

# Stories of Pain & Gain



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# Introduction

**These stories are based on a collection of experiences across Queensland and arise out of interviews conducted through the Mind-Life project. These interviews were part of the Human Centered Design process. While facts and experiences in these stories are true, they have been modified and changed to protect individual identity.**

**Several themes emerged and were sorted into statements that invite us to consider, “How Might We create resources that will”:**

- prevent Groundhog Day experiences?
- help us to dance better together?
- be a cheerleader in each other’s lives?
- ensure “access all areas” passes are available to everyone in our community?
- help you to not “other” and “out” me? (even when your intentions are good)?

**This is a resource for both help providers and help seekers. The aim is to provoke reflection by trying to understand each character’s experiences and explore how you may respond.**

**How you use the stories is up to you. Be creative.**

**Here are a few suggestions:**

- You can use this resource individually or in a group.
- If using individually, write or journal your thoughts and responses – so you can share with someone later.
- If in a group, decide how long the group session will be.
- Decide on some group rules, e.g., no judgement, speak for yourself, do not speak over another person, be curious.
- Appoint somebody to host the discussions and keep time.
- Answer the questions honestly, try and stretch your thinking - maybe ask some more questions.
- Decide what you will do to either learn more or change your practice.

**A clue: the key to this practice is empathy and curiosity.**

## Questions to consider for each story

- What do you notice about this story?
- What stands out?
- Does anything surprise you?
- Does anything shock you?
- What moves you?
- Does anything anger you?

## More questions...

- What might have created this situation?
- What role does power play in this story? Who was in the power role?
- What role does discrimination and stigma play in this story?
- What support has been requested?
- What does the person want to overcome?
- Whose agenda is playing here.
- How much support is required? Is it currently too much or too little? Or is it just, right?
- Is the support being offered sustainable? Will it always require a help provider? Or does it offer opportunities for the help seeker?
- Is the help provider being responsible to the help seeker or are they being responsible for them? What would the difference be?
- Are the relationships in this story parent – child? Or Adult to adult? Which ones would you identify and why?
- Is the help provider a springboard or a safety net? How could it be different?
- What is the real problem here? Is it really the problem?
- How does this story resonate with me in my life?

## How Might We create resources so that “Access All Areas” passes are available to everyone in our community

### Access All Areas

It always seems to me that everyone else gets a pass – but not me – I always feel like the outsider – you know, hand to face - no sorry, not you.

For me it began early at school - I never felt like I quite belonged – others were prettier, clever, richer, had more family. Do you know the feeling? Alone in the playground? Everyone else laughing. Not quite sure where to stand or hang?

It progressed through my teenage years – never quite “in” despite many valiant attempts to fit in – oh, and I tried: a stint in a church group, sometimes shoplifting, drinking, drugs, sex, and clothes.

I started to think strangely too – could see things others couldn't, the sense of not belonging overwhelmed me, consumed me – eventually, I landed in a place that “let me in” - a psychiatric hospital ward, and from then on, the places that did seem possible to me despite my worries, uni, work, career, a family, seemed to slip away – like in a movie when the images fade out and away far, far from my grasp.

Now, everywhere I turn, I experience reasons why I can't do the same things as everyone else – life feels harder for me than most and I get told the reasons why I can't, rather than ideas about how I could – but honestly in my head I really know I can, I could, if only.

It's all about the barriers – a day in my life feels like this - I look for a job and I do not have the qualifications to get a look in, or the experience, or a drivers' licence.

I want to buy a nice dress but like Julia Roberts in that movie “Pretty Woman”. The scene where she goes into a shop in up class Rodeo Drive and the snooty sales assistant judges her and refuses to serve her. I too am shunned.

I imagine what life might be like if I did get a pass ... imagine if someone helped me find the key.



# Barred from Entry

It was a chilly night in the city, the short skirt a great fashion statement – but terrible when the wind ran though the little alley beside the club. Still, the excitement warmed the crowd up as they queued outside the little club called the Village.

Jostling to get in – will we, wont we? What’s the dress code tonight.? It could change on a whim – all black and gothic, bright and flamboyant or even a plastic bag fashioned in some way in past eras.

Everyone wanted the Access All Areas pass – where you could get in no questions asked – plus get to the spaces where the really cool crowd were.

Sometimes you can buy the pass – like in a Comic Con event or a movie premiere, or festival – pay more, get in to meet and greet with the stars and performers.

You could also get one if you worked there – lifting gear, helping, sometimes for free – but the pass, that’s the thing. Easy entry to everything.

That night, Ella felt a crushing blow when they inevitably got turned away – one of their crowd had the “wrong” type of shoes on and another no collar on their shirt.

Really? Deep down she knew it was because their type did not fit – wrong side of the tracks her dad used to say.

It was possible some of the group were keen to get in an argument with the security – that would have made everyone’s night! A fight – followed by the rest of the evening in the watch house – they let it go and moved on.

Anger and exclusion simmered in her bones – disappointment and loss of opportunity.

How different when they walked around the corner to the next club – it was throbbing with music and welcome – instant smile from the security guard and ticket sales, an armband each and in they went.

The joy of the dance, the music the connection – it’s infectious.

# How Might We Create resources that help us to dance better together? (when we seek out or provide help)

## The Dance

I go this way – you go that way – aren't we on the same page? Isn't this the same song? What song are you listening to?

Why are you here? Can you hear my song? Dance the steps with me?

Susan looked out of the window of the hospital ward and thought deeply about her situation. She looked across the courtyard at the metal benches and tired grass, she knew the ocean was just across the road, she could feel it but not see it from this space.

She was tired of the noise and the 'clink' of the environment; the heavy slam of the doors; she longed for comfort, cushions, and her own private space.

Susan was looking for somewhere to live. In fact, she needed somewhere to live. She had been in hospital for some time due to what she considered an emotional upheaval and was now in fact, technically, homeless. Adrift, rudderless - nowhere to go.

This was not a situation she ever imagined she would be in – it didn't fit with her vision of her life.

Susan had clear ideas about her hopes and dreams and where she wanted to live.

Ann, the social worker on the ward, was tasked with finding accommodation for her. Well, in fact, it seemed to Susan that Ann was very keen for her to apply for social housing, and this was the only option ever discussed in their meetings. Ann clearly had her own view on how Susan's life could pan out.

"It's affordable for you" she said. "Everyone goes there. You are eligible, you are entitled. You deserve this".

That was not what Susan wanted to hear – it was such a mismatch with her values and what was important to her. Are you listening to me? she asked Ann.

"I do not want to live in social housing. I want my own place. Private rental. It's important to me – I don't want to be a welfare recipient. It's not me."



## The Dance *continued...*

Why can't you hear me? What would need to happen for you to hear the same music as I do?

Susan resisted and then avoided Ann. Unsuccessfully because Ann would catch her in the corridor with updates about how the housing application was going – and how housing was linked to her discharge from hospital. Susan could see an imminent move to somewhere she did not want to be, her panic arose, her worries – “panic attacks and paranoia”, Ann had said – and maybe she might require a different type, or more medication. “Let me arrange for you to see the Dr”, Ann offered.

Susan had a chat with the cleaner who came in every day, told her about the dilemma and asked for her advice.

The cleaner, whose name was Paula, knew all about house hunting. She had loads of experience and was happy to share her experiences and tips in the brief conversations they had daily as she did her work. Susan listed the websites to look for, got an idea of prices and how much money she would need to demonstrate her ability to secure a property.

Susan set about the job. researching, calling up agents, checking locations. She enlisted the help, in this project, from a friend. Someone she trusted who could give an objective opinion and sometimes practical assistance in going to view a property. However, the decision remained Susan's.

The task was full of highs and lows – yes, I'll get this pretty flat near the park, no missed it, then the next with the nice bathroom – eventually, with the help of Paula and her friend, plus an awful lot of work and determination, Susan did find the place that met all of her needs and in the process, she also negotiated price and deposit with the landlord.

She found her special home.

# Groundhog Day with Chris and Tom

In the Navy, I am told they have another term for this experience, SSSD Same S\*\*\* Same Day.

Do you know that experience – same thing over and over again?

There is no way that brings joy to anyone's life.

It can happen in any environment – let me tell you about Chris. Chris had felt this before, working in a factory, same thing every day, day after day bagging and packing bananas.

“Don't get me wrong”, he would say, “I'm happy to have a job – it pays the rent.”

Later, he changed his life, retrained, and got a job as a support worker. He imagined working with people to help them would be more satisfying, and for the most part, it was until it started to feel like every day was the same and nothing changed.

He felt he could not get Tom to do anything. Every shift, same thing, same questions, same filthy unit, same grunt in response.

What's the point he asked himself. Here's how it went. He got up early, got washed dressed, had breakfast always something healthy, did some affirmations, this had become part of his life now to keep himself focused. Drive up the hill, past the shopping centre, round the bend, up to the block of units. Up the stairs, past the grimy bins, cigarette butts – his mood started to drop.

He knocked on the door – after a few minutes Tom would open the door – turn around and go back to his computer. Hardly an acknowledgment to Chris.

“What's on today then?“, Chris asks cheerily – but, with by now, growing dread in his heart

“Dunno”.

“Shall we go shopping?”

Nothing.

“Come on, let's clean up”. The pile of dirty dishes in the sink and piling food stuff troubling Chris.

Nothing – just the click of the mouse.

Then from Tom – “I need some smokes”.



# Groundhog Day with Chris and Tom

*continued...*

Not again, thinks Chris – every day the same whatever I say.

“Ok then, let’s go to the shops and we can get some food and clean up when we get back”.

Nothing.

“My time’s up, see you tomorrow – we’ll try something then.”

Chris went out the door, past the bins, past the cigarette butts, down the stairs to his car then round the bend, then down the hill towards home.

Wind back ...

Tom was comfortable – he sat at his computer playing League of Legends – he was deep in battle – he has been playing this game for years and he loved it - he looked at the clock “oh no its nearly 10.00am – already”. He winced. Every day at 10.00am Chris came – honestly, Tom couldn’t say why.

Ok, he knew Chris was employed by the agency – he had been to the meetings and been told he had 20 hours of support for community access – anything he wanted – and Chris came.

Every day the same thing – an interruption.

Tom really didn’t want him to come. They had nothing to talk about – Chris knew nothing about him or the game and community he was connected to.

Always the same – shopping and cleaning. “What’s wrong with that man?”, Tom wondered. Occasionally they did play chess together – those were better days – but they were few – it seemed Chris had a passion for cleaning and shopping.

Tom usually needed to go out to get cigarettes so, he thought it would make Chris happy if they did that and could get food at the same time – but honestly, he could go himself – but, if someone was offering a lift?

Tom was a gentle fellow, he never wanted to upset anyone – but he did struggle to understand what people wanted. So, he often said OK just to go along – until someone treated him like a child – that really riled him up. He had learned to avoid those situations and to say very little. “Dunno” usually worked as a response.

So, another day - same thing ... until the door shut, and he could return to the battle and his community.



## How Might We create resources that help us to be a cheerleader in each other's lives?

### Michael

"You can do this" he said.

Michael heard him. He had been terrified about going to the shopping centre.

He really wanted to get out and about. He fiercely wanted his full independence back. He felt stupid that he, a grown man, had got to a point where he felt all sweaty and panicky when he went to the local shopping centre. He knew he could do this, and he applied a logical approach to the challenge – work small and build up.

He started by having a coffee at the café on the edge of the shopping centre, gradually, week by week increasing his time there, then, step by step planning an approach to the supermarket itself.


He did this independently, he knew no one could do this for him, he had to do it alone. He imagined it like a Bungy Jump! He used to be really active and adventurous and while never actually ever having Bungy Jumped, he had been quite an "adventurer" back in the day". As he thought – he loved scuba diving, travelling, rafting – but that was like another life and now, the thought of entering the supermarket filled him with dread – although it was also a challenge he wanted to face. Maybe that was a bit like the old days. He knew he could "get by" without it – only go to the local smaller shop, even get someone to do the shopping for him.

Michael increased his time at the centre every week as he built his confidence up. He spoke about his plans and experiences with Steve. Steve was the person who had said quite quietly weeks ago – "you can do this".

Michael had met Steve through a support service a few months ago – he liked him. He had noticed that Steve was different to other support workers and counsellors he had met before – it felt that Steve really heard his need – and did not get in the way. Steve's belief and encouragement seemed to allow Michael to set himself free from being stuck. It was like he used Steve to bounce off – get some spring back in his step. He could report back to Steve and share his achievements and challenges. Steve was never judgemental, just the right balance of supportive and understanding.

Steve, it seemed had helped Michael see himself. His possibilities.

**How Might We  
create resources  
that help you to  
not other & out  
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your intentions  
are good)**



## The Spotlight

Rachel stood in the spotlight. All eyes were on her. Every crack in her skin, every crease in her dress, as if she could be seen right through.

She was there to apply for the job she really wanted, but she felt so naked.

Why?

Someone had called the café owner – maybe her mum. Maybe the case manager - and let them know she was on her way.

“Hi”, the café owner said brightly. “I got the call. Come in let’s see what you can do. I knew you were on your way – Sophie called me.”

Ah – Sophie, the lady from the health service – she was so nice – but why – what do they think of me? Will they treat me differently/ What did she say? The full thing – that diagnosis? Or something else? Now Rachel was confused – what do I say?

Rachel had been all prepared. I can make coffees - I’ve worked in a few cafes in the city, I’ve got my certificate. I’m nervous as all hell – but I can do this, I want this. Now what was she supposed to say – the situation was suddenly awkward and not what she had planned for.

Sophie knew none of this – she had called the café – just to give them a heads-up Rachel was on her way – she so wanted Rachel to get the job. She

deserved a break, poor kid, she thought. I’ll do whatever I can to help her. They need to know she’s nervous and vulnerable and that I am here to help.

Meanwhile Alysia who owned and operated the small café was confused too and a little disarmed. She was not sure if she was meant to treat this applicant differently. She wondered if she did employ her could she do the job; what if she had to let her go; who was this health worker; what was her role; and if she didn’t employ her, would she get a discrimination complaint against her?

It made the meeting a little odd.

Rachel pulled all her guts together – and focused on what she wanted.

It made the meeting a little odd.

Alysia threw her confusion away and tried to see Rachel as she was (Alysia too, knew what it felt like to be on the outside).

So, unknowingly to each other, they both decided to give life and this meeting a chance.

Rachel got the job – Alysia liked her – in fact more than anyone else she had seen this week. Yes, her vulnerability and her strength shone through and as it turned out she made a really good creamy coffee.

**The problem to solve: Passive, controlling and benevolent welfare systems that rob people of their dreams, self-determination, creativity, and strong voice to live their best lives.**

**How might WE solve this problem together?**

## The Trap

Tom was a gamer trapped in a game he didn't know he was playing.

Caught in a web of others desires and dreams. Unable to move. If this was chess it would be stalemate. A draw, not a win for either player.

In his early twenties Tom had been a bright music and maths student at university, a "wunderkind". Brilliant at solving problems both musical and mathematical. He was tall and lanky with a mop of red hair. But stress got to him and he simply "burned too bright" as his mother said and came to a stop.

His life stalled at 25. Diagnosed with schizophrenia in his second year at university he came home to live with his mother. He was in and out of hospital, trying different medications and slowly retreating to a world indoors and alone.

Today, at 40, he was living in a supported accommodation with an NDIS package and a worker who came every day. He also attended the Recovery Centre.

He had never worked; he had not finished his degree or found the illustrious career he was promised. He had not married his school sweetheart either or had the family he longed for.

He was locked in a daily routine of engaging with support workers and professionals.

Every day the workers tried to "activate" him. Picking him up and dropping him off at the Recovery Centre, taking him shopping. Trying to get him to stop smoking. Tom created nicknames for each of them. "Speedy", or "Chatty", he entertained himself thinking up stories about them. He never felt any of them knew what to do or heard what interested him.

Smoking had become one of his great pleasures. The way he could sit and think while the smoke blew around him, the nicotine buzzed his brain, and he played imaginary games and wrote music scores in his head.

## The Trap *continued...*

The other joy he found was in the moments he could play League of Legends online alone and with his gamer community.

The trap was in the way he was locked into a pattern of help by others – that did not actually lend or show or help him discover a key to step out.

His case manager Shirley, a proficient administrator managed him, making sure he got his depo injections, and any extra PRN if he started to sound cranky or agitated.

She also organised “meals on wheels” so he got his meals daily and did not blow all his cash on “smokes”.

His support workers cajoled him and followed the case manager instructions.

At the recovery centre he sat and drank coffee, smoked when he could and attended the free BBQ on Fridays.

If he ran out of money – which he frequently did – he could walk around to the back of the centre and ask for Emergency Relief.

He was in a maze of support, everything in his life was locked in, there was no way out.

The support staff were the maze keepers, making sure there were never any holes in the maze, and a reward was at every turn, directing round again to the beginning, never getting out.

The maze was beautiful, green and fresh but just too high to see over or through, and no way to test ingenuity or ideas.

Both maze keeper and player were equally locked in.

