

**For Emmie,  
the third of my four children,  
thank you for all you  
have taught us.**

**Emily, who has a life-shortening condition,  
has now, at sixteen, successfully made her  
transition to the WESC Foundation where  
she is fully supported and able to enjoy  
a really good quality of life, returning  
home to be with her family at weekends.**

**This book is also dedicated to all  
those young people with a life-limiting  
condition. We salute their bravery  
and resilience and marvel at their  
achievements and indefatigable  
zest for life.**

## Acknowledgements

**Janet Cotter** has worked tirelessly with the authors to develop their stories and bring this project to fruition. It was her idea to produce the book in the first place.

**Kate Ford** has designed and laid out the book beautifully. Without her generosity and expertise we would never have been able to offer the book as a free download.

**Lucy Watts** suggested the book title and should have been one of the authors but for personal circumstances. We hope that her remarkable story will be told soon.



**Julia Hodgson,  
Myra Johnson  
and Lizzie  
Chambers** at  
**Together for  
Short Lives**

provided help and encouragement throughout the development of the project. They are part of a formidable team at an extraordinary charity.



Courage is Compulsory has been produced by Southgate Publishers and Beyond Words Publishing Printed by Latimer Trend, Plymouth as an eBook, and printed copies by subscription only.

Southgate Publishers, The Square, Sandford, Crediton, Devon EX17 4LW

Published in 2015.

Text and photographs © Tori Elliott, Sam Mildon, Laura Gould.

Cover and book design by Kate Ford.  
[www.kateford.moonfruit.com](http://www.kateford.moonfruit.com)  
[kateford@googlemail.co.uk](mailto:kateford@googlemail.co.uk)

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At eighteen months old Tori was diagnosed with Spinal Muscular Atrophy (SMA) Type 2. A creative child, she was encouraged to draw and paint from an early age. She studied illustration at university and since then she has earned several commissions, including illustrating children's books. Last year she organised a tour of Europe to promote independent travel for wheelchair users. Tori lives in South Devon with her partner.

## **26** *Sam's Story*

Sam has SMA Type 2. Brought up in an idyllic village in Somerset, he developed a love of nature at an early age. After adventures in various parts of the world, he studied, and later taught, Sustainable Design. He has now returned to his roots and is running a business growing micro herbs for local restaurants. Sam is planning an ambitious project: to design and build his own 'home on wheels', in order to be free to explore the countryside of England and beyond.

## **46** *Laura's Story*

Since childhood Laura has had to overcome enormous mental and physical challenges. She was eventually diagnosed with EDS in 2012, and this finally helped her understand the underlying cause of her condition. Instead of buckling under the weight of her incurable illness, she decided to do something positive and founded Facing Illness Together. F.I.T. is an interactive site where those with chronic conditions can find friendship and support. Laura lives independently in Surrey.

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## FOREWORDS BY

### Kate Monaghan and Lucy Watts

#### Kate Monaghan

I feel honoured to have been asked to write a Foreword for this incredible book. The stories of Tori, Sam and Laura are ones that should be heard by everyone, and ones that will resonate with so many. As a disabled person myself, I believe that we should be open to the stories of disabled people in society, those who are achieving great things as well as those who are simply being great by being themselves. Tori, Sam and Laura are examples of just this. And having the same disability as Laura, I too can share her desire to live life in the same way as everyone else because there is simply no other way.

Kate started her TV life on *Blue Peter* as a researcher and was then headhunted to direct a half-hour documentary for Channel 4 as part of the *New Shoots* series for directors with a disability. Kate became a *Broadcast Hot Shot* in 2010. With a passion for disability awareness, and seeing how difficult it was for those with a disability in the media, Kate set up *Markthree Media* in 2007 and she strives to promote inclusivity within the industry. She is currently working for BBC Ouch and is the presenter of their monthly podcast.

#### Lucy Watts

I came up with the title *Courage is Compulsory* because you can't live a life like we do without courage. It takes courage not

to be defined by our conditions, to be able to overcome enormous obstacles, (with the possibility of a time limit hanging over us), and to lead a fulfilled life when so much of it is out of our control.

My own health, like that of the people whose stories are featured in this book, is fragile. We constantly tread a fine line between doing enough to keep us focused, positive and motivated, and avoiding overdoing it, and thereby setting ourselves back.

We could so easily give in to our illnesses, be sad and depressed and shut ourselves away, but we have chosen to live rather than exist. We want to live full and happy lives. We want to do things everyone else our age does. We want to experience the delights of this world, and why should our conditions stop us?

I hope you enjoy the stories of these three amazing young adults, Tori, Sam and Laura. Their stories will give comfort, hope and optimism to many facing similar challenges, and to their families. I also hope that health professionals and general readers will learn from the stories that the potential of children and young adults with severe disabilities should not be underestimated.

Ambassador for *Together for Short Lives* and *Global Youth Ambassador for the International Children's Palliative Care Network*.  
[www.lucy-watts.co.uk](http://www.lucy-watts.co.uk)



Kate Monaghan



Lucy Watts



## MESSAGE FROM

# Together for Short Lives



Together for Short Lives is really proud to have been able to support the publication of 'Courage is Compulsory', in which Tori, Sam and Laura show how their courage has been called on, not through choice, but through necessity. Their stories are a real testament to their positive spirit and determination not only to live their own lives to the full, but also to help others.

Their stories are such great inspiration for other young people who are growing up with life-limiting or life-threatening conditions.

Here at Together for Short Lives we would love to bottle their 'give it a go' attitude and use it to inspire the many services and organisations who are still failing to support young people to change and to help these young people to achieve their aspirations. Let's hope that as a result of this book, this becomes the norm rather than the exception.

We would like to extend a heartfelt thank you to Tori, Sam and Laura for bravely sharing their stories and wish them all the very best in their future endeavours and adventures!



**Tori Elliot**



**Sam Mildon**



**Laura Gould**

**Tori**  
**ELLIOT**

**As I grew,  
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I was born in 1987 and little did my parents know that I had Spinal Muscular Atrophy (SMA), type 2. I progressed well during my infancy, until about eighteen months old when I couldn't stand for long without falling, unable to bear much weight. After a biopsy confirmed the diagnosis, my parents knew our lives would be a little different, but what an adventure we'd had so far. From a young age, my parents taught me to notice the positive things in life and to find

solutions to any problems I might face. They treated me just like any other child. I was rewarded for my achievements, and disciplined when I misbehaved. They did not wrap me up in cotton wool, though I'm sure that they were just as scared as I was. I always got stuck in; I was covered in glitter; I ate the Play-Doh; I cut off my fringe, and scooted along the floor on a skateboard even when my peers stood tall. I was a Brownie, a Girl Guide. I played outside with friends, rode a horse and



learnt an instrument. My childhood was the same as any other: I played with friends and got told off for talking too much in nursery, and my parents were strict in telling people that I was exactly the same as the other children, and to not pander to me just because I had a disability. I can't thank them enough for this, because as I grew, I actually forgot I was disabled. I still forget today.

My parents had to fight for me to attend mainstream education as at the time it wasn't standard practice for a child with disabilities to go anywhere other than a Special Needs school. Their argument led to the local school denying my application as they weren't willing to make the necessary adaptations, but thankfully a smaller school decided that I would be very welcome and I spent my primary school years happily there. I forged friendships that are still just as strong twenty years later, and developed my creativity in a safe and wanted environment. I had two carers at this time, one in the morning, one in the

afternoon, and they doubled up to help me with using the toilet at lunchtime. They would assist me with all my physical needs, but took a step back during lessons. Quite often, I would ask friends to lift my arm to answer a question, or to reach another book, which built my confidence in asking others for help and not be dependent on one caregiver.

During physical education lessons I would practise my physiotherapy. My friends thought I was special for having my own routine and my own exercise ball, and if anyone made a comment that I was different, I'd answer quite plainly, "but I like being different." I attended school trips just like everyone else, though accessible coaches were not available at the time so I felt extra special in my private taxi, where I could take a friend or two along with me. Likewise, during Sports Day I felt extremely important wearing all four of the team badges because I was a 'judge', and it also meant that I could talk to all of my friends! In the early years I joined in with





**I truly believe that an over-protective parent can be far more detrimental to a disabled child's well-being than the disability itself.**

the egg and spoon race on the smooth tarmac path, and a beanbag toss. All my classmates cheered me on.

I haven't even mentioned my wheelchair yet, have I? Mine was special; it was Barbie pink. I had a few electric wheelchairs. They were a new concept at the time. At three years old, a tiny blonde dot whizzing through the corridors, I scared my parents to death, but the independence I gained revolutionised my life. Any other child could be naughty and 'run' from their parents, and so I urge any parents reading this to let their kids just be kids! Let them try to escape from your eye in the supermarket, and 'ground' them afterwards to show that they are just the same as the other children. I'd go on family camping holidays where all the children would play in the adjoining fields and though my parents were anxious, they trusted my friends to alert them if I needed them.

Of course, I got stuck in the mud in my wheelchair; one year I snapped the rear axle over a large rock, and during Drama club the front wheel fell off the chair! But these experiences taught me

my limitations and made me appreciate that I could get hurt. By letting me experience these issues my parents were allowing me to develop my sense of independence and to rely on others to aid me; again, such a vital lesson to learn at a young age. I make my parents sound so cruel but that's not the case at all. I truly believe that an over-protective parent can be far more detrimental to a disabled child's well-being than the disability itself.

Throughout my school life I visited Hammersmith Hospital in London, where they had SMA specialists. A mix of neurologists, paediatricians, physiotherapists and surgeons were active in supporting my family during my childhood. I had regular overnight visits to determine the speed and progression of my condition, initially at three-month intervals, then up to six months and finally annually before I turned twenty. In general I was healthy, and my condition has been stable throughout my life.

As I grew, my body fought with the extra weight of being a young adult, and this in turn caused complications that are to be expected with SMA. I could walk





with calliper leg splints and a frame dragged behind me until I was ten years old, and this was a daily exercise for me. My marathon of 23 metres along my primary school corridor is still a proud memory! This is still regarded as an achievement as my hip sockets did not form properly. As I struggled with hip pain and dislocation, it was decided I would have the tendons snipped in my hips so that the muscles would relax. During recovery I couldn't walk for a few weeks and as a result I lost the ability to walk again. For a year I used a standing frame in class as exercise but had to discontinue this due to the pain. I still suffer with discomfort, but I find a Paracetamol and hot water bottle is sufficient pain relief.

A curvature of the spine (scoliosis) is a condition that a lot of people with SMA face. My parents had always discussed future options with me so that when the time came nothing seemed like a shock. I knew I'd need spinal surgery, with metal rods to fuse my spine straight, and that time came when I was thirteen years old and had just started secondary school. Now, with medical advances, children

can have magnetised rod systems which can be inserted at a much younger age, followed by a treatment to extend the rods as the patient grows; but this was not an option for me at the time.

My spine was curved into a 'C' shape of approximately 62 degrees, causing extreme discomfort, and limiting my lung capacity. An operation would mean that I could sit up straight, and look more in proportion too, as I felt like a bit of a barrel. I had worn a plastic, moulded cast under my clothes from a young age, to support my spine and to allow my body to grow as much as possible, before I was fused. The shorter my spine was, the more likely it would grow after surgery and may lead to further operations, but the time came and I couldn't wait any longer.

With expectations of 5-7 weeks in Stanmore hospital, of which one week would be spent in Intensive Care, I can happily tell you that this wasn't the case. Though the ward was decrepit, I was wheeled on my bed outside in the rain with a cover over me, along the winding path into the preparation suite.

Nine hours later I was released; six inches taller, four dress sizes smaller, and with a curvature of twelve degrees; nothing less than a miracle. I spent one day in intensive care before being moved to the High Dependency Unit, where, still under a high dose of pain relief and a with a breathing tube down my throat, I was unable to talk. I would



urge my parents to remove it, tugging at it constantly.


I was still 'nil by mouth', which was the worst thing I can remember, and after complaining how hungry I was, the nurses let me try a calorific supplement drink. It tasted vile! I pleaded with Mum to find me some chicken nuggets and chips, but the nurse refused continually until 'Super Mum' convinced her to let me taste a bit. Five minutes later and my plate clean, I was surrounded by exasperated nurses thinking I'd choke on the vomit which was bound to expel from my small, weak body. Not one drop. (That's something you should know about me, I'm serious about my food!) The very next day I was back on the ward and very impatient about not sitting up. To cut a long story short, I was home with my parents fifteen days later, chauffeured on a flatbed from London to Devon via ambulance. It felt so good to be home, where I could heal in peace.



My teenage years were just as eventful as anyone else's; boyfriends, break-ups and late nights, followed by long lie-ins. During my school life, I stuck by my close group of friends, through all of the high school dramas. Again, I had two carers throughout the day to assist me, though during P.E. lessons I opted to learn about the rules of the games we played rather than attempting to join in. As my eyeliner got darker, so did my taste in music and clothes. Yes, we all have that 'phase' and so did I! I also had two weekends per year of respite care at Children's Hospice South West, where I met other disabled teenagers and worked through my challenges with their experiences.

As I grew, it was becoming evident that my parents needed some assistance. Gone were the days of picking me up.





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Due to my spinal surgery, hoisting was now the only form of transferring. At a time when I wanted more independence, my parents decided it was time to employ carers to assist me. I can't imagine how it must have felt for them to relinquish their 'duties' to complete strangers, but doing so set me up for life and has been one of the best things they could have done for my confidence.

It began with night care for a few nights per week, as both of my parents worked; they were exhausted from caring for me with very little sleep, and working too. From the age of 13 to 16, the care steadily increased, until we received seven nights per week of night care. It enabled the relationship between my parents and me to grow stronger, and taught me how to give directions about my care succinctly to anyone, not depending on one person. This was so beneficial as it has enabled me to teach anyone to care for me, whether they've had formal training or not. I know I'm able to live independently now purely due to having the confidence to ask for help when needed, and how to arrange it.

My love of art and design flourished at this time and I knew this was my path to follow. Though one teacher told my parents "she can't take A Level Art because she can't manage pottery", I only needed the qualification to get into my chosen university so I defied her and took it anyway, achieving the entire A Level in one year, instead of two. My qualifications focused around my abilities: English Language, Art and Photography, Media and Psychology, all of which enabled me to express myself in a way that others may do so physically. My carers allowed me to explore my own abilities, watching me fail and then nourish my need to find my own way of achieving things. I applied for more hours of care outside of school, for people to help me physically with my studies, because menial tasks, such as constantly washing paint brushes, can become tiresome for family members when they've just come home from work – and it enabled me to become spontaneous and go out to meet friends without relying on my parents to accompany me.

Spinal Muscular Atrophy may hold me back physically but my goodness, does it make me determined! So when I applied to my chosen University with 13 GCSEs A-C Level, 4 A Levels and 2 AS Levels, with a Merit in my Foundation course, they offered me a place unconditionally.

I should mention that I also learnt to drive at this time! I took about two years to progress through the Motability scheme with a 'drive from wheelchair' vehicle, kitted out with hand controls. Quite simply, this revolutionised my life. To cut a long story short, after three fittings during the purpose-built project by Adaptacar, and just ten driving lessons,

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I passed my test first time! Now I was able to visit friends whenever I wanted, with or without a carer. It felt fantastic. I felt free.

The set-up in my vehicle is pretty logical. I simply press the unlock button and the hydraulics lower the rear of the vehicle, the tailgate swings open and a small ramp lowers for me to enter. There's

a lockdown system where I park my wheelchair in the driver's position. The seatbelt is already in position as I drive into it, with a brake and accelerator on the left joystick and a steering joystick on the right. The blepper on the accelerator joystick operates the horn, indicators, lights and wipers, and the control panel on the right has all of the other functions. I simply drop my keys into the ignition hole and we're all ready to go on an adventure! These personalised adaptations were adjusted and built around my chair, to my strengths and weaknesses.

This car saw me well throughout my time at Falmouth University, where I studied Illustration BA (Hons), and I loved every single second! I was two hours from home so I could pop back in an emergency, but my care was fulfilled via a live-in care package. I felt so nervous about the prospect of having



someone living with me but it was the most liberating move I could have made. Within my Halls of Residence flat, I had two bedrooms knocked through to create one, and my personal assistants (P.A.s), who swapped every three or four days, had their own room next to mine. I shared with four different able-bodied people every year. It was awesome and messy all at the same time, but I don't regret any of it. Of course, I found it terrifying, but I kept reminding myself that everyone starting university is in the same boat really, all far from home and missing family, all finding their own feet and learning what to do – so what if I had a few extra things to consider; it's nothing new to me!

I attended university trips; spent my days on the beach; drank far too much alcohol; made friends from all over the world; and I studied a bit too!



Three years of joy were rounded off with a week in New York City for interviews with publishers such as Nickelodeon and Disney, a fantastic and overwhelming experience. During my final months at university I was approached by Lou Rhodes and Strata Books to illustrate a series of her stories for children, and, being a freshly-graduated and eager practitioner, I jumped at the opportunity. We have two published books which can be found in all good bookstores, called *The Phlunk* and *The Phlunk's Worldwide Symphony*, and hope there may be many more projects in the pipeline. Creativity seems to find me in the most unusual ways but I can't ask for more than that.

Just when I least expected it, my life changed - it doubled! I met David. Growing up I had boyfriends and wasn't shy in approaching people to make new friends, but it never occurred to me that I'd meet someone who was so accepting and understanding that I'd never want to leave their side.

David wasn't a stranger when we started our relationship. Technically, we'd 'met' seven years previously, online. He was in a band, had long curly hair and knew how to handle a bass guitar so when I had a friend request, what sixteen year-old girl could resist? Before even contemplating him to be a predator, we were chatting daily about the music and films we liked, even though we lived at opposite sides of the country. Emails and texts turned to phone calls and Skype, and we both knew we had a connection, but being young couldn't act on it. I was jealous of his girlfriends and he was jealous of my male friends, though nothing more was said.

David became my confidant, a friend who knew me, without peer pressure and





without having to fit in with friends. I had told him about my disability but it wasn't an issue for him. So one day, out of the blue, he turned up! One amazing week together at my university flat and my emotions were confirmed; I was totally besotted, and still am to this day.

Five and a half years later and he's still my very best friend. During that time, I have been building my life and future with David, settling into our adapted bungalow with our Labrador, and running the household. I have a live-in 24hr care package provided by an agency, whereby a PA lives with us for assignments of two weeks at a time, to provide the care I need. I use a smaller, local agency that can provide me with PAs who have similar interests to me, and can cover each other in case of emergencies. They help me in all matters of care, from helping me to shower and dress, to just being in the background if I need them. They ensure my safety but promote my independence without mothering me. We believe in living our lives as any

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able-bodied couple, and therefore David does not provide any care for me as I feel it would most definitely put pressure on our relationship. However if I really need his help he is of course there, in an instant, for the important things like fixing my wheelchair or making emergency cups of tea. We are so happy. We are planning our future; who knows



if it might turn into three?

My latest, and biggest, challenge to date was a 4,000 mile trip around Europe, driving my van with David and a PA, through 15 countries, in under a month! Having a physical disability, and using a number of mobility aids such as electric wheelchairs and mobile hoists, can often put a strain on holidays abroad, but this entire trip was to demonstrate how easy it can be, with forward planning, and the ambition to achieve. This combination is all you need to live an independent lifestyle, whether you're able-bodied, or have any form of ailment. This was 'Our SMALL Adventure'.

In the past we've taken my electric wheelchair abroad and it has been damaged on two separate holidays by the airline crew. As a result I've become quite apprehensive about taking it on any more planes, even though I've been thorough and well organized in explaining how vitally precious the chair is to me, and removing certain pieces as

carry on hand luggage. In fairness, I think I've been unlucky in these cases, as I know many other wheelchair users who have had perfect service from both international airlines, and the budget ones too. So I'm not saying that I've given up hope; I just need a little more time to trust flying again!

David and I are at the point of our lives together where we want to explore and take holidays, but overseas city breaks are proving to be far more difficult than we anticipated. With the upheaval of transferring from wheelchair to plane, wheelchair damage, and rushing around for two nights in a European city, only to return home as stressed as when we went, we feel it just isn't worth the cost.

Further costs are having to pay for an extra flight, insurance, and, of course, hotel room for my P.A. which doesn't come cheap, because hotels

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often won't give a single person discount. And not to forget hiring, (and paying for), a mobile hoist and pressure-relieving mattress from a local company. There is so much to think about for two days abroad!

So we thought, let's do it all in one go! We were able to take all of my equipment, in our own form of transport, so we knew it would work effectively and be safe.



**If you would like to read a day-to-day account of the fun we had, and the hurdles we overcame so far from home, please visit:**

**[www.oursmalladventure.co.uk](http://www.oursmalladventure.co.uk)**

On this site you will also find handy wheelchair travelling tips, information about insurance and a whole lot more. Here are short extracts from my blog – the full descriptions are on the website.



## DAY 1: ENGLAND

### Brittany Ferries Plymouth Terminal

After checking the car tyres and loading up, we said our farewells and were off to catch the ferry to Santander, Spain. The boat itself is perfect for disabled visitors. There are ample lifts and members of staff are helpful and smiling. The corridors are really wide so there's plenty of room for wheelchairs.



Plymouth

## DAY 3: SPAIN

### Barcelona's Gothic Quarter

Wow. What a beautiful city! We are completely exhausted after walking miles! The hotel room is absolutely gorgeous, with a breathtaking view, but the bathroom door opened into the toilet meaning there was completely no access for me in my hoist, so Wonder Boyfriend took the door off its hinges!

Lastly before I drop off to sleep, I wanted to show you the note that somebody left on our car this evening. It made my day.



Ferry - Santander





Barcelona

## DAY 5: FRANCE

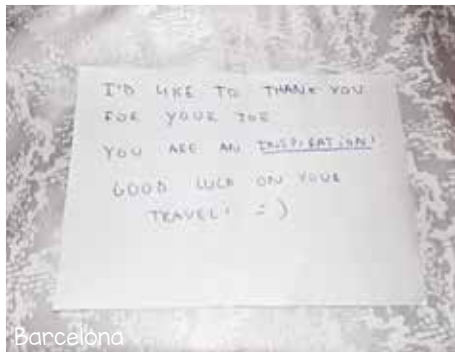
### An afternoon in Marseille

I'm sad to say that I woke up from a terrible night's sleep and in a lot of pain this morning. I think the long day in Barcelona took its toll on my body. So David jumped in and did the long drive to Marseille, after successfully refitting the bathroom door.

A few painkillers and a good picnic later I felt much better, and made our way into the old port to our hotel...

Marseille is not great for wheelchairs so we didn't venture too far, just stuck around the Vieux Port and had a huge portion of moules frites, our favourite...

Thank you Marseille for rekindling my love of French markets, food and wine!



Barcelona



Marseille

## DAY 7: MONACO

### Managing Monaco

I woke up this morning and felt much better so decided to be the designated driver for our day trip to Monaco. I was so looking forward to driving along the famous Formula One Grand Prix roads that I had seen on the TV, so after a quick but delicious croissant we were on our way!



Marseille



## DAY 7.5: ITALY

### A Flat tyre in Milan



We have had our first major set back: a flat tyre. As I write this we are sat in a tyre garage at 10:50pm awaiting a taxi to take us to a hotel. We don't carry a spare tyre as it can't be secured in the car. From what we can gather, someone has slashed our tyre on our way into Milan Centro.

We pulled into a supermarket (which probably saved us from being mugged) and called Motability European Breakdown cover for assistance. Within the hour an Italian rescue team arrived and explained that they would need to order a replacement and fit it on Monday morning, with Motability paying for our hotel and taxi.

I have been told six times that they are trying to find me a hotel for two nights and have finally come up with nothing! So we are going to our original hotel tonight whenever this taxi arrives, and rely on them to find us somewhere tomorrow. I have an awful feeling it's because the cost of hotels in Milan is over budget and they aren't worried about leaving a vulnerable adult without a place to stay.

An update next morning: After many stressful phone calls from European

RAC centre in Lyon, we gave up hope. In total we waited 6 hours for them to organise a hotel and taxi but they could do neither.

The breakdown service originally said they would tow our van on the back of a truck, with us inside, to our hotel, but I refused as I told them I wasn't comfortable doing this, to which they told me, "We don't have the same rules as the UK."

I can't imagine how much I've spent on international calling - when they said they would call back to confirm the hotel or taxi in 20 minutes, I would be calling them in 35. I specified a large taxi with a lift several times, but they sent an estate car the first time and a 4x4 the second time, neither can accommodate an electric wheelchair.

I asked for a police escort to walk us safely to our hotel 7km away in the dark at 1 a.m. as none of us felt safe to walk alone.

Again, nothing. The breakdown team in Lyon kept telling me how difficult it was as Italy do not have the same services as the UK - and they point blank refused an ambulance, but as far as I'm concerned it was an emergency!

We conceded. The garage owner tried hard to explain to us in the strongest Italian accent that not even our translator app could decipher, that he will return the van to us on Monday morning with 2 tyres, one as a spare to carry with us. Eventually we decided to get the tow truck to take us to our hotel. We got to our hotel at 2:30 a.m.

This morning the hotel has confirmed we have another night here, which I'll insist Motability pay for when we are home, as they expected me to sleep on the streets?

## DAY 9: ITALY

### Venice, beautiful Venice

Off to beautiful Venice, a once in a lifetime stop!

Our hotel is called Hotel Ca' D'oro and is in a perfectly central location, a district full of shops, only 5 stops from the Piazza Marco Polo and San Marco Basilica. That night we watched the sun setting behind the Basilica and wandered around the square at dusk which was just beautiful. For those of you who are loving our food updates: we had a big mozzarella and tomato salad to share which is one of our favourite things to eat but this was by far the best we have ever tasted!

I just love this place. It's like a stage set and nothing seems real, it's bizarre and beautiful rolled into one.



Venice

## DAY 13: ITALY

### A wet day in Vienna



Vienna

After just less than an hour's drive from Bratislava to Vienna (which seems like nothing these days!) we were parked up, checked in and ready to explore. The rain wasn't going to stop us - we were set, with waterproof coats and a sneaky hot water bottle in my pocket, and began exploring the city.

Vienna was wet. Really, really wet. But we managed to get around perfectly... I would recommend it for other disabled users for sure.

## DAY 16: PRAGUE - DRESDEN – BERLIN



Berlin

If I'm honest Berlin wasn't somewhere I had expected to fall in love with. How wrong I was. Access everywhere is fantastic. Everywhere has dropped curbs, even where there are road works, we found temporary tarmac ramps!

## DAY 19: NETHERLANDS

### Beautiful Netherlands and onto Amsterdam

I can't deny that I'm starting to feel quite tired now. It'll be nice that we have a few days in Amsterdam so that we don't have to rush and pack up in the morning.

Our hotel is bang in the centre of Amsterdam: The Convent Hotel. This was a Christmas gift from my parents and what a luxury it is! This is awesome!



Amsterdam

## DAY 20: NETHERLANDS

Amsterdam by day and night



First off, we had our rescheduled boat cruise with the Blue Boat company, and hooray, it was totally accessible for wheelchairs! If you're a wheelchair user I'd really recommend that you take this canal cruise to explore the city - it took 90 minutes but we got to see everything that was quite far out of the centre of Amsterdam, and learn about the city's heritage. Maybe I'm getting older but I definitely saw Amsterdam in a different light, (not red for once), and discovered how it was built for trade and can withstand the rise in water levels in time. I loved that each house was different and why it leant forward. Each design of

roof symbolises a different trade with some houses showing tableaux of their past. I was reassured of a different side of Amsterdam that wasn't so seedy. I'd recommend it to anyone! The boat has a platform lift which slowly lowers into the boat, and the ride was very smooth, with big windows. We saw the Anne Frank house, which is limited access for wheelchairs and the watchtower clock with four faces that all tell a different time so that the bells ring randomly: it was great.

We found the Vondel park when we left the boat and explored a little in wonderful sunshine. It's worth visiting if you get the chance and feels a little



like a scaled down version of Central Park in New York City. There's also a huge 'I Amsterdam' sign but it's always pretty busy for photo opportunities. We crossed back over the canal and decided to join in with a tradition and clip a padlock on the bridge and throw the key in the river, as we both made a big wish. The flower market was just around the corner, full of bright colours and seeds and bulbs. Of course we bought some tulip bulbs to take home, I couldn't resist!

We went out for dinner at about 9:30pm in Dam Square and I think I had my favourite meal of the holiday.

It was called 'Dutch Trio'...

We took a quick walk through the Red Light District at midnight as it was dead when we visited the day before, tonight was a different story! It was so surreal, but a must for every visitor. It didn't feel threatening at all. And for those who need to know, most of the booths have a large step so take your time if you want a wheelchair accessible one, haha!

So, so tired now, starting to look forward to being back in our little bungalow again. On to Antwerp tomorrow for the diamond district and shopping central.

## DAY 22: ANTWERP - BRUSSELS



Brussels

We set out in the sunshine in an ambitious attempt to conquer Brussels in a day, deciding to hit all of the big attractions in an anticlockwise circle but knowing we probably wouldn't manage it. How wrong were we? Brussels is actually fairly small and so we were able to visit everything we wanted to see at a leisurely pace, with time to spare! There was also a nonstop jazz festival in the centre which put everyone in a great mood.

Brussels is extremely cobbly and not maintained well for wheelchairs. Anyone visiting the city should be warned of this if they have problems with rough ground with their wheelchair, as mine is pretty tough but still did not cope well with the steep slopes.

This is our last night abroad, I'm so sad it's coming to an end but what an adventure it's been. Off to Bruges tomorrow and then back to the UK.



## DAY 23: BRUGES AND THE EUROTUNNEL HOME

Waking up knowing we were on our way home was a little disheartening, but we are off to Bruges beforehand which is about a 2 hour drive. Of course it started to rain. We spent 4 hours walking around the beautiful streets. The side roads are all cobbled but well-kept so it wasn't too bumpy at all... It was lovely to hear the horse drawn carriages, which are all over the city, and because it's so small you really don't need to worry about taking public transport as an electric wheelchair can absolutely cope here...



The next stop after a delicious Belgian hot chocolate was the supermarket in Calais, to stock up on French cheese and wine before returning to the UK. And woah, what a haul! We filled the van with all of our favourite things!

The Eurotunnel was a few minutes away and so easy to use... Half an hour later we were back in the UK, which was actually brighter than France for a change...

Can you believe that the least accessible "accessible" hotel room was the one in England!...

One more sleep until we are back in our own bed, really feeling mixed emotions about coming to the end of our amazing trip

And so it was over!

But I had one task to do and after a while I added 'A European Accessibility Guide' to my blog in which I detail my experiences under the headings:

- Let's talk about ramps
- Let's talk hotels
- Let's talk public transport
- Let's talk attitudes.

This last is a difficult subject to discuss, as it seemed to affect David and my PAs rather than me. I suppose I'm so used to being stared at that it doesn't register with me (and I like to think it's because they're admiring my hair). As a child on family holidays to France, we'd often be stopped to 'inspect' me and pointed at in the street, I assume because it was rare to see an electric wheelchair and more so because the person driving it was so young. So I had expected a few shifty looks during our trip around Europe, especially in some of the smaller countries where healthcare is dealt with very differently from our NHS system.

Thankfully, in general, it really wasn't as bad as I had anticipated. I expect because we had visited a lot of cities where the tourists just didn't bat an eyelid that I was in a wheelchair as they'd seen one before and they had plenty of other things to look at instead. I did however get some fantastic glares in and around Venice. I guess it isn't every day that you see a big electric wheelchair cruising down

the Grand Canal in the Vaporetto, but it was so worth it! And in actual fact, however cosmopolitan and contemporary Milan is supposed to be, the attitudes and looks that people gave me there were the worst of all the countries we visited, and I'd expect a little more compassion and friendliness from the Italians if I'm honest.

What I'm trying to say here, is that you can be anywhere in the world, even in your home town and someone somewhere will turn to look twice at your wheelchair. Yes, it's rude and it's frustrating that society isn't immediately accepting of peoples' differences, but it's also part of the inquisitive mind of humans to take another look!

There's no need to be cautious about going on holiday to a country which may not be so experienced in handling disabled people, and the more rural you go, the friendlier, accepting, more helpful citizens seem to be assisting,

**Well, one thing  
is for sure –  
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last adventure!!**

which I wouldn't have expected at all.

So you've read the ins and outs, you've got links for all my resources and you know what you need to pack. What's stopping you? Where are you going to go next?

What have we got planned for the future? Well, one thing is for sure – this certainly wouldn't be our last adventure!!





**I spent most  
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and blissfully  
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disability.**

My story starts here. Actually it started at about 8 o'clock on the 20th November 1985.

I had a brother, Toby, five years older than me to get to know. As a new family we lived together on a farm in a small rural village in Dorset called North Dibberford. Shortly after I was born we moved to Somerton in Somerset where

I grew up and enjoyed a large portion of my life. We moved because Mum and Dad felt that bringing up two disabled sons and running a farm could be a bit of a challenge! Toby had fairly recently been diagnosed with Spinal Muscular Atrophy (SMA). They knew there was a high chance I had been born with the condition too. I had the test and it was confirmed. Back then it had only recently



been discovered and identified and medical professionals and researchers were just beginning to understand how SMA took effect. The picture that the doctors drew for my parents was bleak. Toby was only expected to live for ten years!

I've got good memories of playing in the garden at our new cottage home in Somerton, splashing around in the paddling pool on hot summers' days, supervising Dad as he laid a patio, bedtime stories and eventful bathtimes. I made friends with my neighbour Luke, who was born in December and we're still close friends. One of my earliest memories was poking our chubby fingers through the trellis at each other, gurgling and babbling like drunken old men – as toddlers do. Another early memory I have was playing in the utility room where my brother's wheelchair was on charge and curiously putting my soggy fingers into the electric socket. I got

a very abrupt electric shock but mum came to the rescue, with a look of panic on her face.

I suppose I had what is a fairly typical childhood. I had fights with my brother; I was spoilt by my Grandma; I hid from Mum at bedtime, and I loved making a mess. I enjoyed playing in the bath; I was into toy farms and finding fossils, and I loved torches and penknives. I also loved wild gardens, and especially ponds! I was (and still am) fanatical about wildlife and the diversity of living things. I went through so many phases as my interests changed from dinosaurs, crystals, the Egyptians and pirates, den-building and land rovers to airplanes.

I spent most of my childhood completely and blissfully oblivious to my disability. I was born with the spirit I needed to live strong, and was given the love and encouragement to thrive. I'm so thankful for the positive attitudes of my parents and grandparents, aunties and uncles





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and all the good people I had around me. I grew up in an environment where there were no problems. If something problematic were to arise, I was often kept pretty unaware of it as Mum and Dad worked to solve it in a way that it didn't disturb my comfortable bubble of reality. They did a great job! I was known as 'that Sam' who would have a go at anything, quite unaware of barriers and difficulties.

I was a boy who saw no boundaries, but as I grew inevitably there were situations where I was quite brutally and suddenly knocked back by the reality of adjusting to being disabled.

There were times when I was just not strong or safe enough to join in with things and I'd have to accept defeat, step back and watch from the sidelines – sometimes with voluntary reluctance, but more often in angry protest. These battles were incredibly formative and were my first steps in developing mechanisms to cope with my life with SMA. It's been a very personal journey that's led me to master things like self-love, patience, acceptance, tenacity and resilience.

At a young age I realised I was my own worst enemy, as well as my best

motivator and guide. I soon learnt that no one could move me like myself and if anything were to stop me from carrying on, it would be me, and my attitude. No amount of upset and sadness and "why me?" made it better. No amount of outside support would help. I was in this on my own and I knew the only way was to shape up and crack on. Of course there are times when I forget this and there are times when I have to revisit, and reconnect, with my agreement with myself.

I remember Mum spouting out the words, "there's no such thing as can't" if ever I got dispirited or defeatist. Her positivity was annoying sometimes, sickening in fact! But it always shook me from my self-pity and got me thinking constructively. Together, we'd take a deep breath, she'd wipe my tears and we'd get creative. Problem-solving became a part of family life; we became a team. We made adjustments to our physical world, and the ways we did things, to make life easier or make the impossible, possible.

I was encouraged, like most kids with good parents, to satisfy my curiosity. I was given the time, love and support needed to interact, test and play with the world around me. I was given the freedom to explore, get involved and get messy. I was given freedom to make mistakes, fall down, fall off, get stuck and get broken. I was given guidelines and limits and a healthy measure of control and discipline but wherever time and circumstances permitted, I just got on with being a kid.

As a child I got quite used to being stared at. Elderly people especially used to speak to me like some sort of alien because I was in a wheelchair. The manager of a local cinema refused my brother and I entry once because 'we



were a fire risk', and on another occasion we were stopped in a garden centre and asked who was in charge of us, because we surely shouldn't be allowed out on our own!

Like many kids, I didn't particularly like school. I went to a local infant school where I enjoyed the social side especially. I had a lot of friends and I seemed to be pretty popular, not least because my wheelchair offered exciting joy-riding around the playground. That, and my Grandma being the coolest Grandma around who put on the best Halloween parties. I used to play at friends' houses like other kids. My mate Alan, proud to show me his tree house, was rather taken back when I said I didn't think I'd be able to get up into it. We looked around and decided we could make a rudimentary lift from an old dustbin lid and a rope. The rope was slung over a branch and his older brother provided the muscles. We did it. I never told mum!

At school I had an assistant with me a lot of the time. It felt strange being the only one, but looking back, Mrs Deacon did a pretty good job of integrating her support and managing to be fairly unobtrusive in my social development.

I had to leave classes for physio. I remember being quite smug about getting out of class, but it was like a Chinese torture session. However, if it wasn't for the physio I would have lost

my mobility even faster. No pain, no gain as they say. I walked with callipers between the years of six and ten. I'd have to leave classes early to avoid the rush in case I got knocked over. I felt very self-conscious as we disturbed the lesson with the fuss of getting up and waddling out the class. In the years preceding I was lucky to enjoy a few good years with relative strength, moving all over the place. I was a fidget! I was one of the most advanced swimmers in my class too. I refused to use a wheelchair for ages and I insisted that I crawl everywhere, inside and out, whatever

the weather, ground surface or occasion. I even crawled through a whole cave network on a school trip once. I felt quite animal-like, but seeing the world from ground level was great and delighted our cats and dogs. Our pets were a huge part of my childhood; they were such gentle and loyal guides, playmates and caregivers.



In my early years we visited Hammersmith Hospital frequently. Visits to London were quite an adventure in themselves but waiting around for hours in between appointments with various specialists was a real drag. I realise now, looking back, that I spent an unusual amount of time in the presence of adults. I think that gave an interesting advantage in some ways. I got to see how they thought and organised things in their world. It did seem very boring at times though.



**My Mum,  
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The time came for me to have a body brace, like a hard, plastic corset, which was designed to keep my spine from bending. Wearing it was hideously uncomfortable and made me cry a lot. I was embarrassed to wear it at school. I protested so much that Mum couldn't bear it any longer and agreed I could live without it. Months later, in a confined consultation room at hospital, a meeting of surgeons, physiotherapists, doctors and trainees expressed delight at the success of the brace as they analysed my x-rays. I then took the very deepest pleasure in telling them I'd not worn it since it was made for me. It was my last ever brace. They were completely baffled.

My childhood continued to rain with treasures and fruitful experiences. I had a horse called Ricky. Riding was suggested as another of the best preventative exercises for me. He had such a good nature, always very sensitive to my vulnerability, and took good care of me. We were close friends. Animals were a big part of my childhood; we had too many pets to mention. Mum loved dogs and I enjoyed going to dog training classes with her. Our dogs Tessa, Penny,

Arnie, and later George, used to help us out with picking things up when we dropped them and going to ask for help if we got stuck.

Much of my time was spent outside. We were an outside kind of family, members of a local canoeing club. We did lots of camping and went for long dog walks with friends and family. We enjoyed plenty of picnics too. Dad loved to take us to special view points, to soak up the scenery.

I'd like to take the opportunity to describe my wonderful parents here. They were an odd couple to be honest. It wasn't to last forever! They divorced when I was nine. Sally and Reg are so vastly different in their personalities and yet equally tenacious and strong willed.

Sally, my mum, is like a lighthouse out on the roughest and most treacherous bit of coastline. Calm and confident, she stands independently, without showing any signs of fatigue or weakness. She's taught me resilience and bounce-back-ability like no other. What a mum - what a woman! She was strict but fair. She did a good job of activating essential character traits like



respect, compassion, gratitude, integrity and honesty. Verging on being hyperactive, I now know that she needed to be, to survive. There's a lot to be done in the daily routine of a mother! As a single parent with two disabled sons, she coped miraculously well.

My dad, Reg, has simple and sound values. Over the years he's dealt with a lot of mental health issues which has tested our relationship in various ways. It's been hard at times. He's got a golden heart and always seeks to make the world a better place for those he meets. He's very practical and was always good at fixing things, passing on his knowledge and skills in the process. As a boy he taught me to be methodical and analytical in my thinking. He travelled a lot and enjoys telling his stories. We've spent some good times by a campfire talking about history and the future of humanity's journey.

I was making the transition from primary school to secondary school when Paul, Mum's new partner, moved in. I knew Paul already; he was a friend of the family. We'd been on canal boat trips together and such like; he had a daughter a bit

older than me called Gail and I always liked his friendly face and his endearingly boisterous and playful character. I didn't really take any issue with this new arrangement. It was between him and my mum as I saw it and I felt safe and comfortable with him around, he made me laugh. I knew it would make a huge difference to mum's lifestyle and wellbeing. That it did! I was pleased for her. He's always been there to support me when I needed it and was always conscious not to step on my dad's toes, an admirable role to adopt and delicate balance to master. Paul adapted his old beat up, 1960's Land Rover by putting in an extra seat, with all the right support so we could all go off-roading, exploring the over-grown and forgotten lanes in the countryside around us. We had some adventures!

To offer a little perspective and contrast, as we were growing up we knew two other boys, the same ages as Toby and I. They lived just around the corner. They had a similar condition called Muscular Atrophy. It's a sad story but one that illustrates the importance of a spirited attitude. They lived a very different life to Toby and I. I don't judge their mother's style of parenting but they weren't given the encouragement we had, helping us to develop confidence. Instead their mother worried and grieved for their loss, her loss. She loved them dearly, that was obvious. They never seemed to have any friends or social life away from the home. Their only trip out was a weekly food-shopping trip with their mum. As is common with MD, they both unfortunately died in their early twenties after relatively short and unfulfilled lives. I think this served as a stark reminder to Mum as to why she tried so hard to make life for us as wholesome as possible.

My thirteenth birthday present was a flying lesson. I was completely obsessed with flying. At nine years old I won a competition to go on holiday to Florida with a charity called Dreamflight. The trip to Disney World was cool but it was the flying that got me buzzing. It was the beginning of an adolescent fascination. The day of my first flying lesson was dreary and wet; we waited for clearance and it came. I loved it and went flying a few times every year after that. When I joined the Air Cadets I started to fly in gliders. It's such a blissful and empowering experience to feel the freedom of flight, exploring the skyscape with virtually no sound, and powered by the raw energy of thermals. Whilst I was at University I was elated to find out that my lecturer was a member of the local gliding club. I jumped at his offer to go flying again. We had a bad landing once and I bruised my coccyx but I hid my pain because I was worried he'd not want to take me up again – of course we did though! I've had the pleasure of a few trips since then, too.

Little Bridge House Children's Hospice in Barnstaple, Devon became a key part of my life from the age of about nine right up to when I left school at sixteen. I'd go and stay with Toby for weekends, and longer in the school holidays. It gave Mum a well-needed break and some freedom from the usual care routine. It was somewhere I could relax, make new friends and do whatever I wanted. I could get up when I felt like it, stay up late, go for days out to wherever I fancied. I loved chilling in the jacuzzi and dreamily exploring the gardens, or sitting quietly in one of the cosy living spaces with a book.

My teenage years consisted of repetitive days at school following the curriculum,



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I went to a local secondary school. Outside of school I spent a lot of time with my few best friends and I'd also spend a fair bit of time on my own. I loved the solitude of being alone. My new wheelchair went 6 mph instead of 4 mph and had a range of 25 miles so I went for long 'walks' around the countryside, mapping routes to test how far I could go, which villages I could reach. I'd very cautiously try out new footpaths, lanes and tracks, keeping a close eye on the battery level. I was always particularly careful around water in case I fell in and got trapped under the chair. Mum pleaded with me to always take my seat belt off just in case, so I could swim out from the chair. I got stuck plenty of times; I never used my phone though unless I got a puncture or the chair totally broke down. I'd just sit patiently for a friendly farmer or dog walker to come to the rescue.

During my school days I was supported by various assistants who helped me with getting about and with note-taking, writing in exams and with my continuing physiotherapy routine which was getting more and more unpleasant. I was beginning to see a sudden acceleration in my symptoms. I was getting weaker,



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quickly. At the crossover between junior and secondary school I went from being able to lie with my legs totally flat, and being able to sit up in bed on my own and transfer independently from wheelchair to bed / sofa and vice-versa; to being massively dependant on others just to get comfortable. My legs tightened right up; I lost the ability to hold my own weight with my arms and to transfer independently. I was growing quickly, and with that came aches and pains. My hips were dislocating and that was a real drag. It was a constant distraction and was almost unbearable in the colder months. It really drained my energy and made it hard to concentrate in class. At this time I started to push the boundaries of authority and got quite cheeky. I was disillusioned, like a lot of school kids. I upset a few of my teachers who I couldn't see eye to eye with and I went through a stage of having lots of detentions as I rebelled against the system. After one really terrible parents' evening mum had had enough and set me straight in a fierce fury of anger. Wow! did she set me straight!

One perk of school was work experience. Someone I knew helped me to arrange a week with a helicopter

search and rescue team in Devon. At the peak of my flying obsession this was just awesome! I had my back operated on when I was about thirteen and the time was ripe for spinal fusion: it stalls the scoliosis and is a vital move to make. I was in surgery for eight hours and it went well. I came round from the anaesthetic and instinctively, in my confused state, I tried to pull the pipes out from my nose and then went for the intravenous lines. I reacted badly to morphine and found out the hard way that I was allergic. I decided, with the doctor's permission, not to have any pain



control for fear of another reaction. I was discharged in record time, six days after surgery - I'd broken the record for the fastest recovery.

I got through my GCSEs, getting average to good grades and an A in art! I had an evening job working in a printing press, helping to pack orders that had got out of hand. It was something a bit different and it felt good to earn some pocket money. I did a lot of changing through my

final school years. They were formative times to say the least. I gained a lot of confidence in myself but I developed some serious self-esteem issues as well; stuff that would affect me for years. As teenagers, the school environment can be an intense social nightmare as we seek to find out who we are and how we fit into the world. It's 'ego central.' Hormones are rising and constantly changing. Girls and boys turn into young women and men.

As my friends dipped in and out of the typical playground relationships and flirted playfully with each other like teenagers do, I tried my best to fit in with this exciting part of life. There were some very beautiful girls around. I didn't know which way to look. These were very strong feelings of attraction and I needed to explore them. Ignoring them would be unnatural and unhealthy. It's a game and confidence wins. The really awkward thing was that I had huge difficulty in feeling comfortable and happy in my body, let alone sexy and confident! My outside didn't reflect how I felt on the inside. To me, my body was uninteresting, inanimate. It had become skinny, bony, twisted and weak. I just couldn't help but notice how I differed physically to the handsome, broad-shouldered young men striding out of the PE changing rooms.

This is a confusing and emotionally-loaded part of growing up for anyone. When you consider how over-sexualised we are as a culture, and society's unhealthy obsession with the physical, it's a shitstorm cocktail to have to navigate at that age. I felt everyone was enjoying this new chapter but to me it was a burden. To me it felt like an unfair game, one that I could never win and, yes, hormones were the driving force

**It was a really difficult time in my life that brought up deep feelings of inadequacy, alienation and frustration.**

behind it all! Sex is healthy. It's something that we grow into, a gradual process of learning and experimenting at our own pace, so that we learn the relationship between love and lust and the vital difference between the two – something we all need to understand.

It was a really difficult time in my life that brought up deep feelings of inadequacy, alienation and frustration. It's been, perhaps the most persistently challenging part of making peace with my disability. I think it's a common thread for many disabled people too. We're dealing with two of the oldest taboo subjects in society in combination: sex and disability. Male and female experiences may vary but it's a very real part of growing up for everyone and made more complicated by a disability. It needs to be handled with great understanding.

I'm lucky, having struggled with negative feelings for years, I now recognise my need, and right, to enjoy the physical side of relationships and I am happier for it.

When I left school I was fortunate enough to be selected to go on what was to be the most incredible adventure.

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through it.**

I went travelling around Indochina with a charity called Journey of a Life Time, and that was just what it was! From hundreds of applicants they had chosen a team of 22 of us, aged eleven to twenty one. We embarked on an itinerary that started and ended in Bangkok, not stopping for much more than a day in one place. We travelled through Thailand, Cambodia, Vietnam and Laos, through city and jungle, farm land and mountains. We used every mode of transport. We went by foot, wheelchair, bus, helicopter, 4x4, speedboat, cut-out canoe, traditional fishing boats and even elephant! It was truly epic. We covered around 4000 miles in just 28 days, taking in so much culture and landscape. My favourite part was the Tonkin Alps; the mountain tribes were so full of vitality and their rituals and the way they lived fascinated me.

I returned home in a haze. A whole new calibre of possibility had been gifted me. I could do anything.

However, mundane reality soon kicked in and I went off to the local college to study three-dimensional design. The course was a mixture of all sorts

and during those two years I was very focussed and motivated. I did well and was a regional finalist in the prestigious Young Designer of the Year Award, and I was credited by the local transport commission for the design of a radical, sustainable transport concept to alleviate congestion and pollution in Taunton.

However, halfway through my college course I received the tragic news that my teenage love, Kayleigh, had passed away just before her eighteenth birthday. She had fought hard but had finally lost her long battle with cystic fibrosis. She was such a delightful person to know and be close to. I was distraught with grief and sank into a deep depression where I was forced to question life and death, and the purpose of it all. Life felt incredibly strange and cruel and it took a long time for me to come through it and recognise that I had a growing responsibility to make the most of the opportunities life had given me. I worked hard and when I finally left college I had a triple grade distinction and a clear sense of my future career: I had my heart set on becoming a professional designer, with my own consultancy business.

**Adjusting to  
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But things were not to go so smoothly. That summer, after leaving college, I felt confused and disorientated. I had a lot of fun but Kayleigh's death still haunted me. I had applied to universities and accepted a place at Southampton Solent to study Product Design. I felt this was what I needed and was excited to start a new chapter, in a new place, and make new friends. In hindsight I was merely following suit like many other college leavers because, really, I didn't know what else to do with myself at the time. The world was a big place and I felt quite small within it, which was ecstatic and terrifying at the same time!

Moving away brought with it all the usual apprehension you'd expect to experience starting university, but for me there were the added worries of how I'd get around, access social life and cope with using a care agency. Away from home and adjusting to a life lived with Personal Assistants was a huge leap. Yes, I was in control, a boss, but it took me a while to feel comfortable asking strangers to do things in exactly the way I'd like them done. Even to this day I find it difficult. It's weird but I often just feel like I'm being fussy! But over time I gradually learnt to communicate, organise and direct my PAs to help me live my daily life the way I wanted to live it. Eventually I came to love living independently, doing as I pleased, cooking my own meals, and going out wherever and whenever I wanted.

My new life in Southampton was full of the usual student antics; lots of nights out, house parties, sleeping all day and missing classes. Although in the beginning I really engaged with the course and was a good student, my interests soon steered away to others things. The ethos of the course, its tutors and lecturers,

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Freedom!**

were very commercially orientated and market driven. I began to hate it; it was shallow and superficial. I didn't want to be a money-making designer for big business, I wanted to make improvements to people's lives and a planet in crisis and I found the lectures dull and mundane. My interests lay elsewhere. I became increasingly aware of, and concerned about, the ecological crises, the environment and our relationship to it.

I finally decided to leave my circle of friends in Southampton and after my second year I transferred to the University College of Creative Arts in Farnham to study Sustainable Design. It was just what I was looking for.

At about this time another really good thing happened. I had applied to Motability for a drive-from wheelchair vehicle before I was seventeen and after a lot of setbacks I finally took delivery of my van (which I later modified to include a small kitchen, storage, table and even curtains!). I passed my test the second time round at the age of nineteen and my life was transformed. Freedom!



The university campus was small and cosy, a rural setting on the edge of town, bordered by fields – the student village had a real community feel to it. The library was so close I could make a cup of tea at home and take it with me. I enjoyed reading quietly there and browsing the bookshelves. I made some really strong friendships at Farnham. We spent a lot of time hanging out in each other's rooms and houses, in the fields, the park, and of course, the pubs. We were all studying creative subjects and really bounced off each other. Many hazy nights were shared together discussing ideas and philosophy. I'd often be found heading home on my own at 4am, trying to avoid the deep, unlit potholes of Waynflete Lane.

We used to go out in London quite a lot as it was just a short train journey. After the clubs closed at 6 am we'd embark on the daunting task of getting home again, cold, tired and in all sorts of

states but always with the solid support of each other, we'd walk some of the way, attempt to get a taxi, sometimes successfully, and arrive at a very desolate Waterloo Station. Here we would often have to drum up a small army of weary City workers to help lift me and my heavy chair on to the carriage. The platform staff were useless and unhelpful, but then we were only a bunch of students going back after a heavy night out!

I enjoyed University but in the end I was ready to leave. The work had become a burden. I was putting a lot of energy into it but I wasn't sure it was aligned with my purpose, even though I learnt a lot about all sorts, in lessons and out of lessons! I loved the community bond and sense of belonging but I had had enough of formal education. Partly this was because I had come to realise that the job market was immensely competitive, with thousands of graduates fighting for the same jobs and often expected to work hard for very little. I wanted out but I was sad to leave such a dynamic and creative circle of people.

However, it was nice to be back in Somerset. Leaving home always makes you appreciate it in a new way when you return. The countryside was so nourishing and magical and so I set out, full of optimism, to establish a new meaning and direction in my post-graduate life.

Festivals had become a regular feature in my life. I went to my first one at nineteen with a group of close friends. Over the years I've been to quite a few and there's something archaic about the culture that I like – the gathering of tribes to celebrate life and expression. Over the years I've adjusted to the practical problems that face a wheelchair user






going to a muddy field with little or no facilities. In the beginning it was a steep learning curve and I relied heavily on the support of my friends. I remember one incident when the weather was so bad and the mud was so deep, and the site so flooded, that the only way to get me back to my van was to make a sled and float the wheelchair, with me in it, over the mud! Quite inventive, but not to be recommended.

Living back at home with Mum and Paul, together with my PAs, was very different. They had moved on and so had I. We lived pretty well together most of the time but there was increasing tension in the house and we began to argue. I got out as much as I could and spent days going on road trips around the Westcountry with my friend Tom.

Mum and Paul, understandably, put more and more pressure on me to do something with my life, not only to reclaim their space, (which was fair enough), but to gently push me as they knew I was disillusioned and beginning to lose my direction and motivation. It was hard to deal with because I felt content living my days without any plans but I see now that I was in danger of becoming too comfortable doing absolutely nothing. I didn't know what to do. Jobs were hard to come by, and I was running out of money fast. I must admit that, inwardly, I was not entirely happy with where I was and where I was going – or not going.

It was a difficult time when I felt trapped by my disability again; friends had moved on and were fulfilling their needs for



**You have to do  
the best you can  
with whatever  
you've got.**

adventure in various ways. I desperately wanted the same. I'd have taken off with a backpack if I could. This was a time in my life when I felt trapped and frustrated but I reminded myself that life is all about playing the cards you have been given. You have to do the best you can with whatever you've got.

So I planned a road trip to Europe to visit friends in Gibraltar and then Morocco. I'd already flown over twice before, for holidays in the summer, but I was now ready for the road trip; the tunnel was booked and all the preparations made. I had it all organised when the adaptations on my van became faulty. It had to go into the workshop and took weeks to fix due to delays in getting parts and the trip was cancelled. By the time I got the van back I had run out of money to go. I was gutted!

Strangely it was music that finally got me back on track. I had stopped using the care agency after having perhaps twenty different carers from all corners of the globe coming in to do the odd shift. This was not necessarily all bad because I learnt a lot from the range of cultures and traditions that I encountered but I felt I wanted more continuity and so I

started using Direct Payments to employ my own PAs. Tom and Markie were my first and continued with me for about five years, working alternate weeks.

This is when music became a bigger part of my life. With my PAs, we started running a regular night in Glastonbury, once a month, showcasing local DJs. Markie had a sound system. I'd got interested in DJ'ing at uni. I had built up a decent record collection and had got pretty good at mixing. We had some great times. We'd find artists, organise the night and promote it the best we could, getting to the venue early to set up and decorate the place. Some nights it was dead quiet but more often it was shoulder to shoulder, full and the energy was high! We got paid £200 a night, which seemed like a good deal considering how much fun we had! Our reputation spread and we got asked to play at other gigs and put on parties elsewhere. It worked well. Trying to unload the van quietly back at Mum's in the early hours often didn't go down so well but other than that it was fine.

Somehow this re-energised me into a whole lot of other activities. I joined my local Transition Town group, a global and quickly-growing grassroots movement. It appealed to me as it was all about local communities working together to tackle issues such as waste, energy and food production. We ran a particularly successful 'shop local' campaign. I got involved with a youth volunteer network, assisting with various projects and events on the periphery. I ended up leading my own project, to put on a music and arts festival called Future Fest. The idea was to promote an awareness of global issues within a framework of arts and music. Meanwhile, I was serving on the Town Council and teaching at my old college, working towards getting my teaching



certificates. I was a spokesperson for disability equality and joined in a BBC radio discussion, debating issues related to disability. It was a busy couple of years and at the end of it I moved into my own place as well.

I was now really on a roll! At this time too we had a micro revolution in Somerton. It made national news. A local businessman had chaired the Council for years and a lot of corruption was going on. It all came to light and the whole Council resigned en masse in protest. I was elected after a canvassing campaign, gaining around 700 votes. It was fascinating learning about the mechanisms of local government and how that fitted within the wider political system. Amongst many other duties I helped manage a £250,000 annual budget, was involved in planning applications and the independent audit into the previous corruption. My proudest achievement was to establish allotments in the town:

I helped with the land negotiations and creation of the infrastructure for many people, desperate to grow their own food. I'm actually now involved in saving a local orchard in order to create a community garden.

I also enjoyed my teaching; it reminded me of the time when I worked with autistic youngsters at a summer school. It was full on but I loved the interaction with so many talented students. I found it really stimulating to support them in their work. It was weird to be sitting in the staff room at lunch break with some of my old tutors! However, I was two thirds of the way through my training when I decided to quit. It was so rewarding to see the students progress and we had a lot of fun but the bureaucracy became too much for me. It stifled creativity and genuine learning and was ultimately very political. Not for me. Spending hours doing paper work, assessments, lesson plans and mapping





learning targets was just a little too soul destroying.

Around this time my van developed a fault in the space drive system that managed the driving controls; it was going to cost thousands to repair so I sold it and was vanless. For sixteen months I was without transport. The process to apply for a new van and then for it to be built, shipped and converted took a long time. It was painful. I suffered with cabin fever and felt incredibly isolated at times but that's when the next good thing happened.

I got a call while I was away camping with friends, with an offer to see a bungalow in Marston Magna, a small rural village I'd never really taken much notice of before. I went to check it out and fell in love with the place. I've been living here now for five years. It's everything I could want and need, a small cosy home with the facilities I need to help make



daily living easier for me and my PA; a hoist, accessible shower, ramped access, lowered kitchen top, the works.

Whilst I was marooned in Marston Magna – public transport wasn't an option due to the buses being inaccessible – I spent my days reading and meditating and exploring the miles of lanes in my wheelchair. I enjoyed being



a wanderer. I passed through villages and really connected with the local landscape. I became really interested in native wild plants and began studying their medicinal and historic uses. I find it fascinating that there's a whole store cupboard of forgotten medicine growing all year round – an abundance wherever we go, generously offering themselves to us for free!

So while I was stuck at home, I made my nest. My garden borders field meadows, and a stream trickles past beneath a couple of majestic willow trees. I've gradually reclaimed a bit more space on the bank side and adjacent disused land, which needed clearing of years' worth of fly tipping. The transformation of the garden has involved hours of hard work; digging, building and planting. I couldn't have done it without the help of PAs and willing friends. It's now maturing into a well-designed permaculture garden, a complete system providing food, medicine and wildlife habitat. I've got a pond, a couple of polytunnels, chickens, vegetable garden and a little hobbit house with a grass roof and wood-burning stove to relax in and enjoy

**My garden brings me so much peace and wonderment, seeing it change each season and over the years.**

some stillness. There are thirty-one different fruits growing here from grapes to apples and blueberries and everything in between. My garden brings me so much peace and wonderment, seeing it change each season and over the years. I regularly see insects and butterflies I've never seen before; it's a mini nature reserve with newts, frogs, a lizard, moles, a stoat, woodpeckers, owls, and I saw my first snake here! That was one of the most enchanting experiences ever!

Having fresh organic food to eat every day from my doorstep is great.

A good diet is essential for body and mind and the tastes are just sublime. I started my own business, combining my love of growing with my need to raise some funds for an ambitious project – more about that in a bit. So I started growing micro leaf herbs and salad for local restaurants. Before long I had five regular customers and was cropping and delivering twice a week. Two of my customers had recently been on Masterchef and loved the personal service I provided. It's something I'm really quite proud of but it hasn't made enough money to embark on my ambitious project and so, when I saw a job advert for a weekend fundraising role for the Somerset Wildlife Trust, I thought, "Finally, this is something I can do!" I was a member as a kid. It's a difficult job but so rewarding. I often speak to hundreds of people in a day and travel to venues and events all over Somerset which is exhausting sometimes, but worth it. Fundraising has always been a difficult art but in times of recession even harder. It's given me all sorts of useful skills I can

apply elsewhere in life.

So what's next for me?

I've been a bit of hermit lately, working hard to save enough money to start building my dream, a gypsy caravan / shepherd's hut / wagon, to my own design. I want to go travelling – desperately. Airplanes, taxis, hotels and holiday resorts are not my kind of travelling and involve too many logistical nightmares. I want to be like a snail and have my home on my back. Camping and going to festivals are an essential part of life for me; I need that contact with the outdoors and natural spaces, and meeting new people. Staying in tents is such hard work for myself and my PAs and friends and doesn't really meet my needs. I want to see friends around the UK but often their houses aren't accessible. The idea is to have everything I need in a box on wheels that can go anywhere with me. A comfortable bed with overhead hoist, a compost toilet, a shower, a small kitchen and a wood-burning



stove to keep warm. I'll be off grid too, with rain water catchment and filtration and a solar system so that I can charge my wheelchair. I've never felt so sure about anything in my life. I'm so excited about achieving this dream. I crave variety, unfamiliarity and spontaneity. The prospect of living a simple, and mobile, life with my wagon has been my sole (and soul) focus ever since I came up with the idea. Again it's something I wouldn't be able to do without the amazing network of friends around me who are willing to help with the build and make it happen. Watch this space!

Well this is the story of my life to date. There are so many events, formative experiences and relationships that have steered me to where I am now. I've done my best to share with you some of the more significant ones. There are many more humorous situations that I've found myself in with various friends – life in a wheelchair can have its hilarious side! But not only have I run out of word

**Life in a  
wheelchair  
can have  
its hilarious  
side!**





space but my memory doesn't serve me so well these days. I hope you have taken from this the fact that life is good, that friends not only make the best times better but get you through the dark days too.

In spite of adversity I have always tried to involve myself with the world around me in the best way I can, speaking up for disabled equality whenever I get the chance, and through 'Worldshift Media', I joined in debates and workshops based on important peace and justice issues. My work as a freelance graphic designer continues and I am currently setting up a new charity with a friend.

In between my days are filled with some pretty easy-going living. General stuff which forms the substance of a life well lived...working on this and that, lazing around, time with friends, spontaneous trips and visits to here and there, mini adventures and endeavours.

Life keeps me busy but much of it has been about letting the wind take me where it will. I trust in saying 'yes' to whatever crosses my path.

I'm still looking for a way to leave the world in a better place than I found it – an avenue, a focus, a specialism, an idea that will help humanity remember itself and return to a more harmonious existence with each other and this beautiful planet we live on. But in the meantime I intend to explore, have fun, love lots and trust in the knowledge that life will move me. If ever you find yourself asking what to do with your life, instead ask yourself: what will life do with me? In each and every moment and event and interaction we can change ourselves, and the world, in a positive way.

**Little ripples make big waves.**





What's it like having an incurable illness, with life-threatening complications?

The answer is that it certainly isn't all the gloom and doom that you might expect. For instance, you come across many amazing and inspirational people and you are given opportunities, like contributing to this book, which you might otherwise never have had.

However, what made my situation more difficult is that the doctors didn't know what was wrong with me for a very long time. Along the way, certain symptoms were recognised and treated but it was not until 2012, when I was twenty-five, that I was finally diagnosed with Hypermobility Ehlers-Danlos.

So how do I live with it? Well, I came across this saying and it kind of sums up my attitude: 'When something bad happens to you, you have three choices. You can either let it define you, you can let it destroy you, or you can let it strengthen you'. This last one is the one I've chosen to go with!

Illness sneaked in to my young life when I was just nine years old. Slowly I began to suffer physical symptoms of terrible pain. I was naturally upset and distressed, and this caused me to become withdrawn

and depressed. The symptoms crept up on me like thieves in the night, robbing me of my childhood.

For instance, when my Mum used to take me to the cinema, I would sit and eat popcorn, but the outing was spoiled because I experienced so much pain in different parts of my body – my hips, arms and neck – that I just couldn't enjoy the film. However, I had no problem eating the popcorn, because not only was I hurting physically, but by eating I was trying to distract myself from deep-rooted emotional pain. The only way I knew how to cope at the time was to eat. So down went the popcorn, and the chocolate bars that I would hide in my room, along with the sweets that kept on disappearing from the sweet dish at my Dad's house when no one was looking. It didn't feel good, and I felt ashamed, but at the same time it was an urge, a craving, a hole that had to be filled.

I just kept stuffing food into myself, hoping that eating would make the emotional pain disappear. You see, it was not only my painful joints that were causing me anguish but there had been other traumas when I was a small child that I was too frightened to tell anyone about. I tried hard to comfort myself

with food to forget the mental pain. I guess I felt that if I didn't think about the abuse I had suffered, then it would eventually go away. Of course it never did. With hindsight I should have spoken out and told someone, but I was too frightened of the consequences – too ashamed and confused to put into words what had happened, or how I felt. I didn't realize then that pain doesn't go away by simply ignoring it, although I guess that deep down I probably sensed that all along, but back then eating seemed to be the only way to manage it.

With no real answers as to what was wrong with me, my life became even more challenging over the next thirteen years. Harboured all kinds of dark thoughts that I couldn't properly express, this increased my fears and resulted in my 'pressing the self-destruct button' to try to divert my mind from it all.

I would never have imagined that I'd become so severely mentally unwell that I'd find harming my own body a coping mechanism, or that I'd suffer so much physical pain that I'd be beside myself, in tears, not knowing what to do. But that was how it was.

However, looking back, although it was a terrible time, I realise that my illness and all that happened made me strong, and having survived over a quarter of a century against the odds, I feel that with my sword and armour at the ready, I can now cope better with whatever future battles come my way!

When I was nineteen I was diagnosed with Borderline Personality Disorder (BPD). This is a mental illness, and yes, it can come with a lot of stigma attached. Being 'Borderline' is a challenge and this disorder causes me to have an emotionally unstable personality; my emotions are all over the place, and even though I may seem very together, I often feel a much higher intensity of emotions compared to people without BPD. Having 'Borderline' also causes me to act impulsively at times, have strong feelings of emptiness inside, struggle with eating-disordered behaviour and, like the

majority of others who also have this mental health illness, sometimes I harm myself to cope with strong and painful emotions.

Because of using self-harm in this way I have quite a lot of scars on my arms and legs. I am not ashamed of these scars, for they are a part of me and every scar tells a story that perhaps,

at the time, I couldn't express in any other way. Yes, people sometimes stare, they are inquisitive, but if anyone asks about them, I tell them the truth. I've got nothing to hide. If people have the courage to ask, I will have the courage to answer. Hopefully, by being open about my self-harm struggles, people will gain a better understanding of what it means to be mentally ill. I strongly believe that if those affected by mental illnesses can find the strength to speak openly about their experiences then this will help shape the future of how mental illnesses are perceived. Don't be ashamed, have

**Would I have  
lurched from  
one destructive  
habit to another  
had I known  
that I actually  
had a diagnosed  
condition?**

strength – there are better days ahead.

Physically, I face several complex conditions. One of these is Ehlers-Danlos Syndrome, otherwise known as EDS. This is a genetic disorder in which the structure of connective tissue is abnormal due to a gene mutation. This means that all the connective tissues in my body are very fragile and stretchy – and this causes symptoms to arise throughout all the systems in my body. EDS can affect people differently. For me EDS, coupled with Fibromyalgia, causes a lot of pain throughout my body. The pain is the worst symptom as it makes simple tasks like brushing my teeth or folding laundry almost impossible. It's very variable – some days I can't get out of bed and will need lots of morphine to try and take the edge off the pain; other days I feel much better and I can get around using my stick and the pain is more manageable. I have good days and bad days – sometimes both on the same day!

Ehlers-Danlos, I now know, was, and is, the cause of most of my physical problems. It affects my digestive and urinary systems, which makes eating and drinking sometimes more of a challenge and causes stomach pains, reflux, nausea and vomiting. I also self-catheterise occasionally because my bladder can't always empty effectively.

I also have Idiopathic Intracranial Hypertension which is not only hard to pronounce and spell, but I don't suppose you've heard of it either! Basically, it's pressure and fluid on the brain. I was diagnosed two years ago, in November 2013, after experiencing bad headaches and vision problems for several months. Fortunately, I was treated quickly for this condition, as any delay can cause a loss of vision. I had a few lumbar punctures

**I am not ashamed of these scars, for they are a part of me and every scar tells a story that perhaps, at the time, I couldn't express in any other way.**

**Don't be ashamed, have strength – there are better days ahead.**

where they inserted a needle into my spine to drain the fluid from my brain via my spine. Then in January 2014, I had a lumbar-peritoneal shunt put in my spine, which drains the fluid from my brain and into my stomach where it is disposed of, and this happens at a constant and even rate. There have been a few times when I've needed to have the shunt revised, meaning more operations, neuro intensive care and what I always referred to as the 'antennae' – a temporary pressure monitor device that comes out of my head and makes me feel like ET! My dad enjoyed making lots of jokes

about it and kept asking me to get out of hospital and come home! This always made me laugh...

But, like I said, having a serious illness doesn't have to be all doom and gloom. Life is what you make of it, and how you perceive your situation, so although I'll continue to tell you what's wrong with me, I'll also tell you what's right with me as I believe that's the important part!

I shall continue my story by starting from the very beginning – the day I was born. I will tell you about my life and what it's been like being me. Sure, it may not be easy and there will be difficult bits to go over and re-live, but as well as the tough stuff I'll tell you about all the magic moments; things I've loved, the times I've cherished, what I've achieved and the challenges I've overcome.

I was born on the 5th June 1987, at St George's Hospital in Tooting to a very loving couple, Maureen and Terry. I popped in to this world, weighing 6lbs 13oz. after a normal, healthy birth. Living in Staines-Upon-Thames in Surrey with my parents, in a semi-detached three bedroom house with a Red Setter called

Christy, we were a pretty ordinary family as far as families go.

My first childhood memory is of climbing up the stairs at bedtime when I was about two years old. My mother held her arms out close behind me to make sure I didn't fall, and she followed me the whole way up, gently supporting me when I couldn't quite manage the next step. Together we chanted "Up, two, three, four, up, two, three, four..." over and over, starting at the bottom and finishing once we'd reached the top. I remember the struggle to climb those stairs and the effort needed to take each step. I really think that this game was all part of my parents' cunning plan to exhaust me before bed so that I would sleep well and not disturb them in the night!

On my third birthday my parents bought me a teddy bear that was even bigger than me. He was different from your average bear in that when you patted his back he mooed! I remember thinking this was quite strange, a bear making the noise of a cow! Perhaps that's where everything went wrong and the confusion of the mooing bear traumatised me for







life! In all honesty, I'm pretty certain that the bear wasn't to blame but I do know what was.

I was abused between the ages of three and six, and the trauma of this was too much to cope with, too much to understand. I didn't know what was happening to me, none of it made sense. Every time it happened I blocked it out, dissociated myself from it. It hurt me in so many ways, and left me extremely emotionally scarred. I wet the bed a lot between the ages of six and ten. I'd draw pictures with hidden symbols referring to the abuse, and write cryptic stories without realising why. Perhaps I was trying to inform my teachers, my parents, anyone, of what had happened. I felt guilty, like I'd done something wrong. Yet I didn't know what it was. Some nights I would wake up terrified and, unable to get back to sleep, I'd creep across the landing to the top of the stairs and sit in the dark wondering if I should go down and tell my lovely mum I was a bad child. I never did and this went on for several years.

If only I could have talked to someone, I know it would have helped. Thank goodness youngsters today can seek help and support from 'Child Line', which can let them know that they are blameless victims and must always find the courage

to speak out.

I've got on with my life and I don't consciously think about it now, but I know it's still there, buried deep in my subconscious.

**'You are most hurt because you feel**

**That the child within will never be heard.**

**All those years and all those tears,**

**The child inside still cries,  
But no one hears...'**

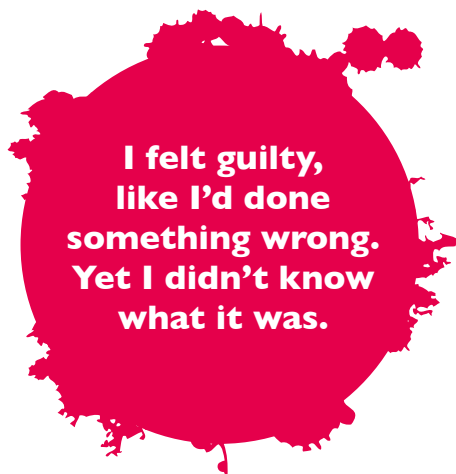
Amazingly, despite the torment in my mind, I did well at school, excelled in fact. It was a welcome distraction from my inner pain.

I worked hard and enjoyed school as much as I could and I loved having friends. I won a 'build your dream house' competition when I was eight, and I remember being very proud of what I had created; a homely looking four-bedroom house made of cardboard, with each brick carefully painted on, and a garden with real grass and real sand in the sandpit. I must admit Dad did help me a lot. Getting involved with my school projects was something he loved to do and I loved him for it.

Sadly my parents divorced when I was eighteen months old. I lived with Mum and a very special time for me was spending most Sundays with Dad and his new wife, Naz. Mum really brought me up, and I know it was difficult for her, but she did the best she could and I admire her for that. She worked full time as a merchandiser, buying clothes from Korea and faraway places, and selling them to shops in this country like Marks & Spencer, Top-Shop, BHS and Zara. She was lucky if she could get two or three weeks holiday a year. My dad also worked full time, in a high-flying job for the local government. Therefore, I had to spend a lot of my school holidays with family or a childminder. Having grown unhealthily attached to my mother, I hated it when she had to leave me with my grandparents in Somerset during the holidays. I can remember clearly the full-blown panic attacks I had when she left. This may explain why as a child, I felt isolated and often played alone, creating make-believe families and playing with my invisible friends.

I was nine when I started getting physical pains. These pains wore me down and I knew they didn't feel right, and were not something someone of my age should experience. Still, my parents thought they were growing pains and didn't think any more of my moans and groans.

When I was ten my mum moved me from my state school to an expensive, private school for girls. The reason was because I'd previously been staying with a childminder after school and her children bullied me; taunting me by calling me names, pinching me and throwing things at me, causing me pain and bruises. They really were awful and even went so far as to make me tidy their room, or do other chores that their parents had asked of



**I felt guilty,  
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what it was.**

them, whilst they went out and played in the fields! When my mum picked me up at 6 pm every weekday, I would get in the car and burst in to tears. Knowing I wasn't happy, she moved me to St David's School as soon as she could.

I spent almost four years there and although it cost a lot of money, I don't think it did me any good as it just replaced one set of problems with another! I spent a lot of time stressed out over homework and deadlines. I stayed up past midnight some nights just to get work done. I became a perfectionist where my work was concerned, and sometimes it would take me ten or more attempts to write a single sentence that I was happy with. I was also in pain and this made things worse. Writing was painful, as was sitting down for long periods at a time. Because I couldn't understand why I was in pain, this made me more frustrated. I guess I spent a lot of my time just before becoming a teenager, wondering if I was just the odd one out.

When I was twelve my mum met a new man, his name was Paul. He seemed



nice enough but just the fact of having another adult man in my life, other than my dad, reminded me of my abuser and this startled me, stirring up past traumas in my subconscious. My Mum thought I didn't like Paul, but the terrible truth was that having Paul around made the terrors of my past awaken.

I couldn't cope with life. I felt like a mess. I didn't care if I lived or died. I was just twelve years old.

Food, after having been a comfort for so long, now became my enemy. Scrambled egg on soggy toast and mum's mashed potato went from being something I looked forward to, to something that scared the hell out of me! I started to restrict my food intake and I became weak. I lost weight, week by week, and I went from almost eleven stone aged eleven, to barely six stone by the age of thirteen.

I had fainted many times from malnutrition and so a few weeks after my thirteenth birthday, my mum took me to the doctor. I remained silent while she did all the talking. I was scared because I knew that by informing the doctor, my secret was now out and I no longer had control; everyone would know what I'd been doing! I'd existed throughout my twelfth year of life on between 200 and 600 calories per day and some days I would eat nothing but a piece of fruit and some mixed vegetables. I think perhaps the common saying, "An apple a day, keeps the doctor away", ought to be rephrased!

The doctor diagnosed me with anorexia. I knew in my heart this was a bad thing but I really didn't care. In fact, at that time I actually felt good; I'd managed to control my calorie intake to the point that it had made me emaciated.





**I guess I spent a lot of my time just before becoming a teenager, wondering if I was just the odd one out.**

I'd reached my goal. I'd succeeded at something. That shows you just how warped my thinking was because the stark reality was that I was very ill. Anorexia had gained control over me. People tend to think that anorexia is some kind of fashion statement or slimmer's disease. The truth is, however, that it has very little to do with being slim, skinny or skeletal.

Anorexia is all about control and because I didn't really know what was wrong with me I felt completely unable to predict what was going to happen next. It was very scary and it made me feel that I must be in control of something in my life – anything. I was desperate. I see now how wrong-headed this was but I also understand why I felt as I did at that time.

Anorexia can develop at any age and affects both boys and girls. In my case it

was a desperate attempt to regain some control over my life when I was very depressed. I started to miss a few meals and found it made me feel good, strong and powerful. That's when anorexia entered my life. I got hooked in and damaged without really realizing what was happening. Be warned: anorexia is dangerous, and it can kill you.

I'm afraid my problems with eating didn't end there. From eating everything to eating nothing, I then again began to eat everything, but digest nothing. I became bulimic. I ate anything I could get my hands on. The desire to eat was overwhelming, but after eating I'd not only feel full of food, but full of guilt too. I'd have to make myself sick. I just couldn't cope with all the food inside me. This became a dangerous habit. The build-up of self-hatred through allowing myself to indulge almost sent me over the edge. I couldn't cope with all of a

**Would I have lurched from one destructive habit to another had I known that I actually had a diagnosed condition?**

sudden being so greedy. I wasn't used to it. Despite the fact that I was getting rid of the food instantly by purging, I wasn't satisfied. I still felt bad. I'd spiralled so far out of control that I didn't know how to cope. So one day, after bingeing and purging, when I was fourteen, I took hold of a knife. And I dragged the blade across my skin and I saw red. Self-harm was something I'd never heard of before. But it was about to take over and almost destroy my life.

I was in turmoil and shortly after my fourteenth birthday, I took an overdose. It was my first of many attempts to escape from the emotional anguish that threatened to smother me.

Would I have lurched from one destructive habit to another so dramatically had I known I was not imagining my pain but that I actually had a diagnosed condition? I can't say for sure, but constantly wrestling with not knowing why I was in such physical pain and why no one understood the cause, was certainly affecting my mental capacity to cope rationally.

I was taken to hospital, and kept in a children's ward for two weeks before



being sent to a psychiatric hospital in Maidenhead. I was admitted to the Eating Disorders Unit because the doctors believed that it was because of the thoughts I had surrounding my eating difficulties that I'd become such a risk to myself.

It was all too much for me to get my head around. I despaired of anything ever going right for me. I felt it all went wrong because I was wrong.

The next eight years of my life up until I was twenty-two years old were mostly a blur, spent as an inpatient, often under the Mental Health Act, in different secure psychiatric units.

From struggling with eating disorders and self-harm to experiencing scary psychoses, I couldn't seem to get any relief from the chains that imprisoned me. For almost a decade I was my own worst enemy and at huge risk to myself. I guess the psychiatrists had to keep me sectioned and hospitalised for my own safety. But spending every birthday and Christmas in hospital for eight years felt wrong and I felt as though I was being punished for a crime.





The only good thing at that time was that I made some amazing friends in hospital.

I still have these friends and they are a big part of my life. What is wonderful is that I can honestly say that the majority, if not all, of those friends that I shared such haunting experiences with whilst in psychiatric hospitals, are now leading fulfilling lives. Many are married and have children, whilst others are studying and holding down successful careers. These are friends that I'd share sad stories with after being restrained and injected with

**Even the  
darkest of night  
skies don't last  
forever...**



sedatives. These are friends that I would pour out my heart to when it seemed like the nurses didn't care. These are friends that alerted staff when they knew I was at risk of harming myself. These were and are true friends, and I'm lucky to have been able to experience such strong and lasting friendships.

"Even the darkest of night skies don't last forever..."

Things slowly began to improve for me. They didn't necessarily get easier, not for some time anyway, but the way I coped with painful emotions changed. I managed my mental illness and the disturbances that came with it a lot better, and over the next few years the admissions became much shorter, lasting a month or just a few weeks at a time.

You may wonder what helped me to be safer and less of a risk to myself. Well,

I think the answer was being given the chance to fly free from the nest as it were, to be discharged from hospital after such a long and gruelling time, and to finally feel like I had made it and that yes, I could build a life worth living. My self-esteem improved; I became more confident and although I admit I was, and still am, fragile, I've proved to myself that it's not about how or why you fall down, it's about how you manage to climb back up. A psychiatrist, of whom I was very fond, once said to me, "Life is all about turning up!" He often said this to me while I was under his care in the adolescent unit and I never really fully understood what he meant, but now I think I understand. I interpret it in this way...

"Life is all about making it... not making it as in having a brilliant career or having lots of money, but making it through the

**I think the answer was being given the chance to fly free from the nest as it were, to be discharged from hospital after such a long and gruelling time, and to finally feel like I had made it and that yes, I could build a life worth living.**

**It's not about how or why you fall down, it's about how you manage to climb back up.**

tough times, and coming out a better, stronger person.”

Being given the chance to leave hospital in my early twenties and venture, at long last, in to what I felt was the big bad world’ in fact did me a lot of good. I really don’t think I’d still be here if I hadn’t been given that chance. I was housed in a self-contained flat in Staines-Upon-Thames, near my wonderful



mother. I lived there, in what is referred to as ‘supported accommodation’ for almost three years, a few months before my 25th birthday.

I had my first experience of a ‘proper’ relationship while living there with a young man I’d met in hospital. Jeremy was two years older than me and perfect in my eyes. Although he had had similar problems himself, we got on so well and things felt good for the first time in my life. We were together for almost three years and during that time we enjoyed life together. We used to go on day trips and when we could afford it, out for coffee and meals. We once went to Bath for a few days and even went abroad to Madeira and Turkey where I swam with dolphins. I think that experience has to be the best of my life. I felt free, unjudged and solely at peace in the water with one of nature’s beautiful creatures.

I love being in the sea – to me it’s a magical place where, with only my face surface, I can shake off my insecurities

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creatures.**



and problems as easily as I can shake the water from my body. It's the one place where I can actually experience a sense of real freedom and happiness.

I guess, looking back, the first year or two I spent with Jeremy was probably the best time of my life. I wasn't completely free from mental anguish but I now used poetry as a way of expressing my pain, and loved to write. This way I could get rid of some of the deep-rooted feelings that were still trapped inside. Now I lived a real life – late nights and laughs, drinks with friends even – all ordinary stuff but new and exciting to me! I even held down a voluntary job at a local hospice. I was happy. My flat became a real home when I got my precious cat. I love cats: they are so loving and accepting and have always been an important part of my life.

So, despite my difficulties, I was at last really living and it was a life that was a far cry from the four walls of a hospital dormitory or seclusion room!

After completing my short-hold assured tenancy in my first supported accommodation, I was able to move on to 'the next step' which was another

self-contained flat in Staines, with a bit less support. I loved the next level of independence I had been given, but shortly after moving in to my new flat, my beautiful cat Jasmine suddenly died from a heart problem. I was devastated and couldn't cope with losing her. The night after she died everything became too much for me and the stress of her loss pulled me under. In desperation I reverted to my old, stupid, risky behaviours. Jeremy, no longer able to trust me, found he could no longer cope, and we split up.

I was sad for many months but I could understand why he left and eventually, as summer approached and the sun began to shine, I got better. I finally met someone else. He seemed caring, charming and protective and we started dating. Our relationship would last another three years.

Just as my mental health was improving, my physical health declined. In November 2011, I was diagnosed with Fibromyalgia. That's when things made a little more sense and at long last I could believe that the acute pains I had experienced since I



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that was a  
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dormitory  
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room!**

was nine were real and not imagined. I wasn't crazy like doctors had previously led me to believe.

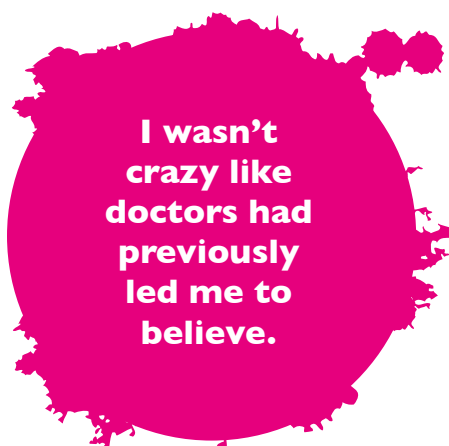
Although not yet fully understood, Fibromyalgia is in fact a neurological condition whereby the brain sends out more pain signals, in response to injuries or simple knocks, than in people who don't have the condition. Pain is highly intensified for Fibro sufferers and this pain is often constant and unrelenting. There is very little that actually helps the pain significantly and living with Fibromyalgia can be debilitating yet



invisible. But for me it was so reassuring to learn this pain was real. Later, I was to learn that this Fibro was just part of a more complex physical condition, but it proved to be a step in the right direction towards uncovering the final mystery illness.

In May 2012, I had to have an operation but with the pain getting the better of me, my GP reluctantly prescribed the strong painkiller, oramorph. Even so, some days nothing would relieve it. There were times when I would wake up in tears and fall asleep in the same state.





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believe.**

My life was falling to pieces again, but this time because of a physical illness.

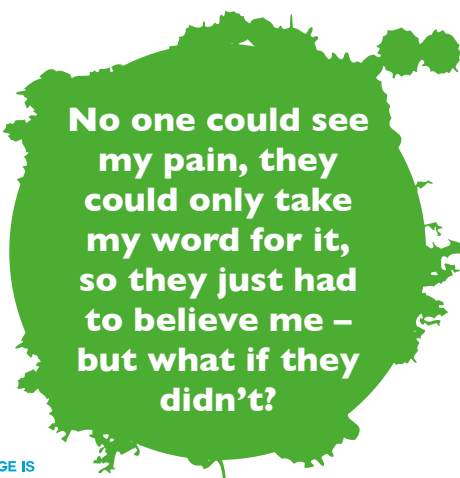
I couldn't get out very often as I found it difficult to walk. The next few months seemed to be spent in the doctor's surgery, which was fortunately at the end of my road because at the time I didn't drive. Even so, getting about was painful and although I considered getting a wheelchair, I was worried what others would think of me. No one could see my pain, they could only take my word for it, so they just had to believe me – but what if they didn't?

I eventually had no other option and my GP referred me on the NHS as I couldn't afford one. It arrived within a few months and made life so much more manageable; I was independent again!

I think that it would be helpful for people who are facing fears about using a wheelchair to know that there's no need to be ashamed or embarrassed. It can feel strange at first but after a short while you will see that having a wheelchair makes a hugely positive impact on your life. Try and learn to love your wheelchair. Embrace it. After all, it is enabling you, not disabling you!

A big turning point for me came in September 2012, when I was twenty-five. I went to see a rheumatologist at the UCL Hospital in London to find out more about my symptoms and why I was constantly in so much pain. She carefully examined me and listened to what I had to say. I felt like she actually wanted to help and she gave me time to express myself in my usual waffley way. It seemed like I might really be getting somewhere!

A few weeks later I received a letter in the post informing me that I had Ehlers-Danlos Syndrome. Although I understood the seriousness of this condition and the worrying side effects of the disease, receiving the diagnosis wasn't all bad; in fact it was a relief! Finally, I could put a name to all my symptoms and hopefully get some treatment or help of some kind. I did feel angry though at the fact this diagnosis hadn't been made sooner. It would have saved me years of having to hear my symptoms explained away by different doctors as 'a virus', 'a part of growing up' or, even worse, 'in my head'! If only I had been listened to, believed, perhaps things wouldn't have turned out the way they did. I might not have become so mentally unwell if I had known what was wrong with me.



**No one could see  
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didn't?**

**The diagnosis was a big step that helped to guide me up the ladder, rather than pull me down.**

I suppose we all ask ourselves the 'what if?' question, and being human we all do, but I know it won't change anything and so I try to be positive and not dwell on negative emotions. My overriding feeling was after all, a great sense of relief that finally I had been given a text book diagnosis. I now knew and could say what was wrong with me! You can only guess what this meant to me. The diagnosis was a big step that helped to guide me up the ladder, rather than pull me down.

The year 2013 arrived and proved to be a more promising year. Some may say the number thirteen is unlucky, but in March I moved away from supported accommodation and into a one bedroom, independent council flat in Walton-On-Thames. My door number was number thirteen. I had been given the chance to live alone without regular support from live-in staff. It felt like I'd received a certificate saying, 'You've passed the test, now go and see what amazing things life has to offer.'


My partner at the time moved in with me and we got ourselves some cats, five of them in fact. Rose a big and beautiful tortoiseshell and Jigsaw her kitten, a



gorgeous ginger, striped boy. Next there was Nilla, a year old, Clarise a tiny tabby kitten who could fit in a tissue box, and finally George.

I didn't realise at the time, the stupidity of getting five cats all at once and expecting them to live in harmony together. It didn't work out at all well. Rose ran away, and Nilla kept fighting with the three kittens, so that sadly, she had to be rehomed. That left us with the kittens and they became the light of my life!

June 2013 arrived, as did my 26th birthday. We had a party with friends at the flat and had a thoroughly great night. Things were going from strength to strength and I felt stable enough to try something new. I had wanted to set up a supportive community on line for quite some time and so I embarked on a journey that has led to remarkable things. I set up a non-profit organisation called Facing Illness Together, aka F.I.T – 'A chronically fabulous community for the chronically ill and fabulous', supporting those facing a chronic physical and/or mental illness, over the age of eighteen.



**So I embarked  
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things.**

In December 2014 one of my beloved cats was run over. I was distraught and things were bleak for a while, but I actually coped quite well having already experienced the loss of a dear pet a few years earlier and learnt from the experience.

January 2015 arrived and the start of another new year. I was still with my partner but things between us were going from bad to worse. When we first got together I didn't know of his addiction to methadone, the drug he was initially given in order to try and conquer his drug habit. I was to discover that secretly he was taking my morphine, filling the bottles with water once he had taken all the oramorph, and lying about what had happened to my painkiller. When I finally realised what was happening, and confronted him, he claimed he had tried to conceal the truth from me in order to 'save' our relationship. In fact, his attempts at deception were making our relationship suffer even more. I couldn't take his constant lying. The months passed and his mood swings and erratic behaviour finally pushed me over the edge. I had had enough! In May 2015 we split up. It was a

hard decision but definitely the right one.

It gave me a fresh start and a new lease of independence. I felt generally more upbeat and positive and that meant I could throw all my energy into Facing Illness Together. I spent all my spare time on it and wouldn't have had it any other way!

These days I find that F.I.T is what keeps me strong. I know that there's a large community of people who are all suffering some form of physical or mental illness and who have come to depend on the support that F.I.T offers in many ways. From online support and a text-line to actual physical, social meet-ups, and support groups in Surrey, Facing Illness Together is thriving, with more than 3,000 members. We have strength in numbers and much like the F.I.T tag line – 'Together We Are Stronger' that is what we believe. Together we can make it through; together we can succeed. And that is what we are doing. We even have the support of the local Surrey hospitals; Ashford and St. Peter's Hospitals Foundation Trust, who are keen to help F.I.T to reach its goals, for which I am so



**These days  
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very grateful. To be honest, I believe that setting up F.I.T will be the making of me.

By founding a non-profit organisation and everything that comes with that, I have grown in strength and confidence. Things are not yet resolved when it comes to my mental and physical health; I'm writing this from my hospital bed at St. George's Hospital in Tooting as my Idiopathic Intracranial Hypertension is playing up again and I'm due to have quite major surgery in a couple of days to try and fix things with the IIH. I know that the surgery, and recovery after, will be a tough time for me and I won't be able to drive for six months after the operation, which will be a test for me in itself, but whatever comes my way, I know the only option is to keep on fighting. If I stop fighting, well... I just can't. There is solace in the fight too and that comes from the inner strength I find when I feel I cannot take another single step forwards, yet I do...

For me, the biggest comfort in the fight is knowing that I am trying my best and it pays off to try. People often recognise

my efforts and give me praise, and, when I am rock bottom yet manage to climb up, no matter what I may say, I do feel a sense of pride. And that pride comes from knowing that I have overcome my battles, through my own efforts.

Despite everything, I'm the happiest I've been in my 28 years of the fight. Often people ask what I want to achieve in life or what I do for a living. I don't feel afraid or ashamed to tell them that what I do is fight every day, to remain strong in mind and body, and what I want to achieve is simply to 'be'.

**To be honest,  
I believe that  
setting up  
F.I.T will be  
the making of  
me.**



As the famous line goes:  
'To be or not to be...'  
'That is the choice we have.  
I choose the former!

What are my dreams – because we all have dreams? Well, mine is to live by the sea where I can hear the gulls' cry as they circle free in the sky, watch the rhythm of the tide endlessly coming in and going out, and have someone at my side who cares for me; someone without 'baggage', (I think I've got enough for both of us!) But, in the meantime, I will face whatever each new day brings knowing that although life seems to be a never ending battle, if you want to win you have to take part and that's exactly what I plan to do!

**Life is all about  
turning up!**



**For me,  
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**When I am  
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## PRIVATE SUPPORTERS

We are very grateful  
to the following people  
who generously donated  
money to make this  
project possible:

Astill, Ceri

Astill, Stuart

Bimpson, Sam

Braithwaite, Nigel, Louise, Elinor

Bray, Hannah

Brooker, David

Chambers, Lizzie

Cotter, Janet

Davies, Elizabeth

Darby, Sylvia

Dowds, Charles

Dubash, Arianne

Elliott, Helen

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Gould, Maureen

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Hodges, Sarah

Hodgson, Julia

Hope House

Children's Hospice

Johnson, Myra

Johnstone, Drummond

Johnstone, Rachel

Le Masurier, Sally

Mackay, Jennifer

Manley, Dorothy and Graham

Martin House

Children's Hospice

Murray Hall Community Trust

Musson, Jen

Quilliam, Gabrielle,  
Hummingbird House

Rowan, Judith

Sereda, Maria, Mia

St Aidan's Church,  
Leigh-on-Sea

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Taylor, Gwyneth

Teague, Joanne

Teague, Laura

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#### **Martin House Hospice**

The aim of Martin House is to provide family-led care for children and young people with life-limiting conditions across West, North and East Yorkshire and the Humber. It is a place of care and support where children, young people and their families can stay for rest and practical help. In 2014/15 we supported 423 children and young people and 151 bereaved families.

[www.martinhouse.org.uk](http://www.martinhouse.org.uk)



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## CHARITIES

The following charities are engaged in providing support, (or conducting research), on behalf of those who live with Spinal Muscular Atrophy,

Ehlers-Danlos Syndrome and Muscular Dystrophy. They have taken a keen interest in the development of this book and have helped us to let people know about it.



### SMA Trust

The SMA Trust is the only UK charity totally focused on funding research into a cure and treatments for SMA (Spinal Muscular Atrophy), a genetic neuromuscular condition that particularly affects children, and is caused by a single faulty gene that controls the nerves and muscles involved in moving, swallowing and breathing. SMA is little-known and yet 1 in 40 people is a carrier and in the most severe cases, children rarely live beyond 2 years old, making SMA the leading genetic killer of babies and toddlers. The SMA Trust funds 75% of all UK charity-funded research into this condition and is completely dependent on voluntary donations to continue its work.

[www.smatrust.org](http://www.smatrust.org)

### EDS International

EDS International is responsible for internationally raising awareness of Ehlers-Danlos Syndrome, managing coordinated medical collaboration, raising funds for research and focusing on the progression of EDS throughout the world.

Email: [lara@internationaleds.org](mailto:lara@internationaleds.org) [www.internationaleds.org](http://www.internationaleds.org)



### Ehlers Danlos Syndrome

EDS UK was set up in 1987 to support, advise and inform those living with Ehlers-Danlos syndrome. We aim to help them live a full, active and positive life. Over 25 years later, we remain the only UK based charity that exclusively represents and supports people with all types of EDS. We have over 30 support groups around the country to provide our members with a local peer support network and we run a freephone helpline.

<http://www.ehlers-danlos.org>



## **SMA Support**

Spinal Muscular Atrophy Support UK offers free information, emotional support, practical advice and guidance to anyone affected by any form of SMA. We also fund and support the research community addressing the causes, treatment and management of SMA. For more information go to

[www.smasupportuk.org.uk](http://www.smasupportuk.org.uk)



## **HMSA**

The Hypermobility Syndromes Association is an organisation which works with people who have a heritable disorder of connective tissue, or hypermobility syndrome, and the professionals who support them.

[www.hypermobility.org](http://www.hypermobility.org)



## **Together for Short Lives**

Together for Short Lives is the leading UK charity that speaks for all children and young people with life-threatening and life-limiting conditions and all those who support, love and care for them. Our Transition Taskforce's vision is for all young people with life-limiting or life-threatening conditions to make the transition to adult services and live their lives as independently as possible according to their wishes, whilst receiving the care and support they need.

[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)



## **Muscular Dystrophy UK**

Muscular Dystrophy UK is the charity for 70,000 children and adults living with muscle-wasting conditions. We provide vital information, advice and support to help people live as independently as possible. We accelerate progress in research and drive the campaign for access to emerging treatments.

[www.muscular dystrophyuk.org](http://www.muscular dystrophyuk.org)



## **F.I.T.**

Facing Illness Together is a non-profit organisation that supports anyone aged 18+ suffering with a chronic physical and / or mental illness. In our F.I.T community it's about strength in coming together. Don't suffer in silence; join us! Together We Are Stronger.

[www.facingillness.wix.com/f-i-t](http://www.facingillness.wix.com/f-i-t)







