A Mother’s Perspective

- Insights and experience gained in supporting my daughter in her recovery

“Courage is resistance to fear, mastery of fear - not absence of fear.”
– Mark Twain

“Scared is what you're feeling. Brave is what you're doing.”
– Emma Donoghue

“Life shrinks or expands in proportion to one’s courage.”
– Anais Nin
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- Introduction -

When my daughter was diagnosed with an eating disorder I desperately needed information to help make sense of what was happening and to help me understand what I should be doing. I would have given so much to know what I now know. If I’d had the knowledge back then, her road towards recovery would have started a lot sooner.

My search for good information highlighted how there are few resources available to parents who are looking for direction and insight. In essence, there is a huge knowledge gap to be filled when it comes to helping parents understand how we can best take on our support role.

What I’ve written here is what I wished someone had given me at the outset. I would have felt more empowered having this information as I would have been able to make better decisions sooner and avoid many mistakes. In essence, the faster the recovery journey can occur after diagnosis, the increased likelihood of a faster recovery. Timing is everything.

A little background

My daughter was 17 when she was diagnosed with an ED.

I’d describe us as a fairly normal family. There is myself, my husband, our daughter (now 19) and son (now 17. He was 15 when she was diagnosed). We own a sheep farm in rural New Zealand and both my husband and I work on the farm although I come from an office background. Both our kids went to single-sex boarding schools from Monday to Friday in the city (an hour’s drive away from home) for their secondary education because secondary schooling in our area is challenging. In hindsight, the boarding environment wasn’t best suited to my daughter although she did make some great friends there. She was heavily involved in her team sport and had a rigorous training schedule, with a very focused coach. The demands of her sport undoubtedly played a part in creating the foundation for her ED to take hold. It also disguised the early stages of it well because the need to eat healthy, stick to a rigorous exercise regime and adhere to strict daily routines in order to meet both academic and sporting goals meant we didn’t notice the ED sneaking in – and nor did she initially. Her ED developed very quickly. Unbeknown to us, the foundations from where it manifested were silently developing about a year before her diagnosis, driven mainly by the external and internal stressors in her life, which she was silently trying hard to manage largely on her own. In hindsight there were warning signs but they were missed by my, then, inexperienced eye (I discuss these warning signs further on). She has since told me she felt things were starting to get out of her control about four to five months prior to her diagnosis. In this short space of less than five months she went from being as fit as any 16-year-old female can be, having just represented NZ in her sport, to being hospitalised suffering severe malnutrition and within a day or two of heart failure. We came within a blink of an eye to
losing her. It floored her father and I how quickly it all happened. We just didn’t know the size and scope of what we were dealing with and felt well out of our depth and very isolated. Through our experience, I now know this is how most of us feel when one of our loved ones is taken down by an ED.

After diagnosis, and once her heart had stabilised, she was transferred to a specialised ED unit in another city. About six weeks of treatment her weight was considered stable and she was released, free to come home. Her care was transferred to the mental health services with our local hospital and we were given information on the Maudsley Programme. We had fortnightly consultations with a mental health nurse and after about two or three months, they deemed her weight gain to be satisfactory, and she was discharged. That was it! In hindsight it was appalling treatment. Her ED was still fully in control and her restored weight meant very little to actual recovery. It was a horrible time and incredibly stressful but we muddled through the best we could for the next eight months until I realised if we didn’t do something else we would again be at real risk of losing her. I had already done significant research and felt in my heart the chance of finding our solution was not going to be within NZ and that we would need to look internationally. So, sitting at our kitchen table one morning in October 2017, my daughter and I discovered Recovered Living via a Google search. From this point on our direction changed significantly. We finally had direction – and guidance, knowledge, understanding, compassion and everything else that recovery coaching entails. My daughter will be the first to admit that even under knowledgeable guidance like she has now, recovery is still far from rainbows and butterflies, but nothing can beat the feeling of knowing we’re finally in the right hands.

Now, here is what I’ve learned through my daughter’s journey to recovery:

‘Why us’ and that feeling of shame

Around the time of my daughter’s diagnosis I felt embarrassed, like I was a bad mother. I felt like I had neglected her basic needs. I can still recall thinking “What kind of mother am I that my daughter is close to death and I let it happen!” There is a fair amount of shame attached to these kinds of thoughts. I must have said sorry to her a hundred times because I felt so guilty. I also felt judged by some of the hospital medical staff as a mother too busy with her own life that she neglected her own child. The ultimate sin! Although many people did say to me that an ED is nobody’s fault and I was not to blame, I just agreed with them outwardly but inwardly I couldn’t buy into it. My saving grace really came via two places. Firstly my daughter, who was insistent I didn’t do anything wrong. I soon realised that if I continued to carry my own guilt and shame then
she would continue to blame herself for how I was feeling, which would fuel her ED even more. In order to help her I had to help myself, and so instead of focusing on what I wished I had done differently, I focused on what needed to be done now that could make a real difference. Kind of like using the negative to fuel the positive. The second saving grace that changed my thinking came from talking with people trained in EDs. Having a trained professional say “it’s not your fault” is very reassuring.

Experience has taught me that an ED loves blame because it fosters guilt, shame and secrecy. On the flip side, it hates openness and bravery. So I decided to not be secretive about what my daughter was going through. I don’t shout it from the tree-tops but my daughter has to be incredibly brave in order to recover and therefore I decided I would be brave too, and be open about everything and ditch any of the feelings that wouldn’t serve our family or her recovery. My husband has adopted a similar approach, which isn’t easy for a male but he too realised the merit in being open.

ED recovery needs to be a “no blame” zone, as recovery is largely positive and needs positivity. So, in hindsight, back when people were telling me I wasn’t to blame, they were correct. It just took me a little while to process and believe it myself.

An ED doesn’t discriminate

In the early stages of my daughter’s treatment (just after her diagnosis) I received some wise and helpful words from an experienced nurse. He had worked in the specialised ED Unit for many years and explained how EDs are still not widely understood and are still very much misunderstood by most, including almost every health professional that doesn’t specialise in the area. In other words, unless a person is actually trained and specialised in the ED field, the value of their ED knowledge isn’t to be relied upon. This particular nurse had looked after young children, adolescents, and even adults taken down by the illness. He talked about an increase in the number of boys and teenage males coming through the Unit and how he had personally noticed a potential link to higher performance sport. He’d seen it all and for the most part said many of the patients (males & female) are from normal families, with normal lives, who have just been going about their normal family business and then finding themselves thrown into absolute mayhem when a family member is diagnosed with an ED. He had a lot of wisdom and felt sure he’d seen every ED characteristic, trap and habit there is, and there are a lot. He was the first person to enlighten me on how EDs are very distinctive in their behaviours and intricacies. His knowledge made me feel a lot less isolated because none of the ED behaviours I was identifying within my daughter’s ED were new to him. He was the first person I encountered who had some real understanding of what my daughter was going through and what we were going through as a family, and this knowledge gave me some comfort and made me feel a little less isolated.
I’m the mother, not the recovery coach

This concept has tripped me up numerous times and caused immense frustration to my daughter – and no doubt to her recovery coach. I know there is an inherent nature within many of us mothers to try and fix everything we can. During our children’s younger years we are their mother, teacher, doctor, nurse, chef, librarian, etc. But when it comes to ED recovery, it really is beyond our scope and it has taken me quite some time to learn how to pull back on the ‘fix it’ lever and just be a mum with a supportive ear. I think many parents can already do this, but if you are like me and find the need to try and fix every problem, you may too find you need to learn how to step back and trust the recovery coach. With stepping back there is a niggling worry at being able to trust the recovery process and those charged with her recovery and I have found this difficult, but in truth, it has been good for me. Better still, it has been good for my daughter. She has her support team in place and everyone has a role to play, and mine is to be her mother. At the same time though I have to say there is a difference between stepping back and stepping out of the picture altogether. During my daughter’s recovery I have noticed many things but one important one is that a lot of parents seem to step back too far. It feels to me like they don’t want to, or possibly are unable to, play a bigger role in recovery. My daughter has told me that other people her age going through their own recovery have told her they wish their parents were more involved. There is no easy answer here as every parent and family have their own story, commitments and demands but I am sure no one comes out the other side of recovery and says they wish they had less support. It is also much easier to ask or tell someone to back off as their support is too much but how many people in ED recovery find it easy to ask for more support? None, I’m sure.

My changing role through recovery

For the months prior to my daughter’s ED diagnosis my role was definitely that of concerned parent, trying to nurture her back onto a healthy road. I knew she wasn’t well physically but I wasn’t sure what was wrong. I was a mother in search of answers as my daughter was struggling with random physical symptoms, but neither her, I or the family doctor picked up on these very early warning signs. Hindsight has shown these symptoms were all associated with emotional stress, a major catalyst to her ED developing. By the time her ED had taken hold and a diagnosis finally confirmed, my role become more love and support-based, as well as one of advocacy against a medical system largely ill-equipped in its understanding of EDs. The advocacy role was probably the most crucial for fast-tracking from diagnosis into recovery because I realised quickly that ED patients fall outside of the normal medical system scope, and so without advocacy there is a real risk of slipping through the system. My daughter was incapable of being
her own advocate because she was too ill and weak, but also her ED didn’t want her to speak up. When recovery finally got underway my role changed again to become more about strength, love, support and assurance – a bit like trying to be the wind in her sails – to help with recovery momentum. In many ways the support feels like helping someone trying to regain their legs and find their confidence to relearn how to walk. A lot of planning and preparation needs to go into meals, social outings and connections, school or work commitments, as well as ensuring her sleep is prioritised. All the planning is to keep anxiety down, to help quell the ED. Our family dynamic changed considerably because we could no longer just do things on a whim, particularly if it involved a lot of other people or food. Spontaneity and ED recovery don’t bode well together. The adage I instead adopted was one of ‘over prepare and then go with the flow’. For all the lifestyle changes ED recovery has required us to make as a family, they have very nearly all been positive and we are all the better for it.

As recovery progresses, the need for love and support is still strong but there comes a point when there is a need to step back to allow for some independence. Stepping back has been the hardest for me because once recovery is moving forward, as a mother it is hard to pull back knowing there is a risk of my daughter tripping up and hindering her recovery momentum. I have learned that ‘tripping up’ is a crucial part of recovery and it is very much like a new born animal finding their feet. They will trip and stumble but this is okay, expected and normal.

Stepping back comes in many forms, from simple things like not reminding her to pack a snack when she is about to go off and do something that will take longer than she expects, like catching up with a friend. I know that missing a snack will potentially fuel her ED but I have to have confidence that she is far enough into her recovery that if this happens, she will deal with it and use the experience to remember to pack a snack next time. My stepping back in the bigger things might be holding back from offering opinions or assistance when she is organising something, unless she asks me for either. Growing in confidence is a big part of recovery and in order to do this, she needs to have room to make her own decisions.

So as much as the recovery process develops and changes, so do the demands of the supporting role. It does feel a bit like learning a complicated dance at times and being unsure of where to stand, but I think this is normal.

**Preplanning, preplanning, preplanning**

The need to preplan, particularly in the early to mid-stages of recovery, is really important.
In hindsight, the constant need to preplan can be mentally tough but I didn’t realise this until nearer the end of having to do it. I found that my daughter’s ED was always ready to pounce, especially in the early stages of recovery, if I was not prepared. Things don’t run smoothly because of good luck. It is because of good preparation. Prior to her ED I took for granted leaving the house without much of a thought for what we would eat while out and about, knowing we could stop anywhere at any time. I don’t think I will ever take this for granted again having spent the past few years always thinking ahead to meal times and the choices available. Preplanning is key as your daughter or son depend on you, especially in the early stages of recovery, to take all thoughts of food choices and preparation out of their hands. My daughter had a list of fear foods and I had to be mindful of these too. PreED, a busy day and a hungry family to feed would mean grabbing a takeaway or throwing a pizza together. But during ED recovery this kind of behaviour would send my daughter’s anxiety levels sky-rocketing so instead I always had to have a plan for what we would be eating. Even just going out to a restaurant or café would need some pre-thought. With EDs, food can become a phobia, and within this there are foods that are feared more than others. The need to be consciously aware of this is important. As recovery progresses, preplanning doesn’t have to be so rigid but in the early stages, you, like me, might try to make it look like the right foods just miraculously appear at the right time, when there is actually a lot of thought and planning at work behind the scenes.

**Life upheaval**

Our life and lifestyle looks very different from what it did preED. Some of the changes are naturally occurring because our children are growing up, but certainly our social circle has become a lot smaller because we haven’t been able to do things that we used to do. Everything takes planning, especially early in recovery. Impromptu invitations often didn’t work for us as they could create huge anxiety for my daughter, particularly when she was on a strict meal plan.
EDs love isolation so there was a catch-22 situation: social gatherings could just be too stressful but being on her own brought other stress. So initially, there can be a lot of micro-managing to maintain ‘doable’ social interaction. We found ourselves putting much more effort into doing things together as a family unit including the building of a one-room hut on our farm. We also have a few isolated beaches near where we live so family outings there for swimming or surfing – often on wet cold days at it turned out – were also common. It isn’t easy to always think of fun things to do when the underlying driving force doesn’t have its roots in fun but it is possible to find a lot of enjoyment in these situations all the same. Looking back, I don’t remember these occasions as being a tool for distraction for our daughter; I remember them as simple and joyful family memories of a family doing normal family stuff.

Healing your own demons

I’ve become a firm believer that in order for my daughter to recovery from her ED demons, I have had to take notice of my own and deal to these too. EDs are clever beasts. They will take any opportunity or sign of weakness and they will dig their claws in. So taking the stance of ‘do as I say and not as I do’, just didn’t fit right for me. I previously thought I had a healthy relationship with food but I was silently a watcher of my weight and a dieter, although I never openly dieted or talked about my weight. I hadn’t realised that my own self-esteem was tied to the size of my clothing. So through my daughter’s healing, I too have addressed my own issues. I chose at the outset to be honest about things – although in hindsight I’ve learned that all the ‘skeletons in the closet’ probably don’t need to be pulled out and addressed. But for me, addressing my own issues around food, body image and weight has been crucial. I can’t expect her to eat, do and be, if I cannot eat, do and be the same. Eating what I want, doing what I want, and being me, without judgement based on food eaten and what the bathroom scales say, is freedom – just like I want for my daughter. It was actually my daughter who introduced me to the theory of Intuitive Eating. She thought it would help her recovery but in actual fact a person has to be well through ED recovery before they can look to embrace Intuitive Eating and she found this out for herself. In the meantime though Intuitive Eating resounded very strongly with me so strongly and so I decided to train in the method. It takes time and courage to drop old habits and beliefs and this was definitely the case for me but I was ready for it. Learning how to become an intuitive eater has changed my life. It’s like a psychological spring-cleaning of the brain where feelings of guilt and shame get swept up and placed in the trash.

What has been really profound about my own healing in this area is how progress actually feels. It is hard to explain, other than to say when you start something new, it feels foreign and you wonder if it will ever come naturally. Over time it does. This learning for me has been really good because I know my daughter has to live her recovery day in, day out, even
though it doesn’t come naturally yet. Retraining the circuits within the brain takes time and practice and through my healing from food, weight and size issues, I have been given a little taste of what it must be like for those doing ED recovery. I marvel at the feeling I have now, although sometimes have to remind myself if I feel old thought processes trying to slip back in, which happens from time to time especially if I’m feeling under emotional pressure. I could never imagine going back to how I was before, which is how so many other mothers I know live. The sense of freedom is very liberating.

The perplexing emotion of anger

An ED can be physically confronting, particularly anorexia but it is the emotional aspect of my daughter’s ED that I have found even more confronting. PreED I’d describe her as having been a very mild-mannered person and never really one to ‘rock the boat’. It was unusual to see her get angry but as I reflect back she did actually get angry and frustrated but just didn’t allow herself to show or express it. So it was confronting to me as the emotion I recognised as being so attached to her ED was that of anger and I just wasn’t used to seeing her angry. I made the initial mistake of thinking her anger was solely the ED but now think that being able to show anger is actually a really positive part of her recovery. When I’m pushing against the ED I find her anger can flare but it is often associated with a look on her face of intense anguish and pain and this really tears at my heart because it is painful for me to see her in such emotional pain. As she has a history of feeling the need to please I can see why feelings of anger might be really uncomfortable. My hope is that as she continues on in her recovery she learns how to understand and express emotions like anger, annoyance and frustration because they are a fact of life from time to time and also, that she learns it is simply okay and normal to feel these emotions at times. Bottling them up only increases their intensity.

The perplexing behaviour of an ED

If there is one thing I’ve found even more confronting than the emotion of anger it is the behaviour of lying to me that pushes me to my own emotional limit. In general, I’m okay about the occasion white lie or little fib particularly if it is to protect someone for the right reasons, but my daughter will lie to my face in order to protect her ED behaviours. It is this behaviour as well as the associated denial and sneakiness that I’ve found absolutely heart-breaking and almost soul-destroying. It is probably too the one ED behaviour that I haven’t been able to take a softly, softly and caring-type approach to. Instead, it is when I have raised my voice to my daughter and used sentences like “is this what you are prepared to become in order to hold onto your ED”, or “is your ED really worth the price of turning you into a liar and a cheat – is this what you really want?” I know my response is far from ideal but I’ve found it very hard to
react any other way. An ED does not play on an even playing field and this type of behaviour is so hard to deal with. I have to confront it even though I know she will fight back but I feel that she needs to be made to feel uncomfortable in the hope she may get a glimpse at the price her ED is extracting from her.

**Recovery is not linear**

My husband abides by the saying “smooth waters never make a great sailor.” His father used to say it to him as a child. Recovery is the same. A smooth recovery is arguably not a recovery. But I have learned there is a difference between full blown relapse and bumps in the recovery road. My daughter has suffered both. When the road to recovery is going well, bumps are to be expected. Learning to overcome these bumps is the means of propelling forward in recovery. The bumps are tough on everyone and can happen for a variety of reasons. Becoming complacent in recovery behaviours, or tiring of the constant need to be focused on recovery are two of these reasons, but there will be many more. I found the bumps in recovery stressful, and emotionally they took a toll on both my husband and I, especially as time went on, because life would start to feel a little normal again and then we would be pulled back into the ED. For all the pain of the bumps, they always do present a silver lining because every bump presents an opportunity to learn from and then move forward.

**The world of fitness, health and clean food**

I’d never heard of orthorexia when my daughter was diagnosed with her ED. Weird how after you learn about something it comes across your path constantly afterwards, leaving me to wonder why I’d never heard of it before. Orthorexia is a modernised form of anorexia with a large component of its foundation coming from health and fitness. The health and fitness industry is a multi-billion dollar industry and feeds right into EDs. Eating clean, eating non-processed foods, sugar-free, gluten-free, boot-camps, fat-fighting gut bacteria, detoxes, celebrity cook-books, self-help programmes to be your best-self... The messages are constant and all over social media, magazines, TV and even the daily newspapers. Recovering from an ED means being able to see beyond this marketing hype and this must be very hard to do. Referring back to what I said above about dealing with my own ‘skeletons in the cupboard’, I had been stuck on my own hamster-wheel in the name of health. But now, having healed my relationship with food via the method of intuitive eating, I eat what I want, when I want and not what any celebrity cook-book recipe says I should. I exercise how I like, not as anyone on a social media post tells me to. My daughter’s recovery has taught me how the fitness, health and clean food movement actually makes people emotionally stressed and unhappy with themselves. Through her recovery I now see the health industry completely different and feel empathy for the ‘hamster-wheel’ most of those within it
are trapped on, many of whom are at risk of developing an ED like orthorexia or at the very least, disordered eating. This also fits with what I was told back in my daughter’s early treatment by the older nurse who had seen an obvious link between high-performance sport and an increase in EDs.

**Love is blind and so is an ED**

We’ve probably all encountered a friend or relative who has fallen ‘in love’ with someone who everyone else can see isn’t a good match. But they can’t see it themselves. ED eyes are like this in that they distort the truth big time. I was aware of this aspect of EDs but was blown away by the reality of it. ED eyes see everything upside down and inside out. I found this really difficult as my daughter could not see her own reality. She was within days of dying and she believed we were exaggerating, even though she was in hospital hooked up to an ER monitor and with a food tube down her throat. Her size perception was completely out of focus too. Mini food portions were like monstrous mountains to her. Her pencil thinness would make me bite back tears but she was convinced she could see fat and felt disgusting because of this thought. It can be truly heart-wrenching. I still feel tears welling up as I think about it, even now. I’ve now learned that accurate perception, for most, only starts to return well into recovery. So this means that each and every day she had to, and still does, push down her own incorrect perceptions and finds the strength to trust the perception of her support team in order to recover. As her family we all find this really difficult knowing her eyes see the complete opposite to ours, and it has been a really hard thing for all of us to get our head around.

**Why won’t she just eat?**

It is a simple question with a complex answer. There is a very good TEDx Talk by Laura Hill “Eating Disorders From The Inside Out”: [https://www.youtube.com/watch?v=UEysOExcwrE](https://www.youtube.com/watch?v=UEysOExcwrE) I highly recommend listening to this as it answers this question very well and gives an idea of how an ED takes the brain hostage. It isn’t the kind of video you would recommend to everyone who asks this question because the answer is intense, complex, and deeply personal but I found it really helpful for me. My husband watched it for his own understanding too.

**Walking on eggshells**

I have never walked on so many eggshells in my life since an ED took up residence in our home! An ED can hold the whole family to ransom if allowed. It did this to us. Leading up to and during the year following my daughter’s diagnosis, no one told me we did not need to walk on eggshells. Only after we found her recovery coach did I learn that this behaviour was actually the ED exerting control over the whole family and that it wasn’t okay that we felt this way. It was
a relief to be told this, although in practice it wasn’t easy to break the habit because it meant I had to stand up to the ED more, which meant increased anger from my daughter. It was this anger that drove our need to walk on eggshells in the first place, so it was tough making the change. Some days I really did feel the need to eat steel or cast iron for breakfast just to stand up to the ED. I found motivation by using my own anger and frustration at feeling the need to walk on eggshells, to stand up to the ED. I’ve learned how to summon inner strength from places inside of me I didn’t know existed before.

One of the ways I made myself stand up to the ED was to ask myself how I would feel in an hour’s time if I don’t ask the question now or say what I need to say now. Questions that in most other situations would be normal are suddenly the hardest to ask. I would sometimes have to force myself to ask: what have you made for your snacks today? Did you eat your lunch? Or, making statements like: you need to put more potato on your plate, or, there isn’t enough juice in your glass. Or tougher ones like telling her to leave her bedroom door open if I was noticing it was starting to creep closed a little bit more each day.

**Siblings and friends**

Siblings and friends can play a really important role in recovery. My daughter’s ED tried as hard as it could to push everyone away and it almost succeeded. My daughter has one sibling, a younger brother. They have always been close and they have stayed close throughout her ED. He cares deeply for her, not that he would opening show or say it, and I have made a point of giving him as much information as he has asked for, as well as keeping him informed of what his sister needs from him. What she has needed from him is quite simply his ability to just be natural, normal and unaffected by the ED. I made a point of reminding him from time to time, especially in the early stages of her recovery, that any of the horrible stuff is the ED and not his sister. It has been tough on him and early in her recovery he did ask a few times if he was ever going to get his sister back. I had to tell him his sister is still there and the more we all did to support her, the more strength she would have to continue her fight for recovery. Conversations like this are tough but important.

Friends, on the other hand, have been a challenge as there aren’t many teenage girls who have the fortitude, maturity or innate wisdom to stand by a friend when an ED is pushing them away. This has been a very sad reality for my daughter and one that I feel too. ED recovery teaches a lot about human behaviour and for my daughter, a big part of her second half of recovery has been about building new friendships and connecting with people who contribute to her growth and joy.
PostED has to look different than PreED

Change is good. Change is hard. Change is necessary. My daughter’s life leading into the ED is not the life that will lead her out of it. EDs are born through a combination of factors, but lifestyle and the behaviours within can encourage the ED to take hold. For my daughter this lifestyle included a busy sport schedule and a busy academic schedule. She was also living within a boarding school environment where she struggled to find time to give to herself, to meet her own needs. In a nutshell, she was under prolonged intense physical, mental and emotional stress. Her stress went undiagnosed despite manifesting in physical symptoms including stomach pain, digestion problems, joint pain, headaches, dizziness, anxiety and exhaustion. In hindsight, all these symptoms or early warning signs acted together to mentally and physically fuel an ED. I’ve found that recovery isn’t necessarily focused on why her ED developed, but for me, it has been important because I like to know where things have gone wrong so I know what needs to change. The time lapse through recovery has meant a change in my daughter’s lifestyle so her future lifestyle looks very different than that leading into the ED, but it needs to be different and I have realised that good recovery involves learning the techniques and tools to carve out a new lifestyle. As a family we have all grown and learned from the ED. Not only have my daughter’s values and priorities changed but also have our family’s. Actually my daughter’s values may be the same but through recovery she is learning how to identify and honour her values and set her priorities around them rather than trying to meet everyone else’s demands. For us as a family our values now resonate more with the effort made rather than the achievement; the joy found in the journey rather than the star-rating of the destination. I personally have also learned a lot about gratitude and how to take joy in the little things.

The art of distraction

I always used to think distraction or being distracted was an annoying habit and something to be avoided. Now distraction has become a friend. Distraction plays a huge part in recovery as it is one of the best ways to quieten the ED, especially after meals. Not all distraction is equal though and social media and TV aren’t ideal. Games, puzzles, jigsaws or anything that draws the mind into having to think and focus is key. Getting the family involved together is key although not always easy. Eating together and at the kitchen table with no TV or devices has been crucial to us and something we will continue to embrace now. It has been a great way for us to connect with both our kids and although at times there have been tears over the pressure of the food on the plate, there have been so many laughs too at some of the ridiculous conversations we have had. Conversations that just don’t happen eating in front of the TV.
Not all recovery advice or help is equal

Getting the right help for my daughter and the right supporting information for me has not been easy. There was help available, once I started looking for it, but I soon realised not all of it is good or helpful. ED treatment and recovery is highly specialised because it is still so misunderstood and I didn’t realise the depth of this issue to begin with. In the early stages, I had to navigate my daughter’s treatment through various negative behaviours, some of which were from medical staff or people working within the medical field including mental health services. My experience shows a person in ED support needs to be specialised in the area, not dabble in it as part of their job description, because ED work is a career path that has chosen them, and not the other way round. Having a recovery coach or therapist who has recovered themselves is also a prerequisite in my opinion because I don’t believe a person can teach recovery if they haven’t battled and won their own recovery. Equally, finding support for the support person, like me, also comes with issues. The ED support group linked with the mental health services of our local hospital never got back to me despite my telephone messages asking if I could join. Then, acting on another recommendation, I joined a Facebook group set up to help mothers navigate recovery, but within a couple of months I realised it was more harmful than helpful because the group embraced a victim and sympathy mentality which I likened to a ‘stagnant pond’ environment where nothing positive could grow from. I’ve learned the hard way that navigating avenues of advice needs a good degree of judgement, and I have also found that some of the kindest people and wise expertise turn up in the most unexpected places. Fortunately my daughter’s recovery coach offers her own online support group and this makes a real difference. It is free to attend and has been gold.

Recovery helps with a team

So many people can take a role in recovery. My daughter has her recovery coach and dietitian as her key recovery experts and then she has her family – brother, father and me, her mother – on her recovery team. There are also one or two people on the periphery that I know keep a caring eye on her and offer words of wisdom and support from time to time. The experts are mandatory but I don’t think it matters what the rest of the team looks like or what its size is. Everyone has their own individual role, be it a set of ears, a great distractor, a provider of company, a mentor, a hand to lend or whatever. Just as there is no “I” in team, there is no “ED” in team either.

Recovery is hard work

My daughter was told that recovery is harder than she could imagine. It is difficult to fathom how hard something is until it is experienced, and I have found that supporting her in her
recovery has been so much harder than I imagined, too. I can see why those who recover can accomplish anything they choose in life, because I think I could tackle most things now and I’m only the support person.

**ED behaviours**

I was initially astounded to learn how defined ED behaviours are, and that they are not unique to each individual. I found it very weird to find people suffering from an ED, who have never met, exhibiting very similar behaviours. My understanding is EDs are illnesses often manifesting from prolonged and heightened levels of stress, be it mental, emotional or physical. Everyone’s stress is different and everyone reacts differently to different stressors, depending on personality traits and external environments. However, once an ED develops, the thought processes of the brain driving patterns of ED behaviour are uncannily similar between ED sufferers. While visiting my daughter in the ED Unit, it was interesting to watch her interact with others who could identify with exactly how she was feeling and thinking. It was surreal, perplexing and comforting all in one. I also found it interesting that when my daughter found the going getting tough during her recovery, she became convinced her ED was different and therefore believed the recovery behaviours she had been advised to adopt would not work for her. I didn’t want to doubt her, but I had to stay focused and trust the process and trust that her behaviour was probably still very much the normal ED behaviour pushing back against recovery. I believe now that everyone’s recovery looks a little different, but it doesn’t take away from the fact any brain, while under the influence of an ED, has distinctive ED thought processes.

**My daughter’s recovery would sometimes make me despise food**

One of the downfalls of being in a supportive role is the strong focus on food during recovery. Food plans, food portioning, stringent meal times, preplanning, etc. Despite my own healing around food, on some days ED support could take all the joy out of food and eating and I found this really frustrating. I knew my anger and frustration was because the ED had stolen my joy of food and turned it into a regimented chore that my daughter’s ED hated me for. So instead of food been associated with joy and nurturing, it had become associated with my daughter’s pain. I dealt with it by acknowledging to myself why I felt the way I did and reminded myself that it’s okay to feel this way, and that it would pass. And it always did. Another thing I found a little revelation was how many times, places and celebrations there are that revolve around food. Suddenly food on special occasions, which in the past was something to be excited about, became a minefield to be negotiated in order to help my daughter through. It can be tough going at times but I’ve learned every challenge is an opportunity.
**Personality traits and EDs**

If there was one thing I wished I knew before, it is the link between certain personality traits and EDs. Traits such as perfectionism, those who feel the need to please, those who shoulder a lot of responsibility and those who are highly sensitive, are at increased risk of developing an ED when under a degree of prolonged stress. I never identified these traits in my daughter because I just didn’t think to, but once she was diagnosed and I started to really delve into understanding EDs, it really dawned on me how much influence these traits have had on my daughter’s thoughts and actions.

There are three types of perfectionism: self-oriented, or a desire to be perfect; socially prescribed, or a desire to live up to others’ expectations; and other-oriented, or holding others to unrealistic standards. My daughter possesses the first two, as well as feeling the need to please people and being highly sensitive. These are all endearing traits but so very hard for any person to master because the standards these traits demand are impossible to achieve, and by default come laden with emotions like guilt, shame and anxiety – all the things an ED feeds upon. My daughter cannot change who she is in terms of her traits, but learning how to manage them is an aspect of recovery.

**Recovery is a choice**

I’ve learned that no one can be pushed into recovery. My daughter teetered around recovery at the outset and I think this is probably normal. I thought she would have to be fully invested in the process of recovery, but I don’t know if this is actually possible in the initial to mid stage because the ED is still very strong. I just know that the decision to recover is often made with a tentative commitment and this is enough for the recovery coach to start making ground. My daughter initially struggled until she found a recovery coach who stated outright that becoming fully recovered was possible. For her, the knowledge of being able to recover was the foundation to her decision to commit fully to recovery, but even then the pull of the ED was still
very, very strong. So yes, recovery is a choice but it’s not a black and white decision. To me it is more of a process towards recovery where, as progress is made, the decision becomes firmer.

Recovery is a process

Everyone’s recovery is different and it is a process. Without ever having an ED to draw my own experience from, I have managed to identify that recovery is on its own just a plan. How each person embraces the plan is what dictates the outcome. Thinking recovery would leap frog her into happiness is possibly what convinced my daughter to start recovery, but then the realisation came, highlighted by a relapse, that full emotional commitment was also needed, not just being committed to the methodical nature of recovery. Through my daughter’s experience, I’ve identified at least three stages in her recovery. Firstly, to make the decision to work towards recovery; secondly, to follow recovery; and thirdly, and most importantly, own her recovery. Just doing recovery didn’t get her to where she expected it would. Just doing recovery leads to relapse. For me, I have found it hard to identify the difference between ‘doing’ and ‘owning’ as they look similar. When doing recovery, it looked like my daughter was making progress because she was doing everything she had to do. But in fact, unbeknown to me, she was still using her food to numb everything out. I liken it to how some children, and even adults, like to block their nose to swallow down horrible tasting medicine. They are taking the medicine but avoiding the unpleasant feeling of it. Learning to own recovery includes allowing feelings to be felt; good and bad. It is hard to distinguish the process but I noticed a lot more tears during eating when feelings were being felt, i.e.; owning recovery. The tears do subside though, as emotions are worked through.

Real recovery comes from being able to emotionally step back into life; a life the ED is accustom to numbing them from. So, as far as I can tell, owning recovery involves eating, feeling emotions, building relationships and participating in life – everything an ED denies. I also now believe the desire to recover has to be larger than the desire to stay living inside an ED and therefore there has to be a reason or goal to help pull and motivate towards owning recovery. I’m sure the goal can take many shapes i.e; emotional growth, trauma healing, positive lifestyle change, etc. What I’ve found is that Identifying the goal isn’t as easy as it sounds and I know what I have thought would be a goal opportunity for my daughter hasn’t resonated with her at all. There is nothing I can do to help make my daughter choose recovery. I can have influence in what is going on around her and I can support her but ultimately only she can identify the reasons she wants recovery and only she has the power to then choose it for herself.
Anxiety and EDs

Anxiety and EDs go hand in hand. I suffered from anxiety in my early twenties so I know what it feels like. It was never spoken much about then so I wasn’t aware of what it really was and I learned to self-manage it so it wouldn’t manage me. I embraced the motto of ‘overprepare and go with the flow’ and over time I grew away from the worries that caused my anxieties. In hindsight I was probably very fortunate to work through this on my own but I didn’t have all the same pressures there are today. I can see how anxiety feeds into an ED and visa-versa. My daughter suffers from anxiety and from what I now understand, an ED thrives on anxiety as it fuels its strength. In fact, I am yet to hear of a person who has an ED that doesn’t have a significant battle with anxiety. It took some time to identify my daughter’s anxiety and what was underpinning it. Fears, trauma, deep worry and prolonged stress can all foster anxiety and to my mind, working through all of this and the anxiety that has built up as a result, is an important aspect of recovery therapy.

There is no easy way around managing anxiety but, again with the benefit of hindsight, I wished I had reacted earlier to my daughter’s anxiety because it can majorly hinder ED recovery. Quite by accident I found a hypnotherapist who came highly recognised from a person who suffered debilitating anxiety after being caught up in the Christchurch earthquakes which devastated the city back in 2010 & 2011. This kind of therapy isn’t a silver bullet but I believe it can have a place in ED recovery. Anxiety is tough and learning to manage it is key. Being on the other side of anxiety, I can say the fight to overcome it is so worth it. For people who don’t experience it, I recommend recalling the last time you felt extremely nervous about something and then multiply that feeling by ten. The physiological response within the body is one of panic, which means digestion shuts down, nausea is common and the heart starts racing – in a nutshell, everything an ED thrives upon. So, learning to overcome anxiety can be one important step of ED recovery.

Mediation and Yoga are common methods recommended for calming anxiety and while my daughter did her best to embrace these methods early in her recovery I had noticed her turning away from them. When I asked her about this she said she didn’t enjoy them because they didn’t really help, which made her feel worse because she felt she was failing in the method. Failure and perfectionism are at odds with each other which is very uncomfortable. It was brave of her to open up and tell me this and I felt I understood a little. Fortunately, a few weeks later I was listening to the audio book Trauma & Memory (Peter A Levin PhD) and I was fascinated to hear him explain why many people at certain stages of their mental health recovery struggle with mediation and why it can even be the wrong thing for them at this time as it can increase anxiety. It felt like he and my daughter must have talked as what she had described to me was exactly what he was saying. His book just gave me the background reasons for why it is so.
Good anxiety management is crucial in my opinion. I wish I had acted sooner in this area for my daughter.

**Thoughts, emotions & procrastination**

EDs are said to be about ‘control’ but to me a much more accurate description is they are about ‘protection’. It sounds contradictory but I find my daughter’s ED acts to protect her from having to deal with uncomfortable emotions, difficult decisions, or deeper worries. I learned how people with perfectionist traits are really prone to procrastination and I’ve found my daughter’s ED not only acts to protect her but also is a form of procrastination. As my daughter has gone through recovery, when she gets worried about something her ED comes in and protects her from making decisions or even having to think about what decisions might be available to her. It’s a bit like running away from problems; in the end they just get bigger. Facing them, owning them and making a plan to work through them is always the right answer but instead, for my daughter, her ED has become like the default position in that she allows her worries to mount up and doesn’t deal with them and so her ED becomes her distraction. It also becomes her voice when she doesn’t feel able to make decisions. Just like someone else might start procrastinating to avoid taking action, my daughter’s ED comes on strong as a form of procrastination. When things get tough going she can experience procrastination and struggle to make decisions. I’m sure this is when she is prone to being drawn back into her ED as it takes her focus away as if to protect her from having to deal with the uncomfortable stuff. I understand this, as certain personality traits lend themselves to feeling things at a deeper level and this is why working through and learning how to deal with uncomfortable stuff is vital to recovery. It also takes practice.

Through this understanding I’ve also learned how an ED becomes viewed as the most valued and trusted friend, as it offers protection and comfort. Not protection and comfort in the normal sense but rather a perverse kind. When I reframed my daughter’s ED and viewed it as her ‘friend’ it helped explain to me why it is so hard for her to want to let it go. Who wants to walk away from their dearest and most trusted friend or their only friend who has been there for them when it feels like no one else has been? It is a weird way to look at things but it has helped me develop an understanding of just one aspect of why letting go of an ED is so difficult. For me, helping my daughter find reasons to make the decision is a big part of our support focus. Ultimately this comes down to her being able to build a better life in the hope she will realise a happy and truly fulfilling life is achievable without the need for an ED to protect her.
She looks fine, she must be recovered

The way an ED sufferer looks physically to the uninformed, which is basically everyone who isn’t on the support team, often leads people to jump to the wrong conclusion. Being active in recovery means my daughter can get back on with life and participate, but at times when she is really struggling, this causes more internal angst as people can’t see how much she is still suffering. On the one hand she doesn’t want new people in her life to know about her ED as she doesn’t want to be defined by it or judged. She wants to be treated as normal. But it also means no one can see her pain and suffering, and this is tough. A physical illness is often visible and the pain is therefore noticeable. Pain inflicted by an ED is largely invisible once weight is restored and this can be emotionally tough. For me, as a mother of a daughter suffering from an ED, I too see this as people just assume we have all got back on with our lives and life is rosy.

EDs and all mental illnesses are largely silent struggles and it can take some getting used to. For me, talking about it with family and close friends helps, and while most people are supportive, I have found they take their cue from us as they don’t want to upset or offend by asking how my daughter is doing. They assume she is doing okay now unless we say otherwise. Every time I have spoken to family and friends about where my daughter is at in her recovery, they often express their gratitude for letting them know and quite often they tell me how privileged they feel that I feel able to share parts of my daughter’s recovery with them. Throughout her recovery I have been constantly surprised at the kindness of other people, which at times has come from unexpected avenues. Because of this kindness I have learned how important it is to keep being open and not secretive. There’s also the possibility others, or someone they know, may have a family member battling an ED and so I work on the basis the more everyone is aware, the more likely they will know where to reach out for help. Unfortunately I do occasionally encounter people who are insensitive and this can hurt but those that are, tend to be quite closedminded or ‘glass half-empty-types’.

Social interaction is scary but vital

EDs isolate. My daughter’s ED pushed hard to isolate her from her friends. It also tried to push her away from us, her family, too. Recovery involves having to get back into the world amongst people and because of anxiety, this is very scary and hard work. For my daughter, hanging out with good people, particularly of her own age, has been very important to her recovery, but it’s far from easy as they have all been getting on with their own lives while hers had stalled. EDs are very good at halting emotionally growth, development and maturity because this is normally learned from living life, working alongside other people and hanging out with friends. So, for my daughter, having to step back into life felt, to me, like trying to catch a moving bus, having already missed the first one that many of her friends had caught. It felt like life had
moved on without her and by the time she realised she needed to step back into it, her old life wasn’t really there anymore. This isn’t actually a bad thing in the long term but without familiarity, taking those first tentative steps back into her social life and working to rebuild it makes things emotionally hard. Recovery coaching plays a big part in working through and accomplishing this.

When the ED fights back in recovery

Recovery is a rocky road and every time I have felt things are moving along really well, the ED loves to remind me it is alive and kicking and wants complete control back of my daughter. I’ve learned to recognise some of the signs as the ED has certain characteristics that my daughter wouldn’t normally express. Anger, excessive happiness, being fazed out, being quiet and secretive and a lack of motivation or tiredness are the common signs I now associate with the ED exerting its control. The bedroom door starting to close again, drinking more water than normal, a need for more time alone. Just general stuff that tends to sneak in. I’ve also identified a push back on needing regular sessions with her recovery coach when the ED is trying to claw its way back. Learning to identify the signs has been really helpful to me because I know this is when my daughter needs additional support. If this support is met with anger it normally indicates I’m upsetting the ED and that yes, increased support is needed. In the early stages of her recovery I would reach out to her recovery coach with my concerns so she could assess whether there was cause for concern. As recovery has progressed, I now suggest my daughter reach out herself to her recovery coach, if she hasn’t done so already. To me, the important thing is I be proactive in my reaction when I see the signs.

The need for space from me and other family members

The need for space is an interesting one as it can be hard to identify where the drive for space is coming from. Experience has taught me that prior to recovery, the need for space comes from the ED pushing everyone away. Once recovery started for my daughter, the need for space came again and it was perplexing because I didn’t know if it was the ED pulling the strings, trying to push us all away again, or if my daughter actually needed some space to process her recovery. Hindsight has helped here as I now know it was a bit of both. This was quite a process and an important aspect of her work with her recovery coach. There is a lot of shame, fear, anxiety and other tough emotions being dealt with and so sometimes pushing loved ones away can give a sense of reprieve from dealing with them. It is hard to know when to step forward and when to step back, and at times I stepped forward into her space when I probably shouldn’t have. As part of her recovery, my daughter has had to learn to use her voice, to say her words, to speak up for herself, and so in doing so she has also learned how to say when she needs space. For me,
finding the strength within myself to ask her ‘why’ she needs it is how I manage my assessment on whether her need for space is coming from her healthy-self or the ED-self. If she recoils or gets angry at my questions then I know it is possibly the ED in play. If she is okay talking about it or expresses frustration or sadness then I know the desire for space is more likely coming from her healthy-self.

**Recovery is a lot to do with emotional growth**

I understand EDs as being made up of different parts, and two of its ingredients are fears and insecurities.

Not everyone with fears and insecurities develop an ED because if this were the case we would all suffer from one. But for whatever the stressors are, coupled with certain prone personality traits, it is over and around these fears and insecurities that the ED digs its roots. For this reason, and by watching my daughter through her recovery, I now believe identifying key fears and insecurities as very important, and by learning to manage and overcome these, it allows her to start growing beyond them. Recovery involves learning and learning leads to growth. This is just another reason why having a recovery coach specialised in ED recovery has been vital for my daughter as no one else could provide this type of expertise.

**Male role-model**

Since my daughter has been in recovery I have heard of other families where the father has taken on the main role of their daughter’s family support, despite the mother being present and caring. This has struck a chord with me. As my daughter has moved through her recovery journey I’ve found it is often my husband that is the voice of reason when things get tough. Where I use 100 words he can say it is 20. Where my daughter’s ED can cloud my vision, he sees clarity. Where I see complication he sees simplicity. Fathers, grandfathers, stepfathers or another male
role model, where there is a complete bond of trust, can contribute a whole lot more to ED recovery than they probably realise. My daughter has a great relationship with her father and as her recovery has evolved, so too has his presence and contribution within it and this has been so positive.

An ED thrives on an absence of communication

My daughter’s recovery coach has some great sayings and one is “an ED thrives in isolation and shrinks in company.” Talking, as a form of communication, is a great tool for shrinking an ED. If an ED had its way, it would zip everyone’s lips. Talking can help draw my daughter out and temporarily away from her ED, because she can’t withdraw and be present in a conversation at the same time. Communication as a therapy tool against an ED is really good too as EDs are secretive, whereas talking is a great means to share troubles and thereby reduce them. Since my daughter’s diagnosis we have talked much, much more than before she became ill and I wouldn’t change this in a million years.

The sneaky nature of an ED

EDs are incredibly sneaky. At times it really does feel like playing a terrible version of the reality show Survivor as we as a family work to out play, out wit and out last the ED. It’s confusing and frustrating too because we are dealing with my daughter’s behaviour, but it is really the ED pulling all the strings. As recovery progresses and my daughter gains more control over her ED, there are still times I have to make myself speak up and question certain behaviours because I don’t know if it’s the ED that is sneaking back in and driving them or if they are normal behaviours. This is confusing and a constant learning curve, but it also helps with building confidence because when I question certain behaviours, my daughter has the opportunity to respond and talk openly about whatever the behaviour is. If it does turn out to be her ED trying to sneak back in, talking about it is one way to help bring it out into the open; openness and honesty are great ways to quell the ED. If the behaviour is actually just a normal behaviour then she has the opportunity to say so and this is a really positive affirmative action. A recent example of my questioning a behaviour was when she spent New Year’s Eve partying with friends. The next day she wasn’t feeling that well and missed eating her lunch and some snacks. My concern was whether her ED saw an opportunity and decided to jump on it or if she had truly just overdone the partying and it was a one-off. So, the following day, when she was feeling well again, I openly asked her about it, explaining my concern. These are always hard questions to ask, especially because my daughter is now a young woman, but still I have to ask in order to quell the risk of the ED grabbing an opportunity. She can lie of course, but to me, part of her
recovery is about building trust and facing truths and so by telling the truth, she stands up to her ED. In this example it was too much partying which did make me smile.

Social media feeds EDs

Personally, I think EDs must have skyrocketed during the rise of social media. The images and information feed into fears and insecurities, fueling an ED. My daughter had been allowed to have control over her social media accounts, but on advice from her recovery coach she removed a lot of the content. From what I could see this helped a lot. For me though, during one of her relapses I realised that leading up to it she was spending more time on social media and although I didn’t know the content of what she was looking at, I just knew in my heart it wasn’t helping at all. As my daughter is now an adult, telling her to disconnect from social media for a period seems like an invasion on her rights but I just had to do it. I say it as a firm suggestion to her, not as a rule. In this instance there was no argument from her and a part of me felt my suggestion was almost welcomed by her. Perhaps the ED was feeding off social media and she didn’t feel the strength to say no to it. When I suggested it, this was all she needed for it to be okay to turn off from social media. I felt like she was relieved to be free from the stress of it. Life isn’t what is happening on social media – life is what is happening around us and so by turning away from social media it felt like she became more present with us.

Handling the emotional waves

While my daughter was in initial treatment, straight after her diagnosis, I was given advice on how to negotiate her ‘waves’ of ED-driven emotions. Specifically, the focus was on teaching support people, like me, how to manage these waves of emotion overload, i.e., catching them early by using distraction or calming techniques. I knew exactly what the ‘wave’ referred to as it was something we were experiencing with our daughter prior to and during treatment. What I have since learned is that during recovery, there comes a point where these emotional waves, while stressful, have their place. To progress through recovery there has to be challenge and the wave of ED emotion can be just such a challenge. My daughter and her recovery coach often now work through these challenges together and I have seen the effect of this in both a reduction of the occurrence and the severity of the emotional waves.

ED stages

The stages of ED have never really been explained to me but I’ve found it helpful to identify at least five different stages to recovery. These are: (1) preED diagnosis, (2) diagnosis, (3) treatment, (4) recovery, (5) recovered. Experience has taught me that only those highly specialised in the recovery process consider stages (3) and (4) to be quite separate from each
other, and that stage (5) is separate from stage (4). I haven’t included ‘relapse’ in here as a stage but where good recovery is underway and a relapse occurs, I would consider it a sub-stage of recovery rather than a specific stage.

**EDs are:**

unfair, not well understood, isolating, frustrating and painful! This description is relevant to the person battling an ED and also to those supporting them. I’ve felt all these emotions at various times through my daughter’s battle. I try not to dwell on any of them but I do allow myself to feel them when they arise. Tears often accompany some of the feelings and I allow myself to shed these too as I figure I can’t expect my daughter to feel and work through her emotions if I’m not prepared to do the same for myself. At times I also feel anger towards the ED over what it has done to my daughter and to us as a family. I always try to be mindful with how I handle anger because more than anything, I know it is actually frustration and sadness manifesting as anger.

**EDs do have positives**

For all its negatives, an ED can have positives. Admittedly it does take a while before these positives show themselves. For my daughter, a major part of her recovery has been about learning to grow as a person. She is learning how to identify and manage insecurities, and her insights into human behaviour are now beyond her years. Her learned knowledge through recovery is very valuable and she herself says how fortunate she is to have this. Her battle has also made us stronger as a family. Each family member has a role to play. For example, our teenage son is relied upon to just ‘keep things real’ for his sister as she really misses, and really wants, that feeling of normality. Hanging out with her brother helps give her this. I feel they have developed a great respect for each other and I expect it will always stay with them. For me personally, my daughter’s ED has allowed me to have more clarity about priorities and values. If I made a list of what used to be important to me compared to now, the items on it would look completely different. So, while an ED is never welcomed into the family, the process of recovery has allowed for a lot of positive things to flow and develop within all of us personally and as a family.

**What I’d do differently:**

If I had all the information I have now, the single biggest thing I would have done is enlist an experienced ED recovery coach for my daughter the moment she came out of the ED Unit. I’m confident this would have fast-tracked her recovery because she was well placed and open to recovery when she was initially discharged from inpatient treatment. I was often told
during her initial treatment that the earlier recovery work starts, the more potential for a better outcome, but I didn’t realise then what good recovery was supposed to look like and where I could find it. No one gave me this information so we had to find it for ourselves. It was a process of trial and error and took us close to a year before finding the right person to help my daughter.

Self-care

Self-care as it is an area I’ve struggled with. Close friends and extended family have from time to time asked me what I am doing to look after myself and I never really have many good answers. What mother isn’t already busy juggling the demands of family, work or other commitments? Add an ED into the mix and there isn’t much room for anything else. More’s the point, when we become a mother the hearts of our children seem to become an extension of our own so I’ve found it really difficult to prioritise self-care when I know one of my children is suffering. During my daughter’s recovery I have had a few nasty flu bugs, a few random aches and pains and latterly a bout of shingles. All are, I know, largely stress driven and the diagnosis of shingles certainly made me sit up and take notice of the need to try and manage my self-care better. I wouldn’t change the degree of support I have given my daughter, although had we found her recovery coach sooner, the demand for my total support would probably have lessened sooner. I don’t have a great solution to mastering self-care but I believe it is important. Perhaps as I haven’t been able to master it well, I have instead used my daughter’s recovery as a means to grow in myself. In other words, it has been a difficult and stressful time and because I couldn’t change this, I have instead opted to use what I can and take as many positives from it as possible.

Just to finish; my experience has led me to believe that everyone’s ED journey is different. ED behaviours may be similar and the recovery process has distinctive stages but ultimately for you and I, as support people, there will always be a degree of ‘flying blind’ as the person we support will have their own individual recovery journey. Making mistakes in recovery support is normal – I’ve made plenty. The irony isn’t lost on me that those with perfectionist traits are prone to EDs, and my daughter has these traits aplenty, so making mistakes and learning to not be in ‘bits’ as a result is good practice for all of us. In the end, all that really matters is that we do the best with what we know at the time and being accepting and open to the learning experience which is constant.