
GRUPO DE CAPOEIRA

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WHEN I AM DANCING I FEEL FREE.

ED CARLOS, 42
DANCE TEACHER,
DIADEMA, SÃO PAULO STATE, BRAZIL

I look healthy, so it might be hard for some people to believe that I have a disorder that impairs my immune system. It means I have a propensity to contract diseases more easily.

My first pneumonia crisis was when I was six years old, and throughout my childhood I was frequently hospitalised with pneumonia. When I was 13 years old my condition worsened. The air sacs of my lung had become inflamed and filled up with fluid, which is known as "water on the lungs". I had to have this fluid removed, and this happened many times over the next five years. Eventually when I was 18 years old I had to have one of my lungs removed.

When I was a child my mother and the doctor recommended that I start to do something to increase my lung oxidation. I started to play "capoeira", which is a Brazilian martial art that combines fighting, acrobatics, music and dance. I loved it, but after my lung was extracted I had to stop. I needed to look for another sport, and that's when I learned to street dance.

At 34 years old I had the worst pneumonia crisis in my life. I couldn't breathe – that's the worst sensation you can have. It was nerve racking – I thought I was going to die.

"If I met a plasma donor I would thank them and ask them if they know how much their act of giving is transforming people's lives such as mine."

Through this difficult time my greatest objective was to stay alive, and to get through this time and go on to complete a dance performance. Through these challenging years, my greatest supports have been my pulmonologist, the São Paulo Hospital, my mother and my wife.

My pulmonologist referred me to a specialist at São Paulo Hospital and at 35 years old I was eventually diagnosed with common variable immunodeficiency (CVID). The doctor told me there was no cure and I would have to live with this my entire life. I was scared, but also happy to have the answer after living with the condition for so long.

"Now the medication allows me to do everything that I want. I feel that I have been granted another life."

My family were also relieved to hear the diagnosis – they had been very worried about me and were tired. My condition had impacted on my family throughout my life. My mother, and later my wife, couldn't work because they had to take me to hospital or take care of me at home. They lost their days with me at hospital.

Of course it is difficult to live with the knowledge that there is no cure for my disease. But when I was diagnosed I was reassured to know that finally I would have treatment. Since I started on intravenous immunoglobulin treatment seven years ago I have not been admitted into hospital again. Now the medication allows me to do everything that I want. I started capoeira again, but I know my limits. I feel that I have been granted another life.

I have immunotherapy with octagam® 5% every month. With immunotherapy I live better and I can live like a true human. I see myself as having two lives: life before and life after immunoglobulin treatment. My advice to someone newly diagnosed with CVID would be: don't worry, immunotherapy will make you feel better because immunoglobulin is life.

My greatest passion is dancing because it really boosts my life. When I am dancing I feel a mixture of emotions: happiness, anxiety, expectation. Adrenalin courses through my body. When I am dancing all of my body moves, and now I am 42 years old each year brings a different challenge. My body doesn't respond in the same way it used to when I was younger. Street dancing needs physical strength. To maintain my physical condition I exercise regularly. I love to dance because I can meet my friends and can do a job that I like. My CVID introduced me to dancing – perhaps without this condition I would not be a street dance teacher today. What I enjoy most about street dancing is learning the choreography and then teaching it to my students. When I am dancing I forget everything. I feel free.

If I met a plasma donor I would thank them and ask them if they know how much their act of giving is transforming people's lives such as mine.

With immunotherapy, I feel like I am living another life.

WATCH GABRIELA'S VIDEO
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MY ILLNESS HAS GIVEN ME THE WILL TO LIVE.

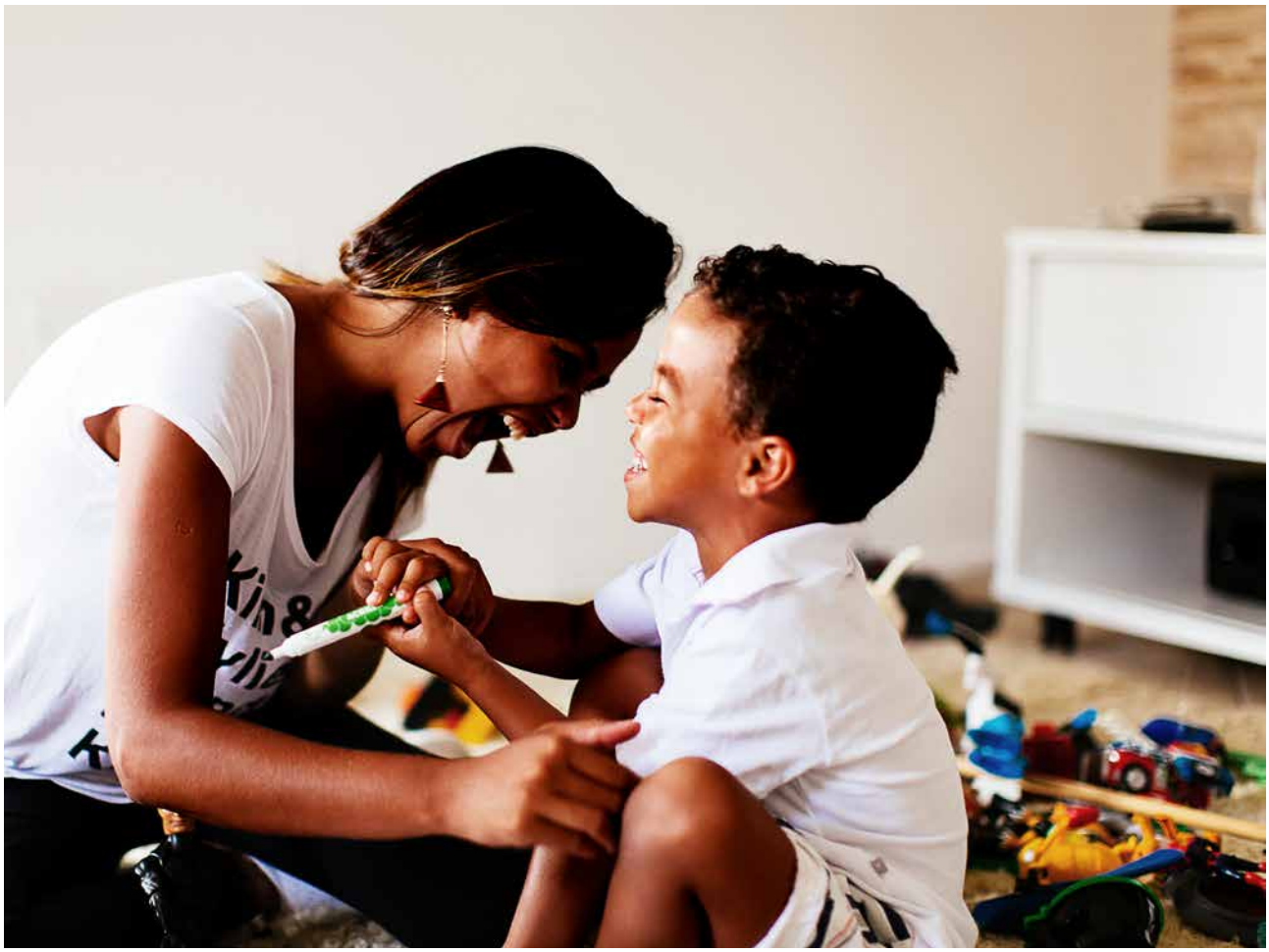
GABRIELA, 25
POLICE CLERK, SÃO CAETANO DO SUL, SÃO PAULO STATE, BRAZIL

As a child the hospital became my home. I had recurrent infections and hospitalisations, beginning at five years old. I lived one week in my house and one week at the hospital. My mother had to teach me lessons there so I would not fall behind at school. I could not play with other kids. I lost my childhood.

My worst memories of growing up were of the pain. I had terrible difficulties breathing. It was difficult for my parents to work and take care of me and my two sisters. I found it hard to watch as my family suffered for me.

When I was 12 years old I had two recurrent infections with hospitalisation. The last one was severe. I had upper gastrointestinal tract bleeding. I felt very bad. I was referred to an immunologist and she diagnosed me with common variable immune deficiency (CVID). I was happy to get my diagnosis because I was so tired of going to the hospital and no one knowing what was wrong. With the diagnosis I felt hope. After that initial relief I asked many questions to try to understand why I had this condition. Why am I the only one with it in my entire family? Why me?

"I lived one week in my house and one week at the hospital. I could not play with other kids. I lost my childhood."

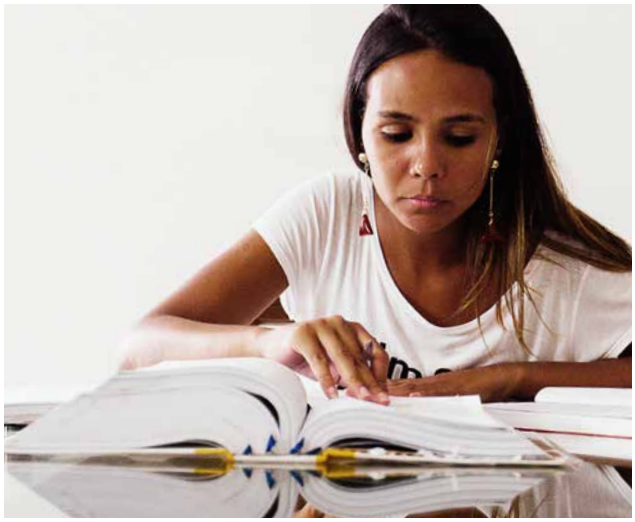


"If my health had been better growing up perhaps I would not have graduated in Law in 2015 and be a qualified lawyer today. My ambition is to be a chief of police."

My family, although they were scared and had many doubts, were relieved that finally their daughter would get treatment. It was hard to find out that there was no cure for my condition. Today my biggest concern is my four year old son. It is a possibility that he too will develop this disease. The thought of this happening to my little boy frightens me.

My relationship with my immunology team is excellent – they are very attentive, helpful, and professional. I have monthly intravenous immunoglobulin treatment with octagam® 5%. Since starting treatment I don't have recurrent infections any more. Before, I was just surviving, but now I am truly living. Today I live with no restrictions. My life has improved 100%. If I could change anything about my treatment, I would choose to do it at home.

My advice to someone newly diagnosed with CVID is: embrace this opportunity. In the beginning you may have many doubts but the immunoglobulin treatment will give you a new life and the possibility to live as you deserve. Now I can live a normal life just like anyone else. The treatment allows me to do everything. I can study, work, have a social life and dance samba. I can live!



If I met a plasma donor I would hug them and say thank you.

My illness has given me the will to live. It showed me how important my family is to me. My greatest passion in life is my son. Perhaps without this condition I wouldn't have the same values and attitude. I might not have worked so hard to finish my studies. If my health had been better growing up, perhaps I would not have graduated in Law in 2015 and be a qualified lawyer today. My ambition is to be a chief of police.

I believe that in life everything is possible. Nothing is impossible in the eyes of God.

PATIENTS USUALLY NEED LIFELONG INTERVENTION WITH IMMUNE THERAPIES TO LIVE HEALTHIER LIVES.

DR MATTHEW BUCKLAND, CONSULTANT IMMUNOLOGIST, ROYAL FREE AND GREAT ORMOND STREET HOSPITALS, LONDON, UK

The immune system's essential functions are to protect against infection, protect against cancer and prevent autoimmune disease. Primary immunodeficiency (PI) diseases are rare chronic disorders in which a part of the immune system is missing or doesn't function properly. Patients usually need lifelong intervention with immune therapies to live healthier lives. By supporting the immune system, infections are reduced and patients are better protected against progressive tissue damage. Some people used to go into virtual hibernation to avoid infection, but with treatments such as immunoglobulin replacement they are more protected.

It is important to understand what the patient wants to achieve with therapy. It is easy to believe you are doing a good job as a doctor if you have managed to get immunoglobulin levels up, but that may not be what is most worrying the patient. If you understand what their life looks like, then you can see how to best approach treatment.

Despite immunoglobulin replacement, some patients continue to get frequent or recurring infections. They can develop gut-related problems or inflammatory lung disease, which requires immunosuppression. The challenge is to prevent inflammation and at the same time the re-emergence of viruses or other pathogens. It can be a difficult path to tread.

My greatest hope is that we will be able to diagnose these conditions in early life before permanent damage is done. We have made great advances in understanding the genes involved in regulating the immune system. Newborn screening would allow us to identify and treat a condition before a child develops complications. In future we hope the affected gene could be edited, preventing morbidity and mortality in later life.

Immunology is genuinely fascinating and touches all areas of medicine. You to get to know people and their families over many years, which is very rewarding.

WATCH DONNA'S VIDEO
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IT'S AS IF A BIG HAMMER FALLS DOWN ON YOU. IT PUTS EVERYTHING INTO PERSPECTIVE.

DONNA HARTLEN, 46
EXECUTIVE DIRECTOR OF THE GBS/CIDP FOUNDATION OF CANADA

I started experiencing extreme back pain while on vacation in Halifax, Nova Scotia during Christmas 2009. I got into the bathtub every two hours to try to relieve the pain. I had a sore throat and I couldn't swallow properly. I was feeling weak. Days passed and things got worse. Then I got on the ground to change my two year old daughter's diaper and I just couldn't get up again.

This happened during the swine flu pandemic, so when I arrived at the emergency room I was put into isolation. They thought I might have swine flu. I had tingles in my tongue and I was very lucky the emergency room doctor recognised that my symptoms were neurological. The neurologist told me that I had either Guillain-Barré Syndrome (GBS) or multiple sclerosis (MS).

By this point I was losing feeling in different parts of my body. I was unable to walk or write my name. I had facial paralysis. I couldn't smile. I couldn't blink properly. I started losing my swallowing reflex. I am claustrophobic and have a fear of not being able to breathe properly. I was afraid I would lose the use of my lungs, which I knew was a possibility. I kept thinking the whole time: "Don't lose your lungs."

Four hours after being seen, I was put on intravenous immunoglobulin (IVIG). The immunotherapy slowed everything down. I was wheelchair bound but thankfully, because of the quick diagnosis and early IVIG treatment, I was not put on respiratory support.

"I was losing feeling in different parts of my body. I was unable to walk or write my name. I had facial paralysis. I couldn't smile."

When I was diagnosed with GBS I had no idea of the gravity of what that meant. I didn't realise it was going to take months away from my life. I ended up spending three months in hospital and three months in outpatient physiotherapy.

After an almost full recovery I was considering returning to work as an IT consultant. I had been off treatment for 15 months and was doing well. Then I had two relapses in early 2011 triggered by the flu. We were in Mexico on vacation. I had been feeling exhausted. I was having trouble getting up the stairs. I called the then Executive Director of the GBP/ CIDP Foundation, Susan Keast, who advised me to call my neurologist.

"I was fully paralysed, unable to move from the neck down. Being paralysed and aware of everything that is to come is scary. IVIG saved me and for this I am grateful."

I was diagnosed with chronic inflammatory demyelinating polyneuropathy (CIDP) after having another acute onset. CIDP is considered to be the chronic counterpart of the acute disease GBS. My symptoms are acute so I present like GBS, but because I am relapsing I am considered chronic. I was put on IVIG therapy and stayed on treatment until 2015. My treatments were eventually spread out to every six weeks. I became tired of the inconvenience of going to an infusion clinic and I wanted to try home therapy. I entered a study investigating subcutaneous immunoglobulin treatment for CIDP. This involved stopping IVIG treatment to see if I developed increased weakness. After three months of no IVIG treatment and no onset of increased weakness, I was released from the trial and deemed not to require treatment. Wonderful, or so I thought.

If I could live in a bubble things would be better. I picked up a virus – it was a typical cold. I developed sensory loss just up to my knees, and was walking like a duck. In March 2016, after being exposed to another flu virus, I had an acute onset of CIDP. I was fully paralysed, unable to move from the neck down. Being paralysed and aware of everything that is to come is scary. Throughout this I never stopped working my fingers and wiggling the toes which still had slight movement. I received IVIG treatment and a moderate dose of prednisone, and 10 days later I walked out of hospital using two canes.

The GBS/CIDP Foundation of Canada was there for me and my family when we needed them. I wanted to give back by supporting newly diagnosed patients. In 2013, I became a liaison for the Foundation, and late that summer I became the Executive Director. Because my CIDP presents acutely I can speak to GBS patients just as well as to CIDP patients.

We are rare disorders, 1 to 2 in 100,000 for GBS. All our volunteers are either patients or caregivers of patients. We have 32 liaison volunteers across Canada and our patients are our biggest source of information. The Foundation builds relationships with doctors and specialists, and we make connections and provide information about services, best practice, challenges, and activities.

I have observed that a common denominator of people developing these disorders is that they tend to be type A personalities – these are people involved in a lot of activities, with busy lifestyles and careers. When you develop a condition such as GBS or CIDP it's as if a big hammer falls down on you. It is a warning bell that puts everything into perspective. Some of us listen; but truthfully, it's hard to change your personality. Now when I am exhausted I listen to my body. I lie down to get a quick rest to get through the rest of the day.

One of the biggest challenges facing patients with these conditions is that not enough emphasis is placed on the management of residuals. Once a patient has either been treated for GBS or has achieved stability with CIDP, many of us are left with after effects that are difficult to manage. After GBS you may be left with permanent physical limitations – you could be in a wheelchair. Imagine you are a plumber and now you are in a wheelchair.

You have to accept that your life has changed. You have to go through a mourning of what you were once able to do. You must come to terms with the new reality and adapt what you can do physically. It is difficult when you still have to walk with a cane, or you still have major amounts of pain. How do you maintain a job when you are exhausted? The consequences of GBS could mean you have to change your career. Or you could find yourself struggling with family life because some people just don't know how to support a loved one who is ill.

We used to be carefree. Now I have a husband who worries about me and two little girls who make sure I am constantly checking in and reassuring them I am okay. Every time you get flu you wonder if you will have a relapse. I don't want to be on treatment if I don't need to be, but every time I get hit with one of these acute relapses I don't know what is going to be recoverable. When you relapse it takes a lot of willpower to get through it. Every time I relapse it becomes harder to deal with. A lot of patients deal with depression.

The Foundation is committed to ensuring that no one with GBS or CIDP suffers alone and that everyone has access to treatment. We are a foundation run by patients for patients. We are here to support and every day we are continuing to get better at what we do. Doing this work, I have met fantastic people from all walks of life. Their courage is inspiring.

IVIG saved me and for this I am grateful. Experiencing this condition, you discover a sense of your own mortality. I have seen my mortality more than once. After coming through that you hug your kids more often. You tell your family you love them more often. You take one day at a time and you appreciate that day. You live life to the fullest. I want to thank Octapharma for the chance to tell my story, our story.

WATCH PATSY'S VIDEO
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THERE IS ALWAYS TIME IN LIFE FOR AN ADVENTURE.

PATSY, 71
CORNWALL, UK

I am living an interesting and varied life. In my youth I travelled the world and spent several years working overseas doing many different jobs; I didn't specialise in one thing. I feel as if I really lived before starting married life. I had seen and done a lot already and marriage was the next step. Women do it all the time now, but back then in the 1970s it was unusual to start a family in your thirties.

When I was 45 years old I was diagnosed with chronic lymphocytic leukaemia (CLL). My sons were young (6, 8 and 10) so it was shocking to find out that I had an incurable chronic disease. When I was first diagnosed the consultant told me that, although she couldn't cure me, her job was to keep me healthy until such a time when new drugs were developed that would suit me. I trusted her and stayed with her for 25 years.

My journey has not been straightforward. I have been through very difficult times. I had to have chemotherapy. I almost died when I had my gall bladder removed and it went badly wrong – my platelet count was so low they couldn't stop me bleeding. My eldest son, a doctor, who was working in New Zealand at the time, had to fly home because they thought I was going to die. It wasn't easy, but I survived and kept on going.

It had always been our dream to design and build our own home. We bought a plot of land in Looe in Cornwall. It is a traditional seaside town with a strong fishing industry and lots going on throughout the year, including music and literary festivals. The land we bought overlooks the river estuary, on one side you see the town's sparkly lights, and opposite you see the woods and their changing colours. It wasn't the simplest house to build – it's on a 45 degree slope – which presented a challenge for my husband, who used to work in construction. I did most of the interiors because I have experience of interior design. The house was built within eight months, which was surprisingly efficient. That project was a big adventure, and the outcome is wonderful: we love our home.

Before moving here we had lived in the same village for 25 years. At first people were concerned about my health when I told them we were moving. Living with leukaemia for so long, my immune system had deteriorated meaning I was susceptible to infections. I was given immunoglobulin intravenously in the winter as that was when they thought I needed protection the most. I would often get sick because my immune system was not fighting infections properly.

When we moved to Cornwall three years ago, I expected I would continue with my seasonal immunoglobulin boosts in winter. However, unlike my former hospital, Derriford Hospital has a dedicated immunology department. I was referred to an immunology consultant, who did lots of blood tests. She rang me on Christmas Eve and asked me to come to the hospital. She explained that my immune levels were very low and I needed to start weekly intravenous immunoglobulin therapy.

My immunology team are amazing: they are warm, helpful and kind people. I can ring them whenever I want. There are all sorts of people treated at the centre from a spectrum of generations – from youngsters to elderly people – all there for a variety of reasons and all of them in good hands.

I was asked if I wanted to take my immunoglobulin subcutaneously at home rather than come to the clinic every week. Home therapy opened up new possibilities of freedom and travel. My nurse, Teddie Trump, showed me how to infuse myself and after visiting the centre every week for six weeks I was ready to infuse at home. Teddie visited my house to watch me infuse and make sure I was confident in what I was doing.

The switch from intravenous to subcutaneous treatment has given me real independence. I take care of my treatment myself. Since I started three years ago my health has improved and I have had only one episode of pleurisy. People should not worry about doing infusions themselves at home – it gives you so much freedom by removing that elastic band that connects you to the hospital. It's wonderful – whoever invented it deserves an award. It is no exaggeration to say that gammanorm® has changed my life.

"People should not worry about doing infusions themselves at home – it gives you so much freedom by removing that elastic band that connects you to the hospital."

Now I just go to the immunology centre for an annual check-up, and for the leukaemia I see my haematologist every three months. We are very lucky in the UK; I cannot begin to praise the National Health Service enough. If it wasn't for the NHS I might not be alive today.

My greatest passion in life is sailing and since my husband retired we can spend more time on our yacht, which we share with friends. I don't do grey, lumpy, stormy water; I prefer to sail calm seas under a shining sun. Last summer we spent nine weeks sailing around the Greek islands. It is amazing to think I am going on these adventures without a care in the world 26 years after being diagnosed with leukaemia. It's an idyllic life. Sailing is the best way to explore the Greek islands, which are all beautiful, each in their own unique way. Even planning the route is an adventure because you have to wait until the wind changes. I take my gammanorm® with me on these voyages and store it in a little pink fridge underneath the chart table where we do our navigation planning.

Before I started home therapy, I had to think twice about doing anything because I was always tied to the hospital. Now I don't have to think twice about it; wherever I am I infuse myself once a week and I know that I am protected. I have a belt which allows me to infuse while walking about or gardening, but I prefer putting my feet up for an hour to read a book.

I am a very positive, happy and active person. Apart from sailing, I do a lot of walking with my dog and I like keeping fit – I do Pilates. I'm creative: I like painting, I belong to a flower arranging club, and at the moment I am renovating an intricate old lamp. I enjoy socialising, cooking and hosting dinner parties. I also love spending time with my wonderful grandchildren. Life is there to be enjoyed and I believe there is always time in life for an adventure.

ONE SIZE DOESN'T FIT ALL, EVERY PATIENT'S JOURNEY THROUGH LIFE IS DIFFERENT.

TEDDIE TRUMP,
CLINICAL NURSE SPECIALIST IN IMMUNOLOGY,
PLYMOUTH HOSPITALS NHS TRUST, UK

I look after immunodeficiency patients on immunoglobulin replacement home therapy.

When someone is diagnosed with an immunodeficiency they are often relieved to finally know the reason why they have been so ill for so long. After diagnosis they must come to terms with the fact that they have a chronic illness and will need treatment for the rest of their life.

I have 90 patients in my care and get to know each one well; it's a lifelong relationship. We tell newly diagnosed patients about the immune system and explain what immunoglobulin replacement therapy involves. There are two main types of immunoglobulin administration: intravenous (into a vein) and subcutaneous (under the skin).

One size doesn't fit all because every patient's journey through life is different. You have a spectrum of patients, from the teenager struggling to accept that they have this condition and seeing it as a weakness, to the elderly person struggling to get to hospital for their infusion. Treatment also needs to be adaptable to changes in lifestyle. You have to look at every patient individually and find the right approach that works for them.

If subcutaneous treatment is selected, we teach the patient how to administer treatment themselves at home. We show them how to use the syringe and how to insert the needles. We go through everything, from the importance of cleanliness to the logistics of how products are delivered to their home. We take time with patients so that by the time they go home they are feeling very confident and happy. I love it when I do a home visit and I can see that the patient is so happy to be at home. I love knowing that treatment will just slot into their life, rather than them trying to slot their life into an infusion schedule.

In our clinic there is a picture of Patsy infusing gammanorm® while she is on her yacht. This is really inspiring and helps our new patients see that they can have that freedom too.