

Making for the Light

- A play about epilepsy by Operating Theatre
In conjunction with Newcastle University

www.operatingtheatre.org.uk

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The CANDO (Controlling Abnormal Network Dynamics using Optogenetics) project is a world-class, multi-site, cross-disciplinary project to develop a cortical implant for optogenetic neural control in people with focal epilepsy.

The implant will modulate abnormal activity and prevent the development of epileptic seizures, providing precisely timed stimulation by continuously monitoring brain waves via implanted electrodes and modifying them via implanted light sources. This requires that some cells within the brain are genetically altered using a safe virus to make them sensitive to light. The goal is to create a first-in-human trial in patients with focal epilepsy.

Operating Theatre has been making work about health and well being for 15 years, working with medical schools, health care providers, charities, researchers and industry to deliver heartfelt drama that aims to change how people think about health.

Their aim in the project is to respond, as theatre practitioners, to the challenges and opportunities that the CANDO project presents.

Making for the Light is that response.

Making for the Light was first performed at Live Theatre, Newcastle upon Tyne, UK on 22 November 2018.

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Operating Theatre is a registered charity

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THE STARRY NIGHT AT THE MUSEUM

(GARY and RACHEL stand in front of a B/P screen and watch as the colours drift gently by. The screen becomes lighter. The giant skylights of the Museum)

GARY It was a large, noisy group, too noisy even for the vast space, a former railway terminal, but once the head had stepped to the front of the group and raised her hand in the manner of a battle hardened general they quietened down and formed an orderly queue by one of the turnstiles. The museum staff opened the gate and did their best to count them as they went through but soon gave up, smiling weakly at one another. None of the kids seemed to understand a word they said and in under an hour they'd be heading home so what was the point. Smile and wave.

RACHEL The teachers did little to guide them, there was too much to see in the time. They would just have to get a feel for the place and anybody that wanted to spend more time looking around would have to come back on the free afternoon, which the teachers had already decided they were going to spend in the Marais. A boozy lunch and then window shopping had been the unanimous decision. Perhaps a sneaky beer or two before the bateau mouche, which was considered to be the highlight of the trip for a lot of the students.

GARY Ellen, who had been one of the first to sign up for the Paris trip waited until the rest had dispersed. She took a quick glance at the map just to confirm she was going to the right place and then headed up the stone stairs and up again until she reached a small room with subdued lighting. She let a couple of Chinese tourists make their way out of the room; nodding instinctively at them as they passed, and then walked directly towards one of the paintings. A relatively small canvas, the painting was predominantly dark, dark blues mainly, not that anything was just one colour, there were all kinds of blue with points of light emerging, scrolls of cadmium mixed with white and sulphur yellow, then more swirls, cornflower blue, viridium. Bold strokes, across and then yellow trails, snaking down.

RACHEL She glanced at the date on the information plate, 1888, Starry night over the Rhone. Van the Man. She knew every part of that painting. Which is why she looked first at the darker areas, the cold night time water, the boats moored along the bank and the

buildings in near silhouette, before taking a few small steps back and shifting her attention to the stars. They didn't look real, her friends had said repeatedly. They look stupid like that, too big, too bright. She always reacted in the same way. As her friends shifted their attention to another poster, Donny or David or Marilyn, she would step back towards the middle of the room, draw her eyelashes over her eyes and take in the whole scene. How could anyone not see that this man, this artist, had done much more than try to represent the stars that night. How exactly had he managed it? How had he fixed the light on the canvas. Half close your eyes and focus on the stars. Then follow the reflections down and across onto the water and let the reflections dance in front of you and you were left with no choice. You were there. By the river.

GARY She imagined the couple walking in the foreground talking softly and then turning to look up at the starry sky and not saying anything at all, letting their heads tilt right back as they tried to take in the whole sky.

RACHEL Ellen found herself tilting back gently just as they had done. She felt her jaw slacken and a smile begin to take over her face. And as the smile broadened she felt a warm pulse in the middle of her chest, the straw yellow and the flecks of silvery grey and the deep, silent water and the boats rocking gently from side to side, the reflections moving on the surface of the water, and her fingers were somehow in the water. The water was cold, and as her fingers extended down into the water, she saw her breath on the water and felt her face, her whole head tip into the blackness of the river, with the stars pouring over the back of her head, the light melting, into the wake, taking her down into the water.

GARY When she emerged, floating up towards the gentle light, with only the slightest flick of her limbs to reach the surface, she noticed she was... dry as a bone. Her head felt heavy and so it seemed sensible to leave it just where it was. Everything was on its side- the paintings, the stockinged legs and pretty leather shoes. The warm parquet floor that seemed to spread out for quite some distance. There were more legs, dark trousers, a rustling skirt and noisier shoes that shifted from heel to pointed heel and then a face, a large pale face quite close to hers.

RACHEL The face belonged to Mr.Dennis. Mr.Dennis who it turns out had really deep blue eyes.

GARY Ellen, it's Mr.Dennis. How are you doing?

RACHEL Fine, resting, looking at your blue eyes, sir.

GARY Mr. Dennis looked at her. Are you all right to stand up?

RACHEL Why wouldn't I be?

GARY Ellen got up helped by the women with the rustly skirt, who she'd seen on the gate earlier and then she felt Mr.Dennis' hand holding her arm, guiding her gently towards the stairs.

RACHEL One or two of her year group were waiting by the shop. When they spotted her coming down the stairs most peeled away but Helen and Katherine moved towards her. Helen had her bag and was holding it up for her to see and Katherine, for some reason Ellen couldn't quite understand, took her own coat off and helped Ellen put it on.

GARY A long coat. To hide the... (*gestures downwards*)

RACHEL Ah yes.

GARY They travelled by taxi to the hotel and then, after showering, Ellen got straight into bed and slept like a baby.

RACHEL The following day Ellen went down to breakfast as usual. Her pals were fine about it. Helen asked if she wanted to talk about it, Ellen said not really and they quickly moved on. In fairness not a single kid on the trip ever mentioned it. Not ever.

SHIFT IN IMAGES – hospital to art school white to colour

GARY Hospital visits, this tablet, then another one, that made her sleepy, so another lot and so on, for quite a few months. A miswiring of the brain, not a lot to be done, a wait and see diagnosis. It might never come back. Sleep, nothing too strenuous, definitely no clubbing. See how it goes.

RACHEL Ellen was fourteen at the time. She had no interest in clubbing. Far too much to do. The posters changed of course. Stiff Little Fingers, Siouxsie and Debbie

Harry, Parallel Lines, Clem with his distinctive fringe. Her friends still came round, less frequently, but that was fine by her. More time to read and draw and thanks to her Christmas list, paint. The smell took some getting used to. She tried oil bars for a while but missed the ritual of it all and so most of her pocket money went on tubes of paint, and books. There were some good books at the time. She'd go to the big central library, check them out first and then put money aside, every week without fail, until she had enough to buy a copy. Most were hardbacks, some weighed a ton. She read them cover to cover and made copious notes.

GARY Her diaries were full of sketches and febrile instructions to herself 'Explore hands- the difficult bits- don't be lazy'.

RACHEL She was never lazy. Always had something on the go.

GARY By now it was clear it was an obsession. She had examples of his hypergraphia and had looked at every sketch and self portrait and knew from a map of France where most of the later paintings had been created, down to the exact village in most cases. The letters to Theo were too much for her. Hundreds of them. She had other things to do. Get her exams, get herself to London or Brighton. Art School. The steps she needed to take were all neatly recorded in her journal.

RACHEL She had been advised to keep a note of her seizures, frequency, intensity. She did, and realised that they were starting to change the way she organised her life. A few sleep overs missed, and then a big skiing trip. She lost the deposit but the thought of having a seizure on the coach with a whole load of people from her new Sixth Form college was just too much.

GARY Overnight bag. Every day, just in case. No chance of an overnight stay though. Her friends started to accept that she wouldn't be part of their plans.

RACHEL There were chances later on. In Brighton, and not just in the first frantic weeks of Freshers. A couple of times it was looking promising but she stopped herself. Concentrate on the work. Get the projects in on time - avoid getting too tired or stressed out. Plenty of time for all of that. Plus, try explaining why you can't stay over.

GARY A glorious final summer. A few of them hanging around, waiting for their results. With the pressure off, everything was easier. By then Callum had made it very clear he was definitely 'interested'. He said it as flippantly as he could, but he was serious about it. She felt that deserved an honest conversation.

RACHEL She was very honest with him. She didn't want it to get in the way. And anyway, they were just hanging about, for now. Friends with very nice benefits. Callum was lovely about it. Didn't ask any awkward questions. Let's see how we go I think he said. They made good use of the time, worked during the day, then walked and talked along the beach till they were too distracted with one another to talk anymore. Once they'd earned enough they got the ferry to Spain and did some travelling. They decided to explore the Northern coast, see if it was everything they said it was.

GARY They wild camped on the smaller beaches and got mussels off the rocks and cheap fish from the fishermen. Callum it turned out could cook. Really cook. They'd get up early and once they'd had their swim Callum would walk to the nearest market while she dozed or read, lying on her side, one hand shielding her eyes from the sun. The fish was amazing, and while he tended the fire Callum talked about maybe getting a job somewhere along the coast. Far better prospects as a cook than a potter.

RACHEL Ellen wasn't as convinced. She was keen to paint. To paint some of the same landscapes Van Gogh had painted. She had a plan. Get to Cannes or Antibes, sell some stuff on the beaches and then, after a week or so in Grasse or Vence to paint the lavender fields, start visiting all of the places she had marked so conscientiously on the map.

GARY Callum finally agreed. He would get a job on the Cote D'Azur, meet up with her whenever he could, and then they would see what happened. They were both happy with the arrangement. No use rushing into things. Plenty of time, no need to get heavy.

RACHEL France was pricier and not as easy going but they stuck to their plan. It took a week or so but Callum found a nice place to work in Juan Les Pins and Ellen somewhat reluctantly set off into the hills. Maybe she had been a bit hasty. The thought of being on her own wasn't quite as appealing as it had been.

GARY The lavender fields were amazing though. Rows and rows of intense colour, purple fields swirling around small hilltop villages. Almost too painterly, too overwhelming. The heat was intense too. She didn't have too much time so she worked pretty much all day, finding shade when it got too much.

RACHEL Callum had sent her a long letter raving about the restaurant. He was learning a lot. One of the chefs it turned out was from Arles and had promised to take him up there in a couple of weeks time. They made arrangements by phone, the sounds of the busy restaurant making it heard for Callum to be heard. They missed one another, that was obvious, and unexpected for both of them.

GARY Ellen carried on sketching and painting. If Vincent could produce over 2000 pieces in his short lifetime then she would have to get a move on.

RACHEL Sketching was easier. Watercolour was way too tricky and oils were not practical, so she posted her first small canvases back to her mum along with most of the paints she had brought over and got to work.

GARY She got to Arles two days before they were due to meet and decided she would take it all in before seriously getting to work. She hadn't expected to be so tired from the travelling. It was very hot and the day before she had fallen asleep in the sun waiting for a ride. The woman who ran the hostel seemed quite concerned about her. Ellen felt she was making a fuss over nothing. A couple of hours rest and then a long walk she decided.

RACHEL Ellen had never had such an intense attack. The owner of the hostel called an ambulance when she heard Ellen fall to the floor, taking the bedside table with her, and Ellen was taken to hospital. Sunstroke. A sudden fever had induced a series of violent seizures and Ellen was effectively in a coma for several days.

GARY The brain within its groove
Runs evenly and true;
But let a splinter swerve,
'T were easier for you
To put the water back
When floods have slit the hills,
And scooped a turnpike for themselves,
And blotted out the mills!

Emily Dickinson

RACHEL They didn't meet up in Arles. Callum and Ellen I mean. By the time Ellen's mum and dad had been informed of Ellen's condition and flown out to see her the news, the other news, had made the British papers. Ellen's dad had made a point of putting the paper he had been reading on the plane deep into his suitcase and zipping it up. They waited as long as they could to tell her.

GARY Callum wasn't driving the motorbike. There was no alcohol involved apparently. It was quick, instantaneous they said, neither of them would have felt anything, which was absolutely no consolation whatsoever.

LIFE

RACHEL The next few months were hard. That she had done well was frankly meaningless to Ellen. They had even suggested she stay on, do a Masters, they would help her get some funding. Ellen preferred to go home, she needed time to get herself sorted. The sunstroke had complicated things and so began a round of trial and error treatment that lasted months. It was exhausting and frustrating and interfered with everything.

GARY As she wasn't really up to it she decided to take a complete break from drawing. She decided she wanted to get as far away from it as she could. She chose insurance.

RACHEL Ah yes, the cut and thrust of the actuarial arts.

GARY Look everyone is allowed one really dumb move.

RACHEL And that was it.

GARY Ellen thought it would distract her, numb the pain somehow. However, she very quickly realised it was just plain boring and there was no-one in the office she really warmed to. The lights were too bright and it was always way too warm. She had dared to open a window one time and when she came back from lunch it had been shut and locked.

RACHEL What made it clear just how wide from the mark she was, was when a few weeks in, after a relatively minor seizure, she found herself on the floor by her desk. Someone was calling an ambulance, and as she was

trying to explain from her foetal position that that wouldn't be necessary, that her head was already beginning to clear her boss literally stepped over her to get to his office. Right over her, like she was a bin bag that had split open and was waiting to be cleared up by someone, anyone. Certainly not by him.

GARY Change of plan. If she worked from home, in her bedroom with the map of France, and Debbie and Clem looking on, then she wouldn't have to explain anything to anyone. No awkwardness, no drama, she could do everything by correspondence. Scientific illustrations at first, which she found surprisingly satisfying, then after a few months an anthology of poetry.

RACHEL It was a small, independent publisher. Basically run by one guy who cycled everywhere in garish dungarees and crocs. She had met some of the contributors at an event her mother had dragged her to, and once she heard they were preparing a collection she suggested herself for the job. She would never have done that before, but frankly she needed the work. Her sketches of the lavender fields and an early portrait of Callum clinched the deal.

GARY The drawings were quite spare, just a few lines in some cases. But they were bold and seemed to fit. She thought they looked a little like Picasso's owl pots, the ones she had seen in Antibes. They had emerged from who knows where one night and she had not stopped drawing till they were all done. They were well received and Roger asked her to consider a longer term collaboration. Her one steady income stream it turns out, from one of her truest friends.

RACHEL For several instants I experience a happiness that is impossible in an ordinary state, and of which other people have no conception. I feel full harmony in myself and in the whole world, and the feeling is so strong and sweet that for a few seconds of such bliss one could give up ten years of life, perhaps all of life.

GARY Fyodor Dostoyevsky.

RACHEL Ellen could draw and paint all night if she felt compelled to. Her dad would insist on bringing her tea when he woke as he often did in the middle of the night to find her scribbling away. He didn't speak, just pointed down to the tea and tiptoed away. Ellen began to take an interest in other artists who, like

her, experienced the heart stopping and brain twisting incidents that Edward Lear resolutely refused to mention in his diaries.

GARY Lewis Carroll didn't consider himself off or crazy so why should she? Ellen filled the pages of her sketchbooks and when she was short of money used rolls of lining paper. Her drawings were skilful if a little disturbing at times. She sold nothing. She did earn a reasonable amount with the commercial stuff when it came in. She had no desire to move out and so without even realising how it had happened, she found herself ten years away from that sun drenched summer.

RACHEL But we shouldn't dwell on things for too long, there is a lot to understand, to bring us to where we are now. Or where we are about to be.

GARY Indeed. We have to get to the white walls of the white room. Before we do, can we at least agree that epilepsy is like a thumbprint, that no two cases are the same?

RACHEL That's not in question.

GARY So she was just one of the unlucky ones.

RACHEL What do you mean?

GARY Untreatable. To all intents and purposes.

RACHEL Her epilepsy became untreatable that's right.

GARY Which is why she is where she is.

RACHEL I'm not sure what you're driving at?

GARY That it has to be a personal decision.

RACHEL Of course, I don't think either of us would want it any other way.

GARY I'm just struggling to understand. The why of it I mean. And if we're going to help then we need to at least know the why.

RACHEL I don't know if you want to help.

GARY Of course I do. I wouldn't be here otherwise.

RACHEL Honestly? You have no vested interest in the final outcome?

GARY Of course I do. But there are other views to contemplate. Other 'Russian mountains.'

RACHEL Nice. The one phrase that lives on from the trip. Is that a deliberate thing. Take her back to happier times, maybe she'll decide she doesn't want to turn off the lights.

GARY It popped into my head. It's a nice way to describe a rollercoaster. That's all. Can't I delight in the strangeness and beauty of language?

RACHEL Do you think she isn't going to be able to string a sentence together, afterwards I mean?

GARY You know I don't think that. You know it doesn't work like that.

RACHEL I know if it's successful she will never have to have to try and fight it when it comes. Even though she knows there is no point in fighting it. Even though she is worse off fighting it.

GARY Are you saying she won't miss the sensations that can only come from the sacred disease? What if she decides not to paint any more. What will we do? I'm not hanging around on the off chance. Life is way too short. What do you expect me to do?

RACHEL Wish her well.

GARY Wish her well?

RACHEL When you wake her give her a little squeeze and let her know it will be all right.

GARY It's a probe. A device inside her brain. That will require more than a little squeeze to get her to agree to it.

RACHEL When she stood at the top of the stairs, aged five, and began to speak.

GARY In a voice that her own mother did not understand.

RACHEL She couldn't have seen the look on her mother's face. But you saw it.

GARY Yes I did. I have to say her mother's response didn't surprise me. It sounded nothing like Ellen. I would have been equally...

RACHEL There's a perfectly reasonable explanation. To do with the vocal folds under stress, but let's not get caught up in details. When she stood at the top of the stairs, the rabbit hole appeared. And a whole menagerie emerged.

GARY You're including yourself in that menagerie I take it.

RACHEL Of course, and you... When that happened, it set her on a course. A trajectory if you like. And here we are.

GARY Like Dorothy waking up after the twister.

RACHEL Psychogenic heart attack. Different thing altogether.

GARY All right, Ellen is waking up now and she is going to want to make sense of it all. So has all of this raking up of the embers been of any use to her?

RACHEL We won't know. If she decides to sign up then we will have to check out pretty quickly. There won't be time for anything, no time to fill in the tick box survey or raid the mini bar.

GARY And if she decides not to sip from the little bottle labelled Drink Me?

RACHEL Then we can enjoy one another's company a little further down the road. When we are summoned. You can brush up on your Spanish in the meantime.

GARY It's back there somewhere. I just need to unlock it. Before we go. Can I ask you something?

RACHEL Only if I can answer completely honestly.

GARY Would you do it? Have it done I mean?

RACHEL I can't answer that. Honestly, I have no frame of reference. I know what I know. And it's not what she has experienced. I'm not altruistic, it's not in my nature.

GARY I appreciate your honesty. Right then, time to help her to her feet. Then we can leave her to make up her own mind.

RACHEL My thoughts exactly. What would life be if we had no courage to attempt anything?

GARY Van the Man. Nice touch.

GARY and RACHEL *turn back toward the screen as the colours merge and brighten. They intensify and bleed into one another. A white screen.*

END