

# My Health Journey

1964 - 2022

## Jenny Wainman

Hi, I'm Jenny a 58-year-old Yorkshire born, mother of two grown-ups, who has a diagnosis of Common Variable Immunodeficiency, Bronchiectasis and more recently Squamous Cell Carcinoma leading to Gynae cancer treatment. I am awaiting extensive surgery and have been having regular 3 weekly, Ig treatment over the last 10 years. I considered myself 'fit and healthy' and able to manage most things, including my health for both the cancerous and immune suppressive context.

### Journeys to diagnoses:

I was born with severe eczema and an allergy to milk (developing more severe allergies as food was added to my diet) and spent a lot of my childhood in and out of hospital, subsequently missing a lot of school in the process, although I was hospital schooled in patches.

Wendy Doyle, Head of Patient Experience and Partnership, said:  
"Giving patients and families opportunities to express or share their experience is important to me.



At the age of 14 I entered hospital after being diagnosed with my first experience of Idiopathic Thrombocytopaenic Purpura (ITP) and was treated with steroids and underwent my first bone marrow fine needle aspiration (FNA). I left school at 16 and worked in a number of jobs before moving 'down south' in my early 20's to work for P&O ferries. On attending my medical interview, I was told I would not pass the medical and therefore could not work for P&O because of my allergies. So, I found a job onshore firstly in Dover, then to Marlow before moving to London.

**Working in London as a training officer for a large hotel chain, I muddled through periods of good health before being unwell and being identified with additional diagnoses.**

My sinus and chest symptoms became more concerning, and I was referred to different departments of my local hospital. I came under the care of ENT and the Chest Clinic being eventually diagnosed with bronchiectasis and the Haematology department for repeated ITP, IgA & IGG deficiency, Haemolytic Anaemia and Autoimmune Neutropenia and was subsequently given the diagnosis of Evans Syndrome.

Things began to change near my 30th birthday when I was hospitalized 3 times in one year with pneumonia. Up until this point my Evans Syndrome had been treated with steroids and hospital stays and my Respiratory problems were treated with numerous antibiotic treatments and steroids. The Haematology department took me under their wing when seeing that long term antibiotic therapy was not the best solution for me. At this point I resigned my post and took to being a full-time mum with enthusiasm and got involved in lots of other things. Over the next 10 or so years I counted myself lucky that I could make this decision, one factor being my partner earned just enough for us to live on. Over time I lost confidence in my ability to convince an employer to employ me with my health being so erratic/unpredictable. I began studying, catching up on what I missed as a child, became a trustee, worked part-time for a landscape gardening company before applying to university.

In my late 30's I had another bout of ITP, was found to be iron deficient and was in hospital again, I was given an Ig infusion for the first time.

I was eventually referred to an immunologist for a second opinion and travelled to Hampshire regularly to see her. After 3 appointments and numerous tests and recounting of my health history I was diagnosed with Common Variable Immuno Deficiency (CVID). To which I would have regular infusions of Viagam, a human serum product, for the next 13 years.

I did a research project for my dissertation, at my local Medical Education Service, looking at the 'Breakdown in Communication between school and home when a child has chronic ill health'. After the project they asked me to stay on and continue my work with the students, so just before my 40th birthday I became employed full time again as well as graduating with my first degree in Health Studies (Biopsychosocial aspects of health).

Whilst working full-time, managing my condition and regular treatment I went on to study for my PGCE and gained my QTS, completed an MA (Counselling in Education, 3 years part time) at the Tavistock Clinic and then I was seconded for a year at Kings and the Anna Freud Centre, completing a PGDip in Children and Young People Therapy and became a CBT specialist. 14 years ago, during the first year of my Masters, I developed Non-Hodgkin Lymphoma and had a course of chemotherapy which left me in remission and to be monitored closely by the oncology team. I came under the close eye of occupational health at this point, and it was documented that my regular treatment could not be classed as time off from work and I no longer had to fill out forms for each treatment. I continued to work full time and managed my many appointments by booking them at either end of the day, so it did not interrupt the school schedule too much.

In 2016 I developed a squamous cell carcinoma, and the consultants were contemplating 'radical mutilating surgery' or radiotherapy, which I questioned and became a watch and wait patient regularly seeing the Gynae/Oncology surgeon and CNS over the next 4 1/2 years.

## **The Squamous Cell Carcinoma is now developing further and extensive radical, life changing surgery is imminent.**

### **How is health now?**

The 'watch and wait' is now over and the 'Total Pelvic Exenteration' surgery is awaiting me. I am now back in the routine of visiting numerous hospitals for different aspects of my health including the Royal Marsden, Chelsea and Sutton, St Georges, Frimley Park and St Anthony's.

I still receive regular Immunoglobulin infusions, and these reduced my chest and sinus infections, leading to fewer occasions to take antibiotics, whilst having FB testing for levels of Ig's, Iron and platelets on a regular basis. My Ig infusion product changed for me in August 2018 to Octagam a product which metabolises more quickly. Since the product change my chest function is changing and I have a continual productive cough and am seeing the Respiratory experts again and back on antibiotics to keep it at bay. However, the benefit of the new product is that a previously 8/9-hour treatment (due to preventing an allergic response) became 2 hours from start to finish.

### **How did family manage it?**

My partner and I separated 16 years ago and so I have brought my children up, for the most part on my own, their father and I remain friends. During my periods of ill health, he had to have repeated time off work to look after the children, sometimes at a moment's notice. He was able to do this and managed the physical and practical things very well.

It was difficult for him to be the main breadwinner and watch me lose confidence and not be able to support myself financially.

My two sons have both had to watch their mum dip in and out of difficult health situations, visit me in hospital and sometimes support me when I've been unwell at home. I have always spoken openly about my health to them, and they have been great sources of support during difficult times. My sons have learnt to and are able to name and explore their worries and concerns, are empathic and supportive characters. On speaking to them recently, they are able to express how they feel about my health and wish to be included in my cancer journey. They are, thankfully, fit and healthy although just like their mum they 'just get on with things' and 'push through'. Sometimes this is a useful management tool but at other times it can be a block to asking for help. My daughter in law is now included (out of choice) in the rounds of hospital visits for my cancer diagnosis and is a fresh pair of eyes and ears on the journey to diagnosis, treatment, and recovery.

### **How do I get on with everyday life?**

For 16 years I worked for the same London Borough, running an Induction programme, working with adolescents and their families as a teacher and CBT specialist. In December 2019 I made the big decision to leave the school setting, Covid and a CEV lockdown meant that I could not go out to work so I set up my own CBT practice online and expand my working collaboratively with others in developing training courses and support for ethical and well-being practices in organisations. I currently work as Clinical Lead for Mental health Support team across 14 schools, heading a team of 7 therapists. This is 21/2 days a week and I continue with my private practice on the other days.



**I am a trustee of two national charities, Ruth Hayman Trust, RainbowsBereavementGB and am a member of Patient Voice at St Georges Hospital.**

Despite my health journey I have travelled extensively over the last 20 years following my love of athletics, to Olympics and World Championships and have been a Field Official for UKA since the 2012 London Olympics.

I have, over the years, been lucky enough to have support from a whole host of consultants particularly Haematology, Oncology, specialist nurses, staff on the Ruth Miles Unit (RMU), the Full Circle foundation (a group of complimentary therapists who offer their services to cancer and haematology patients whilst they are having treatment in hospital), the South East Cancer Help Centre (SECHC) where I sought out other relaxation therapies and counselling. After many years of treatment and understanding my conditions sometimes better than those who treat me, I am able to ask searching questions, feel able to make decisions on my health and am able to look at the most recent research and thoughts about the differing treatments I am being offered. Increasingly I am free to speak with my immunologist and haematologist departments and consultants over the phone or skype if I have questions or concerns.

### **What would I say?**

I have lived with health uncertainty all my life and am never sure what health concerns sit around the corner. I have often written down my thoughts and experiences in little vignettes.

I have become emotionally strong, worked hard on my understanding and responses to difficult situations and over time I have learnt to appreciate today,

I continue to plan for the future (even though the plans don't always work out), enjoy what I have and cherish my family and friends.

I would suggest that anyone being diagnosed and facing treatment for the first time, ask as many questions as you need to, write down your questions and the answers, take someone with you in the initial stages, find out what services the hospital has to offer, what your treatment entails and then make sure you give yourself time and space to get to your treatment but also have time afterwards to make your way home and relax.

The treatment regime can be tiring at first but the benefits for your health overall are worth the initial discomfort. You will soon get used to the routine and it will just become a part of your life.

There is life after CVID treatment and all its complications. Currently I am looking forward to life after cancer surgery and all it has to offer.

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