

## **Trauma-inducing and trauma-reducing health and medical experiences” drawing on stories from 390 people and some of the values of trauma-informed practice**

**Collated and written by Dr Karen Treisman, MBE, Clinical Psychologist, Author, Trainer, Organisational Consultant, and Director of Safe Hands and Thinking Minds Services**

### **What information is this paper based on? How did it come to be written?**

This paper is not a formal research project nor an evaluation. It is a free and accessible paper which has been written to bring some experiences of those who have accessed medical and health care settings alive. It is not in relation to Covid.

It is easy to read academic papers or clinical guidelines and lose the person amongst the text or the statistics. So, this brief paper was intended to bring some of the theories and concepts which we may read about alive. This is because people are the experts of their own experiences and people need to be put back into policies; people over processes. Services need to be humanised and ideally places which are secure bases and safe havens; and not ones which can add to one’s stress and distress. Whilst some context will be given, the main focus of this paper is around the stories expressed by 390 people.

So, some of the motivation for writing this was shaped by my own health and medical experiences throughout both my own childhood and adulthood; as well as having a mother with Multiple Sclerosis. Following a difficult health appointment a few months ago (one of many), as an avid tweeter ([dr\\_treisman](https://twitter.com/dr_treisman)), I tweeted about trauma inducing and trauma reducing health experiences. I had no intention to formally write this paper, and I was surprised, moved, and overwhelmed that overnight I received 390 requests from twitter and Facebook from people all over the world to share their health stories. This in itself says how important this paper is, and as a hopeful disruptor and someone who feels incredibly passionate and dedicated to trauma informed system change; I felt I wanted to capture some of the richness of those stories which people had generously shared and which I was honoured to receive. It felt like a call to action. Therefore, I decided to write this brief paper to give a flavour of some of the themes, and so here we are. Please note, that whilst this was not formal research, people were asked a series of questions in written form, and it feels important to mention that they were asked in equal measure about their positive, healing, and helpful experiences, as much as their difficult and upsetting experiences; however, as we know, unfortunately, often more emotive, negative, and difficult memories stick, shape, and can be easier to recall.

This paper of course has also been shaped by my own background as being a Clinical Psychologist who specialises in trauma, being an Organisational Consultant, and an Author; as well as my Winston Churchill Fellowship which focused on trauma, adversity, and culturally informed, infused, and responsive organisations which saw me visit 14 cities across the USA and have over 100 meetings with specialists and experts in the field.

The stories (not a representative sample) were received from a range of contexts including inpatient, outpatient, and community settings from the UK (the majority), America, Australia,

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New Zealand, Egypt, Kenya, South Africa, Israel, Sweden, and Canada. The majority of feedback was direct experience; however, some was from the voice and perspective of a carer, a spouse, a parent, and so forth. Health areas included a wide range such as:

- Diabetes
- Burns
- Accidents and injuries including spinal cord, breakages, knife wounds etc.
- Multiple Sclerosis and Parkinson's
- Dementia
- Cancer
- Down's syndrome
- COPD
- HIV
- Sickle cell
- Pregnancy, fertility, and gynaecology
- Dermatology
- Heart attack
- Cystic fibrosis
- Cerebral palsy
- Self-harming
- Vision and hearing
- Anorexia and bulimia
- Celiac and crohn's

### **What will be covered in this paper?**

We will start by briefly sharing some of the reasons why trauma and adversity informed care is important in the health arena. Then we will go on to explore some feelings which people experienced and some ways in which they described their health encounters will be shared. Followed by some examples of how the intervention was triggering and resurfaced past traumas and/or life events for some people. Then some comments about the ripple effect and subsequent impact these experiences had on people's relationship to help and future medical/health interventions. After this, some feedback from people about some of the positive and healing experiences within these contexts. Followed by some brief recommendations for future improvement.

### **Some brief reasons as to why trauma and adversity informed, infused and responsive care important in physical health and medical settings?**

*Please note this is just a flavour and not an exhaustive or prescriptive list.*

From evaluations, professional accounts, voices from those who use and have used services, and from research (including the Adverse childhood Experiences (ACE) and Dunedin longitudinal studies); we know that there is a high and widespread prevalence and common occurrence of trauma, dissociation, toxic stress, loss, social injustice, and multiple different types and layering of adversity amongst individuals, families, communities, and societies. For example, population-based data from various countries indicate that a majority of adults will experience a traumatic event at some point in their lives (Benjet et al., 2016; Burri &

Maercker, 2014). And the ACE study showed that almost two-thirds of study participants (just over 17000 people) reported at least one ACE, and more than one in five reported three or more ACEs. This prevalence is why adversity, culturally, and trauma-informed, infused, and responsive approach generally advocates for a universal, inclusive, and integrated approach. Partly, because unlike if someone has a diagnosis of downs syndrome or is a wheelchair where it is more visible; trauma is often camouflaged, unseen, missed, and invisible. This can be compounded further by some of the silence, shame, and secrecy which in the context of trauma people and society can be marinated in.

Additionally, due to the very nature of trauma and the at times ill-equipped systems and societal response it can be difficult to name, share, put words to, or to disclose. Therefore, taking this into account, there are more multi-layered benefits for everyone at every level of an organisation of becoming more adversity, culturally, and trauma-informed, infused, and responsive; and of being more preventative, proactive, compassionate, and healing. This is also about missing less people and hopefully reducing people falling through the radar; as well as minimising people being re-traumatised and having their trauma worsened or reinforced by the system itself. Examples of re-traumatising and stress-inducing experiences will be shared in the following sections.

I find it helpful to liken this universal approach to how hospitals where possible, respond to infections. For example, hospitals assume that everyone receiving services may have a blood borne infection. So, to reduce the harm, staff take various precautions and universally wear gloves, change syringes, and clean/dispose of items, and so forth; rather, than trying to identify the few people at entry of the hospital for whom this may apply for. They look to a strategy which supports all, is inclusive, prioritises safety, and aims to reduce people being singled-out, or being stigmatised. This is similar as to why it is helpful to have an adversity and trauma lens for all, especially as we don't know whom has experienced adversity and trauma, as well as having this lens is unlikely to cause further harm, whereas, not having it is more likely to add to someone's distress. As they say we should tread carefully as don't have emotional x-rays.

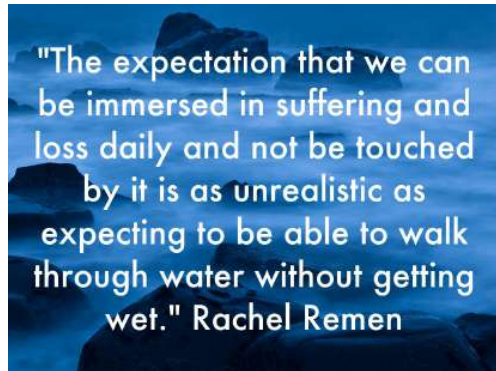
Another example of this is when you go to the hospital and you have to wear a gown when you are going to have an x-ray. For some people this is extremely stressful, exposing, humiliating, and triggering; for others, it is uncomfortable but tolerable, and for others, they don't even notice and are indifferent to the experience. However, if there is a process to make the gown procedure more comfortable, the people who didn't notice and were indifferent, it isn't going to harm them and it will probably be unnoticeable, for the people who were uncomfortable with it, changes will hopefully increase their comfort, and for the people who were feeling exposed and triggered it will make a massive difference to their experience and engagement with the service, which also will have a ripple effect on the staff's experience, on the efficiency of the procedure, and so forth. This is the essence of a universal approach.

We also know that the mind and body are intrinsically linked, and that trauma and stress can be held in the body and in our nervous, arousal, regulatory, immune, and sensory systems (the work of Bessel Van Der Kolk, Stephen Porges, Peter Levine, Pat Ogden, Vincent Felitti, Nadine Harris Burke, Babette Rothschild to name a few). Therefore, not only do we need to ask if the body could talk what would it say and be mindful and responsive to the whole person. But we also need to, as beautifully captured by Desmond Tutu, "Stop just pulling people out of the river and we need to go upstream and find out why they are falling in". In addition to how one's health can physically be impacted by adversity and trauma, building on

this, in the context of trauma, people may have had numerous experiences which can impact their relationships to their bodies and health. For example (just a flavour and will be different for each person):

- too much or too little touching.
- hurts or wounds not attended to, and medical attention not given.
- shamed or humiliated for certain body responses or needs.
- basic care not attended to e.g. Brushing teeth/ wet nappies etc.
- pain, injuries, and wounds as a result of abuse.
- one's body being used as a weapon and/or objectified.
- Bodies where boundaries have been breached and violated.
- Not taught or educated about one's body.
- Having to survive by disconnecting, dissociating, separating, cutting off from one's body.
- Discourses and narratives around body image, puberty, attractiveness etc.
- Attempts to survive and protect oneself, such as not washing or putting on weight in an attempt to keep an abuser away or to be less "attractive".
- Forcibly drugged or medicated.

And many others- please see my various books and the other people's works for more on the impact of trauma on the body.



Additionally, trauma informed is about everyone. To be a culture of safety you must become one. We know that working in health and medical settings can be highly pressurised, emotive, exhausting, and so forth. Even more so when over stretched and under resourced. We also know that in addition, those in caring and helping professions, are also more likely to have been drawn to the work due to their own adverse and/or traumatic experiences. This can include in childhood, adulthood, but also adverse cultural,

community, and organisational experiences which they may have experienced. Therefore, trauma informed services are also about reducing the occurrence of staff burnout, secondary trauma, vicarious trauma, and compassionate fatigue. This has huge ripple effects on staff retention, staff satisfaction, staff sickness, staff decision making, and so forth. See "A Treasure Box for Creating Trauma-Informed Organizations: A Ready-to-Use Resource for Trauma, Adversity, and Culturally Informed, Infused, and Responsive Systems (Dr Karen Treisman)" for several chapters on this area.

Having briefly explored some of the reasons why trauma-informed may be needed, some feelings and experiences from people who shared their stories will now follow.

### **Feelings and ways of describing difficult experiences:**

In the questions people received they were asked to describe their experiences (positive, negative, and all the shades in between) using 3 words. They were also given the option of describing their experience/s using a metaphor, an analogy, and so forth. The following words captures some of the direct quotes and feedback which were shared. Some were said

so many times, that they were grouped into themes. Please take your time to read, as they are more than just words on a page.

- *“Feeling out of the loop”/ “silenced”/ “unseen”/ “not listened to”/ “Invisible”/ “unimportant”.*
- *“Powerless”/ “done to”/ “helpless”/ “fragile”/ “vulnerable”/ “at people’s mercy”/ “desperate”.*
- *“Dismissed”/ “invalidated”/ “minimised”.*
- *“Lack of being believed”/ “overreacting”/ “silly”/ “trivialised”/ “time waster”/ “an over exaggerator”/ “a burden/a problem/ a pain in their arse”.*
- *“Violated”/ “intruded”/ “exposed”.*
- *“Shocked”/ “stunned”/ “disbelief”.*
- *“Embarrassed”/ “shamed”/ “humiliated”/ “ashamed”/ “not dignity”/ “Demeaned”.*
- *“Rushed”/ “unimportant”/ “looked at and treated with flippancy”. For example, “Just answer the questions, don’t tell me the other things”, “I don’t have time”, “that is irrelevant”.*
- *“Confused”/ “Scared”/ “Overwhelmed”/ “frightened”, “disoriented”.*
- *“Feeling like a lab rat/ a pin cushion”/ “a statistic”/ “a number”/ “a body”/ “an object”/ “an unusual specimen”.*
- *“Exhausted, depleted, tired and drained”.*
- *“frustrated, infuriated, and angry”.*
- *“Judgemental, shaming, and taking the expert position. For example, “You will get diabetes because you are so fat/ You will get cancer because of...”, “I’m sure you will want children you will change your mind eventually”, “There is no way that is a symptom of..., only to find when saw another specialist it was very common and obviously it was real as I was experiencing it.*
- *“As a family member being shut out, pushed aside, silenced- forgetting that to you, that person is your whole world”.*
- *“Feeling like they don’t care if I die because I am old” (one of many examples of ageism within services).*
- *“Am I worth their time?”, “Am I making a mountain of a molehill?”, “Can I disagree?”, “Am I being a baby?”.*
- *“So many assumptions made- no interest or care”/ “judged”/ “questioned”.*
- *“Thrown off a boat and drowning”.*
- *“Caught out in the rain in insufficient clothing”.*
- *“I would describe being lost on a desert island with sharks at the shore (my own fears or internal voice) but dangerous animals and terrain behind me (the health service)- most of the time I stay away from the edge of the shore in no man’s land, worrying about my health, but sometimes those sharks come too close (i.e. My detached retina) and I have no choice to run towards the dangerous terrain . . . and more often than not, I get hurt there and my fears were realised”.*
- *“I always pictured my husband and I as a small boat with our family battened down inside, caught in various weather ranging from calm seas to hurricanes. We could often see harbour lights, but it was a battle and exhausting to try get near. Sometimes, our child would be overboard, and we would be clinging on to her until we reach some calm.”*
- *Much of the above included non-verbal which as we know is as if not more important e.g. rolling eyes/ look of disgust/ guarded and folded body language/ no eye contact/*

*hiding behind a screen/ sighing/ looking disinterested/ looking preoccupied/ looking at their watch/ tone of irritation.*



values?

- ?? How might these experiences reinforce, resurface, activate, and retrigger people's past experiences of, for example, feeling powerless?
- ?? How might these unintentionally do more harm?

Having shared some of the rationale of trauma-informed thinking within health care and some of the feeling which people shared, we will now go on to consider further about how some experiences can add to one's distress and be re-triggering. This is also a huge reason why we advocate for trauma informed organisational commitment and change.

### **Retriggering and activating experiences:**

Health/medical systems and services should be helpful and healing; however, as explored in this paper, instead they can be stress, trauma, and fear-inducing. When people use services, it is generally because they are unwell, in pain, in discomfort, worried, and so forth. Moreover, depending on the context, the person may have been waiting for some time for an appointment, there may be cost and employment implications; and their health experiences can understandably be coloured by previous health/help/system experiences, the media discourses, family narratives etc. And then within this complex interplay of factors the experience within health care provisions, generally unintentionally, can add to the harm and distress the person is experiencing including being triggering, dehumanising, dysregulating, and so forth. This can cause system trauma and some people share how the system trauma

As said, these are so much more than words on a page. Pause for a moment and think.

- ?? How did you feel at a cognitive sensory, and body level when reading these words and experiences? Which if any struck a chord, resonated, were surprising etc?
- ?? How do we want people to feel?
- ?? How would you want to be treated or your loved one to be treated?
- ?? How do we want people to describe their experiences to themselves and to others?
- ?? What might the impact of these feelings and thoughts have on their overall experience, on the intervention itself, on future encounters with health care providers?
- ?? How do they feelings align with our own, our professional, and our organisational

and experiences can be worse than the reason for seeking help in the first place. This is why a universal approach is also indicated, as previously discussed because trauma can be unknown, unseen, invisible, and camouflaged. Some reasons why these experiences can be triggering will follow (these are just a flavour); and then some direct lived experiences will be shared to bring these alive.

- Health care inevitably can trigger and resurface feelings around authority and power. This can be particularly difficult for those who previously in the context of trauma have been made to feel done to, out of control, helpless, and powerless; and who have been exploited, let down, hurt, and abused by those in positions of power and authority. In the context of trauma, people can understandably also feel that their needs and feelings have been silenced, ignored, dismissed, minimised, and invalidated. These feelings can be triggered and re-felt again within health settings. This can catapult people down a chain of pain and into a memory time hole. These can be relational triggers/hotspots (e.g. feeling silenced/ ignored/ exploited), sensory, environmental, or physical triggers (e.g. a smell, a sound, a touch/texture, a sight, a building, a place, and so forth), emotional triggers (e.g. feeling trapped, powerless, stuck etc) and many others.
- Trauma can be an integrity, dignity, and body violation. Trauma get render someone feeling out of control, intruded on, invaded, and powerless. Trauma can include being touched in painful, unwanted, non-consensual, and cold ways. Trauma can make someone feel objectified and dehumanised, and so forth. These experiences can be mirrored, echoed, and felt within health and medical settings/procedures.

These experiences not only can add to people's harm but can have a ripple effect on people's trust to and engagement with services, people's "compliance and adherence" to interventions, people's tendency to wait till things have escalated or in crisis until seeking support, and so forth. This has psychological, relational, and emotional consequences; as well as physical and economic. Therefore, we need systems that resist re-traumatisation and do not add through system trauma further harm.

The above information will be bought to life with some direct quotes and experiences. These may be difficult and emotive to read, so please be mindful about where you are and how you are feeling. They are not intended to shame or blame people but instead are about putting a person behind the statistic and stopping and thinking. Sometimes, particularly, in overstretched traumatised systems we can be on autopilot, we can be in our survival brains instead of our thinking brains, we can react and act instead of reflecting. Our minds can be full instead of being mindful. It can be side lined or diluted how we make people feel. As a practitioner we might do something numerous times a day but to that person it is their only time and often holds a lot of weight for them.

*"The doctor sent me into a full-blown trauma response during a gynaecological procedure and instead of stopping, slowing down, or talking to me, he pushed through without ever acknowledging the state I was in."*

*"After having a still born baby I was placed on a busy ward full of women and their happy well babies and left alone to it- it was horrific and felt like ongoing torture".*

*“Some of the responses to me after self-harming due to abuse and so much pain was- You are so beautiful why would you do this? You don't want to be ugly with those scars. Cheer up it can't be that bad. It can't be that bad to be this sad. What have you got to be so sad about? It's much worse for other people, you should be grateful for what you have”.*

*“So much echoes and mirrors my early abuse, not stopping when they should, not explaining the procedures so feel like an object, not believing me when I report symptoms, viewing me negatively, the list goes on and on”.*

*“I was badly burned. I entered the building where there was strange graphic fear inducing images of burns on the wall, a red abstract painting that looked like blood and burns combined; and nothing to drink despite being overheated and dehydrated because of the burn. Then I was stripped naked and left standing in a room whilst the nurses left to get some cream, they left the door open for anyone on the busy ward to see my naked body. Several people walked by and stared in- it felt incredibly exposing and inhumane”.*

*“When I go to the dentist just being made to lie on a bed, have something inserted in my mouth, and smelling the chemicals can be a sensory overload and triggering experience”.*

*“A doctor was asking me questions in such a tick box robotic way and then asked in such a matter of a fact way, parents are they dead or alive? My mum had just died weeks earlier. The appointment was about my chest. It felt so cold, irrelevant, and when I got upset, he looked completely shocked and confused; and awkwardly stared as didn't know what to do”.*

*“The doctors had gone on and on about my immune system and keeping as clean and away from germs as possible. Yet when I went for my appointments. The toilets all had poo in them, there was toilet paper on the floor, the sheets looked unclean; and I just thought how the hell can I trust these people and believe their advice”.*

*“When I had just had my baby and was still recovering from the c-section, a midwife just drew the curtain grabbed her out from the cot next to me and started walking away with her. It felt like she had kidnapped her. I had no idea what was wrong, who she was, where she was taken etc. It would have taken her seconds to introduce herself and to explain that she needed a blood test and would be back shortly. How would she feel if that was her baby”?*

*“It took me 6 weeks to get a GP appointment, plus having to take the day off work and get childcare. I walked in there with 3 serious concerns. He was snappy, short, and irritated. He only got to the first one. He was dismissive about the second too and rushed me out. Turns out a while later I was diagnosed with cancer, I often wonder how my treatment would have differed if caught earlier, but also made me feel like a hypochondriac so hadn't returned for a while”.*

*“When I was 12, I was beginning to go through puberty. I had lichen sclerosis so had been in numerous hospital appointments. It was a rare condition so was often researched and discussed at medical meetings etc. However, that time, lying there naked conscious of puberty and my body, a whole group of male students stormed into the room, pointed, started writing notes, staring, whispering to each other etc. It took my mum to tell them it wasn't appropriate and to leave the room, and the response from the consultant was it was a teaching hospital”.*



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*“6 monthly smears, then yearly smears which took a huge toll on my emotional and mental health. I just wish professionals especially those carrying out very intimate tasks were trauma informed”.*

*“I was physically handled on a number of occasions and this caused me lots of distress. I know now this triggered me back to the abuse, I panicked when being held by adults. Furthermore, I had to be observed while bathing and this added another level of distress. As often when home I would have to watch/join him in the bath”.*

*“I had to walk around the hospital corridors with one of those open gowns feeling completely exposed and stared at- it was humiliating, and I felt like that child again who had been humiliated and my body disrespected”.*

*“I would say professionals reinforcing the secretive narrative of my abuse experiences by not talking to me, explicitly naming, or asking me about it”.*

*“They spoke to him like a child, a nuisance, they left him in there whilst she went on her break and with him in a distressing state, very unapologetic, and when she returned and cleaned him up like just another task on her list, this experience has stayed with him for a long time”.*

*“I weed in the bed due to my bladder issues and was so embarrassed and waited almost an hour to buzz the nurse as didn't want to be a pain to her and felt like a child. She scolded me, huffed and tutted and changed me in the most rushed irritated way”.*

*“I went to see the gastroenterologist, and he was feeling my tummy for tenderness, and then asked me to turn onto my tummy and the next thing I felt his finger inserted up my bum- with no explanation or communication. I got such a shock, was so confused, caught off guard, and felt violated”.*

*“Hospitals are very hard for me. My mum died in one when I was young. My dad died in one a few years later. My oldest sister died too. They just are scary eery hard places for me. Each time I have to step back into one is terrifies me and my mind goes to the worst place”.*

*“I could probably write a book at how often I was told I was attention seeking, stitched up without Local anaesthesia, treated as a drain on staffs time and responses, told that why should they had to waste their time on me and I would just do it again when they had people who were sick through no fault of their own to treat. ”*

*“I needed to have a blood test, or my blood pressure taken, and my 20-year-old scars are viewed, most health professionals look away and I sense there perception of me as a professional changes. It's almost if I can't escape my past and I'm taken immediately back to how I felt as a teenager”.*

*“Having a doctor call to ask if I would take part in a study around celiac which involved some invasive testing and when politely declining saying this is why you will probably get bowel cancer because people like you stop research being done and better treatments being able to be created”.*

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*"I was in treatment for a diagnosis of anorexia. Eating was very triggering and difficult. No one ever asked me about my trauma history whilst on the eating disorder unit all those times. Eventually when a trauma therapist helped me, she asked me about what happened when I ate, and I was able to explain and connect to how each time I ate it catapulted me down to a memory of being forced to give a my uncle oral sex".*

*"When I told the nurse I was HIV positive, she looked disgusted, moved her seat back, and put soap without water on her hands".*

*"When the doctors told me, I needed medication and I politely explained I felt really worried about taking medication. They were rude and dismissive. If they would have been curious, they would have learned that as a teenager I was repeatedly raped and forced to take drugs during the rapes. Not to mention how my mum was addicted to drugs and I was so worried to go down that road, so it was a double whammy".*

*"When I walk into a doctors surgery and there is disinfectant or all those clinical smells it just shoots me back to when I was a kid and my mum had been beaten up by my dad and afterwards she would have to clean up her cuts with disinfectant and then often bleach and clean the floor where all the mess had been. So naturally I feel on edge. When you did your training about sensory triggers, I had a lot of lightbulbs moments, that was very amazingly healing".*

*"I don't really feel it should be up to survivors to educate professionals that are working in an intimate way as to what trauma can do to the body as when I am going to an appointment I am literally using all my regulation tools to survive it, but time and time again I feel like I have to educate and then I am left to deal with the emotion that this invokes."*

*"Each time my daughter (has learning disabilities) showed her distress, she was told to "settle down" and "calm down". When she tried to communicate what had happened to her, the response was that she didn't have the capacity to understand what abuse was and that she had gotten confused".*

*"As someone in a wheelchair, I often people like speak through me, or direct it to the person I am with, as if I am half a human".*

*I had a phone consult with a GP. I was in agonising pain and not someone who often seems medical help. She was short and snappy when answered. She started asking questions as I tried to answer she said I just need yes and no, be quiet and listen. Then as she asked about history, I started explaining to her some key information which was directly related and after about 3 words she said get to the point. I felt so dismissed and shut down, and it made me just retreat and not seek further support despite the symptoms continuing".*

*"I went to the doctor to discuss my broken wrist and yet they went on and how about how obese I was and how I needed to change my lifestyle. They have no idea what I was trying, what my body image was, why it was difficult; and besides I went to talk about my wrist- I didn't expect a lecture which was clearly delivered in a rude, patronising, and attacking way".*

*"I went for months and months to the doctor talking about feeling weak, tired, dizzy and so forth. Each time as I was a uni student they were dismissive just saying it was stress and*

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*partying. I wasn't partying a lot or stress. Months later I was driving and lost my vision suddenly. I ended up admitted in hospital with serious anaemia amongst other things".*

*(from my book)- Mustafa was made to go to 11 different services to get his different needs met whilst having to navigate the complex social care, legal, education, and health systems; and without speaking English or being familiar with the systems. He said he felt like a "human pin ball".*

*(from my book). Fatima shared with her GP her story of abuse and torture both in her home country and in the refugee camp she had been in. The GP continued looking at their computer and said, "mmm, ok". There was no acknowledgement, connection, validation, empathy, appreciation and so forth. She then went on to share her spiritual beliefs and faith and noticed an eye roll and a look of minimisation.*

*(from my book). Cece was on an inpatient ward, and when she "acted-out" was held down by 4 strange men who pulled her trousers down and injected her with medication. This experience was not dissimilar to a past experience of abuse.*

- ?? How do you feel physically, emotionally, and from a sensory level when reading these stories and experiences?
- ?? Which really resonated with you? Which others would you add?
- ?? How are these from a power, privilege, fear, safety, trust, the multi-sensory experience, communication, injustice, oppression, humility, relationships, collaboration, and much more lens?
- ?? What might be the ripple effect of these experience?

Having shared some of the ways in which health experiences can be harmful, we will go on to think about how these experiences impacted subsequent feelings and actions towards health settings/practitioners.

### **What were some of the ripple effects of these experiences and how did it shape one's relationship with, attitude to, and behaviours towards future health care?**

As shared previously not only do these experiences leave an imprint in the moment but they can shape, influence, and guide people's later responses, feelings, and behaviours; as well as how they would describe, recommend, and story healthcare to their friends, family, and so forth. This can change how soon someone might seek treatment, the anxiety and feelings which might colour the experience itself, the avoidance of treatment, the mistrust of health services and interventions, and so forth. As previously shared, direct quotes will be used and where numerous people said similar things, these will be grouped together.

*"It made me cautious, apprehensive, and uneasy".*

*"Honestly, I avoid it like the plague, feels like it has made things worse in the past, so I don't trust it".*

*"I will wait till I can't wait anymore".*

*"I have a feeling of dread and tension before I have to go to any appointment. I have to gear myself up to be ready".*

*"I have to say I still have flashbacks and nightmares to my time and treatment in the hospital, it really has had a lasting impact. The emotional distress has been worse than the accident itself".*

*"I've just had no answers so many times, I just have now gone into why bother, shut down mode- so avoid avoid avoid. There is only so long can bang your head against a brick wall".*

*"Having cancer was and is horrific but honestly the treatment and stress around chasing people, organising appointments, being cancelled on, not being communicated with and all sorts has been worse than the cancer".*

*"The legacy of this made my husband more fearful initially about going into hospital and feeling like he was a "problem" which has been something he's had to work through in his emotional recovery".*

*"Left me very sceptical and weary of services".*

*"I often am so anxious about the appointment, that I go blank, freeze, and/or can't take in anything they are saying".*

*"I have been so much more anxious and stressed in this pregnancy which can't be good for the baby. I just have the ghost of the last birth mistakes hanging over me".*

*"I just feel like I will be treated like I'm silly, a baby, and time waster so I avoid going, and if I really have to, I just sit there nodding and not really sharing what is actually going on".*

?? How might these beliefs and perceptions impact future interactions or engagements with health practitioners?

### **Healing, helpful, and stress/trauma reducing experiences:**

It feels important after sharing some of the difficult and distressing experiences to also balance and share some of the positive, helpful, and healing experiences which people shared in their stories. These are as important to integrate and translate into some recommendations; and as we will see sometimes the small things are the big things. "Every interaction is an intervention" (Treisman, 2018).

*"However, after this horrible experience, I talked with my main doctor and she was very validating, apologetic and helpful in answering my questions and getting me resources. This was very healing, and I am forever grateful."*

*"The ambulance driver who listened to us and supported us through our tears on the way to the second hospital. Look out for the helpers".*

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*“As an overall metaphor- being on a tiny boat without an oars or motor in a huge and frightening storm, not knowing where the boat is going but every now and again the sun shone, and the seas calmed for a while”.*

*“I was alone again as my mother was unable to be with me. I remember it was Christmas and my birthday at the time I was in. There were two nurses who really stick out in my memory who made a fuss of me and another boy on the ward. The nurses made water pistols out of syringes and we had a little paddling pool in the middle of the ward. Having this good memory of my time in hospital gave me real hope that people do care. I think showing that, giving that time, not only made a difference to me then but also now as an adult reflecting back on my childhood. Those nurses may not have realised this at the time, but their kindness meant a great deal to me.”*

*“Finally meeting a health professional, that allowed me to leave a door open, move the furniture to be by the door and place theirs in a position that kept me feeling safe”.*

*“When I had my son, the treatment could not have been more different. I was treated with such kindness; they got the male doctors out of the room and I had a lovely student midwife who I think must have had some trauma training or lived experience as I felt so cared for. It was such a different drug free experience (by choice) but I felt very much in control which was important to me. Just being listened to and respected – totally made a terrifying experience to one that I reflect on now as being very empowering.”*

*“Having a doctor who truly listened and didn't make me feel rushed. Listened to each fear and made me feel validated”.*

*“Having a nurse hold me hand when in pain and just be there- she probably doesn't realise it but it made a world of difference”.*

*“Having a doctor who put his laptop down and listened. Asked questions that allowed me to tell my story and to give the pieces of the puzzle which then meant he was able to get to a diagnosis as the others just were so focused on their agenda and rushed. He also took the time to say I'm so sorry this must have been so tough. You are a trooper. Things are going to be better. You did the right thing coming here”.*

*“The nurse who took the time despite being so busy to read a poem from my dad's favourite poetry book each night and would send us text updates as we lived far away”.*

*“A doctor who just was very aware of consent. He explained each time what he was going to do and why. He told me I could tell him if wanted to stop and he would stop, and more importantly he did. He gave me an option to have someone else in the room. He asked me what he could do to make me feel more comfortable”.*

*“It might sound silly but just have a couple of moments to chit chat before diving into the serious stuff. Small things make a difference. I instantly felt like a human being and some of my stress dissipated”.*

*“When I got my cancer diagnosis, the doctor said he knew I was unlikely to remember what he said next as I was clearly in shock. So, he gave me the option to record our conversation on the phone and said he would write jargon free notes if not that I could refer to. I was also*

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*so moved when he took the time to phone me a few days later to check in and see how I was and if I had any questions”.*

*“After my transplant I really wanted to help others and become an advocate. It isn't for everyone but really helped me to share my story and fundraise. The doctors not only were so supportive and encouraging of this, but they took their time to come to events, to make videos for YouTube and all sorts”.*

*“When I went for my yearly neuro review, the doctor said don't rush, take your time and I am here to go through each question. This is your time and it is once a year and important that you have the opportunity to be heard. I breathed and felt so cared about”.*

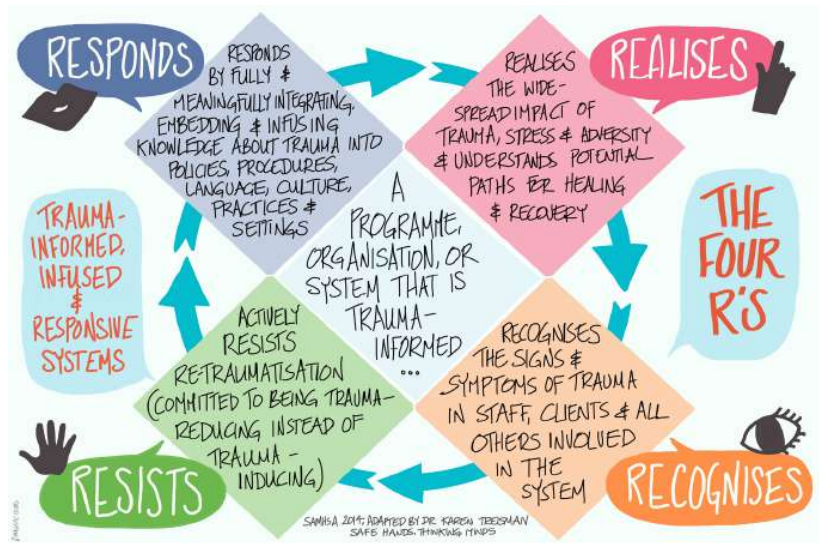
*“Sometimes, it is the small things- changing the pillows, giving an option of meal choices, playing gentle music, saying your name, making eye contact etc. I have had a few of those really personable people and it doesn't take more time but makes a mountain of difference”.*

- ?? What has made a difference to you as a “patient”?
- ?? How would you like to be treated or your loved one?
- ?? What of these do you already do?
- ?? What of these can be integrated into your practice? So often it is easy for them to get lost amongst pressurised, under resourced, and emotive environments. Again, why staff wellbeing is so crucial.
- ?? How do these link to why you do the work you do? How you want people to feel?

**Some brief recommendations for health and medical care including linking to the values and principles of trauma informed practice; these also incorporate the people who wrote their reports wishes:**

This is a brief paper intended to plant seeds for further training, consultation, supervision, and reflective practice. It is beyond the scope to go into the minutia of recommendations, especially, as these are not a cookie cutter approach and need to be tailored to the specific context. However, some recommendations will be made by connecting them to some of the trauma-informed guiding values and principles; alongside using some direct quote recommendations from the 390 people. These are hugely expanded on with reflective questions and accompanying worksheets in my full colour 2 volume book- trauma informed organizations (Dr Karen Treisman).

Some guiding aspects of trauma-informed practice has been helpfully created by SAMHSA, referred to as the **four R's**. These are **realising, recognising, resisting, and responding**.



### **Realising:**

The first R is about realising, being accepting, and being aware of the multi-layered and widespread impact, prevalence, and common occurrence of trauma and adversity, through an active engagement with this knowledge, through meaningful high quality training,

through reflection, and through the rationale part of the journey (understanding and committing to the why), and so forth. This realising also includes acknowledging and holding in mind that anyone may have experienced trauma and adversity which may or may not be known to others, it is not and us or them. This is also about realising the current and historical impact of trauma and adversity on ourselves, individuals, families, teams, communities, organisations, and societies.

### **Recognising:**

This second R is for recognising how the trauma, adversity, inequalities, and stress can show themselves, and present themselves through symptoms, signals, behaviours, coping and survival skills in individuals, in families, in communities, in teams, and in systems (including through mirroring and parallel processes).

### **Resisting:**

The third R is about actively recognising and acknowledging that the systems/interventions/practices themselves can add, reinforce, and exacerbate the trauma and stress; and within this can be re-traumatising, dysregulating, and triggering. And therefore, the third R is about committing to and finding ways to reduce, resist, and decrease this re-traumatisation, and aim to be trauma-reducing and healing, instead of trauma-inducing and harmful.

### **Responding:**



The fourth R is around actively responding to what we know about adversity, trauma, and dissociation by trying to find ways to embed, infuse, and integrate this information, understanding, and knowledge; into the attitudes, practices, culture, structures, and policies of a team/organisation. This is about moving from knowing and being informed, to being, feeling, doing, and actioning. This is also about sustainability and hardwiring



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the ideas and values into the fabric of the organisation. This is about moving from “this is what we do” to “this is who we are”.

For an additional 5 R’s which can be incorporated please see “A Treasure Box for Creating Trauma-Informed Organizations: A Ready-to-Use Resource for Trauma, Adversity, and Culturally Informed, Infused, and Responsive Systems (Dr Karen Treisman)”

🤔 Take some time to look at each R (Realise, recognise, resist, respond). What do these mean and look like to you, to your team, to the work, to the organisation? Can you think of examples of them? How do they apply and resonate with you and the work, or conflict and jar? Are there ones which are fore fronted, and others which are less developed? And so forth.



Having looked at some of the four R’s and how they are relevant we will look at some of the **core trauma-informed values** and briefly touch upon some of the ways these can be incorporated.



## Safety and trust

Without safety everything else exists on fragile ground. What is being done to support someone to feel culturally, emotionally/psychologically, relationally, morally/ideologically, and physically safe?

This includes so many elements, from asking someone for their consent and listening when someone says no; supporting someone to have a signal or word when feeling unsafe or need to stop or have a break; considering and being sensitive to possible triggers and hotspots; and having skills and processes to support if one does become dysregulated.

This also includes aspects such as being mindful of one’s position of power and privilege and how this can play out in the patient-practitioner role. One of the main elements that should be discussed and reflected on in

supervision and reflective practice. This also includes thinking about elements like one’s privacy and dignity e.g. (Of course, these will vary for each person but things like asking



permission before touching someone or doing something; and where possible, closing doors when someone is undressed or undressing or having a private conversation, knocking before entering, showing one's ID badge, supporting someone to have a loved one with them, having water and tissues on the table, breaking a procedure down into steps etc). This value of safety is also about reflecting on for example, does someone feel safe to speak up, to share their concerns, to show their vulnerability, to communicate their distress- do they feel listened to? This can be echoed within the staff team, for instance, do people feel able to respectfully put in a complaint, to whistle blow, to speak up or to question something in a team meeting etc.

Some further examples follow:

*"I don't really feel it should be up to survivors to educate professionals that are working in an intimate way as to what trauma can do to the body as when I am going to an appointment I am literally using all my regulation tools to survive it, but time and time again I feel like I have to educate and then I am left to deal with the emotion that this invokes."*

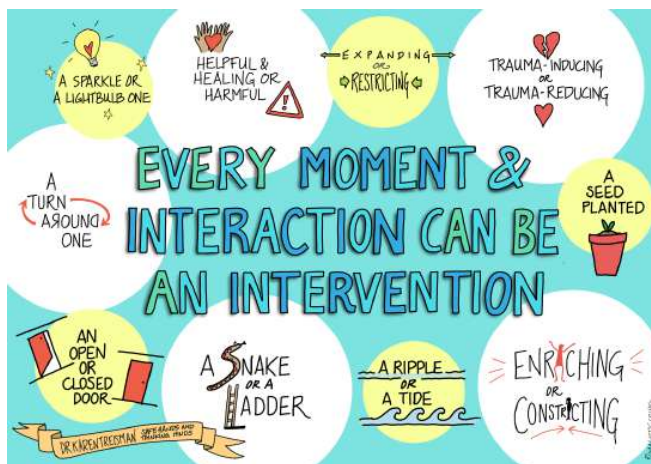
*"Learn about triggers- you might think you are just wearing a mask same as everyone does but remember to me, a mask represents that the man who was hurt me; or you might think stripping is just a body to you and you see hundred and that's it, but in the context of being forcibly stripped it is a whole lot more to come people".*

*"The small things make a big difference. Having sheets pulled over my body, letting me choose where I sit, giving me clear info about what to expect".*

*"Once a doctor does something without checking like touch me, I'm in hypervigilant mode, I just feel this isn't someone I can trust".*

*"I won't feel safe going to a doctor or nurse until I know they are trained properly in trauma informed care, and not just a few hours tokenistically but a good high-quality training with reflection and ongoing practice. This should be standard practice".*

### **Curiosity, understanding, empathetic, reflectiveness, and compassionate:**



This overlaps with so many areas but in essence capturing something in a brief way includes things like:

How can we see the person behind the label or the symptoms (particularly important in the context of diagnostic overshadowing, attentional bias, and confirmation bias). And within this, how the person is not the “sickness/illness/disorder/ problem”; and should not be reduced to it or defined by it.

How can we see the person behind the gown or bandages? How can we see the person within the context of their life experiences and beyond? How can we see the person as the expert of their own experiences?

What is important to them/ what matters to them? What do they need? What can we do to make them more comfortable before, during, and after?

What is the impact of these “symptoms” on their life, on their sense of identity, on their day to day activities, on their family? How can we take the time to listen, to not just see the person as a statistic or tick box? What is their understanding of their symptoms and to they make sense of them including within their family and cultural context? What are their hopes and goals? If someone is dysregulated, disconnected, or whatever it might be, are we able to be curious about what might be going on for this person, if the behaviour could talk what might it say? This way of being actually saves time because we avoid multiple wasted appointments and missing key information; as well as a more positive experience for all.



As shared above, medical practitioners are not expected to be therapists, but they can and should be therapeutic, human, and caring; and certainly not add to the distress (if can be reduced or avoided). Sometimes, simply showing someone that you are there to listen. That they have done the right thing, that you are sorry for what they are experiencing, that it sounds tough, and that they are not alone can be huge and affirming. This extends to simple but important elements as to how we welcome someone,

how we check in with people, how we validate people’s concerns etc.

Remembering that as a practitioner you might be seeing numerous people that day and might do that procedure over and over again but to that person it is possibly their first and only time. It is so important to perspective take and stay connected to this. As said many times previously, how would you like people to feel, how would you want to be treated or a loved one? Some of these are captured by the positive experiences above but also from some of the following direct quotes.

*“Respect and value people- see the person behind the injury”/ “See beyond the notes on a screen”.*

*“Look in the eye of someone- connect”.*

*“Ask questions- be curious- the person knows themselves best- you aren’t in their body”- they are the expert of their own experience.*

*“Start from a position of trust, dignity, and respect”.*

*“The importance of dignity! Covering one’s body up/ support staff for giving their time to put lipstick on someone/ giving some privacy”.*

*“Be warm and understand- people are often scare and looking for some sort of kindness”.*

*“Remember it is the most important thing to that person- not just another task in shift”/ “One person’s trauma is a medical person’s day to day non- doesn’t diminish incredibly scary for that person experiencing it”.*

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*“I guess for me the take home message is to be kind, read up long term somatic reactions to trauma especially if you perform intimate tasks or are a dentist. I feel if people were trained in this area it would take a huge amount of responsibility off me for trying to educate whilst additionally struggling to process the experience, and allow as much control as you can about how people would like procedures carried out, as sometimes it can be something as small as pulling a curtain round the bed or area for blood tests. It won't necessarily cost time or money just 'care, kindness and respect'”.*

There is also a huge part about practitioners having a culture that is about learning, developing, and growing. A culture that allows people to think, to reflect, to acknowledge the impact of the work, to share concerns, to magnify things people are proud of. To have a space to process and digest what they are doing and so integrating a culture of high quality and meaningful reflective practice, collective care, and supervision (this is different to line management and task focused).

For a whole chapter please see “A Treasure Box for Creating Trauma-Informed Organizations: A Ready-to-Use Resource for Trauma, Adversity, and Culturally Informed, Infused, and Responsive Systems (Dr Karen Treisman)”.

### **Communication and transparency:**

Think carefully about the power of language and the words which we use. Words can stick, shape, and wound. They can be powerful and yet they are free. They can instil hope and support someone to feel heard, seen, and validated; but equally they can be humiliating, shaming, minimising, cutting, and so forth. They can send someone down a memory timehole and a chain of pain. They can pierce, they can alienate, and they can replay like a broken record. Communication is so much more than just how we talk it includes wider communication such as the questions on the assessment forms from how accessible they are, to how culturally sensitive they are, to how triggering they can be, to how people would like to be called and how their names are pronounced, to the pronouns they would like used etc.

Communication also extends to things like the reading material, brochures, and posters which we see. For example, the posters in the waiting room (e.g. NO and DON'T signs everywhere/ Breastfeeding is best posters/ Graphic fear-inducing images/ keep calm and carry on signs/ chaotic outdated display boards/ disorienting confusing directions in hospitals etc).

This communication also extends to the wording used on the letters and in the text messages. So often the wording is alienating, acronym heavy, and full of jargon which not only creates miscommunication and confusion but feeds into them and us and othering. Also, what might this be like for someone where English is their second language or for someone who has learning difficulties or disabilities, or for someone with executive and cognitive function difficulties, or someone with speech and language difficulties, or for someone who is in a dysregulated heightened place and so it might be harder to process and absorb the information and so forth. The wording on letters (e.g. Did not turn up letters) can also feel blaming, shaming, and uninviting- small tweaks can clearly communicate the point in a more welcoming and inclusive way. Including for example, things like when someone is referred to as patient or middle-aged lady, as opposed to their name.

Building on the above in terms of dialogue and how we communicate. Is the person looked at using eye contact? (Communication also extends to eye contact, facial expressions, tone of

voice, body language and so forth. How a rolling of the eye, guarded body language, a look of disgust, a sense of disinterest can have a powerful impact).

Is it a monologue or a dialogue? Does the person understand their, for example, diagnosis or intervention plan? Do they agree with it, how do they feel about it? Has the person been communicated with before, during, and after a procedure about what is going to happen, why, the rationale, what to expect, what and how to prepare, and so forth? Do they feel able to speak up or to ask questions? Are there effective mechanisms of feedback for patients and staff?

Are key people supported to be involved in the communication such as family members (including in adult and older services- people do not function in silos or in vacuums)? If difficult news needs to be delivered is there thought around how to convey the information in a transparent and honest way but also one which is clear, accessible, sensitive, and thoughtful. We can say what we mean without being mean saying it.

We also need to be open to having questions asked, with people needing clarity, repetition, and/or disagreeing. We also know that emotive conversations can sometimes be hard to recall as people can be stuck, frozen, in shock and so forth. So, thinking about how this information is conveyed is very important (e.g. In a regulated place, with someone there if they want, recording it, repeating it and describing it in a few different ways, using multi modes of communication, such as props and videos, sending clear bullet point summary, having a phone line or opportunity to ask questions, having frequently answered question documents, conveying info through videos or more accessible info like an infographic or graphic designed posters etc). A whole other area which cannot be covered here but is discussed more in my books is about the effective use of interpreters and thinking about how we use interpreters in a safe and effective way.

It is also so important for systems to consider communication with each other and amongst teams and systems. So often people can feel like human pinballs and the services can feel so fragmented and disconnected. This is not helped by having IT systems and patient logging systems which don't coordinate but this means that often one is left repeating the same information over and over again, having test results not shared with another professional who needs them so a wasted journey or incomplete appointment; and/or having repeated appointments which do not connect the dots or look at the whole picture. Some examples around the theme of communication follow.

*"I think professionals can have compassion fatigue or they are so used to similar stories that they forget how scary it is for carers, and also assume that they are the expert and brush aside family observations."*

*"I don't care about you sounding clever, just talk to me so I understand, I am not stupid, I'm pretty smart, but clearly I am not medically trained- just let's have a conversation"*.

*"I sat in the doctor's surgery and they had a keep calm and carry on poster and I already went from zero to hundred from being in the waiting room- keep calm and carry on, I have f'cking terminal cancer!"*.

*"6 monthly smears, then yearly smears which took a huge toll on my emotional and mental health. I just wish professionals especially those carrying out very intimate tasks were trauma informed and could approach stuff in a sensitive way, it's not necessarily about not asking the questions about swabs but asking in the right way. I often think if the question*

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*could be asked – is there anything that will make this process easier for you would be so helpful”.*

*“The threatening letters if you miss an appointment need to be changed. No wonder no one wants to go back. On three occasions they cancelled the appointments and then said I hadn’t turned up and blamed me! On another occasion they booked it whilst I was on jury service, I called the number over 10 times and left voicemails and no one answered. I agree that we should call and act responsibly, and I know lots of people don’t do this which is not OK- but the tone and way we do it makes such a difference- like you taught us in our power of language workshop- that training was revolutionary it should be compulsory”.*

*“Sometimes, the process is so infuriating you have waited months to see a doctor and then you finally see them and they don’t have access to the other specialists notes or results and then the only action is for them to get them and you have to wait for months later in pain. Then when you return it is a different doctor so not only have months gone by with nothing happening but now you need to repeat the whole story and sensitive information to another person- lack of communication and continuity of care”.*

*“I went with my mum to an appointment and it was so awkward and uncomfortable it said transgender on my notes, and the doctor constantly was tripping over himself and saying the wrong words or trying to avoid referring to me, and then he wasn’t making sense as he was clearly overthinking it. I mean it would be great if you could educate yourself and if not cos you are busy and no one can be expected to know everything, then just ask, be curious, show interest, and I’m happy to say”.*

Please see [www.safehandsthinkingminds.co.uk](http://www.safehandsthinkingminds.co.uk) for an online module on the power of language or “A Treasure Box for Creating Trauma-Informed Organizations: A Ready-to-Use Resource for Trauma, Adversity, and Culturally Informed, Infused, and Responsive Systems (Dr Karen Treisman)”.

### **Strengths based:**

Whilst, it is important to focus on the “problem” in health care settings, it is also important where appropriate to think about, acknowledge, and magnify what is going well, what strengths and skills does the person/ team/organisation have? How are there messages of hope and recovery? How is progress noticed and celebrated? Are best and innovative practices magnified and discussed as much as serious case reviews and “mistakes”? Are there opportunities to advocate for others or to share messages of hope and advice?

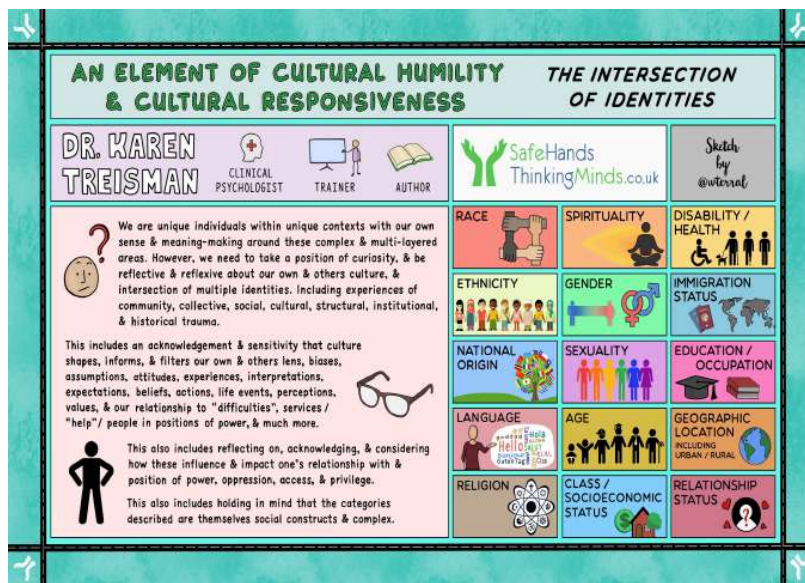
*“I’d like someone to also give me some hope and comfort”.*

*“It would be good if I wasn’t just seen as problem and we could also think about progress”.*

*“Being told I was brave and courageous were so needed”.*

*“Hearing stories about other people who made it, in a realistic non cheesy way, really gave me something to hold on to”.*

*“At work it is so nice and just fills your tank when we celebrate each other like on a birthday but also when we share good news or celebrate a patient’s progress or something that we are proud of”.*



**Cultural humility:**

This is a huge area and only briefly touched upon here so will not do justice but, for example: How are we thinking about the intersectionality of identity for each person (including race, ethnicity, religion, spirituality, socioeconomic status, immigration status, sexuality, age, gender, language, and many more)?

How are we thinking about how our own biases and lens is colouring, shaping, and influencing how we are responding to that person or group of people? What assumptions, values, and attitudes are at play? How is power and privilege impacting the decisions made, attitudes, responses and so forth? What barriers and obstacles are there around, for example, the accessibility of our services or differences in responses? How does someone’s own lens impact their conceptualisation, understanding, and perception about, for example, a diagnosis, medical explanations, the role of spirituality, gender roles, family scripts around health/death/treatment, and so forth? How are we reflecting on health inequalities and aspects such as system oppression? Are we considering the interplay of factors such as housing, poverty, racism, social exclusion? The list goes on and on. Please see chapter 9 “A Treasure Box for Creating Trauma-Informed Organizations: A Ready-to-Use Resource for Trauma, Adversity, and Culturally Informed, Infused, and Responsive Systems (Dr Karen Treisman)”.

**Collaboration, mastery, agency, voice, and choice:**

Again, this covers a huge range of areas and will be briefly touched upon in this section.

However, these values include things like:

Are services being led, shaped, influenced by people using them? Does the person feel done to, or with? Is there an acknowledgement of the power dynamics? Is there an awareness that someone can be triggered when feel powerless or out of control? Is there respect and honour that the person is the expert of their own experience? Is the person given, where possible, choice in their appointment/intervention? (This will vary depending on the health context but might be things like having someone come into the room with them, choice of positioning of



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seat, different intervention options, appointment time, having a comfort item with them, how they are called and referred to, who they see etc).

Is the person clearly communicated with about what is being done and why; including what to expect? Are their voices heard and listened to? Is there space to feedback on one's experience and for this to be heard and acted on? Are there clear channels and forums to feedback, complain, shape services, and give suggestions?

Sometimes, asking questions can also support people to feel their opinion matters and is valued; and also, opportunities for agency and mastery. Such as, "Are there questions you wished I asked that I didn't?", "Or if you were the person asking the questions what do you think I have missed?", "When you leave this room what would you like to have happened?", "Are there things I could have done differently, are there things I can do to improve- we all have blind spots?", "If you do begin to feel distressed or uncomfortable, what shall we agree to do? Would you like to agree a technique or a signal?", "Do you have any particular triggers, hotspots, or boundaries that I should know about so I can try to support you?" and so forth.

I hope that this paper plants some seeds, gives you some food for thought, creates some reflections, and leads to some commitments. I hope it does some justice to the incredibly moving and powerful stories which people shared with me. I was honoured to receive them and to have the platform from which to share some of their richness. This is just a small flavour of those experiences.

Thank you for taking the time to read and look forward to ongoing dialogues

For more on trauma-informed organisation change please see "A Treasure Box for Creating Trauma-Informed Organizations: A Ready-to-Use Resource for Trauma, Adversity, and Culturally Informed, Infused, and Responsive Systems (Dr Karen Treisman)". For a range of trainings, online modules, and consultation please visit [www.safehandsthinkingminds.co.uk](http://www.safehandsthinkingminds.co.uk)