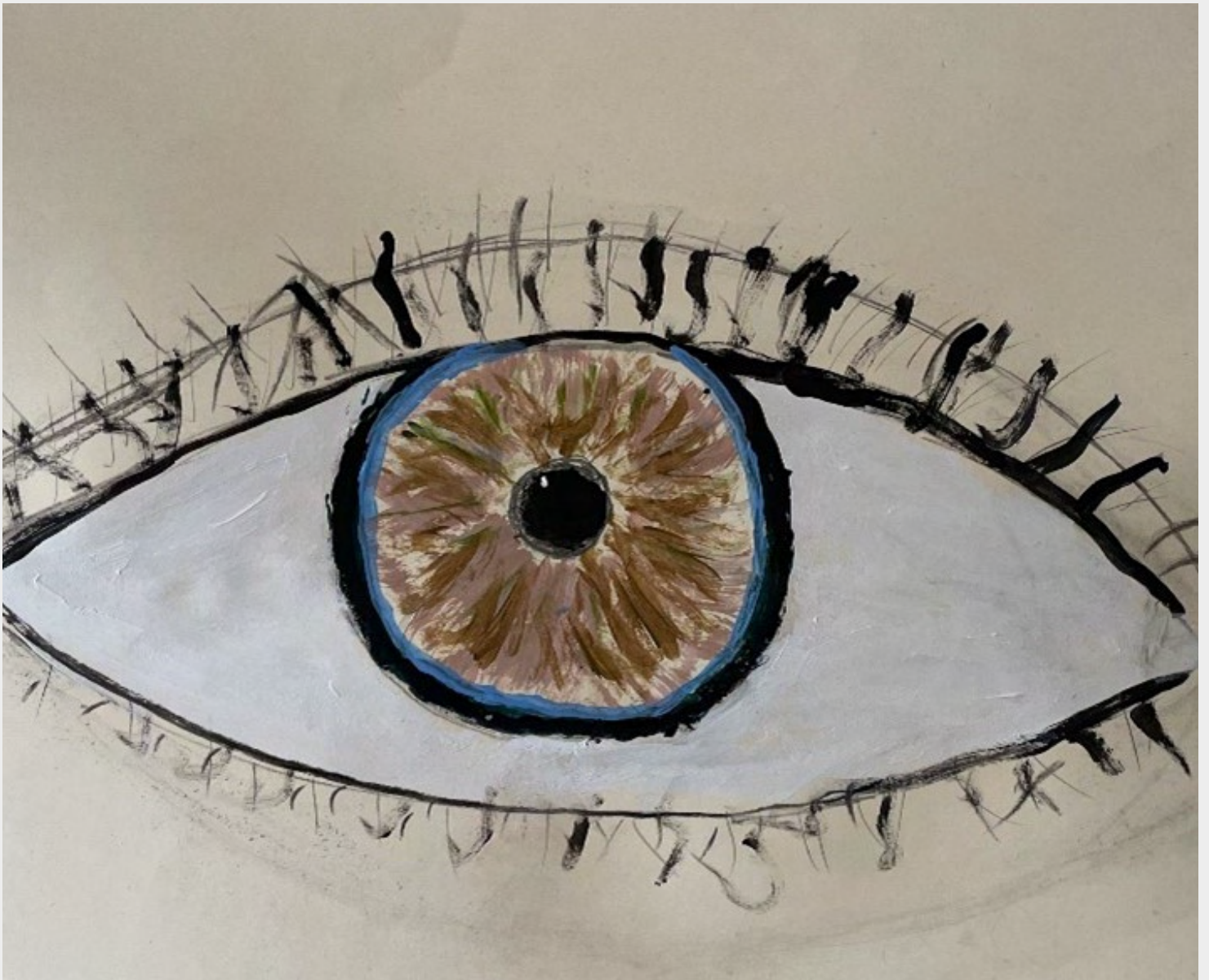


LOOK INTO MY LIFE

*A JOURNEY THROUGH
MITOCHONDRIAL DISEASE*

By Paul Unsted

Edited by John Holden





FOREWORD

This account is transcribed from Paul's conversations with Care for Veterans staff and volunteers. Because Paul's speech was not always completely clear or coherent as a result of his condition so the words and sentences have been tidied up to make them read more smoothly. It is written in the first person as it is "Paul's Story" as told by him. Some of the dates may be slightly out of place due to the fractured nature of the conversations.

Family



ME, LINDSEY AND MUM

FAMILY

Theresa Unsted - Mother – 10.3.1951 – 18.6.2009

Peter Henry Unsted - Father 14.3.1949 – 18.6.2011

Lyndsey - Sister - Died age 34, February 2009

Louise - Sister – Died age 16 - July 1996

Karen - Wife

Eva Theresa - Daughter – Born 14 September 2011

Ian (same age as me) and Jenny, cousins living in Rustington

John - Ian's Dad

OTHERS

All the staff at Care for Veterans throughout my stay.

All the volunteers directly or indirectly involved with me during my stay.

Childhood Memories

When I was about three or four I would get the collection of toy cars out of the box and then Dad would have to go round and clear them all away later.

Christmas 1987 - I attempt to recreate a scene from "Only Fools and Horses" where Del Boy makes music by "playing" a glass. Mum had got out the best crystal glasses for dinner and it seemed a good idea to me to try this trick with Mum's best glasses. Unfortunately, in doing so I flicked the glass knocking it over and breaking it – it had been a present that my grandparents had given to Mum.



Me and my sisters

I remember kicking a ball against the wall at school but I was never good enough to play in the school team. I had no particular friends at school, just hung around with a group. When I was 9 years old I was diagnosed with dyslexia but was told to just try harder. It didn't really affect me in later life – that's why I became a chef in the first place. Although I liked science my GCSE exam results were all low grades including Maths, English, General Science and Cookery. The careers advice I got was that I should be a gardener or a chef!

Leaving school at 16 I went to a part-time job to learn cookery. I have been a chef ever since with a desire to travel to experience different cultures and the foods associated with them.

1989 I went to my first Chelsea game with Dad who was a Chelsea supporter and watched them draw 1-1 with Stoke. I went to Chelsea whenever I could but because the cost was too great and my sisters were disabled we mostly watched on the TV.



John, me and Ian

Nine years later I went to my first Rugby Union game with Jen, Ian and their Dad, John, which was a 38-35 win for the Barbarians against Argentina at Twickenham. We were back at Twickenham in June the next year when an inexperienced England team pulled off a shock 51-43 win against the Barbarians.

Karen and Paul – Together

November 2003 was when Karen and I first met at Masons Solicitors in London. I'd had one serious relationship before Karen but split up after three years so I could be with Karen.

In 2004 we were working together at Masons where Karen was the Facilities Assistant, but it wasn't until October that year that we started seeing each other but had to keep our relationship quiet as this sort of thing was frowned on by the company. Karen told one of the caretakers at the company that she was dating me and they then told everyone else that Karen was "in a close and personal relationship (!!!)" with the chef" (original words amended to protect the innocent).

5.11.2004 – Our first date.

Soon after we met I was invited to visit Karen where she was living in a shared house in Shepherds Bush. She cooked for me, spaghetti Bolognese, but instead of using mixed herbs she used mixed spice. It tasted like cake! That's when she knew I really liked her because even though I was a chef I still ate it! I'll never forget my Moroccan Spaghetti.

Jan 2005 saw our first trip to Rome for a romantic weekend away together where we explored the Colosseum with its Roman pillars and old foundations followed by wine for lunch. Karen was very caring – ice cream three times a day every day from the same place the Pope gets his ice cream from. This was the first time I knew I was in love with her and told her so. She responded, "I love you." From then on we spent all our time together fitting each other perfectly and with the same ambitions and aims in life. She was my sounding board so I could bounce my ideas off her.

We had another short break in 2005 with a trip to Paris but in 2006 we set off on a longer trip when Karen and I traveled to Australia to meet Karen's family for the first time. Karen had arranged a surprise early birthday present for me on our return journey with a stay in one of Hong Kong's 5-star hotels.

In the September and October of 2006, we had a two week trip through Germany visiting Munich, Nuremberg and Berlin. Later that year we were in Egypt visiting the Pyramids and looking at the hieroglyphics when, equipped with an Egyptian ring, I made my spur of the moment decision to propose to Karen.

Aunty Sheila's 60th birthday in 2007 was celebrated in London with everyone staying at the Richmond Hill Hotel. After the dinner we were having drinks in the hotel when Ian and I gate crashed the wedding in progress next door. After enjoying their free bar for quite some time I was asked (or offered) to make a speech. For some reason that offer was declined

Australia and Back

On 3 August 2007, Karen and I got married at Painswick Rococo Gardens near Stroud, Gloucestershire, then went on honeymoon to St Lucia.

A two-week holiday to Turkey followed, then in 2008, a visit to Amsterdam. But in September 2008 after pooling our money we fulfilled the goal of a round-the-world trip when we took in Zimbabwe, Botswana, Namibia, South Africa, Ecuador, Bolivia, Peru, Chile, Argentina, Brazil, (where we were when my sister Louise died), Vietnam and Cambodia finishing in May 2009. By then I had also decided to move to Australia and take Australian citizenship. By September 2009 we had moved to Australia and the beginning of a longer stay. Karen's Dad and brothers were living between Sydney and Hunter Valley whilst her Mum, who was separated, lived in Central Australia.

We stayed with Warren, one of Karen's brothers. We both talked about staying permanently in Australia, but Karen had a falling out with her stepmother and things began to get difficult. I was working two jobs, one in the Central Bank preparing and making food and in a stadium kitchen as well. My relationship with my Mother-in-Law also went wrong and we felt we were being pushed back to the UK. Meanwhile Karen found she was pregnant with Eva who was born on 14 Sept, just six days before my Dad died. Although he never met Eva, he did get to see photos of her. We wanted more children and I would have liked a boy to be called Peter after my Dad, but this was not to be.



Me and my parents

Eva



With Karen and Eva, September 2012

Holidays

Eva was only weeks old when, in October 2011, we had our first family holiday this time to Hunter Valley, Australia. Life was fun in the sun and I would have stayed out there but Karen wanted to come back to the UK. Australian Christmas was spent on the beach eating glazed ham and salad – I didn't miss the traditional English Christmas at all. We had lots of good times. In the end we lived there until October 2012 before returning to the UK where we lived with my Aunt and Uncle in Crawley before renting our own place nearby and where Eva started nursery school. I was a bit sad to be back in the UK but decided to make our home over here – no more thoughts of becoming Australian. Karen was working in an office and I found agency work as a chef which gave me more time with Eva. She and I had "Dad and Eva Days" when we would go for days out pushing her round National Trust Parks in her pushchair.

Eva was noticeably stubborn, a trait or characteristic she inherited from Karen and not from me. Eva had a closer relationship with me until I got sick but then she would get embarrassed being with me when I fell over. It was in Saltdean when Eva was nearly eight that was our last "special place" as a family.

"I'm just a family man – I wanted to provide for them - holidays etc."

Family holidays after return to UK were as follows:

- 2013 - Woolacombe, Devon
- 2014 - Kos, Greece
- 2015 - Costa del Sol, Spain
- 2016 - Cornwall
- 2017 - Woolacombe, Devon
- 2017 - Munich, Germany, for the Christmas Markets
- 2018 - Lake District and Peak District
- 2019 - Taormino, Sicily
- 2020 - Somerset.

The Sicily holiday took place when Eva was about 8 years old and we would buy cannolis every day saying "Cheers with the cannolis."

Our family holidays came to an end when my physical and mental health became too difficult.

Gigs

My 21st birthday was memorable - me and Ian singing Queen's "Bohemian Rhapsody" complete with head banging - obviously after a few drinks! But later gigs included the following.

- REM in Hyde Park
- Reading Festival
- The Darkness
- Prince
- Bon Jovi
- Lenny Kravitz
- Powderfinger
- U2
- Cabaret (and Karen singing in the streets after the show)
- The Lion King



My Wave

Paul - Warning Signs

In 2015 Ian and I used to enjoy "Game of Thrones" and "Risk" nights with lots of wine. Ian described how my face looked every time I rolled the dice, he called it an "ecstasy face" - maybe the early signs of facial seizures!

In May 2016 I was suffering with a pain in my elbow then by September of that year I was experiencing a very painful jerking motion in my right arm. I was also getting intermittent headaches and back pain which I put down to Repetitive Strain Injury. At that time I was Head Chef at Kingston Grammar School with a staff of 12 under me. I loved the job as it was good money and a good team and enabled me to take our daughter Eva on holiday during the school breaks.

Over that year I was given 17 different diagnoses from 17 different doctors, but it seemed that no-one could link the signs and symptoms.

On Christmas Eve 2016, with all the presents under the tree, I went to East Surrey Hospital with severe pain and jerking in my arm but was sent home with painkillers. Shortly after returning home I had a massive tonic clonic epileptic seizure lasting eight minutes and was taken to hospital (having collected Karen and Eva on the way) and I then spent Christmas Day and the next three weeks in hospital undergoing test after test before being discharged with a diagnosis of a low grade myeloma (tumour).

By 2017 the problem had developed further and I went on Statutory Sick Pay until June of that year. The effect of the condition meant I was suffering seizures, the pain in my arm became more severe and I started to experience facial twitching.

At this stage no-one had linked my symptoms to my sisters' symptoms, Louise who had died age 16 in July 1996 just after I had left school, and Lyndsey who was 34 when she died in February 2009. Both had been diagnosed with Cerebral Palsy and NOT with mitochondrial disease, something that wasn't known about at the time.

“I’m Angry at the Disease”

Fifty tests later, backwards and forwards to hospital, a muscle biopsy eventually confirmed my diagnosis. A specialist surgeon had been asked to look at my brain scans and he decided that he couldn't remove the tumour which was the size of a kiwi fruit as it would be too dangerous. It turned out to be lesions which caused the different symptoms including the seizures/epilepsy. The first lesion was on the sensory part of the brain and then to the optic nerve. As soon as the doctors determined that the “tumour” was lesions they told me that “that was it” and I was given MRI scans every three months for two years.

Christmas 2017 offered a distraction with Ian and I spending Christmas Day at Jen's dressed up in Snowman onesies sitting in the garden “snug” doing quizzes and drinking.

The doctors had originally said there was no diagnosis, but Karen pushed the issue with Queen's Square Hospital and I was referred to a consultant and had further tests with the Genetics Department. Then nothing – no follow up and never heard back from the Genetics Department! I then had a referral to the Neurological Department at Queen's. It was while waiting for things to progress that I was fired from my job pre-empting what was surely to come but I felt I could have continued for some time more.

I should point out that the actual diagnosis was delivered via a phone call out of the blue from Queen's Square Hospital – sort of like “Congratulations, we have your diagnosis!”.

All I see are people who deal with the symptoms and not the cure, it's all research. Every single person's Mitochondria is different so each person with the disease is unique. It has been discovered that the cause is a defective gene and that it is inherited – my Mum had the defective gene and although unaffected she passed it down.

Because of my previous salary and our savings of £35,000 I wasn't eligible for any benefits, so I contacted the Lily Foundation (a UK charity dedicated to fighting mitochondrial disease) for help and advice. By now although I was mobile and still coherent my right arm wasn't functioning properly. Karen was working out of London commuting daily to and from our home in Crawley and Eva was at primary school aged 7 or 8 and too young to understand what was going on.

June 2019 and I was diagnosed with 80% loss of sight and was suffering with Charles Bonnet Syndrome - the main symptom of which is seeing things that are not real (hallucinations) after losing a lot of one's sight.

2020 and I was starting to choke when eating food and this was put down to “silent aspiration” – food entering the airways by accident. As a result of this I was fitted with a PEG tube (percutaneous endoscopic gastrostomy tube) so that my medications could be delivered safely.

By now walking was becoming tricky and I was starting to be sensitive to noises, especially background noise. Carers were brought in to assist me as I was less able to care for myself unsupervised.

As if this wasn't enough, in January 2021 I got Covid and my condition further deteriorated meaning I had to retire. Personality changes started to appear, my mobility became more of an issue and eating became more difficult.

My worsening condition I think led me to attempt to end my life and Karen called the police to get help. I spent the next five months in a home but pressure to discharge me resulted in me moving to Care for Veterans. In mid-2022 I moved into Gifford House, Care for Veterans, a nursing home in Worthing, where I was settled in and met Elaria who had been nominated as my main carer – unfortunately some time later she moved on. I was further welcomed by Len who, when we were sitting outside in the heat drinking juice, offered to top up my juice with whisky. "I'm going to like it here!" I thought.

December of 2022 brought another change when I started hearing voices and was prescribed anti-psychosis medication. My legs no longer had any strength.

By mid-2023 Karen and Eva had moved back to Australia and I could only speak with them via my weekly video calls but even then Eva has difficulty keeping in contact.



Eva, age 11

"I just wished I could have lived a normal life."

Eva



Eva's School Photo 2023

Gifford House - Care for Veterans

My "safe place" is at the end of the Orangery, part of the Wellbeing Hub, where I have an easel and my art materials. I am supported in my art by Gill and the sessions are usually half an hour on a Tuesday morning, I wish I could have more than one a week. At one of these sessions I tried to draw a sinking ship and explained this by saying I'd had a bad night's sleep. The voices in my head were telling me that no-one wants me and I don't deserve to be here or even to be alive.



"The Sinking Ship"

When I was explaining this to our Volunteer Counselor the three voices were there again taking the piss out of me for planning on writing a book. I tried to tell them to "f*** off" but they ridiculed me none-the-less. I tried to show this with my painting "Why You Looking At Me?"



"Why you looking at me?"

"The voices are like a speaker – three voices, one female and two male – always repetitive – makes me feel they are ganging up on me."

The Wellbeing Hub and Beyond

Note by Ed: The Wellbeing Hub is one of the communal spaces and is where residents can gather for a wide range of social activities including keep fit, film shows, cake making, TV watching (especially major events), quizzes, talks from visiting speakers, jigsaws, paper crafts and just having a doze.

Wednesday afternoons I often go over for the film show – they are okay but I can't see the screen and I often fall asleep. The one-handed pumpkin carving at Halloween was a bit awkward but with a bit of help we created something that looked like a Jack o'Lantern.

.The wheelchair keep fit sessions led by Gill can be noisy but they allow me to stretch and to move so as to maintain as much mobility as possible.

In August of 2023 I met John who had volunteered as a "Buddy" and we started to get to know each other. Once he had proved he could manage my SOS medication we started going out for coffee, such a change from sitting in my room. Our first trip out was along Worthing promenade towards town and I asked if we could go to Costa for a coffee. This first time was good and we managed to get into the cafe and find a table that allowed me to get close enough to be able to lift my cup. This outing became something of a routine testing out the various accessible venues including Pret a Manger (good access and good coffee) and Marine Gardens Restaurant (reasonable access, decent coffee, too much background noise, chip fryer fumes), Just a few hundred yards north of Gifford House is the Heene Community Centre and we tried there one cold day before Christmas. This was good; plenty of space, few customers, quiet and ideal for a good conversation. The second time we went was busier and not as convenient.

It was shortly after we started our outings that John commented that my Bucket List was too short and I said I'd wanted to do the London Marathon but no chance now - we are now doing it in short segments with a coffee halfway through each leg!

My other outings include trips to St Wilfred's Hospice and St Barnabas Hospice, to Queens Square Hospital in London, to the Charles Dickens pub (with Karen before she emigrated). Early in 2024 I was registered with Sight Support, a charity in Worthing, who offer IT support and are helping me with access to audio books via the RNIB.



"Flower in Acrylics"

The Bucket List

- To publish "Paul's Story" (this book)
- Hold an Art Exhibition
- Use the cycle machine in the gym
- To get out more often
- To do a Marathon (maybe in small stages!)



Eagle

References and Sources



SIGHT SUPPORT



WORTHING

Towards the Art Exhibition

Introduction by Editor.

The following section is a good representation of Paul's art output over his time so far at Care for Veterans. It is not in date order but with some themes grouped together.

It must be recognised that Paul has very limited vision and has to be very close to the canvas to see what he is doing and so does not get to see the whole picture. He also faces the challenge of being naturally right-handed but has little or no use of his right hand. Most pieces have a title given by Paul and some have additional comments.

When experiencing a bad day Paul often selects dark colours and angry brush strokes; good days are to be seen in works such as the Eagle and the Elephant.



Working on the title page with Gill



An early version of the Highland Cow - they got better!



"For Echaria" (my key worker)



I Love Beautiful Things



Phoenix



“Pathway Through Life”



“The Road to Hope” – Painted when feeling low



Memories of our 2008 trip



Victoria Falls



“Flowers from Memory 2” – Not a good day.



“Roses for the Ladies”



“New Strokes”.



Contrasts



"The Joker" – Unaided Art Session



Working with Shadows



“Playing With Colour”



“Explosion of Colour”



“Highland Cow” – to replace the version that was lost



“Butterfly”



Early work with perspective on “Christmas Stars”



“Christmas Stars”



“White Christmas”



“Church”



“Peace at Christmas”



“Owls about that then!”



“The Ninja”
Could be the Occupational Therapists!



“Rugby Forward”
Need more practice with people!



This is NOT a self-portrait...

Neither is this!e!



“Giraffe” – I wanted to draw a giraffe, but didn’t intend it to look like 5-year-old’s attempt!



A better attempt - with guidance



A penguin - from memory



Dung Beetle



Memories of Thailand 2008



And more palm trees on the beach



Gecko 1 - my wife collects these



Gecko 1 - my wife collects these



PAUL'S STORY

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