

# Re-emerging from turbulent times as a change agent

## A very personal story

### Andrea Gewessler



*Let me tell you a story about my personal experience of transitioning through turbulence. It is an incredible story. It is not a fairy tale. It may even make you squirm. But I hope that you'll find it instructive as AMED goes through its own not-knowing.*

**Keywords:**

transitions, turbulence, chaos, change, grief

### Entering turbulence

It was the Queen's Diamond Jubilee weekend in 2012. It was a beautiful, sunny weekend. People were having picnics, there were celebrations and fireworks. Life was good. I took my husband to the local emergency care centre because his headache, that a week prior had been diagnosed as sinusitis and treated with antibiotics, was now compounded by speech difficulties. We were immediately sent to the nearest hospital for a CT scan. The preliminary cognitive functioning tests were probably enough for the consultants to form a conclusion, which, just a few hours later, was confirmed. We were told he had a brain tumour, the size of an apricot. For some strange reason the big C still had not dawned on us until I came across it in his medical file later that evening.

### Diagnosis

I do not know whether you have ever been on a plane going through a very bad stretch of turbulence. For me these experiences are usually accompanied by white knuckles, crazy, incessant butterflies in your stomach, a light-headedness that makes me almost faint, or simply gut-wrenching fear? We never quite left that feeling behind on the whole journey that followed.

Upon transfer to King's College Hospital and a comprehensive MRI, the consultants' hunches were more or less confirmed. An operation was scheduled for the following week. The diagnosis, to be confirmed through a biopsy, was GBM.



My husband, Octavio dos Santos Neto,  
ready to sing in concert

Whatever medical texts I came across the verdict was the same:

*“Glioblastoma, also known as glioblastoma multiforme (GBM), is the most aggressive type of cancer that begins within the brain. Initially, signs and symptoms of glioblastoma are nonspecific. They may include headaches, personality changes, nausea and symptoms similar to those of a stroke ... Despite maximum treatment, the cancer usually recurs. The typical duration of survival following diagnosis is 12 to 15 months, with fewer than 3 to 7% of people surviving longer than five years. Without treatment, survival is typically three months ... about 3 in 100,000 people develop the disease per year.”*

Writing this, nearly eight years later, does not make this more real or acceptable. My husband was tall, dark and handsome. A portly opera singer of Brazilian heritage, aged 47, with a huge appetite for life and a personality to match. He wanted to live as long as he could. We had plans, we had dreams, we wanted to grow old together. All that changed in an instant. He was told that his life expectancy was 15 to 18 months; three years were considered hopeful but unrealistic.

### **Treatment**

After the operation, which involved a clinical trial, 30 days of radiation with concomitant chemotherapy, 29 cycles of chemotherapy, changing in severity and frequency, a daily dose of steroids and anti-seizure medication and as the disease progressed, the medications increased. Hospital appointments galore for blood tests, MRIs, a couple of PET scans, which we fought for and which bought him months, if not years, of extra life. We were faced with huge decisions about treatment pathways and clinical trials. Many of my evenings I spent researching different treatment options and evidence-based complementary approaches. The readings always made me feel sick, because no article ever left me with any doubt that this was terminal. The first year was a rollercoaster of indescribable proportions, then hope grew that life could be hung on to for a while longer. But the fear was ever present, and notably increased before and after each MRI scan. The 18 months had gone, the three-year mark passed, four years, the fifth year became tougher still. While he was referred to as the poster boy in hospital, our day-to-day life was indelibly changed. There were many dreaded words including: recurrence, growth, inoperable and spread. The pleasures of daily life changed.

### **Endings**

Being alive was great in itself, eating, watching a film, going for a tiny walk, doing sudoku together, drawing together, sitting on a bench watching the sunset. Holidays happened but they did not resemble any normal holiday. They were dictated by medications, accessibility, walking distances and access to medical care. My gloriously charming husband was no longer who he had been. We had to adapt to a new normal an incessant number of times. He experienced a number of seizures, some so small they were barely noticeable, others so profound, he needed hospitalisation. He died four months short of the sixth anniversary of the diagnosis. The ending was cruel, painful and undignified.

An article on the 'Symptoms and problems in the end-of-life phase of high-grade glioma patients' describes that

*"The most commonly reported symptoms in the last phase of our cohort of HGG patients were drowsiness (87%), dysphagia (71%), progressive neurological deficits (51%), seizures (45%), incontinence (40%), progressive cognitive deficits (33%), and headaches (33%)."*

He experienced them all, and more.

The last three and a half weeks I was with him almost 24/7. He hung on to my hand for dear life. Hearing his breath change and seeing him die was the worst thing I have experienced and yet I felt extremely privileged that he allowed me to accompany him on his way.

### **Chaotic transition**

The turbulence stopped and internal chaos set in. I never knew that the sounds that I expelled existed in my body, the tears were truly incessant, the pain too much to bear. My body aged by several years in the timespan of a few months. In the immediate aftermath of his death, the only thing that spoke to me was W.H. Auden's poem 'Funeral Blues' (1938), more popularly known as 'Stop all the clocks, cut off the telephone'.

And yet the world moved on, relentlessly. I was livid, outraged, perplexed that the death of my person was just a newsflash in most people's lives. Our cats, a handful of very good friends, writing poems about grief and loss and making art have become my release valves.

### **Respite in lockdown**

The recent lockdown, brought about by COVID-19 in March 2020, finally brought the world to a stop. While I did not want the virus, the deaths, the misery, I longed for the quietening of the earth. I wanted a period of mourning. I did not want to be cheered on. I wanted someone to witness my tears and my pain. I wanted to reconfigure myself. For the first time, I felt that my atheist soul was allowed to hunker down and catch up. The whole world spun into turbulence. Never having understood maths, the concept of two minuses being added together or multiplied making a plus, suddenly made sense. Rather than being perturbed by the lack of social contact, I have experienced the lockdown as a gentle wave in the raging waters I have been navigating for nearly 8 years.

Recently, I reacquainted myself with Kris Hallbom's model of 'The Universal Cycles of Change'. I met Kris many moons ago while on an NLP Master Practitioner programme and felt instant affinity with his model. On reflection, the lockdown allowed me to move into the final two phases of droppings off; and mediation and dormancy.

He describes the droppings off cycle as:

*"...about letting go of what is no longer serving you. Once chaos has set in, there must be some kind of a release or dropping off to bring the system back into balance."*

Kris defines meditation and dormancy as:

*“the final cycle in which the system regains its balance, which will allow it to recycle back up into Creation. The system now has less mass, yet more energy because it contains all the learning from the previous cycles.”*

So, while I can say for sure that I am not over the loss of the most important person who has ever been in my life, nor would I want to be, I now find myself in a new phase.

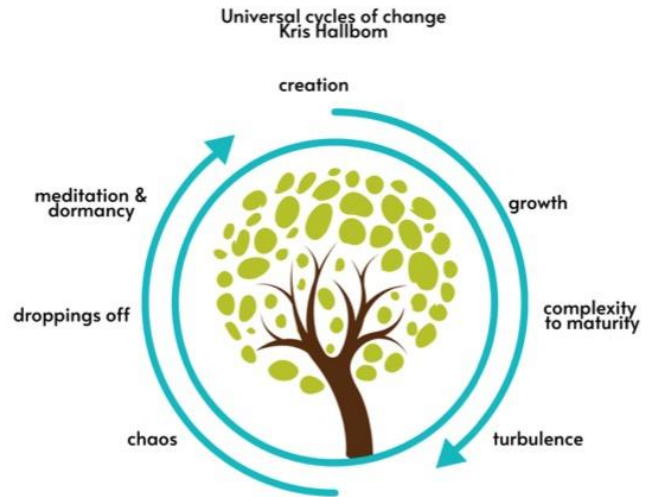


Diagram 1: re-drawn by Andrea Gewessler from the original in Hallbom 2010.

This is one that, despite the grief, allows me to create again and feel an active change agent once more. I am not off the roller coaster of Stroebe and Schut’s (1999) dual process model of coping with bereavement and I still oscillate between loss-oriented and restoration-oriented states of being and doing. I am no longer wandering merely on the path of chaos (loss-oriented) and not purely in a new sense of order but right on the edge of the chaordic path.



Diagram 2: re-drawn by Andrea Gewessler from the original in Stroebe & Schut 1999

## Learning to come through turbulence

So, what have I learnt from this eight-year long phase of being in turbulence and chaos and pivoting my way out back into creation? Here are 16 personal observations:

1. Be in the present. Right now, this second. This minute, this hour, this day all is well.
2. Individually, even as a species, we humans are insignificant beyond measure, which does not mean that we cannot do good work while we are alive. Show some humility.
3. We only have the illusion - more likely delusion - that we are in control. Unpredictability, ambiguity and change are not part of life. They are life.
4. Life is not fair and shit happens to good people.
5. We will all die and all the external status symbols including positions of power, titles and wealth will be meaningless as we face death.
6. Stay with love and vulnerability. They are the only authenticity we have.
7. Keep working on yourself, work on your weaknesses, become the best possible version of yourself you can be. It's your only route to leaving a meaningful legacy and your only way to lead authentically.
8. Keep helping, supporting and championing others.
9. We are all essentially alone and interconnected at the same time.
10. Being present for another being, unconditionally, is the greatest gift we can give and receive.
11. Unconditionally means unconditionally. It encompasses all the ugliness you can imagine or not.
12. Park the 'shoulds', and live your life in balance with the earth's capacity.
13. We will all become bereaved one day. Make friends with yourself as soon as possible.
14. Everyone hurts, even if we cannot see it. Exercise empathy and compassion.
15. Most people need to be taught how to talk about illness and death. Their platitudes need to be challenged. Birth and death are the only universal experiences we share.
16. Our society is terminal too because we have brought planet Earth to its brink. Get skilled up to become [a death doula](#) (Saixue Watt 2019), also known as a death midwife, a change agent or both. Society and the planet need us to show up.

## Re-emergence

So, in the midst of the pandemic, I became active again. I started collaborating with an amazing bunch of people - Jim Rough, Corrina McFarlane and Markus Goetsch. Together we have been pioneering online dynamically facilitated, choice creating conversations with people from across continents online about how we can come out of this pandemic in balance with the ecological boundaries. Whilst we are at the beginning of this societal journey, I now feel increasingly confident that a new professional life can emerge following the turbulent years I have experienced. The grief and pain will always be a part of me, as will the love for my husband. And yet, it's a duty to show up and be the change we want to see in the world. I hope that this can happen for AMED too.

## References and websites

W H Auden (1938). 'Funeral Blues'. The Year's Poetry.

Glioblastoma. Wikipedia, <https://en.wikipedia.org/wiki/Glioblastoma>

Kris Hallbom (2010 version). The Universal Cycles of Change—Patterns in Nature Translated to Human Behavior. <https://thewealthymind.com/the-universal-cycles-of-change.html>

Sizoo, E. et al (2010 Nov). Symptoms and problems in the end-of-life phase of high-grade glioma patients. Eefje M. Sizoo, Lies Braam, Tjeerd J. Postma, H. Roeline W. Pasman, Jan J. Heimans, Martin Klein, Jaap C. Reijneveld, and Martin J. B. Taphoorn. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3098016/>

Strobe, M. S. & Schut, H A W. (1999). The dual process model of coping with bereavement: Overview and update. *Death Studies* 23(3):197-224. PubMed. March. [https://www.researchgate.net/publication/12470676\\_The\\_dual\\_process\\_model\\_of\\_coping\\_with\\_bereavement\\_Overview\\_and\\_update](https://www.researchgate.net/publication/12470676_The_dual_process_model_of_coping_with_bereavement_Overview_and_update)

Saixue Watt, C. (2019). End-of-life doulas: the professionals who guide the dying. *The Guardian*. 6 November. <https://www.theguardian.com/lifeandstyle/2019/nov/06/end-of-life-doulas-the-professionals-who-help-you-die#img-1>

## Acknowledgements

With special thanks to **Bob MacKenzie** for his patience and encouragement to birth this article. This article is dedicated to **Octavio dos Santos Neto** ([www.divadivo.co.uk](http://www.divadivo.co.uk)), my husband and best friend, my friend **Andressa Pisa**, who has brought laughter, kindness and Brazilianness to my life, my childhood friend **Renate Holly**, who has shared all life's ups and downs and our four ginger rescue toms **Mr Darcy**, **Ferdinand**, **Wolfie** and **Sebastian**, who rescue me every day.

## About the Author

**Andrea** is director of **Change that Matters**, always learning, facilitating conversations, nudging change, co-creating, leading, coaching, supporting, challenging, mentoring, writing, training, horizon scanning, visualising, caring and hopefully making a positive and lasting difference.

Contact: [andrea@changethatmatters.co.uk](mailto:andrea@changethatmatters.co.uk).

# A note about AMED



AMED stands for the Association for Management Education and Development, [www.amed.org.uk](http://www.amed.org.uk). We are a long-established membership organisation and educational charity devoted to developing people and organisations.

Our purpose is to serve as a forum for people who want to share, learn and experiment, and find support, encouragement, and innovative ways of communicating. Our conversations are open, constructive, and facilitated.

Through AMED, we strive to benefit our members and the wider society. Exclusive Member benefits include excellent professional indemnity cover at a significant discount, free copies of the quarterly journal *e-O&P*, and discounted fees for participation in a range of face-to-face events, special interest groups, and our interactive website. We aim to build on our three cornerstones of **knowledge**, **innovation** and **networking** in the digital age. Wherever we can, AMED Members, Networkers and Guests seek to work with likeminded individuals and organisations to generate synergy and critical mass for change. [www.amed.org.uk](http://www.amed.org.uk), or contact **Linda Williams**, our Membership Administrator, E: [amedoffice@amed.org.uk](mailto:amedoffice@amed.org.uk), T: 0300 365 1247