

Chapter 8

Every pebble counts

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Recovery is not the word I recognise when it is used in mental health practice, and it stretches the point even further when considered from a carer's perspective. To me, recovery is to get something back again after a temporary loss. It is also linked with the wellbeing of the person you support. Relationships are built on desires and needs, common goals and working together to achieve them, giving freely and sharing. What happens when one person loses their way through ill health? We become individuals performing a dance with each other, trying to find some form of balance. Sometimes we can participate as equals but usually the carer is the one giving, working within a process that does not always recognise us as people or support us in times of need.

Sometimes others around you do not see the tears behind the smile or the pain in your life; this leads to further isolation and, potentially, a downward spiral. Questions about how you are will often be posed while you are in the presence of the one you support. How can you give an honest answer about your feelings without destroying them? Can you bear the pain, or should you be so brave as to say 'I can't cope'? Watch them physically shrink before your eyes as another person says they have given up on them and can freely give no more. Why, if professionals really care, do they ask the question at that time – is it more a signal of *not* caring or understanding than an offer of support?

From a personal perspective, I give support 168 hours a week or 8,760 a year. What about the professional support? At best, when the service user is in the community, it comes out at maybe an hour or two a week. We do not have an evening or weekend off. Respite is dangled in front of you in words but it fails to become a reality. On the rare occasions it is available, it usually has a prohibitive cost.

To start to get some understanding of life it has to be redesigned, considered from a fresh perspective and fought for. It requires a lot of hard work and inner

strength to achieve this. It often means foregoing parts of your life that may once have been very special to you, which can cause an inner conflict as you struggle to come to terms with the loss of the person you once knew while seeking a new ideal. To seek out something that offers you a remote glimpse of hope for the future is a struggle and a long process.

The beginning

As it is not something that stands alone for me as an individual I do need to start at the beginning and work my way through our joint journey of discovery, what happened and how I survived the process to the present day. It has been a journey of much pain, hardship, anger, frustration and guilt but also laughter and enlightenment.

My life as a carer has been a period of over 11 years. It's not a title I asked for or one I believe to be appropriate but it is one the system usually recognises and even occasionally does something about. Once you have this piece of information you can start to learn what it means to you and others around you. As an individual, it's something I found I liked and then hated; like so many parts of the journey, it takes a long time to get things understood. I now know it's a badge I must wear sometimes to get a response to a need or recognition that I am either part of the problem or a potential part of the cure. There it is again, 'cure' – another word, but something that is needed for a true recovery in my eyes. Even if the person I support regains what they lost (true recovery in my eyes) and then decides they no longer want it and moves on to something else.

Digression – always one of my failings (note to self: don't see it as a failing, there are enough of those anyway – and so we're back to guilt again). My mind rambles sometimes, which gives a sense of freedom but also one of a lack of control. Is this a good or a bad thing?

My journey started with a wife, Bluebird, becoming unwell. Not an illness I understood, and that in itself was a learning curve. Much frustration with her for not helping herself, anger because everything depended on me and nobody helped, fear because there was no control over what was happening and desolation because the important parts of life were being torn violently away. The loss was something I could see for my own part but it was harder to understand what it meant for her as she seemed not to care. Time has taught me that her loss was as great as mine, although at the start of the depression

she was so withdrawn that days would pass without any acknowledgement from her that life existed.

The first grasp for some control

The doorbell rang and I opened the door. The stranger asked, 'Does Bluebird live here?'

'Yes,' I replied.

'Is there anyone else at home at the moment?'

'No,' I replied.

'I'm going to have to ask you to go out because I need to talk to her,' said the stranger.

I shut the door firmly and leant against the inside of it. Anger and fear boiled up inside me and tears welled up in my eyes. Anger because I felt battered and bruised and above all useless, fear because the action I had just taken could remove what little help there was and leave me totally alone to deal with the situation. I felt my hands tremble and took a deep breath. The bastards were not going to beat me into submission. Bluebird deserved better than this.

I opened the door again. He stood there looking bewildered; I sensed a spark of pleasure inside me, a small feeling of warmth. There was also a small bit of guilt because I had possibly hurt another human being, but overall it was good to feel that I had some control again.

I said, 'I'm Morris. And you are...?'

He still looked bewildered, lost – like a little boy who'd done something wrong and didn't know how to get out of trouble. Then he suddenly recovered and sprung to life. 'I'm Dr. _____.'

I invited him in and offered him a drink, which he declined. I asked if we could have a few moments when he'd finished as I had some questions to ask, then led him through to Bluebird. I left him to talk to her while I continued with my work.

I was lucky in one sense that my work meant periods of time at home, where I could try and support Bluebird while also maintaining employment. The downside was that it also involved travel throughout the UK and parts of

Europe, and this often meant being away from home for a week or more at a time. The need to balance being at work and being at home often led to extended days: it was common practice for me to leave her and the children behind early in the morning, drive to a customer site, spend the day there and return in the evening. Glasgow could even become a day trip.

Hearing the door close with a quiet click, I got up and walked quickly from the study to the hallway. There was silence in the lounge, so I gently opened the door; only Bluebird was there. Turning and opening the front door, I saw the doctor disappearing at a rate of knots along the pavement and getting into his car. So much for gaining a bit of control! What about that chance to talk to him I'd asked for? What was going to happen, how was she going to get better, what could I do to help! A glimmer of hope had gone in an instant, and now it was back to the isolation and loneliness. Life was once more this strange existence, my new so-called normality. All I had found so far was some information on the internet, which seemed to be full of contradictions.

I walked into the lounge and sat down. Experience had taught me that if I came in and asked a question straight away it was likely to result in a very pained expression from Bluebird, and that she would not hear the question but appear to struggle to find out why I was there – almost as though she didn't know who I was. We sat in silence for a bit. I asked how she felt and how she had got on with the doctor. It was a slow response: he seemed nice, we chatted, I can't remember what about but I think I have to call him or someone to get another appointment.

This was one of the early situations where I tried to bring some control to a process that did not seem to see me as an individual with my own rights. I have learned a lot since those early days and can now see why this situation ended the way it did, as well as the part I played in allowing it to happen. Time has taught me to understand that it would have worked better if I had seen the doctor first. The fact that he needed to see Bluebird would have given me a bit of leverage, as without me showing him where she was he wouldn't have got the access he needed. I also understand now that, for the most part, it is the care coordinator, CPN or other support worker who's more able to give up-to-date information on how the patient is and the general plans, if any, for helping them move forward. Building a relationship with these people will take time, and it is unlikely to happen if you (rightly or wrongly) have a go at them for what has happened or is happening. In my experience they generally have far too big a caseload to work as effectively as they'd like and are usually

fighting the system just as you are. Give them time to decide whether you are part of the cure or part of the problem. Remember that they are human beings too.

Being linked to the expectations of the person you are supporting means that there is a constant process of readjusting your own. Flexibility is something you'll need to learn. Just because something worked out one way a month or even a day ago doesn't mean you should expect the same result tomorrow. Bluebird can quite often get a fixation about something – a diet, a garden design course or all the books by a particular author, for example. This will give you a momentary glimmer of light at the end of the tunnel, only for you to find it's the express train coming at you. It takes a lot of skill to be able to support an interest with enthusiasm while at the same time getting ready for it to potentially crumble and become of no significance to the cared for at all. Quite often the support team (if you have the luxury of one) will be behind this wholeheartedly, also looking at the potentially short-lived enthusiasm and seeing, as you do, someone you love looking closer to happiness than you may have seen them for a long time. Unfortunately they're not the ones who have to pick up the pieces financially (it's usually something costly that catches Bluebird's eye) but, like everything else on the journey, it's about learning on the job by your own mistakes. If you can build a relationship with the team, you may have a bit more influence on how things go and it might save a bit of the expense and heartache.

Mental wellbeing

A crossword or Sudoku puzzle can become a huge thing. Succeeding and solving the puzzle makes you feel good – you've won, you are a winner – and the challenge gives you something to focus on. It takes your mind to a place of freedom and respite. You can get there easily; no walking out of the house, no questions over where you are going or when you'll be back. A part of the survival toolkit, like a book taken in with you to A&E to fill out the long wait with a semi-comatose cared for. On a good day, not solving the puzzle is usually okay. On a bad day it can plunge you further into the black hole. Can't even do a simple puzzle! What use are you?

I nearly deleted this piece just now. I read through what I'd done and decided it was a rant. What use is a rant in a piece of work designed to help others to either understand or recover themselves? But I must have learned something

during this process, because I didn't go with the snap decision; I saved it and waited before coming back to it on a better day. Make a much more reasoned judgement. I'm lucky it's still here. It's still the default for me to jump to a decision quicker than I should. Bluebird is not the only one to have changed; my life was always about measured decisions, what's the best angle and how to get to the end goal in the best way. That was back when I had a degree of control over my world and some confidence. When I had a partner at my side, supporting me as I supported her. When life was about some degree of freedom and choice over what happened.

Back to the Sudoku, let's look at this again. Can't do a puzzle so you're a failure? It's something of an overstatement but in the cold light of day, with emotions running around the racetrack of your brain, you can't see the stupidity in it. Learning that this is one of the symptoms of your own illness means you can try and do something about it. Depression hits a lot of people who are carers – not just those who look after people with mental health problems but people from the whole spectrum of caring. Don't forget that there's a lot of it about, and it doesn't take long to find another carer who is also on antidepressants or getting (if they're lucky) some talking therapy support to help them with it. It's not a sign of failure, in fact it's the opposite: you're starting to put together the toolkit that will help you stay as well as you can. It's only when you are in a good place that you can help your cared for. That shouldn't be your ONLY reason for looking after yourself, though – you are, after all, a person in your own right, and are entitled to as much good in your life as you can get as long as it's not at someone else's expense. A good maxim is 'self first with due consideration for others'. Don't expect your cared for to understand this, but it's not that they don't care. It's that their illness doesn't.

A sample of life

Today has been about cooking and misunderstandings; how do we end up like this? A simple discussion about who was going to cook and it's blown up out of all proportion. I was going to do it but then there was a phone call and I was off to my mother's. She's in her eighties now and has been a widow for over ten years. She's had issues with pain for a long time, going back to the days of being a teenager and having an accident. Recently, though, it's been getting worse, and after a lot of doctor's appointments a stage has been reached where a medication without too many side effects may have been

found. She does have trouble swallowing tablets but seems to be coping. Now I've found out she's going to run out earlier than I thought, but I can borrow a couple from Bluebird (for once, a bit of luck that they both have the same medication but for different reasons). I can put the repeat prescription request into the doctor's on the way. It should just about get the prescription into the pharmacy in time for me to pick it up before they close tomorrow and get the tablets to her for tomorrow night's dose. I'm sure having only two instead of three for one evening won't cause a problem.

Anyway, job done but I upset my mother by not stopping for tea and a chat because I needed to get back to cook dinner. When I got home I found Bluebird part-way through two different meals; she had started on one but then found she didn't have everything she needed for it, so started on something else. As soon as I came in the door I knew it was going to be a volatile situation. 'Why didn't you tell me what we were going to have tonight before you left?' 'It's on the white board, like I said.' What an idiot! She'd forgotten that we'd written up the menu for the week as a prompt for her, but I shouldn't have mentioned it – now she was blaming herself for not remembering. I'd been thinking about my mother and how little time I get with her. How much longer with her do I have? Another guilt trip, and as a result I'd taken my eye off the ball. It took the rest of the evening to settle things down a bit, and even then I knew that, under the surface, Bluebird was still upset.

Material support – retail therapy

Books, books and yet more books but no getting on and doing. Dragging heels, lost, lost, lost! (Just a friendly rant to myself – a few thoughts running about the way life can go...) Books were indeed a fixation for a while, being bought faster than they could be read. I'm sure many were never even opened and just went directly to the bookcases, shelves and cupboards, and they piled up on the floor in many other places. To make life easier I had moved a lot of my books off the shelves and packed them away to make some space for a while. I didn't think this phase would last for long and I wasn't wrong, but it made sense to stand back and let it run its course. Somewhere in the fug of depression the message hadn't been taken in correctly and she'd decided I was going get rid of my books because I didn't want them, so there was space for more books. What I had done had exacerbated the problem – with good intent, but I had made the situation worse for myself. In charity shops,

at car boot sales and various other places, books kept appearing. A few times a duplicate copy would arrive – if this was questioned it caused upset (‘One might get spoiled, so I have a spare now just in case’).

I was beginning to learn how the game needed to be played. Let it run its course. Standing back and trying to look at it as an outsider, I could see the books being almost stroked as they were moved from one place to another. There seemed to be a peace and serenity about it all. I never did understand it and still don’t today but it did something for her. Many of these must-have books are gone and forgotten now (‘Where did this come from?’). This is now something Bluebird won’t even remember, and to be told of it would only cause her pain as it’s not how she would act normally. When well, she is a very considerate, kind and caring person. It’s the illness that makes the changes. The book-collecting is still there, though now with much more control and meaning. It’s a part of her life that has grown in importance, but there is much more of a selection process and a good number of books are read and passed on to the charity shops.

Cutting this short as I’m about to be pestered again. I know it’s not meant as pestering but that’s how it feels – it’s like a lost lamb checking all the mothers in the field, looking for its own.

Free time to do something at home without a figure appearing and asking questions, always looking for reassurance, that’s one of the things I miss. I usually find it by working with the problem rather than fighting it as I used to. She sleeps more than me so it’s either stay up late or get up early and do whatever needs my full concentration. Easy to say but not always so easy to do, as if she wakes up and finds I’m away from her side it sparks an anxiety session that means I get watched and followed more closely for the next few days.

Knowledge

Gaining knowledge of the illness helps, but finding a reliable, trustworthy source is difficult. Other carers are a good source of information but beware: they may be in a worse place than you, and you may come away feeling worse for the experience rather than better.

After nearly three years I became aware of a local carers' support group. This met once a month, very close to where I live. Sharing my thoughts and feelings with people in a similar situation helped me a lot. It took a few sessions for me to find my feet, open up and talk. I still remember the first time I said I hated the person I cared for but loved them at the same time, and how I was confused by this and felt guilty because of my thoughts. The person next to me asked how long I'd felt like this. To my response of 'Most of this year' he said, 'You lasted a lot longer than me before you got there – it only took me the first six months of it before I felt like that'. The meeting helped me come to terms with how I felt, and I soon saw that my feelings were seen as 'normal'. Other people talked of the behaviour of their cared for in a way that made it seem like normal, reasonable behaviour. A few years ago I would have thought this very odd but it gave me the space I needed to talk to people who could understand the life I was living; my turmoil was their normality. Just being able to sound off and release a bit of tension was helpful, and there was so much free advice on how to make my life better.

This is an important message – when you're caring, everyone's focus is on the person who's ill, so you as an individual can get lost and cease to be a person with the right to a life of your own. You are so busy keeping the world on an even keel that you forget to look after yourself. Do you ever have the time? It's a difficult concept to get your head around at the start, but unless you look after yourself you won't be in a fit state to help anyone else.

Balance in the relationship is important. It may be that there is a need for change, but there must always be a balance of needs. The carer cannot become secondary to all that is going on. For some, the only way to cope with that is to leave.

Leaving is something I've thought about many times, and it's not always been clear in my head whether it's guilt about going or my feelings for Bluebird that have kept me here. At times, all that has kept me here has been the thought that I cannot pass on my caring role to the children. That just wouldn't be fair – they never asked to be brought into this world so I would not pass the burden on to them. As time has progressed, the appeal of walking out has lessened, but the idea has never left me. I can now honestly say that my staying *is* more about my feelings for Bluebird than what my family, friends and society at large would think of me for going or the impact on my children if I did.

It's a question of stability, but how do you achieve this magical state when both you and your cared for are bouncing about between extreme highs and lows? Add to this the effect of people around you and the pressure of working, paying the mortgage and all the other bills and keeping up with the rest of life and it's bloody hard.

Experience has taught me to try and live in the long-term rather than the instant of now, but once again that's easier said than done. When you've worked hard to resolve a situation but all the cared for does is point out the flaw in your solution or bring up another problem, it's not easy to step back and build up some positive feeling about your achievement. Banking good stuff is helpful for me. I try to remember the good bits that have happened, writing them down in case I forget – things like the 'Thank you' I got five days ago for putting up some metal stakes to hold up the side of a raised bed for a potential fruit cage that may never happen because Bluebird forgets about it, or finds another project that is more interesting. All the hard-earned money spent on things that suddenly ceased to be important – money that could have been used for things *I* saw as important, or foregone altogether so I wouldn't have had to spend so much time working for it – just disappears. She'll say, 'Well, you spend some money on what *you* would like'; the comprehension that that would mean working even harder to get even more money never even comes close to sinking in. This is a good example of how the good bits get lost. I did get a thank you, there was some short-lived temporary recognition that I'd done something for her and I did get a hand-squeeze and a hug. A bit more learning: if you do something for someone it is reasonable to expect them to respond in a positive way and give something in return, but carers can't always afford to think like this. It's nice to receive thanks but I needed to learn that anything I do for Bluebird has to be because it's what I want to do. If I do things looking for something back in return then I am expecting too much.

Doing something for yourself

Tomorrow I'm going out to meet a friend, a fellow carer. We're meeting as friends, not carers, and although part of our time will be spent talking about our caring roles and how our lives have been it will be much more about us as people, enjoying the garden we're visiting and a shared lunch. The caring bit will soon disappear as we both enjoy the companionship. I won't feel guilty about not attending another review of medication and what progress

has or hasn't been happening. I've done my bit and made a few notes for the professionals to consider. I've made it clear what I feel is needed and it's up to Bluebird (if she agrees with my thoughts) to fight for what she wants today, not me. I can't do it all and it's not right for me to try to. It's good for her to do what she can for herself and take as much control of her own life as possible. This is as important for me as it is for her.

Finding a way that works for us

This is a real jumble of thoughts, ideas and suggestions, which in many ways reflects the life I live. Trying to force what is happening into a tightly controlled style of life doesn't work. I get tired and worn down very quickly if I try to make life work in an ordered and controlled manner. Mental health doesn't fit into patterns, at least not for us. I mustn't lose sight of the 'us' because we can only move forward by working together.

The sometimes-erratic behaviour of one of us means that the other has had to fit in with what is happening. Sometimes life is like pushing a huge rock uphill: once you get the momentum going it's easier. Every now and then the rock gets harder to push and your instinct is to try and keep the motion going, but it's not always the best thing to do. Sometimes you have to stop, walk around the rock and look to see if something is stopping you from moving it forward. To do this, you need something to stop the rock from rolling backwards; a small pebble is often all you need. It might only be a small pebble, but it's enough to stop the rock from moving. Walk around the rock, study what is blocking it and then move it, but only when you understand what it is that you're moving. Why? Because it might be there for a reason, or it might only be another small pebble, or it might be that you are going in the wrong direction altogether. It could be that the small pebble is the one thing that will be there to stop the rock rolling backwards when you next need a rest. It might be better to push the rock around the pebble and leave it there.

What does all this mean? For me it's a picture in my mind of what I'm doing (yes, I have a strange mind). To manage life you need a strategy, and your strategy has to include the person you support. Sometimes the rock of life – i.e. responsibilities like work, cooking, cleaning and everything else – needs to be put on hold, and the small pebble behind the rock is there to help. It gives you a chance to walk around the rock and see what is in front of you. The small pebble might be a chat with a friend, a carers' group meeting, a walk along the

seafront or a bar of chocolate. All of us need to build up as much support as we can from what's available; sometimes it only needs to be a small pebble. The small pebble in front of the rock is what's holding up the person you are supporting, so removing it might not be the best thing to do. You might discard something that's important for them. Losing it might mean that the support you both need won't be there in the future.

Don't lose sight of the fact that your cared for is also pushing a big rock and that the small pebble might be there for them. When you stand in front of the rock, try to have the one you support there with you. Ask them what they see; their perspective as to what you should do next might be very different from yours. This is part of a business meeting (more on this later) and it gives you the chance to find out if you are pushing the rock in the right direction. Remember, it's hard pushing it uphill but to manage a reverse action and move it downhill is another matter. Planning where you need to go and keeping things flowing freely... well, I'll leave that for you to ponder. While on the subject of the rock, remember that you sometimes, maybe only on rare occasions, have the option to ask the cared for to hold the rock for a short time while you get your breath back; they might feel helpless, but don't make them feel useless.

Standing in front of the rock does give you a better view. Sometimes Bluebird and I do that individually, sometimes we do it together. Both approaches are important. It helps each of us to try and get some forward planning in place and think about where we might like to push the rock. Sometimes we both need to put a small pebble behind it and walk forward without the burden to get a better view of the future. Maybe, in this case, the small pebble is a day out with simple rules like no talk of work, health issues, money or any other problem. Just enjoy the moment, or at least try to.

Collect the pebbles and understand them. Use them like a bit of spare cash under the mattress and pull them out in times of need. Just don't hoard too many of them or the mattress will get lumpy and you won't sleep well.

A business meeting

I'm lucky in that although my cared for may not always have a good memory of what has happened in the short term there is a degree of understanding, so it's possible for us to try and make plans for what we might like, discuss how

things are going for each of us and try to resolve any challenges we might have. We try to approach this like a business meeting. We set aside some time to talk to each other; no blame is given, just free expression of how we feel. What might be a challenge for her and what might be a challenge for me. We have an agenda of sorts – easy things like what food we might have that week, who is going to cook it and on what days we might share the cooking, a review of what we have in the freezer for emergencies if I get home late and she doesn't feel like cooking and what jobs have what priority for each of us. I'm always the last one to think the bathroom needs cleaning and she's always the last to think of putting the wheelie bin out for collection; understanding something as basic as this helps us to understand that we are both doing things for each other, that it is two-way traffic. After our planning session we write up what we are doing and when on a whiteboard, including the menu for the week and our shopping needs. By the end of the week a lot will have changed but some of it will have happened, and although things never work out as we planned we are at least starting from the same point with a feeling of shared existence.

Bluebird says that having a plan for the week helps to remind her of what is happening and what she wanted out of the week. This doesn't always work, of course – it all depends on how well she is at the time. But it is a common start point. We both understand that we are both pushing rocks and need to respect each other for the work we are putting in. By planning, we can each learn about what the other needs and what they identify as a support. This goes back to not discarding the small pebble without understanding what it does; we can easily see the possibility of getting comfort from a teddy bear, but a picture of a cactus? Get real.

Some of my pebbles

I have built up a good reserve of special moments. Some are written down and some are in my mind. Pictures of good days out when we have both been able to put a pebble behind the rock. I allow myself to wallow in self-pity and tears if I want to – why not, it's my life – or to lose myself in distraction, laughter. I give myself permission to get things wrong and learn from them *and* to get things wrong, not remember and repeat the same mistakes. Why feel bad about feeling guilty? Try a bit of objectivity. If someone else made a mistake and got something wrong, how would I judge them? Most likely I wouldn't dwell on it for long.

Keeping well strategies are a great help. Keeping physically busy, keeping up what social life I can. All of these things help me keep well.

Every now and then, to add a bit more interest to life, the services that are there to support our loved ones lose their way and do some bizarre things. They all have policies about what they do and how they do it. But many of these policies are developed with the involvement of service users and carers, to try and achieve the utopia we are all looking for and make the process work well with good outcomes for all.

Getting involved

Occasionally a spanner gets thrown in the works and we're the ones who have to pick up the pieces. The resultant damage can vary from a slight bit of upset for the service user to complete devastation lasting many weeks or even months that takes us a long time to repair. Among the examples in our lives has been the loss of the local CMHC (Community Mental Health Centre) when it changed to an older people's service that excluded those of working age. A period of consultation was declared and promises were made ('We'll arrange for meetings to take place locally so you can avoid travel') and then promptly forgotten.

N.B. for the uninitiated to this sport: there is very rarely an option to say, 'No thank you, let's leave it as it is'. The options given come from the service provider and are usually derived from a national organisation such as the Mental Health Development Unit or the Royal College of Psychiatrists. Little thought is given to the application of these ideas in widely varying communities, or to the context in which they were first developed. Typically, what might happen is that an idea is conceived in a major city about the number of Community Mental Health Centres that are needed per head of population. This is then applied to a very rural community where a visit to a meeting is not a five minute bus ride away but a journey of 40 or 50 miles. Another scenario will be a comparison between the numbers of inpatient beds in two areas. From this, a conclusion is reached that area A has X beds and area B has Y beds, so area B has a surplus of capacity. Consideration to what area A may have in the provision of other services that enable this to work effectively is left out of the planning, thus distorting the result of any decision.

It is nonetheless important to get involved and follow the process, speak out at every opportunity and make sure you have a copy in writing of any promises made, especially those that affect you or your cared for directly. The direct benefit to me has been an understanding of how the jigsaw of service provision fits together, and who to call (and when) to get problems resolved quickly.

Bereavement

In amongst all the other emotions there is still a feeling of loss. This other person in my life is still basically the same but also very different at the same time. The values, intentions and desires we once shared have gone for one of us and been replaced with others (or, in some cases, nothing), creating extreme differences. This raises all sorts of doubts: were they ever really shared, or was it all just an attempt at appeasement by Bluebird? Was it the effort of maintaining this front that has caused all the problems? Should I cast aside what I've enjoyed and wanted for all of our lives together and look for something different? I have searched for a replacement life with new ideas and fresh challenges, but somehow it's doesn't quite hit the spot for me. It has left me with an empty hole inside. This hole is a vacuum which I sometimes feel is going to make me implode. I think this is the next stage of my learning, and I will try to use the knowledge I have picked up on the journey so far to guide and support me. I will try to be objective and realistic about what I do and how I do it. But it still scares me and often leaves me tearful if I think about it for too long.

The future

I still don't have the courage to even start to consider this, it's too much to even contemplate working on... But maybe, just maybe, life's like that for everyone: the unknown has always been the biggest part of it.

Writing this has been very hard, a strong and at times relentless reminder of the fragility of the whole situation and me in particular. I have tried to use it to focus on my wellbeing and keep myself well with the skills I have picked up on the journey. I am aware that with the passing of each day a bit of the future becomes a piece of the past, but it doesn't feel as good as it used to – quite often it's more like a day-by-day record of survival. I hope that, one day, 'recovery' will become a reality instead of a dream.