

FUTURE SELVES

Beth Hopkins

A note

In this publication, I use the terms 'well' and 'unwell' as shorthand to describe complex states of mind. Other people use different, non-medical words to describe their experiences. Bipolar is very nuanced and setting boundaries of being well and unwell (and having capacity or lacking it) is a difficult task – both for clinicians and for ourselves. This leads to the question, can and should we divide our identity into distinct well and unwell selves?

Other Voices

Throughout this publication you will find anonymous quotes from people who took part in a survey through Bipolar UK, which gathered their thoughts on advance directives. The data from the survey formed a basis for a new study into advance directives at the Institute of Psychiatry, Psychology and Neuroscience at King's College London, by Dr Tania Gergel and Dr Lucy Stephenson. You can read more about their research at www.mhj.org.uk

Impossible Questions

When are we our true selves?

Is it when we are judged to be well*,
and have capacity to make decisions
about our own health care?

Should the right to make our own
decisions ever be taken away?

Often people experiencing bipolar
are told ‘You are not yourself’ – but who
are we when we are not ourselves?

And where do our true selves go?

ADVANCE DIRECTIVES

An advance directive is a type of living will written by someone with experience of bipolar. It is usually written with the input of a medical professional and sometimes with your loved ones. It sets out how you'd like to be treated when you're unwell, it might include what medication you would want – what has worked well in the past and what hasn't. You might state whether you would be willing to go into hospital or if you want to be treated in the community. These decisions would be upheld even if you disagree when you are judged to be unwell and lack capacity to make decisions about your own health care.

Advance directives raise a number of questions. Can we predict how we will become unwell in the future? Capacity is a grey area – how do we measure it? Should the right to make our own decisions ever be taken away?

The stories presented in this booklet respond to these issues.

ULYSSES PACTS

In book twelve of the *Odyssey*, Homer describes Ulysses' encounter with the sirens. Half women and half birds, they lure sailors to their deaths with their song. Knowing that he will be unable to resist them, Odysseus asks his friends to bind him to the mast of their ship.

When the sirens surround the boat, Odysseus asks to be unbound: 'I bade my comrades loose me... presently Perimedes and Eurylochus arose and bound me with yet more bonds and drew them tighter... When they had rowed past the sirens, and we could hear no more their song, then straightway my trusty comrades... loosed me from my bonds.'

Advance Directives are sometimes known as Ulysses pacts. In writing one, you are binding yourself to the mast. You are making an agreement in advance that might mitigate the damage caused by future mania or depression and putting in place ways to be cared for and controlled, restricting yourself for your own protection.

‘Just because a sufferer is unwell does not equate to lacking capacity to make decisions. Perhaps some of their judgement is impaired but they still know what foods they prefer, what colours they like. It’s a very difficult and vulnerable area.’

‘You need protecting from yourself with this illness.’

ON BINDING

Binding is about care and control.

When we are sick, we wrap ourselves in a duvet. When we injure ourselves, bandaging gives support whilst we heal.

It also speaks of restraint, and a history of straight jackets and control by institutions.

Swaddled babies, bound feet, burial shrouds – we bind our bodies from the cradle to the grave.

In binding an object, you are considering what it means to you, and what it has witnessed in your life.

You might tear strips of old clothing to bind with, worn next to your skin. Bed sheets that you've slept in for years, ribbons found in a family sewing tin. You can use threads, string, wire, tape – anything that means something.

The binding process muffles the object, cocoons it. You might be wrapping it for protection, hiding it, or restricting it.

A Collection of Bound Objects



CRUSHED CAN

Lizzie Evans

I chose an empty, crushed can of Alcohol Free Lager. I stopped drinking just over a year and a half ago to benefit my mental health.

The fabrics and haberdashery that I chose were mostly in summer colours of yellows, greens and blues to represent how this summer I will enjoy the weather and the countryside, the sea and rivers and I will be alcohol free. At the moment I am in a positive place on my bipolar scale and feel optimistic.

I used some old fabrics and pieces of lace and ribbon that had belonged to my Mum. We had recently found them in a bag of her old sewing scraps from when she made rag dolls for people. She never made a doll for my sister or myself as she had a stroke before she had a chance to.

The last fabric I used went around my object in a different direction and was some of my own that I had bought to use for my own sewing.

As I was binding my object I was thinking of my Mum. She was ill from when I was 6 until she died when I was 30. Her illness and the age that I was when it happened could be a contributing reason for me having Bipolar Disorder. She was very creative and even from a young age I was inspired by her to sew, write and make things.

I loved the sensation of the fabrics twisting in my hands and the layering around my object. The can was slightly crushed and the fabric fitted easily around its grooves. As I layered I chose whether to twist the fabrics or lay them flat to expose the patterns. I knotted the adjoining pieces or tucked them in. There are glimpses of the layered fabrics and ribbons, ric rac and lace but you need to know what you're looking for to identify it all. The finished object is a reassuring round chunk. It feels soft but firm and as you give it a gentle squeeze you can hear the can crinkling. It smells of musty old fabric but I like it.

I reflect a lot on my mental health and I have a lot of tools that I use to try and support myself but sometimes I can't see the obvious when I am becoming very unwell. I have written a kind of plan of how my mental health looks when I am well, ok and unwell but not how I would like to be treated if any of the extremes in my behaviour occur or my illness is at its worst. The hardest times for me are when I require intervention due to a mixed episode. Depression and hypomania I have mostly learnt to self manage. As much as I can look back and reflect on how I have been in the past and what my experience has been, I don't feel that I am prepared for the future and if I do become unwell in an extreme case.

I find the idea of a directive difficult to grasp because with my bipolar there are different states that I find myself in. I don't feel that there is much choice in how I would be treated as I don't think I understand the options and there is no pre-planned medication for me to go onto. I don't think I understand the differences

between clinical care and any other, it all seems a bit of a muddle to me. I would sometimes be given the option of shutting myself off from the rest of the world until I have recovered in some way but I am not sure that this would be an option.





PHOTO IN A FRAME

Sharon Johnson

My experience of binding – I bind a picture of my son at three weeks and myself in the mother and baby unit at Bethlem. At first I did the binding tight and it felt comforting and protecting towards my son and then when I put the thread on it it became loose and that reminded me of letting go and him growing up to be a nice young man in his own right with its own ideas and thoughts. The background is my messy dressing table and that is the ups and downs of being a mother but sometimes you get it wrong and sometimes you get it right it's is forever changing.

BOOK

Catrien Eagles

This book has meaning to me as it was the book I read when I was in hospital years ago. It was escape from my life living on a psych ward into a dark but hopeful story about a strong women at the time of the plague.

I started the process enjoying tearing up old clothing and trying to place the pieces of material between the pages and tying them. I realised after I'd done this trying to spread open the pages of the book it wasn't going to work if I wanted to bind it more fully. I then continued to tear up different piece of material but this time I wrapped and the began weaving around the book binding it closed. This contradicted my previous attempt to have control over the object opening it's pages however I accepted and realised I had somewhat lost control over what was now being created and relaxed into it. Much like mania and losing control is sometimes a relief at first I thought. Once I had bound and weaved enough material around the book I then suddenly found it was covered and looked complete so I took photos.

Special mention to my cat Hebe who took part playing with the torn pieces lying in the fabric at times and accompanied me and being curious.





BREAST PUMP

Sarah Carpenter

Binding reflection is not so easy. I should have written this closer to the time. Perhaps if I bind again, my memory will be fresh? Movement helps to bring back thoughts and feelings.

It was tough.

Knotted headache.

Low.

Bad place.

Needing distraction – perfect timing.

Frustration because I need to release tension and face the knots?

Trying to choose an object was the first challenge: Decision making with depression and anxiety and frustration, perhaps actually mania? Who knows? It's all still new.

A necklace from Finland: so many memories, all positive, trying to lighten things, turn things around.

Not getting anywhere, not feeling it – should I stick with it or follow my instinct and settle with another choice? The decisions we make daily about our mental wellbeing: to pursue and push on? Or would it be best to stop and show ourselves compassion... rest? Depression needs life and energy as it's cure, but it takes a physical toll. This is why knowing what to do is so difficult.

Constantly being told to monitor, catch ourselves, notice triggers, look after ourselves (not something that would happen with a broken arm!)

Becoming too aware makes me sick. Too much focus on what's right and not enough living. Should I be making decisions or taking advice?

I'm in a knot!

It's not new to me, but my diagnosis is like starting over.

I pick up the breast pump. Wanting to express my tension. Glass and rubber that could shatter at any moment.

Knots in my stomach.

Headache like binding of the brain.

Endometriosis is the first thing that comes to mind. A question of fertility and images of fibrous insides of myself all fused and tangled.

Using a bra, tights – “female” undergarments, all restrictive physically and mentally – asking us to be what others want us to be.

I'm beginning to feel calmer now:

Caring.

Gentle.

Wrapping with the same love I wrap myself up in, under a duvet, on the sofa during the down days. Perhaps this is what I need right now?

Trying to let go and allow the materials to dictate my movements / make decisions for me.

A relief.

A release.

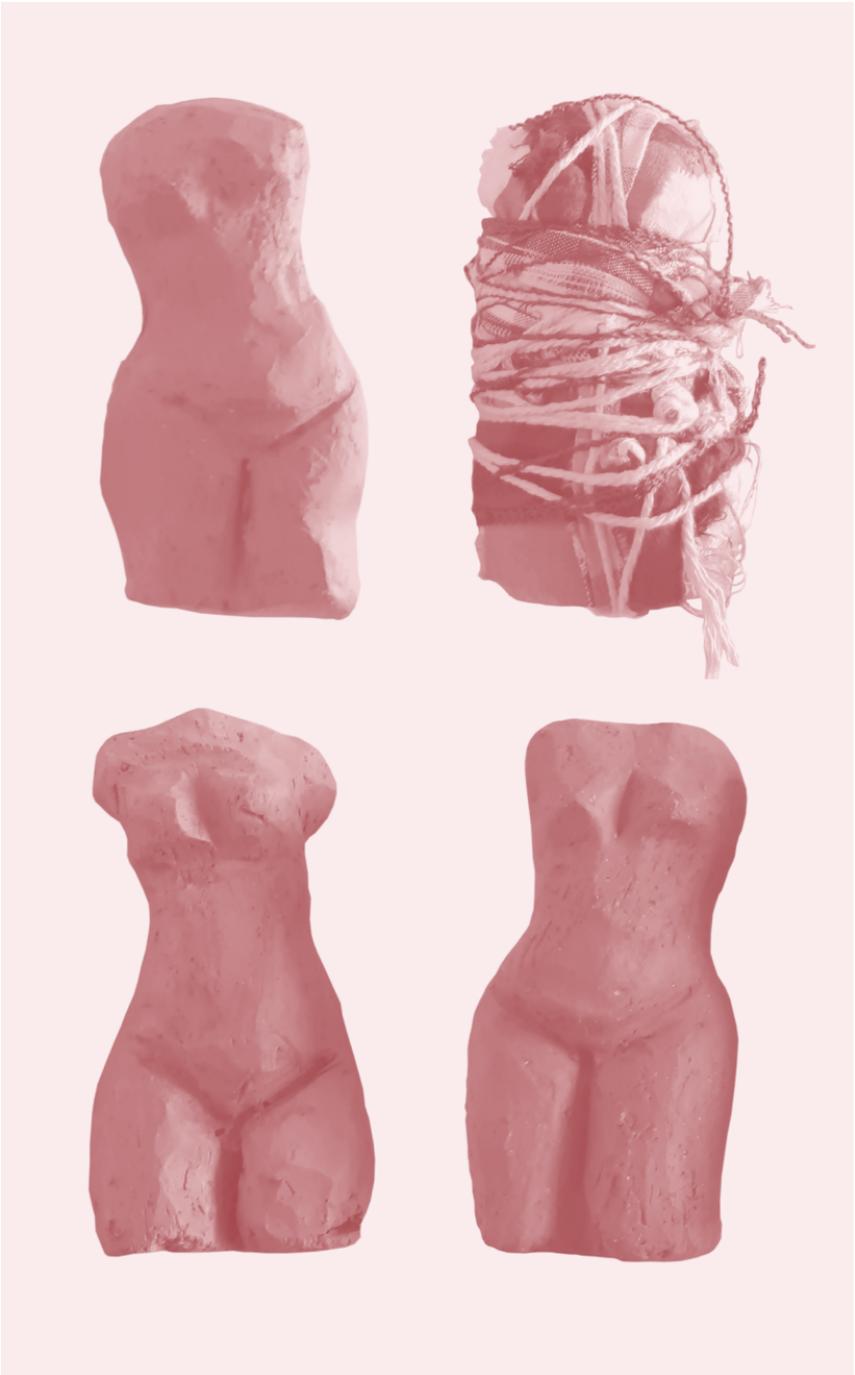
Realising I think I've let go of control, but I've actually been setting parameters: I want to keep the beautiful original form from underneath – not fully covered / immersed. It's pleasing just how it is.

I begin binding thin thread around and around and around, flattening fabric, back to something recognisable... comforting.

I'm feeling more at ease now: A relationship between myself and the piece. Equality in decision making.

Now I feel free to move away from the original shape and allow the threads to create their own new form – they must leave the original shape in view.

Reflection: Everything in my life is about freedom within constraints. Is this good for me? Or is this my downfall – never quite letting go of control / authorship? Is the restriction holding me together? I like a balance of being advised and being given my freedom. I appreciate clinicians expertise but also recognise I am my own expert.



TERRACOTTA WOMAN

Beth Hopkins

I chose to bind a small female figure I made out of terracotta several years ago. When I first made her I felt I needed something to keep me safe. I made a series of four similar clay figures, without limbs or heads, not individuals but symbols of women. I was thinking of fertility fetishes, self portraits, anonymity.

The binding process was very familiar, and a social thing – we talked while we worked. I wove under and over, tearing smaller and smaller strips of fabric. Thinner threads formed networks and nets. I built layers out of strips of red tartan and teal string, wrapping in a continuous spiral knotting one strip of fabric to the next. Her cocoon grew and her original form was lost.

I used strips of a white sundress which I wore in hospital when I was 21, it has become fragile now and is yellowing. That summer it was a heatwave. I was preoccupied with my own shadow, following it around. My personality broke up and my lower levels, or what I thought of as a shadow self took the lead. I began to suspect that I may not be myself, but someone else entirely. This led to the idea that I was Eve, the first woman and mother of mankind, and responsible for everything that had gone wrong since. I got so far from myself that I couldn't recognise my own hands.

Binding is a way to protect the vulnerable young woman I was in hospital, hiding her in layers. My advance directive

is also a way to keep myself safe – an act of care for my potential future self. Writing it opened a discussion between my past, present and future. My past self, in the midst of a manic / psychotic episode. My present self, reflecting back and trying to put plans in place to protect a potential future self who might become unwell again.

After a milder episode of psychosis a couple of years later, my Community Psychiatric Nurse said to me, ‘You were still Beth, just more so.’

MY METRONOME GOT BOUND TODAY
John McAllistair



METRONOME Continued...

C
My metronome got bound today

G
To stop it's racing heart

F
It dictates all my timing

G
When I am at my work

C
I used the ribbons black and white

G
The colours of my moods

F
When I am either high or low

G
Or going with the flow

C
I spoke of my past treatment

G
How I'd like be heard

F
Not a nuisance but a being

G
Healing – myself

‘in a manic state often the decisions made previously are distorted by florid thoughts, a health care professional reading the ‘self-binding statement’ to the patient would help to bring some sense to the chaos’

‘It’s different each time. And hopefully it continues to be a learning curve where you gradually get better at managing your condition, so who is to say what the next time will be like, how ill you will be, what the medical staff will be like, what new drugs they might offer etc... so giving up control in advance is a difficult decision to take.’

UNRAVELLING IMPOSSIBLE QUESTIONS

Between May and July 2021 I ran a series of workshops with other people with experience of bipolar. The group included a writer, a musician, an artist and a person living within the mental health system in Iran. Each brought their own expertise and experience to the sessions. People were at different stages, from being newly diagnosed with bipolar to living with it for most of their adult lives.

I asked people taking part in the workshops to bind an object that held meaning for them. A number of themes arose during our discussions while binding, among them notions of control and care.

Mania and psychosis can be experienced as a loss of control – we talked about how at some points it can be exhilarating, at others terrifying. Writing an advance directive is a way to prepare and feel more in control should the worst happen. It recognises you as an expert in your own illness. As empowering as this is, we discussed how it might be equally disempowering to have the directive enforced at a later date outside of your control.

We talked about care (or lack of it) by medical professionals. Also, care by and for our loved ones – how agreeing to hospitalisation in advance can be an act of care for family and friends, reducing the need for them to take on a caring role. Writing an advance directive can be an act of care for your children, so that they are looked

after if you become unwell. Motherhood emerged as an unexpected recurring theme – the impact of losing your mother as a child, the desire for someone to care for you as a mother when you are in distress, and the difficulties of being a mother with bipolar. We talked about caring for ourselves: the necessity of self-monitoring, and tools we might use, such as CBT. The expectation that you will fend for yourself without regular medical support. Ultimately, finding ways to have compassion and care towards ourselves.

We did not find answers to the impossible questions, but we will continue asking them.

MENTAL HEALTH AND JUSTICE PROJECT

Bethlem Gallery's mental health and justice project is funded by Wellcome and commissioned this work by Beth Hopkins. It is an artist-led programme that aims to challenge the often exclusive or hierarchical conversations that have characterised the areas of mental health, law and fine art. The project responds to and informs current research into the complex space where mental health and mental healthcare interact with principles of human rights. Beth's work shows exactly how an artist with lived experience can be a researcher in their own right and further a greater public awareness.

We'd like you to get to know some of the other artists working on the Mental Health and Justice Project. The themes explored by them range from:

Metacognition. Thinking about thinking, knowing about knowing, awareness of one's own awareness.

What does it mean to have our capacity assessed?
What is our relationship to the state and how fragile is our position?

What does it mean to have or to lack insight? How can insight be measured? And who gets to decide?

How can we do this better? What conditions and space might help people with lived experience to work alongside those from the mental health industry to consider what can be done better?

Bethlem Gallery is a practice-led gallery and studio in Beckenham, Kent. We support artists in opening up conversations around art practice and mental health, and advocate for change in health and society.

Please visit www.bethlemgallery.com to find out more.

Lucy Owen,
Producer Mental Health and Justice Project

Sam Curtis,
Curator Mental Health and Justice Project

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BETH HOPKINS is a visual artist working across a range of media, including sculpture, textiles, drawing and working with found objects. Her work is often autobiographical and explores shared histories of mental illness and its treatment, past and present. Research and collaboration are core to Beth's practice. See more of her work on her website: bethhopkins.weebly.com

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Should the right to make our own decisions ever be taken away?

This is a collection of accounts of discussions between people with experience of bipolar. It addresses issues raised by Advance Directives, a type of living will that enables you to make decisions about your healthcare in advance of becoming unwell*, which would be binding should you lose capacity to make decisions. This research, led by artist Beth Hopkins, interrogates themes of agency, control and care, and ultimately, our human rights.

What decisions would you make for your future self?

Part of Bethlem Gallery's Mental Health and Justice project, funded by Wellcome.