TIMELESS VACUUM

Facial Paralysis - a Photo Diary

Helena g Anderson

March 2018

FacialPalsy UK
INFORM • SUPPORT • RESEARCH

"We all have a 1 in 60 chance of developing facial palsy, but this condition has been scarcely mentioned in either House of Parliament. This exhibition of photos by someone experiencing Ramsay Hunt syndrome, one source of facial palsy, is a unique opportunity for many of us at Westminster to understand a bit of what this condition can feel like. With so many people and their families affected by it, I warmly invite you to join me in supporting this exhibition."

Helen Whately
Member of Parliament for Faversham and Mid Kent
15 February 2018

"Consider the arrangement of the face. It is key to our relationships, both with ourselves and with others. The face we show the world reveals a part of who we are - what we're thinking and feeling."

Anne-Marie Martingdale
Research into acquired facial disfigurement, 2015

With grateful thanks to:

Helen Whately MP

Red Eight Consulting:
www.red-eight.com

MODU exhibitions:
www.moduexhibitions.co.uk

theprintspace:
www.theprintspace.co.uk

4th March 2016

"A photographer, I had just finished the 'Time and Time Again' exhibition at Babylon Arts in Ely and was very excited about future plans."

Helena g Anderson

11th March 2016

Unusual frightening pain in the tragus of right ear. As it was Friday I decided to 'wait and see' before contacting the surgery.

15th March 2016

A pull on the right side of my face. The 'pull' was gradual but real, determined and frightening. I didn't know what to make of it.

16th March 2016

Doctor suspected 'Temporal Arteritis' which was ruled out following a blood test - thankfully.

No follow-up was suggested.

17th March 2016

My face was continuing to deteriorate and at midnight I called 111. I was taken to hospital by ambulance. A stroke was ruled out and prednisolone prescribed. I had no specific diagnosis. Sent home alone at 6am. Concerned, frightened, tired, and none the wiser. The right side of my face virtually paralysed.

They hadn't looked in my ear or mouth.

18th March 2016

Totally lost, didn't know where to go for help. Phoned osteopath in desperation. Cranial osteopathy and lymphatic drainage soothed me and distracted me from this scary new reality.

19th March 2016

Pre-planned photo shoot went ahead in my studio despite my 'new face'. This distraction offered some calmness to my burdened mind. A friend popped in with flowers and drinking straws, as by this time I was drooling. Food dropping from my mouth when eating and talking had become a problem.

Basic facial functions were lost.

20th March 2016

When 'faced' with these reflections on Sunday morning, I lost something within. Torn, deeply hurt and alarmed at what was happening...

Where has my face gone?

21st March 2016

Another visit to the doctor. A locum saw small vesicles in my right ear. Rushed back to hospital as apparently there was no time to lose. The discomfort on the inside of my right cheek and throat that I'd had for some time had gone unnoticed, I didn't think to mention it and

the right questions were not asked.

Finally, a diagnosis… 11 days after first pain trigger

Excerpt from medical notes:

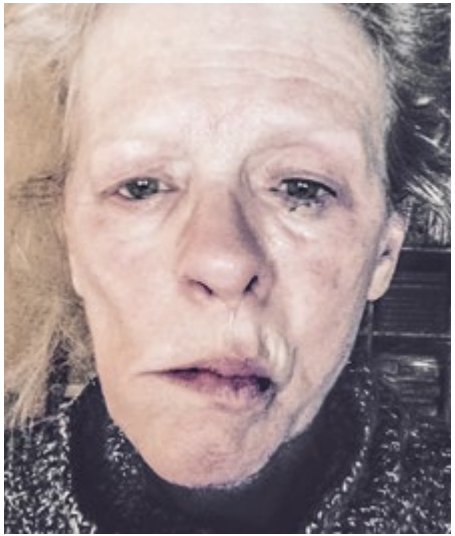
"1-2 week history of right sided pain and then development of a right sided facial droop. A possible vesicle was noted on her right external ear canal. O/E: possible vesicles on right tragus. Right-sided facial nerve palsy (Grade V - severe dysfunction).

However, in some cases facial nerve function may not recover. Please could you kindly monitor her mood in the community in this difficult time?"

Ramsay Hunt syndrome, a rare form of shingles.

Distraught, anguished, lost.

Advised to collect antivirals the next morning from GP.



I was informed that: "Full recovery is highly unlikely in your case…"

"…tonight I feel life is over…"

ENT provided ordinary sellotape to tape my eye closed. I didn't use it. Bought gentler micropore tape from chemist to help eye close.

22nd March 2016

Collected the antiviral medication, Acyclovir, this morning, unaware that it should have been given promptly by the hospital. Acyclovir should be taken within 72 hours of onset to secure a better chance of fair recovery. Today was day 12! I was very upset and disappointed that the specialist had not thought it important to give the antiviral yesterday. 16 hours were lost between end of hospital appointment and collection of the medication. I also needed gel to stop my eye from drying out which I had to buy myself.

Right ear swollen with virus, and I was frightened it would exPLOde. It felt hot, eerie and bad.

25th March 2016

I had a good relationship with my GP who I could see when necessary. It was easy to remain hidden from view. Solitary confinement.

My sons came home to support me. It was Easter weekend. The love, kindness, fun and patience they gave over those few days resulted in lopsided laughs, amusing drooling breakfasts and very slow meals; a brief moment of relief in an anxious moment of life.

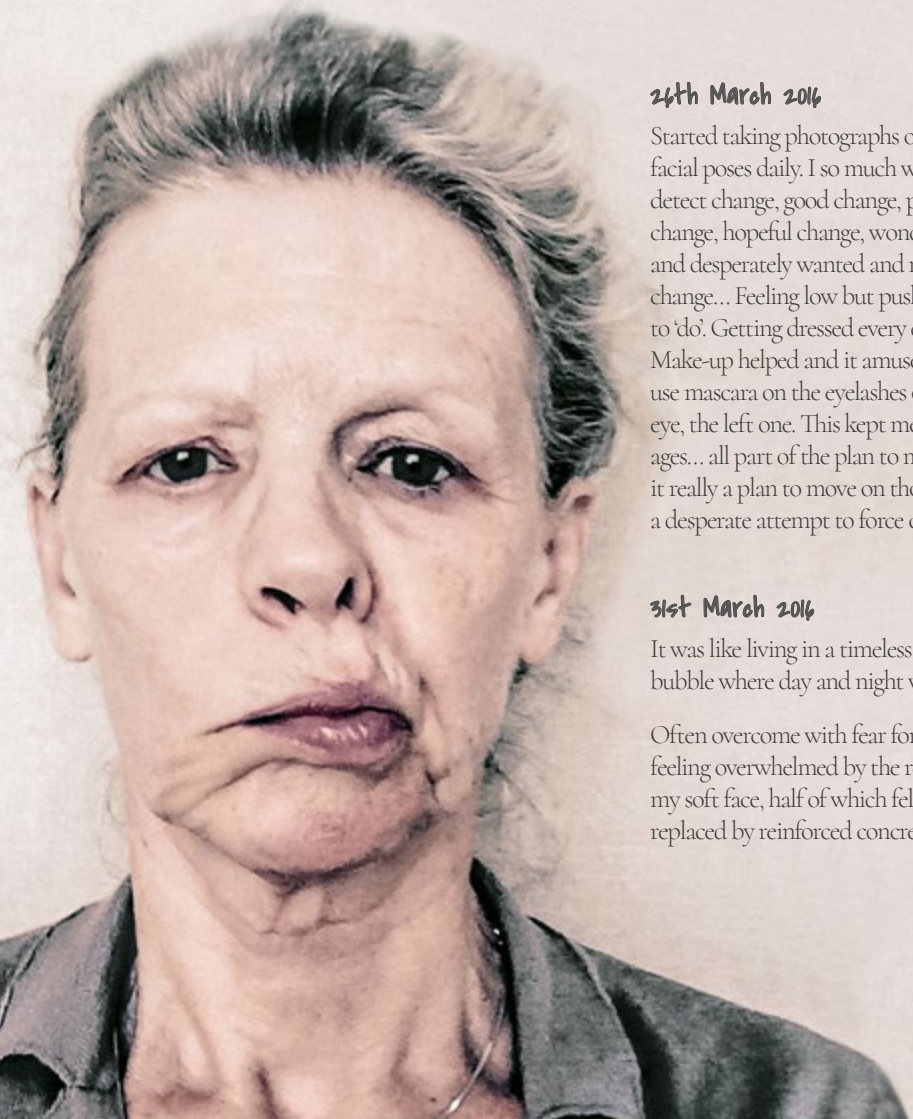
A lover of mirrors for any design projects, I dared look in one, and 'seeing' my face was a powerful and crucial moment. I started eating in front of the mirror at this time and continued this during all my waking hours from then on - 'facing my new face'. I had to be confronted with it, dare look at it, and while I was horrified by and frightened of it, it was better to accept it. It was a long arduous journey. Did I really feel a tiny flutter underneath my right eye?

"full recovery is highly unlikely in your case..."

Surrounding myself with beautiful things, such as the flowers my sons bought, the sunrays streaming through the window and creating reflections on my bed. Seeing the beauty in things always helps, but despite the sun and the roses they were dark dark days. "Been feeling very low."

"I had already decided that I would deal with this on my own."

Disbelief.
Disappointed.
Broken.



26th March 2016

Started taking photographs of different facial poses daily. I so much wanted to detect change, good change, positive change, hopeful change, wonderful change and desperately wanted and needed change… Feeling low but pushing myself to 'do'. Getting dressed every day helped. Make-up helped and it amused me to just use mascara on the eyelashes of my 'good' eye, the left one. This kept me amused for ages… all part of the plan to move on… was it really a plan to move on though, or more a desperate attempt to force change?

31st March 2016

It was like living in a timeless vacuum bubble where day and night were merged.

Often overcome with fear for the future, feeling overwhelmed by the reality of my soft face, half of which felt as if it was replaced by reinforced concrete.

'… it feels like a big punishment…'

3rd April 2016

Wonderful improvement two weeks from diagnosis, do I dare feel joyous?

"full recovery is highly unlikely in your case..."

These words kept ringing in my head.

The damage words can cause!

4th April 2016

A new set of problems. Off balance, thumping head, progress slowed down but the small tremors on right side of my face were cause for hope. Then tinnitus developed causing extreme discomfort, stress and pain.

Hospital visits became torturous, as well as my own noises in the head. I was plagued by doors opening and closing, chairs scraping on the floor, every day chatter, phones ringing and the coffee machine frothing milk.

Even the silence between the sounds became noisy and painful.

Hospital appointment: 4th April 2016

"Possible Ramsay Hunt syndrome, Facial nerve palsy now grade 3."

I had a confirmed diagnosis, I had shingles vesicles, I had endured severe pain. Had I imagined this?

Confused and let down.

Actions for GP:
None.

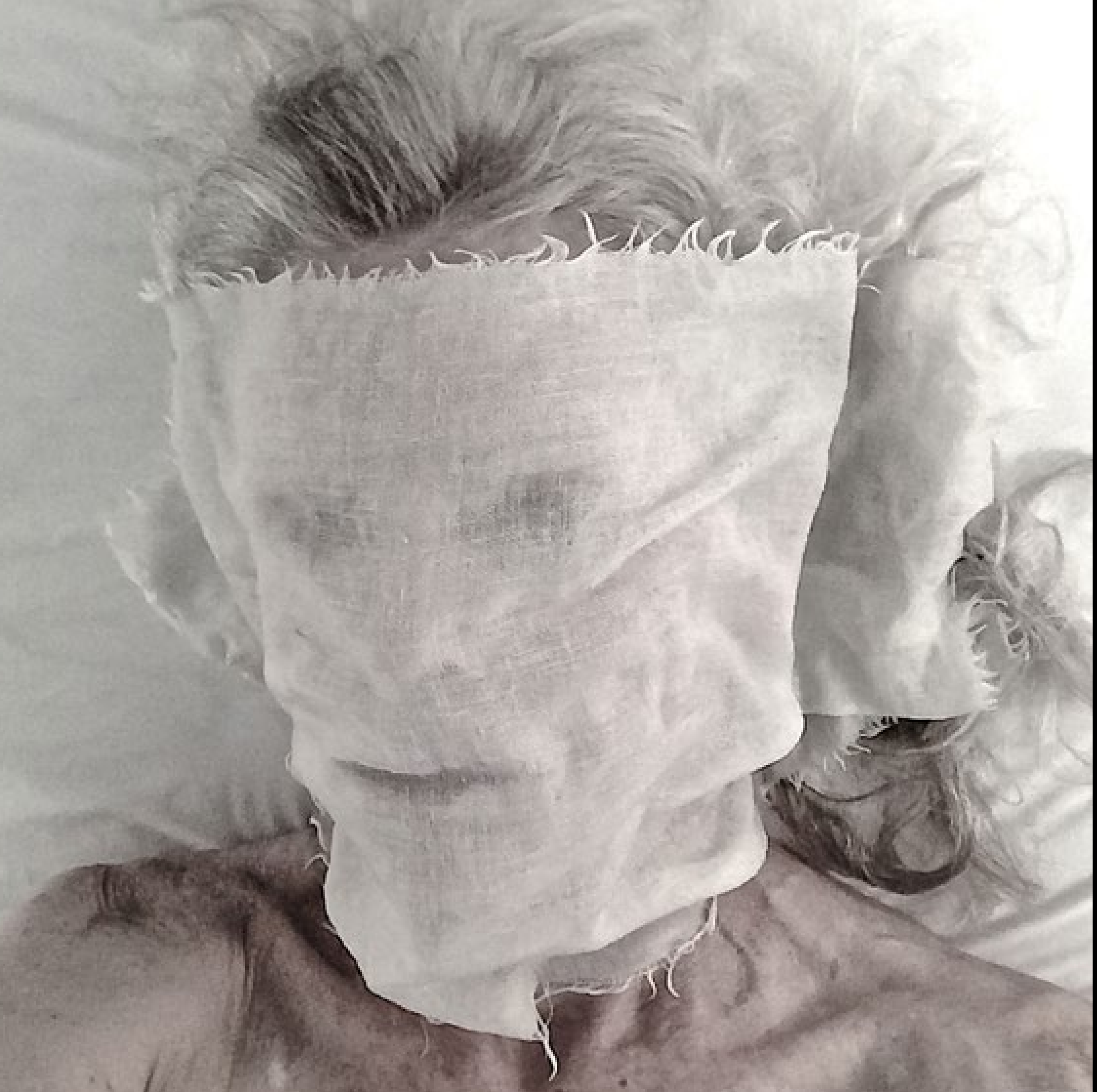
Management Plan:
Ophthalmology appointment in next few weeks. Finished Acyclovir and steroids. No further ENT clinic follow up, re-refer to ENT if any concerns in the future.

Medication changes:
None.

9th April 2016

Face of grief,

of deep disappointment,
of overwhelming hopelessness,
of excruciating despair,
of constant pain,
of inevitable guilt.



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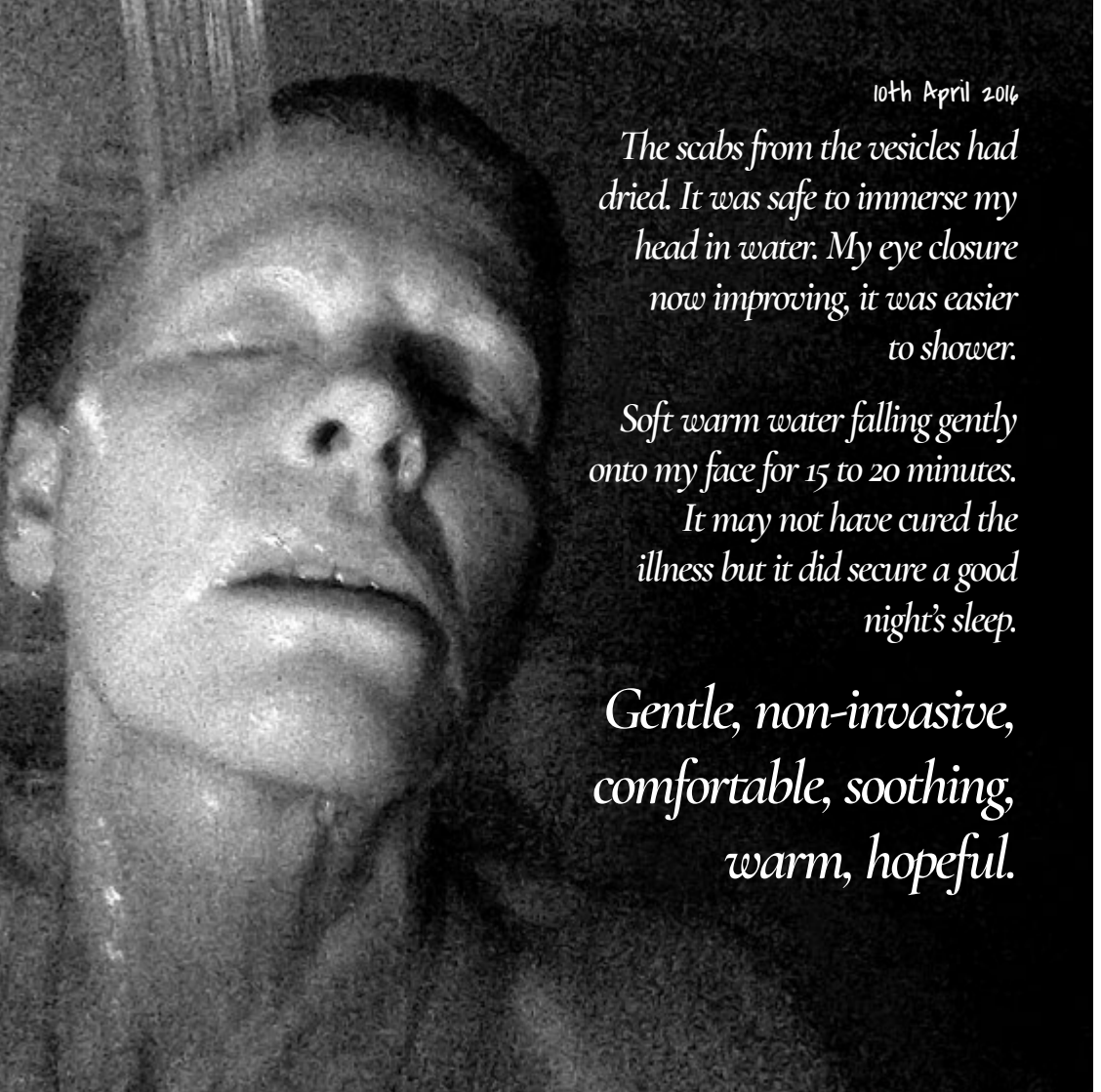

10th April 2016

The scabs from the vesicles had dried. It was safe to immerse my head in water. My eye closure now improving, it was easier to shower.

Soft warm water falling gently onto my face for 15 to 20 minutes. It may not have cured the illness but it did secure a good night's sleep.

Gentle, non-invasive, comfortable, soothing, warm, hopeful.

22nd April 2016

A photo shoot, the first project since the onset of Ramsay Hunt. It took great effort, but I did it. Although my face had not regained its former shape it was so much better and as long as I didn't look people straight in the eyes and as long as I didn't smile or laugh, I was going to be safe.

I developed a greater fear of space, open and enclosed, and if the space had people in it I would panic. I am panicking at the thought as I am writing this.

March 2018

Ramsay Hunt syndrome is also about what lies beneath the physical. It affects an entire life and lives - physically, emotionally, socially, and financially.

Ramsay Hunt syndrome plummeted me into a world of darkness. This debilitating condition is fraught with complexities and changed my life as I knew it. I hope that the portraits are helpful in understanding the extent of damage it can cause, so that research can commence, knowledge be gained and help offered to those who need it.

It has been nearly two years since the onset and I am still healing.

I am fortunate and grateful.

The photos in this leaflet and exhibition were entirely for my own use, and were not meant to be 'photographic art' and made public. However, if they can help convey the realness and seriousness of Ramsay Hunt syndrome, I gladly share them.

Helena

Facial Palsy

It is estimated that over 100,000 people in the UK have facial paralysis. There are more than 50 different causes with Bell's palsy being the most common.

About 1 in 60 people
have a Bell's palsy at some stage in their life.

FacialPalsy UK
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About Facial Palsy UK
(established 2012)

Facial Palsy UK's mission is for every person in the UK affected by facial palsy to have access to the best information, treatment and support available.

The need for the charity was recognised following the development of the Facial Palsy Clinic at the Queen Victoria Hospital in East Grinstead. A 2009 survey carried out by the clinic found that the average duration between the onset of paralysis and referral to a specialist for treatment was 5.6 years.

Added to the frustration of living with facial palsy is the public perception that the condition is purely a cosmetic issue, rather than a functional one affecting communication (facial expression), eating and drinking, and the closure of the eye on the affected side. The psychosocial impact is also considerable.

Ramsay Hunt syndrome

Ramsay Hunt syndrome, a form of shingles on the facial nerve, has similar visible symptoms to Bell's palsy but recovery outcomes are poorer and recommended treatment differs. It is commonly misdiagnosed as Bell's palsy.

The NHS website states if treatment is delayed, only about half of those treated will recover completely.

A survey carried out by Facial Palsy UK in 2017/18 of 152 people officially diagnosed with Ramsay Hunt syndrome found:

More than half
57%
were initially misdiagnosed

Just
52%
were prescribed antivirals within the critical 72 hours

Only
53%
were able to return to work within three months

19%
received no eye care advice

55%
were still suffering after 12 months

The Top 3
health issues reported:

Facial pain

Facial paralysis

Fatigue / Dry eye & vision problems (jointly ranked)

FacialPalsy UK

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Helpline: 0300 030 9333

E-mail: support@facialpalsy.org.uk

Website: www.facialpalsy.org.uk