

LIFE AS A STORY

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eBook



QuadruplegicWriter.

By Mark Miljons-Rostoks

A VOICE FOR THOSE WHO ARE SUFFERING

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“Health challenges and disabilities seem to be the ultimate levellers in life. No matter how rich you are, how beautiful, how talented, you are still stripped back to basic human needs and survival. But most importantly, this is where you find out what you’re really made of.”

Documenting Life

OUR MISSION

A VOICE FOR THOSE WHO ARE SUFFERING

Copywriter, Author, Adversity Advocate, Advice Columnist. Studies Life Coaching, Marketing and Creative Writing. Loves a Good Rant... and Sneakers

For several years I've searched the internet for role models and stories of disability, or to put this in my terms, I've been searching for someone who gives voice to those who are suffering. Over the years, I've found a few people of interest, most being amputees or cancer patients (and most being in pre-existing relationships), yet none of these people shared their struggles as openly and authentically as I would have liked. There was always censorship involved. Maybe they had something to lose or a lot more than I do?

This frustrated me; all I wanted was somebody I could relate to —a transparent role model to help ease the pain. Only I was surprised how hidden the world of extreme disability was. I never found my role model nor the "voice for those who are suffering."

To bring light to situations similar to my own, for years now, I've written publicly about my struggles. I've even dreamt of making a documentary about my life.

I'm trying to provide the voice that I never had. A voice to offer comfort and a knowing that you're not alone.

Providing this voice, honestly, I've started to believe that a large portion of my life purpose revolves around this. And as you'll see, a lot of my decision-making and life choices revolve around this as well. I'm committed to my mission.



Our Core



OUR DELIVERY

TO HELP PEOPLE OVERCOME ADVERSITY AND FIND FREEDOM
THROUGH WRITING

The Quadriplegic Writer

There's something special about writing, it's like this textual voice has a life all of its own. It can be funny or informative, direct or obscure, but what I find especially cool is that words have this rather strange in-built longevity to them. And nah, this isn't about re-reading a social media post a few days later, this is more like publish a book and one day your great, great granddaughter might be reading it.

Writing has a truly unique and diverse spectrum of benefits. For example, one way I use writing is as a healing tool. Then, another is to straight-up document my journey, then another is to let people know how I'm feeling; or it may even be as a creative outlet, or as a tool to communicate with others. No wonder I often find myself saying that writing is life.

What does amaze me about this special writer's voice thing though, I believe that many, many people are underutilising this simple gift. Too many people are focused on consumption, maybe even on crafting fleeting fast-fashion type content, not a hearty meal. And honestly, this is what a short time writing every now and then practice can create – additional substance and fulfilment. That second voice.

Which, this is where The Quadriplegic Writer comes into it, we want you to find and harness your unique writer's voice. Be direct, obscure or outright hilarious. We all have something important to say. Yep, tell your story with pride and passion; words have power.

So, whether it be through our online courses (coming soon), or interacting within our online support group (coming soon), or learning as you watch my personal writing journey unfold on social media; what we hope is that you learn some tools and experiment with them bravely. It's not even important for you to share your rambles publicly, instead, what is important is that you find your own unique style and prose. This is what will give you the greatest satisfaction, plus I'm certain that this is what your great, great granddaughter will want to hear.

Your essence captured on the page, it truly is possible.

So, storytelling secrets, journaling, persuasive writing, even exploring the art of copywriting; we aim to please. But more importantly, we aim to be useful. For this gift that gives us so much pleasure and meaning, in sharing this and the relevant skill-sets, to help grow your second voice, this is where amazing-ness and smileyface-ness reside. Write on, right on.

Our Projects

OUR DELIVERY



Adversity Answered

Over these twenty years of chaos and disability (which undoubtedly would've been way less mentally and emotionally taxing if I found suitable mentorship), what I ended up doing was gathering snippets of support from countless different places.

I'd read something, meet someone, undertake these crazy educational adventures; all to find that little bit of peace and self-worth. For me, overcoming adversity has been like putting together one big jigsaw puzzle.

This is what I don't want for you. Instead, what I want and what I'm doing through the Adversity Answered platform, I'm creating a one-stop-shop for all your adversity needs. I want to provide the resources that I never had. And, the tools at the core of this platform, these will centre around online courses that cover key adversity topics.

You see, it's funny how life turns out. As a rather bizarre twist of fate, I've become the person and mentor that I was always looking for. I am the rock. I am the adversity encyclopaedia. And as such, the way I'm approaching this, I want to give that scared naive twenty three year old boy (that I once was) everything that he needed.

A crash course in becoming bullet proof, well so to speak. And who will become the biggest beneficiary of this... it's you!

Finding purpose beyond your pain.



Halfway Decent Advice

Having such a unique perspective on the world, what I'm doing through this advice column, I'm endeavouring to apply this perspective to some of your everyday problems and not so common conundrums. Honestly, with my rather chaotic life experience thus far (which through it, I have learnt a lot), and I really want to be to pass this knowledge forth and to help people.

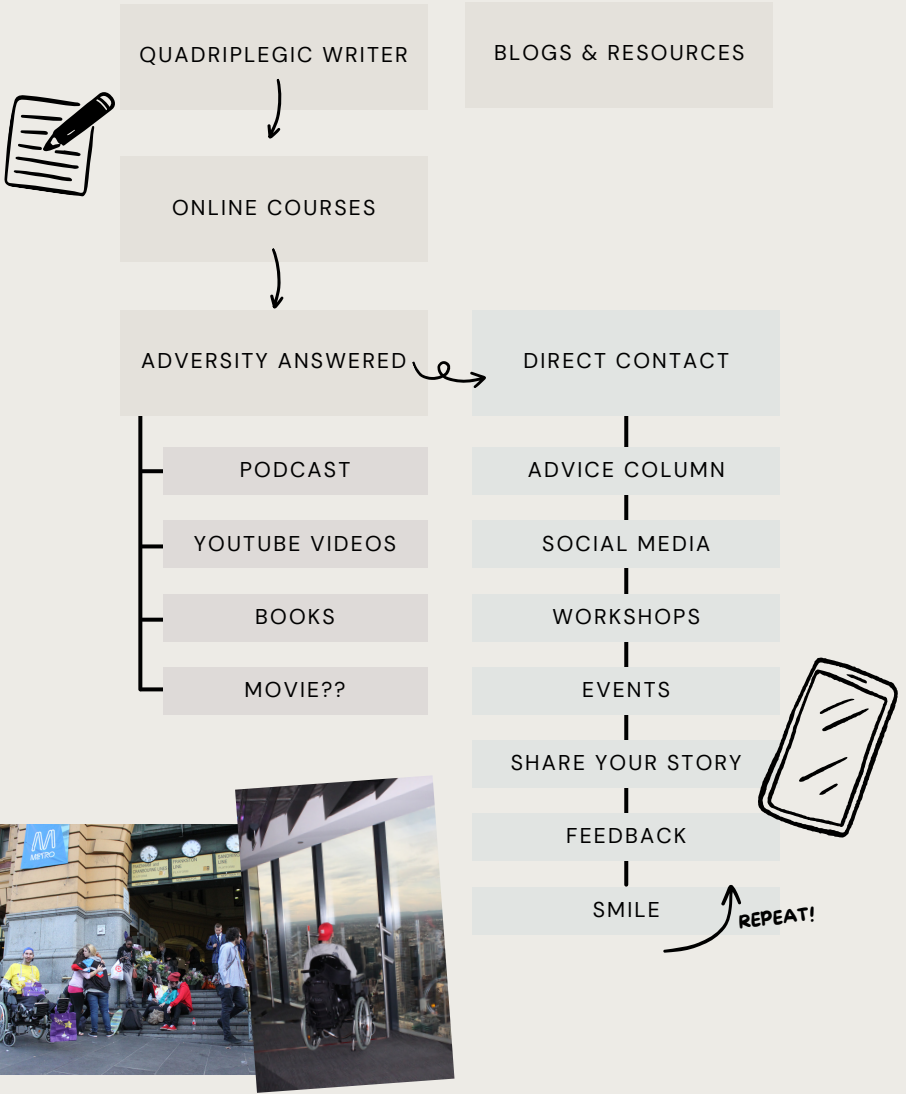
So, much like any traditional advice column format, you (or anyone for that matter) can write in with a question and I will do my absolute best to answer it with smarts, empathy, and to offer up some practical workable advice.

I really do have this bizarre lens through which I see the world. It's this lens that somehow weirdly combines ambition with extreme suffering and medical complexity, then making this all work at all costs to achieve the things that are important to me.

I'm resilient and stubborn, but also incredibly creative. I get stuff done. This is what I want for you too – well, maybe not so much the stubborn part.

Adversity Flowchart

OUR PLATFORM STRUCTUE



Disability Education

LEADING BY EXAMPLE

WHAT TWENTY YEARS OF DISABILITY HAS TAUGHT ME



ADVERSITY
IS ONLY THE
BEGINNING



No matter what your circumstance, there's a lot that is still possible. I know I prove this. But beyond all my accidental disability advocacy and the unintentional inspiration I provide, at heart, I am a writer, and the stories I tell are my link to the world – blogs, books, social media posts – and I publish these in a steady stream.

But it's through my stories that I educate and contribute to the world. I give extraordinary insights into the "patient world," especially on an emotional and mental level.

This is why I'm making writing and course creation my career. I want to expose people to the hard lessons I've learned in life, and hopefully these can help others greatly – ideally those juggling adversity and for staff within the healthcare sector. Stories are my voice in the world, and words are the medium I use to make an impact.

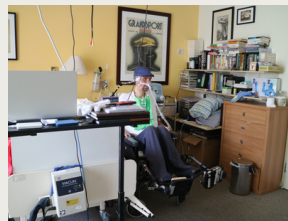
Quadriplegia – for me that's zero finger movement, zero arm movement, no legs whatsoever. Yet just a tiny bit of shoulder flex. And my neck is quite weak too.

Breathing Insufficiency – I can't breathe for shit. Prior to July '17 I used nasal mask ventilation, this was for anywhere over 20 hours per day (increasing over a 10 year period). Then in July '17 when a tracheostomy tube was inserted, and subsequent 24 hour ventilation required.

Feeding Tube – As I can't swallow, I can't eat (nil by mouth). So, I had a PEG tube inserted directly into my belly for all my nutrition, medications and liquids. And on a side note I only eat soups & smoothies.

Speech Difficulties – These days, I currently can't talk at all, it's been two years. This is a situation I'm trying to improve. I'll keep y'all posted.

Manual Handling – Being a quadriplegic obviously I can't do anything for myself. I have people move my limbs for me, I'm ceiling hoisted out of my bed and into my chair, and I also have people to roll me over at night. All of this is often a slow process.



Books and Output

Blogging

Writing is my happy place, and as such I write all the bloody time – and often this is about the nuances and complexities of my everyday life as a way to find understanding. I do find a lot of peace in the blank page, thankfully.

Anyhow, just follow my blog link to find a big chunk of my heart... Mark My Words – Inspiring, Determined, Dreamer.

Themes, Accuracy and Authority

In general, the crux and primary themes of my writing centre around acquired physical disabilities, then I often gasbag on about the subsequent mental and emotional battles. Funnily enough, these are topics that I fell into because of the life I've lived. You see, I'm dealing with a chronic disability and throughout I've always been striving to reclaim my life.

Every single day has its challenges. But what I've realised, many people are in this same boat, and like myself many people are searching for bold voices in this unusual niche to help with their own journey

This is a very complex niche, there's no room for pretenders nor can you mentor by reading a book, you need lived experience. This world knows trauma, despair and disaster intimately. Nevertheless, my accuracy and authority comes from my own journey, an all-consuming and extreme disability; and I've been living this life for twenty years. I've been through almost every mental battle and emotional insecurity you can imagine, and I've managed to still build a life. Yes,

Burstiing Bubbles

Publishing is something I aspired toward for years, and I did it. Writing a book is one of my prouder moments. Plus, I may be wrong but I reckon my first book needs some serious acknowledgement as it has to have one of the longest titles in history – Bursting Bubbles (Making Adversity Okay), The Ramblings of a Complex Quadriplegic in Quarantine. Now say that with a mouth full of Smarties.

Anyhow, this was essentially a diary that I wrote amidst the initial COVID lockdowns, yeah it gave me something to do. Or, as it says in the blurb on the back cover, it's one massive vent-fest which was originally a personal writing challenge, however with a few sprinkles of fairy dust it magically transformed into a hard copy. And what it ended up being, it's like the cliff notes of my life.



Our Short Backstory

WHAT STARTED IT ALL

My holiday of a lifetime took a drastic—turn, some freakish neurological event took place. The symptoms started as I got home, and how it played out, I began losing strength then movement in my limbs. Gone were my studies and career aspirations, all of a sudden I face-planted into the hospital system.

Tests galore, specialists galore, but I never did end up with a diagnosis. Instead, as my physical decline continued, and as I began relying on things like mobility aids and ventilators, I didn't really have anywhere to live. My needs were too high. So, I ended-up living in a few different care facilities. As the years began to pass, despite my continued search for answers and a cure, I settled into this weird institutional life. It sucked. I kinda lost myself. So, to re-discover who I was and to test my capabilities, I started a bucket list which led to some amazing adventures. But the most notable life development, I started writing a blog.

I was always trying to share my journey, it was my way of helping people to understand the complexity in my life. To help me to understand the complexities, I started studying life coaching. This was awesome, and it re-ignited a fire in my heart to return to my uni studies again. Only disaster struck, another respiratory event, and this one resulted in a second tracheostomy. After a long recovery, quite amazingly, I did manage to get back to on-campus studies. Bingo. My life purpose of becoming a biographical writer and adversity advocate unravelled.

Next, after sixteen years of institutional living, I was able to move into my own apartment with my own staff team. Then I started a business. The journey rolls on.

LIVING IN AN INSTITUTION



RECLAIMING LIFE



Life as a Story

OUR PERSPECTIVE

Storytelling Secrets

In the art of storytelling it is very common for a central character to have an essential flaw, and without doubt, in my life this flaw has been my deteriorating health. Now, to think of my life as a story, this essential flaw has led me down many different paths and these have primarily centred around self-discovery and finding out what I'm made of (or not). Well, I say it way to put a slightly positive spin on things, like we always need to remember, my essential or fatal flaw has also involved a lot of raw struggle as well.

But to stick with this storytelling train of thought, I find it fascinating how a story (or life that has been documented in my case), how it can have an algorithm – especially when comparing the key points in something like Joseph Campbell's hero's journey.

Then, a story also tends to be cyclical, and quite amazingly our own lives tend to follow a similar pattern too. The call to adventure, passing through troubled waters, redemption, rebirth, etcetera. Or, at least my life seems to have followed this path, quite uncannily. It's like there's an unintentional extra-terrestrial navigator.

I've always believed in such a thing to a point, only having my life on paper as I do now, I see my adventure algorithm a little more eerily. I can see exactly how God has plotted things out. For instance, I've always managed to meet the right person at the right time or have learnt the appropriate lesson at the right time to take me to the next level. I've always been supported – kinda like Super Mario style.

To access this support though, there really is this woo woo of getting out of your own way lesson and concept, so essentially surrendering and allowing the magic to happen. You really do need to think like Frodo, nah let's stick with the video game references, let's go Sonic or Zelda. Still, this is how your life falls into place, yes, again very much like what takes place in your favorite fantasy game or novel.

Now to keep comparing my life and journey to that of... hm, okay now let's go Disney... Cinderella or Pinocchio... nah, how about Anna from Frozen... the central character (or protagonist if you want to call it that) has to change, has to have stuff thrown at them to force change (oppositional forces), otherwise what a shit-boring story you'd have huh!?

By the way, I'm intentionally using all these different well-known character examples, like if you think about it, they really are the same story at their core. Mind blown.

Storytelling Secrets Continued...

Nevertheless, my story (as like with *Mister Theory of Everything*, Stephen Hawking) I certainly have had stuff thrown at me physically, mentally and emotionally too, only as a result, as a quick question, do you think I'm still the same on the inside? Think oppositional forces. Or, did my call to adventure make or break me? Maybe both? Consider *Into The Wild* and Christopher McCandless.

Which, I think this is something beautiful about storytelling and about life in general too huh, it's this evolution (or the lack of evolution, for example as seen within some anti-hero tropes) that drives the narrative. And, it's the juicy bits – the internal struggle or drive, the chaos or idiosyncrasies – that shine through amidst an adventure. This right here, this is the really good stuff that can make a body of work stand out, even make it exceptional.

For this reason, as you've probably noticed, this is why I try to share as much of myself as possible. The Clint Eastwood, the Sergio Leone. Actually, I think Robin Williams mentions something along similar lines in *Good Will Hunting*, to paraphrase, "juicy is good."

And moving right along... in my eyes, and I'm sure a number of other people will feel the same as well, a story needs to be more than a series of events. A story shouldn't be a Volvo. Still, the events relating to my "character," this is what drives my story. How I reacted, responded, adapted – storytelling 101 – nope I'm not that special.

But what I guess I'm getting at, or the point I want to make, my "character" was definitely not the same as it was in the beginning. I went on one of these hero's journeys, a transformational journey, and organically there was juicy bits everywhere.

Because of this, I couldn't help but develop and grow. Like I now had a list of complexities to deal with that I'd never even dreamt of being a possibility, I mean, beforehand I barely even knew that this world of disability and healthcare even existed. Yet, in this, what I also discovered was my deepest fears. Wooooo. Eek. Vulnerabilities and dependence, but I also learnt how to live with and/or overcome them

Anyway, yeah, so I ended up on this quintessential journey that I didn't want to go on and at no point could I really turn back – hero's journey 101 – Hollywood 101. So, this being forced the change I referred to earlier, coupled with the overcoming of my fears, this is what created the most impactful change for me, plus, combined with several other antagonists (both people and circumstances) that I encountered my journey too. I honestly do believe that these are the most powerful parts of my story and life.

I could've saved myself a lot of time here by simply saying that my journey was one "big mind-firetruck that I was trying to un-firetruck," yet, quite notably, it was my mind here that was growing and changing the most. As such, I've always had this rampant thirst for education, and this education has primarily been a means to an end – to help me overcome adversity.

AS MY BODY HAD STOPPED WORKING MY BRAIN IS THE TOOL THAT I HAD TO WORK WITH

Storytelling Secrets Continued...

This is totally verging on *Deadpool* self-awareness... yer could I possibly over-think this anymore? Well, apparently so.

You see, my "character" always had the inherent purpose of trying to return to wellness (haha, or to save Arendelle's populous from Elsa). Maybe you could even think of this as the journey from darkness to light, and it was here that my resolve was tested most. Juicy bits galore. Or, it was here in this underlying darkness to light narrative where my essential flaw shines (self-discovery and finding out what I'm made of) was exposed the most. Or, it is here that my flaw was tested the most.

To then chunk this down one level further, I think it was the other part of my essential flaw (my deteriorating health) that actually opened my eyes to the true value of life. *Lion King* 101... well, if you consider the similar shame elements of Simba's essential flaw. But personally, I believe this life value thing is the truest essence of my story – as is seen in many other epic tales as well. Think *Shrek* now, hm nah stick with Simba)

Yep, a story will most commonly be life affirming, well okay *Nightmare on Elm St* excluded hey. Then, it's not the events themselves that are the backbone of a story, it's how they transform us, and to me this is the truest representation of a hero's journey.

This is the way a story can teach, touch hearts, even make people value their own lives and story. This is how Luke Skywalker became the Jedi master, it wasn't purely Yoda or Obi Wan's teachings, it was mainly because of the textbook-style journey that he went on – which, funnily enough, you're probably on your own hero's journey right now Yup, loo. Life is a story.



Quiz

YOUR PERSPECTIVE



The Hero's Journey

Joseph Campbell's concept of the Hero's Journey is a narrative pattern that has been observed in many myths, legends, and stories across different cultures. As a bit of fun, to see if you are traveling a similar path in your own life, you can ask yourself these questions.

Call to Adventure: Have I encountered any situations or opportunities that significantly deviated from my normal routine and/or comfort zone, urging me to embark on a new path or challenge?

Meeting with the Mentor: Is there an individual or a source of wisdom in my life that has provided guidance, encouragement, or inspiration in times of uncertainty or decision-making?

Trials and Tribulations: What significant obstacles, conflicts, or tests have I encountered on my path, and how have I responded to them?

Transformation: In what ways have I changed or grown as a result of my experiences and challenges? How have my perspectives, attitudes, or beliefs evolved?

Atonement: Have I reached a point of reconciliation or understanding about my journey, including its struggles and triumphs, and how does this affect my sense of self?

Return with the Elixir: How have my experiences and the lessons learned enriched my life or the lives of others around me? What wisdom or knowledge do I bring back?

Integration and Application: How am I applying the insights and growth from my journey to my daily life, relationships, and future aspirations?

Online Courses

KNOWLEDGE FROM LIVED EXPERIENCE

COMING SOON

First-hand lived experiences offer a practical understanding of challenges, emotions and nuances that textbooks or wannabes can't convey. This humanises the learning process, fostering empathy and a deeper connection to the subject matter. Also, real-world examples (as you'll find sprinkled everywhere throughout these courses) can enhance comprehension and critical thinking, ultimately leading to a more well-rounded and insightful education.

Acceptance and Resilience

Learning to embrace life's rollercoaster with open arms and a hearty laugh builds the unbreakable armour of resilience, making you the knight in shining humour through adversity's challenges.

Positive Psychology

Unveiling the magical art of positive psychology turns your mind into a playground of hope, where even in the face of adversity, you discover that a smile is your most enchanting wand.

Lessons in Legacy

Carving your legacy is like writing your own story on the walls of time, ensuring that even after adversity's tale is told, the echoes of your resilience inspire generations to rewrite their own destinies.

Body Positivity

Mastering the dance of body positivity transforms the mirror into a canvas of self-love, so when adversity knocks, you strut confidently with the reminder that you are your own masterpiece.

Build a Body of Work

Embracing the wild ride of entrepreneurship is like turning adversity into a thrilling rollercoaster – with creativity as your seatbelt, every twist and turn becomes an opportunity to craft a unique path to success.

Opportunity in Adversity

Amid adversity's puzzle lies the golden piece of opportunity, waiting for you to find it and turn life's challenges into stepping stones towards personal growth and a brighter future.

The Bucket List

PROVING THAT ANYTHING IS POSSIBLE

To further my quest for a normal life, many years ago while in hospital I started writing a 'to do list' (or a bucket list). However, the reality was that my physical inadequacies held me back and somewhat squashed these dreams.

You see I always thought a bucket list included things like Running with the Bulls or Climbing the Eiffel Tower, and well sadly these are unachievable for me. Still never one to shy away from a challenge I decided to get creative.

So instead I came up with a more realistic list with an equally diverse range of challenges with the hope that they would get me out and about and living life again – because in reality I've already let far too many years just slip by.

- 145. Singing telegram
- 146. Walk a mile in somebody else's shoes
- 147. Security guard
- 148. Below -10 degrees
- 149. Sailing adventure
- 150. Step back in time

And to me this is the essence of a bucket list. It's about challenging yourself and achieving things you might normally see as unattainable – and of course living a fulfilling life.

So fingers crossed the experiences bring some adventure and excitement to my life; not to mention a lot of anguish.

To begin living again is the ultimate goal.

- 64. Elaborate surprise
- 65. Naked pose (nude model) – done
- 66. Make a short film
- 67. Ride in a Lamborghini – done



What People Are Saying

SUCCESS ISN'T ABOUT EMERGING UNSCATHED, WE ARE CHANGED, AND QUITE OFTEN FOR THE BETTER.

Lyn

"Mark is so open and honest about his journey as a quadriplegic, which I for one have learned so much just by reading Mark's writings. Whether they be on a good day or bad. I feel so much more "educated" about the type of disability Mark has and that's because he's upfront and honest about how it is."

Nadine

"The one story I share about in order to let those who are going through their darkest times know that there's always a way. And to remind me that there's always a way. Never give up, and even if you do, you rise after you fall over and over again."

Lorraine

"I have never been so affected by someone I have never met... ever. You reach out to people even through a screen. It says so much that a person can touch your life forever, without ever having to meet. The way you tackle adversity and still end up doing more with your life than most ever will is truly mind blowing to me."

Deb

"an intelligent and articulate individual, that is discerning in his observations of life and the challenges he faces daily as a quadriplegic. His quirky humour and honesty make for interesting and at times very poignant reading."

Sarah

"Mark is proof that we are more than our bodies and circumstances. His spirit and determination have transformed physical and life challenges that would defeat anyone, into success and inspiration for all of us. I am grateful to witness and benefit from his courageous sharing of his thoughts."

Gillian

"I've never met Mark but it's as though I've known him all my life. His honest, open, funny, pissed off way of engaging the readers is amazing. He has opened my eyes to the world of disability, from a very raw place. It's ironic that Mark is the disabled one but emotionally he's years ahead of most people."

Embrace Your Journey

THE TRUEST VERSION OF YOU

What would be important to you?
Who do you care for?
Who would care for you?
What if it was you whose life hung in the balance?

What would you do differently and where would your priorities lie? Who loves you? What is worthy of your time? Maybe sit with these questions for a minute. Really think about it...
What if it was you whose life hung in the balance?

These are some of the things I've contemplated for years, and I know this stuff may be a little confronting and morbid-ish to begin with, but people don't tend to think about this shit. People tend to think about their 500 inch televisions, the iPhone 46, their big plastic boobos, or about the lives of people they don't even know.

I also believe that with these questions, this is a great way to start looking at adversity a little differently too. To begin to see the absurdity in the superficial, to relish that missed opportunities can be new ones, and to weigh up, is there benefit or boredom in staying the same.

Anyway, how do you feel about your present day life after reading these questions? To start with, for me, it's like I rediscovered this tiny part inside of me that had died. I felt ashamed. How about you? Have things like happiness, work/life balance, or even authenticity strung to mind? Family, shared experiences, deeper relationships? Or, meaning for that matter???

Quite possibly this could be deemed the opportunity in adversity.

Like again for me, it was a lack of health and facing my own mortality that opened my eyes; it made me appreciate so, so much more, and the important things. For example, just imagine, only for a moment, that you were struck down with something. Or, maybe you were in a serious car accident and 'broken' yourself.

Who will catch you, who won't?

Are you being the truest version of you?

• **MARK MILJONS-ROSTOKS**