia Working Group and a former board member of Dementia Alliance International. In 2016 I was awarded a Churchill Fellowship which enabled me to travel to Canada and Ireland to seek examples of best practice relating to sensory challenges and dementia.

Being able to travel independently is so important to me and I am interested to see how we can use comics to describe our experiences. We need different ways to help people to understand the challenges we face and how they can support us to keep getting out and about.”



## **James McKillop**

“After a diagnosis of Vascular Dementia in 1999, I stayed at home fearful of what people would say. After support to get back out in the community, I began to understand that, despite vascular dementia, I was still a person. I realised that I would be able to help others, by talking openly, to cope with a devastating illness. This meant having to travel far and wide, and this presented new difficulties. That is why I got involved with Go Upstream and this project, to pass on my experiences. To make life easier for others, and avoid the pitfalls.”

# DRAWING FROM OUR EXPERIENCE

## STORIES OF TRAVELLING WITH DEMENTIA



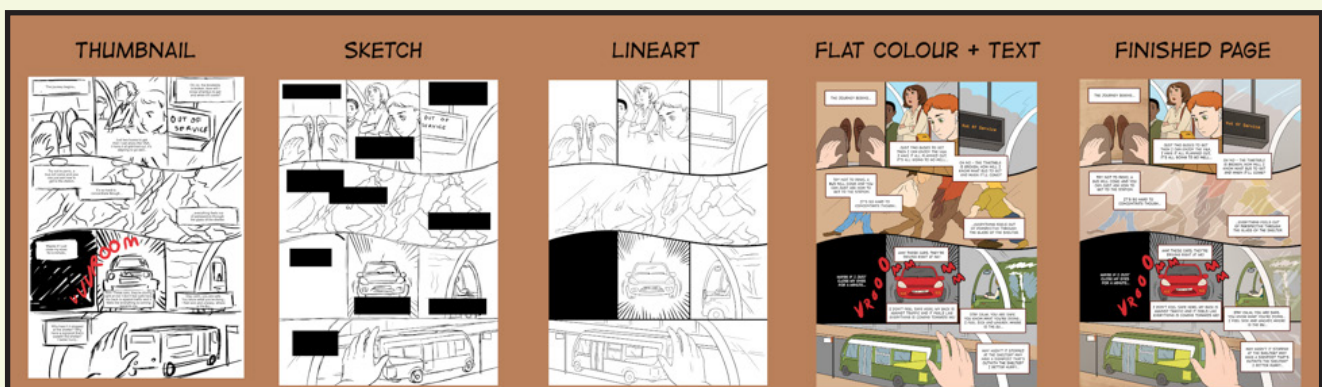
In June 2019, Andy, Ashling and Megan spent a day travelling around Dundee with Agnes, James and Martin. The group was supported by Maureen McKillop, Go Upstream intern Emma Lawson and volunteers Anna Hyde and Rosie Kenneally. We travelled in groups from the rail station, to the city centre and then to V&A Dundee where we compared notes and discussed our experiences. We took pictures, made notes and sketches.

Ashling and Megan then developed the stories and artwork in association with Agnes, James and Martin. We checked in with the group to ensure that we were creating an accurate portrayal of the experience.

In choosing a name for the comic, the project name gathered an extra word which nicely describes the representation we are trying to achieve - Drawing from Our Experience. This became the comic title.

### The creative process

We learned about the various stages of creating the story and artwork and how accessible they were for the group. Initial sketches were too 'rough' and needed more definition. Some colours in the later stages were too bright and distracting. We began to wonder if black and white lineart was a useful format to use - some people with dementia might find it easier to read? We need to test this further.



An important part of the project was to learn how we can work together to create comics that truly represent some experiences of travelling with dementia. Andy, Agnes, Martin and James began to understand the artistic process, while Megan and Ashling began to understand the challenges of traveling with dementia and how to express this through their work.

## **Here are some of the key things that we learned:**

- The stories we created focus on the challenges of travel. In the future we will begin to suggest ideas for better journeys too.
- Black and white artwork might be more accessible for some people living with dementia. What do you think?
- Sometimes pictures are better than words. We took many of the words out of the first draft.
- We chose to use the comic font for the story - it uses capital letters. We thought it might be difficult to read but found it easier than expected. What do you think?
- There are a number of audiences for this work - people affected by dementia, service providers, fellow travellers. We might need to think about telling stories from different points of view in the future...

## **Thanks**

We would like to thank the following people:

- The Dementia Services Development Trust for their support and funding
- Agnes, Martin and James for sharing their expertise and experiences.
- V&A Dundee for generously hosting the initial workshop and supporting the project throughout (your staff were so supportive during our various visits)
- Emma, Anna and Rosie for their commitment, ideas and energy!
- Megan Sinclair and Ashling Larking for the creative content.
- Phillip Vaughan, Chris Murray and Golnar Nabizadeh at the University of Dundee.

**For more information please contact:**

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The Scottish Centre for Comics Studies (SCCS) leads a research project on the use of comics for educational purposes. It has, in collaboration with various private, public and third sector partners, and working with other researchers, produced comics that communicate the findings of research, or engage the public with important issues related to healthcare, science communication, and social justice. We are proud to be working with Go Upstream in the production of this comic.

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# **DRAWING FROM OUR EXPERIENCE**

## **STORIES OF TRAVELLING WITH DEMENTIA**

Getting out and about is essential to our wellbeing, particularly after a diagnosis of dementia. We all have a right to remain connected and active in our communities and yet many people affected by dementia describe difficult journeys and travel experiences.

Go Upstream works with people with dementia and service providers, bringing people together to create a shared understanding of travel challenges and potential solutions. This work has highlighted the emotional impact of the challenges that journeys can bring. We see that journeys aren't just about the transport but about the plans we make, the people we meet, the services we use, the environments we travel through and the destinations we visit.