



RECOVERY

**(A talk given at the Scottish Recovery Network Conference on 16th February
2007)**

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Hello, as has been said my name is Graham Morgan and I work with the Highland Users Group which represents about 350 people up in the Highlands.

A few months ago Simon asked me to talk at this conference about recovery. This is something that I am so happy to do, but I did have some reservations about it at the start .

People talk and talk about this idea ‘recovery’ - its hard to find a service or a professional who doesn’t say that they will incorporate the recovery model into the way that they treat us and act with us and so on.

And yet for me the idea and the word recovery are slightly alien and I have little or no background in what it really means to those who have immersed themselves in the ideas and concepts that float around so freely nowadays.

It was a few months ago that I thought that I might possibly have something relevant to say. I was talking at a conference and a consultant came up to me after my speech and said that she had heard me speak twice now and that from listening to me and watching me she was sure that my diagnosis of schizophrenia was wrong.

Initially I was very offended – it just seemed inappropriate to say such things. Also, I have grown so used to this diagnosis that to throw it away in a casual conversation seemed quite demeaning – but it made me think. I have hung on to the idea of illness for so long, it is a huge part of the way that I define myself and view myself – is it possible to get caught in a world that, though comfortable, traps you and smothers your growth.

My wish to speak out was confirmed a few weeks later when I received a call from the Royal College of Psychiatrists asking me to speak at their summer meeting. And what were they wanting me to talk about? – my road to recovery and what it is like to have regained my health.

My mind turned a few cartwheels of surprise – “bing bang bong” I went and “wait a minute”, “since when did I recover and why didn’t anyone tell me?” A sort of “just excuse me for a second, but, don’t I have a say in when I can be regarded as recovered and well and whole and satisfied with the journey my life takes me on.”

I really was a shocked person for a time but then a little balm of soft joy slipped into my brain, all the wheels turned cautiously, frightened of unpleasant truths or skipped uncertainties about to ambush my security.

This small inkling of a new world muttered about “what if I really am well?”, “what if I have recovered?”, “what if, unknown to me, my journey has become rosy?” - and I agreed to talk in the summer about that journey. So I better do my very best to achieve the joy of a world that is not mind numbingly caught in the world of sadness

and illness and the maintenance of helplessness. The request I had found offensive became a token to light my way and provide new invigorating ways in which to see the world, to take that big leap in self definition and see myself as whole rather than damaged and shattered.

Since then I have enthusiastically adopted the idea that I am now well. I bubble around the office telling everyone that I never was schizophrenic, which alarms everyone as Debbie our awareness raiser relies on my story for our awareness training and then I talk about stopping my medication, stopping seeing my psychiatrist and CPN and living free of the cloying world of lost hopes.

But that is wrong isn't it? - to be well or recovered or to lead a fulfilling life doesn't have to mean that you reject your past or the world with which you are familiar or even mean that you have to be any where near well.

Let me set the scene of my life for you. Most of you won't know me so perhaps some descriptions may help.

I'm 44 years old now and its twenty three years since I was first admitted to a psychiatric hospital. I had spent some years piling on the adolescent angst until it became too much to bear, life leached itself of the colours that make it vibrant and my core became a place of aching sadness, tense anxiety and numb fear of those around me, the life I lived and the things I believed in, which was nothing. The only bright thing was the sting of a razor blade which helped me relax and sleep but also made me sick inside with disgust at myself – I remember the white cold fear when I finally took an overdose and failed miserable at the idea of dying.

Those years were a time of huge emptiness, a lost and lonely time, where I rejected those around me and found the idea of communication and emotion too much to handle but then, it was finally my friends that took me out of it and of course, activity and time and finally love and meaning and purpose - these changed my world and opened up a new dimension where the world became a place I loved being a part of, where, instead of being frightened of everyone I began to look forward to the meetings with strangers that can enliven life, where instead of staring at the pavement, I wanted to meet the eyes of those that I walked past.

I had a wonderful few years until with a huge bang everything collapsed around me and my reality became so confused that it didn't even make sense to me. Those years became the years of Haloperidol and Largactil and later on the injections of Depixol, which still make me indignant.

I now live with symptoms that bubble enough to sometimes worry but never spill over into downright alienation.

I am fortunate that I have had experiences that give me a glimpse of the abysmal hell that illness can be but, usually, I have been on the edge looking in, lucky to keep myself sound and whole for most of the time.

However the years have shaped me. I see myself as ill and damaged. I define myself as different - I don't trust ordinary people, instead I light up when I meet those that have been through similar experiences. I feel a bond with the world of mental illness which provides me with identity, security, friendship, acknowledgment, communion and respect. It makes my life at times wonderful - and this is where I worry about the world of recovery. I don't want to leave my world behind, my identity of illness and difference has been informed by my experiences over the last two decades. These years have reinforced the message that this is the safest place to be. It's where I find my friends, it's where I earn my income, it's where I meet people who understand me - I really really don't want to leave it, I fear a world without illness. And yet a big part of me says take that risk, step out into the real world, engage with those normal people that you are so frightened and sceptical of, cut through all the strings of restriction that you have wound so tightly about yourself, that you can't breath the bright fresh air where new worlds beckon. And then I turn back and feel confused and something Simon said comforts me, because, I heard him saying that recovery is a personal journey with a personal definition. That lifts my heart because I don't, in the name of a rosy future, want to reject my past or the experiences and people that are dear to me.

So for me, my recovery will not mean discarding the past or my experience or my friends but it will mean that I embrace new identities. I suppose that in the last few minutes I have defined myself along the tram lines of impairment.

There is an alternative way of looking at the last 23 years of my life. I have had the huge fortune to live a life of great richness. I have sailed across the Mediterranean twice and across the Atlantic twice, where I have seen beautiful dolphins and whales, where the phosphorescence in a gale has made the sails glow. I have sailed over seas in the Philippines where the coral beneath our boat has seemed close enough to touch. I have sat mending our tent in the Sahara after a sandstorm blew it in two, next to some lonely soldiers patrolling a deserted coast with just two camels for company. I have climbed to the top of mountains in Borneo with my son where our breath has become tight in our chest, but, across the bare rock we have seen the rising sun and the clouds far below.

I have had the privilege of having friends that have let drunken conversations flow erratically through the night, the joy of falling in love and knowing that another person cannot wait to see me again. There is the angst and agony of bringing up and growing up with my son. I could go on for ages and ages about all those parts of my life that have nothing to do with despair and sadness, and so, I suppose, that for me my route to recovery involves opening up my world to all those experiences that have

nothing to do with schizophrenia but which have shaped me just as surely as the labels our world is so keen to adopt.

When I get to my conference in the summer I hope that my message of recovery is about Graham who loves to be silly, who can't wait for the chance to talk nonsense, who loves to cook and to drink and to walk by rivers and to write and to work and bask in the joy he gets from those that he loves and who love and respect him in turn. That is me too, an awkward smoker who doesn't smoke at the moment, a little puppy who basks in a hug or a compliment and a person who just wants life to be nice and friendly and for whom razor blades represent a bright escape which will hopefully never need to happen again.

I don't know where my journey will take me, I don't know whether I will become ill again, whether the world will be rosy or sad and in many ways I don't want to try to decide on the shape of my journey, but I do thank that consultant who told me that I wasn't schizophrenic. She did me a great favour – I am going to keep that label as long as it fits my internal vision but, I do feel I have been given the liberating responsibility to look at a world that is wider than illness and disability; that embraces a fuller view of the world, and that gives new perspectives to a life that is sometimes wonderful. Yet my journey has grown out of pain and that journey has only been successful because of my connection with those who have suffered even more than me. That is my past and my bedrock, and will continue to be a part of my reality and is something I will never reject, just because some people choose to see me as well rather than ill.

I could finish here but Simon has asked me to challenge a little bit and so far what I have told you is a story not a challenge.

I talked a little time ago about those who have suffered so much more than me. Some of my friends and acquaintances have had experiences that are so much harsher than mine and many of you here will have suffered in ways that I cannot grasp or imagine. I suppose, what I have to say is that people are now saying everyone has a right to recovery. Well, for some of us, we don't need to be told that - it is, to some people, just plain insulting. If your life has been devastated and wrecked by illness, your job has disappeared like a rush of leaves, you are seen as unfit to look after your children, you have no friends, nothing to do, almost no money and the professionals do not even seem to understand your distress, well, sometimes it can feel as though our lives have been wrecked without any hope of repair - the journey is fractured and unwelcome and its end the only bright solution. Then in this situation we may not welcome some bright person coming along to empower us on our journey of recovery, we may get downright angry when the end of the day is the furthest we can possibly look to, and yet we are being encouraged to develop hope and optimism. There may be an instinctive "how dare you underestimate my despair?", "how dare you ask me to find the slightest degree of hope in the poverty of my life?". So many of you here will have reached that point where journeys and belief in yourself are

irrelevant, where there is absolutely nothing to celebrate and, in those places, some of us will not welcome the guidance of optimism. It will seem patronising and misplaced - yes, good for another point of our lives, where we are slightly freer to look around us, but not when the whole world has imploded and all there is, is greyness.

To me I find that the word 'hope' that we bandy around so readily is something that is potent and dangerous. Yes - fantastic, if we can find it, desperate if we have lost it and dangerous, if we dare, in the dark days to hope, and then find that it doesn't always work and that it isn't the sure fire route to deliverance. We have to be careful when our professionals or friends offer hope - it is a powerful thing that can damage as well as inspire. We also have to be careful when we are denied the bright vision that hope can provide because without it our lives can close down.

And theories - I am sorry I have often talked about theories, models and concepts, they are good, they do enliven and illuminate but they are still theories. Recovery as a concept in Scotland has become embedded in our conversations within the mental health community but there is that danger of making it the be all and end all of services - we don't want, what can be a valuable and potent tool, to turn itself into a minor religion or political philosophy. Too often, really good ideas become so acceptable and correct that they brook no argument and the non believers are looked down upon and scorned and excluded - we need to be sure that there is always a welcome and healthy scepticism to ideas such as this, we need to be sure that we can express stupid ideas, get the theory wrong, just plain not get it at all, because debate and questioning, far from damaging, will help ideas grow and develop and flourish whilst complete acceptance may stifle and diminish.

I do really like the fact that we define what recovery is. As you will have just heard, I have created my own personal recovery journey in the last few sentences; but there is this nagging worry in my mind, that if we all create our own unique versions of what recovery is, then does it just become an amorphous and intangible web of vaguely related ideas which change from person to person and which cannot be challenged or discussed because really there is nothing consistent to talk about? Everything becomes right according to an individual's personal experience. Maybe that is good, maybe it is hugely liberating, but, maybe it stops challenge or rigorous debate because there is nothing solid to talk about.

I pause here because as I am writing I am learning. Isn't there something truly invigorating about the idea that we can develop our own recovery journey, that our route to recovery is based on our own internal vision, our own culture, our own beliefs and way of looking at life? This really is about taking control of our lives and about giving ourselves the belief that life can be better. However, each story is different. There is no one answer to what works and what doesn't, there is no guarantee or evidence that our vision will be positive but there is that great liberation of being given the opportunity to find our own path. It is this very individuality that is

exciting but something sparks in my head - what works for one may not work for another. In fact it may damage other people.

As we gather the narratives we may be tempted to gather evidence about what does and doesn't aid recovery - is that good? Or does it detract from the personal vision at its core? I can imagine a researcher or a psychiatrist saying that the idea is all very well but does it actually work? And, what is the proven evidence that the routes to recovery work? There is a temptation to say our route is better than the scientific and medical route, but they are both viable if very different options. You can see how we may pit science against recovery when, in my mind, what we need to do is to find a way of integrating two apparently confrontational ideas. Maybe we can learn from the world of cancer treatments where treatment is based on evidence but that this evidence of what works for the disease medically is bound up with a philosophy of care that also includes quality of life and hope and personal goals and visions - all those other things which make life bearable and liveable.

I have another thought in my mind. Everyone assumes that we want to recover and want to get well - we take it for granted, and yet for some of us, there can be a perverse romance in illness. For some of us there can be a warm glow in the protection and comfort we are offered when we are ill. Sometimes we don't want to search for new horizons and new hope. We want to huddle up in the comfort of limited horizons and a supportive community –leaving it is just not attractive – it's a place where we feel a sense of belonging and the very idea of recovery threatens this. Now why shouldn't this be so? Do we not have a right to our own space and our own quiet world safe from disturbance and from those that think they know what we really need for a good life?

Lastly who owns the idea of recovery? Well, its obvious isn't it? My vision of my journey is mine and mine alone. No one can make me recover. No one can do recovery to me, it is up to me and it is my decision about where I go. And yet, that vision will be influenced by all those around me - whether they be helpers, friends or family. This of course is where it gets confusing. I do hear people resenting the fact that the major voluntary organisations are taking over the delivery of recovery and almost steering it away from the user movement where it should rest. I even hear people saying that the Scottish Recovery Network is not in the right place for us because it isn't user run.

But then why should recovery be purely based in the user movement? If it has to be integral to our movement then why not everything that is to do with us? Maybe as users, we should lead and control all those services that are there to help us – after all it is our lives that are being affected, our journeys that are being influenced . I don't see why recovery should be a special case - it's just that it originated in our movement and it only starts to be a special case if the very act of promoting it as a service detracts from the philosophy of the whole idea. It will be debased when people set out to **make** us recover just as I feel angry about people who seek to

empower me, so would I feel angry about someone who because they are paid to, feels that they know more about my recovery journey than I do. But we are all connected in different ways - to be precious about an idea and not allow its growth because it should just be **our** idea seems self limiting. My feeling is that anyone or any organisation that can help us find a brighter journey is welcome in my life. It's a question of maintaining respect and sharing common values. To me, it's about assuming the vast majority of us are trying to find a common goal - drawing up the barriers can just lead to confrontation and anger, instead of the joy of finding mutual connections and shared experience.

I don't suppose any of this is really challenging, so my apologies - Simon I have really enjoyed reflecting on how I personally see recovery.

You will all have loads of material from the Recovery Network but if any of you are interested in the HUG report on Recovery you can find it on our website at www.hug.uk.net.

Lastly I read a book recently called Poppy Shakespeare. After a shaky start, it really grabbed hold of me and I found it to be one of the best books I've recently read on mental health and a great description of why the system we live in needs the liberation of new ideas and ways of thinking that are embodied in this word recovery.

Thank you.