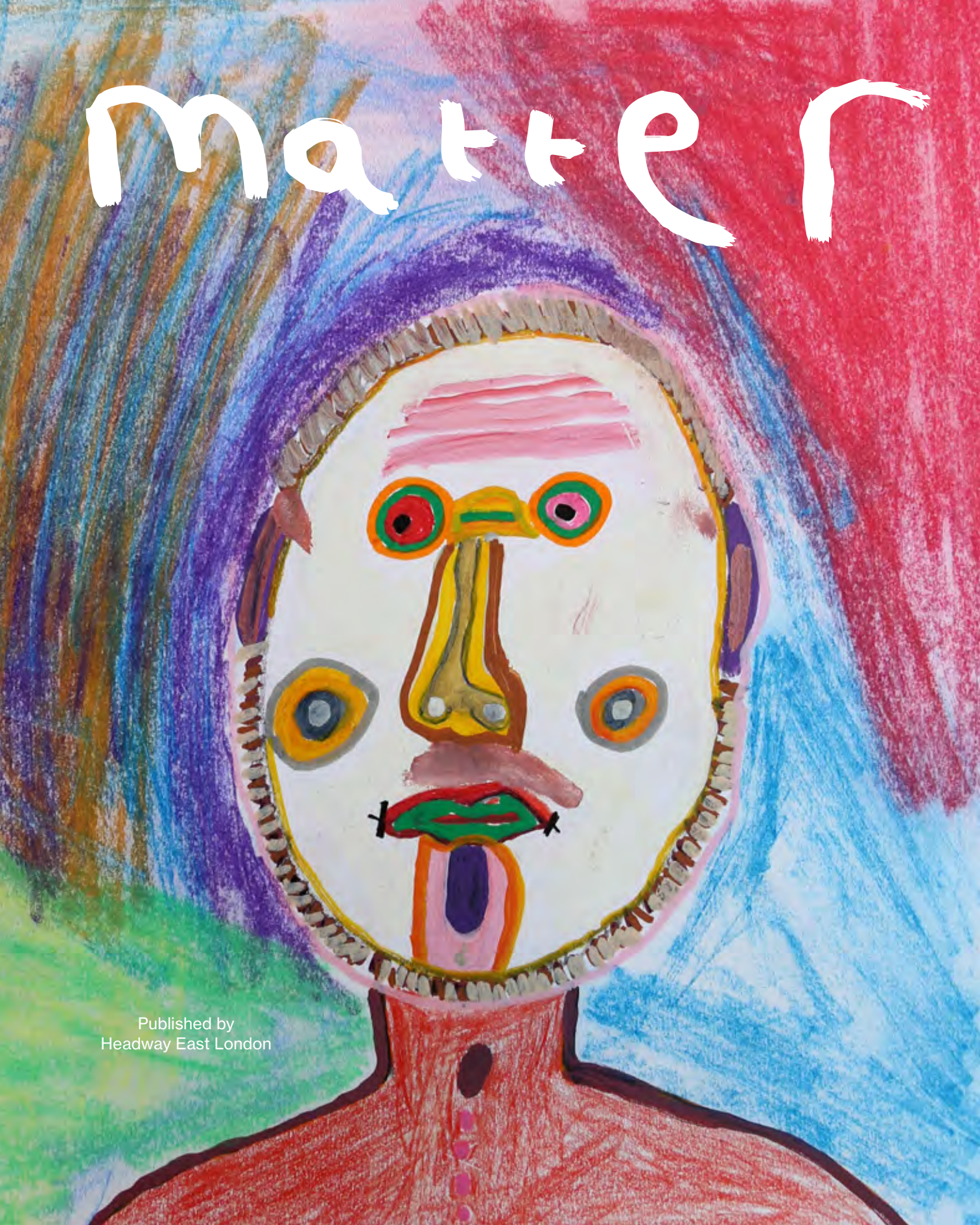


matter

Published by
Headway East London





We are a serious matter

"Nobody has lived the same life. We all have different experiences and view the world in our own way.

Sometimes this can separate us, but at other times it raises questions that bring us together, like: what gives us value, what's important and what makes us happy?"

In *Matter*, contributors with one unique shared experience explore these questions and invite readers to do the same.

Everyone featured in these pages is a member, a volunteer or staff member at Headway East London, a Hackney-based charity supporting people affected by brain injury. For many of them their injury has turned their lives inside out – their sense of self changed irreversibly by something beyond their control. The diverse community at Headway East London navigates the challenges of that experience while nurturing new roles, ideas, and friendships into existence.

Matter was conceived as a collaborative project, a collective exercise in sharing decisions as a group while still allowing individuals to explore and discover what matters most to them through their submitted works.

Covering fiction, art, music, food, philosophy and more, *Matter* embraces what makes us different and what we share; the good, the bad and the ugly – and the true value of it all.

Who are you?

STIRRERS & STARERS

(editorial & editing):

Philip Chimes, Firoza Choudhury, Bryn Davies, Affiong Day, Kitty Edwards, Josh Ewulo, Ken Hazeldine, Mike Hoyle, Chris Miller, Zara Miller, Ben Mills, Laura Owens, Rosy Ross

MATTER BUCKET (contributors):

Thomas Alexander, Tony Allen, Tony Brooks, Matt Chappel, Philip Chimes, Firoza Choudhury, Bryn Davies, Affiong Day, Stuart Donaldson, Errol Drysdale, Paul Elliot, Lesley Farmer, Paul Greenan, Quentin Goss, Brian Hackett, Ken Hazeldine, Joe Hector, Mike Hoyle, Laura Jacobs, Sam Jevon, Gary King, Cleveland Livingstone, Natasha Lockyer, Sandra Lott, Jon Lusk, Malachi, Matthew, Martin Mangan, Alix McAlister, Sarah McAlister, Yoki Mekuria, Chris Miller, Zara Miller, Ben Mills, Margi Milner, Richard Moss, Martin Mossop, Lesley Roberts, Martin Rogers, S, Sherri Snell, Evaldas Sorocinskis, Jimmy Stafford, Danny Towell, Cecil Waldron, Carol Zeniou.

PROCESS WIZARDS:

Billy Mann, Alice Snape

SPECIAL THANKS:

Leon Foggitt, Mike Poole, Andy Sewell

PHOTON WRANGLING (design):

She Was Only

PRINTED BY

Buxton Press

COVER ARTWORK:

Jason Ferry

COVER TYPOGRAPHY:

Paul Wright

INSIDE COVER ARTWORK:

Lawrence Carroll

GET IN TOUCH:
www.mattermag.org
matter@headwayeastlondon.org

Published by
Headway East London
Supporting people affected by
brain injury

Headway East London
Timber Wharf,
238-240 Kingsland Road,
London, E2 8AX

Tel: 020 7749 7790
www.headwayeastlondon.org
info@headwayeastlondon.org

Registered Charity No: 1083910



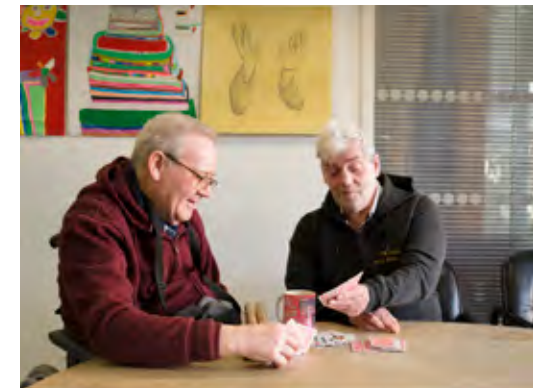
ART MATTERS

4. Brain Injury, Art, Headway and Being Human
44. Remember
46. An Excerpt from The Other World
64. Drawing Things Together
60. Aspects of British Life by a Lithuanian Living in London
84. A Mysterious Gravity



HEART OF THE MATTER

8. The People Out There, A Prayer
42. A Bridge, A Gateway, A Flash
48. Us Lot (Friendships at Headway)
56. Lina's Song
76. Three Women and I



DARK MATTER

18. Albatross (The World Beyond My Head)
22. Who Are You Now
38. To Answer the Question Who is to Tell the Story of a Life
62. People Watching
80. The Space-Time Continuum



NO MATTER

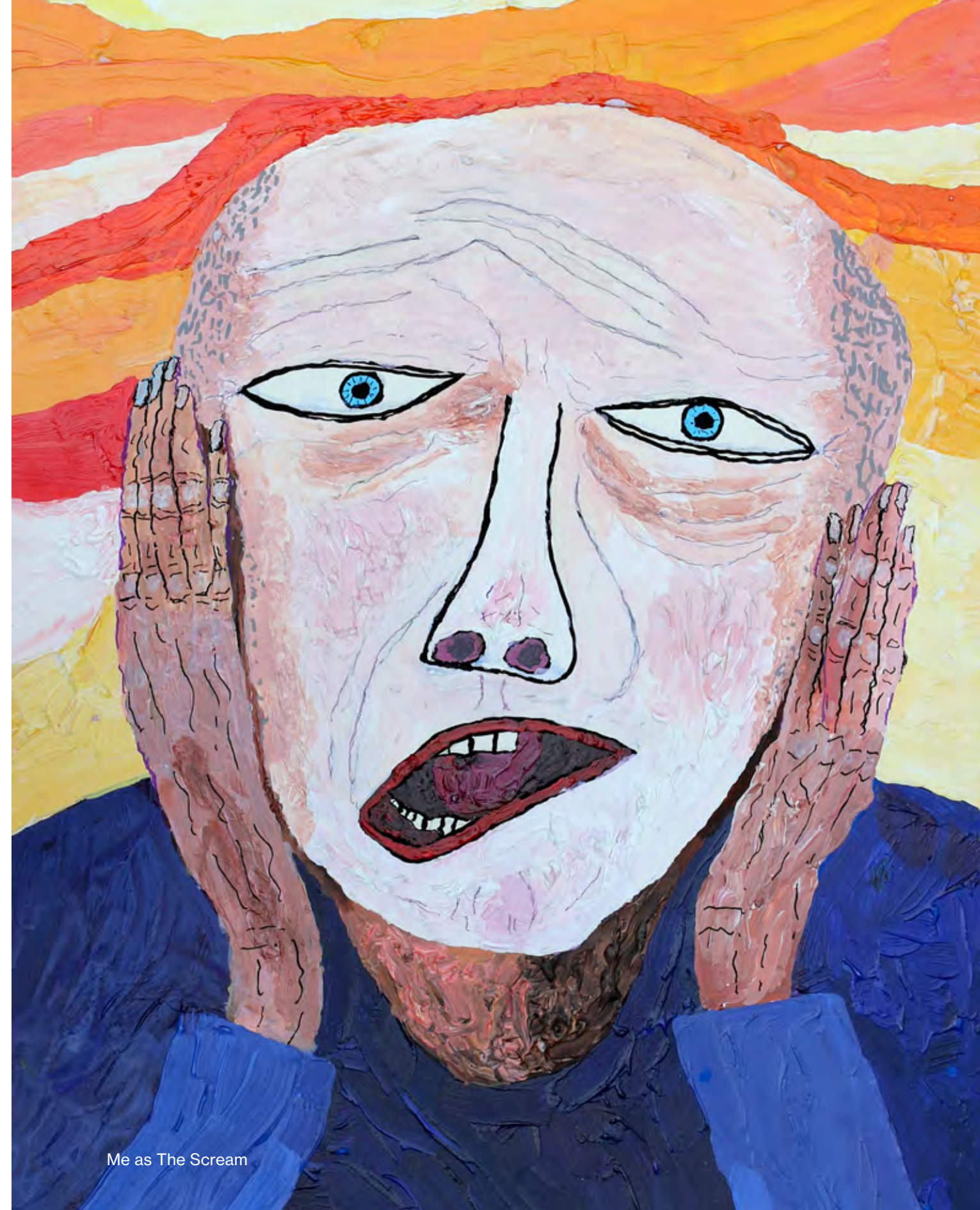
14. The Way of the Head
32. Lunch Reviews
34. Lost & Found
70. Garden Diary
88. Carol Reads the Stars



BRAIN INJURY,

ART,
AND BEING
HUMAN.

Words & Artwork by CHRIS MILLER



Me as The Scream



Me as Ophelia



Me as Botticelli's Venus

Cure, perfection and being normal?

The artist Stephen Wiltshire has an extraordinary ability which he uses to draw what he remembers. One of his most famous drawings is of the Houses of Parliament and forms part of the exhibition on the brain at the Science Museum. Stephen also has a diagnosis of autism. Is his autism an illness that he can be 'cured' from, or is it an extraordinary ability that is beyond what 'normal' people can do?

When I first went to Headway East London, as a member with a brain injury, I went to the art studio. Although I hadn't painted since primary school, Michelle, the studio manager, encouraged me to paint a picture of the Houses of Parliament. Unfortunately, I do not have Stephen's extraordinary artistic skill or memory. I had to work from photos, and I was adapting to using my writing hand again after my stroke. Even so, in my mind, there is a connection between this painting and Stephen's drawings.

Let me come clean about what I think. I look on my brain injury as a bad thing. Some members at Headway say they are better people since their injury but, for me, it is an impairment that makes my life more difficult. It is a more catastrophic version of what happens to all of us. We all have to come to terms with the fact that after the age of about 30 our bodies can do less and less. In my 20s, like most people, I thought I was superhuman. Perhaps I didn't think I would go on forever but, it would be for a very long time. That is now around 40 years ago. To be blunt, all of us are on a road towards death. It is part of our human condition. Being 'normal' can lead you to ignore the inevitability of this. On the other hand, brain injury can force you to face up to your own end. I am not decrying medical advances but, at best, a 'cure' merely puts off the inevitable for 60 years or so.

Mark Haddon, the author of "The Curious Incident of the Dog in the Night-Time", in an introduction to a collection of writings on the mind, wrote that we "fall too easily into the trap of thinking that, on the one hand, there is the healthy, functioning consciousness of 'normal' people, and on the other hand there is the unhealthy, damaged

consciousness of 'abnormal' people, people we class as ill or damaged or mentally diminished in some way. But that says more about society than about consciousness itself. In truth no way of experiencing the world is intrinsically more or less valid than any other. And all of them are fascinating and informative."

Hitler and the Nazis thought that a 'perfect' world could be created by doing away with people who did not fit into their picture of perfection. For them, their 'perfect' world would only be populated by 'normal' people, but in reality, 'normal' people don't exist! All of us have a special ability and something that is 'wrong' with us, even if it is just a discoloured toe nail, or a less than perfect face. This is all part of what it means to be human. Stephen's autism perhaps has taken him beyond the 'normal', to the superhuman. We need to listen to everyone, including those with a 'disability', if we are to find out what it means to be fully human. We must recognise that we can never create our own perfect world and to try to do so is dangerous to us, and to the whole of humanity.

What alternatives are there then to normality, cure and perfection? My answers might seem small in comparison to these big questions but perhaps they need to be small, human and incomplete: We each have to admit that we are who we are. We are not perfect and we have to accept and live with these imperfections. Cope with it. Get on with it. This might seem harsh, but we have no choice. This is the human condition.

Other people are key to helping us accept our imperfect lives. For me, Headway has been very important. Conversation, art and writing help me to stubbornly express my personality. Headway has helped me communicate my story to other brain injured people, my family and friends, medical people and the wider world. People with a brain injury, just like other people, need to have their say because we all have something important to contribute on the question of what it means to be human.

THE PEOPLE OUT THERE, A PRAYER

by LEON FOGGITT & MIKE HOYLE

In 2017, photographer Leon Foggitt visited Headway to take portraits of our members working in the art studio. His series “The Artists” celebrates the creative talent of a community – here five of Leon’s works sit alongside member Mike’s own work.

“Power to the people, the people of love.

Trying so *hard* for the people can: people in Headway and people in mental institutions.



I am the witness and discoverer of a man who had
a broken leg, broken my back, fracture, coma -
I’ve done all that.

But I’m still fighting over the music what I can love.

The people out there: a prayer;

sing, song,

dance with the arms –

have a moving with a moving: moving with a
moving the music.”

– GARY KING

“When
you

~~are unable~~
~~to speak~~
~~can’t find words~~
~~have lost your voice~~
~~can’t access language~~
are unable to communicate,

people assume
you are unable
to think”

– MATT CHAPPEL



[Matt has aphasia: his language is affected by his brain injury. This statement was arrived at collaboratively using suggestions and gesture.]



“Come out of yourself – come out of your thoughts, and think.

Think,

“I’m gonna follow this person”

– follow what they’re changing in themselves.”

– PAUL ELLIOT

“Headway has helped me to be a man:

to stand up for my rights.”

– ERROL DRYSDALE





“Thoughts of
delinquency.
Styles of lacking.”

– QUENTIN GOSS

[Quentin's work 'A
Mysterious Gravity'
is featured on p.84]



“I am
the champion.”

– LESLEY FARMER



Emails sent by Headway East London member, STUART DONALDSON, to his keyworker, Bryn Davies

[24 MARCH 2017 18:17]
Subject: Re Stuart
Dear Sir/Madam, sorry to disturb you. Just to notify you of some news concerning one of your members, Stuart Donaldson. Tragically his head was found floating in the canal last weekend and currently remains unattached to the rest of him. To deter other potential head-injury victims it's been mounted on a pole overlooking Mare Street, Hackney, where it's attracted many sympathetic and admiring comments. As a result he's presently unlikely to require your support for the foreseeable future but thank you all anyway and please keep up the good work. Best wishes,

Horatio Trout, Dredging Services PLC.
X.

[18 APRIL 2017 00:20]
Dear Sir/Madam, sincerest apologies for contacting u so very late in the evening. We have some most important information concerning one of your members, Mr. S Donaldson. Following a most disturbing incident this week in Dalston Mr. Donaldson has been placed by Hackney Council Safeguarding officers under a home detention order pending investigation. To cut a long and somewhat sordid story short he was spotted outside Spud-U-Like potato shop by first a coach load of schoolgirls and minutes later a no.253 bus load of nuns en route to a retreat. In both cases the hysteria caused led to his receiving an Asbo and home detention order, both for the safety of the general public and himself. Mr. Donaldson has had to live with the consequences of being absurdly good looking for many years both pre and post brain injury and we ask u to please treat him with compassion.

Many thanks,
Phyllis O'Hara,
Hackney Safeguarding Team.

No Matter

[29 APRIL 2017 15:47]
Subject: apology.
Dear everyone, this is an apology from Stuart Donaldson for my having sent another 'spoof' email stating that I'd been given an ASBO and banned from leaving my home because I was so good looking I was a danger to the public. If I've caused anyone any inconvenience, fear or unnecessary work I apologise. I promise not to do anything so misguided and foolish again,

Best wishes, *SD*

[23 JULY 2017 11:20]
Good morning. Father Sanctimonia here at Hackney Chapel of most tarnished and ravaged souls. Once more you have failed to grace us with your malodorous yet welcome presence. May I remind you that Lord's patience is not infinite and that you are paving your way to hell one stone at a time by refusing His call.

Good day. S.

[29 JULY 2017 16:42]
Dear customer, Tesco have teamed up with MENSA to give you a special offer.

[1 AUGUST 2017 12:17]
Thanks for signing up for the Tesco/Vatican Loyalty Card Scheme! From now on all your purchases will earn you Eternal Life Points! Only recently Dr. Theosophus Herbt, a former sinner, earned an astounding 10 years bonus after purchasing three 'boil in a bag' curries and a bunch of reduced bananas. Happy spending!

[1 AUGUST 2017 21:13]
Dear B,
Really the last this evening. An air of sadness has descended here tonight. My cousin has been visiting Ypres in Belgium and the site of the Battle of Passchendaele in 1917. I have spent an hour or so peering at photos of gravestones.

[7 AUGUST 2017 15:22]
Dear B,
Somerset House Customer Services here. We've been reviewing our records and have encountered a matter of some confusion. Can you please confirm to us that your correct surname is 'Trifle'? Thanks so much and best wishes, Florence Grout, records secretary.

[8 AUGUST 2017 21:42]
Subject: From S.
Dear Sir, once more my heart and spirits soar and I'm emboldened by your considerate, thoughtful and erudite missive. If I might just momentarily lapse into the French - 'L'homme est ne libre mais partout il est en les fers.' (Rousseau - 'man is born free but everywhere he is in chains') I thank u for echoing this sentiment so admirably.

Like u Sir I'm not 'lovin it', nor do I endorse the consumption of animal entrails in whatever complexion they may be presented. Detritus remains ever thus. Nor, to quote a recent popular rhythmic confection, am I ever 'up all night to get lucky.'

In actual fact I usually spend the twilight hours reacquainting myself with some Proust or for lighter reading the book of Deuteronomy with full colour illustrations. I wholeheartedly concur with your opinion that we and other kindred spirits must unite and resist this seemingly inexorable decline into illiterate redundant mediocrity. To quote the oft much maligned Mr. Churchill 'we must meet them on the beaches, on the landing strips, in Costcutters, Tesco, Boots the Chemist, Alfredo's coffee and fry-up lounge, Pogo's Self Righteous Vegan Restaurant, Bet Fred gambling den, even dare I say it the public facilities in Leicester Square although for this one u will have to venture alone.

Sir I must leave u now to tether the horses, polish and buff my boots for the morrow, gently but firmly admonish the servants for their tardiness of late and wind my wrist born chronometer. I wish u a peaceful, spiritually verdant and abundant eve and a night of uninterrupted restorative slumber mercifully free from intoxication, unforeseen tremors of the earth below or satanic rumbles in the firmament above,

Rt. Hon. *SD*. X



Further excerpts from the correspondence papers of STUART DONALDSON

[10TH AUGUST 2017 18:05]
Subject: Quick One from S.
Hi again B, so sorry to disturb u yet again and hope all's well. Just to say what an indubitable pleasure indeed a joy it was to see u again today at Headway, albeit briefly. May I also add how spiritually uplifting it was to see u looking so well despite your recent vasectomy. Not one to wallow in self-pity your fortitude and resilience are a beacon to all of us in these confusing times. Not so sure about the Mr.Buy rite pink and orange dayglo boiler suit however but each to his own. Finally the Doc Marten steel tipped 'Headkicker Max' boots were a brave choice. Also, thanks for the info about not being allowed to associate with other inmates outside Headway and hope my enquiry didn't annoy - I'll just have to find someone else for next week's bank job.

Brother Stu x

[11TH AUGUST 2017 20:04]
Dear B.
Take control of your life! Rid yourself of all unnecessary distractions! Buy a pair of flags on sticks, some wellies and a shower cap, and rediscover the joys of Semaphore. Bye bye, mobile, i-pad and laptop, and Hello world! This is truly wastage free. Here at Semaphore Central we hear heartwarming tales all the time. Just last week Duane Trimble proposed to Harriet Blunt on a 242 bus to Leyton and she signalled her joyful reply, just moments before he stepped off the kerb into the path of a passing hearse. Such tragic irony – but for a few precious seconds, such happiness! Waste no more time and send £75.99 to Sempahore Central tomorrow.

[25TH OCTOBER 2017 19:29]
Subject: From the White House
Dear Mr. Bryn, please be advised that Re-calcification is a myth perpetuated by the Russians to undermine and subvert all Homeland efforts to maintain a nutrient rich water supply and protect the toothpaste industry. So now you know you Limey, *Trump* x (president).

[14TH SEPTEMBER 2017 17:42]
Dear Brother Bryn, I have just stepped over the threshold of my modest but accommodating abode and felt once more moved to thank u for your spiritually wholesome and emotionally reassuring company and chat today at the Way of the Head. I'm sorry I didn't get to speak to u for longer but may I say u looked truly resplendent in that taffeta and chinoiserie ball gown.

A bit of a strange choice for a 'bloke' but 'if u have it flaunt it' as my Lithuanian child minder used to say before she was finally led away in handcuffs. Thanks too for your display of dexterity and modal transpositions on the balalaika and I promise to find the 'missing chords' before our next encounter - my memory is not the same since the Cape Verde shark fishing episode, about which the least said the better. I must now attend to my small holding and phosphorise the dahlias- a task long overdue. Please have a good evening and take care, if in doubt Deuteronomy Chapter 7 verse 16 should help.

[5TH NOVEMBER 2017]
Subject: A Sunday's Gentle Rebuke
Dear loyal parishioner, I scanned the pews in our humble chapel this morning, I sniffed the air for a whiff of your telltale underarm odour and in desperation I even prayed but nowhere could I detect any sign of you. I must assume u have absconded to resume a tawdry life in the netherworld of your sinfulness. Therefore may I gently but firmly remind u that the Lord is bountiful in His patience but His is growing a bit thin and He's anxious to begin stoking the eternal inferno which surely awaits u on your arrival 'downstairs.'

Please reconsider and return to our fellowship, your clothing modest and presentable and your head bowed in shame. I must now away to fertilise my radishes before it rains but I wish u a safe and peaceful rest of the day and evening.

Go in Peace,
Rev. Arthur Trimbald. X.

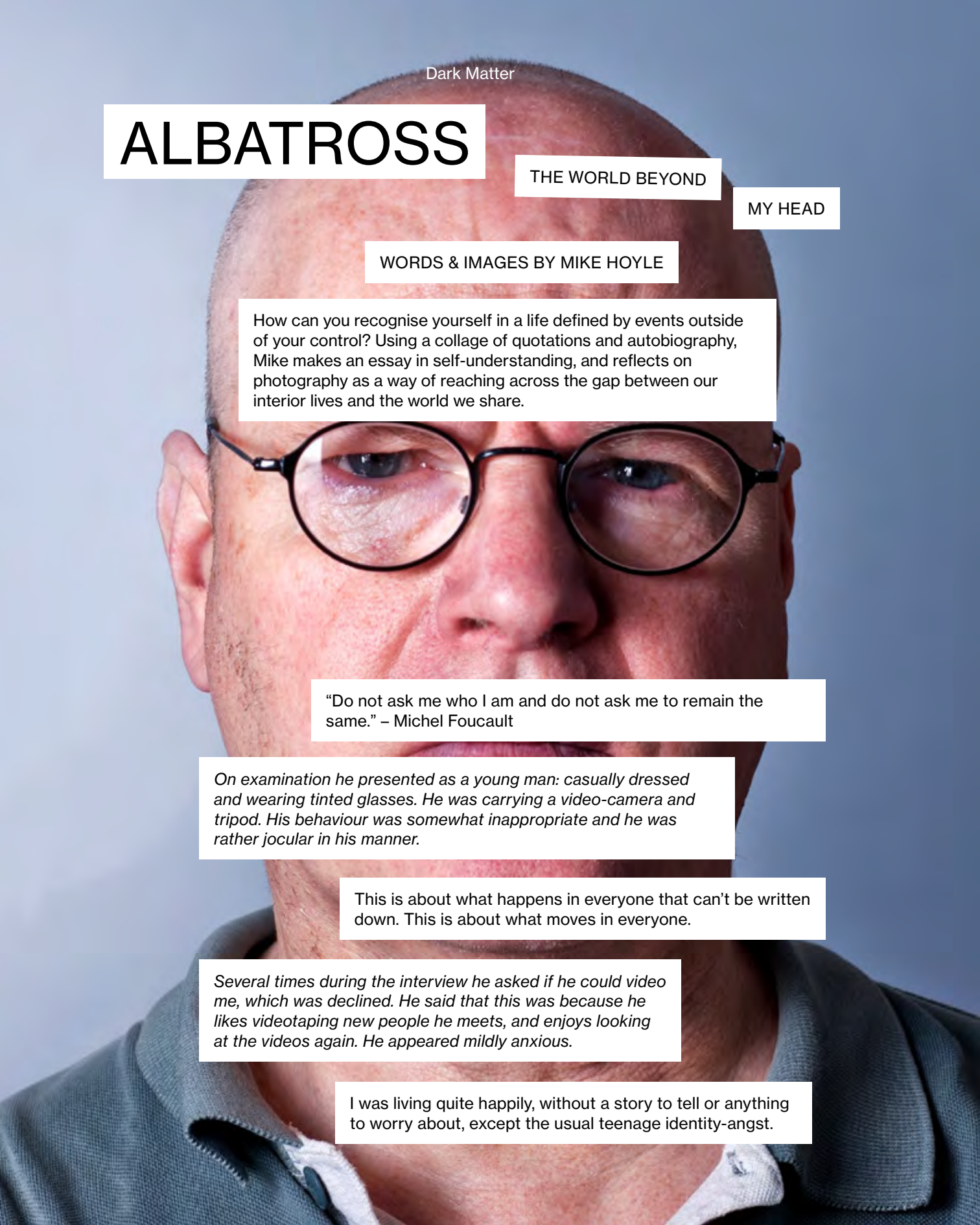
[23RD NOVEMBER 2017 22:00]
Subject: ...Continued
Dear Sir, further to my previous correspondence I can now offer u the following choices :- Right/left Temporal lobe haemorrhage £76.99 inc. Collapsed cerebellum limited time offer only £82.30 inc. 'Bonce Blowout' all inclusive brain disaster inc. Guaranteed Paralysis only £125.76 inc. *Nb. All of the above include Festive Christmas Bells tinnitus as standard! So go on, enjoy yourself!

[20TH NOVEMBER 2017 23:09]
Subject: Late Nite Health Watch
Dear Reader,
There's been a lot of talk in the press about brain injury recently, including the now fashionable low salt/ low cholesterol varieties, but its got me wondering - which one is really right for you? Are u a timid soul and tempted by a modest, economy model right temporal lobe haemorrhage or are u brave enough for the 'Double Whammy' full on stroke ? In brief, which injury is Right for You ?! These days dear reader we are spoiled for choice. Gone are the days of banging ones head against the wall. Now you 'pays yer money and takes yer choice.' Stay tuned for an in-depth summary of tempting offers- all within your budget!

Best wishes, *Dr. Alopecia Horton PhD. X*

[11TH JANUARY 2018 20:41]
Subject: Late Night Gratitude
Dear Brother in Faith and headlessness, I must confess it doth perplex me greatly that upon my return this eve from the Way of the Head I couldn't remember whether I saw u there today or not. If I did and we partook of a modest beverage or two plus a biscuit I apologise deeply. I imagine your conversation must've been riveting, uplifting and theologically accurate as always but sadly since my 'contretemps' with the hay bailing machine my memory is not what it was. I do however remember the strong aroma of fresh manure and unwashed socks so perhaps the clue therein lies ? No matter, please enjoy the rest of your evening, dine modestly but sufficiently for a man of the cloth and sleep the sleep of the brave.

Most Reverend S x.



Dark Matter

ALBATROSS

THE WORLD BEYOND

MY HEAD

WORDS & IMAGES BY MIKE HOYLE

How can you recognise yourself in a life defined by events outside of your control? Using a collage of quotations and autobiography, Mike makes an essay in self-understanding, and reflects on photography as a way of reaching across the gap between our interior lives and the world we share.

“Do not ask me who I am and do not ask me to remain the same.” – Michel Foucault

On examination he presented as a young man: casually dressed and wearing tinted glasses. He was carrying a video-camera and tripod. His behaviour was somewhat inappropriate and he was rather jocular in his manner.

This is about what happens in everyone that can't be written down. This is about what moves in everyone.

Several times during the interview he asked if he could video me, which was declined. He said that this was because he likes videotaping new people he meets, and enjoys looking at the videos again. He appeared mildly anxious.

I was living quite happily, without a story to tell or anything to worry about, except the usual teenage identity-angst.

Clearly his history is very complicated and he is not able to give a detailed outline of his past. A more detailed letter or neuro-psychometry report would have been helpful. Nevertheless I shall relate the history of the patient as he has given it to me today.

He is originally from ----- . He has little recollection of the accident that he had when he was 18 years old. He says he has lost all memory of six months from around that time.

It was a bright sunny day in the hills, or so I am told. I had photographed the wedding of a local farmer and was collecting the developed colour pictures from a laboratory in a nearby town.

His father, who was the doctor for the area, attended him at the scene.

Witnesses reported that I had zoomed past them on my motorbike towards a blind bend on which two cattle-trucks were overtaking.

He was unable to give a clear history as to what has happened to him since his accident up to the present day.

I became conscious of my father wiping my bottom. This was my first spark of awareness after the accident in 1983. It seemed strange that an adult should have this intimate relationship with his parents. After a brain injury, you are sometimes treated like a child. In a way, you have the body of a child.

From accounts of friends who had visited me in hospital in ---, my journey in this helpless state gradually formed into a story. My language was uncensored: I swore at everybody and told them what I thought. My mother was shocked. I broke a chair over my brother during an argument. These incidents alter the narrative in your head. What were you like? Were you an animal?

My impression is that this man suffers from cognitive impairment and personality change, most likely related to frontal lobe dysfunction as a result of his head injury.

Unlike in the films, recovery from an accident is a painfully slow process. There is no eureka moment when you suddenly become normal, get out of bed and continue with your interrupted life. Like Alice's fall down the rabbit-hole, recovering awareness is surreal, slow and alarming; and even now, life seems like just one accident after another. What had happened to my cognition? What had happened to my balance and sense of place in a room?

“Either the well was very deep, or she fell very slowly, for she had plenty of time as she went down to look about her and to wonder what was going to happen next.” – Lewis Carroll, Alice's Adventures in Wonderland

The process of recovery involves a collision of the private and the personal: being observed, studied, catalogued and assessed in your most intimate habits. I had read that it is better to be philosophical about life, so I read a lot of philosophy:

“Discourse is not the majestically unfolding manifestation of a thinking, knowing, speaking subject, but, on the contrary, a totality, in which the dispersion of the subject and his discontinuity with himself may be determined.” – Michel Foucault, *The Archaeology of Knowledge*

At some point after I left the hospital, I was advised to come to London by a chain-smoking, bored (or cool) woman at a ‘spectro-photography’ workshop in my nearest city. I managed to get into a London university, where I learned the theory behind the power of the photographic image. This was my rehabilitation back into the world of the arts. Photographs anchored my identity: through them, I was able to create a story of my past life. I was introduced to philosophers who wrote on the psychic subject; the history of the treatment of mental illness; truth, reason, and knowledge.

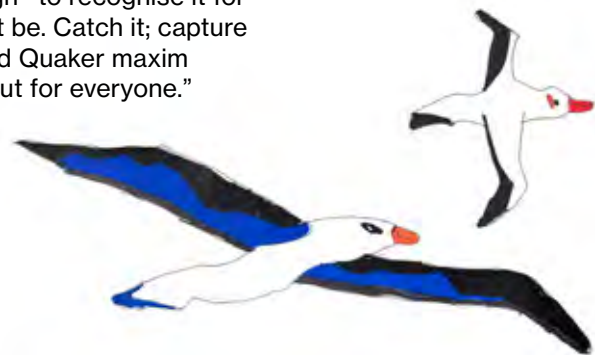
“The idea of eliminating all personal elements of knowledge would, in effect, aim at the destruction of all knowledge” – Michael Polyani

At some point it was suggested that I should live on disability benefits for the rest of my life. I was ashamed. I had come to London to educate myself and find meaningful employment, only to be told I was too damaged to make a meaningful contribution to society: a useless unproductive albatross around the neck of every working person in Britain, trying to compete against the rest of the world in the ‘new global economy’.

I still have *perseveration*, or the persistence of a single thought, making me repeat the same thing, with a loss of what the medical jargon calls ‘flexible thinking’. When your disability is cognitive, it is hard to separate your problems from madness or insanity, and in popular culture, madness is used as a metaphor for otherness. There is a certain stigma attached to mental impairment which is not connected with more ‘heroic’ disabilities, first in line to be made bionic with their state-of-the-art articulated limbs.

After the death of my old self on the northern roads, I have been given a second chance at life: reborn, in a disabled body, with a troubled memory and an anxious mind. This second chance is about rewriting my own history,

What do you do when you cannot compete, in a world which is all about competition? You have to view life philosophically. The past is dead, but not gone. Try to live in the present moment, if only you are fast enough – unimpaired enough – to recognise it for what it is, and not just what you think it might be. Catch it; capture it; as a photographer tries to do – with the old Quaker maxim ringing through your ears: “Not for oneself, but for everyone.”



Albatross by Evaldas Sorocinskis



WHO ARE



YOU NOW?

During 2015 and 2016, Headway East London published a series of stories about the lives of brain injury survivors. This is a slightly edited version of one of those stories – narrated by SARAH, who survived a brain injury in 2002, and her youngest daughter, ALIX, who cared for her during her recovery. Co-written by ALIX McALISTER, SARAH McALISTER and CHRISTINA PETRIE

1 SIMPLICITY (SARAH)

My grandfather clock needs to be fixed. It doesn't strike the hour and that's usually something that measures my feeling of time. But I don't actually see that as a big negative. I can always find out what the time is. Light and dark, day and night, the seasons and my radio; I think they are a very practical way of functioning, especially when you are my age of seventy-five.

I think all of us change ways that we function over time. Imagine when you were a little kid; you experience time in a different way, you're learning so much and so fast. You notice different things as you get older. You think, 'Wow, I've come past here hundreds of times but I've never noticed that before.' It might be some feature on a building or a change in season. Look at us now; we're on the last day of February and the evenings are slowly but definitely getting lighter. There are very lovely signs of bulbs and other plants coming up.

I often wonder if I am different now from how I would be if I hadn't had a brain injury. I'm not brilliantly good managing time and I do feel I can waste many a day. Partly, I have found that to be the case since the brain injury, which was twelve years ago now. But I'm not sure I was ever particularly good at it.

The way that we get things done on time is important, especially when we're dealing with children or trying to get something made. One of my jobs, about thirty years ago, was to write a listings section for *Time Out* magazine and you had to get the copy in by a certain time every week. My deadline was something like 5pm on a Tuesday. One day I didn't get the things I was meant to be writing in at the right time. The next week *Time Out* came out without my bit in it and there were a lot of complaints from buyers of the magazine. Imagine if it had not been just my listings for a magazine that were late but something more serious.

Today, when I was slow in making the tea, it was partly because I'd forgotten I was making a pot of tea for you and me to share. Normally to do that I would put two teabags in but I forgot and I put in one bag and when I poured the tea it was a bit weak. It was a perfectly good cup of tea in the end, thank goodness, but it took me longer than I thought.

I am, in my own way, running my life, but also I feel it's a complete muddle. I speak to my daughters on the phone every day. They give me very good practical ideas when I feel confused, which helps me make decisions and not regret them. A support worker - a friend of my daughter - comes once a fortnight and helps me organise my diary and all the things that are going on, or book tickets for trains and that sort of thing - very helpful. And I have a cleaner every fortnight for two hours.

I have all these boxes with old stuff in them that need sorting out. Who's going to make a programme to do that? I want to sort out all the things I have so that I'm in a room with a table, with the absolute basics of what I need to live – what, in my own mind, I know is necessary. The other things I'd like to give away to people I like or who want them.

Simplicity may not seem to be a big responsibility or a need but, in a funny way, it is. We need to be able to convey thoughts.



My calendar - Sarah

2 IN OTHER PEOPLE'S HANDS (Sarah)

My head injury was in August 2002. I was sixty-three when that happened; I'd just had my birthday. How much more devastating it would have been if it had happened twenty years before. My two sons, Dan and Ben, and two daughters, Leila and Alix, were grown up; if they had been very young it would have been more desperate, for me and them.

When you get an injury like that and you are in hospital for four months, as I was, you're in other people's hands. You're reacting to whatever happened to you; you don't realise everything that's happened. So it's only now that I feel hugely thankful that I was lucky enough to have my offspring and good friends to help and that I was in a good hospital. Without the help I've had, I'd never have got back on my feet. I'd be even more different from what I am now and from what I remember.

I know that my family had arranged a get together to say goodbye to me for going away to teach with VSO in Rwanda for two years. We had had a party in my former partner Bill's garden. I don't have any memories of what actually happened on the night of the injury. I've seen photos.

I know that the party finished late and I was on my way back to my flat, which was a couple of roads away. I was walking home with a friend, Vlasta, who had come to visit us from Prague. Walking in front of us were my daughter Alix and Miguel, a boyfriend of hers from Portugal. Vlasta has told me that we were just walking along chatting. Suddenly she looked to the left and I wasn't there. She turned around and I was struggling with a man she didn't know.

He pulled my bag from me and then he must have pushed me. I fell into some railings along the side of the road, bashed my head hard and was unconscious. Alix and Miguel turned round and realised I was injured and Alix used her phone to call the ambulance and the police. It just happened one thing after another. Miguel apparently ran after the man who had taken the bag, who went along some paths and then into a flat.

The ambulance and police were not terribly long – it must have been minutes. The paramedics took me to the Whittington Hospital. They did some tests on me and said "She's got a severe head injury and she needs the National Hospital for Neurology and Neurosurgery". So all those arrangements were done without any of my knowledge and I had an operation that night.

My son Dan has told me that a few days later it seemed another operation might be necessary. The family and my friend Sue, who is a doctor, gathered together at the hospital to discuss it. It must have been a difficult situation. Dan asked the neurosurgeon, "Would you recommend this for your own mother?" and the surgeon said yes, he would.

I can't tell you the details because I don't know them. You'd need to ask the doctors or my family; they would have a clearer picture.

3 I'M OK (Alix)

I was walking home with my mum when she was attacked. The whole thing took maybe a minute. She struck her head on the curb and was out cold. She didn't come round until two weeks later. They first operated that night, to release the internal bleeding that was putting pressure on her brain. A few days later she had a second life-saving operation. They removed part of her left frontal lobe (that was bruised and swelling) and cut a hole in her skull to act like a pressure valve. Her surgeon discussed the consequences with us - that she may lose many higher brain functions. Two that stuck in my mind were losing language or not recognizing her children.

She remained in a coma for a long time. They tested her on the Glasgow coma scale, and she recorded the lowest reaction, a 3 - just moving her limbs, kind of turning out her hands and feet in response to pain. This went on for long enough that the doctors had basically written her off. Phrases like 'Permanent Vegetative State' were used. We were told they had referred her to Putney - that's the neurological hospital where people who don't recover go.

We pleaded with them to let her stay in the acute injuries ward. I think it was a combination of things: believing that she was in there somewhere. Not being ready to confront this future the doctors were painting. Not wanting her to be moved miles away from where we lived. We were coming in every day, taking it in turns to sit with her. We asked that she could stay a few more days, just for us to sort ourselves out. We really were pleading. They agreed to three days, I think.

That was when she first moved a finger in her right hand. Soon after, she opened her eyes. I can't remember the time lag between these events. You lose perspective when you sit and wait for hours on end. Next she moved her hand enough to use a pen. She wrote the note: 'I'm OK.'

That note said so much to us. Firstly, she was saying she was conscious and alive. Secondly, she had chosen the most concise and efficient way to communicate. This was evidence of a higher faculty at work, to make that rational choice. And thirdly, it was typical of my mother. To be concerned about us, and say something to make us feel better. She wasn't bloody ok. She was semi-paralysed, couldn't speak, didn't know what was going on, but she still wanted to reassure us.

23/9/02
Monday



For my wonderful Ma
I am thinking about you
even when I'm not here
Tons of love
Veronica

4 LITTLE SCRIBBLES (Sarah)

Slowly, over the next four months in that hospital, I began to recover. My huge praise and thanks for their skills - and the skills also of my family and friends – visiting and helping.

I don't have memories of the time after the injury. The thing I do have is the visitors' book my children gave me while I was in hospital, which is a very precious possession.

In that book there are things that show how I was getting better because there are weird little scribbles I have put in when I realised I could do something. People would write things that they realise you couldn't do last time they came, and of course I wouldn't remember the sequence of those without it.

There are messages from close friends, neighbours, work colleagues; people I knew in many different ways. It makes you realise what a difference it makes to go and say hello to someone when they're ill. It does make a difference to your life, however bowled over it is at the time.

5 SHE'D CORRECT THEIR SPELLING (Alix)

Sarah was conscious but had post-traumatic amnesia: her memory lasted about fifteen minutes. She knew who she was and who we were, mostly, but didn't know where she was or what had happened to her. She'd need it all explained again and again. I remember nurses writing her notes. She'd take the paper to reply, but first she'd correct their spelling and grammar: they would have misspelled 'subdural haematoma' so we knew that the fastidious Sarah, the knowledgeable Sarah was in there.

Finally she was assessed and accepted onto the National Hospital's rehabilitation unit, which at the time felt like a huge victory, like she'd won a prize. We knew that their unit was amazing, and that she was doing incredibly well if they had accepted her. She was staying in this place that we all knew really well by then.

The medical staff treated her case like some miracle. Doctors and nurses came to see for themselves, as if they didn't believe it. For years after, when we went for outpatient appointments, staff would come and say hello and remark on how extraordinary her recovery was, and tell colleagues who didn't know: "this is that lady who we thought... the one I told you about."

On 6 December she was released into our care. She still couldn't walk unaided, feed herself, dress herself, go to the toilet. Someone still had to sleep in a bed next to her for when she woke in the night. I'm one of four children. I did four days a week, and they each did 24 hours. That situation lasted for about eight months. Gradually, slowly, Sarah gained more autonomy. After eight months she could walk unaided, but not go out alone. Someone had to be there through the night, but they could be in another room. After about three years she was living in her new flat alone. Of course with much help and support, but living alone and sleeping though the night without needing help.

Throughout all of this time I don't remember my mother getting angry, or frustrated, or feeling self-pitiful or bitter or depressed. She had a childlike appetite to re-learn things. She laughed a lot. She'd get the giggles that she couldn't stop, that made all her muscles relax to the point where she might collapse and hurt herself. But it made us laugh too. Her disposition made caring for her so much easier. During our time in intensive care, on the wards, in the rehab unit, we'd seen other patients and their families and we knew how lucky we were.

6 THE FUNDAMENTALS OF LIFE (Sarah)

What are the things we need - the things we could not manage without? We all need somewhere to live, a home, our own space. I grew up in a family with Mum and Dad, four older sisters and two brothers, one older, one younger. We lived in a semi in a town between Bristol and Bath. There were always other people and other things going on. Even if you were doing your own thing, it wasn't like you were alone, whereas many people grow up with much more of that individual space and time. So we need a place. I am realising more as I get older that I don't want it to be too noisy.

We need food and water. We need to be able to move and to carry things. I depend on other people for a lift at the moment. Since my head injury I don't drive a car, but I'm glad I could do when my family was smaller, otherwise we wouldn't have got to a lot of things that were a great joy to go to. I had a small Volkswagen Beetle which I got when they were quite little - my dad lent me some money to buy it.



This is me with my brothers and sisters in about 1945. I'm the little one in the bottom right corner.
- Sarah

I feel I can still move around. I'm certainly slower now. I can't run for a bus like I used to. I don't use a bicycle anymore. I can still ride one actually but functionally it wouldn't really be a sensible option. I go once a week to Pilates and I am lucky because it is paid for by my compensation. I really feel it keeps me moving well.

We all need some sort of income. We must be able to get food and clothes. I need a pension as I am not working now and haven't worked for money since my head injury.

We need to use our time. The regular things I do are not very many but they are really important to me: guitar lessons, a monthly book group. Guitar is not my profession but it's just my love of doing things in life, regardless of whether your skills are such that other people like them and want to profit from them.

This week the spring-like weather brought me back to the allotment. It's funny how much it becomes part of your daily life because it is your particular given space and it needs ongoing simple, practical things like digging and weeding and clearing and planting. It's quite a lot to cover for one person, especially my age.

I did lie in bed one day thinking 'do I really need the allotment?' but there is such a pleasure in picking your own things and in using them, making things like crab apple jelly and sharing them with family. So I think at the moment I will keep it going.

7 THE NEED FOR TAXIS (Alix)

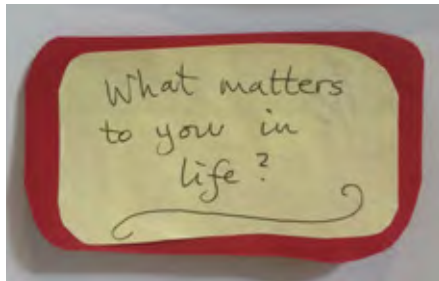
I speak to my mum every day, often many times a day. For at least six years after her injury, we used to write a weekly schedule for her together. If she was going to a guitar class, for example, we'd work out what time she should wake up, how long to get ready, the time to leave, what time she'd need to have her rest, set the reminders on her phone, and book a taxi to bring her home.

We disagreed for many years about the need for taxis. My mum has always seen them as a luxury or an unnecessary expense. But when she's tired, or something has been intense, her balance is worse and her walking is unstable. Mostly she can't recognize it, even when you see her lurching and point it out. So we book her taxis. If she says she doesn't need it, we ask her to do it for us, her children, so that we won't worry about her. That's a reason she accepts. And in the past few years she has accepted it as part of her life. She'll organize it herself now.

Often our phone calls are about little decisions that cause confusion. She can have an erudite conversation about the book she's reading, then talk about waking up in the middle of the night and listening to the birds, and they all somehow become fused with a decision she needs to make. I'll talk it through with her, firstly working out what the decision or dilemma actually is. It might be buying a train ticket, and then separating her reactions to the book from the need to buy the ticket. This will take twenty minutes or so.



This is our best family photo. It was taken in 1977 by Paul McNicholls, a photographer Mum knew from Time Out. That's me in the bottom right corner.
- Alix



I wrote this. It's stuck to the wall in my loo. - Sarah



We'll come to a decision and work out when and where she will get the ticket. She'll be much relieved and say how good it was to talk to me. On days when she's really muddled I tell her to just leave it, go have a rest and I will pop round later to talk. There's no point going over things when she's not in the right frame of mind.

It feels like my mother is interested in everything. She finds people fascinating, engaging in full-on conversations with strangers and friends alike. But sometimes she has problems with working out boundaries. And she doesn't want to cause trouble for others, or be a burden. Her default mode is not to ask for help, but then she'll try to do something that's beyond her and get in a pickle. So we remind her to call us. Just give us a ring. It's better for us to do a small errand for her now, than spend three weeks looking after her because she's had a fall. We use her fear of being a burden to persuade her to rely on us more.

It's like my mum is the swan swimming elegantly above, doing all her interesting activities, and my sister and I are the feet, paddling fiercely underneath the water.

8. ACROSS EUROPE, THROUGH TURKEY AND INTO PERSIA (Sarah)

I meet my grandson, Ruben, at school on Mondays at the moment, which makes it more practical for my daughter Alix to get her plans going. She works three days a week and she needs help on those days so that she can continue her work. Ruben finishes school at half past three and the school is not too far from here so I usually meet him and we come home together.

Usually he has a half hour guitar lesson - which I pay for and is not hugely expensive - with a lovely guy who comes to my place so I don't have to go out, someone I luckily met through my other daughter Leila. So that is one of the things we do. We play Ludo or canasta - those odd things you used to play when you were a kid - and do jigsaw puzzles and that sort of thing.

Sometimes he sits on a cushion and reads the old kids' books I have got leftover from my boys and girls, mostly Tintin or Asterix. I also found some old children's books that I had as a kid. My teacher at primary school used to read a story to us every Friday afternoon. Once, when I was about eight or nine, she was reading this book called *Chang*, by Elizabeth Morse, and I was absolutely wrapped up in it. It was about a little boy who grew up in a jungle village in Siam, in what would now be Thailand. In the story there's an elephant that is born white and in Thailand they are very special; you have to give them to the King, a bit like finding gold. So the story is partly about the little white elephant. The elephants, when they want to die, go to a place where they don't let humans or other animals in. It is like a secret graveyard in the forest and this little boy is one of the very few people who see it. The boy gets separated from his family because there is a forest fire. He rides on the little baby elephant and the other elephants don't kill him.

I found that I still had this book and I remembered that when I was about Ruben's age it was making a big impact on my life. I started reading it to him a few months ago and he is absolutely immersed in it now, which is really amazing.

Things you grew up with become part of your life - that is all I am really trying to say.

When I was a kid I used to go to school with my older brother. He was someone I followed around a lot. In a funny way he has been an example to me all my life and still is, I think. The very first travelling he did in his first summer from university was to hitchhike to what was then Persia. He went all across Europe and through Turkey and into Persia and he took photographs as he had been encouraged to do all his life by my parents. I was really amazed and inspired by that travel and those pictures. So in a funny way, even though it might sound adventurous to go off on your own I never thought about that. I just used to follow in his shoes and go to places I was curious about. Anthropology was one of my favourite subjects as a student.

I came to live in London after I left school. London itself is a very international city - it always has been, pretty much, since the Romans came nearly two thousand years ago. I feel lucky in many ways living here and getting to know people and bringing my kids up here.

There are things that I learnt from my mum and dad and my brothers and sisters: the reality of being in a group. Even after your children have left and got on with their own lives you sort of keep going that way. Being a grandma to Ruben, Eddie and Eva has been one of the most wonderful changes in my life. Children grow fast and their growing-up, with all the new technology, helps me get used to change.

All of us need that love and care in order to get through life, because otherwise it would be so empty. How would we get by if we didn't have that? It's like with any creatures, not just humans, any animal - that's partly why we get so much pleasure out of nature, I think, because we see that in other creatures as well. The social and the living side of life.



9 FULL CIRCLE (Alix)

The first thing that happens is a kind of inversion. I was thirty years old and I was suddenly the parent. I'll always remember how she looked at me in the early stages – completely without flinching, like a newborn baby. It's a kind of rebirth. It's very freaky to see that in your own parent. And it's so sudden, so total. I had to feed her, change her clothes, take her to the toilet. It was very primal. And yet she could talk to me – she was like a baby that could talk.

In time things gradually slid back and I realised, 'Actually, my mum's cool now. She can cope.' At first it was hard letting go but then I suddenly thought, 'I want her back – I want our relationship to be about us again'. We'd got to a place where she could take that role in the family again – and be Ruben's granny.

I know I'm very lucky to have had that come full circle. She did have an incredible recovery. I had to learn to grieve a little bit for that part of her that was lost. But also to let go of that and accept who she is now.

It was odd on a personal level that I became a mother about two years after her injury. Mum and Ruben shared something quite strange. He was her first grandchild and she was just strong enough to care for him and at the same time it was like she was growing up too. It was extraordinarily beautiful watching them together. She could enter into his child's world in a way that I almost felt envious of. I would go to the shops and come back and she would have a tea-cosy on her head and they would be totally in their own zone together. They still have this wonderful relationship, this strong friendship. I appreciate hugely that she's there to share her wisdom and stories with Ruben. Sometimes I have to remind her that just because she's not earning money and cooking meals for everyone – she still has this huge value as a figurehead for the family, and her history is very important for us all.

Mum is very honest and philosophical. I enjoy the conversations we have now. She has a perspective and a simple appetite for life that I find useful - it reminds me what is and isn't important. I think there's something when anyone goes through a near-death experience - of valuing and relishing life in a more vibrant way. I've piggy-backed on some of that!

It's helped me in life - the realisation that in thirty seconds your life can change. It's just the luck of the draw. But also not being scared of talking about death. There's no reason to be scared or shy away from it. It just is.

You can read the full version of Sarah and Alix's story, along with 17 others, at www.whoareyounow.org



Every weekday, a team of brain injury survivors put on aprons and cook for everyone at Headway East London's Haggerston headquarters. Between 40 and 60 people per day share lunches that range from bangers and mash to bulgar wheat salad. Earlier this year we asked a handful of Headway members to review their lunch.

Artwork by SAM JEVON

No Matter

SPAGHETTI WITH
TOMATO SAUCE
11/01/18

"Reasonable. Nice. Not too hot or anything like that. I'd give it a ten. I'll eat anything you put in front of me."
— Cecil Waldron



Sam
11/1/2018

SOUTHERN FRIED CHICKEN
30/01/18

"Nice, tasty. It was – eh – spicy but just right for everyone. I had it before in the Mediterranean. The other side of Spain, down there over the other side of the Mediterranean – Greece. That's where I had it. I went there about ten, fifteen years ago."
— Danny Towell



LUNCH

REVIEWS



Sam Jevon
18/01/2018

STUFFED PEPPERS
16/01/18

"It was rice but I didn't like it. They put it in a thing. A fruit – I don't know what it was, it was red. I liked the cheese but that was the only thing. I'd like some ackee and some rice and peas. Some West Indian food."
— Carol Zeniou



SWEET POTATO TAGINE
31/01/18

"This is the first place where I've tasted three different flavours at the same time – sweet, salty and spicy. It's a bit confusing. It's like French food. I've never tasted French food but it's something like that. It's better than nothing though. It's the thought that counts. It's like somebody's tried their best."
— Joe Hector

~~LOST~~ & FOUND

A place for things which might
have been forgotten

Is all time speared just a shimmer

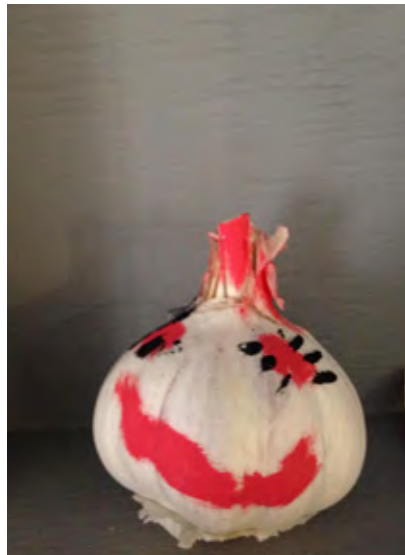
Is all time speared just
a shimmer
JON LUSK

DRIFTING
OFF
SAFELY
IN TO
3 WHOLE
HOURS of
SLEEP
battered by
OBJECTS
ESPECIALLY
TODAY.

Ooglies
by SHERRI SNELL
Artist's note: "Bored"



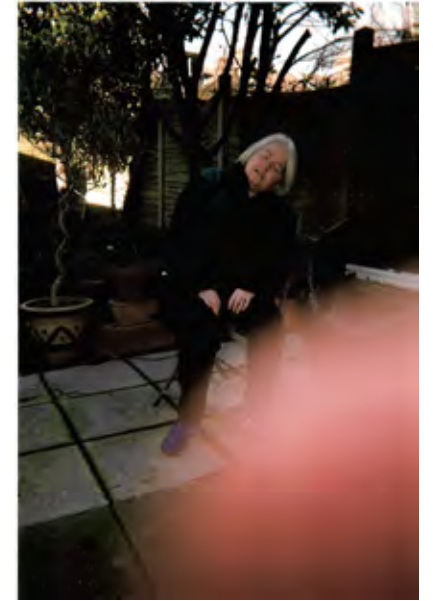
Fennel, map pin, blu tack



Garlic bulb, marker



Tea-light, drawing pin, blu tack,
leaf vegetable[?]



SANDRA'S MEMORY DIARY

The memory group was established at Headway for people with memory impairments to support one another. Sandra kept a record of her week, in words and pictures, to share with the group.

WALKING

Small step astonishing and I walked
FOREST OUR WOOD

Happiness
SLEEPINESS

I have to that 2 hours afternoon, and my friends are ok

From an anthology of writing about memory, Sandra chose this quotation:

"The peculiar value we attach to discursive memory, the recollection of what things were like, seems to derive from its connection with imagination in the developing story of a life." – Mary Warnock, *Memory* (1987)



Lauren by SANDRA LOTT

Here is the Lauren story, beautiful.

I have really Six Feet Under - maybe you might them.

Woman / Lauren

Woman / Lauren

"Lauren". On a Starry Night, forever, you remember. Serenity is freedom. Quiet, tranquility, calm, peaceful.

"Lauren" dying in dark woods fatally killed her. She was beautiful, gentle and fearless which didn't save Lauren from her grave.

XXXXXXXXXXXXXXXXXXXXXXXXXXXX
XXXXXXXXXXXXXXXXXXXXXXXXXXXX

If you want to, the YouTube is good.

Lauren Ambrose
Peter Krause
Michael C. Hall

(Fisher)

Breathe Me (Six Feet Under
Finale)

<https://youtu.be/eNwARV9tPUw>

See ya

Sandra

“TO ANSWER THE QUESTION ‘WHO?’...

LAURA JACOBS, Occupational Therapist at Headway East London, has just completed her MSc in Social Anthropology. For her dissertation, she wrote about the idea of ‘emplotment’ at Headway East London: suggesting that ‘time takes on a narrative form’ at the centre, engaging both brain injury survivors and centre staff in a story that writes itself. BEN MILLS asked her some questions.

IS TO TELL THE STORY OF A LIFE.”

Ben: The word ‘emplotment’ makes me think of *entanglement*. The literary associations are slightly creepy. Plotting. The plot thickens.

Laura: YYeah, I suppose so. The idea of emplotment uses narrative theory – the idea that as people we might present ourselves as a story; that life is a story with a beginning, middle and end. That’s how it relates to memory. When someone has a brain injury their life story has been disrupted.

Ben: It’s missing key plot elements?

L: Yes. One Headway member, Nifty, has a really powerful story about this. I used it in my second chapter about memory and identity. She describes getting rid of all her old things after her injury. And she talks about an occasion when her sister says to her ‘Oh, you wore that dress at my wedding,’ and the awful feeling for Nifty of not remembering something so important.

“At the time when I had the accident I was twenty-seven years of age. Due to the brain injury, twenty years of my life disappeared from within me. I was like a picture on the wall, something to be seen. I was there, but I didn’t really have a true identity. It’s difficult for family and friends, because they go back to the past. It’s hard to say goodbye, but sometimes you do have to shut that door and open a new door and see what you find.”

— Nifty

L: It’s something that also came up in the memory group I’ve been facilitating. A member was saying that her friends talk to her about things they did together before her injury, asking if she remembers, and because she doesn’t want to hurt their feelings she’ll say yes even though she might not. I can’t imagine what that must feel like.

B: There’s a dual effect there: reinforcing a version of self that’s inaccessible and therefore self-alienating. And also alienating you from your loved-ones because they’re relating to what - to you - is a redundant narrative.

L: I think that’s why Headway works because no-one here knew you before the injury. You can develop relationships with people that only know you as you are now. There’s generally very little idea of the past here. There isn’t much reminiscence. Everyone is constantly looking towards the future,

a constant propelling drive. There’s always things coming up. The supper clubs, the shop last year, the art exhibitions. It feels like it’s really important here because the sense of who people are is more in the future than in the past.

B: Important because of the loss of the self from before the injury?

L: Yes.

B: So these events form plot points towards which the new self can move as in a narrative?

L: Yes. So, for example, two people in the art studio, one, whose been here longer, says to the other ‘It’s taken me a while to feel like I belong here, you will too.’ It’s setting a story that’s not about your injury so much as about how things can be in the future. Or someone like Danny, who’s cooking here, he’s got a role. Or Cecil, who’s become a public speaker. People can go from having a very limited role to being an actor in time.

“Headway positions itself as a community where members, staff and volunteers are transformed into actors in time. With a continuous gaze towards the horizon, brain injury survivors can develop a sense of identity located in the future, rather than the past...”

— L. Jacobs

B: An actor in time?

L: A lot of people feel disempowered, have lost a lot of social roles, so just being here people create their own roles. Being an actor in time is about being the protagonist of your own life story.

B: There’s an ethics paper by Bruce Jennings called *The Ordeal of Reminding*.^{*} He talks about the task of rehabilitation being that of maximising semantic agency and moral subjectivity. I feel like agency and subjectivity are important in what you’re describing.

L: Yes. Den is good example. He comes into the morning meetings. Every Monday and Friday he waves through the window when he comes in and then he comes into the room. He might shake everyone’s hand. He’ll give oranges usually. It came from him completely, this role. It’s just something that happened. Obviously if everyone started doing that it wouldn’t work at all. But for him this is what he does.

“Narrative time is different from bio-medical time because it is centred on the actor rather than the disease.”
- Cheryl Mattingly

B: What do you think he gets out of it?

L: I think it's that agency. He's giving something back.

B: Why is he doing that rather than doing something else?

L: He's quite a rebel isn't he? There's another person I interviewed for ages who said she feels quite stuck here. She'll say she doesn't particularly like it here. When she started, she thought she was coming here to do more physical rehab, to keep getting better and better, so in some ways she hasn't bought into the community story yet. She's fiercely independent. She isn't accepting help, maybe, the way others might. But in other ways she has bought into it – she said 'I can see myself being an old lady and coming to Headway'. So she does see herself as being here for a long time.

B: It makes me think of another piece I read about something called *Rilkean Memory*. The idea is that there's a type of memory that has its origins in episodic memory but where the episodic components have disappeared through forgetting and what you're left with is style, a physical and emotional way of being. Perhaps the people you're talking about are following their style.

L: Totally. With Den, he's still completely Den. Coming into those meetings is a completely Den thing to do. No-one can say really how it began. But no-one's stopping it either.

B: You talk about the importance of staff being emplotted as well. How do you see that happening?

L: By the fact that they can completely be themselves. The best versions of themselves. Often in organisations if you're struggling with something,

people will say 'Oh, you should do it more, you'll get better at it!' Whereas here you're completely supported to do what you're best at rather than battling with things you aren't so good at. Everybody wants to go out of their way because they're in a place that's going out of its way for them. Staff are given the ability to do what they believe in, what they're passionate about. People feel they've been given something. When I was interviewing the staff, one of them said to me, 'I don't know where I'd be in the world if I wasn't here.' Another said 'I would never be living in London if it wasn't for Headway.'

B: Who is doing the emplotting?

L: Everything, it's just happening.

B: Are people self-emplotting?

L: Yes. And then you get the positive feedback from others. That's what's propelling you.

B: We emplot one another and self-emplot.

L: Mutual emplotment.


Nifty's story, referred to in this piece, was part of Headway East London's life stories project, Who Are You Now? You can read it, and others, at www.whoareyounow.org

* '...the preservation and restoration of capacities for human flourishing and self-realization, such as semantic agency and moral subjectivity, are appropriate goals of care[...] A moral object may be well cared for; a moral subject calls forth and commands care by dint of his or her identity, status, and agency in a shared skein of subjectivity, a moral commons or space of moral recognition.'
- Bruce Jennings, The Hastings Centre Report, 2006

BAYES: Ay, now the plot thickens very much upon us.

PRINCE PRETTY-MAN: What Oracle this darkness can evince?
Sometimes a Fishers Son,
Sometimes a Prince.
It is a secret great as the world;
In which I, like the soul,
am toss'd and hurl'd.
The blackest Ink of Fate,
sure, was my Lot.
And, when she writ my name,
she made a blot.”

- George Villiers,
The Rehearsal, 1671



A BRIDGE, A GATEWAY, A FLASH

Sitting in our canal-side garden, S talks to Bryn Davies about the power of drawing - connecting her with herself, helping bridge the gap opened by amnesia.

In a way, the art studio is the reason for me to come to Headway. It's away from other people but it's nice to have the company there too. I couldn't sit in there on my own. I'd feel like a block of cheese in a fridge. It's a safe environment with familiar people, but with no pressure to socialise or to do anything you don't wish to.

Most of us do our own work, but we start up conversations too – about current news or what's happening in our own lives. You get ideas from other people. And if I'm stuck on a drawing I go to someone else there and say, "What do you think I could do here?" And if they can they'll give you a hand.

Sometimes I copy old masters – it's always good to see if you can actually improve the work of Van Gogh or something. One mustn't aim too low.

I quite like drawing with charcoal. It's a very easy flowing material and if you stuff it up you can just smudge it off and start again. Control has always been a really important thing for me. I get angry with myself when I don't get things right: even as a child, if a sandcastle wasn't working out – "Bugger bugger bugger!"

As a child I did a lot of kicking. Then I started karate and became British Universities Champion. But the drawing has always been much more relaxing than the fighting. I draw to take the aggression out – it's a release.

It's the memory thing that's a stress. My memory doesn't exist. The previous day doesn't exist. Even when I read my diary it's like a storybook. It's only because I can see my own handwriting that I know it has happened to me. You just think, "Why me?"

Is that a bee or a wasp?

Sometimes when I start a drawing it'll remind me of something else – it's like "oh yeah, shit, this reminds me of something that happened twenty years ago" – and it brings it back. It builds a gateway. An event will come back to me, or a place, or a person - it can be anything. It just happens, like a flash of lightning.

With the memory issue it's difficult to finish work because I can't remember what the idea was when I started. But sometimes I look at a drawing and think "Oh yeah, I had this idea to carry it on". Some things do come back. I know my own handiwork. I know who I am. It's not always strong,

but it's always me, and when I'm whinging to myself "Oh why the fuck is my memory so bad?" then I go - "Come on, pick yourself up, you're just dragging yourself down by doing this."

Look at the lovely ripples in the water!

Because I've been drawing just now I'm paying attention to that. Generally when I wander around I'm in my own thoughts rather than looking around me. That's a bad habit – I should pay more attention to what's around me.

Nature is what I like to draw. The shapes are so intricate; it's difficult to get them straight. It's a challenge, but a relaxing challenge. Reflections are great. They form their own picture when you look at the water. You and I could be looking at the same reflection and see two different things entirely.

What do you reckon that puppy is, about six months old? Or four months maybe?

For a lot of people coming to the art studio gives them a sort of a mission in life – almost like a job. Some sort of purpose, rather than idling about. I would always doodle at home but now when I actually draw something I think, "if you're doing this, do it properly, otherwise don't worry about doing it." I look at old drawings of mine and think, "This is quite nice," and then I think, "Fuck, that should have been this shape." It's the improvement in quality and the new ideas that are exciting.

What is this bird please? Sorry, I probably asked you already.

I'm happier when I've been in the art studio even if I can't remember I've been there. It's like, even if you haven't got the champagne glass in your hand anymore, but you drank the champagne, do you not still feel pissed after?

It's not always easy to be at peace with yourself. I get very frustrated with the memory issue, when I'm constantly struggling to think, "What was I supposed to do now?" and "What did I just do?" When you're creating something, you don't think about the rest of the world at all because you've got a pleasurable project at hand. And when you get it right in your own mind you think, "Yeah, that's great".

Sugar, look at those butterflies. What are they? I do know but I can't get the name. Sorry, what were we talking about?

Oh yeah, drawing – you're doing it and you think, "The world is well."

IT CAN'T
REMEMEMBER
FUCK
TA

AN EXCERPT FROM



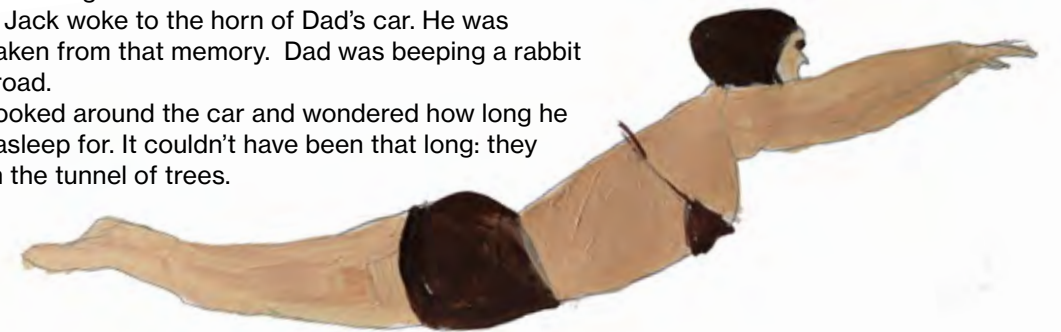
THE OTHER WOIRLD

Words by PHIL CHIMES
Artwork by Evaldas Sorocinskis

Jack was dreading going to Nan's house. In the car, he sat with his palm supporting his chin while he scanned the curved trees of the avenue from behind the glass window. He loved how the beautiful tunnel formed by the trees allowed fingers of sparkling light to reach through the gaps in the branches. He closed his eyes and in that moment, he could see Nan playing the guitar, or in her swimming clothes. The large goggles made him smile. They were halfway down the enchanted tunnel formed by the trees, colours and lights blurring into one. Jack took in a deep breath, closed his eyes and started drifting off.

BEEP. Jack woke to the horn of Dad's car. He was suddenly taken from that memory. Dad was beeping a rabbit out of the road.

Jack looked around the car and wondered how long he had fallen asleep for. It couldn't have been that long: they were still in the tunnel of trees.



When Nan came back from her travels a year ago, she was different. She spoke of odd things. She talked about having lost her guitar. Jack remembered his last visit to the hospital. A flood of tears wanted to come out. He held them back and swallowed them down. Awake and looking back out of the car window, Jack returned to his memory of Nan.

He remembered one of many times with her at the swimming pool. Nan was in her large flower-print swimsuit. Cap to match and large goggles. Jack and Nan had just finished their swim.

"I just want to do a quick dive before we leave for our chips," Nan said.

Jack stood to the side of the diving pool and watched Nan climb to the tiptop of the highest diving board. She walked to the edge of the board and waved to him, shouting something like she always did, but like always, he couldn't hear her. Like always, he just put his thumbs up in agreement to whatever it was that she said.

Soon after Jack's thumbs-up, Nan would leap from the board to do one of her dives.

She went into a forward somersault; then she stretched out opening into an eagle pose. Then she spun sideways like a corkscrew; then into a flamingo posture. Throwing herself into a double backward somersault, she then lined herself up for the entry, hands forward and toes pointing up: she calls this one the *spear pose*. Just at the last second before she enters the water, she looks at Jack, smiles at him and winks, and then -

splash.

There's no splash really. Nan's entry was always flawless. I just said 'splash' because I don't know the true word for it.

Heart of the Matter

US LOT (FRIENDSHIPS AT HEADWAY)

Photos by ANDY SEWELL

MARTIN: My dad was at Headway as well, and Brian and my dad were so close – he always put a smile on my dad's face. I can still see my dad – the image of him – over there where Brian is now. So when my dad passed away, I wanted to... *step* in is the wrong word – I wanted to *look out* for Brian... *company!* *company* is the word.



BRIAN: He ain't
a bad old boy.

PAUL:
Longside me old spar.
S-P-A-R. Me *sparring partner*.



CLEVELAND:
Everything. Rasta.
Bad boy. Everything.

RICHARD:

YEAH. I KNOW

RICHARD 500,000 -
JIMMY 500,001



JIMMY:

i THINK I'M WINNING
AGAIN RICHARD
COMING UP TO OUR
MILLIONTH GAME
HAHA HA

TONY:

IT LOOKS Q
Q-U-I-T-E
2.900D



SAM:

Tony is always friendly
he always asks how
I am

MARGIE:

Thomas is a hardworking caring
staff at Headway and he is
trustworthy to work with when
you're under pressure



THOMAS:

Margie always brings such joy and energy to the
kitchen. She's been there since the beginning and
has been really instrumental in making the kitchen
project work.

MIKE:

Ken is a top bloke but knows
nothing about music



KEN:

Mike would be a nice
guy if he didn't like
Abba so much!

YOKI:

From what I remember me and Tash was
talking about nails. What nail polish colour
should I go for? If I have to choose one
word to describe Tash it will be caring.



TASH:



LINA'S SONG

Words by MALACHI

“Don't worry,” Lina tells me, holding up her diary, “I know what I need to do for next week. I've written it in here to remind me.”

“Ok, great,” I say, turning away from her as I put my guitar back into its case, “but, er, you can't read anything you've written, right?”

“I know,” she says, and as I turn back I can see she's smiling.

“But you might not even remember that you've written it.”

“Don't worry,” she tells me, “if I see something in here and I don't know what it is, I can ask my daughter, or someone else, to tell me. You need to stop worrying. We can only try, and if it doesn't work, we'll find another way.” This isn't the first time Lina has told me not to worry.

When I'd been asked if I could help Lina, a Headway East London member, it had all seemed quite simple. “Lina has a CD of songs written and recorded by her father,” I was told by Tasneem, the Volunteer Co-ordinator. “She'd like some help adapting one of them so that she can sing it. How do you feel about helping her?” I thought it sounded easy enough, even given my difficulties. I'd suffered a severe brain injury two years before this, and now had a form of aphasia, which meant I couldn't read or write very well, and had problems with my speech. But even so, I felt fairly confident about doing this. I could play guitar, so all I'd have to do was figure out the chords, learn the lyrics, and rehearse it a couple of times with Lina. It would be easy.

“Sure,” I said, “sounds great.”

So we were introduced, and talked together for some time; Lina with a strong French accent

spoken with a notably husky voice, due to damaged vocal chords caused by the tracheostomy* she'd had while in a coma. And I regularly paused while speaking, desperately searching for the words I needed to use, but which were so often placed beyond my reach by my aphasia. She told me how the brain haemorrhage she'd had twelve years ago now meant she had great difficulties with her memory, and that while she had no difficulties writing, she couldn't read at all, including anything she'd written. We got on really well, and very quickly we were laughing together, talking about some of the more ridiculous experiences we'd each had as a result of having had a brain injury.

She had her CD with her, so we listened to it, trying to choose a song to use.

“My Dad was a well-known singer,” Lina told me, “and we were very close. He died when I was still in a coma, and I feel very sad that he never got to see me recover. I want to sing one of his songs as a tribute to him.”

As we listened to the songs, I realised that they were not exactly what I was expecting.

“Lina, are all the songs like this, y'know, in, erm, French?”

“No, silly, this is French creole. I'm originally from Guadeloupe, in the West Indies. That's where my family is from. But I would like to sing the song in English as well as creole. So we can translate it, yes?”

“Sure,” I said, trying my best not to show my anxiety.

As the songs continued, I thought “I can't do this. I can't speak English very well, let alone translate from French creole. This is gonna be the same as when I tried to go back to work.” I had



returned to my job as a research assistant soon after my injury, but I just couldn't keep up. Both with the work, and socially, I found it totally exhausting. I spent all my time and energy trying to fit exactly into how I'd previously been, and continuously felt bad about not being able to do that. I kept thinking that I wasn't good enough, so was almost relieved when, as a result of my injury, I had some seizures, and could use this as an excuse never to go back. Inside, however, I felt I was a failure.

The CD had come to an end, and we'd agreed on a song. I realized I needed to be honest.

“Lina, I just don't know how to do this. I mean, I struggle with English a lot of the time, so my use of French creole is gonna be, well, worse than useless. I don't know how we're gonna translate this.”

“Well”, said Lina, “you never know when you have to learn something new in life.”

We looked at each other, and started laughing. So we agreed: We'd take our time, and together we'd find ways of doing it. If they worked, great, and if they didn't we'd simply find a different way. But we agreed that whatever happened, we'd enjoy the process, and try not to worry. I wondered if “not worrying” was something I could do.

So we met for an hour, every Tuesday morning, and while things sometimes went just as we wanted, often they just didn't work at all. Like when Lina wrote a reminder in her diary for her to write out some creole words at home, and then forgot all about it. The following week she turned up without the words she'd intended to have written.

“Don't worry,” she told me, “my daughter speaks creole. I'll do it with her tonight, and bring it in next week.”

“But what if you don't remember to ask her tonight?” I asked, trying not to frown.

“Ok, well I'll phone her now,” Lina called her daughter. They arranged to write out the words that evening, and put it in her bag. The call came to an end.

“Well she's not in a good mood,” Lina said, laughing, “maybe it's a bit early in the day for her. But

see, I told you not to worry, next week, it will be in my bag.” Lina was always keen to remind me not to worry, and after a while I was able to start saying it to myself. And over time, I began to develop a new way of judging what I was doing, and how I was doing it. Not that my use of English improved, and I certainly didn't learn to speak fluent French creole, but I began to stop seeing myself as a failure, simply because I was now different.

After about four months of us working together, the song had become something that Lina and I both felt worked well. Now when we met it was simply to practice. While practicing, Lina would sometimes comment on her voice, saying she was not comfortable with it. She'd say “I don't like the way it's different now. It doesn't sound ok.” To me her voice was beautiful. It was exactly what it needed to be: Lina's voice.

One morning, Tasneem, the volunteer co-ordinator, said to me “I've heard the song is going really well. There's an evening event happening here soon, with a large group of people, and it would be great if you and Lina could perform it then. How do you feel about doing that?”

“Erm, ok”, I said, “but let me ask Lina.” So, in front of a large audience, Lina is standing with a microphone in front of her. I'm sitting next to her, with my guitar. We are introduced to the audience, and the room becomes quiet. I start playing the beginning of the song, which we've arranged so that Lina can take her time, and start when she's ready. I notice Lina is looking at me. She is not smiling.

I mouth “Don't worry” to her. Lina laughs, and with that she turns back to the microphone and starts singing.

**Tracheostomy: a surgically created hole through the front of the neck and into the windpipe (trachea), often done so that a tube can be inserted to assist breathing.*

MON MON VOU KA ROULE
Joseph Lacides

(Originally in French creole from
Guadeloupe, West Indies)

G Em Am D

VERSE

Mon mon vou ka roulé
On champ con la é entre
Grand bon matin
Poutra vailn pou rivé

Your mum is working hard,
In the field of sugar cane,
working night and day,
To feed you every day

CHORUS

Ooh ooh ooh ooh ooh
Cope can, mare can
Ooh ooh ooh ooh ooh
Secle can, mare can

Ooh ooh ooh ooh ooh
Cut the cane, put it there
Ooh ooh ooh ooh ooh
Tie the cane, put it there

Esus2 / / / Em / / / Am / / / Am / / /
Esus2 / / / Em / / / Am7 / / / D7 / / /

VERSE

Mon mon vou ka roulé
La nuit con la jouné
Pou bavou mangé
Pou pe fait onuet sejë

Your mum is working hard,
In the field of sugar cane,
working night and day,
To become somebody

Chorus (x2)



ASPECTS OF BRITISH LIFE BY A LITHUANIAN LIVING IN LONDON

Artwork by EVALDAS SOROCINSKIS



A BOXER:
Boxing remains
a popular sport
in Great Britain



MR BEAN: an English clown



JAMES BOND: a British spy, also known as '007'



THE SPICE GIRLS: a British pop group (from left: Sporty, Baby, Posh, Ginger, Scary)

PEOPLE WATCHING

by FIROZA CHOUDHURY

I wonder what it would be like to return to that time: that life, that body, that mind?

I see those people working, laughing, rushing: no time to think about what could stop life in its tracks, suddenly throw you in another direction, make you relearn the processes you took for granted, that came so naturally.

Taking the spoonful of food, directing it into your mouth... but wait, why can't I put the spoon in my mouth? I can't aim, it's all over the place, my arm and wrist don't bend, and it's too heavy. It's an odd feeling, like I've become a robot – static, I'm numb on that side, yet it's tingly, the brain is confused. After several attempts, it's in!

You will never remember the first steps you took as a child: how easy it would have been then; the look of delight of proud loving parents.

That happens again after a stroke: people around you watching you take your first steps. This time you get to take part in that celebration: it means more, but you don't comprehend the way a fragile brain works. As a child nothing is thought of it: it just happens. But now the process is slower and much more painful and every step is thought through carefully and you don't have spongy blubber to protect you if you fall.

“Don't think about it: just walk– walk as you would normally”, the physiotherapist said to me. Those words jolted me into thinking that maybe I could do this. Let me try it: “Walk as you would normally” – processing those words in my mind, and with sheer determination, both hands firmly gripping the walking frame, I got ready for that motion, to try and walk. I was doing it – taking my first small steps and strides for the second time in my life. This is progress: a big sense of achievement and pride. Yet the exhilaration I felt was mixed with bewilderment. It was a strange thing.

I'm in awe of these people. How do they do it? They make me feel dizzy. Rushing to get from A to B, all in a line, walking side by side, some quicker than others, getting lost in that flow, desperate to reach their destination. I've been among them. It's not pleasant feeling anxious that I have to pick up the pace. I'm not keeping up. I'm getting in the way.

But maybe among them there others like me – who can tell? Who knows what they are going through? Just like with me, it is hidden: perhaps they are as anxious as I am among a crowd. We could be one of them: we don't stand out and it's too subtle to see. Is that good or bad?

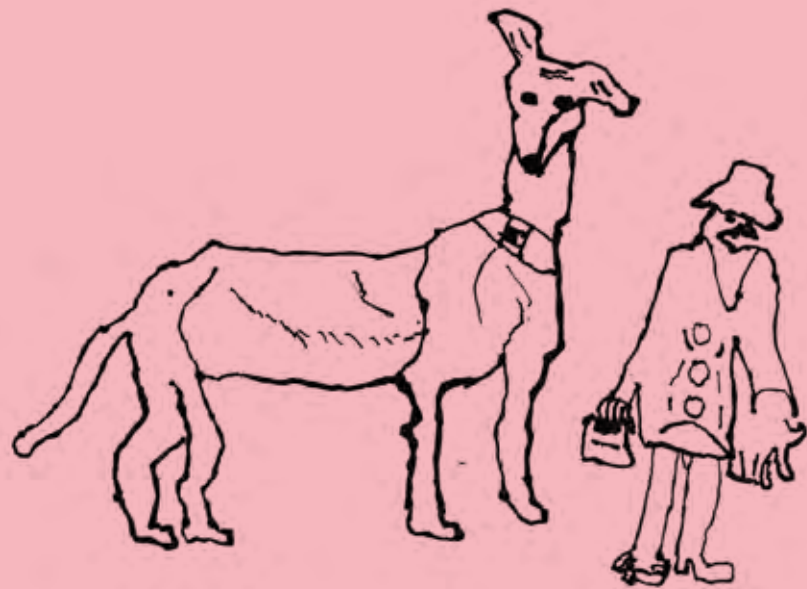
No matter how hard the challenges have been, and continue to be, the experiences I've had so far have been enriching – have made me into the person I am now. I've grown up a lot and learnt a lot. I've been made to think about life: the wonders, the strain, the resilience and pain, and again that second phase of starting over from infant to adult. The journey continues: from first to second life. One thing I can say – it's given me an education I would never have had otherwise.

DRAWING THINGS TOGETHER

Words by ZARA JOAN MILLER
Artwork by Tony Brooks

Housed in a railway arch beneath the East London Line, Submit to Love Studios is a space where survivors of brain injury can re-imagine the world through drawing, painting and sculpture. Here, studio volunteer Zara writes about drawing with other artists and the significance of a single line.





Drawings are everywhere at Headway; colouring the walls with characters, fantastical scenes, giant brains, animals and limericks. When Tony draws, his sharpie often blots the paper, punctuating moments he has to pause and surrender to limited mobility. Jovan's hand tends to jerk from the page, landing marks in unintended places. Martin only draws portraits; characteristically frying-pan flat with stubbly hair and mouths crowded with tiny teeth.

Discovering ability through disability (or through recovery) is something I have considered in depth. I experienced a seed of this one evening when, following surgery and tackling boredom, I picked up a pencil. A single line curved into an ear, a hairline, a nose, an arm, until some time passed and I had completed a mural of figures with bodies morphing and dancing in and around each other: a wild party in a sardine can. I had never drawn like that before. Beyond the odd telephone-call doodle, in fact, had rarely found the time or inclination to draw at all.

That was five years ago. I now draw almost every day: line drawings, quick and continuous, often with my eyes closed or looking away from the page. There is something about drawing in this way that requires both a level of focus and foolhardiness; a balancing act I find strangely fulfilling. Hundreds of scribbles later, this desire - to draw, to string a line between human experience and representation - still holds an element of mystery. Like walking a tightrope, the slightest movement could ruin everything, yet there is freedom in the attempt: to follow that line to the end.

Some of the most prolific artists at Submit To Love Studios will tell you they were not really

interested in art before their injury. While it may be alluring to ponder whether a bump to the head could awaken an otherwise latent talent, this cannot be the whole story.

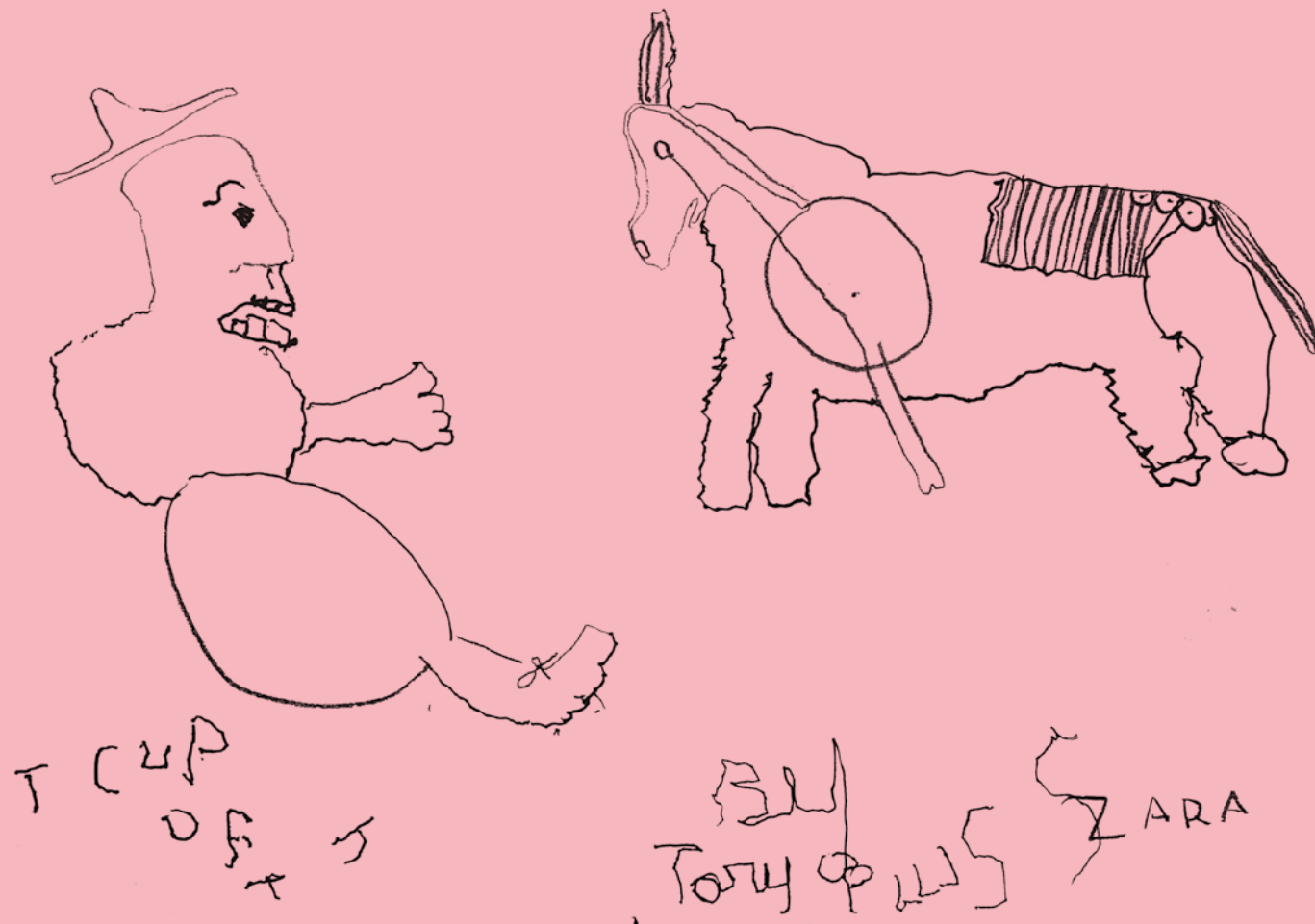
Many members paint, draw or write about their personal brain injury experience. You see this in Yoki's huge annotated brain diagrams ("Why do I feel like I'm not who I was anymore?") or Tony Allen's aphorisms ("I Can't Remember Fuck All" and "Everyone has got a brain in their head. It's up to them if they use it"). I have been working closely with another Tony, Tony Brooks, whose portfolio is a weighty thing, consisting of over 15 years of drawing at the studio. Each piece is a testament to Tony's will - with his characteristically "shaky" line illustrating the complexity of his experience. Tony has no choice but to draw very, very slowly and, while the process is often painful, he has learnt to use these limitations to his advantage. To look at one of Tony's drawings is to witness a collection of marks: the evidence of a tremendous effort that is no longer visible, yet somehow felt.

I was diagnosed with a benign astrocytoma; a kind of cancer originating in star-shaped brain cells called astrocytes. Today, nearly five years on, the realisation that even tumours can contain stars is ridiculously romantic and, for me, very necessary. Even if the body recovers, the mind must come along too. For many of us this will require much coaxing and, for some, drawing is one way of celebrating life through the (sometimes rosy, sometimes dark) lens of brain injury.

To draw is a deeply sincere human act, after all, dating back to parietal art. Even the earliest astronomers, gazing at the night sky while their



WRONG



sheep were sleeping, connected the dots. Drawing constellations, the celestial world was made to reflect the terrestrial one of fish, cranes, archers and rams.

Since writing this piece, I have become more aware of lines than ever. Denoting the edges of things; furniture, floorboards, window frames, telegraph poles, the trail of an airplane, the horizon - life is made up of lines, a series of networks, both visible and invisible setting limitations to be reached or surpassed.

"I no longer have the temperament or the physical ability to place too much emphasis on the accuracy my drawings," Affiong writes. "Mistakes naturally occur, but I can't care like I used to. This carefreeness makes the drawings lighter, less conforming, more expressive and more free. I can find a use for my mistakes." So while the sensibility towards creating art may well be heightened following injury, there must also be a willingness to represent the world through this altered perspective.

I work in a live music venue just up the road from Headway where there is a regular customer (I will call him H) who lives with paranoid schizophrenia. H helps me write events on the chalkboard in the morning and, in return, he gets his coffee on the house (double espresso: "one for me, one for my shadow"). It soon became evident that H could draw very beautifully. With some prompting, he has drawn several flowers, a horse, a palm tree and a Picasso-esque self-portrait. More recently, we tried drawing together. I began with a short pink chalk line; H joined the loose ends together with a blue line, completing a kind of kidney shape. We repeated this idea, again and again, creating shapes across the blackboard until we had a dozen or so pastel-coloured constellations.

The following day, I suggested the idea to Tony Brooks. Sitting side-by-side at the easel, I began by drawing a curved black crayon line. It had been

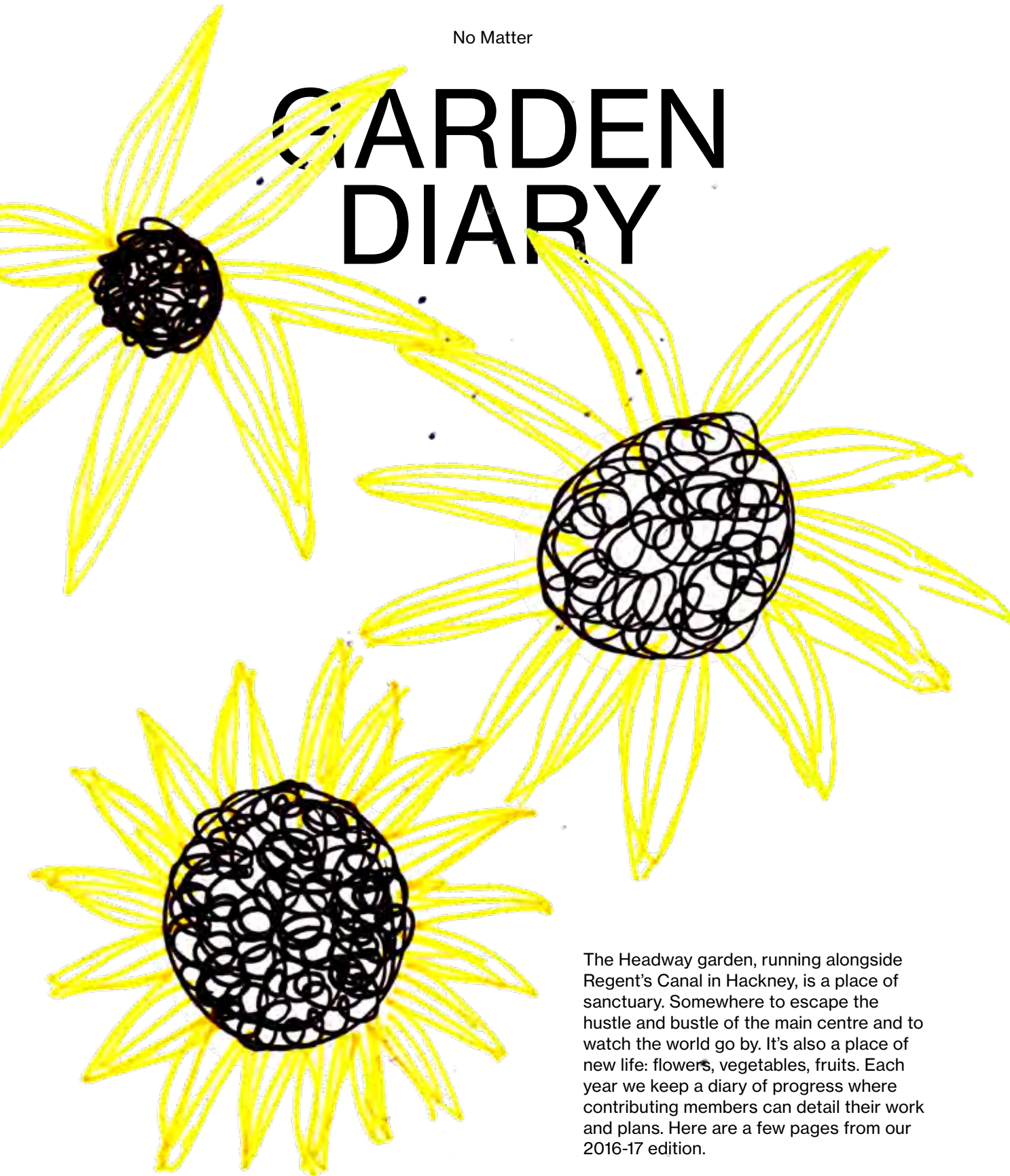
a particularly long morning for Tony, however, and he was almost falling asleep in his wheelchair. "I can't move", he told me. Tony cannot use his right arm and has limited mobility to his left, which he uses for drawing. We tried some gentle stretches to ease his back, but eventually rest was the most sensible suggestion. At the word "rest" Tony perked up, jerking his head as if by strings, and signalled to me to hand him the pen. Tony is a fighter. His spirit is remarkable. Wielding his sharpie, sword-like towards the page, my initial crayon line grew upwards, forming a second darker curve. I joined Tony's line with a third and we continued on like this until a spinal cord formed into a neckline, rising up to a crown, curving down to a nose and an open mouth, which Tony filled with teeth. By the end, we had drawn two figures: a semi-reclining one-armed man staring at a four-legged creature, plus a written request for '1 CUP OF T'.

I can't help but look at that drawing today and see a kind of peculiar self-portrait – a one-armed man and a creature attempting to communicate with him.

You don't have to spend long in the art room at Headway to notice the various ways members have adapted to their strengths and limitations. If the will to draw is present, it cannot be easily dampened. So when habitual modes of communication become limited, we must invent new ways of understanding. This sentiment lies at the core of Submit To Love Studios: within twenty years of work made by members and the individuals that support them. The line, in these instances, becomes a rope flung between two people: a telephone cord; a tool for both connection and survival.

More details about Submit To Love Studios, along with the work of Tony Brooks and the other artists mentioned in this piece, can be found at www.submittolovestudios.org.

GARDEN DIARY



The Headway garden, running alongside Regent's Canal in Hackney, is a place of sanctuary. Somewhere to escape the hustle and bustle of the main centre and to watch the world go by. It's also a place of new life: flowers, vegetables, fruits. Each year we keep a diary of progress where contributing members can detail their work and plans. Here are a few pages from our 2016-17 edition.

THURSDAY 7 JULY
THURSDAY 7 JULY

TODAY WE
TODAY WE

PLANTED
PLANTED

SUNFLOWERS.
SUNFLOWERS
PAUL WRIGHT

WILD FLOWERS



15-4-2016.

B Hackett

PLANTED TWO
CUCUMBER PLANS

FR 24 APRIL
~~PLANTED~~ PUT ALL VEGETABLES
OUT FRONT TO START TO HARDEN
THEM OF
B W Hackett



29 MARCH 2016

THERE ARE FROM
ALL THE PEOPLE AT
HEADWAY WISHING ALL
THE VERY BEST INDEED

↓ Note from Brian H to Miriam.

PLANTED
RADISH
BEETROOT
1. APRIL. 2016

29 March 2016

⇒ We wait the Palates
out The Front
Paul Harris

1-4-16
HERBS



GARLIC
CHIVES



CHIVES



MARJORAM



MINT



DILL
DEAL



BASIL



THYME



PARSLEY



Heart of the Matter

THREE WOMEN

An exploration of the many relationships that define and affect one life

Words & artwork by
KEN HAZELDINE

AND I

HELEN: A shared path

I've known Helen for years. She has always been very popular among our social circle, far more so than I ever was. We had a lot in common. We were the same age, lived quite near each other, were both with partners we'd met in middle age, both Manchester United fans, and both seriously ill at the same time. I suffered a brain injury after falling on my head while she was struck by cancer. The main difference between us now is that I'm still around to tell the story, unfortunately she is not.

I know it sounds clichéd but nobody ever had a bad word to say about Helen. People sometimes like to gossip and run each other down. Our social group is no different from anyone else's, but in Helen's case it just never happened.

She was a most generously spirited person. I remember her coming to visit me in hospital with her partner Bob. It was one of the most uplifting visits

I received. She often took people under her wing if they were down on their luck. I'm told she would have done the same for me if she hadn't known I was being looked after by my wife Judie.

She worked as a counsellor and used to give her private phone number to clients so they could ring her to share their problems. She kept this going right up until a fortnight before she passed away.

One of the hardest things I've ever had to do was to attend her funeral. At Helen's own request no one was allowed to wear black, and at the front sat her partner, Bob, and her ex-husband, Mark, twin widowers side by side, both still completely smitten.

I did wonder once, in my worst nightmare, if anyone might have expressed disappointment that I had survived while she hadn't. I now think this was unfair and purely my own paranoia.

But there is something deep inside me that feels guilty for having outlived her.

JUDIE: Everything

I have been married to Judie for 22 years now. She is my carer, mentor, lifeline: she is virtually everything. The thought of having to get by without her chills me to the bone.

People disabled by illness or injury tend to become a bit self-obsessive, and the expectations they have of their partners can be overwhelming. I have heard horrific stories of other couples ending up in divorce courts, living separate lives in the same house, even coming to blows. A rather chilling statistic revealed that over 60% of marriages affected by brain injury actually break down. Looking at it from the partners' side, they often welcome a stranger come back into their home, and have no idea if they'll ever see the person they first fell in love with again. I watched a documentary recently where a stroke survivor became infatuated by the white van he had used in his career as a joiner... his wife's best comment was "He loves that white van more than he loves me!"

My own marriage, so far, seems to have survived. One thing happened a while ago between Judie and myself which, although traumatic, brought us closer together. We were tidying up garden waste and throwing it into a large wheelie bin. I was getting concerned that we weren't going to get everything in and had what I thought was an ingenious idea. Then I made a rather stupid mistake. I climbed into the bin and tried to tread down what was inside. Judie ran over to support the bin in an attempt to avoid exactly what happened next. Somehow I lost my balance and both the bin and I fell on top of her, breaking her leg. We were both lying flat on our backs on the patio, and the first thing she said to me, in severe pain from her leg was, "Did you fall on your head?" Considerate to the last.

Although I would not suggest that other couples try this, it does seem to have changed things between us for the better. Having spent the previous couple of years exclusively as the 'cared for' I suddenly became the carer too. The goalposts were completely moved, and my expectations of her had moved as well.

This reality seems to have cleared the air. I wouldn't be so foolhardy to assume that everything between us will be rosy from now on, but I live in hope.

JENNIFER: Why not?

It happened in 1974 in what was then a part of Yugoslavia. Up until then I had spent most of my time hanging around with a gang of East London yobos, but I was getting a bit fed up with them and needed a new outlook. My mum had realised this, which was why she suggested I come along with her and one of her friends from work.

Lake Bled is a beautiful part of the world. OK, I was with my mum, but there was plenty around to distract me. Its main distraction soon became obvious. She was from Vermont New England, well educated, cultured and a sometime lecturer at university. And she was 31, 11 years older than me. We got on very well. So I didn't spend as much time with my mum and her friends as I had envisaged.

When we got home Jennifer and I continued to see each other. She had what I considered the strange notion of wanting to go to art galleries and theatres, something I'd never even thought of before. The main question that occurred to me was 'Why?' 'Why not?' she responded.

So reluctantly I went through with it and do you know what? It was great! It really changed my life. Being the son of a carpenter, I never did art at school. I chose woodwork instead. I wasn't bad at English, but I'd never set foot on a stage. So I began taking art classes and joining amateur drama groups. I enjoyed all of this, but it wasn't really enough. I wanted more. I eventually decided that I wanted to go back into further education. The question was whether to go to drama or art school. After a lot of consideration, drama school won. So that's where I spent 3 years in the late 70s, leading ultimately to my career as an actor.

I never ever went to art school, that is, until I arrived at Headway East London. That's where I rediscovered it. Now I spend 2 days a week painting and I've taken over our back bedroom at home for the same purpose. I spend a lot of time walking around art galleries and I had great pleasure in recently designing and painting a new complete colour scheme for my house. I seem to give myself very little time for anything else, except, dare I say, writing magazine articles.



THE SPACE-TIME CONTINUUM



MATTHEW was working as a software engineer when he developed the symptoms of a cyst growing in his brain. Since the surgery that saved his life in 2005 he has lived with profound fatigue. He tells us how this has changed his life, his mind, and his thoughts about the value of love.

To wake up after eight hours of sleep is to rise expectant of rejuvenation - a genuine exaltation of one's mortal ~~temporally-bound~~ presence. I cannot remember the last morning I woke up with any sense of that exaltation, though I am hopeful every night I lay to bed. My brain injury is more than a decade old. Ten years of fatigue. Even now it is very clear how unclear I feel in body and mind.

The journey which led to my current predicament has never been clear to me either. I remember the headaches: each a cauldron of diffuse pain through my head. ~~This was no precisely pointed lance of a pain - rather, it seemed to be everywhere my brain considered a part of itself, all at once.~~

As a software developer, your Outlook Calendar could be considered a proxy for your line manager. You know where you are required to be at each hour of the day. The Outlook Calendar presents to you a grid like a flat planar representation of Einstein's Space-Time Continuum. Your allocated tasks distort this grid in length and width, and colours give you a sense of context like stars and nebulae in space. You can navigate this. You know what, when and where everything signifies. Like a master navigator, you will sail out into the space-time of the day and then safely home again.

There was never a point along this represented traversal of the day which signified a blinding headache, but like clockwork it would arrive at noon. It was a stickler for precise time-keeping. And it was crippling.

A week after the headaches began, I woke up one morning to realise that the visual ~~clarity of the world presented by my brain to my mind~~ had become obtuse and nonsensical. There were two of all and everything I could see, with my vision blurred in the middle. I had to squint or close one eye to function but function I did. I picked myself up and marched to work, and started on my tasks with one eye closed. I was in love with my job. I have heard in songs that love can kill.

Eventually I found myself at Moorfields Eye Hospital. I consider myself blessed that the examining optician could identify that the problem with my vision was not solely to do with my eyes. Rather, I had a growth in my brain called a colloid cyst. The growth had interrupted the flow of cerebrospinal fluid and had compressed my brain, putting pressure on my optic-nerve: thus my distorted vision. I have heard of an optician misdiagnosing the same visual problems in a child. The child soon died, and the colloid cyst was only discovered during the autopsy. The optician I saw sent me to the Royal London Hospital for an immediate surgical intervention. Everything after this is a blur riddled with poor cognition and fatigue.

I suffered a brain injury during the surgery. A colloid cyst is often to be found in the third ventricle of the brain, somewhere in the middle of the mass of soft, delicate neural tissue and not easily accessible. Brain tissue had to be cut and stretched to access the cyst.

I ~~had~~ became cognitively impaired. My memory and concentration have taken a hit. I do not remember some of the things that happen and I do not seem to see some of the things that are happening. All of this is somewhat bearable I suppose. But surely not this unyielding sense of tiredness, this weariness and this physical discomfort given the imprecise name of 'fatigue'.

According to friends who visited while I still in intensive care, all I kept saying was, "I am exhausted, I am exhausted", over and over again, as if trying to conjure myself into wellness. It did not work. I am still exhausted.

The fatigue is all-encompassing of body and mind. It breaks one's spirit. It makes one feel trapped. One cannot fight it for one has no weapons to bear against it. Few people understand one's struggle because it is unseen. ~~One cannot complain because people do not understand.~~ It is always there, even behind the occasional reprieve when I come up for air to breathe and have a sense of normalcy. It is an unyielding presence. It is tenacious and persistent. I suppose it takes after me in that respect.

~~Since I had the first surgery and lost my career as a consequence of the brain injury and the resulting fatigue and deficits,~~ In coming to terms with my difficulties I have learned a useful emotional trick: a very simple skill really, but a powerful one. Gratitude. Be grateful for everything you experience while you are still alive. It is an amusing thing about the human mind, how ~~focused we can be on the things that we presume are wrong in our lives.~~ we somehow manage to ignore all that goes well in our lives and remain focused on the things apparently missing. This I think might be a by-product of evolution in an environment of scarcity. We have this way of thinking built into our cultures and our minds. Yet in modern societies we are in many ways blessed beyond measure and imagination.

The most amazing thing I've noticed lately is tap water. The sheer miracle of this goes unacknowledged daily. I cannot remember the last time I was ever really thirsty for a drink. We never really are thirsty in the west - we merely have a desire for a drink of water. But count the amount of times someone around you has said in a tired voice, "Oh I am so thirsty!" Those that are truly thirsty have not the strength to exclaim.



Remember too that you flush the toilet every time you take a piss and or a shit. And we all do take many a piss and do take many shits – nine million of us in this heaving mass of London. Where does all the piss and shit go? It does not just vanish does it? We all know the answer to this question, and yet we forget the miracle of engineering beneath our feet: this thing of wonder that could make or break a society. In my circumstances I could not function without such things.

I remember now also that I have had two brain surgeries without having paid a single penny for either of them: yet I complain about the consequences of the interventions that have saved my life. Should not gratitude once again be my persistent mantra in all of this? Instead of being so focused on my losses I should be bowed in thanks: even if the morbidly logical part of my brain sometimes tells me that being dead is better than this malaise. Shamefully I will admit to having thought that way. So mind-altering and distracting is the fatigue that it causes me to forget all that is well with me, all that has been done and is being done on my behalf. One should and must always reach for gratitude and even graciousness.

Thankfully, the suicidal ideation has all but disappeared. There is just a hint of it left. Imagine a darkened room with a single bright candle and a big round dark dense amorphous shape hanging by itself in the room without any tethers, casting an equally amorphous shadow on the walls. That context represents what the suicidal ideation feels like in my mind, or perhaps in my soul. ~~An indefinable entity, an unwanted presence.~~ It doesn't seem malicious or terrifying: rather it is beckoning you to relax and to let go of your pains. A sleight of hand by a truly dishonest trickster, for it leaves a trail of devastation behind. And that truly is ~~indeed~~ a malice and it should be feared. All that is left of it now are the shadows on the walls and they are not as inviting. They hold no attraction.

What would my life be without the care and patience of my enduring family and friends, who have looked after and cared for me despite the distress of seeing me suffer, seeing me fail to make head or tail of my life ~~and own existence?~~ Being always tired makes one an excruciating person to be around: one's face is in a perpetual scowl; one's head persistently drooping. One's shoulders always tensed with ~~the expectation of nothing in particular.~~ When you fail to exercise gratitude you become morbidly pensive ~~about the distress of circumstances.~~ You fail even to recognise the fact of the care others offer you in love and well wishes. Surely all of this supposed pain would be bearable if we did not neglect the love offered us so freely.

A MYSTERIOUS GRAVITY

By QUENTIN GOSS
These pages are taken from the introduction to an unfinished work of 'religious science-fiction'.

AM T
A SERIOUS GRAVITY

ADAM & EVE
We are a serious matter with our differently various concerns, our love for the earth is more than the ^{concern goes above it} elements of anybody's ^{and} concern ^{everybody} and people feel's the import of importance when it comes, somehow we are one in heaven ^{we await to know the truth of} Words and money ^{we might be money till} bathe in heavenly water. of the rights and wrongs, of the light we are aiming to follow: Follow the Light of Christ to God with

The Holy Spirit

I thought comedy was very easy and very stupid and very sexist
The Apple of They Begot Divine and they began to make the way
It takes while for Jesus Shows the way the West is seeking to be with the East.

Earth and meaning?

Sir, Dominic Kinnaman tries to deconstruct Lord Sacks' perspective observation that opposition by the acts of the state of Israel is now a cloak for long-suppressed but apparently ineradicable antisemitism. He says that the real cause of the concern and hatred we have seen is 'Israel's belligerence, aggressive-colonisation and indifference to international law'. If this were true, we would see boycotts of Russian goods, attacks on Russian Orthodox churches, pickets of shops which sell caviar and nesting dolls and shouting-down of Russian lecturers by enraged students. JEFFREY LUTTMAN London NW4

The Song of the Earth

Time Matter Phenomena The World Space Numbers

1 is the ^{weight} of money: Gives description: For force

Our song 1. Is first of all about fundamental law and order, noting that

these 7 qualities have some circular criteria:

The curve of a clock, the shape of the atom, the day, year, and the shape of the bones of your ankles and the muscles of your shoulders.

the Realm of our existence (in which order occurs) is grounded by gravity

with God Animal Solid Mercury Our hips round (us) off
2nd - Vegetable Liquid Venus The hips of our trunk off
Mineral Gas Earth

1 is about more than the Earth, more than Her phenomena but normally you yourself will be so interested in what has already happened to you (your past), what is

The Dance of Life

On the balls of our feet, and heels, we dance with life

happening (your present) and/or what may happen to you (your future) that unless you fear the continuing sanity, you will not be concerned about your identity (I just your character). We aim to sail gracefully in our hips over the Earth. Without us, we may all be drawn.

(If you go off the rails and rail at your existence, beating your sanity and generally risking your life then I refer to me). I of course am: For everyone.

The song is called The Dance of Life.

Man is made in the Image of God.
Upright And Infinite

A couple of Christmases ago I was reading Salman Rushdie's much-maligned account of his Salanic Verses ordeal and was struck by the idea of the creation of Joseph Anton, the "shadow" version of himself that allowed for a necessary degree of reinvention. Rushdie

Joseph

Sin causes death.

Jesus died for the sins of the World!

With the inkling of ghosts that I, Quentin, possessed rather less firmly than the assurance of its power which like many memories has been coming back for quite some time now,

Woman is Life

The warmth of life is from the sun, is yellow.

Man is Time

Even in the inky depths of space man has colour

A We are going for **reality**

W M

W M

with blue for man and yellow for woman together in the universe.

A is **B** balanced

Comes to a point, there is purpose.

We have stability.

There is a high shelf, an upper compartment

Man is I believe for life to rise for all life (at least on Earth). There may be like-life aliens. Going Green is Going Organic to the Delightedly.

light

to rise together. God Life Time is making us better so that we arise in good time, according to our lives, order with the goodness of God. Our lives Order, Our future, let it be with:

The one of delight.
The two of delighted.

The free case.

Our drive to reality

No Matter

Carol Reads the Stars

Words by CAROL ZENIOU
Drawings by Lesley Roberts,
title design by Martin Mossop



♈

ARIES
Very good. Always arguing
and fighting their way. And
competitive. But very good.

♉

TAURUS
It's a bull. This person tells people
off. A prediction? You're gonna
fall in love. It might happen and it
might not happen.

♊

GEMINI
This one loves me a lot. Takes
me to dinner.

♋

CANCER
The strong and silent type. And
when she's strong, she'll give it to
you, oh boy.

♌

LEO
I don't like Leos. Well, some are
good, and some are bad. What
goes around comes back around.

♍

VIRGO
Virgo is the cow? Or the twin? I
don't know any Virgos. The one
thing I know is they're kind.

♎

LIBRA
Good with women. Looks and
looks and looks until he sees one
he likes.

♏

SCORPIO
I like Scorpio. It's very nice. I know
a Scorpio guy. He's very relaxing
and faithful.

♐

SAGITTARIUS
This is me. We got wisdom,
knowledge and experience. We're
happy-go-lucky. And we can sing.

♑

CAPRICORN
Your future is loveable. You're
kind, gentle and appreciated.

♒

AQUARIUS
Polite, tidy and clean. Likes
to spend money. I married an
Aquarius.

♓

PISCES
Oh my god – I fell in love with
a Pisces. Green eyes and light-
skinned. It's the fish. A fish with
green eyes!

AFTERTHOUGHT

Seasons make remembering time wistful
Seasons help create something
That's been & gone
It's better gone

Time to move
on

By SCARLET WILLIAMS,
from "It's For You"

matter

www.mattermag.org