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One year on: an essay on grief, gratitude and growth

Today marks a year since my mum died.

It took me 5 weeks to say out loud “my mum is dead.” Saying those words sent a ripple of physical pain through my body, reaching what felt like my soul.

Today it still feels like we lost her yesterday, the wound is raw and the pain still lingers just below the surface, rearing its head in the form of migraines, exhaustion and a call for aloneness.

However, when I reflect on the period of her sickness, it seems like a completely different life.

I lost my mum to a disease called Creutzfeldt-Jakob Disease (CJD). She was 51, the youngest of 6 siblings and absolutely doted on her 90-year-old mother.

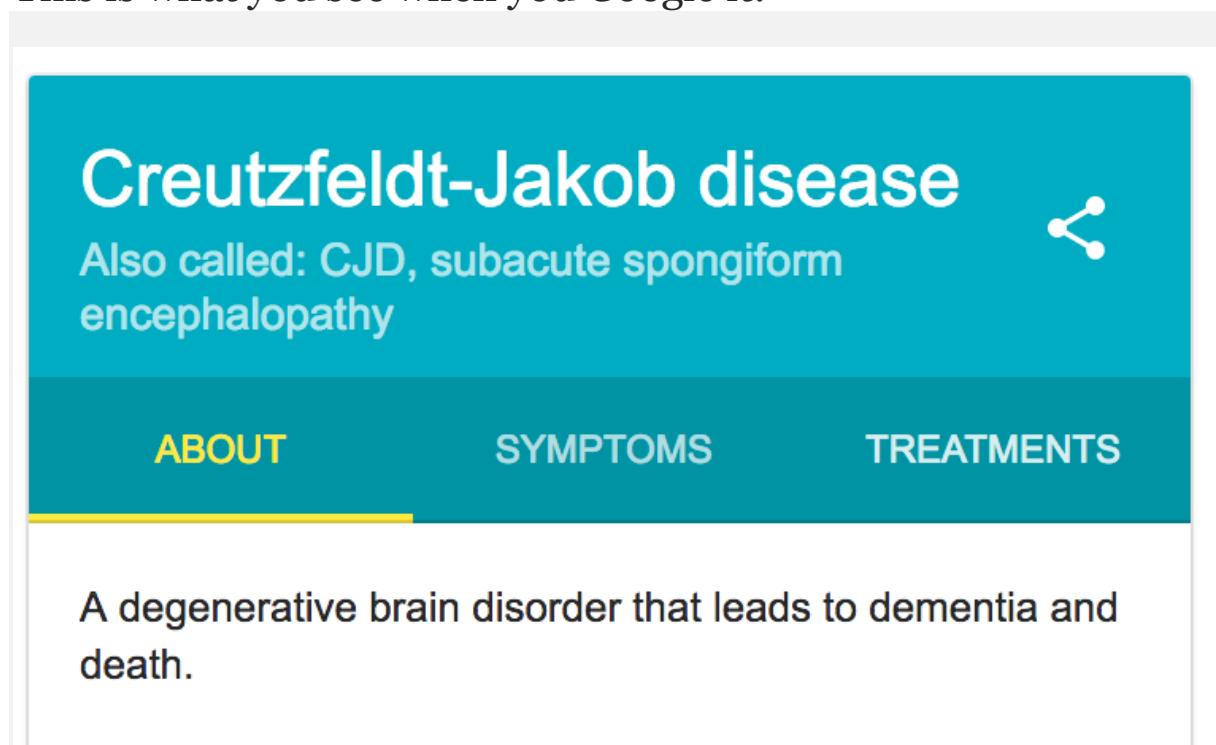
CJD is an extremely rare disease and affects about 1 in 1 million people. None of us in our family had really heard of it before.

Mum started showing symptoms of behavioural change only 6 weeks before she died. We had only 10 days left with her after we finally received the prognosis, following weeks of unanswered tests and misdiagnosis, all while watching our mum rapidly mentally and physically deteriorate.

If you were you wondering as many do—CJD is not Mad Cow Disease which is a common misconception. Mum had never visited the UK and from what we know, never ate the infected meat that has plagued visitors and residents of the UK for the past few decades.

At first, we didn't tell many people what disease took mum from us. The hopelessness and brutality of what it did almost made the disease unspeakable.

This is what you see when you Google it:



The image shows a search result card for 'Creutzfeldt-Jakob disease'. The card has a teal header with the title 'Creutzfeldt-Jakob disease' in white, followed by 'Also called: CJD, subacute spongiform encephalopathy' in a lighter teal. A share icon is on the right. Below the header is a teal navigation bar with three tabs: 'ABOUT' (highlighted in yellow), 'SYMPTOMS', and 'TREATMENTS'. The main content area is white and contains the text: 'A degenerative brain disorder that leads to dementia and death.'

Pretty brutal to read huh?

The dates of her fast decline are pretty much seared into my brain, every date and doctors meeting has replayed this year with the change of season from Autumn to Winter.

At first, mum was misdiagnosed with MS when she started to lose some mobility, she was experiencing tingling in the right side of her body and moments of blurriness in her eyes.

Our family friend Patrick Cronin was killed by a Coward Punch during this time. Pat's funeral was the first time we noticed that her emotional and logical reasoning was off.

Only two weeks after this, mum was unable to walk without assistance. Out of pure instinct, a nurse discovered that mum was actually experiencing epileptic **seizures** every few minutes, instead of the anxiety and MS that we thought it was.

Just a week later she was placed into an induced coma to test for an extreme form of epilepsy.

5 days later, we received the news none of us will ever understand.

I was reading an article last week that said;

“It’s not just loss that we feel when we have our mothers taken from us, the reality is far more violent. It is an un-mothering that feels raw and fundamental, a pain that reaches all the way down to your ligaments and bones. If you think about it, before we are born, we swirl in the cocoon of that space in our mothers’ wombs. Our first firmament, literally, our first homes, the universe from whose substance we were formed.”

While I don’t know and will never know why mum had to leave so early, what I have discovered, is that death is the only thing every living creature in this universe shares.

As a society, death is something we resist, repress and refuse to talk about.

However, I believe, that when you accept that death is inevitable, and somehow find beauty in it, I truly believe that your entire outlook on the world changes.

While the past year has been somewhat traumatic and challenging, my life has been filled with more love and gratitude than I’ve ever experienced in my 24 years of life. The world has never seemed more beautiful than it does today.

The support that my family has received over the past year is so *overwhelming* that I’m still left speechless just thinking about.

It took me nearly 6 months to stand up in front of a group again without becoming overwhelmed and lost for words as I did the day of her funeral, looking up from my notes and seeing 700 people waiting for me to speak. I could feel the love they had for my mum, I could feel their pain and saw their offering unwavering support.

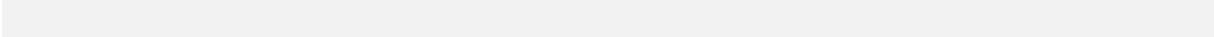
700 people there to say goodbye to my mum...

This was and will be the most humbling experience of my life.

All of us were asking the same question, and we still are today.

Why?

I want to share with you some of my experiences over the past year today in the hope that when someone you know leaves, I guarantee that you'll be sad, **but you will find ways to be okay again.**





My beautiful mum

Rewriting your story

“We live in a culture where it has been rubbed into us in every conceivable way that to die is a terrible thing. And that is a tremendous disease from which our culture in particular suffers.” — Alan Watts

In Western society, we're told at a young age that the success story of your life, should go something like this...

“Go to school, get a degree, find a job, fall in love, buy a house, marry the person you bought that house with, have kids, retire and finally travel. Don't worry about dying, you'll be so old and well-lived that you'll be happy to die.”

And when this narrative doesn't play out, people don't know what to do.

They feel like a failure, they marry the wrong person out of fear, they work in jobs that are unfulfilling and leave them depleted of energy.

What we aren't told, is that Life never *ever* guaranteed us a future.

Our modern world and the media that determines what we should think about and care about has been designed to brainwash us and believe that we deserve certain things like good things don't happen to bad people, etc.

And we just accept this as “*how life should be.*”

Accepting how society tells us to live is far from truly living.

And the result of this is most of us just ‘cope’ through life, making ends meet.

But for us to truly live, we need to figure out a way to thrive, rather than simply *cope*.

The *first thing* that flashed through my mind when Dad called me to say the doctors were confirming the diagnosis of CJD was “Mum is never going to become a Grandmother.”

That was part of ‘our’ narrative that mum and I had written together. Mum LOVED being a mum, she always told me it was her calling in life, and she was so great at it. She couldn’t wait for the day to become a Grandmother and help me tackle parenthood.

My second thought was an image of me trying on a wedding dress and coming to terms with now knowing, “If I get married, I’ll have no mum at my wedding.”

My heart was breaking to pieces as I saw my life without mum flash before my eyes as I sunk into the concrete floor beneath me.

My third thought was guilt.

How could I feel like this when there are people in the world who experience death and pain every day? There are people who

live in war zones, are victims of sex trafficking, domestic violence, rap, poverty or even have no family at all?

No matter how bountiful your life is, how lucky you are to live in a first world country, to have food on the table, to have an amazing job and great support—losing someone doesn't hurt any less. And beating yourself up with guilt for feeling like shit about it also doesn't help.

At one point, it was really painful to think about my future. It took me a number of weeks to think of any day beyond the present—which I learned is actually a smart thing to do.

You don't have to force yourself to do or think anything during this period.

What I eventually had to do to work through, and what my psychotherapist helped me do, was to **rebuild the foundations of my life story without a mother.**

I had to. That was reality. I couldn't live in a bubble of today forever or I'd never get out of bed.

When I finally let myself see my world and my future without my mum standing next to me, it was like seeing the world new again.

A clean slate.

And I could map-out *whatever* I wanted for myself that made me feel LIBERATED! And safe again.

That's really all we do, isn't it? We tell ourselves stories that make us feel safe.

Dad, if you read this, part of my new story is that you'll be wearing a mother-of-the-bride dress at my wedding.

Once you've learnt how to re-write your story, you'll soon realise you can pretty much do it any time you like, and I promise you'll feel stronger than you ever have before.

It's important to know that **we will never, ever understand why these things happen.**

Why it had to be them, why now, why like that?

But we can find growth.

The Stages of Grief

You know the stages of grief: First comes denial, then anger, bargaining, depression and finally acceptance.

Whilst psychologists have since discovered that this isn't linear, it's an extraordinarily narrow view of what it's like to grieve.

For me, **acceptance** happened straight away. How could it not? We had zero hope, no treatment, no more tests, not one case of survival to give us even a glimmer of hope.

Bargaining? After seeing what the Cronin's went through, losing their youngest son Pat to a cowardly punch at a pub brawl with no time to say goodbye just weeks before, I was so grateful and felt blessed that we had time with mum.

Grief? duh... I had a counsellor officially diagnose me with 'Grief Disorder' and suggested I be monitored for suicide a week after mum's funeral.

I was horrified that someone whose job it was to help people process grief would think it appropriate to 'diagnose' someone with a disorder... I laughed at this response and never went back.

I found a 'holistic' therapist instead who understood that I didn't need a label, I needed someone to help my subconscious process the trauma that this experience had put me through.

My body ached, I needed about 15 hours sleep a night and any physical exercise left me exhausted.

They tell you to be kind to yourself, so I made sure I gave myself that sleep and didn't go to work if I didn't feel like getting out of my pyjamas.

I was lucky I could work from home.

While I experienced about 15 different emotions every 5 minutes, the one that affected me the most was **fear**.

For weeks and weeks, I dreamt about my friends dying, tragically and graphically. Some of them were like Game of Thrones meets my real life... Not a joke.

I was always worried about Dad, Brige and James.

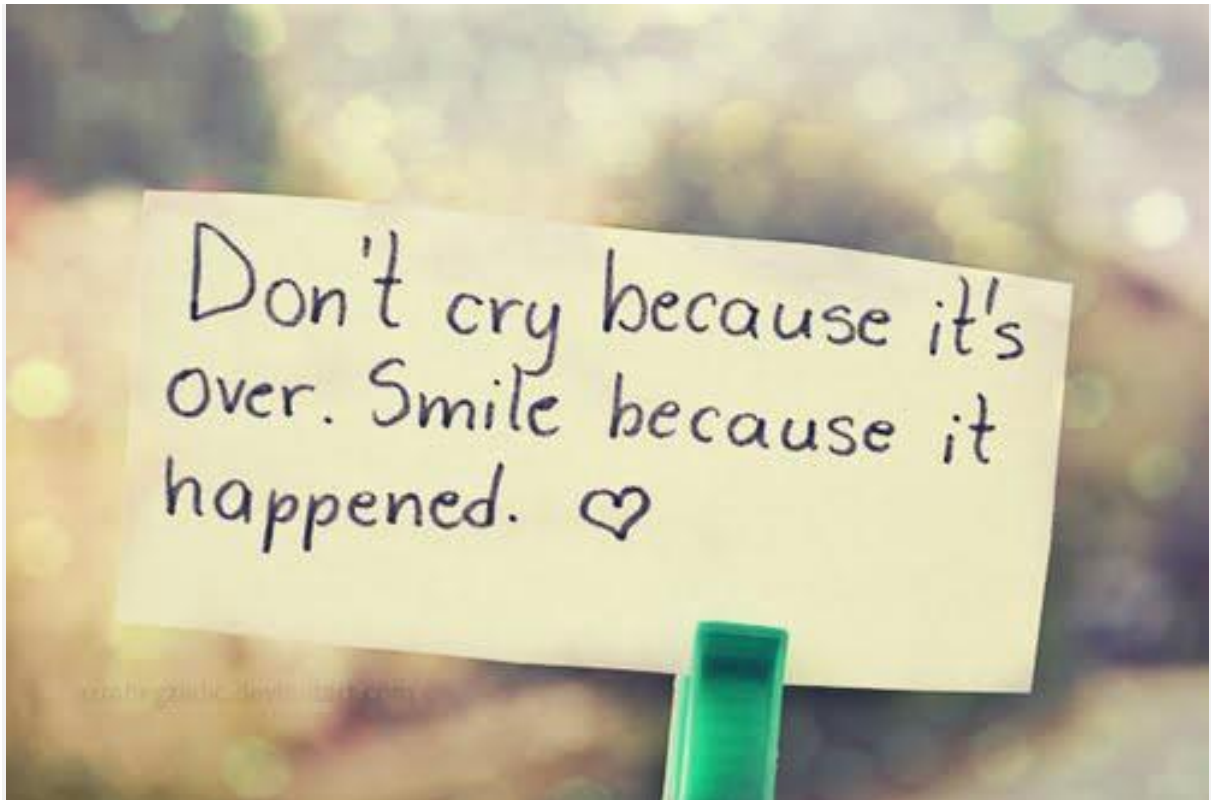
Was James going to get in a car accident?

Was Brige going to accidentally poison herself at work?

Dad has a sore stomach, does he have cancer?

It was constant, consuming and terrifying. I'd never really experienced anxiety before and it took me a lot of meditation and writing to move past it and take my confidence back.

My mantra became, "Don't cry because it's over, smile because it happened."



Post Traumatic Growth

Psychologists have more recently been studying post-traumatic growth instead of the stages of grief.

Forms of Post Traumatic Growth



They're pretty straightforward so I won't explain it, but it's comforting to see those stages and say "You know what, I have grown. I appreciate life more today, I haven't gone backwards, I'm not broken."

The newly strengthened and deepened relationships formed with my family, close friends, family friends, mum's friends and even complete strangers is the most fulfilling thing to come out of this experience.

I rekindled old friendships that had gone off track and found so much gratitude in knowing that living in Australia made me one of the luckiest people in the world – especially because

following this was the election of Donald Trump... Talk about perspective.

Finding Your Resources

As a logical and rational person, I compartmentalised my grief, if people cried when they spoke to me, I'd sometimes awkwardly laugh.

I felt like a burden and automatically comforted them. And this worked for me. I never judged myself for it, as weird as many people thought it was.

I don't think my friends saw me cry except for at mums funeral. At first, I thought something was wrong with me because my dad and sister would cry at the drop of a hat.

But while I didn't cry in public, what I did know is that ***I had to cry.***

I set myself times, almost in my calendar, to let go and I made sure I cried and became consumed by whatever I was feeling in my body so that I could begin healing.

I was reading Sheryl Sandberg's new book Option B the other week and she spoke about the concept of the 'button.'

A psychology study put people in a high-stress environment which including a heated room with loud noises and sounds and were then told to pass a test.

Over 90% of the participants left the room in frustration, some cried and majority of them failed the test.

All participants ended up experiencing physiological fight-or-flight responses, leaving them with high-levels of cortisol in their bodies.

The second group were put in the same high-levels environment, challenged to pass the test.

This this time they were given a button to press an 'opt out' if they couldn't handle the high-stress environment.

The people with the button all passed the test, and were seen to have significantly less levels of cortisol. They were able to handle the stress.

They didn't need to press the button, but knew that button would be there to keep them safe if it became too much.

All of my friends, you were my buttons.

— — —

Tapping into my instinct, I knew that if I were going to process this traumatic experience properly and come out the other side stronger, I needed professionals.

So I made a list of all the help I needed to make it through, as I knew I couldn't do it alone. I thought, fuck it, I'll find people whose *job* it was to help me.

I found a psychotherapist, a spiritual mentor, a personal trainer, a great Chinese massage place for \$1 a minute on Swan St, and my work at the same time also gave me a business mentor.

Someone also told me, "If people offer to help you, just say yes, it's more for them to feel like they can do something to help as people feel helpless."

So I said to yes the angels who wanted to cook us dinner, clean our house or buy us groceries. It was overwhelming and I'm so stoked we said yes because coming home to a home cooked meal without having to actually cook it every night after work was bliss.

All I had to do was buy the bottles of wine.

Between wines, I then consumed book after video after blog, covering Hinduism, the afterlife, the Eastern vs Western views of death, Chinese energy to learn how to conserve and tap into mine, books on psychology, reading other people's stories, and the list went on.

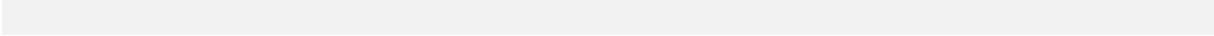
Some turn to faith, spirituality or religion, I just tapped into as many resources as I could and took from it what felt right instinctively.

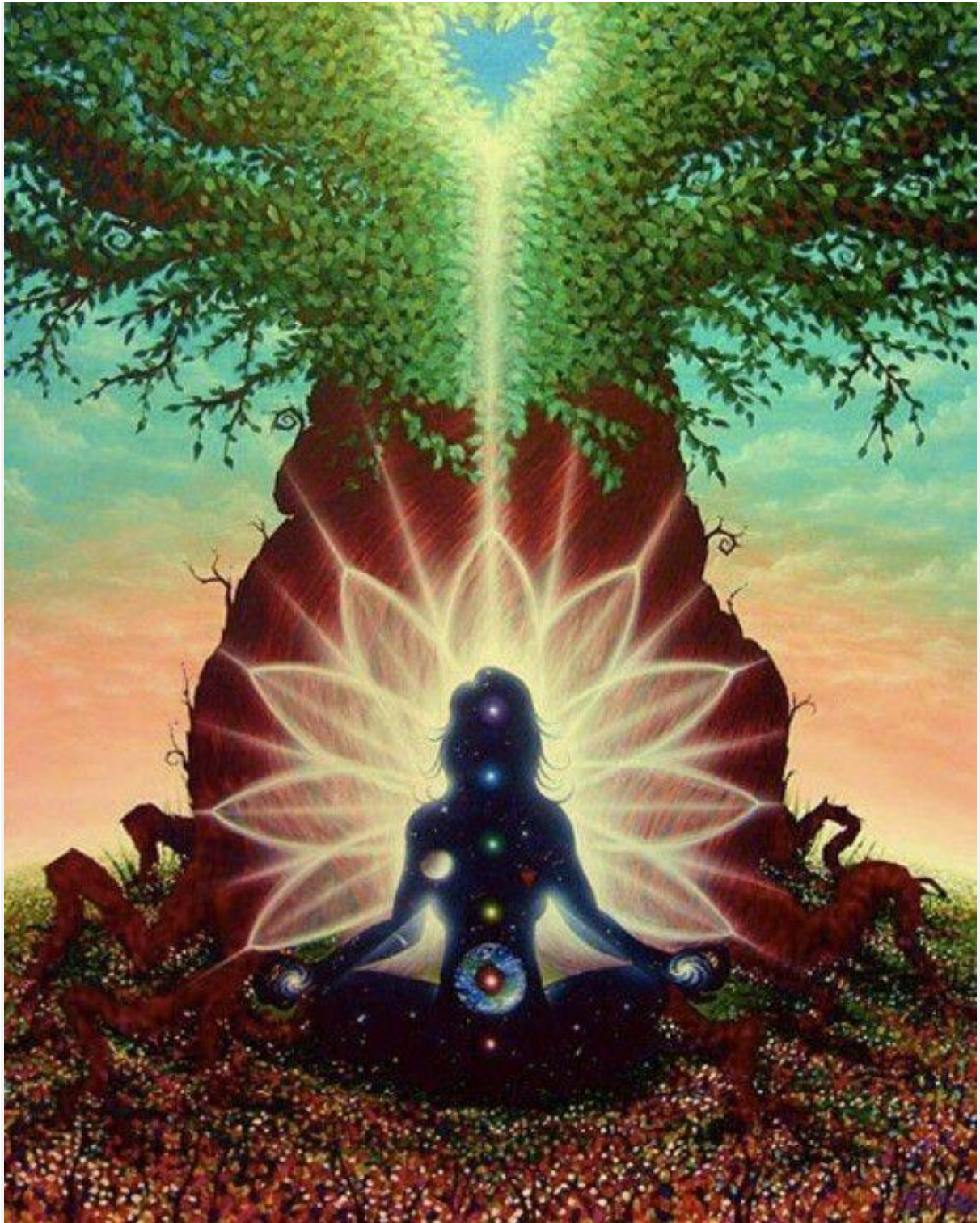
I knew logically that I should listen to my gut and learn everything I could as to come out of this and grow somehow, even if it was just growth in knowledge, so in every instance I did.

A few of my favourite books:

1. [The Tibetan Book of Living and Dying](#)
2. [The Power of Now – Eckhart Tolle](#)
3. [Dying to be me – Anita Moorjani](#)
4. [The Perfect Day Plan – Jost Sauer](#)
5. [Option B – Sheryl Sandberg](#)

I also watched some pretty crazy shit on [Gaia](#), it's like Netflix but all the content is about spirituality.





Culture

One of the most important things to do at any time, is to look at yourself from within, not the outside in. The outside in is when

anxiety will take over your body. That's when society will decide who you are.

I spent a lot of time terrified that my identity would become "*The girl with the dead mum.*"

After all, I was brought up on movies and TV shows about people's entire lives being shaped by their dead parents.

Harry Potter, the Vampire Diaries, Cinderella, Beauty and the Beast, The Lion King, Snow White etc. Plus a whole lot of other cool stuff I watched...

I was always thinking, should I be crying at work so people know I'm sad? That's what they do in the movies? Do I collapse on the dance floor at my birthday as I realise I shouldn't deserve happiness ever again?

When does the plot kick in when I get to become a princess as the trade-off for losing my mother at 23?

Am I actually a wizard?



As dad kept saying, turn to page 25 of the manual for what to do when you lose your wife....

It's blank.

You honestly just have to make it up, listen to your instincts and remember that life is fleeting and whatever comes next is unknown. Don't waste it feeling sorry for yourself and butthurt that it was you and not that mean person over there.

Happiness



I read this quote about 4 years:

“In every situation, you choose how you perceive and then react to any situation.”

It changed my life.

The one thing our family never denied ourselves was to choose joy.

Music is on in our house every day, it was on the day mum died, and the day after, and the day after that. If our favourite songs came on the radio, that music was turned up. We never denied ourselves happiness.

We could've chosen despair, anger, fury, hatred and denied our own smiles, but we chose to lean into the sadness and find joy every day.

Mum's diagnosis was the most hopeless feeling.

You hear stories about Stage 4 Cancer sufferers finding the strength to heal to remission and people learning to walk again after severing their spinal cord.

But it's not all too often you get a "There's absolutely nothing we can do and there isn't much time left."

We all made the decision to chose to find happiness and gratitude in each and every day and most of that came from being surrounded by some of the world's most incredible friends, unbelievably understanding and kind partners, and purpose-driven workplaces.

This is my story.

My dad, brother and sister's stories I'm sure are very different as are all of those who have experienced losing a loved one to CJD.

I really appreciate that you've taken the time to read this, it felt good to put pen to paper.

If you'd like to know more about CJD head over to the [CJD Support Network](#).

Unfortunately, this disease is so rare it doesn't really see any government funding.

One last thing, I highly recommend getting a puppy when you're sad.

Thanks again,

Kate



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- Death
- Happiness
- Survival
- Marketing