

HONEYBEE

LIFESTYLE MAGAZINE

World renowned Storyteller & Author Kez Wickham St George joins the team.

What's
your
Story?



HONEYBEE

LIFESTYLE MAGAZINE

What's your Story?

Our team welcomes several incredible new contributors this edition, including our cover Kez Wickham St George. Published Author & renowned storyteller.



Jaymee-Lee Farrelly

Jenny Gleeson



Brand New
Lifestyle
Website
Coming
Very Soon





From Melissa Dumitru, Editor-in-Chief

EDITOR'S NOTE

Welcome to Honeybee

Storytelling is one of the world's oldest forms of communication. Each of us has a unique life story that is as important as the next person's story. Sharing stories can be painful, liberating, inspiring, and educational. Our magazine is based on sharing stories from lived experiences.

When I shared my story about the rebirth of Honeybee, I allowed myself to be vulnerable and open to critique. I allowed readers to be able to relate it to themselves and their stories. Throughout my 14-year journey of living with the progressive rare disease pulmonary arterial hypertension, I have had to tell my story numerous times.

People want and need to share their stories; it is an important aspect to acknowledging what they have been through or are going through. It is integral that what they feel can be felt by others, which then lessens their feelings of isolation.

As Editor-in-Chief, I act as the caretaker of all the words printed in the lived experience stories we share with you. These words can be raw, shocking, sad, uplifting, humorous, thought-provoking, and so much more.

Sometimes it is hard to read what others are going through. This is where we learn to **"sit with the discomfort"**. Each writer is at a different stage in their own story, their own recovery, growth, and journey to realisation. While we intend to uplift you and inspire, it is important to us that you are aware also of the reality that so many within our community live with.

These so incredibly important stories have been shared with you by our writers in the hopes that you find a place to relate, and that there is enough of the good stuff to enjoy and look forward to in each edition.

I chose the theme of this edition, after seeing what I considered to be a **powerful statement** from Keely Cat-Wells, the Founder of C Talent in the USA.

”
"What happened to you?"
"What is your story?"
”

Her credo is: *"To change the world; we have to learn to tell and listen to a new set of stories about the world we want to create"*.

So many times, over the last 14 years, people have said to me, **"What happened to you?" or "What have you done to yourself?"** - as if my illness and disability were somehow my fault, or my choosing. It's time to stop and think, and actively change the way people in our community who live with chronic illness, disability, and mental health conditions are spoken to. It's ok to be curious if it's appropriate.

Asking someone "What is your story?" is so much **kinder**. Let the storytelling begin, love & blessings always Melissa xx



Acknowledgement to Country: Chronically Inspired would like to acknowledge Aboriginal and Torres Strait Islander peoples as Australia's First People and Traditional Custodians. We value their culture, identities, and continuing connection to country, waters, kin and community. We pay our respects to Elders, past and present, and are committed to making a positive contribution to the well-being of Aboriginal and Torres Strait Islander young people, by working on providing services that are welcoming, safe, culturally appropriate and inclusive. We are committed to embracing diversity and eliminating all forms of discrimination in the provision of health services. We welcome all people irrespective of ethnicity, lifestyle choice, faith, sexual orientation and gender identity.



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Meet the CONTRIBUTORS

It takes a lot of hard work to compile a lifestyle magazine and guide our readers to a more mindful and intentional life while living with all our extra challenges. The powerful stories and engaging content from our dedicated lived experience experts are so greatly appreciated.



Jacqueline De Grussa

Sociologist specialising in the area of Trauma, Addiction & Recovery, Founder Women's & Men's Recovery Community Founder and Managing Director Recovery Collective Ltd
[Facebook.com/womensrecoverycommunity](https://www.facebook.com/womensrecoverycommunity)

Jacqueline consults for an indigenous organisation, developing various new culturally specific recovery-based projects. Her Women's Recovery Community and Men's Recovery Community offer 24/7 support in WA, interstate and overseas. Jacqui is the Managing Director of The Recovery Collective Inc. She is a mother to three children, and is a documentary buff. Jacqui is passionate about all things that empowers our most vulnerable on their recovery journeys.

Angela Famiano

Masters Social Science (Counselling & Psychotherapy) Grad Cert Disability Studies Bachelor of Arts, Psychology Family & Children Services Diploma Community Services/Child Services 0-15 yrs

Angela is an accomplished Counsellor specialising in alcohol & other drugs. She has a special interest in men's advocacy and believes that counselling is not so much about fixing things, but acknowledging them and working with your strengths. Her vision is to be part of people's journey to self-improvement and helping them find a place that makes them truly happy.

Helen Blanchard (Lifestyle Editor)

**Registered Nurse (retired)
Diploma of Arts Psychotherapy
Health Educator (Published)**

Helen has a wealth of experience, knowledge and practical skills gained over more than 35 years working in a variety of senior roles within the health, community service and not-for-profit settings. She has a lived experience of chronic illness, and is passionate about creating and sharing health-related education information and resources. Helen is committed to advocating for a person-centred approach to health care and has a particular interest in the expressive therapies and art as a therapy for people living with chronic illness.

Dianne Murphy

**Carer Representative (Palliative Care)
Carer & Disability Advocate NDIS
Carers Event Coordinator
Business & Administration Manager**

Dianne has worked in the Business & Administration field for over 40 years. She is also a Carer & Disability Advocate who supports her adult children (all with disabilities). Di is the Founder of Creative Carers whose focus is around art, craft, and nurturing mental health. Inclusion is very important to Di. She coordinates a social group called "Staying Connected" for those who care for others, and she is an organiser and coordinator for Retreats & Events to celebrate Carers in the community.

Jaymee-Lee Farrelly

**Bachelor of Primary and Secondary Education (Honours)
Former Disability Support Worker (2.5 years)
Facebook Blog: My Chronically Breathtaking Sister**

Jaymee-Lee is the creator of a Facebook blog called 'My Chronically Breathtaking Sister' – a blog dedicated to her late sister, Rachael, who lived with a chronic lung condition. Her blog aims to bring awareness to often unspoken topics, to educate others on chronic illnesses and organ transplants/donation, to help manage her grief and to carry on her sister's legacy. Jaymee-Lee has a passion for providing equitable opportunities to those around her and plans to predominantly work with EAL and disabled students once she graduates her teaching degree at the end of 2022.



Jackie Rowe

**Qualified Mindset Coach - Training Facilitator
Advanced Psych K Practitioner - Motivational Speaker
Certified Women's Circle Facilitator**
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Jackie is a University qualified Life Coach, Strengths Based Practitioner, Psych K Facilitator, and Women's Circle Facilitator. With a background in Early Childhood Years, Families and Community, Jackie now works predominantly with women to empower and inspire. Her vision is for all women to realise their amazing true potential, to speak their truth without fear and live a life they love.

Fay Bahemia (Technical Editor)

**Winner "40 Under 40" & multiple Community Awards
Cert IV Professional Writing & Editing
Cert IV Community Services
BSc (Microbiology & Pharmacology)
Grad Dip Food Science & Technology
Clinical Trials Coordinator in Radiation Oncology**

Fay has worked and volunteered with peer-support groups and NFPs, helping them to reach their goals and visions through freelancing. She has held key industry positions in quality assurance, regulatory affairs, biomedical research and manufacturing, training, and communications in various sectors. Fay has a lived experience which changed her life trajectory in 2015. She is an avid dancer, lover of visual art and a fan of beautiful cars. She has a quirky nature that draws people to her. Fay is meticulous in all she does, and I am thrilled to have her on our team as our Technical Editor and Copywriter..

Hayley Solich

**Connecting Communities to make positive change
Consultant Advisor Mental Health Sector**
[linkedin.com/in/hayleysolich](https://www.linkedin.com/in/hayleysolich)
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A multi-award-winning community engagement and Lived Experience professional who is nationally active in advocating for change in the mental health system. Hayley builds capacity and awareness to create social change by listening to the perspectives of others, validating and uplifting them. She uses her creativity, communication, leadership, facilitation and engagement skills to influence change at the highest levels.

Marie Williams



**Founder, The Platform WA
Intellectual Disability Advocate and Change-Maker
Mental Health Educator for WARCA
Certificate III in Education Support
E: theplatformwa@gmail.com**

Marie founded The Platform WA, a new community group focussing on intellectual disability for young adults like her daughter, Laura. Marie has been trained in Leadership and Mental Health education to become a WA Recovery College Alliance educator, where she co-designs courses aimed at people living with intellectual disability. She is a change-maker working at the coal face to improve perception and awareness. She has several years' experience working in non-profit charity sector, and the early childhood field as a teaching assistant.

Mystery Writer

The Girl in the Silk Green Dress - Fiction

The writer behind the "Girl in the Silk Green Dress" is someone with many years' writing experience. This mystery writer studied Journalism and has a very good understanding of social justice and community. I approached this mystery writer to offer a fictional character storyline that we can all enjoy and look forward to. I hope you enjoy their work as much as we are enjoying sharing it with you.

Meet the CONTRIBUTORS

It takes a lot of hard work to compile a lifestyle magazine and guide our readers to a more mindful and intentional life while living with all our extra challenges. The powerful stories and engaging content from our dedicated lived experience experts are so greatly appreciated.

Kez Wickham St George



www.kezwickhamstgeorge.com
[linkedin.com/in/kez-w-stgeorge](https://www.linkedin.com/in/kez-w-stgeorge)

Kez Wickham St George is an award-winning author who champions people from diverse backgrounds to reveal the best of their creative side. As a leader in her profession, a public speaker, an accomplished author in magazines, Kez leverages her extensive travels, experience, and expansive authorship to encourage readers to think outside the box. It is not surprising that Kez is known globally as 'The Writers Consultant'. Kez has written work for two royal families, one in the UK, the other in Sweden. She has co-compiled an anthology on the lives of various women internationally. Recently Kez published a trilogy of poetry books and her dream of the big screen was realized when a movie was made from the prologue of her last novel Scribe in the trilogy Campfires. Kez is passionate about promoting high-quality growth opportunities for all.



Jenny Gleeson



Educator & Facilitator
Disruptor and Annoyer (In a caring way)
Expert Personality Dimensions Profiler
A person known to help people get their shizzle together!
Website: www.jennygleeson.com.au

Jenny started as a Secondary English Teacher but then became extremely disillusioned with the Education System (it didn't take long - less than a year), which led her into completing a Graduate Certificate of Career Development, leading her to work with youth at risk, people with disability, First Nations people and winning National and State Awards. Jenny was diagnosed with depression and anxiety (way before the terms were even heard of by mainstream Perth-ites) at the age of 11 and institutionalised at the age of 13. Although anxiety is still in her life, she keeps it in the periphery of her vision, accepting and acknowledging it is there but it doesn't control her anymore. Her drive in life is to assist people be the best they can be...warts and all!

Testimonial

Erica from Disenyorita Studio is a dreamweaver....

I may be a little biased because I have been working with Erica for nearly a year and I now consider her part of our team. This woman has a generous spirit and she very quickly becomes intune with your needs. She is the epitome of professionalism and warmth, wrapped in a package of talent and endless enthusiasm. There is pretty much nothing she cannot do. I highly recommend you consider working with her in any design or website capacity.
Melissa Dumitru - Chronically Inspired - Life.Beyond.Disability

Disenyorita^{STUDIO}

Love-Soaked Brand & Web Design

for Businesses that
make this World a
Better Place

www.disenyorita.com

Follow our Adventures at Chronically Inspired

Destination Wellness

A woman with long brown hair, wearing a brown wide-brimmed hat and a long-sleeved, pleated, floral-patterned dress, stands with her back to the camera on a paved walkway. She is adjusting her hat with both hands. The walkway is bordered by a white metal railing and overlooks a vast ocean under a blue sky with scattered white clouds. In the distance, a low-lying island or coastline is visible.

New beginnings are coming...
New Website Launch...
New Contributors...
New Topics... New Socials...
Advertisers... Competitions...

The Chronically Proud Sister



From
Jaymee-Lee Farrelly

Attention - Possible Triggers

I sat at the end of Rachael's hospital bed, her toes digging into my crossed legs as I tried to set my back comfortably against the stiff footboard. The bottom of her hospital bed was what I always considered to be my honorary spot – a spot reserved for me, 'Rachael's little sister'. It was an uncomfortable, yet endearing spot that I knew all too well.

I glanced sideways at my parents who sat dolefully on either side of her bed. I sensed a part of their hearts being drawn out of their bodies, never to be replaced. Why her? Why us? How are we meant to live on?

I guided my attention back to Rachael, trying my hardest to memorize the feeling of her presence; a feeling I never want to lose. We didn't know when this dreadful time would come, but the thought lived in a deep dark pocket in my brain for years. For my parents and for Rachael, the thought lived for even longer. After enduring years of exceptionally poor lung function, a few dozen chest infections, multiple pneumothoraxes, a pleurodeses and a double lung transplant, she was ready to take her final breath. We took it in turns entwining our fingers with hers, as we hung our heads in disbelief and said our 'good-byes' and our 'I love yous'. Our tears flowed and our hearts ached, but we knew that her body had had enough.

Well... that's how I had pictured how Rachael might go.

Instead, her death involved a medication change while in the process of getting on the lung transplant list and Rachael just not waking up one morning. She didn't get her lung transplant. We didn't get to say our final 'goodbyes' or our 'I love yous'. It was sudden. It was unexpected. That was it.

It may sound weird or morbid for me to think about how my sister might die, but for many people growing up with a chronically ill sibling, child or parent, the thought can become a reality.

”
**Our minds tell us we must prepare,
even when our hearts don't want to.**

”

Although Rachael's death was sudden, her 23 years on Earth were lived.

Here is our story...

The first few years of our lives involved shifting between a few houses and states. We went from a small country town in NSW called Griffith, then to Canberra, and then back to Griffith. It wasn't until we moved to Melbourne in 2002 that our lives truly began. Mum had met an incredible Melbournian man online and within months, we went from a family of three to a family of four. Rachael had fallen sick two years prior to moving to Melbourne, when she was four and a half years old. What started as a typical winter virus, resulted in the obliteration of her bronchioles, leaving her with only twenty five percent lung function. She went from running track at Little Athletics, to not being able to walk up a flight of stairs without vomiting. A lung biopsy later confirmed the diagnosis of a rare lung condition called Bronchiolitis Obliterans. Why and how this happened to her is a mystery. There is currently no cure for the condition besides receiving a double lung transplant, which, ironically, can lead to the development of the same condition. Crazy, I know. But it was a gamble Rachael was willing to take.

For most of Rachael's life, we all tip-toed around the 'T' word. I think we were all too scared to talk about it as we didn't quite know where it would lead. Losing Rachael was always my greatest fear. I mean, I would've taken the lungs out of my own chest if I could have. Funnily enough, we would actually joke about me giving her a lung, if she'd give me a kidney (I only have one). That would be a fair trade, right?!

Moving to Melbourne didn't only grow our family, but it also meant that we had greater access to Melbourne's Royal Children's Hospital, and later, The Alfred Hospital, where Rachael could receive the most specialised care. What used to be a monthly seven-and-a-half-hour road trip to the closest big hospital, turned into a half-an-hour one. Although Rachael was admitted to hospital numerous times over the years, for often weeks, sometimes months at a time, she managed her condition quite well from home with the help of an oxygen tank (in her younger years), a nebulizer, and a cute little drawstring bag full of pain meds (a.k.a. her most prized possession!).

Growing up, Rachael and I always had a close relationship. We never fought, not even a tiff. I do believe that Rachael being sick did contribute to the strength and civility of our relationship. We had been through so much together as a family, that we were able to see life through a different lens than most. Little things were never a bother as we understood just how fragile life could be.

After Rachael's passing, I opened her laptop and up on the screen was a document titled, 'Growing Up Disabled in Australia' where Rachael had started to write about her life, including the role myself and my parents had in her story, and the impact disability and chronic illness can have on a whole family. After creating my Facebook blog, 'My Chronically Breathtaking Sister,' and posting her piece, I discovered that Rachael intended to submit her writing as an entry into Carly Findlay's edited book.

Within Rachael's story, she described me as not only her "sidekick" and "best friend," but also her "mentor" and "protector," despite her being the older sibling. As the "healthy" sister, I agree that I inherently took on the role as her "protector". Whether it was ever-so-kindly informing the abusive lady out the front of Woolworths that Rachael was in fact allowed to park in the disabled parking spot, or subtly asking people to slow down when we all walked together so that Rachael didn't feel embarrassed or feel like a burden, or formulating hypothetical plans in my head about how I could quickly get Rachael on my back and run if we were ever in danger - I was ready. This dynamic in our relationship was one we never spoke about. Although it made me feel appreciated, I have always felt somewhat guilty that the roles weren't reversed – and through her expression, I can tell she felt the same.

Nevertheless, I think the mentoring role definitely went both ways. Rachael taught me more than she will ever know. Firstly, Rachael was one of the most optimistic people I've ever known. She embraced all life had to offer and often used her condition as a motivator to do the "impossible". She worked hard to finish Year 12, went on to become a nurse, got her license, travelled overseas, played an extra in a TV show, and completed countless fun runs.



"Let's do Relay for Life this year!?"

"We should do the Kokoda Track Memorial Walk next weekend!"

"The Lung Foundation is doing a Fun Run, let's go!"

I mean, she'd wheeze her way through them, either coming in last or taking triple the expected time, but she'd turn up and she'd do it every time, and through struggling breaths, she would always ask the person beside her whether they were doing okay. I believe her health journey, as well as her caring nature and empathic streak, was reflected through her nursing career and within her general life, helping to instil a level of understanding and compassion within me that, up until a few years ago, I didn't even realise I had. She taught me what it means to stand up and advocate for the rights and needs of myself and others and how important it is to share our experiences, even those that aren't all sunshine and rainbows.

One of the quotes that Rachael lived by was a Latin quote, Dum Spiro Spero, meaning:

”

WHILE I BREATHE, I HOPE

”

She had the quote tattooed on her ribs, near her biopsy scar. I have promised myself that while I breath, I hope... to carry on her legacy, to share her story, our story, to educate others and to bring awareness to those difficult topics that are often left unspoken.

No more tip-toeing. Our story must continue.

Links:

Bronchiolitis Obliterans:

<https://rarediseases.info.nih.gov/diseases/9551/bronchiolitis-obliterans>

Carly Findlay's Book - Growing Up Disabled in

Australia: <https://carlyfindlay.com.au/growing-up-disabled-in-australia/>





Empress of Authenticity

Let me introduce myself Let me tell you my story!

Firstly, know that I am a person just like you. There is nothing special or particular about me, except the fact that I am extremely determined and somewhat stubborn. I am not sure if these are learned behaviors or traits that I have built over time due to circumstances or if they are attributes that have always been in me and have come to the fore over the years.

As a child, I've been told that I was very introverted and kept to myself – preferring to observe others rather than interact with them. However, this changed when my parents put me into a psychiatric hospital for children after I witnessed my Auntie die of an asthma attack when I was 11 years old.

Being involuntarily placed in the hospital brought out traits in me that I never knew I had. Being the eldest in the hospital, I became the person other children turned to for support and advice. Several of the girls had their first period while we were there, many of their parents had their own trauma to deal with and were absent parents, and several had ongoing suicidal tendencies. Although I didn't ask for it, I was their support person and someone they respected and admired. I became a Leader. This then carried over to the school I attended, where all of a sudden other students were asking me if they could sit in "Jenny's Group".



I found myself in and out of psychiatric units until the age of 23. It was then that I decided to stay on my medication for the rest of my life. It was too distressing to myself and my loved ones weaning myself off them all the time, then missing the subtle signs of going downhill, and then having to build myself up again. I am proud to say that, even though there have been extremely rough times where I felt I was going to completely and utterly fall apart again, I have utilized the amazing resources I have cultivated over the years to keep me on track (I guess this is where the determination comes in).

I am now 46. I have lived with anxiety and depression since the age of 11. It is exhausting sometimes, and I can see it sitting in my peripheral view, constantly waiting to infiltrate my life again. But, considering I have been dealing with it for 35 years, I now know how to acknowledge it, respect it, and keep it at bay.



From Jenny Gleeson
Attention - Possible Triggers

Routine, consistency, staying fit and healthy, being honest with myself and others, and recognizing when I am getting overwhelmed AND doing something about it, is what keeps me on track. I keep a daily Five-Minute Journal, see a Naturopath, Chiropractor, Counsellor, and make sure I take my natural and prescribed medications. I speak openly with loved ones when I am struggling and am continuing to learn how to let go of the ridiculous expectations I set for myself.

Even though some days I feel quite close to simply ending it all, my strength and determination to keep going and fulfilling my life's ambition to support others, keeps me going. There is a reason I am here. There is a reason every single one of us is here. Sometimes it might not be clear, especially in those really down times, but I sincerely believe we have been placed on this earth for a reason. It may not seem clear right now but hang in there. You never know who is grateful that you are here.

I wish I could have told my best friend this when I was 19. He had just turned 21 and suicided a week later. Even though this was long ago, I think of him often and it brings tears to my eyes. I wish he was here still. I miss him incredibly. If only he had known how much I would mourn for him all these years later. He simply didn't realise how important he was (is) and that, if he had just hung in there, life just 'might' have improved.

This is on a small part of my story. When we tell our story we make choices. We decide what we want people to know. For me, this is enough of my story, for now. It is a story of strength, grit, stubbornness and hope. A story that I will continue to live into. A story that, I hope, will bring inspiration and determinations to others.

Thank you!

Jenny



BLOOM

WHERE

YOU ARE

PLANTED



A Walk in my Shoes

Attention - Possible Triggers

From
Dianne Murphy



Letting Go

We all have a story, a journey, a life. Like many people I know, I had hopes and dreams for the future, some realistic and some not.

Now that I'm older, I tend to set more achievable goals but I had to let go of many of them, especially when I became a Mum and Carer.

Giving birth to my first born was the best and worst day of my life. I had suffered many miscarriages over the years (6 miscarriages and 7 babies), so, finally giving birth to my beautiful son was a dream come true.

Being told there was something wrong just after he was born was devastating. Having the Neonatal team from Princess Margaret Hospital (PMH) take him away to prepare him for urgent surgery has had a lifelong impact on me.

It wasn't an easy birth, and I needed further medical treatment after he was born. My darling husband supported me during a 21-hour labour and then followed the Ambulance to PMH to accompany our beautiful newborn baby boy to Intensive Care (Neonates).

Our beautiful baby endured major surgery just hours after his birth. When I eventually went to Neonates at PMH, my beautiful baby was on life support. My husband hadn't slept for days and we just held each other tight and hoped that our baby would come through this. My husband hadn't even had the joy of hugging his son, his first born. It was not an easy time for us and not the introduction to parenthood we had hoped for.

While I was in Neonates, I noticed a poem in a frame ... it was "Welcome to Holland" by Emily Perl Kingsley. It was about what life was like having a special needs child and the journey it takes.

The poem references, "When you're having a baby it's like planning a fabulous vacation trip to Italy. You buy a bunch of guide books and you make wonderful plans to visit the most wonderful places like the Coliseum, the gondolas in Venice etc. You even learn some handy phrases in Italian and it's all very exciting.

The time finally comes and you're all packed and travelling to Italy, then the stewardess says, "Welcome to Holland!" Holland?! but I signed up to go to Italy. All my life I've dreamed of going to Italy... but there's been a change in the flight plan and you've landed in Holland and there you must stay. Holland is still a lovely place, it's just different.

But everyone you know is busy coming and going from Italy... and they all brag about what a wonderful time they had there. For the rest of your life, you will say... yes, that's where I was supposed to go. That's what I had planned and the pain of that will never ever go away.... because the loss of that dream is a very, very significant loss".

"Welcome to Holland!"

I stood there and re-read that poem about ten times over. I cried and cried and cried. My husband read it too and we just looked at each other, and looked over at our beautiful son. Our baby, our son, our joy, our heart, our everything.

Our difficult journey didn't end there. Over the years, we became parents to another beautiful son and a beautiful daughter, too. Nothing has gone to plan in our lives but we love our children unconditionally. They are everything in life to us.



If we compare our journey to the poem, we might have been heading to Italy but our plane crashed. We didn't get to Holland either because we survived the crash and we came straight home. We nurtured our way back to the best health that we could, and, because we face many challenges as a family, we enjoy life when we can. Home has become our safe place and we only travel locally.

Our travels might have ended that day but we are alive and living a life. It might not be as we had hoped, but we are still on a journey, our own life journey.

Letting go of original hopes and dreams can be hard. It feels as though you are saying goodbye to the life you wanted. On our particular journey, I have learnt one important lesson... The little things really are the big things in life.

As I write this article, I am reminded of something else. Caring for loved ones doesn't define me. I don't know why some people look down on Carers. I had a medical appointment once and during the consultation, the doctor (whose children happened to go to the same high school as my eldest son), said "How does someone like you afford to send your son to our school?"

THE LITTLE THINGS REALLY ARE THE BIG THINGS IN LIFE..

I was absolutely floored by this comment. It implied that it is degrading to be a Carer. I had not only been a Carer, I had also worked for 40 years in paid employment, and I told her that. Fancy having to justify yourself to someone you don't even know!

Sadly, this wasn't the first time I have had to justify myself, and advocate for myself and my family, to fight for inclusion and to ensure that I am worthy to be here and live in our community.

SOMEONE LIKE YOU

Since that day, I have been sickened by that comment and there are times I have felt down and withdrawn because of it. But today, whilst compiling this, I am going to let go of this horrible feeling inside me. I won't forget the words she decided to use that day but I will not allow her to define me in a negative way. I am hard working, caring and compassionate. I am inclusive in every possible way and I stand tall and proud knowing exactly who I am and I hope that other Carers do too.

This is only part of my story...

Until next time,

Dianne xx





From
Angela Famiano

Adrenoleukodystrophy, to many people, is just another word with no significant meaning. I call it “The Beast” and for me, it holds a heinous association. It came into my life when I was 12 years old, uninvited, and still remains the most hated member of my family.

“The Beast” brought terror, sadness, anxiety, self-doubt and disconnection. But as the years went on, and after difficult and intensive work with my psychologist, I can now see it through a positive lens. It allowed me to develop a robust sense of humour, compassion for others, curiosity for the unknown, and a special sense of purpose in my life.

“The Beast” lived in my Papa until he sadly took his last breath at the age of 53. As I move closer to that age, I feel frightened, and also very sad and angry. There was so much of life my Papa was not able to see for himself. The saddest reality is that I am not able to share my life journey with him in person.

I know that my Papa walks alongside me, guiding me through life. Over the years, he has given me strong and significant signs that he remains as my guardian angel, particularly now with the uncanny connections with my supportive and loving partner, Phil. I just hope I have made my Papa proud of the person I have become today.

At the age of 17, five years after nursing my Papa, and after having a battery of medical tests, I was informed that I am a genetic carrier of Adrenoleukodystrophy. I had a 50% chance of passing the gene to any daughters I may have and a 50% chance of passing the evilness and hatred of “The Beast” to any sons. If my son won “The Beast Lottery”, I would watch the same malicious battle I saw with my Papa and his Nonno.

THERE IS A SILVER LINING IN THIS JOURNEY OF MINE..

If I became pregnant, my child would require genetic testing while in utero. If the result was positive and it was a son, how could I knowingly give life to this son, whom I would love wholeheartedly, while knowing the evilness “The Beast” can unleash on a human being?

There is a silver lining in this life journey of mine. During the era when my body could have carried and birthed children, I did not feel the desire to having my own children. Don’t get me wrong, I have loved and still love children, their innocence, honesty, curiosity and sense of fun. I often ask myself how much has “The Beast” factored into me not having children? I cannot honestly give a definite answer, but I suspect it was significant.

I’ve helped to rear children while their parents were unable to do so due to work or study. I was able to care and guide children, with the added bonus that I could go home every night to peace and quiet after handing back the children to their parents.

For some, not having children may feel like a disaster, but for me, I can focus on different priorities in my life. I did some travelling, experienced different cultures, foods and lifestyles. I have been able to undertake academic study and have the honourable role of caring for my aging mother.

Research in the area of a rare disease like Adrenoleukodystrophy is often not seen as a priority. The little research done so far indicates that women under the age of 40 have a 20% chance of showing signs and symptoms of this rare disease. This chance increases to 90% for women aged 60. This means as I continue to celebrate life's adventures, I also move closer to the probability of developing symptoms and/or signs.

The symptoms or signs to look for are still very unclear, as there are no prescribed symptoms or signs to look out for. All I have been told is that I require regular neurological examinations and tests for anything that may appear. Currently this feels like doing a jigsaw puzzle - just when I get an understanding of what the puzzle will look like, I find out another piece of the puzzle is missing and I cannot find it anywhere.

RESEARCH IN THE AREA OF A RARE DISEASE LIKE ADRENOLEUKODYSTROPHY IS OFTEN NOT SEEN AS A PRIORITY...

The advantages continue, as I now find myself in a loving and supportive relationship with an amazing man who never envisioned children in his life. Except if our "children" have 4 paws, fur and bark - now that is the perfect child for us both in our future together!

Sadly, I am already experiencing and battling symptoms and signs of "The Beast" as my ability to move around during regular activities and tasks has become difficult. This is despite my decision in 2021 to have bariatric surgery, and losing around 60 kgs. My balance is an issue; when I walk on most surfaces, I drag my left foot and feel like I am going to fall. I have given up hope of doing normal activities most take for granted, such as running, jumping and moving up and down stairs. What more do I have to experience as years go by? I cannot answer this, and finding out just seems out of my grasp.

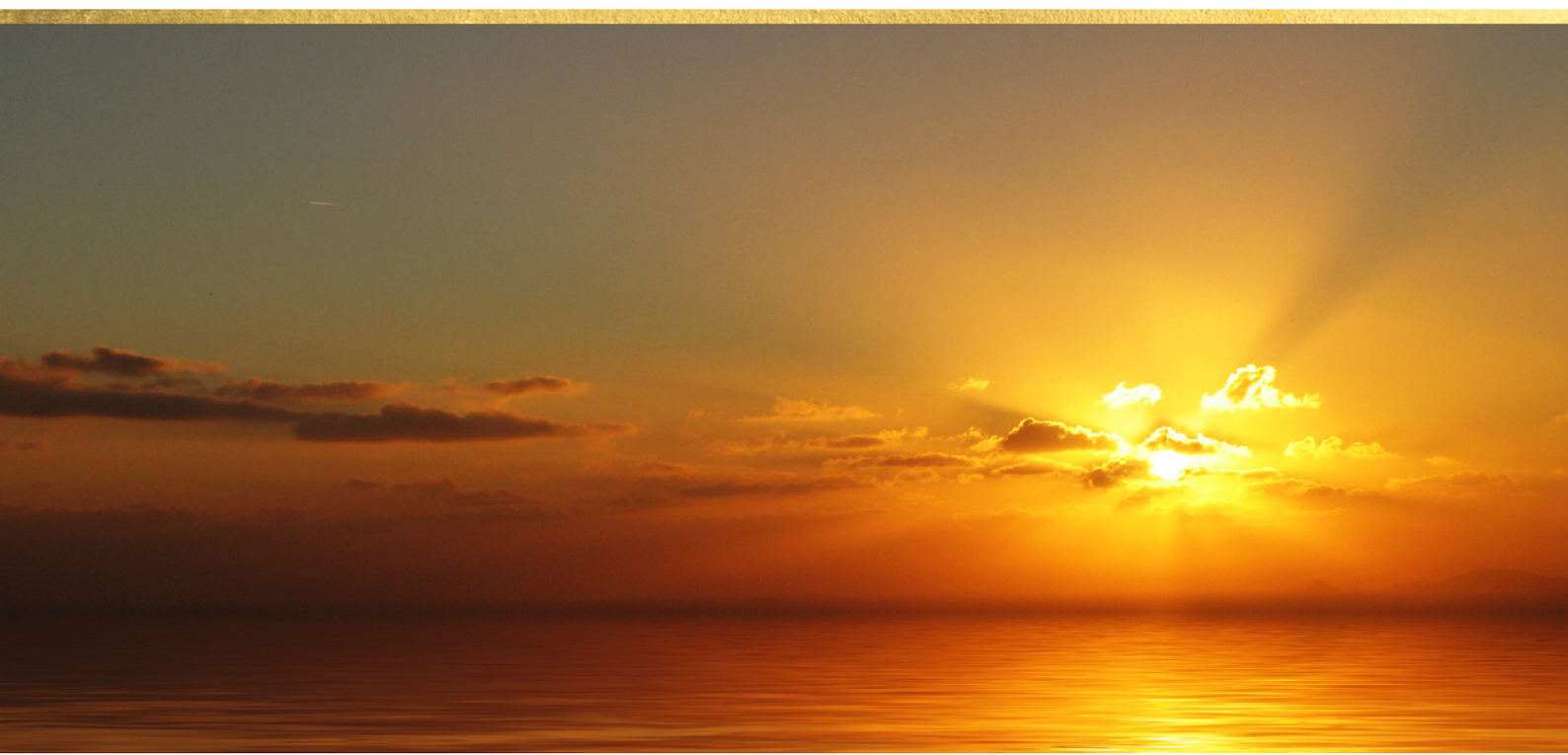
Whenever a new symptom or sign appears, my first thought, is this "The Beast"? Years ago when I was diagnosed with glaucoma, I felt an uneasiness until I was assured that glaucoma has no correlation with this disease. But I still cannot shake the feeling that "The Beast" is several steps ahead of me, and at times, it feels like it continues to mock and frighten me.

Has this life of mine been a bed of roses, and would I want it to be? Absolutely not. There have been many highs and there have been many lows.

Would I wish to change my narrative? No, because it's all the things I have experienced in my life that have made me the person I am today.

It's not about what has happened to me, this is my story.

Angela



BE Nourished



from Jackie Rowe

Bliss in a Bag *The Journey*



Sometimes in life, something wonderful evolves without any pushing and pulling, as the universe leads you to a place that you love. Bliss in a Bag is one of those stories.

To begin the journey, we go back to a tiny ancient village in the North East of England called Winlaton. Its original name was Wynlaktan which means "Twisted Oak" in Saxon, as the village began its life around AD 650. It was high on the hill, so it had great views of the river Tyne, which allowed the people of the village to see and prepare to defend against any raiding boats sailing into view.

Like many villages in England, Winlaton has plenty of stories rich in history and its people. The Witches Circle is one such place and tale. The Witches Circle is a ring of oak trees that stands just outside of the village. As a young girl I walked for miles, often down to the Derwent River and along the lines where railway tracks had once carried coal, and when I chose, into the Witches Circle which I was fascinated by. There was an amazing energy within the circle that I loved.

Fast-forward many years, after living and working in Paris and London, I'm now living in Perth Western Australia. After a number of major ups, downs and crisis, I found myself longing for the connection of village life again. Working as a Life Coach to support and empower women, I needed true belonging and couldn't find it.

I discovered circle work and I was drawn to its ritual, and the connections and power as women gathered together in a circle. I thought about the village and how there was a circle of women always there for each other. They would naturally gather together to support, to listen, to share wisdom, and to help find a solution. At the time I felt completely isolated and decided that if I felt like that, then maybe other women would be feeling that as well.



I studied, gained certification as a Circle Facilitator, researched as much as I could. Not just about circle, which is used across many cultures all around the world, but also the power and significance of circle in nature and in our universe.

As I created and designed a signature circle journey that carried an intention to empower women, I thought of the Witches Circle. To create the perfect space for this new element of work, I had an internal wall in my home knocked through to create a circle room. As soon as the sledgehammer broke through that wall it was like the house took a breath, there was a huge shift of amazing energy.

I leaned into new experiences, always learning, growing and exploring. One experience was Cacao Ceremonies. My daughter Beth came along, as we were both keen to try Cacao and experience a Ceremony. Unfortunately, it was not the experience we expected! The cold, brown, bitter and gritty liquid served in a plastic cup was a ceremony that was energy draining rather than uplifting.?

We wondered if this was what a true Cacao Ceremony was actually like?

Beth and I did lots of research on true Ceremonies, and the traditions and history behind Ceremonial Cacao. We learned that Cacao Ceremonies are centuries old rituals used for significant life events, such as births, marriages, coming of age, and even death. We found that this natural healthy product helps the body to heal, has the ability to reduce stress, and trigger the release of dopamine. We discovered some of the best Ceremonial Cacao in the world is grown in Peru, and that it is referred to as the "Food of the Gods".

Our aim was to create something special to form beautiful connections whilst respecting the amazing power of Cacao. Little did we know that this would set off a chain of events which would lead to the birth of Bliss in a Bag!



Beth loves cooking and experimenting with traditional recipes, spices and natural ingredients, so she led the research on the spices and Ceremonial Cacao, while I looked at traditional uses, rituals and ceremonies. We bought some Ceremonial Cacao and began experimenting in the kitchen - mixing, tasting, going through trial and error over weeks and weeks, until one day we both said, "Mmmm, that's good, that's it!"

I was excited to offer it to the ladies in circle that week, and Beth got everything ready. The intention of the circle was "Release and Renew" planned around a beautiful Cacao Ceremony and meditation. The Cacao was served, we spoke our intention and followed a simple ritual. We hoped the ladies would enjoy this new warm rich, nourishing, chocolatey Cacao drink with a hint of spice, served in beautiful china dishes.

The ladies sipped, smiled, sipped again, lots of "mmm"s and "aaah"s were being shared. Fingers were used to scoop around the bowl, and dishes were licked to get every last drop of this beautiful Cacao. Things were looking good, we settled down ready for the meditation I had written, with the room in soft light and everyone comfortable, the release and renew meditation journey began. As the meditation came to an end, we journaled and then we shared.

"It was like being in Bliss". "Wow, the images and colours were amazing". "I had such a profoundly peaceful journey with unexpected visions of people and places that made me feel special, loved and empowered". These were some of the amazing feedback we received. It was clear that the Cacao provided a deep blissful experience, as it opened the hearts and minds of all of the women in the circle.

From the Witches Circle in a tiny ancient village to an empowering Women in Circle in Perth, Western Australia, I felt the universe had a hand in leading me here to this moment.

We repeated the Cacao Ceremony again a few weeks later with another circle of women. We were delighted when we got the very same results.

One lovely lady asked if she could take some Cacao home to share with the women in her family. I gave her a small craft bag and Beth weighed out the Cacao and spice blend. I added a handwritten ritual and popped a sticker on the bag with the name Bliss in a Bag on it, as the word Bliss had come up many times as the women enjoyed their Cacao and came out of their meditation. I also gave her a link to a favourite meditation to try. She called me a day after holding her own Cacao Ceremony to say it had been amazing to set her space, enjoy the Cacao and have this beautiful connected experience with the other women in her family.

We developed the most beautiful collaboration with a small farming collective in Peru who grow high grade Ceremonial Cacao. As we are 100% committed to only buying high grade Ceremonial Cacao in a way that is ethical and sustainable.

We launched in November 2021 and enjoyed a fantastic night, sharing our journey and our plans with family and friends. Now we keep growing and sharing Bliss in a Bag, and watching beautiful connections develop with the unique product we created. We are really proud of what we have done.

One year on, after lots of hard work, late nights and product development, we have learned so much about having a product business, working together, and keeping each other going when things get tough.



We now have a thriving growing business with Bliss in a Bag being sourced by distributors and retreat providers. We have responded to the demand from retreat providers by creating our new fabulous Retreat Pack which serves ten people.

Bliss in a Bag was awarded Trademark status earlier this year. We have amazing plans for the future with some exciting collaborations coming up. Like all journeys it has had twists and turns, highs and lows, and we can't wait to see what the future brings.

Jackie

Soul Journey Retreat with Cacao Ceremony

If you would like to enjoy an incredible weekend away in beautiful York (WA), being supported through some lovely activities in the company of other soulful women, then this retreat is just for you.

Find more information on our Facebook page.

facebook.com/jacqueline.rowe.events

Soul Journey Retreat

Book Here:



[BOOK NOW](#)

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COMPETITION & PROMOTION

We are so excited to share our first Bliss in a Bag promotion Giveaway in collaboration with HoneyBee magazine.

Read the Bliss in a Bag story to find out more about us and our journey.

To enter this fabulous Giveaway and enjoy Bliss in a Bag for yourself follow the steps below:

- ☿ Follow us on Instagram @blissinabag_ and @chronicallyinspiredau
- ☿ Like our Honeybee / Bliss in a Bag promotion posts
- ☿ Tag two friends who you would love to have a cacao ceremony with
- ☿ Share the post

GOOD LUCK AND THANK YOU!

.....

The winner will have this beautiful gift box delivered to their door.

To find out more about this story and its products go to www.blissingbag.com.au

(Only eligible if living within Australia - Winner will be notified directly on their social media)



NEW YORK IS CALLING!

Calling Flight 22 on Tastebud Airline World Tour

Would you like to go overseas but don't want the hassle of travelling at the moment due to all the issues, like flight delays, cancellations, and lost baggage?

WE'VE GOT YOU COVERED!

Instead of visiting New York City in person just send your **TASTEBUDS!**



Here is a fabulous, **easy recipe** that everyone in your family will love. (It's cheaper too)!

NEW YORK STEAK

Calling the following passengers:

- 4 teaspoons crushed garlic
- A quarter cup French mustard (Try Coles Supermarket for this product)
- Two and a half tablespoon of Worcestershire sauce
- 1 kilo of rump steak (or your favourite cut)

Baggage: The quantities of the ingredients can vary according to your taste. If you love garlic just add a touch more.

Plane boarding now:

- Measure out all your ingredients and combine in a small bowl.
- Spread over your steak/s.
- Ensure you bring your meat out of your fridge at least 30 minutes before cooking.
- Drizzle both sides of your steak with a little oil and season with salt and pepper if desired.
- On a medium to high heat, sear your steak and turn every minute or so until cooked to your liking.
- Leave meat to rest under foil for five minutes to allow the juices to be reabsorbed and the meat to relax.

This is your Captain speaking:

This recipe can be prepared a day ahead. If you have extra meat you can use up any leftover marinade and freeze for your convenience.

You've arrived at your destination:

Serve with a side of salad and chips, or a nice vegetable stir fry. Works really well in a steak sandwich too!



Support Group

The Tastebuds Club

SOCIAL SUPPORT GROUP
BRINGING WESTERN AUSTRALIA TOGETHER

Come along and feel supported today

This initiative is a wonderful way to connect, make friends, socialise, receive and give support, all while enjoying a lovely meal together. Bring along your carer, family and friends.

Anyone with a rare disease, lung disease, heart failure, chronic condition, disability, or mental health condition is welcome at our table.

The Tastebuds Club is available in WA only and meets at a central location just outside the city, to make it as accessible as possible.

We meet on a Tuesday from 11.30 - 2.30 every second month.

For more details you need to become a member. You will be subscribed to both our quarterly magazine and e-newsletter, and receive invitations to our luncheons and other events. Individual support can be offered where needed in regards to information and education.

Website: chronicallyinspired.com.au/community

Email: chronicallyinspiredau@gmail.com

Telephone directly on M: 041 893 0291

Proudly supported through the Lung Foundation Australia
Facilitated by Melissa Dumitru - Consultant & Educator



Gather Together

Everyone is Welcome



**Lung
Foundation
Australia**

when you can't breathe... nothing else matters®



“Please don’t make me do this,” I pleaded with Kayla as she pulled up outside of the local community centre.

“When you decided to give your poor mother anxiety by staying in the city with a severe health condition, rather than going home and letting her care for you, I promised her I would make sure you were supported.”

“It’s not a severe health condition,” I scoffed. “And, besides, I have you to support me.”

She gave me a stern look. “It’s not the same. At a support group you can meet others going through something similar.”

“Well I really can’t think of anything worse than sitting with a group of sick people crying and feeling sorry for themselves.”

“Oh, don’t be so dramatic! It’s an hour or two, tops. Besides, I’ve heard support groups aren’t really like that. Give it a chance, you might actually have fun.”

Fun? Oh, I highly doubted that. This was two hours that could have been spent researching Connor Merrick. The force usually took months to plan these types of operations, but I didn’t have that luxury. I needed to be allocating every minute of my time towards this case.

As I entered the building, I was welcomed by a young woman with the type of smile and bubbly personality you’d expect from a kindergarten teacher.

“Hello, I’m the group facilitator, Lana. Kayla has told me all about you, and we’re so thrilled to have you joining us today.”

I forced a smile back at her and signed the register, snatching up a few chicken sandwiches on my way in. At least I was getting free lunch out of this.

Scoping out the meeting room, I was more than a little surprised. I’d expected a cold, desolate room with cheap plastic chairs placed in a circle. Instead, the room was warm and bright, with sunlight pouring in through the windows. Couches and trendy armchairs were placed about the room, still in a somewhat circular formation, but in a way that encouraged conversation organically. There was a handful of people already sitting and conversing, their enthusiastic chatter and laughter filling the room. One glanced up at me as I walked past, a girl who looked to be similar in age to me, whose hair was so bright you could have spotted it a mile away. It was dyed a vibrant pink and cropped jaggedly in an edgy way that contrasted starkly against the soft features of her face. She wore a black mini dress that flared at the hem and a pair of outrageous pink sequined ankle boots. Her right eyebrow rose as she caught me staring, and I shuffled into the armchair furthest away from everyone else in the room.

“Good morning, everyone!” Lana took a seat across the room, and the chatter gradually came to a halt. “We have a few new members attending today, which is very exciting! We’ll start as usual with a check in, and a chance for the newcomers to introduce themselves. Then, for those who would like to, we have an arts and crafts session to follow.”

I somehow refrained from rolling my eyes. Kayla would have been incredibly proud of me. As they proceeded with the check in, I zoned out somewhere between a teenage girl sharing the news of her positive scan results and a man talking about the side effects of the new drugs he was taking. Instead, I starting planning in my head how best to involve myself in the Merrick case. I’d considered watching his activity and gathering intel from a distance, but it would be impossible to get the information I needed. No, I’d need to be on the ground, which meant creating an entire identity for myself. I sighed internally. Creating identities took time, and time wasn’t on my side.

It was at that moment that I realised the room had gone silent. I looked up and all eyes were on me, expectantly. *Crap*. I cleared my throat nervously. “Sorry, what was that?”

Lana gave me a gentle smile. “Would you like to share your story?”

“Oh.” I looked around the room awkwardly. “I, ah, I don’t have a story.” The facilitator looked at me blankly and I shrugged. “I’m just here temporarily.”

“Aren’t we all?” The pink-haired girl drawled, causing a few light laughs amongst the group.

“No.” I sighed heavily, “I mean, I promised my friend I’d come along to a few sessions.” And I was majorly regretting that. “I’m not that sick,” I said with a shrug.

“I see,” Lana’s tone implied she wasn’t all that convinced. What the hell had Kayla *told* her? “Well perhaps you’d like to share your story anyway?” she encouraged, with another intoxicating smile. “You don’t have to, but you might find it helps.”

Did I want to? No. But pink-hair was looking at me with a challenge in her eyes, and damned if I could resist a challenge.

“Sure, okay.” I took a breath as I considered where to start. It wasn’t a story I’d really told before, and it still remained jumbled in my head.

“I guess I first noticed something was off when my fitness levels dropped?” That seemed like a good place to begin, and Lana was nodding encouragingly, so I decided to continue from there. “I’d always been in the top times for sprints, but somehow I’d moved to the bottom five in a matter of weeks.”

That had been a killer for an overachiever like me. I could remember the frustration I’d felt as I’d pushed myself harder, working my body day and night to try to rebuild fitness, but instead of getting faster, I’d found myself getting more breathless.

“My GP put it down to stress. She gave me self-care exercises and told me to take time off from training. So I did.”

I’d deferred for a month to focus on my mental health. I’d tried yoga, meditation, mindful colouring, float tanks; every bullshit self-care activity that I previously would have mocked.

“When that didn’t work, it was clear there was something more going on.”

Then came the tests. Bloods, X-rays, CT scans, ECGs. In and out of appointments when I should have been completing my training at the academy.

“Six months later, and here I am.”

“Thank you for sharing your story,” Lana said to me warmly with a soft smile. **“It is so important to feel connected to others who share your lived experience”.**

As I waited for Kayla at the front of the building, I heard the rhythmic click of heels approaching from behind. Turning, I saw it was the pink-haired girl, half-eaten sandwich in hand. Apparently she also wasn’t keen on arts and crafts.

“I hate to break it to you, but you’re a rubbish story-teller,” she said with a sly grin.

“Didn’t know I was being assessed.” I looked her up and down. **“What’s your story, then?”**

“You mean you weren’t listening?” She put a hand over her heart with feigned offence.

“Sorry,” I shook my head. “I zoned out during check in.”

“At least you’re honest.” She smirked. “I’m Zoe, stage 2 lung cancer.”

Oh. Lung cancer was serious. My mouth opened slightly as I tried to find the right words to say, and before I knew it, I realised I’d just given her the same expression people gave me when they saw my oxygen tank.

Zoe’s smile instantly turned sour. “How do you feel when people look at you like that?”

I cringed. “Point taken.” My eyes found her feet and the pink sequined ankle boots that covered them. “They have to be the ugliest shoes I’ve ever seen.”

She let out a loud laugh. “Well now I feel sorry for you. Not only are you sick, but you also have terrible taste.”

“I’m not sick,” I corrected her.

“Of course, not.” She winked and moved towards the car park. “See you next week.”

“I doubt I’ll be back.” I had better ways to spend my time than listening to other people’s depressing stories each week. Although it hadn’t been quite as depressing as I originally thought...

“Well it’s paid for by semester, not by session, so whoever booked you in paid for the full 8 weeks.”

Eight weeks?! I was going to kill Kayla.

this is me[♥]



by Marie Williams

Attention - Possible Triggers

My story has for the most part, gone unnoticed and kept in the dark, because only a small minority throughout the world experiences it. Therefore, it is not perceived to be noteworthy for most people.

This story is one of the struggles endured by families who have a loved one with an intellectual disability. We live in a world that remains in the shadows where most people will never know of the heart ache and the challenges that this community faces every day.

My daughter was born with Down syndrome, and from that moment, my life changed - all due to public perception about the syndrome.

Where do we go from here as a human race? What disability will be targeted next? The aged? People who rely upon heavily subsidised medication to keep them alive? People with low IQs? Those who don't have blue eyes? People who don't fit in with society or are no longer productive?

Is there going to be a standard set for a minimum viable person? Where will it end?

Families of loved ones have been fighting; trying to change the way the world sees intellectual disability. We want our loved ones to experience the joy of life, rather than despair, loneliness, sadness, and the poverty that usually accompanies intellectual disability.

However, that will not happen unless those **without** intellectual disability take up the challenge and **include** our loved ones in their world.

We as parents are so tired, so exhausted, by all the questions and inappropriate comments such as:

- *Did you know she had Down syndrome before she was born?*
- *Would you have terminated if you did?*
- *You want homework?*
- *They are placid children...*
- *They are funny!*
- *Don't expect her to amount to anything, she won't achieve anything...*
- *We can't cater for academic learning outcomes because she won't meet any...*
- *You're not accepting her disability!*
- *She got lucky...*
- *She didn't know what she was doing...*
- *Your expectations are too high!*
- *God gives you only what you can bear...*
- *You're special; God wanted you to have this child...*
- *She doesn't need to vote due to her disability!*
- *She can catch public transport by herself?*
- *Isn't it marvelous she has a job?*
- *Do you need the number for counseling services?*
- *You have expectations of her?*

"People seem to think they can ask questions or make inappropriate comments about anything to someone with a disability, why?"

The list is endless. If this were your child, would you appreciate any of these comments/questions? How would you feel hearing them not just once, but on many different occasions? It is unpleasant, it doesn't make it any easier – it makes you feel worse. These invasive and personal questions and comments come from complete strangers, family, and friends who think they are helping. But they are not, their comments and questions are condescending. Until society's perception changes, many other families will have to endure such inappropriate remarks.

There really is only

One question that we want to hear

One question that will be appreciated

One question that will give us hope

One question that will change our world

One question that will make a difference

It is a basic question that has only been said to me once and just recently. If the education department, politicians, city councils, community, businesses, medical professions asked this question, it would have made my journey less difficult, traumatic and sad.

And that question is:

WHAT CAN I DO TO HELP?"

So, if you don't want to ask this question, please don't say anything at all because we simply don't want to hear it.

My story is the fight of human rights for those with intellectual disabilities, to empower them and their families for the courage to demand the same treatment from government, education, employers, organisations, and to have the same opportunities, and healthcare enjoyed by society's majority. And for politicians to put aside their differences so our loved one with intellectual disability can live a life that most of us take for granted.

No one can predict when their life will change; it is like a role of the dice or a toss of a coin. You may not have a loved one with a disability at the moment, but one day it may be your daughter, son, niece, nephew, aunt, uncle, sister, or brother.

We are all authors of our own destiny; our future is not predetermined. We have the power to change the future, to make the world a better place, if we want to.

I came across a quote:

"One moment can change a day, one day can change a life, and one life can change the world."

"One moment can change a day, one day can change a life, and one life can change the world."

Author Unknown

Hopefully my story will encourage people and organisations around the world to start asking the one question which will change public perception about intellectual disability. And that question is, ***"What can I do to help?"***

Marie X



**THE
PLATFORM
WA**



Purposeful Storytelling

I have always felt like there was a sticky note on my forehead saying, “Tell me your story”, because I was a non-judgemental, active listener and felt like people used me as a personal service for them to offload their deepest, innermost thoughts.

Initially, I responded by open-heartedly sharing my story. I had survived a series of tragedies and complex trauma spanning four decades, and I wanted everyone to know I was a survivor, who was still a victim, but oh-so wanting to inspire others. But eventually I realised that our stories are powerful and private, and cannot be taken back once made public, so we need to be very careful about how we share them.

In 2018, I was inspired to write my memoir, “**Fat Girls Can Dance.**” I sat down and put down onto paper all the gory details: the good, the bad and the downright ugly. It was cathartic to see all of me there on the page, it meant that it mattered. I quickly shared it with a workmate I respected. It was as if I was receiving the return email that I realised how much she now knew about me. I felt exposed and fearful. Fortunately, she gave amazing feedback and support. But in that moment, I recognised the risk and it made me pause.

My story had many twists and turns and wisdom which I longed to share with others. I needed someone to say, “Hey, you are amazing for surviving all that!” But when I recognised that my need to share was greater than the need of others to hear it, I realised I could choose to keep it to myself, and my children, for now. Writing it down was enough for me.

“Hey, you are amazing for surviving all that!”

Storytelling can come from one of two spaces:

1. **A place of brokenness**
2. **A place of healing.**



When coming from a place of brokenness it shows as unresolved grief expressed as self-justification, anger, blame and shame - which are very exposing emotions. If shared with someone who can help us process them, it can be very powerful. Shared publicly, however, it can cause untold grief.

But when stories come from a place of healing, they hold a mountain of power and can have a profound positive impact, but we must be purposeful to achieve this. Using shocking detail has its place, but weaving a magical tale full of wisdom that leaves the audience breathless, is regal in its simplicity.

The purpose of sharing my story-telling experience is to save some of you from the judgement and pain that I felt from oversharing information because I was not yet healed.

Some poignant examples of where my sharing has bitten me:

✧ Telling my girlfriends intimate details of my relationship with my partner to get support or validate my feelings. This led to judgements, a mortal wounding of his heart, broken trust and a stressed relationship. Although well-intentioned, it did not consider potential repercussions, as the judgements extended to my whole family. I have learned that it is disrespectful to share information about another’s private life without permission.

✧ Telling the intimate details of our family struggle with the media. On two occasions, with the best of intentions, I shared some of our stories, but it was misrepresented by the press and left family members vulnerable.

✧ Telling clients' stories to help build empathy through shared experiences but ultimately undermines relationships.

✧ Providing written information about my story, which was read out while I was standing on stage receiving the Consumer Impact Inspiration Award at the ceremony. The information was never intended to be publicly shared and included intimate details of our family tragedies. I was mortified and it spoiled the experience for me.

✧ Sharing too much personal information with work colleagues, which ultimately undermined my professional relationship.

I have also been very successful in sharing stories. Golden Pen Magazine was a vivid collection of shared wisdom gleaned from people's life experiences and it was a pure joy to hunt for the gold. But even in that space, there was the danger of sharing something that could have had a negative effect on people. It is an enormous responsibility.

As a Lived Experience worker in a designated lived experience role, I get paid to share my story, but I am very selective about what I share. I have learned that people may tell you things about themselves, then regret the level of sharing, so it is vitally important to hold people's stories very carefully.

Like the characters in a never-ending Hollywood drama, people's stories have indelibly marked my life. I have always found people's stories fascinating but struggled to remain emotionally aloof. I just cannot understand how you cannot cry when you are holding a person's grief in your hands, when it is now sitting outside their chest and so palpable. The problem is that words, and stories in particular, are incredibly powerful, especially when we are in a state requiring recovery.

When we recover, those stories will remain out there, circling us so we must be careful how we share other's stories, as they don't belong to us.

I was recently participating in The MHS Autumn Conference on Psychosocial Disability. An advocate with lived experience of Psychosocial Disability shared a story as her participation on the panel. Her story was simple. She explained how her life was now comfortable since receiving NDIS assistance, she had a good home, was living independently, able to have choice and control over her life. Then she described her friend who had a similar disability and his experience of NDIS whilst living in a group home where he had little choice or control over his environment and lifestyle. The contrast was so powerful you immediately understood the issues. **This is the power of purposeful story sharing** that transforms theoretical conversations into real-time understanding.

Writing my story was one of the most liberating things I have done. I may never share that written version of the good, the bad and the downright ugly, and that is perfectly okay. It was cathartic and I got to externalise the pain and the successes. I encourage you to consider how you share your story and to recognise that it matters, it has value. It can be shared to help others to heal and to feel inspired, as mine has done on many occasions. But always be aware that once it is out there, you can never get it back. What you share is a reflection of who you are and how you share is a reflection of how you care for those who will hear it.

Hayley 

"We are the threads of our past, collected and woven and then rewoven together over time, as we gain understanding."

We start with disconnected pieces that lack meaning and we end up with a wonderful tapestry that tells our story."

Hayley Solich

COMMUNITY



In our Winter edition of Honeybee's **Community** we wanted to share with you what the incredible team at ConnectGroups WA have been up to.

This amazing team who make up the Peak Body for Self Help & Support Groups in WA, are always looking for ways to be innovative.

This is such a great idea to support another worthy cause and with our country literally drowning in clothing that has been thrown away, this is much more fun!

I think this idea could catch on, what do you think? **Editor**

ConnectGroups promotes the philosophy and practice of peer support throughout Western Australia.

Fostering empowerment among Peer Support Groups allows people dealing with stressful life problems and situations to share their experiences and to offer emotional and practical support to one another.

ConnectGroups aims to help people help each other by providing Peer Support Groups with:

- Links to community networks and information.
- Assistance with group development and management.
- Support with community resources and services.
- Individual and group skills training.



Plastic Free July is a global movement which originated in Fremantle to encourage people to reduce consumption of single use plastics and reduce plastic pollution at a household level. ConnectGroups has participated in Plastic Free July for the last 2 years and has been able to make positive changes such as reducing the use of disposable coffee cups and sharing a meal which has been prepared with minimal use of plastic packaging.

ConnectGroups participated in Plastic Free July this year by organising a Clothing Swap. Each staff member bought in unwanted clothing or household items to donate to others in the team. This was inspired by a documentary watched by the team, **War On Waste**, which was published by the ABC about the impact of fast fashion. The documentary looks at the issue of fast fashion and its contribution to plastic pollution. As many clothes are made of synthetic materials derived from plastic, and purchased at large volumes by consumers, clothing is making a large contribution to plastic pollution in Australia. Planet Ark has declared the average Australian purchases 27kgs of textiles per year and disposes of 23kg of clothing to landfill.

The ConnectGroups team has been able exchange unwanted clothing and household items with each other and family members through the Clothing Swap which has saved money and diverted clothing from landfill.

To find out more about Plastic Free July go to www.plasticfreejuly.org
To find a support group near you in WA go to www.connectgroups.org.au



NEXT TIME



SPRING EDITION NOVEMBER 2022

TOP
TOPIC

"YOU DON'T
HAVE TO BE
PERFECT TO BE
BEAUTIFUL".

THE
PERFECTION
AND BEAUTY
MYTH BUSTED!

The Honeybee Team welcomes
two new contributors..

ERIN BOUSTANI

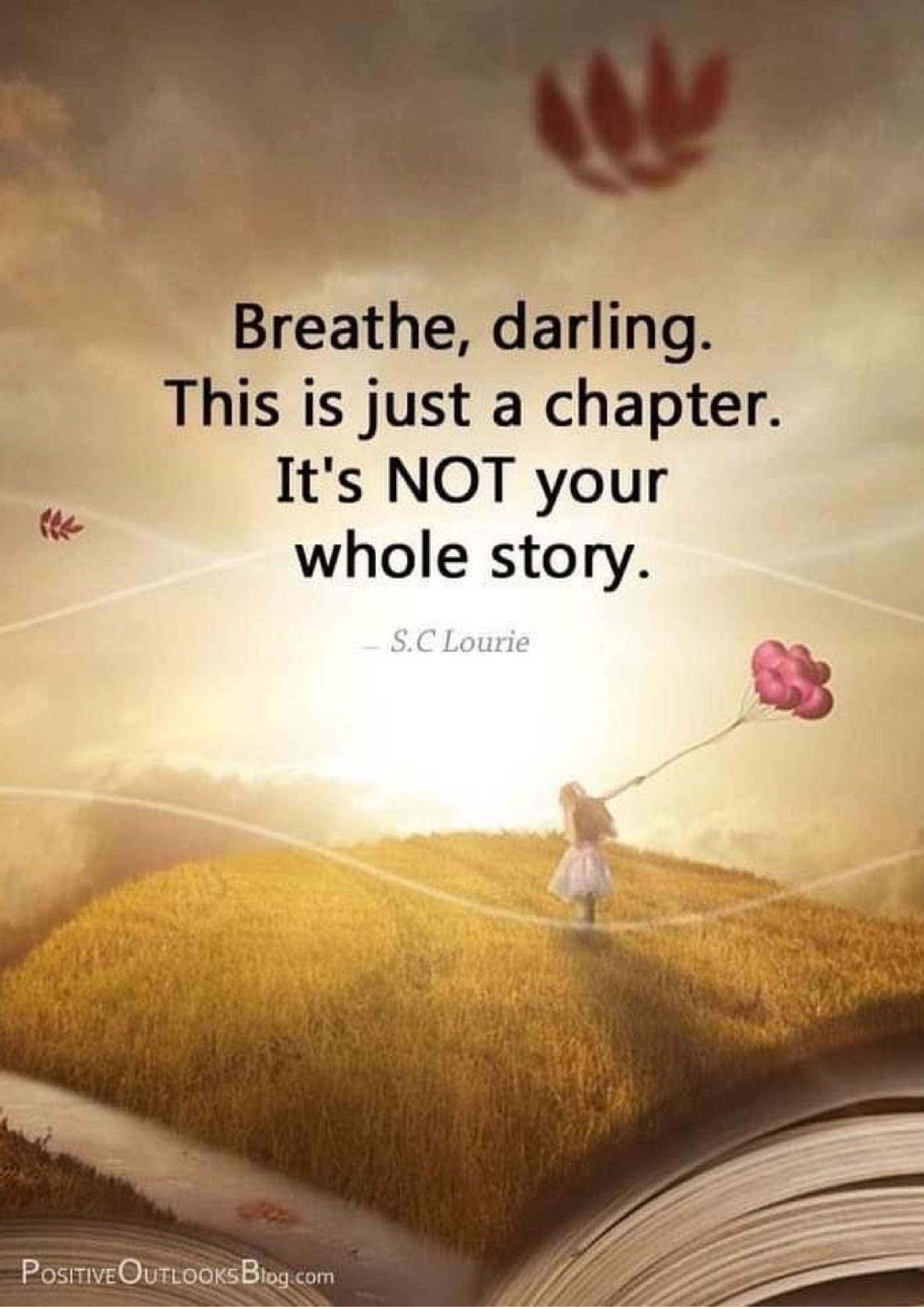
Pulmonary Arterial Hypertension

BEN GARDNER

Anti-Beauty No B.S!

COMING TO HONEYBEE

ISSUE 7 - WINTER

A woman in a white dress stands in a golden field, holding a large pink balloon. The scene is set against a sunset sky with a large, glowing sun. The image has a soft, ethereal quality with some faint, stylized floral motifs in the background.

**Breathe, darling.
This is just a chapter.
It's NOT your
whole story.**

– S.C. Lourie

Broken Heart Syndrome

By: Fay Bahemia | HealthScienceWriter

Several years ago, my friend Merry experienced a series of highly traumatic events in just one week. Her stress was so intense, that she suffered a heart attack. Merry, a 52-year-old mother of two, wife, and businesswoman, was winding up her retail business when her nephew took a drug overdose, her best friend was admitted to hospital with a brain tumor, and her elderly mother entered hospice after many months of end-stage Alzheimer's disease.

"I was under extreme stress, and then my husband and I got into a heated argument. That was when I experienced chest pain," Merry said. At first, Merry thought she was having asthma or a panic attack, but when her inhaler failed to ease the pain, her husband took her to the hospital. After initial examinations and blood tests, Merry was sent to another hospital for an angiogram, the medical imaging procedure that displays the heart and coronary arteries under x-ray. Merry recalls the cardiologist's words. "I have good news and bad news – there are no blockages, but you have had a heart attack."



Sometimes, a sudden surge of adrenaline produced during extreme stress or emotion can temporarily overwhelm and "stun" heart muscle. When this happens, the main pumping chamber (left ventricle) becomes weak and misshapen. As with a heart attack caused by blocked coronary arteries, the heart cannot pump blood properly.

Also known as "Broken Heart Syndrome", the condition is called Takotsubo cardiomyopathy, because the misshapen heart resembles the takotsubo pot used by Japanese fishermen to trap octopi.

Merry experienced typical heart attack symptoms (shortness of breath, chest pain) and received precautionary medication while doctors continued their investigations. Takotsubo occurs almost exclusively in post-menopausal women. Despite being potentially lethal, the heart muscle does not die or carry permanent damage and there are no long-term effects. People usually fully recover and never experience it again.

Since her heart attack in 2012, Merry takes better care of herself. She has a less stressful job and practises yoga and meditation.

”
My biggest advice to women is to realize that we cannot and should not do everything. We need to slow down, learn to relax, and ask for help. Do not feel guilty about that. Treat yourself. You only live once, don't let anxiety take over.

”
If this topic interests you, read more here:
[Takotsubo cardiomyopathy: The octopus trap](#)
[True stories about couples dying together from a broken heart](#)
[Managing stress – protect your heart](#)
[Managing stress at work](#)

Fay

The Art Between the Words

Kez Wickham St George



It has often been a conundrum to me why some writers cannot feel the pulse of a poem or feel the passion when they read a book. It has puzzled me for many years, why folks just do not get that we began a sort of communication with cuneiform hundreds of years ago, and look at us now!

Of course, there are many debates and opinions about the beginnings of humankind and his communication, so when I began to read then write as a child, I found myself dedicated to finding out the way humans have communicated over the years.

I am an author of many novels and a creative artist in different genres and have studied many modalities on these two skills. The English language, for example, with its many meanings with using just one word, or why we have silent letters in the English language, totally fascinates me.

As an ESOL tutor (English to Speakers of Other Languages) to many young impressionable Asian teenagers, I saw that they, too, found it difficult to wrap their minds, let alone tongues, around the English language. So, to assist their understanding, I brought art into the class. There was an immediate breakthrough in our communication. I then introduced mosaics which they enjoyed.



Yet the lesson was to be mine, as these young ones taught me origami and paper cutting. We became united in teaching each other our countries' different crafts, including cooking.

From young faces that once expressed boredom, we now had thirty or more students all willing to add their villages' specialty of craft. The difficult part for me was the word Artisan or Artist? These young people certainly showed their many skills.

In later years, I began tutoring the art of tourism to my clients who were all artists in one way or another, as the curriculum called for entrepreneurship. We reversed the learning, now the art or subject of art was written to express and advertise what they were offering to the public and how to reach them or visit a studio to make sales.

As I go deeper into Art Therapy and Creative Arts, I find myself agreeing with the professionals that Art can heal, there is an Art between our Words.

May you always have enough, Kez Wickham St George

New release Of Poetry by Mmhpress
Photo of Kez Wickham St George

Chronically Booked

BOOK CLUB & REVIEWS

From Author Kez Wickham St George



Angelical Wisdoms

Author Julia Van Der Sluys

eBook \$6.95

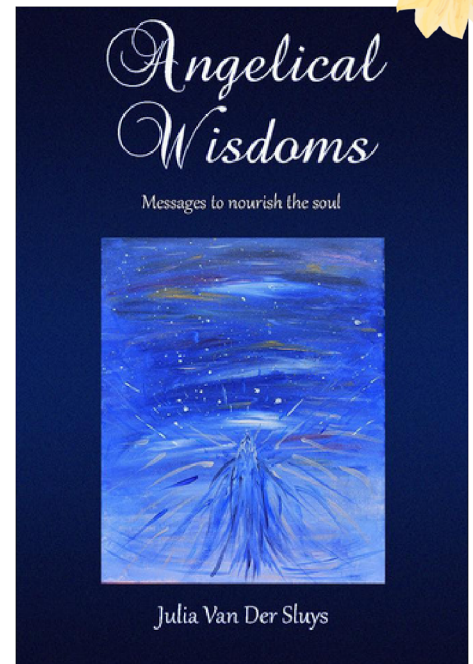
Published by White light publishing Perth WA

Review By Kez Book Reviews

We don't always allow ourselves to feel love and light every day. That is when the Author's insights for every day plays an important part in your life.

Julia Van Der Sluys has clarity about life and makes it is a joy to open our eyes to the new day.

Angelica Wisdom was created to lift and give joy to the readers. Open any page to read and receive a blessing, let the wisdom flow over you as you turn each page.



"In the end, we'll all become stories." Margaret Atwood

Mad Hatter MD

Author Dr Anita Campbell

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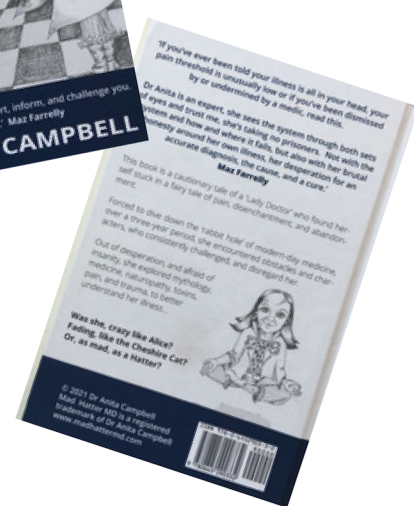
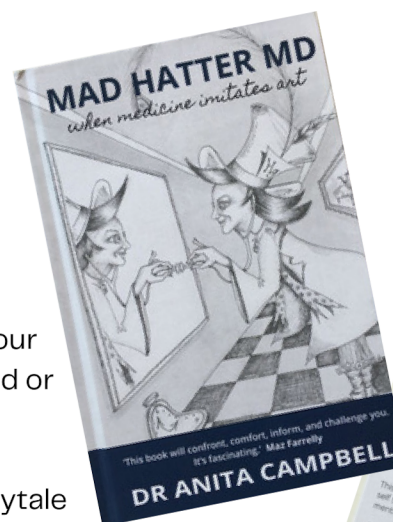
Published by Rondel Publishing Perth WA

Review by Kez Wickham St George

Have you ever been told your illness is all in your head, or your pain threshold is unusually low? If you have been dismissed or undermined by a medic then this may be the story to read.

This story is about a lady Doctor who found herself in a fairytale of pain, disenchantment and abandonment. Forced to dive down the **Rabbit Hole** of modern-day medicine, feeling dismissed by her own peers, Dr Anita challenges modern-day medicine by exploring every option available to her.

I found this book a gripping story of bravery in removing the divide between evidenced based medication and integrative medicine.



WRITERS

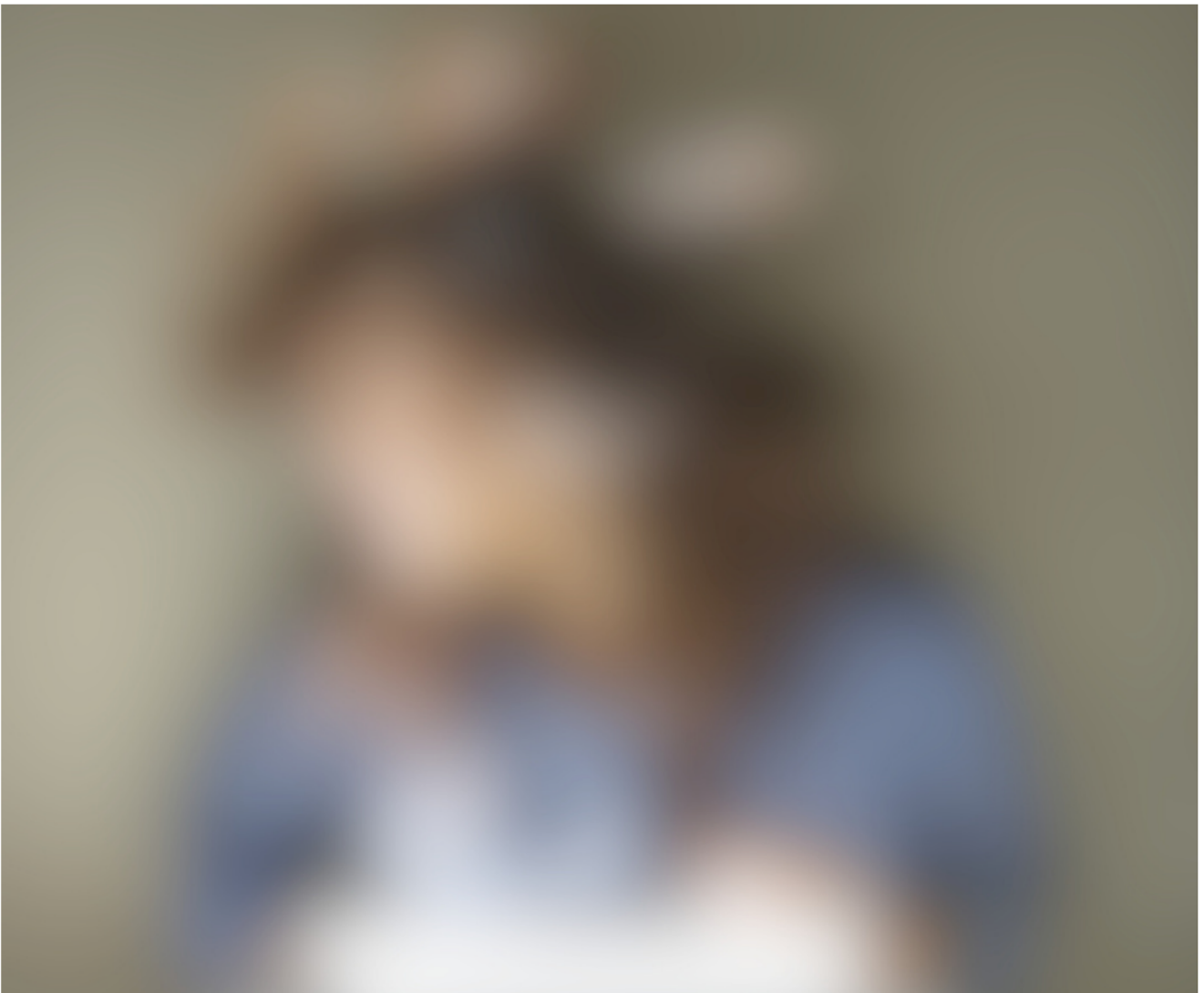
We Want to Hear From You!

Honeybee Lifestyle Magazine exists to reinforce the purity of one message:

The Lived Experience and Patient Expert!

We want to hear your voice and publish your words and story.

Join our vibrant and growing team.



Head to chronicallyinspired.com.au

We are looking for experienced or aspiring writers to add to our amazing team from multiple backgrounds. If you are someone living with a chronic illness, intellectual or physical disability or mental health condition, your story may be exactly what we like to feature and share with our readers.

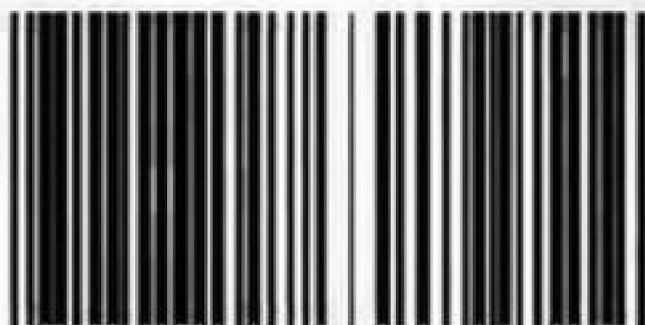
If you are an organisation or business that works in any of these industries supporting others, then we would like to feature and showcase your services and/or products with our growing community. To be considered log onto our website and on the toolbar go to 'Info & About - Contact' and send us an email.

We can't wait to meet you and collaborate together!

#HoneybeeLifestyleMagazine

Coming to Honeybee Anti Beauty - No BS!

CONSUMPTION



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IDENTITY

With Ben Gardner

KONECT

WITH THE WELLNESS SOCIETY

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- Adopt a healthy mindset towards relationships
- Understand the signs of abuse and how to deal with it

Head to our *Free Tools Library* to download a copy today.

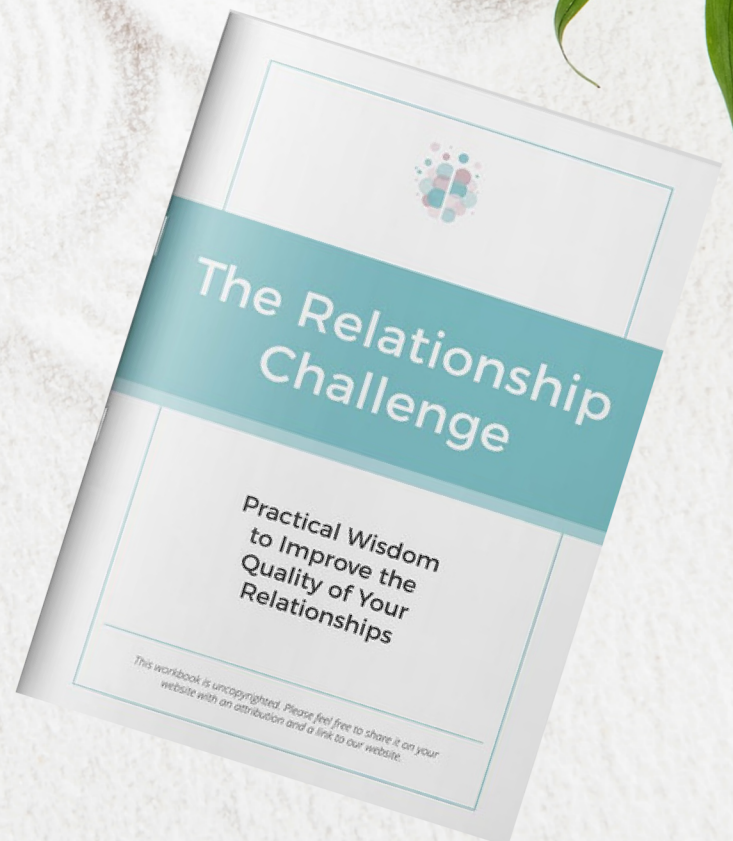
We hope you find it helpful.

Proudly shared with permission from Rebecca and the team at the Wellness Society

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be anything,
be kind.*



Gabrielle Worthington

Gill McGimpsey-Evans

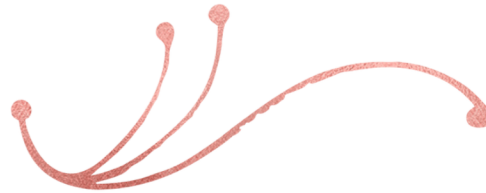


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Chronically Inspired - Life.Beyond.Disability, and Honeybee Lifestyle Magazine are proudly supported through the generosity of our beloved member and friend Gill, who passed away in 2021 from Pulmonary Arterial Hypertension.



DEPENDABLE
LAUNDRY SOLUTIONS



TESTIMONIAL from our sponsor..

As a Sponsor of Chronically Inspired - Life.Beyond.Disability we are very proud to support Founder Melissa Dumitru in her endeavours to provide an excellent resource for people living with chronic illness, disability, & mental health conditions. The HoneyBee Lifestyle Magazine would have to be one of the most helpful, informative magazines that absolutely inspires those with health challenges to live their best life. Melissa speaks and informs from a lived experience... a very powerful insight into individuals suffering chronic diseases... a fantastic read for sufferers and their Partners, Friends, Supporters alike. One day, this fabulous magazine will be in all sorts of Medical Practitioners offices as a little Life Saver for those afflicted in so many ways.

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Last words

from the Divine Ms. M



Integrity costs nothing.
Use it wisely.

Janelle Bostock WN Australia

The final story for this edition...

After I was diagnosed with PTSD in 2020, I was so traumatised that I made myself very small. At times I wanted to disappear altogether. I fought that darkness, sometimes daily, before clawing my way out of the abyss I was living in. I know a lot of you understand these feelings too. It is comforting knowing that I am not alone, and neither are you.

It took me a good two years before I could stop myself from constantly thinking about, and talking about my trauma. It became my only story for a long time. The disbelief, the disgust, and the impact it had on me, my husband and my family; I was in what is referred to as a **"trauma loop"**. Some people are in this loop for many, many years before something happens and allows them to stop and pause long enough to change direction, start to deal, and heal! Because that, my darlings, is the moral of most stories.

Give yourself
permission to
live a big life.
Step into who you
are meant to be.
Stop playing small.
You're meant for
greater things.

The stories we have shared with you in this edition are a mix of raw emotion, anger, realism, hope and rebirth. This is the lived experience that is, for many of us, our reality. The beautiful thing about most stories though, is that we often have the power to write our own endings, change the plot, and move in a new direction. I think that no matter how dark it becomes, if you try not to lose hope then you have everything you need. I've heard giving birth is painful. Well, rebirth is a pain all of its own, shared by so many of us today. It is important to be able to share our stories with each other and be given the opportunity to be heard, grow and heal.

Our world is currently a very uncertain place, now more than ever we need to be able to connect to others and feel the anchor of safety that comes with a community who truly cares. Let's try not to make ourselves small in order to cope or survive. I will leave you with the words of the above quote and hope they resonate with you as they have with me. Don't live small my friends, and never give up hope!

Until next time my lovelies



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The personal Bios for each writer can be found on page 4 and on our website under Magazine.

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ON THE COVER



Kez Wickham St George is an award-winning author who champions people from diverse backgrounds to reveal the best of their creative side. As a leader in her profession, a public speaker, an accomplished author in magazines, Kez leverages her extensive travels, experience, and expansive authorship to encourage readers to think outside the box. It is not surprising that Kez is known globally as 'The Writers Consultant'. Kez has written work for two royal families, one in the UK, the other in Sweden. She has co-compiled an anthology on the lives of various women internationally. Recently Kez published a trilogy of poetry books and her dream of the big screen was realized when a movie was made from the prologue of her last novel *Scribe* in the trilogy *Campfires*. Kez is passionate about promoting high-quality growth opportunities for all. **Her favourite quote is: "May you always have enough".**