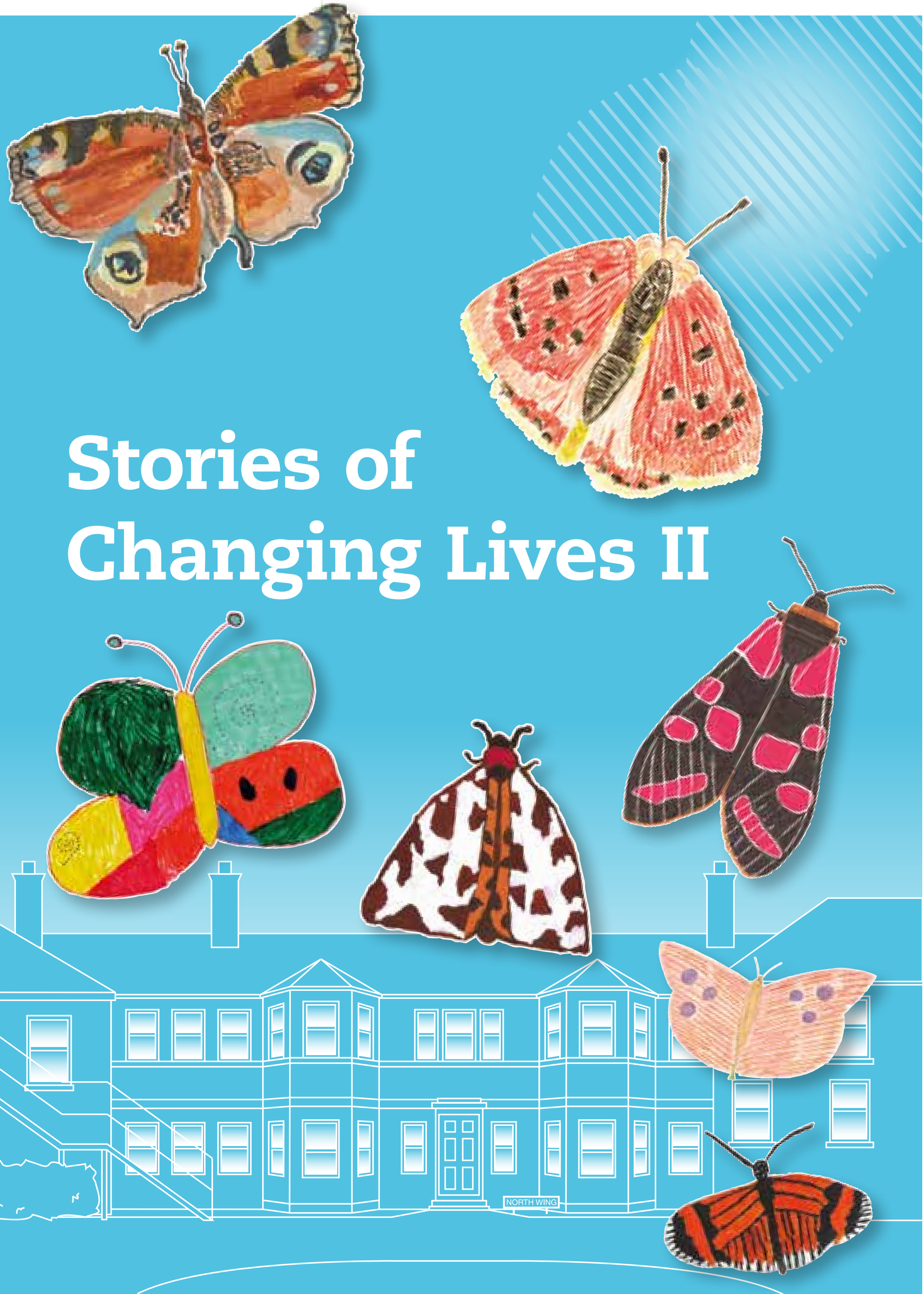
Stories of Changing Lives II



The Patients' Council, Royal Edinburgh Hospital

Stories of Changing Lives II

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Artist: Sarah

> ‘We delight in the beauty of the butterfly, but rarely admit the changes it has gone through to achieve that beauty.’
>
> **Maya Angelou**

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Butterfly images created by members and staff of Functionsuite,
an Artlink project based in the Royal Edinburgh Hospital.

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Contributors have chosen whether to use their own name or a pseudonym. All other names have been changed and services made anonymous to protect confidentiality.

Introduction

Does the road wind up-hill
all the way?

Yes, to the very end.

Will the day’s journey take
the whole long day?

From morn to night, my friend.

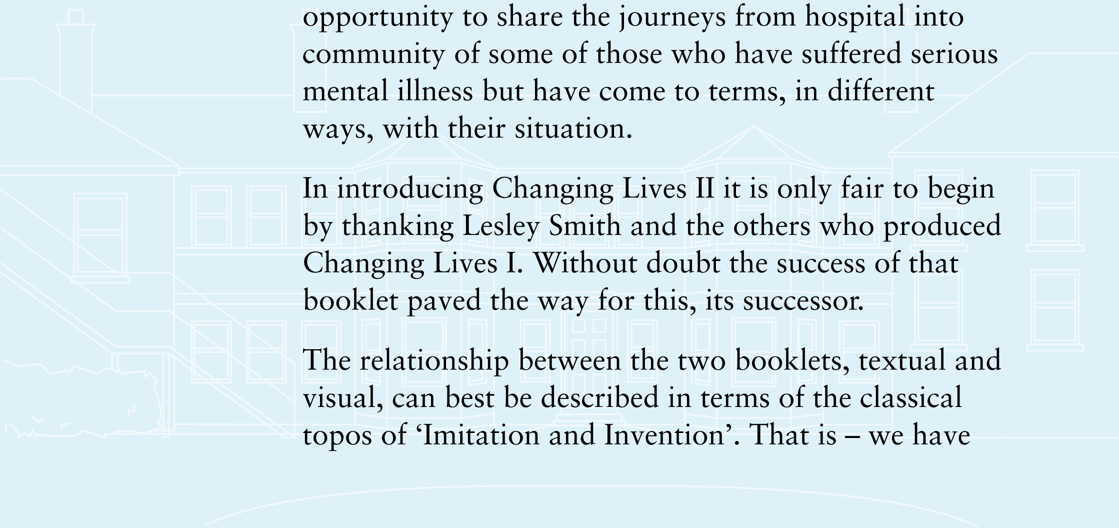
Christina Georgina Rossetti

This is the second volume of ‘changing lives,’ published under the auspices of the Patients’ Council at the Royal Edinburgh Hospital. The Council is a user-led independent collective advocacy organisation whose members also have representation on many of the major committees in the hospital.

Like its predecessor the booklet offers readers the opportunity to share the journeys from hospital into community of some of those who have suffered serious mental illness but have come to terms, in different ways, with their situation.

In introducing Changing Lives II it is only fair to begin by thanking Lesley Smith and the others who produced Changing Lives I. Without doubt the success of that booklet paved the way for this, its successor.

The relationship between the two booklets, textual and visual, can best be described in terms of the classical topos of ‘Imitation and Invention’. That is – we have



‘imitated’ the central, story-telling model of our predecessor but ‘invented’ in other areas. For instance, Jo McFarlane has contributed two poems with ‘rehab’ themes.

Thanks are also due to our colleagues in Artlink. Here too the principle of imitation and invention pertains. Thanks to Tommy, Anne and Alison the butterfly motif has been retained but new butterflies and new colours give the book a distinctive appearance.

The second and most important debt of gratitude is to the ‘story tellers’ themselves. As an academic specialising in the Middle Ages, the authors whose works I edited were all conveniently dead and therefore unable to protest. That made me more than a little concerned about the reaction of living authors, and especially living authors writing about their own lives, to any editorial invasion of their texts which I might judge necessary.

As it turned out, I need not have worried. The standard of the stories was so high that intervention was seldom necessary and when offered, graciously accepted. What I had not taken account of was the strong and higher motivation of the group. They had all unselfishly offered to relate the high and low points of their journey from hospital into community in order to give courage and guidance to others who might be embarking on the same voyage. In that context the well-meant, if at times pedantic, changes made by an editor paled into insignificance!

The third and last focus of gratitude constitutes the willingness of staff members to offer their personal perspective on the major initiatives affecting the hospital at this time. David Budd was asked if he would provide a broad survey of the hospital year as it affected the Patients' Council. His reflections follow the Editorial and precede the stories of changing lives, which form the central part of the book.

Three further staff contributions round off the professional part of the book. Debbie Mountain gives a specialist's view on current 'rehab' developments; Michele Harrison explains the aims and achievements of the Wayfinder initiative while Dick Fitzpatrick brings us up to date on the 'New' Hospital. Amazingly, given the pressure they were working under, they all agreed at first time of asking and were as welcoming of editorial suggestions as the 'wayfinders' themselves.

Having cunningly combined a gratitude motif with an account of the contents of Changing Lives II, I shall simply conclude with the hope that the quality of this volume will encourage support for Changing Lives III.

Ronnie Jack

A butterfly's lesson

One day, a small opening appeared in a cocoon. A man sat and watched for the butterfly for several hours as it struggled to force its body through that little hole.

Then it seemed to stop making any progress.

It appeared as if it had got as far as it could and it could not go any further.

So the man decided to help the butterfly. He took a pair of scissors and opened the cocoon. The butterfly then emerged easily.

But it had a withered body, it was tiny with shriveled wings.

The man continued to watch. He expected that at any moment the wings would open, enlarge, expand and become firm, enabling the butterfly's body to be supported.

None of this happened.

Artist: Giuseppe

In fact the butterfly spent the rest of its life crawling around with a withered body and shriveled wings. It never was able to fly.

What the man in his kindness and his goodwill did not understand was that the restricting cocoon and the struggle required for the butterfly to get through the tiny opening were nature's way of forcing fluid from the body of the butterfly into its wings. It would be ready for flight once it achieved its freedom from the cocoon.

It is the struggle that enables the butterfly to not only gain its freedom… but also to take its flight.

Sometimes struggles are exactly what we need in our lives.

If we were to go through our lives without any difficulties it would cripple us.

We would not be as strong as we could have been. We would never been able to fly!

‘Joint working and the passion of volunteers’

By David Budd

I resigned from my post as development manager in June 2014. Moving on from the REH Patients’ Council was one of the most practical yet the most difficult moves from a job I have ever had to do. There is something about the work, which whilst being tough is very rewarding. This is mostly due to the wonderful, interesting, different and sometimes challenging people you get to work with, including staff as well as patients and volunteers. There is something about the positive outcome which collective advocacy can generate for groups and individuals. Then there are the buildings and grounds themselves, which are steeped in 200 years of history. The REH is a fascinating and challenging place to work.

Remembering what happened in 2013 to 2014 is even more of a challenge for me, but this is not something new. When I was in post it was typical that a large volume of work was covered, driven by the passion of volunteers to fulfil every need and every request. Often the work would be completed and then we would move on to the next without the volunteers stopping to congratulate each other.The PC did develop better ways of recording their achievements and work flow;

mainly to give an account of their actions and outcomes to funding bodies and keep or fight for their funding. One piece of work to mention is the history project. It resulted in a brief history of the Patients’ Council from 1990 to the present. You can find it on the PC’s website in the ‘about us’ section. Even though it is outside the time span remit I have been asked to write about it is also worth mentioning that without the commitment to joint working and efforts of the staff at AdvoCard and the Carers Council there may not have been a Patients’ Council to talk about in 2013 and 2014. The bravery and determination which Chris Mackie at AdvoCard and Ruth Rooney at the Carers Council showed in sticking with a difficult process, during the dark days of the advocacy review in 2011 has paid off finally for the provision of mental health advocacy in Edinburgh.

Taking an overview, jointly working with staff in the NHS and other third sector organisations was an ever present important theme and agenda for the PC. This is inescapable regardless of the work being something the PC was invited to participate in, such as the reprovisioning meetings, or the collective advocacy meetings the PC organised. It’s difficult to tease out specific pieces of work without fear of leaving something important out. This is not just because of the quantity of work but also that even what might seem a small issue can be enormously important to patients. Nevertheless I will give it a bash!

One very enjoyable project was working with Artlink on the bicentenary. Artlink provide such a valuable service at the REH which is massively valued equally by patients and staff. The PC was part of the bicentenary steering group and was able to put ideas forward and volunteer for different tasks. A fabulous contribution was made by our volunteer and editor of this book Professor Ronnie Jack who delivered a lecture on the life of Poet Robert Fergusson as part of a bicentenary lecture series.

We participated regularly in the Wayfinder project. This initiative was developed through joint working between Napier University and the NHS and led by Michele Harrison. Many meetings were attended to assess and redesign the care of patients in adult rehabilitation wards. Some very interesting and thought- provoking discussions took place as part of this process. They centred on establishing what was the best rehab pathway and, moving forward, for a modern model of psychiatric rehabilitation. Of prime importance for me, and no doubt others, was the consideration given to those patients who had been on rehab ‘continuing care’ wards for decades. Over time we saw these patients re- housed in appropriate community settings, which suited their individual needs beyond the confines of a large institution.

We continued to hold our collective advocacy meetings on wards and document the issues and compliments raised by patients. The ever-present concerns from adult acute patients were about staffing numbers. Patients were always quick to recognise the challenges staff faced and how hard staff worked, but patients were worried about their own personal safety and the number of occasions on which wards were locked. We also improved the way we dealt with older patients by meeting them one to one, rather than in groups.

We continued our joint working relationships with Edinburgh and Napier universities. Our volunteers were involved in many aspects of their work from interviewing prospective new students and helping to design curricula to delivering workshops and training to students.

As part of the ongoing reprovisioning work at the REH, our volunteers attended Clinical Brief and Design Task Group meetings. The work progressed from an overview of the first phase through to 1:200 scale designs. Our volunteers were able to feed in patient perspective on what’s needed from the new hospital. We were impressed with the design team and their willingness to hear the feedback and incorporate it into the new design.

For an example of our lobbying and campaigning work we wrote to Mr Tim Davidson of the Lothian NHS Board to raise concerns about staff to patient ratios at the Royal Edinburgh Hospital and the 3.7% savings target the hospital is being asked to achieve. Taking into account the good progress made with the reprovisioning of the Hospital, and the stage it has reached, we felt it was particularly important to raise these points to ensure that the staffing is correct and care is deliverable for the new business case and for the future provision of care in the new building.

We were also pleased to move from what were the leaky, cold and damp port-a-cabin offices to delightful warm and dry offices within the Robert Fergusson unit. Both Maggie and I had a moment when we realised just what kind of environment we had been working in. One morning in the new office members’ room, during a diary meeting, rain began to pour down outside. Maggie and I both paused mid conversation and began staring up at the ceiling. Even though there was a whole floor above us, years of conditioning had meant we were both waiting to see where the rain would begin pouring in, so we could place the bin under it. On realizing we were no longer in the port-a-cabin with its leaky roof we began to laugh.

Stories of Changing Lives

Mirror image

By Jo McFarlane

This is what I want
to be: a carbon copy
print of me

A billboard plastered
high above: my picture on it,
look of love

This is what I want
to write: my signature
bold and wide

A book about my tawdry life:
the tears I've wept,
the rope, the knife

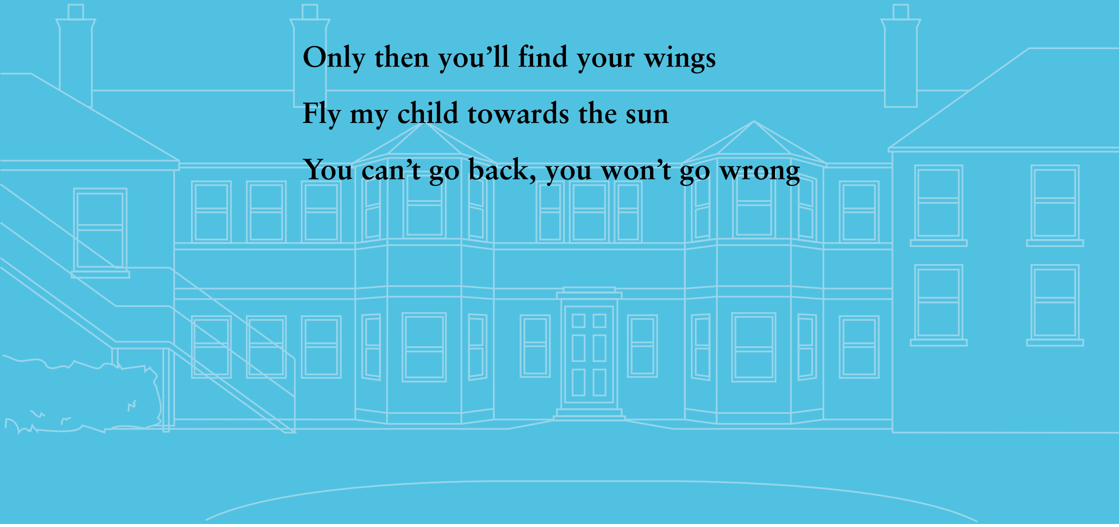
This is what I want
to show you: how I've grown,
how I know that you

Can find the love
within, Your beauty's
in your suffering

So don't deny it,
don't belie it, don't escape
on drugs or diets

Look your mirror
in the eye, cry your tears
then wipe them dry

Only then you'll find your wings
Fly my child towards the sun
You can't go back, you won't go wrong



Albert's story

'Out of Sight, Out of Mind'

Q: What was it like being admitted to the hospital?

A: With hindsight, my entry into the psychiatric mindset was for all the wrong reasons. At my admission, the doctors only assessed my symptoms, which to me, totally missed the point.

My original problems (rather than the so-called 'symptoms'), stemmed from what I had to contend with at work, but this was never accepted, taken seriously or recognised as key to my condition. The professionals chose to ignore my experiences and believed only their own observations to be valid; they only looked at the frustrated, hyper-active antics that followed, not at the big picture of my life.

Due to their investigations and treatments starting from this flawed premise, I came to mistakenly believe I was mentally ill. I believed for 53 years that I was a second class, if not a fourth class citizen.

Q: What was it like being a patient in the hospital?

A: In 1960 my Dad and I had to sign papers permitting me to undergo ECT (Electro Convulsive Therapy); if we didn't, I would have been sectioned and given it anyway. Nobody I knew had been a patient and in reality, it felt like being an alien. I felt like I'd lost the plot and been made a scapegoat.

I was prescribed a course of ECT, which only made me forget the factors that had brought me to hospital in the first place. The emphasis was on treating only the symptoms, not the cause of distress. To me, the cause of my problems was the lack of care and harsh treatment I'd received in my workplace, but the ECT had the effect of masking and blocking this truth from my mind. I was unable to see the cause of my problems and so unable to find any solutions!

At that time, there was no real peer support amongst patients; we were not encouraged to speak to each other and the old-fashioned medications meant conversation wasn't really possible anyway.

The real challenge was to measure up to the staff's requirements, in order to get myself out of hospital.

Q: How did you feel when you were discharged from hospital?

A: I went back to work, but couldn't remember why I had been in hospital, or how workplace issues had created the 'monster' I had become. I had also forgotten how to draw. I did end up working with some colleagues for around a year before becoming unwell again.

Work has always been very important to me. When I was discharged the second time, I wasn't allowed back to the drawing office, so went to the Industrial Rehabilitation Unit (IRU) in Granton, where I learned joinery. This IRU assessment led to a six-month course in County Durham, and then on to a job in a Newcastle joinery firm. I cracked-up before I started there and received a further eight ECT treatments in Winterton Hospital, Sedgefield (which was later to become Tony Blair’s constituency). I then moved back to Edinburgh, married and started a job in a rubber mill: the courses I’d done down South weren’t recognised in Scotland at the time.

I wanted to work, but always had a feeling of being observed by my colleagues and employers, once they knew my history. People may have had good intentions but this scrutiny always felt counter-productive to me.

Q: What helped you to settle into your new life?

A: Getting married and finding a secure job meant I had long periods of stability; I worked as a labourer for 28 years, for a company first called Wilkie and Paul, then Borden UK and finally MY Plastics. Team-work and working with others was important and this helped me keep well. There were still inequalities in that workplace, but I became the general handyman over time and carved out a niche for myself. I did the painting, plumbing, some electrics: a real jack of all trades.

Bear in mind, this was all at a time of great political and social change: the old guard still had the ideas and ideals of Empire and this was reflected in a lot of old-fashioned professional attitudes. Others were more enlightened.

Over the years, I found a way to accommodate people, and others learned to accommodate me. I learned to be my own person and to understand that I had to get myself right first. I believe there is a lot of kindness going on in the world, but at the same time that true sanity is actually a very rare condition.

Q: How do you feel about your new life in the community?

A: For 20 years I was an NHS 'junkie'. Then a relative suggested yoga to my wife and me: I achieved enlightenment after 6 months of yoga and reading books on Buddhist and Hindu philosophy.

Around this time, I had pains in my lower bowel so I saw my GP, then a Consultant about the risk of possible ulceration due to the lithium treatment I was on. I decided to stop taking it. I had an appointment with a young psychiatrist to give my regular blood sample to check lithium levels. At this meeting I told her I had stopped the lithium for medical reasons and that with yoga I'd found alternative coping strategies. She went bananas and I later found out (when I accessed my medical records) that all she had recorded about this meeting was "He'll be back". I have been out of psychiatry and off its treatments for 35 years; I even gave up cigarettes 33 years ago.

I don't feel that I'm 'in the community'. To me that is the same mindset as telling people to 'keep taking the tablets'. I think every person has to find their own way: this takes time and, for me, accepting that nature is in charge and having self-discipline is what works.

Even after all this time, I still feel like an outsider. I believe that what 'humankind' does in the name of progress is often insane and that many people have a misplaced sense of power over others and over nature. I believe you really need to go through hell to see the whole picture; that you need to have experienced insanity to truly understand sanity. I think that this is my problem now.

The story I thought would never happen

By Kerry MacIver

The doctor stood up in front of me, smiling and shook my hand. “Congratulations, it’s not often I see this. It’s really nice to see a happy ending! Good luck for the future.”

I smiled back at him, “Thank you… I hope I never see you ever again!” I picked up my bag and left.

Outside the building I breathed a huge sigh of relief. I was free at last! My life was just beginning and the world was waiting for me!

This was the day I never thought I’d see. After a decade in the mental health system with 20+ admissions under my belt, institutionalised… dozens of psychiatric meds that didn’t work and 15 courses of Electroconvulsive Therapy (ECT) that didn’t work much either, I was pretty much dismissed as a hopeless case. My diagnoses included treatment resistant Depression, severe Anorexia and Bulimia Nervosa and the infamous Borderline Personality Disorder.

I bet you wouldn’t believe me if I told you that that girl who was destined for a life of hospitalisations, weigh-ins, pills, nasogastric tubes and drips, bandages, suicide attempts, self-hatred, paranoia and despair, lives a very different life today.

I can trace my depressive tendencies back to when I was 12, intensifying at university and culminating in a horrendous breakdown just before I graduated.

I developed anorexia in hospital when trying to pick up the shattered pieces of my life. It wasn't about the weight. I was running away from a life I felt too young for. Buying time… Bulimia followed later when my body's demands for food became too much.

It wasn't long before the eating disorders took a firm hold. For 10 years I didn't cook a meal… I'd lost the concept of mealtimes completely and as eating is centred round many social events, I eventually became a hermit. I'd torn my family apart and my friends had all but deserted me. I don't blame them. After the fifth or sixth hospital admission they got fed up with it all. The girl they knew so well had turned in to a complete stranger.

It was a pretty grim time.

In the beginning anorexia was thrilling and exciting – pushing my body to extreme limits, rebelling against everyone and everything, knowing there was danger involved. The bulimia I wasn't so proud of. It made me ashamed. It disgusted me and I detested myself. But it kept me safe and I felt protected from the grownup world.

However, over the years there was a gradual shift in my attitude towards the anorexia. After many repeated cycles of the slimming down and fattening up drama in hospital it wasn't exciting any more. It was getting harder and harder to be anorexic as my metabolism was completely mucked up. What was the point in going to all that effort if I never achieved what I set out to do?

I was sick and tired of being sick and tired… and lonely, cold, miserable and broke. I had spent all my money on binges and in deep financial trouble.

I wanted a normal life. I hated the life I had and I wanted more. After being banged up in hospital for a decade, I wanted to travel the world. I wanted to see places that people talked of. I wanted to be free.

I wanted to enjoy a cuppa and cake with my friends, and taste foods I had never tasted before without the frenzied calorie counting that went with it.

I wanted to be able to buy a pair of jeans without having to hunt for hours in the children's section in the shops. I wanted to be able to go out where no-one would stare or look at me in pity. I wanted a normal body with boobs, hips and an arse you could grab on to. I envied women who were so obviously women… Finally, I wanted someone to share my life with. Someone who found me attractive, and believe me, with a Body Mass Index of only 9, I definitely was not attractive!

If I wanted a better life, only I could do something about it. Nobody else was going to do it for me. And that's when I had this thunderbolt moment when I realised I couldn't go on like this and I'd have to give it all up. It just wasn't worth it anymore.

I had made my decision. Upon discharge from the ward I told them I wouldn't be back. I don't think they believed me.

It sounds silly, but before I started eating again, I said a proper goodbye to the body I knew so well. It had been my companion for the last 10 years and I knew I'd never see it again. In a way, it gave me a sense of closure and prepared me more for a new beginning.

As I started to gain weight, I closed my eyes to what was happening in the mirror. I shed many tears over the loss of my anorexic body. It was a bereavement in a way.

Getting over anorexia has been the hardest thing I've ever had to do. It was like walking on a tightrope with my eyes shut. I had to relearn the most basic of things… eating in public, shopping in a supermarket, and having to force myself to eat 3 meals a day, even if I still felt full from the last meal. I had to set a timer to remind me when mealtimes were.

My initial rapid weight gain slowed down and eventually stabilised. I got used to having a bigger body and grew to love my new curves, not forgetting all the clothes shopping that went with it!

As soon as I started eating normally, my bulimia disappeared overnight. It took about a year of relentless hard grind and determination for eating to become a habit and years after that to lose my anorexic tendencies.

I knew I had made huge progress when one day I was in town, quite hungry after a hard morning, made my way to a café and had lunch without a second thought. I only realised afterwards how big that was and how far I'd come.

These days – 7 years on – I consider myself fully recovered from my eating disorders. Most people find this hard to believe. "There must be something left over from those years that you still have trouble with?" is one I get a lot! Well, if you want to count osteoporosis, dodgy teeth, a compromised immune system, loss of muscle, digestive and gastric troubles, food intolerances and sensitivity to the cold, then you'd be right. You don't think about how things will be after you get over an eating disorder. Recovery is unimaginable when you're gripped in the eating disorder vice. You think you'll be like this forever or it will eventually end up claiming your life.

I don't think twice about eating now. I don't calorie count. I don't get jealous if I see an anorexic in the street – I used to, but not now. I rarely weigh myself these days – I just go by the waistband on my jeans. The day I ditched my scales was a huge liberation! The old shackles finally gone!

Most anorexics are very determined, focused, perfectionistic and extremely stubborn – I was no exception! But it's these very qualities I owe my recovery to.

Believe it or not, I am now completely free from psychiatric medication. Given the severity of my depression in the past, I was told I'd be on anti-depressants for the rest of my life.

I found the side-effects intolerable… almost worse than the depression. I think the worst was the continual raging thirst which made my mouth so dry it was painful. Drinking 4-5 litres of water a day was not fun. And then there was the restless legs, jaw spasms and tongue-biting which made life a misery.

I never felt the pills did any good and I tried for years to persuade my doctor to let me come off them. He said No – I'd been so ill in the past and he couldn't take the risk.

Years later I got a new doctor. I had my arguments prepared for coming off medication, but she stopped me a minute into my spiel, “You obviously can’t tolerate the drug, so why not taper off slowly, keep a withdrawal diary and come and see me frequently.” I nearly fainted on the spot!

Four years after my eating disorder recovery the medication withdrawal began. I tapered off the drug over a period of 6 months. My first night without any medication in over 10 years was scary – was I doing the right thing? What if I got ill again? My determination to live a medication-free life was stronger than my fear.

I knew from what I’d read the withdrawal was going to be very hard but I don’t think I was prepared for how difficult and long it would be. I didn’t sleep at all for a month, lost 20lb in 2 months as my appetite had gone. Add on to that itching, nausea, vertigo, restless legs, flu-like symptoms, anxiety attacks, brain zaps and hot sweats. It took a good nine months for things to settle down, and a year for my appetite to return to something resembling normal.

Sleep continued to be a problem long after that. The drug I was on had been very sedating and I had to relearn a new sleep routine and do a lot of experimenting with different bed times and the amount of hours I slept. Several times I considered giving up, but I told myself it was only temporary and my determination kicked in again.

Two years on from the withdrawal and I’m a different person. I’m more alert and have more mental and physical energy than I did. People comment that I am “present” now whereas before I had a vacant glaze in my eyes.

I was right. The medication didn't do much to help me. I never had the huge mental collapse my doctor was expecting and it's been a big learning curve in getting to know my mind and body better.

The depression is still in my life but I control it by diet, exercise and mindfulness meditation techniques. I learned what my triggers are and focus on preventative measures. If I have a depressive episode, then something in my life isn't right. It could be that I'm too stressed, or too lazy to get to the gym, or there's not enough creativity in my life, or I've been tempted by the chocolate aisle in the supermarket or even just having too much caffeine or starches. I also ask myself "What can I learn from this?"

The Borderline Personality Disorder (BPD) is also still in my life but not to the same extent as it used to be. I used to have a terrible hang-up about it. Nobody likes being told they have a personality disorder.

At one point, anything that went wrong in my life or relationships, I blamed on BPD. One day I caught myself blaming something totally trivial on the disorder and I stopped dead in my tracks. I suddenly realised I was using it as an excuse to avoid taking responsibility for my actions and mistakes, and when I made the connection things changed. It sounds harsh, but it was true. Don't get me wrong, I still have strong emotions, black and white thinking and the odd dissociative attack from time to time, but I don't let the disorder (or the depressive spells) define who I am as a person.

The single most effective thing in combatting the BPD was meditation. It seemed to stop my internal chatter, silence the demons and gave me the calm and peace of mind I never thought possible.

Somebody once asked me if I regretted that lost decade. There are parts of it I do regret… like having all that ECT. My brain function is very different now than when I first entered the psychiatric system. I've had to renegotiate life with an acquired brain injury and come to terms with what I've lost. It took years, but I'm finally at peace with it now. My life might be very different to what I had originally hoped, but in a way, that breakdown was probably the best thing that could've happened to me. I'm much stronger because of it. You don't go through something like that without changing as a person. My priorities have changed, with my health and happiness at the top of the list. I understand myself and other people much better and am more tolerant and empathic. I'm more relaxed about the bigger picture, and after several brushes with death, I stopped taking life and the people around me for granted. Having been about as low as you can get and still here to tell the tale, I know somehow that everything will be ok.

I'm living the life I wanted to live and don't know why I was so scared all those years ago. I have been discharged from mental health services and no longer see a psychiatrist, Community Psychiatric Nurse or support workers.

I am realising my dream as a writer and blog regularly which I find very therapeutic. I now use my experiences to help others and to give hope that recovery is possible. If I can do it, anyone can!

Long journeys home

By Steven Kelly

Admission

What was it like being admitted?

It was traumatic. I left home without socks and shoes. It was a week before I got any other clothes. I was brought in by police, sectioned and admitted to Ward 5.

Ward 5 staff were very caring but I was left to my own devices. I was there from January to November 2008 then I went to Craiglea. I was looked after by Dr Mountain.

I couldn’t settle in at Craiglea. I had to leave the ward all the time, I felt tense and nervous. Craiglea has changed from Rehab to Acute and I feel I suffered as I wasn’t getting personal attention as the staff were too busy. The environment changed – people in the ward were much more unwell than me.

Feelings on discharge?

This is the first step on a long journey.

I feel at home at the flat. I feel a sense of responsibility. I felt institutionalised and was worrying as I didn’t have to take responsibility when I was in Craiglea.

It was a lengthy process to find the right accommodation – looking at lots of different places. My house is the best I could have asked for.

I have the right package of care.

My faith has helped me through this. I pray and attend mass.

Time helped. Time is the biggest healer.

No noise in the flat. No alarms like the ward.

I feel at peace with myself in my flat.

The staff in Craiglea were stressed.

The staff in St Leonards are good; they have my best interests at heart.

What helps you enjoy life?

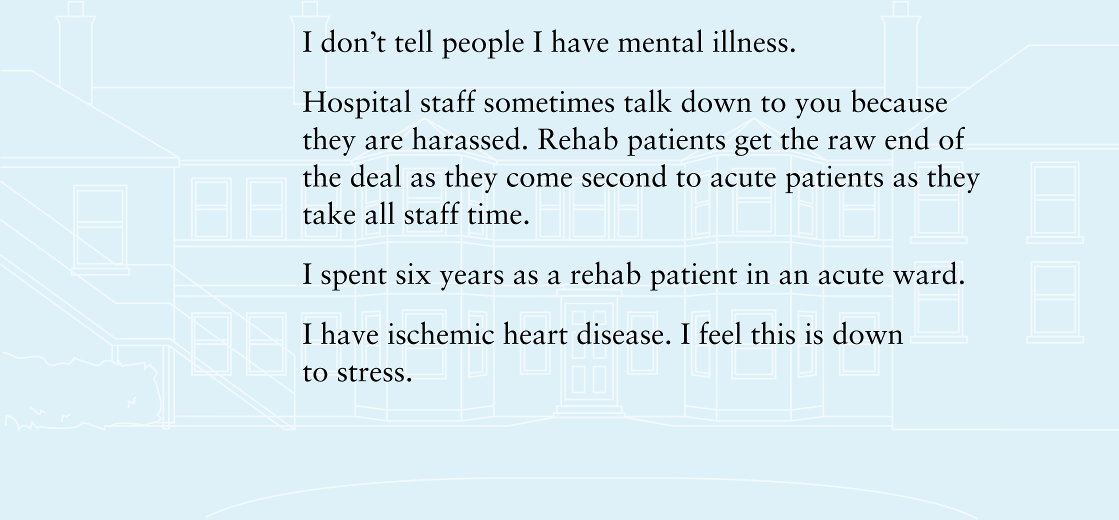
I am beginning to enjoy life. Talking to others helps – local people. Meeting new people. Talking to launderette women. I go to the pub for juice. It was my birthday three weeks ago, I went to Fort William.

I don't tell people I have mental illness.

Hospital staff sometimes talk down to you because they are harassed. Rehab patients get the raw end of the deal as they come second to acute patients as they take all staff time.

I spent six years as a rehab patient in an acute ward.

I have ischemic heart disease. I feel this is down to stress.



What is unhelpful?

I don’t have a social worker. Joanne had to do that, both nurse and social work.

I benefited from working with Joanne, the Care Manager, who helped with a lot of practical aspects of moving on, such as getting furniture. There is continuity with Joanne as she knew me and what I needed. I have a good relationship with her. I had problems opening mail as I worried about what I would find inside. Support staff and Joanne help with this.

Flu symptoms – Bird flu – contained in room on ward – very stressful.

Advice to others – don’t lose your faith, be fearless and ambitious, as incentives, to tranquillity and hope.

Worked with two different Care Managers – the first showed me wrong types of accommodation – hostel and shared – homeless – alcoholics hostel, therefore refused to move.

Joanne showed me a flat that allowed me to be more independent – gave me control of my life again.

Voices remain – argue with me – hear women’s.

I have learned to cope – listen to music, hearing voices group, write it down – I know they are not real and I try to not let them get me down.

I fight it, I have never lost my faith.

There is always someone worse off – people on ward in worse state than me. People need to be readmitted. I am frightened that may happen to me.

I comply with everything but at times could scream as voices are constant.

Voices echo – scream in my head.

Have problems sleeping – feel exhausted.

I like visits early in morning as I have to get out during the day due to side effects of depot making me restless.

Visits from Moira and Joanne help me but they have limited time. Use self help for support as well.

Go to visit a friend whom I met from Craiglea – he is in hospital again and I will visit him.

I use drop in at St Leonards and mix with others.

I can relate to people as they have similar problems to me – hearing voices and have heart problems. I have empathy for them.

I am not alone – there are people around me I can talk to and relate to.

The communal area in my block of flats is very helpful as helps me keep in touch with others.

I want to move to country and have a dog in the long term future.

Buying books – would like to volunteer at soup kitchen.

Now have more responsibility for own finances – feels good but sometimes scary as never had bills in hospital. Need to accept help from support staff to pay bills and help with weekly budget.

I like not having to eat at certain times – love the flexibility of making my own meals. No real choice in hospital.

Must be cheaper to keep me here than in hospital. Trying to get more patients out but not enough suitable accommodation.

Sleep and lack of it is my main worry.

I have learned life skills in hospital; these made me more assertive as would get walked over by staff and patients. Hospital is chaotic environment.

Being able to tell this story is like confession. Is good for the soul.

I find it therapeutic and hope it will give others hope for the future that they can move on and recover too.

‘Life begins at forty!’

By Lesley Smith

Such a cliché yet for me, my life DID begin at forty and here’s why.

At 18, I arrived in Edinburgh proud, enthusiastic and full of optimism, embarking on a student life that was the gateway to freedom and my dream of becoming a teacher. I was on the cusp of adulthood and independence, looking forward to all that life had to offer. Unfortunately the dream was not to be. By my final year I was signed off sick and meeting with a psychiatrist. I was depressed and deeply distressed. To cut a long story short, medications and counselling weren’t helping so I agreed to be admitted to hospital. I was very scared.

It still makes me laugh at the absurdity that even though I was in hospital, I still managed to finish the graduation ball gown I was making for one of my classmates. I worked on it in the ward kitchen and as long as I handed in the scissors was left to get on with it. It provided a bit of normality at a confusing and disorientating time. At least my friend has a story to tell of dress fittings in the games room of the local psychiatric hospital. I held onto the knowledge that my turn would be next year but the reality became very different.

I was discharged in late summer and decided to stay in Edinburgh and take a year out to focus on getting better. Unfortunately I sunk deeper into depression and distress culminating in a suicide attempt. I felt the life I had hoped for was over and I had failed as a human being. My dream of a teaching career became lost as I became lost to myself. My sense of shame was overwhelming as I embarked on what I can only describe as a very different life path, that of a psychiatric patient. I became a regular on the acute ward and as my distress increased, my world collapsed around me. The ward became a safe, if at times despised, place to be. It was a world within a world, with its own social culture and rules, cocooned, in a way from the reality of life and the wider world. I had no idea how to find my way out.

In time my whole life revolved around mental health services. If I wasn’t in hospital, I was in some form of supported accommodation and I didn’t care if I was sectioned. If anything it gave validity to my pain. My peers were entering the world of work, social lives and relationships, whereas I found myself estranged and could only watch enviously from the side lines. My life revolved around finding the right medication, attending appointments and wanting to die. My scarred body bears witness to my distress, my means of appeasing the taunting voices that no-one else could hear. I didn’t believe they were part of an illness but retribution for a sinful life.

Over the years there were many people who were very supportive and good to me, yet I’m afraid that the systems that supported both me and them often got in the way. I withdrew more and more into myself. I certainly didn't expect to see my 30's, never mind my forties. Yet, something changed. A series of circumstances that slowly helped me see that I did have a future and it would be one that I would lead, control and enjoy.

It's empowering to have, never mind share, my own experience though also a bit of a challenge! To think that there are folders upon folders of notes documenting my life in health and social care services, it's interesting that I haven't seen them or contributed to them.

How can I explain in a few pages what others have recorded in countless files? How did I change from someone who had given up on themselves and wanted to die?

To think, the highlight of my year was meeting with the Consultant to assess whether my section would continue or not. I didn't care, or at least that was the impression I gave, but I cared very deeply.

My understanding was that schizophrenia was a degenerative disease and I was ashamed and frightened for my future. My physical body had also changed so much and I despised the various effects different medications had on me. Still, I thought the answer was only in finding the right combination so begged for more. Reflecting now I can see that what I really wanted was the pain of living to be removed.

I also had a deep sense of shame that came from my understanding of my place in the world. This was also reinforced by the world around me. I felt judged and undeserving whenever I collected my benefits or explaining that I didn't work. When I moved to a rehab ward, my first night reinforced for me my place in the social order. At evening medication time, the ritual was to line up in the hallway, so I joined the queue. I felt very lost and lonely, scared that being in a rehab ward was further reinforcement that I had no future. As I came to the head of the queue the nurse turned to his colleague and asked who I was. I felt as if I had been slapped in the face. I clearly understood the new terms of engagement where I was invisible.

But change happened, often in very unexpected ways. I did find my voice, my sense of self and my future. It has been a great voyage of discovery, though at times hard. I managed to get discharged from the rehab ward in what was a very unorthodox way. I essentially pushed the Consultant to agree but on his terms that I accept support. As I was still under section I was in no position to disagree though I did try. I resented the support but in reality didn't think it would amount to much and I would quickly get rid of them. I was SO wrong! I had a care manager from a newly formed team in the hospital and a social worker and they were very different to anything I had experienced previously. Initially I found it really difficult even to be in their company and we spent many hours nursing a cup of tea in literal silence. Over time I began to trust them and our relationships slowly began to build. The ethos of understanding that it took time and continuity to build relationships was invaluable and on reflection I would say that this was the point when I started to change. I began to trust and take small steps outside of myself. I began to feel less lost as they reinforced that I did have a future and it didn't have to be the one I feared. Foundations were beginning to be built and they were coming with me!

Over time, I moved in and out of different services and finally pushed to get my own tenancy. I felt both ecstatic and frightened. I now had a home that was mine, my bolthole. Around the same time, I was searching to understand my experiences and picked up the book ‘Accepting Voices’ by Romme and Escher. My experiences were very real but I still couldn’t accept that I had an illness called schizophrenia. For the first time I learned that other people heard voices and they weren’t distressed by them. I started to ask questions and discuss my experiences with people involved in my care. Whilst it was helpful, it was also frustrating as I felt that most conversations were one sided. I felt listened to but would really have appreciated more of a dialogue. People did try and I sensed that they were going beyond the norm for me. In fact the best support I have had was always with people who challenged the system so that they could provide what was best for me. It’s a shame that their actions were seen as radical rather than accepted practice.

At this point I was still taking large doses of different medications. Beginning to really understand their purpose began to change my relationship with them. Rather than a solution in themselves, they became a tool. As I began to make sense of what the voices were saying to me, I began to see meaning in how they related to my life. I began to feel more in control and empowered to deal with them. I realised that, for me, antipsychotic medication was a bit of a misnomer. Medication didn’t take away my psychosis and as my CPN explained it was more they helped to deal with my distress. This opened the door to exploring other ways of dealing with that distress.

As my world revolved around mental health, I wanted to get more involved. I loved the conversations I had with my social worker, amongst others, about the subject. I was envious of conferences she attended. I wanted to make a difference and had a lot to say about how mental health services could be different. I was challenged by others that to do so I would need to get involved-couldn't hide for ever! So, very tentatively, I did. I joined the Patients' Council at the hospital and quickly found respect and my voice. I really had my eyes opened when another member pointed out I had a great laugh. I wasn't even aware of enjoying myself! The same happened when I joined the Board of my support provider. I was certainly out of my comfort zone but was determined to contribute. In both environments I learned much more than I ever contributed building on both my knowledge and expertise. I felt valued and took opportunities as they arose. I was even mistaken for staff at times!

Through my involvement, I began to hear the word 'Recovery'. I was both intrigued and suspicious while also feeling threatened. How could you recover from serious mental health problems? I certainly hadn't met anyone who had. I thought you just had to live with it as best you could and accept a limited life. The more I heard and learned the more my understanding was broadened. I had just discovered the internet with its vast encyclopaedia of knowledge at my fingertips. For someone who was initially scared of a computer, I quickly valued its power and potential. I relished discovering different viewpoints and making sense of my own experiences. I began to understand the role of trauma in my life and that one of my voices related to an abuser.

I then heard about peer workers and a course about to be offered in Edinburgh. I wanted to know more and thought it was vital for the Patients' Council that they become involved when these roles were being developed. As they say knowledge is power. I was offered a place on the peer course and for two weeks my sense of self was turned upside down. I had an amazing and enlightening experience as I learned about wellness and peer relationships. Very different from the illness frame of reference I was used to. Whilst my intentions were honourable, I really didn't expect to find my own recovery! I was challenged and my foundations rocked yet I had a deep sense that this was the beginning of a transformative experience. I began to explore my own wellness.

An important stage for me was reducing my medications. My Consultant didn't think it was wise but he was willing to support me. I knew from others' experiences that it wouldn't be an easy process and I would no longer have medications as a buffer for the deep emotions that I would now fully experience. I expected this and in many ways I had to relearn how to deal with the full spectrum of emotions. It wasn't an easy process but I am so glad that I did and to be honest I still am learning! I no longer take medications though have done and will do, if I feel it's something that would help me through a challenging period.

As I approached my 40th birthday, I was excited. I had spent many birthdays in hospital thinking I had no future. Here I was now planning what I was going to do and thinking 'it may be 20 years later but I am that teenager again on the cusp of adulthood'. I was beginning to experience life in ways that being mentally unwell had cut short. I was very busy being involved in numerous mental health projects and was offered a part time job. Tentatively I agreed and started the process of coming off benefits into employment. Within 6 months, I had been offered a fulltime post with a different organisation and 5 years later I have a job I love.

My biggest challenge has been overcoming my deep sense of shame and recovering my sense of self. Having people who believed in me, when I couldn't do so for myself was essential. For the opportunities I have been offered and taken. To be given the freedom and support to take risks and to find my way through. I learned so much from picking myself up. Above all, I am so glad that I didn't believe the prognosis. I was often told, life would be so much easier if I accepted my diagnosis. Sometimes it pays not to accept others' reality but to find your own.

John's story

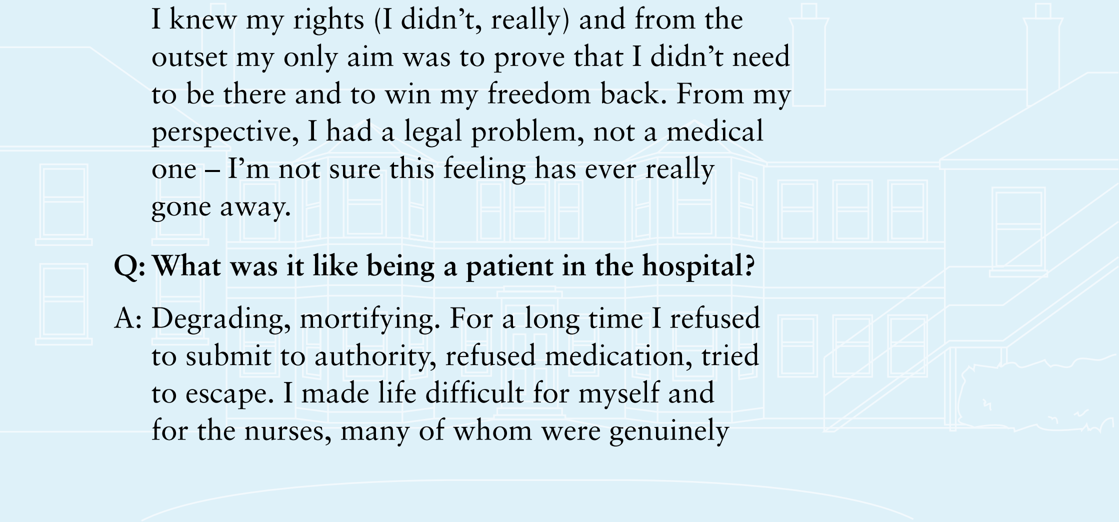
Q: What was it like being admitted to the hospital?

A: Surreal, absurd; I remember saying it felt just like the play *Waiting for Godot*. My Dad and I waited for hours before I saw a psychiatrist, who then asked me a series of bizarre questions. I generally acted the fool, told the doctor stupid jokes (e.g. "Where are the Andes? On the end of the armies!") and refused to take any of it seriously – right up to the point where I was huckled away by two burly male nurses. One on either side of me, they each encircled a fleshy hand around my wrists (like human handcuffs) and marched me over to a locked ward. It suddenly stopped being a funny story that I was looking forward to telling my friends about.

Like everyone else in history who has ever been detained, I felt outraged. I hadn't done anything wrong and they had no right to take away my freedom. I frequently and noisily asserted that I knew my rights (I didn't, really) and from the outset my only aim was to prove that I didn't need to be there and to win my freedom back. From my perspective, I had a legal problem, not a medical one – I'm not sure this feeling has ever really gone away.

Q: What was it like being a patient in the hospital?

A: Degrading, mortifying. For a long time I refused to submit to authority, refused medication, tried to escape. I made life difficult for myself and for the nurses, many of whom were genuinely



compassionate and caring. It took me far too long to realise that I could not hope to win my freedom back this way. My fellow patients helped me see that I needed to take another tack and at least appear to be more compliant with treatment. I learned from patients and family how much weight the doctors gave to the concept of 'insight' and so sought to assure them that I could indeed now see myself as others were seeing me. I realised that from the psychiatric perspective, the thoughts, feelings, experiences I'd had (that secretly seemed so hard-won and important to me) were more properly to be seen as part of an illness, of interest only insofar as they matched up to lists of symptoms in the medical manuals.

I don't think for a minute that I really fooled anyone with my show of compliance, but I took enough medication for long enough for the doctors to begin the painfully slow process of discharging me. I diligently jumped through every hoop they held up for me, inwardly certain that my only hope of regaining my sense of self was to wriggle off the psychiatric system's hook as soon as possible.

Q: How did you feel when you were discharged from hospital?

A: Out of the frying pan, into the fire. I now had a shiny new identity: mental patient, madman. I saw myself differently and so did my friends and family. It was the beginning of a long, long period of adjustment and reconstruction. I was obliged to continue seeing a Consultant as an out-patient, going through the monthly motions of answering the same old questions. How are you sleeping?

How is your appetite? Any strange thoughts or feelings? I had to continue taking medication that palpably blunted my capacity to think and feel and gave me unpleasant side effects.

By far the most helpful professional input came from a psychologist, who was able to give me some hope for the future and just made me feel more ‘normal’. On the back of this, I began some voluntary work with a local mental health charity and slowly a sense of purpose returned.

Q: What helped you to settle into your new life?

A: The turning point for me was undoubtedly discovering the existence of the mental health service user movement. Here was a worldwide group of people whose lives had also been changed by their contact with psychiatric systems. The more I learned, the more interested I became and I grew convinced that this was where my future lay. I began to believe that my experiences could be put to good use, that I wasn’t necessarily on the scrap heap.

I also can’t underestimate the importance of my relationships with family and other loved ones. They had to go through an adjustment period just as much as I did, and put up with a lot of my bad behaviour and self-pity without a guide book or much help from the psychiatric system. They seemed to continue to believe in my ability to recover and reclaim an independent life for myself, often when I didn’t have much hope myself. I’m forever in their debt for all their support.

Q: How do you feel about your new life in the community?

A: I've been lucky to have stayed well enough to have carved out a life and career in the user movement. I'm just as fascinated and passionate about mental health as I ever was and believe that some genuine progress has been made over the 20 years I've been involved. Like anyone with a long-term, fluctuating condition, the fear that the rug could suddenly be pulled from under me never really goes away. I hope I've got enough resilience to be able to pick myself up and dust myself off if need be.

Artist: Giuseppe

A changed life

By Mary

Since 1998 I have travelled a long way from being a person who found it difficult to walk out from a hospital environment without crying to one who is determined that people with mental illness should be supported to make decisions about their care.

I am confident in saying that Care in the Community played a major part in my recovery.

I spent most of the time from 1998-2002 in hospital moving to the Rehabilitation Service in 2001. I was discharged in 2002 with a Care Package from a 3rd sector organisation and support from a multidisciplinary team of Health and Social Care.

Unfortunately, it's difficult for me to accept that I have an illness or be aware of symptoms leading to a crisis which sometimes means I am unable to eat or drink.

I really try to resolve this issue myself and have learnt techniques. But I am still under a Community Treatment Order part of which is to receive support on a regular basis to monitor my mental health and to keep appointments with Health and Social Care staff. Another requirement is to take medication.

At first I saw the support as an intrusion particularly when unwell as in that state I prefer to withdraw from all contact with anyone.

However, as time passed I built up trust with the organisation and can honestly say I only had one staff member with whom I felt uncomfortable when coming into my home.

I often mention "coming into my home" because it's important for me to emphasize this in my story. When caring for people particularly in their homes it is crucial that you respect and treat them with dignity.

My support is successful because I know my team will behave in this way and are truly there to help support me however difficult their day.

It's a two way process as they get to know me so I understand many of their needs and hopes. They, therefore, have some satisfaction from supporting me! I meet other people who receive care and support and gratitude is often expressed regarding their care/support staff.

It's not easy living with a Community Order and the fear you may be recalled to hospital at any time. Usually I don't remember much about a hospital admission except to feel powerless. As soon as I see my Mental Health Officer I know that I have no choice and decisions are made for me.

The difference for me now is that I trust the Social Worker dealing with my case and I know that he will be thinking independently if he is required to countersign a form depriving me of my liberty.

He was the first person in 8 years to tell me that I was entitled to free legal representation at a Tribunal whereas previously I tried to represent myself.

That said, my experience of the Tribunal was very disappointing. I had optimistically thought there would, perhaps, be a table and other people drinking coffee whereas the reality was solitude in a bare room which reminded me of a prison cell!

I questioned my previous Social Worker as to how she could countersign a form restricting my freedom when she never saw me and she told me that she received updates from other members of my team.

In fact my present Social Worker doesn't spend any more time with me. I don't want or need his time but I have his card, know that he will speak with me if I need it but more importantly I trust that he will work in my best interests.

To be or not to be! Here's my effort!

Recently I have experienced another change of direction in my journey. I was asked to join the core group looking at self-directed support (SDS}. At the group I listened to other people's stories – mainly people with physical or learning difficulties. Many of the story tellers had their support staff with them and I could see how well the liaison worked. In particular, the person being supported chose his or her Support Staff.

I realised that SDS was the way forward for me. There were different options open. I chose Option 3 under which a Support Provider organises the employment of a staff member acceptable to me and also takes care of my budget.

Every week I sit down with the person I have chosen and decide when the support will be delivered and what I wish to do during that time. On occasions the support has been delivered in the evening because it suits us both.

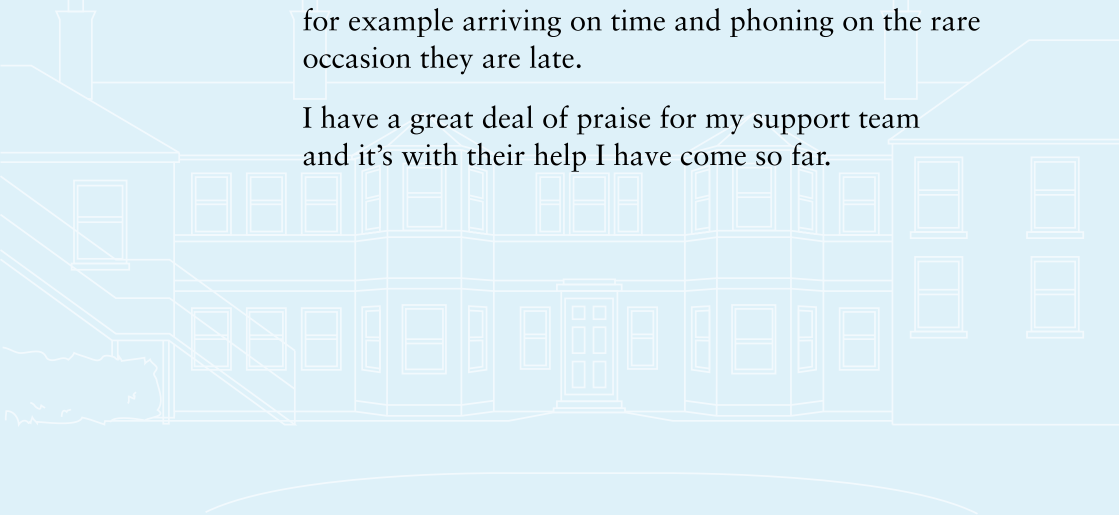
I enjoy having the freedom to lead my life with the support that seems to be required to keep me active. I have developed 'Goals' or, as the Council prefers to call them, 'Outcomes.' Mine are to stay out of hospital and work towards a time when I shall no longer require support or a CTO to maintain my wellbeing.

For those in a similar position, my advice is 'Go for It!' Don't hesitate! The initial Assessment process is not daunting – more of a conversation with very understanding Staff.

Finally, kind words are never forgotten. Staff do leave but I certainly remember all those who have supported me with respect, who instinctively know when I am unwell and are so professional in their approach.

Even little things show that I am valued as a person, for example arriving on time and phoning on the rare occasion they are late.

I have a great deal of praise for my support team and it's with their help I have come so far.



‘First aid’

By Jo McFarlane

On a day when death’s preferable
to breathing in and out,
I’ll look back on this reminder,
try to think of all that’s good

The pastel sunset in the sky,
the chatter of the rain
The resurrection of each day
again, again, again

The comfort in a friendly voice,
the smile that fills my heart
The beauty of sweet poetry,
the miracle of art

A flower rejoicing in its prime,
a bumblebee in flight
The curling up of purring cats
into the breast of night

The healing hand of strangers
when I cannot feel my pulse
The bandage in a silent prayer,
the grace to simply trust

Artists: Lorna & Lisa

Professional Perspectives

Changing lives: a professional's perspective

By Debbie Mountain
Rehabilitation Psychiatrist, Royal Edinburgh Hospital

I am delighted to have been asked to write something from a professional's perspective for the Changing Lives II booklet which describes the changing lives of service users. This request recognises the mutuality between services users and professionals via the relationships they develop with each other, which has the capacity to change the lives of both parties. It also recognises the influence professionals have on people's lives. Professionals, in their daily life often don't notice how much influence they do have. Sometimes, in spite of their best attempts to improve the lives of people they work with, they often feel overwhelmed by obstacles. In these situations, it's easy to miss opportunities that can make a difference, that can initiate a flicker of hope when people start to believe their lives can change.

This sort of hope is not superficial wishful thinking, denying the reality of what challenges lie ahead, but a considered and sustained expectation of a positive future. This can be slow to develop and hard work, as it has to overcome years of low expectations, adversity, numerous ventures when things haven't worked out and for some people, years of disruption and chaos. It's human nature to assume that the past will extend into the present and future, and overcoming those expectations in a meaningful way is hard work and worthy of respect. People describe “turning points”; sometimes it’s a pivotal event, other times it’s a slow gathering of self belief after experiencing new opportunities or little achievements.

Effort goes alongside hope to bring about change. These efforts require special attention. This is the process of recovery and some people require a lot of support to initiate change until it gathers a momentum of its own, generated by experience of recent success. Alongside many other factors, service design and relationships with professionals are sometimes key to achieving this first hurdle, which is often the biggest and most challenging step of all.

On occasions, compulsory measures are used to support this process, but always along with attempts at negotiation and cooperation with the service user. It’s important that service users have a sense of the direction of their recovery and know that even at times when they may lose hope, there are others to hold both hope and the recovery process for them.

Working in this way is not only deeply rewarding as professionals witness changes that people make in their lives, but also humbling when we consider what it takes for people to change their lives. We need to find out more about “turning points”; we need to better understand what people already do to manage their lives as best as they can, so that service design and professional practice are better equipped to support people to change their lives.

Wayfinder Partnership

> "The future is not a result of choices among alternative paths offered by the present, but a place that is created – created first in the mind and will, created next in activity. The future is not some place we are going to, but one we are creating. The paths are not to be found, but made, and the activity of making them, changes both the maker and the destination."
>
> **John Schaar**

I am honoured to have been asked by the Patients' Council to write a short piece for Changing Lives II. I selected the quote above to begin as it seems not only relevant to the work of the Wayfinder Partnership, but also to the service users who utilise rehabilitation services and whose stories are included in this book. All change involves creativity and an aspiration that things can be different, perhaps beyond what can be readily known and understood. I am going to share the work of the Wayfinder Partnership, its aspirations and what progress has been made so far to support a change in how rehabilitation services are delivered.

I will make reference to stakeholders throughout, and want to clarify that stakeholders involved in the Wayfinder Partnership have included service users and service user representatives, carers and carer representatives, staff from rehabilitation services, adult mental health services, health and social care services, third sector organisations who provide support in the community and other activities and represent smaller third sector groups.

The Wayfinder Partnership

The Wayfinder Partnership is a knowledge transfer partnership between NHS Lothian and Queen Margaret University. The aim of the Wayfinder Partnership is to redesign rehabilitation services for people with complex mental health needs. Initial consultation with stakeholders identified that they wanted the rehabilitation pathway to be clearly defined, responsive to service users' needs, underpinned by evidence and ensure that service users' rehabilitation needs are met in community and hospital settings.

Understanding what works for service users who use rehabilitation services

To begin to understand what the rehabilitation pathway could look like, the Wayfinder Partnership studied published research, carried out its own research and collaborated with stakeholders to get their perspective. All this information has been used to design and develop the rehabilitation pathway. This information was brought together and identified the following key factors that are important for service users.

- Having a place to live which is safe and secure whether people are in hospital or living in the community. Recognising that the physical and social features of the environment people live in influences their motivation and ability to organise and do activities. In addition, the support provided to service users has to be responsive to people's changing needs, supporting their recovery.

- Ensuring person centred choice, that is, working with people on identifying their needs and strengths which will allow positive risk taking and provide opportunities for service users' recovery. Having relationships between service users and staff which are respectful, allow for partnership working and clear communication are important.
- Having the opportunity to engage in activities which support service users' interests, help them to maintain relationships with family and friends and assist them to make connections within the community, for example volunteering, art groups, exercise groups, work, etc. Understanding that sometimes service users may need support to organise their day, creating routines which allow them to do the usual everyday activities like looking after themselves and their home and engage in activities they are interested in.

Creating a pathway

This information was shared with stakeholders and as a result of further consultation, the Wayfinder Graded Support Model was created. The Wayfinder Graded Support Model describes the rehabilitation pathway. It defines the different levels of support and accommodation provision required for service users living in the community through to being in hospital. It also describes the type of assessments, interventions and support from health, social care and support providers that would be needed at each level to support their rehabilitation. The aim is to ensure that service users are assisted to move to the next and most appropriate level of support when they are ready. To do this Wayfinder has been working to make sure that there is the right support and accommodation provision for service users in the community.

Collaborating to develop support and accommodation provision

To ensure that the different levels of support and accommodation can be provided, the Wayfinder Partnership has been identified as a Public Social Partnership (PSP). Public Social Partnerships are a co-planning approach where organisations (public sector and third sector) jointly design services based on service user needs. Partners share responsibility for managing, designing and piloting the PSP. The Wayfinder Public Social Partnership has been a great opportunity to work closely with stakeholders from third sector organisations who provide support and accommodation and other activities in the community, the City of Edinburgh Council, Housing Associations, service user and carer representatives and staff from rehabilitation services. At present they are working on:

- Designing and developing new community based intensive rehabilitation support and accommodation provision
- Looking at how current support and accommodation provided matches with the Graded Support Model and what additional provision may be required.

Encouraging opportunities

As a result of collaboration with stakeholders, reviewing existing evidence and undertaking research, a new pathway for rehabilitation services has been created. Wayfinder is now delivering the pathway, evaluating and refining it so that it meets service users' needs. Changing Lives II is a timely reminder of the importance of creating opportunities and pathways for service users which offer hope and respect.

Michele Harrison, Lead Research Practitioner
Wayfinder Partnership

Re-provisioning of the Royal Edinburgh Hospital and campus development

By Dick Fitzpatrick

The Cabinet Secretary for Health performed the ceremonial ‘turf cutting’ for the first phase of the Royal Edinburgh Hospital Campus Redevelopment Programme yesterday. It was a low key affair on a very cold and frosty morning, despite attendance of some very senior people from the organisations involved. It was all over in 25 minutes.

Walking back to the project office, I stopped for a while and looked out over the large sprawling site where a new 165 bed acute mental health facility will sit when completed in the autumn of 2016. I began to reflect on the journey that led up to this point. For me, involvement began in late 2009 when I was asked to move from my project management position supporting the implementation of the mental health strategy to taking on project management of the hospital re-provision. This was by no means the start of the re-provision’s long journey though – this dates back to the early 2000’s and has had a very ‘stop/start’ history. My reflections only cover the period since my involvement as project manager.

When I began in 2009, I was asked to look at dusting down and updating a business case that had been prepared and approved some 5 years earlier. It was a weighty tome. I spent the first couple of months reviewing the content and meeting a wide and diverse range of stakeholders. The NHS Lothian Nurse Director was the Project Sponsor, a title given to the person who represents NHS Lothian's views within the project and who can make major decisions required to allow the project to progress. The more I read and talked to people, the more uneasy I was becoming about the direction of travel. Then came the first of many changes, twists, turns and challenges that were to become the hallmark of the project over the years since.

Part of the work in updating the business case required us to look at the options for where the new hospital should be built, and we commissioned independent outside consultants to carry out the required exercises. This in itself was an unsettling prospect and a departure from the previous assumption that it would be built on the existing REH site. The outcome was worse. It suggested that different services would be best located at different hospital sites including the adult service moving to Edinburgh Royal Infirmary at Little France. This was a devastating prospect and one with which many were very unhappy. Then another major change in circumstances occurred.

The Nurse Director left for a new job in England and the Director of Strategic Planning picked up the role of Project Sponsor. After a period of settling in and getting to know the project in more detail, she and I had a meeting where she asked me to speak candidly about my thoughts on the direction the project was taking. I did exactly that. My view was that what we were doing was a huge mistake and not what we needed for a mental health service that had changed beyond recognition since that business case was first written. I knew this wasn't a view shared by all and likely to be unpopular with some. She sat in silence throughout my explanation; I was starting to think that I had gone too far with expressing my views. When I had quite finished she sat in silence and after what seemed to be an age she declared, “Good, my thoughts exactly. I think we need to draw a line under all of this and start over”.

This was a huge decision with huge consequences but one which I am convinced was absolutely the right thing to do. This is not to say there was anything wrong with the work that had been done before, it was just of its time: done at a time when the service was very much hospital-centric and when community services were scant, where they existed. It would have resulted in building a huge institution at the expense of being able to develop the extensive networks of community services that we have today.

Thankfully, our project Stakeholder Board and others agreed with this approach when the proposal was put to them. The work on building a totally new project began. The first step was to develop a new masterplan for the campus. As the Government made clear to us at that time, there was no money to support our developments so whatever we did had to be at our own financial expense. This meant that we could only do small developments on a phased basis over quite a number of years. To this end, a masterplan was developed that would see small 60 and 90 bed units being developed as inexpensively as possible and located around the perimeter of the campus. I started to write a business case and asked stakeholders to get involved in a variety of discussions and exercises to move this along. What amazed me was people’s ability to put the past behind and move ahead with enthusiasm despite the number of set backs and false starts the project had over previous and more recent years. Just as we had achieved a good deal of momentum and enthusiasm for the first phase of the project, the next unforeseen and unexpected major thing occurred; actually, four things:

- The government advised us that there would be some financial support for what we were doing in our little first phase 90 bed development after all!

- Then a new Chief Executive with a keen interest in mental health joined NHS Lothian and very quickly took an interest in what we were doing. He took the view that phase 1 development was not ambitious enough to meet the overwhelming need for new fit-for-purpose accommodation. He invited senior Government representatives to come and meet with the project team and told them exactly that. Amazingly, they agreed there and then to increase the financial support to allow us to be much more ambitious and provide way more than the planned 90 beds; 185 as it turned out in the end. The news was universally welcomed.

- The final major twist was a decision that the REH campus would become one of 4 major sites for hospital services across Lothian and we should look at consolidating smaller sites in need of upgrading onto the campus.

- More recently, and in response to our service users' views on the importance and therapeutic benefits of the external green and art environments, we set up a public social partnership (PSP) involving a wide range of 3rd sector and other groups and individuals to look

> at developing therapeutic spaces and activities across the grounds of the campus. Lots of ideas and plans were developed by the partners and I took a proposal to the Edinburgh and Lothian's Health Foundation looking for financial support. The trustees were persuaded of the merit and potential benefits of what we aspire to achieve and supported the proposal. They have given us just over £1m to progress plans. This will allow a significant refurbishment of the Hive (a listed church building on site) to be used for a wide variety of artistic, recreational and entertainment purposes in support of the PSP ambitions. It will also allow us to progress other PSP developments including developing garden areas, installing temporary shelters for a wide variety of purposes and developing outdoor and play and exercise areas.

As a consequence, we now have a programme that will see major developments over the coming years and which the Government have committed to financially support. This will involve lots of building and demolition and other services moving onto the campus.

So, that's the business end of the story, but it's also important to emphasise that none of these things would ever have progressed without the will and commitment of the various stakeholders involved. Many of the staff who were involved in the earlier efforts to move the project along have long since retired or moved on to other things. Other organisations that were involved have changed, as have the people working in them and some have disappeared altogether. The one constant, though, has been the active involvement and participation of service users throughout. Some of the faces have changed, many haven't.

We pride ourselves in mental health on being better than most at engagement and working with service users and other stakeholders. There is very little that we do in terms of service or policy with which they are not involved. In terms of the phase 1 development, they have been with us right from the outset and worked with us every step of the way. Their influence on the final design is very visible and more importantly, they can recognise it. They can see how vastly different the design of the ECT suite is compared to the first tabled design. They can see the enclosed therapeutic courtyards that allow everyone easy access to a secure outside environment. They can see that all patient accommodation is on the ground floor and all the bedrooms have a view of the outside green environment. The list goes on, all things that they told us are important to them.

I'd like to finish off by telling of one of my proudest moments when managing the project and no, it's not about getting business cases approved or the financial deal being closed off or the formal 'turf cutting'. It related to a conference a couple of us from the project team and a couple of representatives from the Patients' Council attended down in England last year.

The conference was over 2 days and themed around innovative design and approaches when designing new mental health facilities. A highlight of the conference was the official unveiling of what was supposed to be the ultimate bedroom design that had been worked on for nearly 2 years by a raft of architects, designers, other experts and stakeholders. When unveiled, it looked astonishingly familiar – it was pretty much the same as what our stakeholders had come up with over a 4 month period! The only real differences were a sliding door on the ensuite and a built in window seat, nice touches admittedly.

An often repeated theme across the 2 days was that of involving patients in the various processes of facility planning, design and delivery. This was being presented as a daring and innovative thing – we were astonished! I suppose it was very reassuring that we were very much ahead in both our thinking and our approach, but all of us were pretty taken aback.

Then came the best moment ever; it was the final session of summing up and close of the conference and the chairperson of that session actually talked about the concept of having patients involved in the planning and all stages of design and put it out as a challenge to all in attendance. One of our Patients' Council members was very quick to her feet when invited to comment and spent the next few minutes regaling all with the tale of patients' involvement in our hospital planning and design, and the tangible difference that had brought about. She also said that the fact that the 4 of us were there for the 2 days as colleagues on a level footing was testament to our collaborative and partnership working throughout our hospital development. After a short period of stunned silence, the event chair thanked her for the contribution and said he had intended saying a few words to close the event but after this delivery there was little more to be said other than suggest that perhaps next time we should be on the stage presenting our experience. This was a proud moment for all of us.

Dick Fitzpatrick, Project Manager
REH Campus Redevelopment Programme Jan 2015

For many years now it has been realised that people who were considered to have long term mental illness should be supported to live in the community and have a home of their own. Stories of Changing Lives II is based on the experiences of six people as they share with us how their lives and those of their relatives have altered and what helped to make the change happen. We also include contributions by those who have a special interest in improving rehabilitation services. Fittingly, in 2015, the book ends with an essay on the progress being made on the new hospital.

Some people embraced the move while others were more hesitant. Here we can read of the different ways in which people did create good lives for themselves thanks to their own hard work along with the belief and support of key people in their lives. The support being person-centred reflects the pace and support that each individual felt they needed each step of the way.

Come and share their journeys.

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