

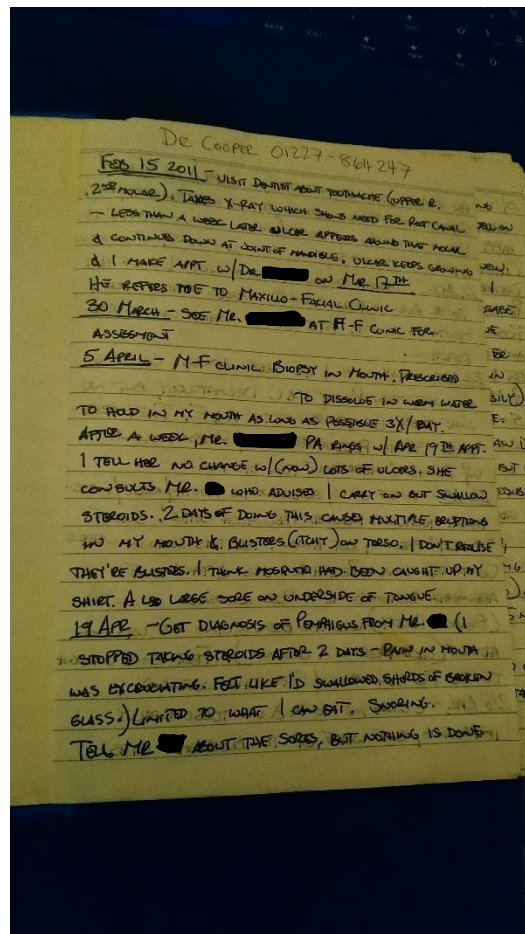
Keeping a PEM journal

I was first diagnosed with Pemphigus Vulgaris (PV) almost ten years ago. I contacted Pemphigus.org, the website for the International Pemphigus and Pemphigoid Foundation (IPPF) and was assigned a peer counsellor who advised me to keep a journal of my Pemphigus journey. If I could offer one piece of advice to those with any disease, it is to keep a journal. Over the years my Dermatologists and I have found the journal invaluable and have referred to it on many occasions.

These are some of the things I log in my journal:

- Hospital visits and what is discussed,
- My meds and if I am reducing or increasing and how my body reacts to the meds,
- How I am feeling physically and emotionally including and especially how my blisters are increasing or decreasing
- Test results including blood pressure checks, weight (worth checking if on steroids), immunofluorescence and blood tests.

Keeping a journal can help you see patterns in your physical and emotional wellbeing that might otherwise be forgotten. Looking back for example, I was reminded that I suffered from muscle stiffness while on Ciclosporin, an immunosuppressant, something I had completely forgotten about. I would like to share with you the first page of my journal from 2011 when I was first coming to terms with living with a rare disease and trying to make sense of my body somehow slipping away from my control.



Transcript from Julie Martin's PEM journal:

- Feb 15th 2011 – Visit dentist about toothache (upper r. 2nd molar). Takes x-ray which shows need for root canal – less than a week later ulcer appears around that molar & continues down to the joint of the mandible. Ulcer keeps growing & I make appt w/Dr on Mar 17th. He refers me to Maxillo-Facial clinic.
- 30th March – See Mr. at M-F clinic for assessment.
- 5th April – M-F clinic biopsy in mouth. Prescribed Bethamethasone to dissolve in warm water to hold in my mouth for as long as possible 3x/day. After a week, Mr’s PA rings w/Apr 19th appt. I tell her no change w/(now) lots of ulcers. She consults Mr who advises I carry on but swallow steroids. 2 days of doing this causes multiple eruptions in my mouth & blisters (itchy) on torso. I do not realise they are blisters. I think mosquito had been caught up my shirt. Also, large sore on underside of tongue.
- 19 Apr – Get diagnosis of Pemphigus from Mr. (I stopped taking steroids after 2 days – pain in mouth was excruciating. Felt like I had swallowed shards of broken glass.) Limited to what I can eat. Snoring. Tell Mr about the sores, but nothing is done.