

Ember Vincent

A personal reflection on
the social and emotional
challenges of living with
Myalgic Encephalomyelitis



Contents

Page 3-11	Research 1:	Japan
Page 12-17	Research 2:	Health
Page 18-25	Materials:	Ceramic and Metal
Page 26-28	Final Pieces:	Concept and Process
Page 29-41		Bound
Page 42-51		Missing
Page 52-66		Hidden
Page 67-79		Exposed
Page 80-86		Emerging
Page 87-104		Identity
Page 105	Image References	

Research: Part 1

Japan

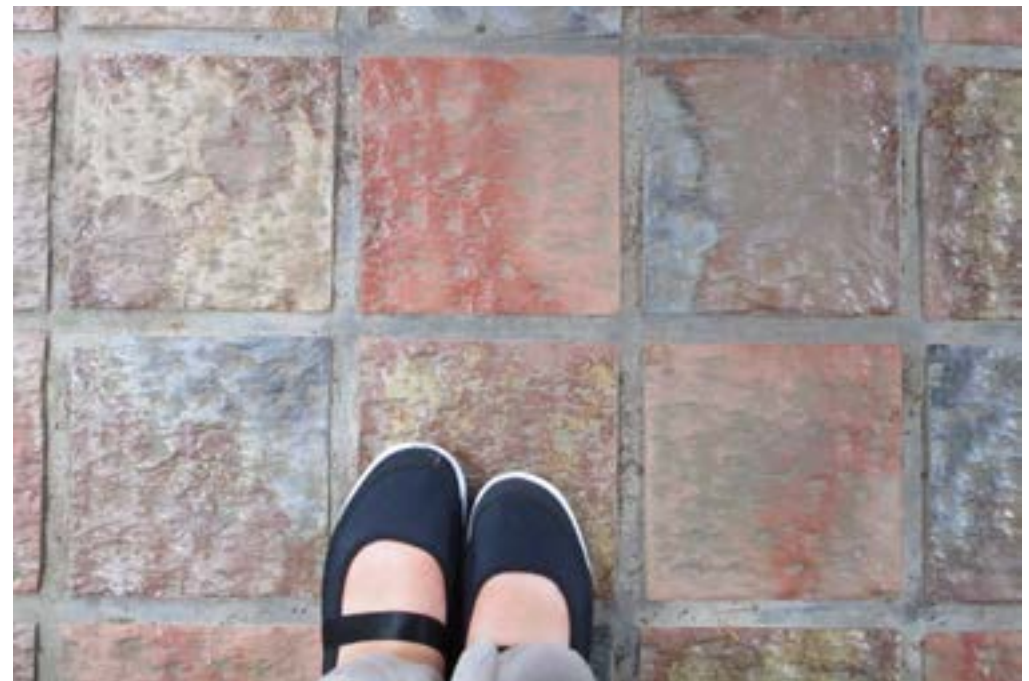


In September 2016 I travelled to Japan to research and study traditional Japanese ceramics. I visited Bizen, a small village which produces Bizenware ceramics. Bizen is one of Japans 'six old kilns' and the only remaining village still producing ceramics in the same style today as it was in the 14th Century.





Bizenware is wood fired in large communal kilns. It is unglazed, instead using the ash from the wood with the occasional addition of straw to give it its distinctive and recognisable patterning. As well as traditional vessels, Bizen ceramics can be found in paving slabs, street signs, roof tiles, walls and shrines.



I wanted to research the origins of Japanese Raku firing so visited the Raku museum in Kyoto, part of the Raku family home and workshops. The Raku family is a generational lineage of potters making tea bowls for the Japanese Tea Ceremony. Their techniques and knowledge have been passed down through the family line from father to son for 450 years. These tea bowls have been created in the same way since the 6th century, incorporating aspects of Japanese culture, history and heritage in their form, glazes and firing methods. The differing attitudes to culture and tradition in Japan and Britain, in particular when comparing attitudes to ceramic techniques and traditions such as Raku firing, became the focus of my dissertation.

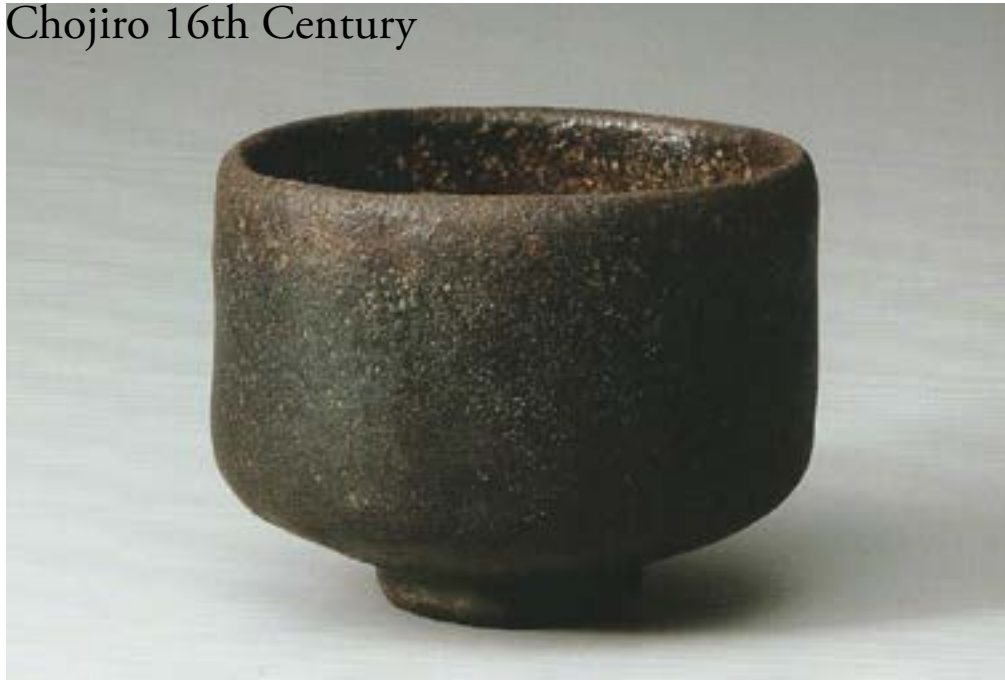




I attended a workshop to learn how to make a traditional Raku tea bowl, led by master craftsman Rakunyu Yoshimura. His Raku kiln which is set into the ground of his workshop is one example of the difference between traditional Japanese Raku and the techniques used in the west.

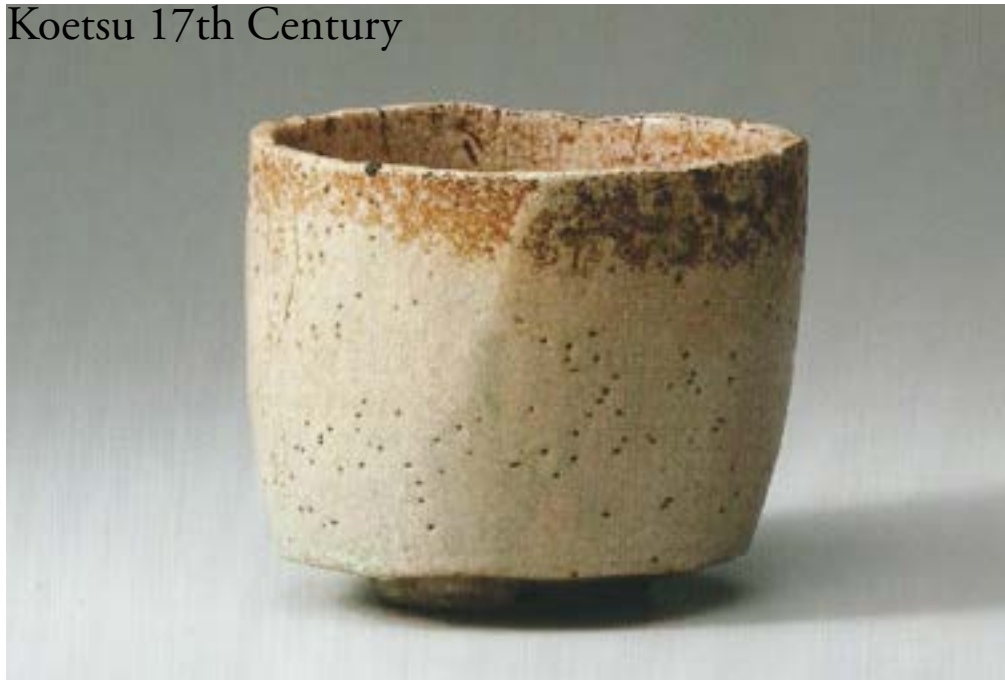


Chojiro 16th Century



This research, in particular into traditional tea bowls installed in me a newfound respect for the deep significance placed in the making of these objects. This led me to begin to regard forms and vessels as holding the ability to convey a deeper message than just function or decoration.

Koetsu 17th Century



Kichizaemon XV 21st Century



I wanted to search for an equivalent experience amongst my own culture so attended a wood firing at the Cass Sculpture Foundation, organised by West Dean College. The organic and unpredictable reactions of wood and smoke on ceramic shared the aesthetics of Japanese ceramics but not the cultural and historical depth of significance.





My journey to Japan rekindled my previous interest in Raku firing, inspiring me to consider the technique in a different way. I built a portable gas-fired Raku kiln using a metal dustbin and ceramic fibre. Although the techniques of Japanese and British Raku are very different, both share an alchemic and elemental celebration of the unpredictable.



Alongside considering these techniques and traditions I also found inspiration in the Japanese concepts of Wabi Sabi and Kintsugi:

Wabi Sabi: A philosophy and way of life conceived around the idea that beauty can be found in the simple, unpredictable, imperfect and transient so demonstrating an acceptance of the natural cycle of growth, death and decay.



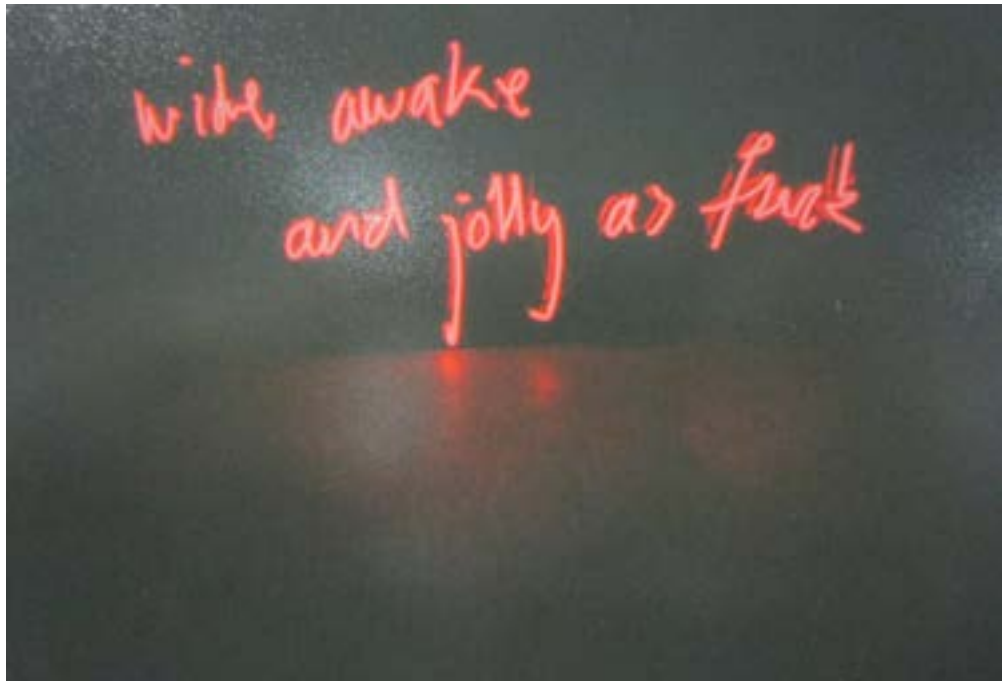
Kintsugi: The art of mending broken pottery with gold, putting forward the idea that something can become more precious, beautiful and interesting through its experience; something broken then mended gains strength and value.



Research: Part 2

Health

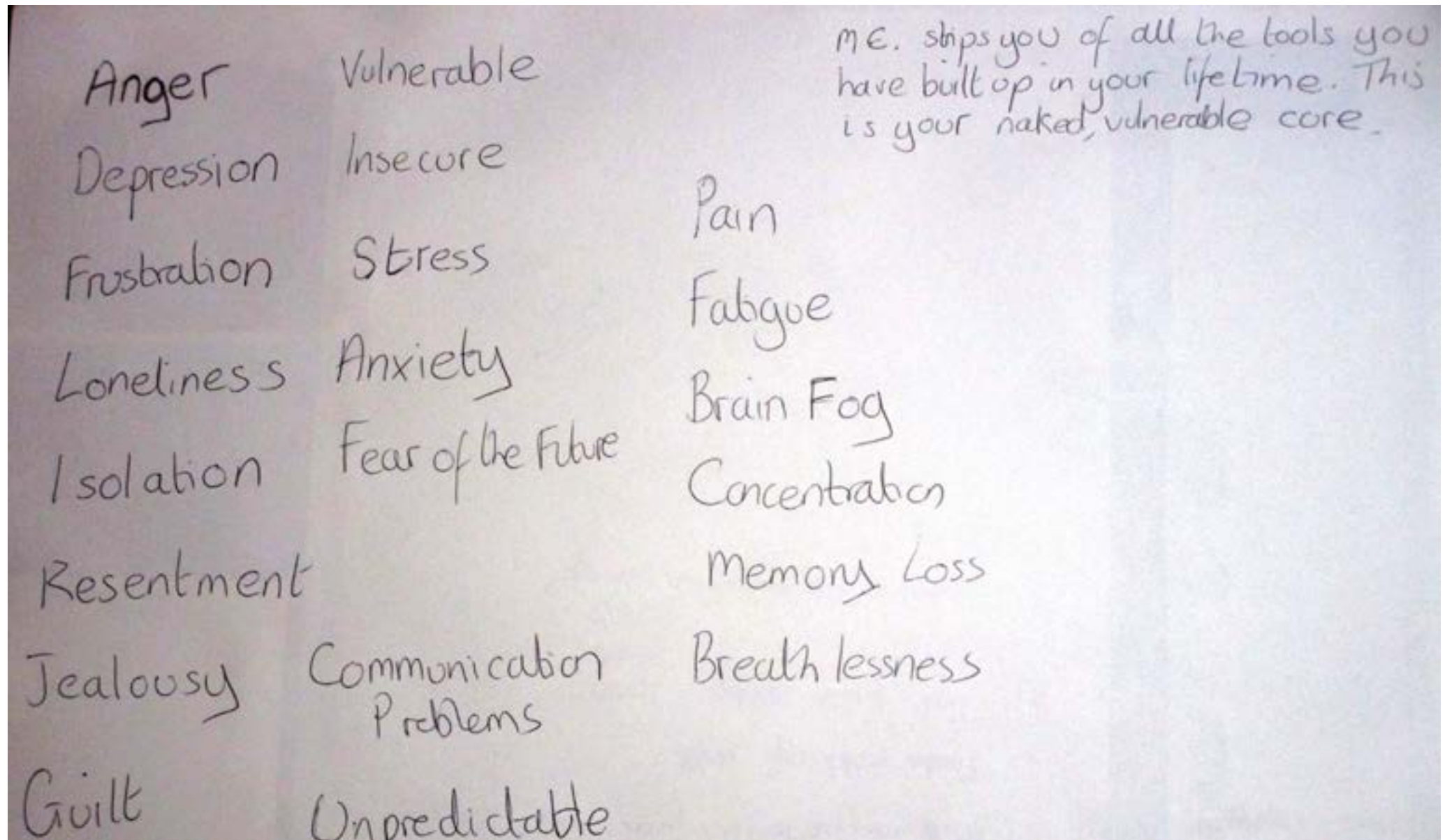
Whilst considering these Japanese ideas of celebrating imperfection, I began to think of a significant period in my life when I also needed to find positives in the broken and damaged. I decided to look further at an 18 year period of my life when I lived with Myalgic Encephalomyelitis (M.E.) This debilitating disease is one experienced by an estimated 250,000 people in Britain. It is a much misunderstood condition that sufferers can often find hard to describe due to the many and varied symptoms. The most common symptoms are chronic fatigue, muscle pain and episodes of cognitive disfunction such as memory loss and brain fog.



I began by looking at how others have used art to interpret and express illness, attending exhibitions and performances including 'Manifestations of the Mind,' an exhibition by a group of female patients using photography and moving image to express their own experiences of living with mental health conditions.



My personal reflection began by considering some of the symptoms and impacts I had experienced whilst living with M.E., using freethinks and creative writing.



I decided to focus on aspects of M.E. that are sometimes harder to understand such as social and emotional impact. I wanted to look beyond my own experiences, so I set up a social forum in February 2017 to gather information and experiences from other people living with the condition. 49 members voluntarily joined the group to respond to questions and images in regard to living with M.E.

<https://www.facebook.com/groups/258642187895371/>

The screenshot shows the Facebook interface for a group named "M.E. / C.F.S Research Project (Ember Vincent)". The page is set to "Closed group". The left sidebar contains navigation options: Discussion, Members, Events, Videos, Photos, Manage Group, and a search bar. Below these are shortcuts for the group, the user "Ember Vincent", and another group "Brighton 3D Design and...". The main content area features a header with the group name and a search icon, followed by a navigation bar with "Joined", "Notifications", and "Share" buttons. Below this is a "Write Post" section with options for "Add Photo/Video", "Add File", and "More". A notification banner states "1 person wants to join this group". A "PINNED POST" by "Ember Claire Vincent" dated "25 February" is visible, with the text: "Hi everyone and thank you for being a part of this group. I thought I'd start with a bit of background info. I developed M.E. way back in 1994 after contracting Hepatitis whilst travelling. I had sudden onset and was severely incapacitated for a good few years. I then plateaued for another ten years". The right sidebar includes an "ADD MEMBERS" section with a search bar, a "MEMBERS" section showing "49 members" with profile pictures, a "DESCRIPTION" section with the text: "A group for people living with M.E. / CFS who are willing to help me with my degree research project leading to the creation of a final show of 3D work that will aim to raise awareness of the condition. Please read pinned post for more information.", and a "TAGS" section with an "Add Tags" button.

Question to Social Forum:

What are the main challenges you face living with M.E.?

- Other peoples lack of understanding of our variable and often debilitating condition and it's symptoms
- Being completely misunderstood and often ignored by the medical profession
- Finding a way out of isolation, loss of identity, depression and chronic frustration
- Having an invisible illness starts to turn you invisible too
- The ridiculous amount of energy it takes to do even the simplest things when you just don't have any
- Holding it all together when all you want to do is scream
- Putting on a brave face each day trying to match the face that everyone else sees which says "I'm FINE"
- Accepting the physical and mental restraints which become a daily routine
- Struggling to find the person you once were and mourning their loss
- Being undiagnosed for over a decade and feeling confused, alone and freakish
- Being unpredictable- not knowing from one day to next if I'd go from fully well to unable to stand or walk.
- Struggle, Exhaustion, Frustration, Weakness, Silence
- Learning how to accept my limitations and stop fighting against it all the time. Letting Go. It is enhancing all other areas of my life too - a fabulous silver lining (the gold in the shadow - or in the cracks?!)
- Finding people in my life who accept me as I am and who believe me. Also people who have a lifestyle that I don't feel overwhelmed or left behind by. Part of this has been getting my family to accept things as they are
- Dealing with officialdom - doctors - benefits people. I know that if I improve they cut my benefits - I can no longer afford the treatment that allowed me to improve and the chances are either I will stop improving or I will get worse again!
- Accepting loss and dealing with pain

Materials:

Ceramic and Metal

I decided to use metal and ceramic to create a body of work which would look at and communicate some of these challenges. My reason for combining metal and clay began to form when I started to look at the scope and significance of their properties. When considering ways to represent a physical illness and its impacts, clay could signify the substance of body and form. Metal with its capacity to move organically and freely in its molten state could be seen to represent more fluid aspects: emotion, spirit, energy. In its solid state it could also take the role of a hard exterior, a frame or cage, or to represent a physical or emotional barrier. I also see the combination of the two as comparable to the earth with its solid exterior and molten core.



Metal Table



Water



Metal Tube



Edge of Crucible



Water



Sand



Water



Metal Tube

Although I had previous experience of ceramics, metal was a new material to me. My first technical explorations had begun earlier when considering the philosophy of Wabi Sabi: I wanted to capture a moment in time; a celebration of impermanence and unpredictability. I played with pouring molten metal into water, onto the floor, over other materials such as metal pipe and onto different surfaces such as kiln brick and earth



I then started to combine metal with natural materials such as stone, leaves and driftwood. In most cases the molten metal would partially destroy the organic material, creating some interesting reactions whilst at the same time altering the substance of both materials. I limited my research to pewter and copper, both affordable metals with significantly different melting points so capable of producing very different effects.



I tested the boundaries of clay by pouring molten metal into small pod-like forms. These produced some interesting results and stretched my expectations of the limitations of combining the two materials. I had previously assumed that molten metal would be too hot for ceramic and the impact would result in explosions and cracking. This was not however the case, and although I suffered a few minor cracks, the ceramic remained intact.



This inspired me to push the process further to see what else was possible. I wanted to push the boundaries of these two materials, looking at ways of merging them to become more integrated. I started to include metal in ceramic firings, taking the pieces above the melting point of the metal to see what would happen. The most interesting reactions were with copper fired above 1200, which melted and eroded into the ceramic, leaving a textured blackened surface.





Looking at how these techniques could be utilised in a more finished object, I made a piece in response to a small woodland in Billingshurst. Using clay and organic material gathered from the area I created a vessel to hold the imagery and memory of the space. I added metal wires and contrasting clays to represent the patterns created by the tree trunks.



Final Pieces

Concept

Process

Conclusion

Conceptual Framework

I decided that the aim of my final body of work would be to raise awareness of M.E. whilst creating a greater understanding of some of the symptoms and effects that the condition brings. I also wanted to provide a platform for communication for those living with M.E. or other similar hidden illnesses. I separated the main areas I wanted to explore and represent into six categories, giving each a single word heading. I then created six individual pieces or series of pieces to represent each of the headings

Bound: Feelings of being immobilised, stuck, restricted, tied down.
The chronic fatigue element of the condition resulting in long periods of bed rest

Missing: The number of people affected, missing from everyday life.
The feeling of missing out, of life carrying on around you and without you

Hidden: The challenges of living with a hidden condition. Emotions and symptoms, feelings of being broken and cracked are invisible and hidden away

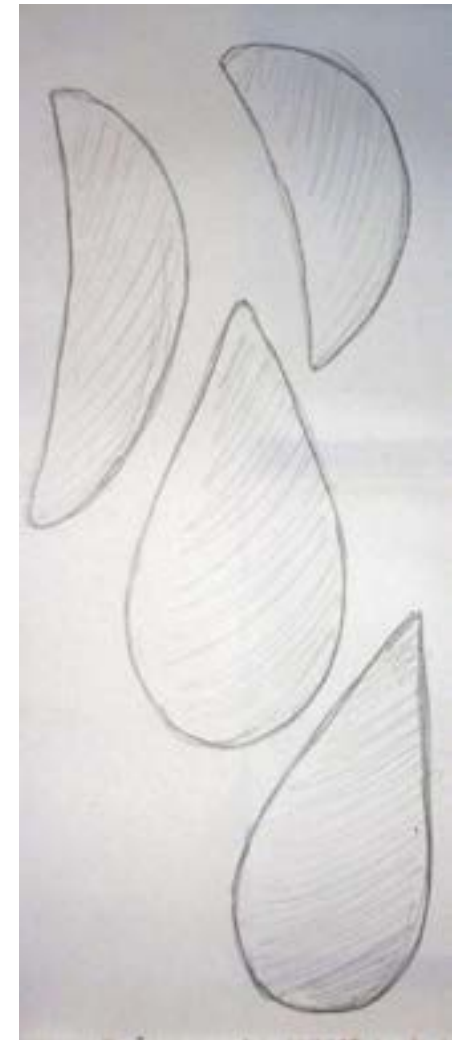
Exposed: The vulnerability of exposing these inner cracks and scars.
The importance of seeing the beauty in them

Emerging: Tentatively reaching outwards from an insular place.
Moving into healing and hope; a response to my own recovery

Identity: The challenges of defining your identity when experiences and life choices are restricted by your health

Bound

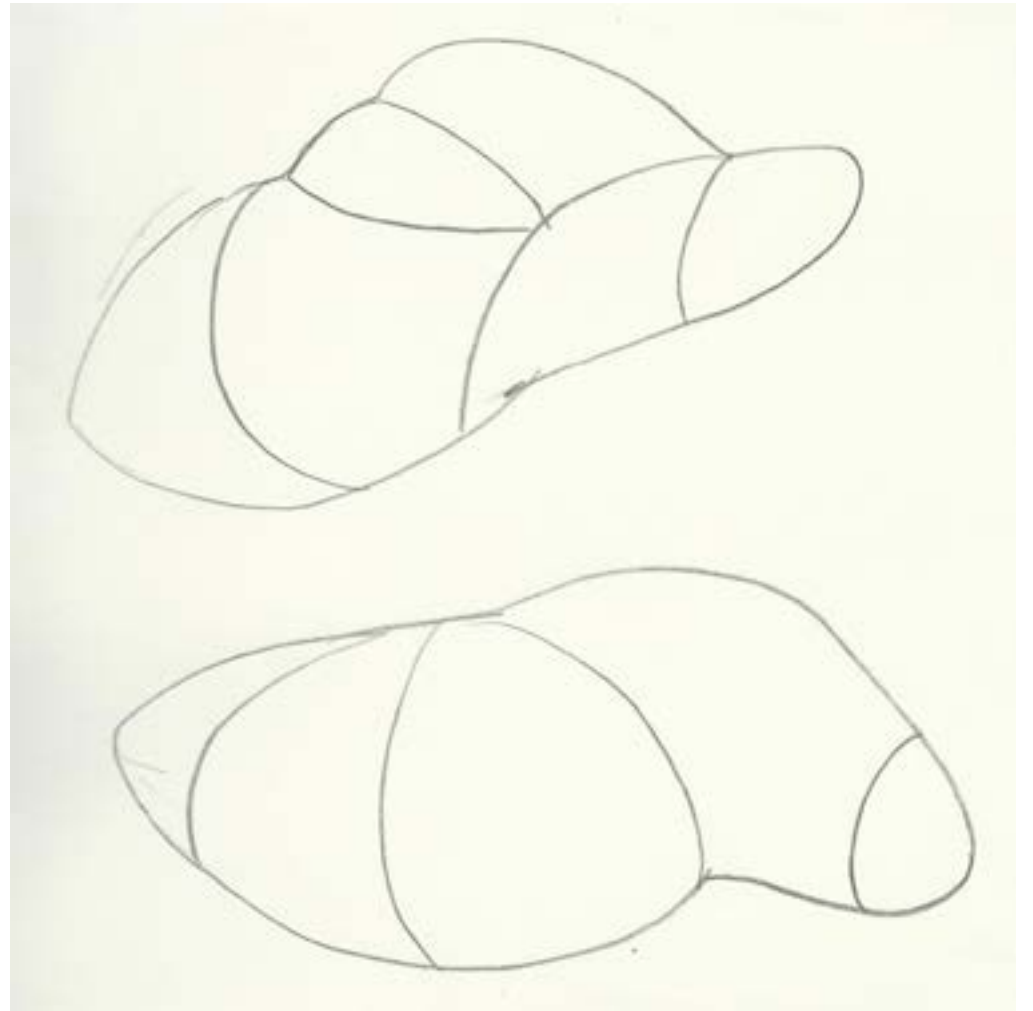
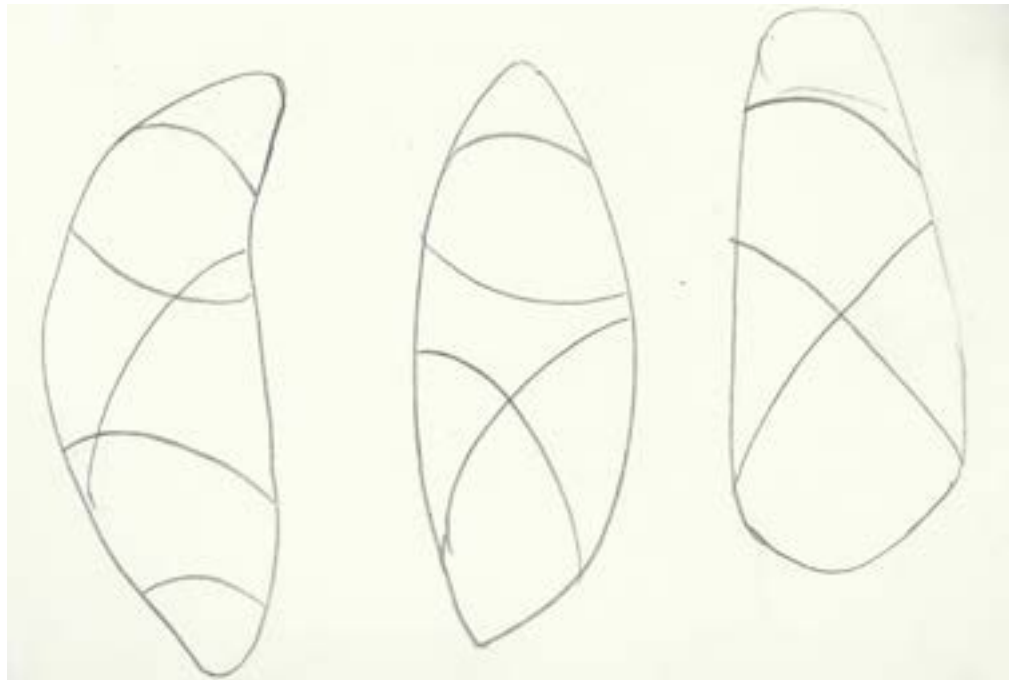
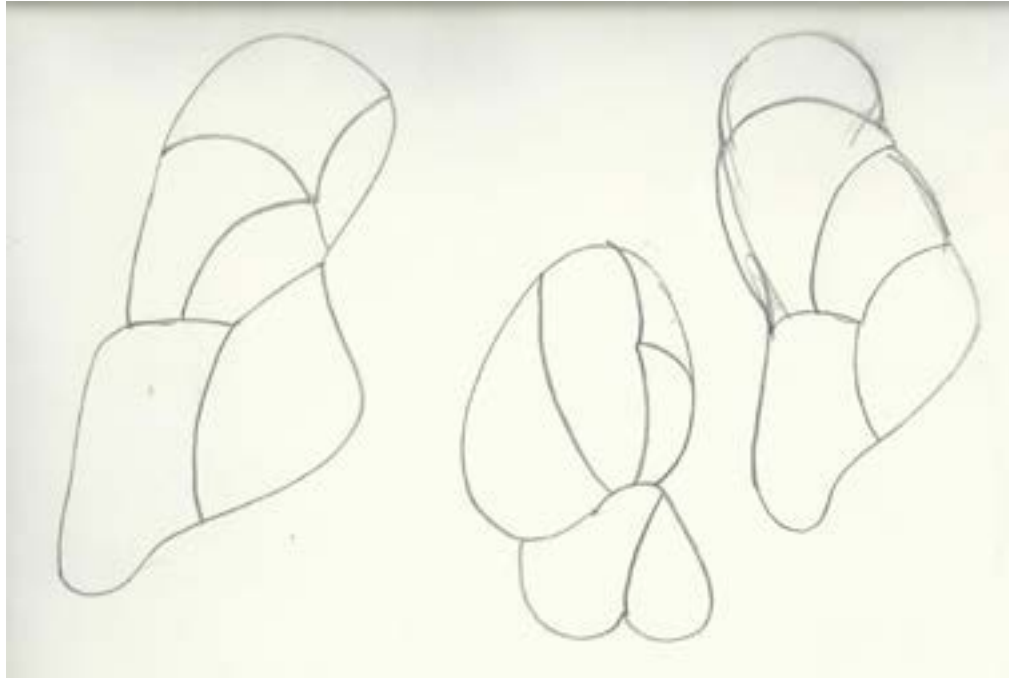
Bound Immobilised Life on Hold Static
Trapped Stagnant Held in Suspended Animation



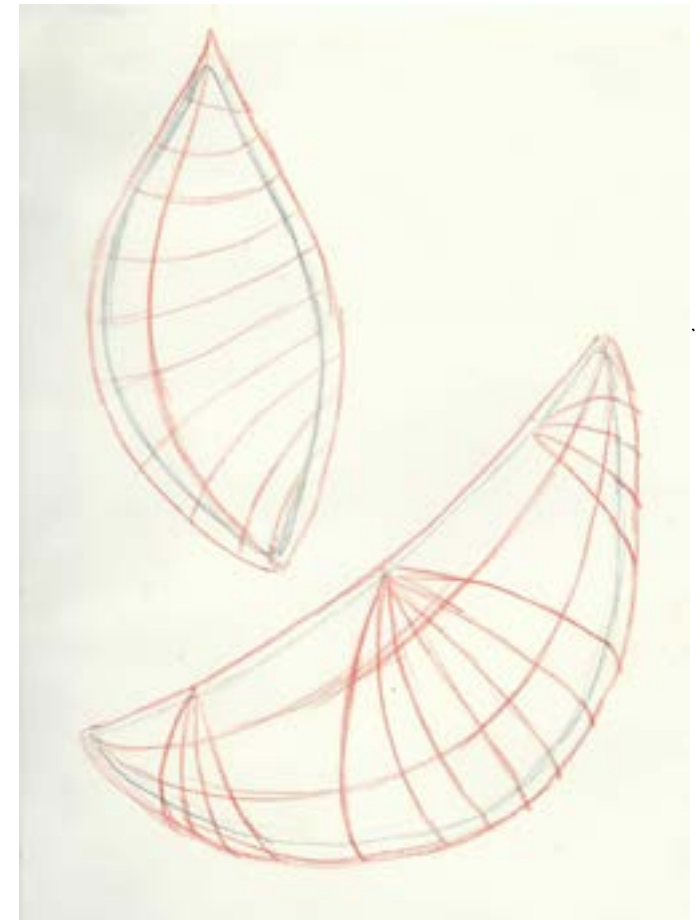
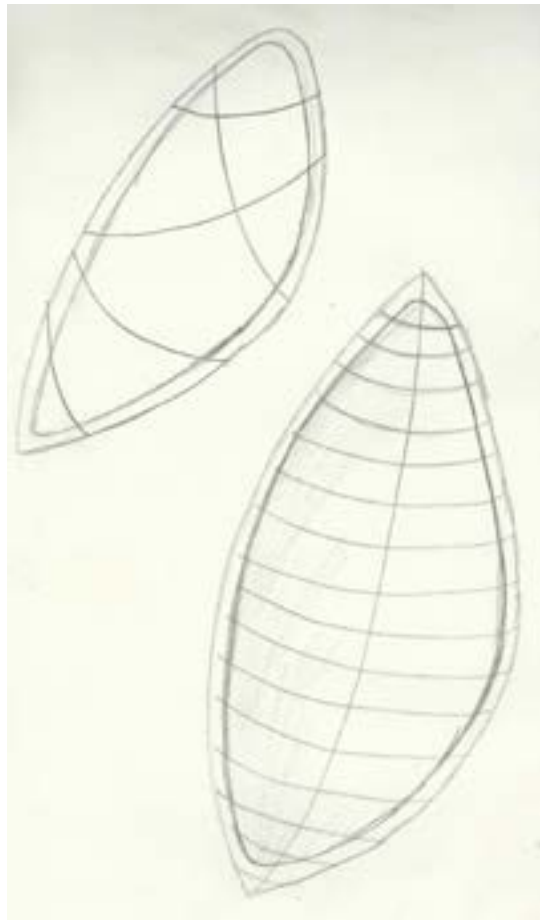
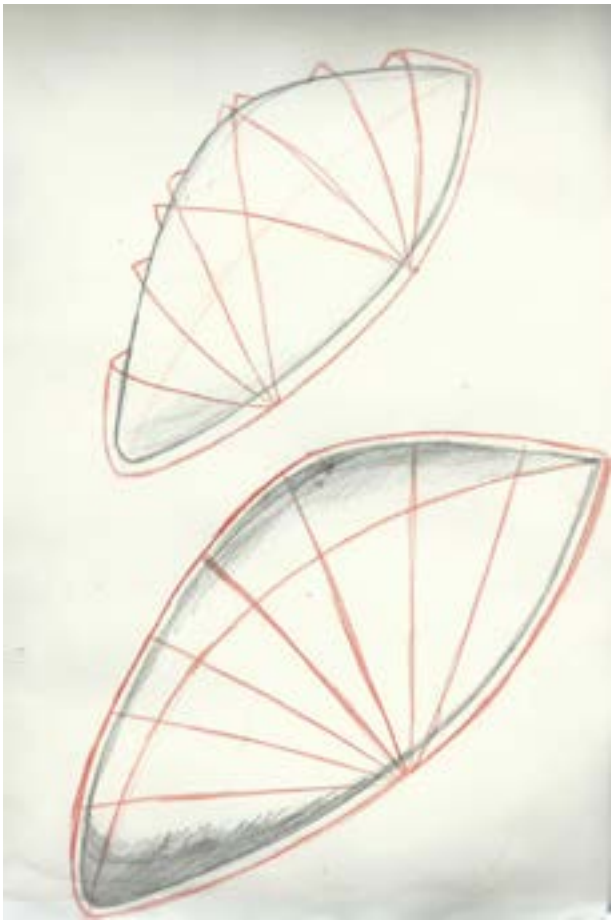


I began to explore the sleeping form to represent the long hours spent ill in bed, however this felt too peaceful and I realised I needed to convey the sense of being bound and restricted by the condition and the chronic debilitating fatigue it produces. I started by taking photos of a friend tied into a sleeping bag





From this I decided to work on creating a piece to represent restriction, using clay as the body / form and metal to bind and restrict



Questions asked in this line of research:

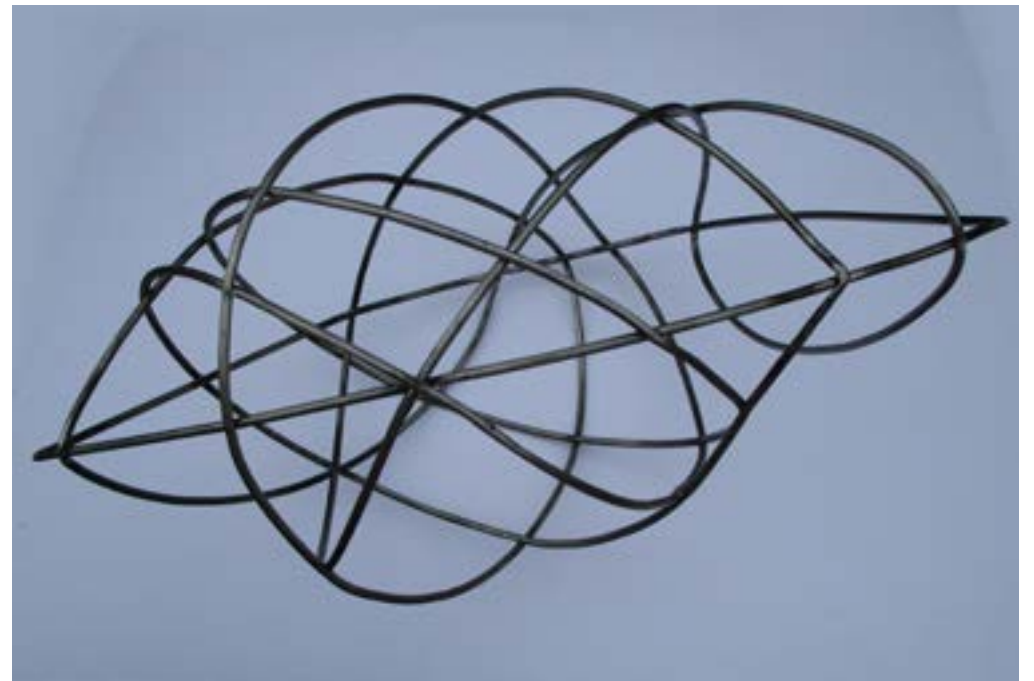
- Will binding a fired ceramic form with wire create a feel of restriction? Do different metal wires leave different impressions?
- Is it possible to build a metal frame first, then form clay inside the frame? What happens when the clay dries and shrinks?
- If clay is enclosed in a metal frame and fired in an electric kiln how will each material react and interact with each other?
- What changes will take place at increasingly high temperatures, e.g. going beyond the melting point of the metal?







After a series of technical tests I decided to make a steel rod frame with ceramic interior, fired to 950c in an electric kiln. I used TIG welding to build the frame, then rolled out clay slabs to build the pod, pressing each slab against the metal to create an imprinted form.





I decided to make a second piece continuing with the idea of restriction, this time using a contrasting white bodied clay, wrapped with metal wire.





I wrapped the piece with copper wire and fired it to 1200 c, therefore going beyond the melting point of the copper. I wanted to exploit the reaction between the two materials. The copper turned black, eroding the ceramic as it melted.





The first piece plays with tension between the materials, creating feelings of restriction and immobility

This second piece looks at the marks that are left behind as a result of the condition and its restrictions



Missing

#MillionsMissing is a global protest to raise awareness of M.E. The protest has taken place in locations around the world with people living with the condition placing a pair of shoes as a representation of themselves. This means that those who are too ill to attend are also given a voice and a presence. The title Millions Missing refers to the millions of people with M.E. who are missing from society, as well as missing out on living a normal life

I wanted to make a series to represent the missing, and the diversity of those affected



The series was created using techniques such as Raku, smoke firing, wire binding, melting copper and inlay with slip and silver clay



One technique involved binding pieces in copper then applying glaze over the top. I fired these inside saggars; ceramic pots made specifically to fit tightly around the forms. The copper on the pods fired in an electric kiln seeped blue into the glaze, whereas those fired in a Raku kiln produced a deep red as the copper reduced.



At this stage of my work I volunteered to take part in the Silver Project to continue with my explorations in different metals. I was able to make a series of pods which combined ceramic and silver, incorporating the final pieces into the Missing series.



The three pieces in black clay and silver were displayed in a small exhibition. The top left image shows the cuttlefish casting material used to create the central pod.



Process of casting silver in cuttlefish

The cuttlefish is cut in half and the soft sides sanded to create flat surfaces.



The shapes to be cast are pressed into the cuttlefish then removed to leave an imprint, whilst a funnel is carved where the molten metal will be poured. The cuttlefish halves are bound together and placed in casting sand and the silver is heated until molten.



The molten silver is poured into the mould, ensuring the heat stays on the metal right up until the point of pouring. The whole piece can then be quenched in water and the cast metal removed.



In this case I decided to cast the three segments together and separate them afterwards. After filing and polishing they could be fitted into the pre prepared inset in the ceramic.



Question to Social Forum:

Which of these pods best represents your condition?



- This is one I resonate with. The gleaming part is solid and strong. Strength in silver linings.
- Also beautiful and resonant but I can't explain why.
- Beautiful!! Represents wealth and happiness to me. The shining silver line being born out of the blackness.
- The silver represents, to me, the embedding of the illness into my being. The illness is not me, it is an invader into my body, but over the many years, it has sunk deeper and deeper into me, slowly embedding itself into me, almost "me" now.



- I love the shape of this one, and the veins of light illuminating the mass of darkness. Most represents my ill years I think
- This feels like my life sometimes, on a knife edge, slightly dark and with tiny roads out of this mess, too small for me to travel along :(
- There is something reassuring about the solidity and weight of the darkness - I think it speaks to me of hitting a point when I stopped fighting it and just let go. That was a turning point.



- The constraints imposed upon my body and its abilities have become a part of who I am. Eleven years of pain and fatigue and myriad other symptoms have marked themselves upon who I am. And sometimes I can choose to view the lessons it has brought me, bravely, with gold.
- This pod is squeezed into something that it doesn't fit, it's bulging out and it looks painful. This is how my clothes feel to me, and every squeeze from my clothes is reminder of my emotional pain, of what I have lost. It is also how my soul feels in my body.
- This reminds me of how something is soft and vulnerable when it has been under water too long (like after a long bath). It is pierced and hurt and a bit defenceless. pale and unhealthy and needing some sun.



- Scarred but healing and finding strength.
- There is real strength there, like growth
- Represents the years of brokenness, twisted and painful. Then an emergence, as if from a shell, still shaped by it but moving on and feeling the way forward into wellness
- Expanding within restriction
- I find this one a bit oppressive - something on my back wearing me down?
- This is me struggling against bonds no one can see, having light days & dark, trying to stand when all I want to do is curl up & die.
- The shackles have cut deep here, so even when removed they continue to disfigure



- Scarred by my experience, but a survivor.
- I find this one difficult. There is a beauty to the colours. But there is a jaggedness and difficulty in the lines. The broken shape cannot find continuity and is constantly pushed back and down. Finding a path is impossible - nothing works. This reminds me of dark days. the restrictions leave a stain on the form like shadows. Maybe the beautiful colour hints at some hidden benefits yet to be discovered - some resulting growth - but it has not emerged yet and this is a tough place to be (really feel for anyone in this space). Also the heaviness of the wires - they are like fear. It took me a long time to acknowledge how frightened I was at how much of my life was disappearing and of how much worse it could possibly get. The fear alone is debilitating.



- It makes me think of all the different symptoms, all the different causes, the different treatments - it can be overwhelming trying to make sense of it and just trying to is exhausting and muddling. No wonder we get brain fog!
- I see not only the binding, which makes me think of the suffocating tightness of the restrictions M.E puts on our body, forcing us to be prisoners inside it, but the colour has bled onto the pod. For me that colour represents how those restrictions have bled into our lives, thwarting ambitions, relationships, creativity, careers and for some of us our parenting.
- Seeing this the bindings or limitations are central to my life and when I struggle against the limitations they bite into me and wound me more



Hidden



Myalgic Encephalomyelitis (M.E.) is a condition that can be hard to understand and to explain. One confusing aspect is that it is a 'hidden condition' meaning that despite the severity of the symptoms, there are often no obvious outward signs. I wanted to explore this idea further, looking at the specific challenges this brings such as feelings of being cracked, broken and scarred on the inside whilst being told that we look fine on the outside.

Question to Social Forum:

What are the main impacts of having a hidden illness?

- I find it most challenging when people comment on how well I'm looking when I feel like I'm dying!
- I think we get so used to putting on a front just to get out of bed that we get so good at it it fools everyone then you're confronted with people telling you it's basically in your head & to think yourself well, I feel like screaming "What the fuck do you think I'm doing every second of everyday!"
- I think as well because ME is so hard to explain its sometimes easier to just pretend you're feeling fine rather than going into that discussion- sometimes i just didnt have the energy, and sometimes i just felt i wasnt in the right frame of mind to deal with any challenges or negativity...which i suppose could be seen as an advantage of having a hidden condition. When your disability is more obvious i imagine you're often not given the choice of hiding behind the well mask!
- With regard to hidden illness rather than chronic illness I would say specifically it would be being totally misunderstood and the frustration that that causes. It seems illness is only legitimised by visibility by most people. Because for that moment you are holding yourself up, speaking and appearing to understand what is going on when on the inside you are trying not to fall, feeling pain that is distracting you from listening or conversing in a way you would like, planning your whole day around that one conversation at the expense of the rest of it and maybe more. All of these things are invisible and to express them or explain them is too much information for most. How people with invisible illness achieve daily life is inconceivable to people who have never experienced it.

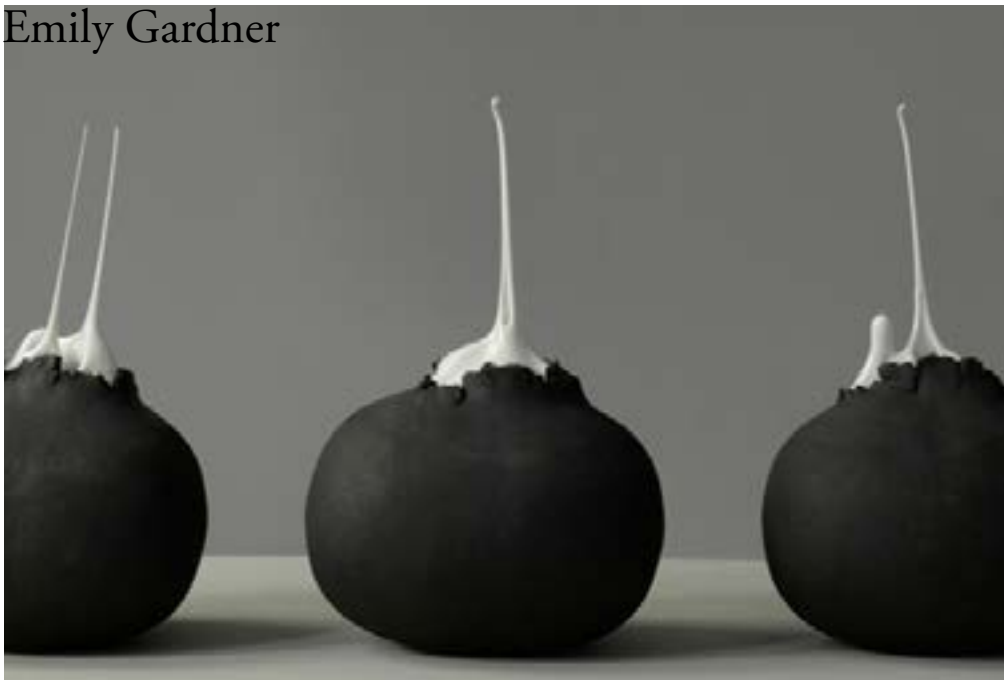
- It and my other conditions rule my life so much that I often don't want the endless discussion trying to explain it to people who however well meaning will just never quite get it, I don't have the energy to spare.
- It made me feel like I should be better than I was or am and i should do more. When I had days when I was ok people assumed I was fine when actually I'd go home and spend two days in bed. It can be really hard. I've heard people say it's laziness too. One GP when I was young suggested I was bullied and therefore made up my symptoms... this wasn't the case. X
- When I was out, interfacing with the world and I would 'run out' of energy, I couldn't speak, think or construct sentences, never mind explain what was happening. I'd feel so frustrated and incompetent, fearing what people thought and unable to explain myself. It does come back to how ridiculous it can look to well people. I remember having parked my car and realising I didn't have the right change. I knew I didn't have enough reserves to get change and come back. Luckily a passerby was generous enough to help me out with a few pence
- When first I admitted to having this illness I was told you look so well it's because we work so hard at appearing well I was constantly told by doctors it in my head
- It's just the general lack of understanding. The 'Oh you look well today, are you feeling better?' People get upset when I answer with 'No, but I did.have 5 minutes of energy spare to put make up on'.

Andy Goldsworthy



Certain artists helped me consider different ways I could express this idea. Andy Goldsworthy's rocks show an inversed cracked surface over a solid core. Emily Gardner's pieces reminded me of an inner light desperately trying to escape, whereas Margaret Curtis' tea bowls embody the Japanese celebration of the imperfect through Wabi Sabi

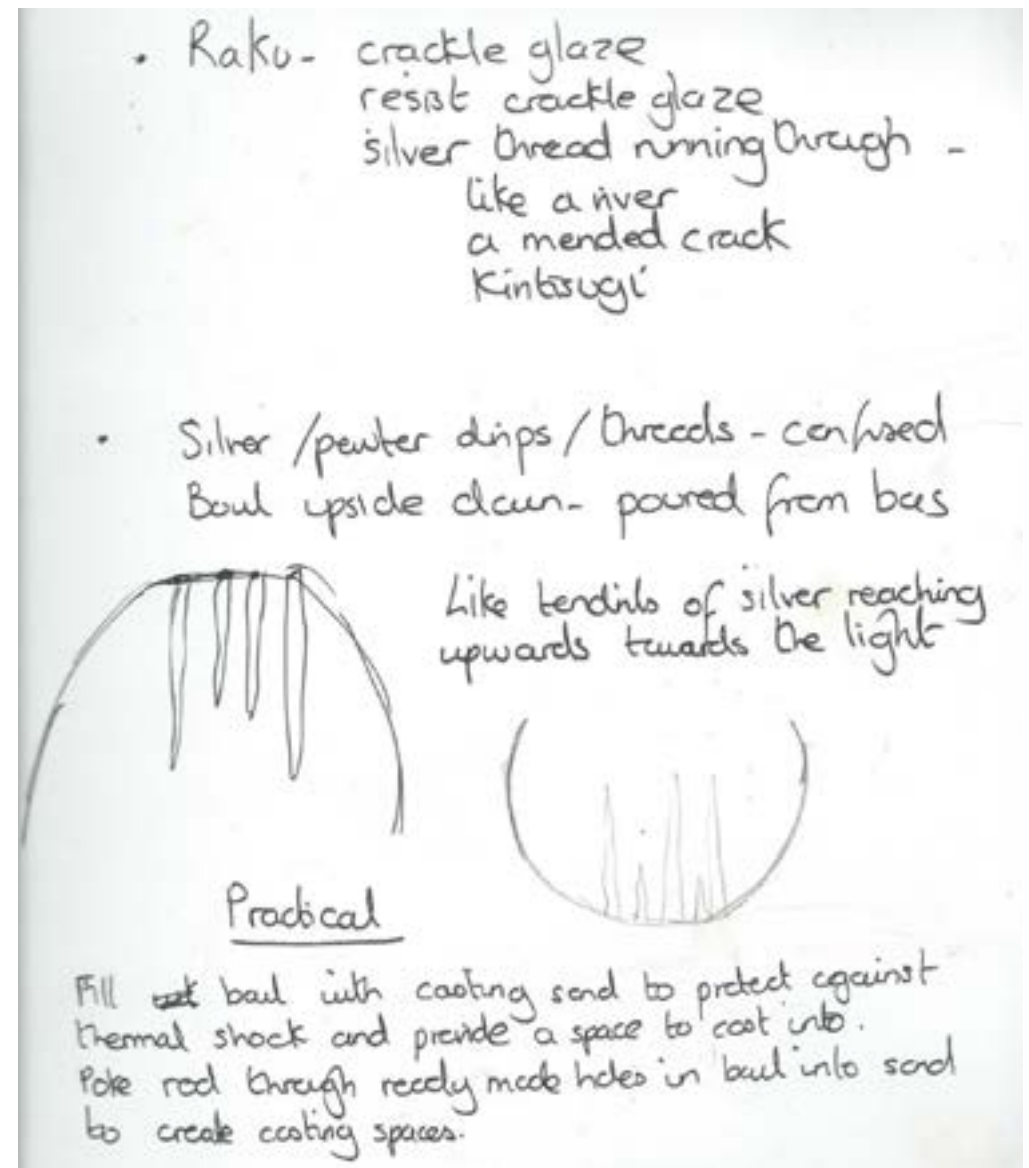
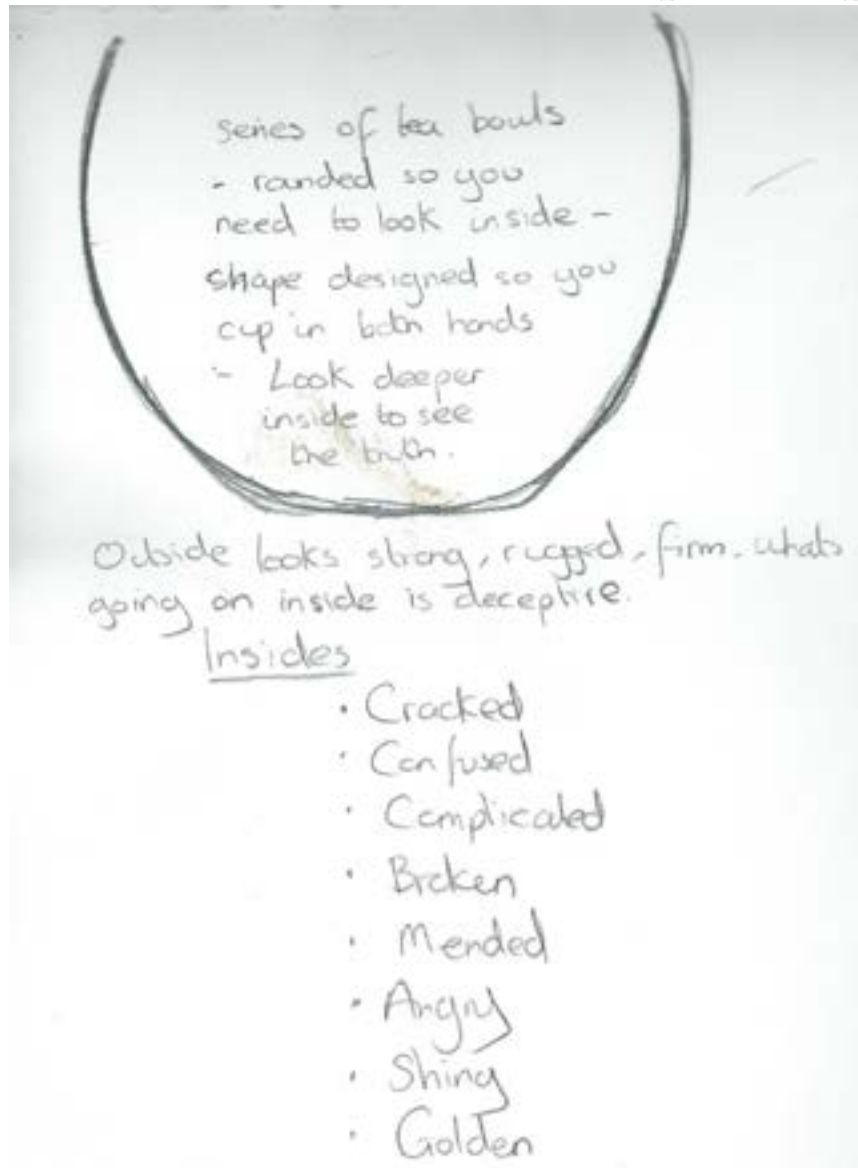
Emily Gardner

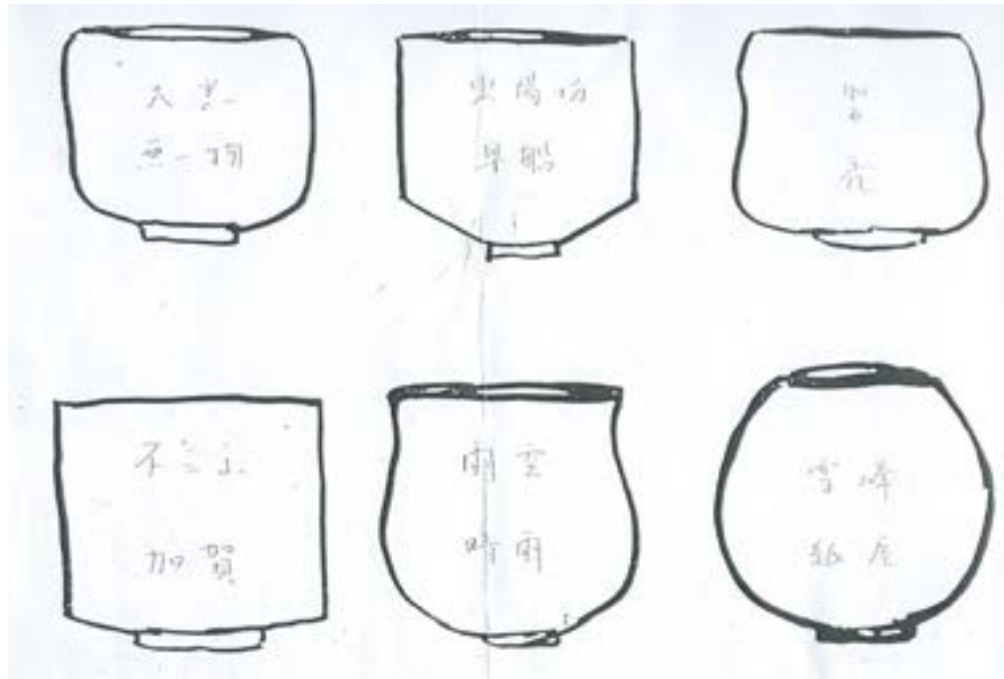


Margaret Curtis



I decided to create a series of tea bowls to look at these hidden internal spaces. The shape of a tea bowl means that the outer surface curves inwards, making it necessary to lift the bowl up or to peer closely from above to see what is inside





I used the traditional shape of Japanese Raku tea bowls made for tea ceremonies. I also followed the traditional method of hand building by starting with a ball of clay, making a rough form, then leaving it to become leatherhard before scraping back with curved metal tools. I used the Japanese tools that I had bought when on my research trip to Japan.



Each bowl shows a strong hard outer surface whilst holding a hidden interior. These inner spaces represent inner emotions and hidden symptoms. The bowls as a whole symbolise the urge to maintain a brave face despite what is going on inside and the tendency to hide our cracked and broken selves from the world .

Bowls 1 and 2

Bowls formed in black clay. Pewter poured through ceramic creating silvery tendrils reaching from the dark and into the light

Bowl 3

Bowl formed from black clay with inlaid cracked interior

Bowl 4, 5, 6, 7

Black and Raku fired bowls showing cracks and lines. A silvery seam runs along the inside - the hope in the dark, a crack mended to be stronger, more beautiful

Bowl 8

Cracked bowl with melted copper - chaos, destruction, anger, frustration



Bowls 1 and 2:

I began by testing techniques of pouring pewter through ceramic. I made simple vessels with holes in their base and filled them with casting sand, carving negative space through the holes and into the sand. As the pewter was poured, a plug was created on the base of the vessel which secured the metal to the ceramic.





Melting Pewter
<https://vimeo.com/217487601>



Bowl 3:

I made the third bowl from smooth black clay, then coated the inside with a thin layer of wax. The wax makes it easier to carve a thin, defined line. I drew a cracked design freehand, following the patterns from the cracked rocks of Andy Goldsworthy. I then applied white slip to the inside of the bowl. The wax helps the slip to flow into the engraved pattern and any excess slip can be easily wiped away leaving an inlay of contrasting clay.



Bowls 4, 5, 6 and 7:

For the next four bowls I wanted to embed a metal line along the inside of the form. I experimented with different ways of achieving this, not all of which were successful. My initial idea was to use silver clay; a compound of silver particles and binder which burns out at 750c leaving solid silver. Despite having previous success with this material in smaller pieces (pods), this did not work on the larger bowls. In conclusion, to work as an inlay the silver clay needs to be applied thinly to a flat or outward curving form. On an inward curve the shrinkage rate causes the material to warp and lift, remaining brittle and unfired where it is applied too thickly





I decided instead to cut the inlay from sheet pewter, and file and sand it to fit into the carved space. This provided a precise and affordable option whilst still creating the desired effect. I used paper templates to replicate the carved line precisely.





Bowl 8:

My final bowl looks at inner feelings of anger and frustration. Using layered clay, pushed deliberately into the space to create a cracked surface, I then laid copper wire and fired it to above the melting point of the metal. This encouraged an erosive, dramatic interaction of molten metal on ceramic to invoke feelings of high emotion





Exposed

In response to the 'Hidden' series I felt it was important to look at ways of moving forward emotionally. I wanted to create a series of open forms to look at what might happen if we exposed these inner vulnerabilities. By acknowledging and accepting our faults and cracks we can begin to own them, moving towards a state of acceptance. In order to support the structure of these forms as well as to maintain consistency I made a plaster mould. I rolled out slabs of clay and pressed them into the plaster to create the base of each piece.





I used Raku firing to explore the raw elemental impact of fire on clay, with contrasting spikes of pewter and strips of molten copper. Some of these forms express an outpouring of anger and frustration alongside a chaotic energy previously contained



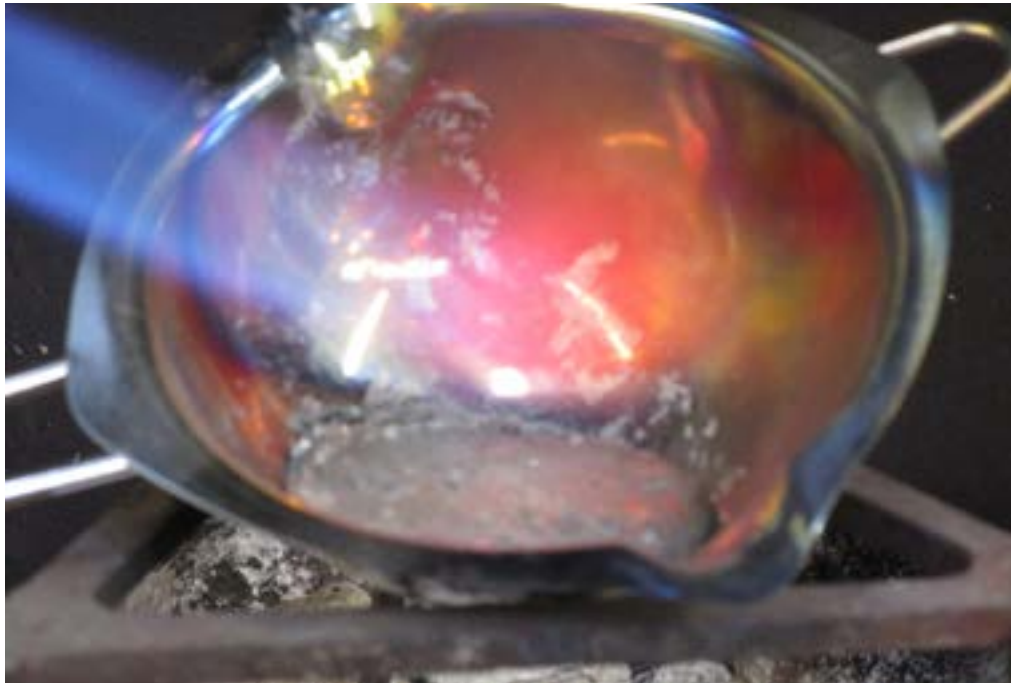






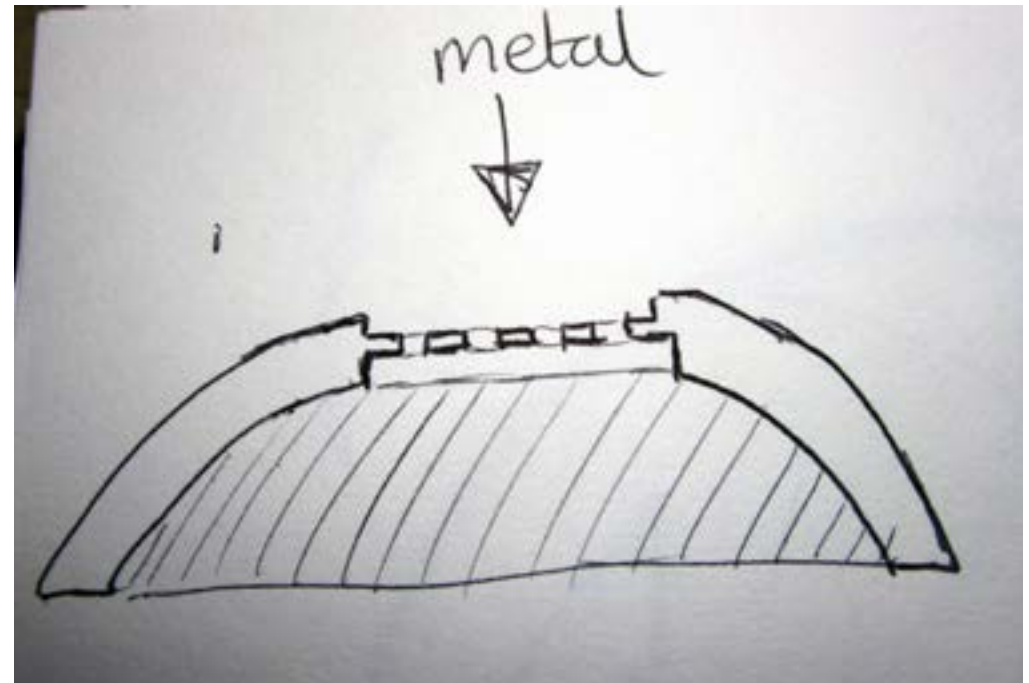
I also wanted to create one piece where the metal scars were more defined and controlled, suggesting a possibility of reaching a state of being at peace with our imperfections. I experimented with casting into plaster instead of sand, so creating more defined and controlled areas of metal inlay. My initial tests were with silver but this did not flow well into the plaster: the metal cooled instantly and did not travel into the space. My tests with pewter were more successful. When poured, the molten pewter filled the gap between the ceramic and the plaster creating a smoother inlay

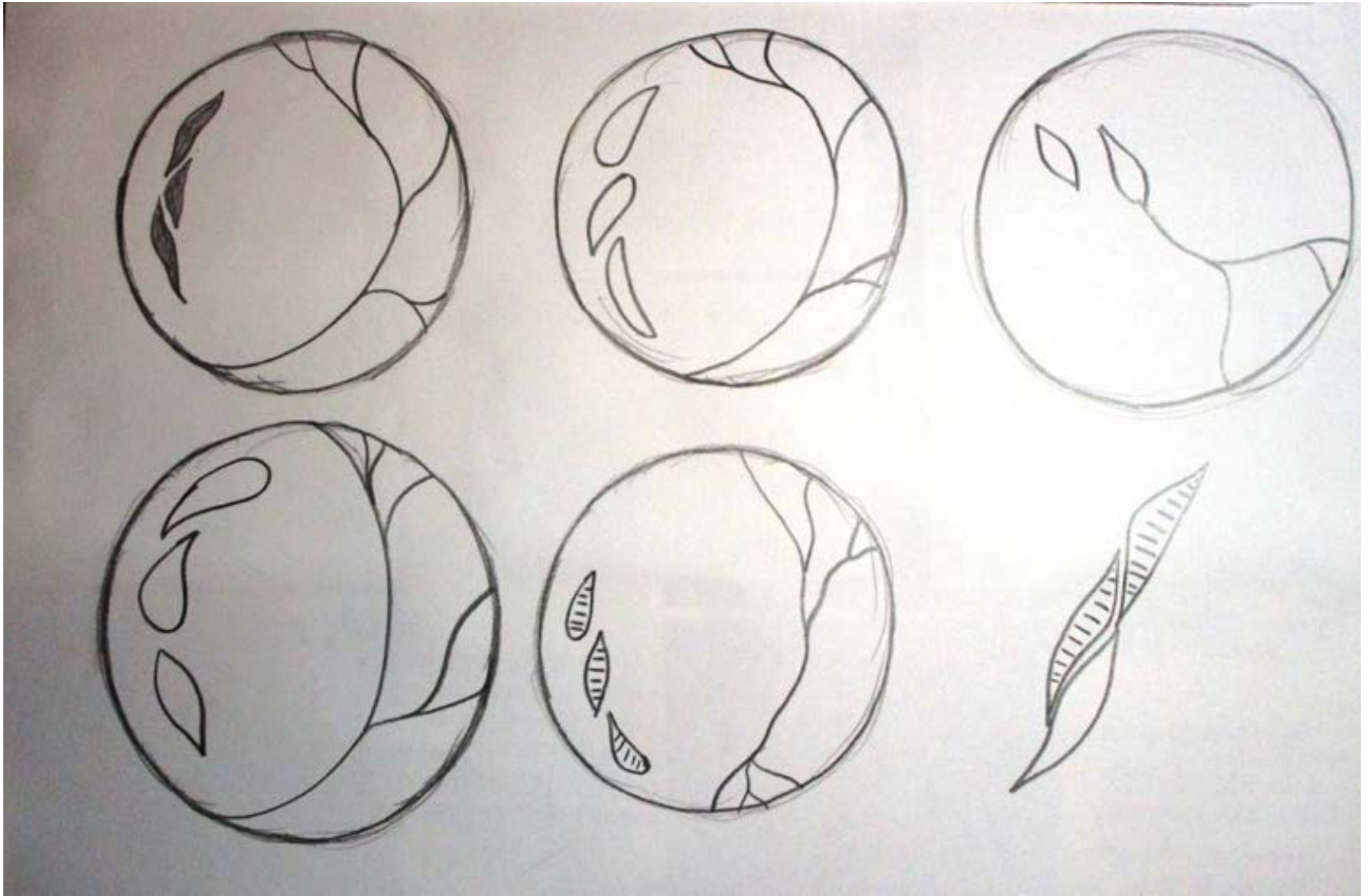






I wanted to push this process further, so began to carve into the plaster in the area beneath the ceramic. Again this worked well with pewter, the molten metal flowing to fill the carved out space, whilst creating a plug to fix the piece in place once the metal had cooled







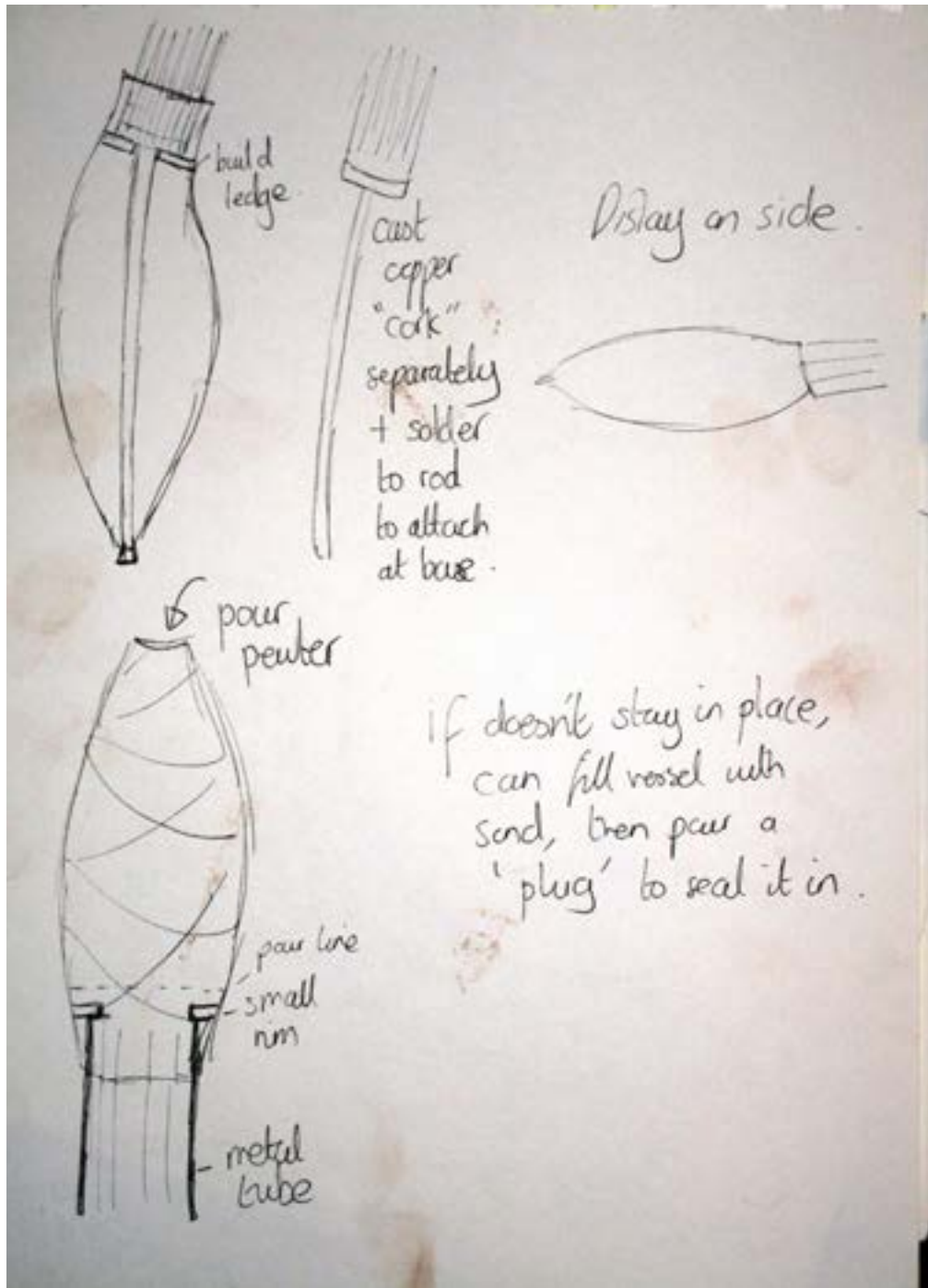




Emerging

For my final series I wanted to continue with the idea of reaching out from an inner place. When I recovered from M.E. it was a slow and tentative process of returning to the everyday world and a time of transformation

I used copper and pewter poured into sand to create delicate tendrils emerging from the enclosed safety of the cocoons representing that first precarious glimmer of hope











Identity

I felt it was important to create a piece to look at the challenges that rise regarding identity when living with a long-term health condition.

When you are no longer able to do the things you previously believed identified you as a person, it is easy to question your own integrity. We form our sense of identity from our experiences and life choices, but if choice is taken away by illness, are we still the person we were before or are we now identified by our current status?

Question to Social Forum:

How do you feel your sense of identity has been affected by developing M.E.?

- I have no sense of identity anymore. I refuse to identify with the person I have become & out of everything this is the hardest to deal with
- I found relationships particularly hard- I was single when I fell ill so felt that any new partners didnt know the 'real' pre-illness me that I identified with. It took many years to shift my perception of my identity
- I lost my identity. This was quite overwhelming, as it was as if I had nothing to show who I was. Once a palliative care nurse with passion for my job, life and position in my family this was gone. I gradually learnt how to value my self as a whole person and not just be defined by my job or family role. This was initially very challenging , but has taught me so much more about my self and also how I perceived others.
- Hugely. I lost my partner to it. I lost my ability to be sprightly and energetic and burn the candles at all ends. I developed an ability to show up more softly. I lost the ability to do recreational excercise. I had to stop teaching yoga. I had to stop going out at night. I went from a toned and sprightly size 8 to a busty curvy wobbly size 12-14. I went from having the energy to be a perfectionist about myself and my life, to being very much less crafted and much more just getting through and being real. I had to do more spacing out and writing to replace what i had been doing that was more exuberant. I aged about 25 years in one year. I developed more gravitas. I lost a lot of choice I was used to having in how I craft my life.

- At the beginning as things were lost one by one it was a blow to my identity every time. First my job, then driving, then some friends, then going out at all, choice and even decision making, all of these chip away at your soul and all of the things that make you what you are seem to disappear. Taken over by pain and discomfort and sometimes a little madness. You feel your place in society has gone forever. Over time you adjust (unwillingly) and try to find ways to bring some of your identity back within the limits imposed on you. I am generally a dulled down version of myself, I have these high flashes of excitement for the future usually followed by a huge down desperate fear I will never return. Loss of identity is anxiety fuelled and depressingly suffocating. I think it's especially hard when you have previously provided service to others that enhances their happiness. For me that was teaching and mentoring.
- This illness constrains me from expressing my identity. I am a hockey player who can no longer play hockey; a swimmer who can no longer tolerate chlorine, so can no longer swim; a teacher who can no longer teach in a classroom; a parent of adult children who can no longer guide and support them in this phase of their lives; a grandma who can no longer share her love of physical activity and crafting with her granddaughter; a DIY enthusiast who can no longer improve her home and feel the proud satisfaction of "I did that!"; a charitable worker who can no longer make a difference in the lives of those less fortunate; a doer of puzzles and mathematics who can no longer think clearly enough to figure out the tricky stuff. Intellectually, I feel like I shouldn't define myself by what I can or cannot do, but the reality is that we all express who we are in our actions and our words and how we treat other human beings. I don't have the energy to be who I am. I am not completely lost, but I am constantly making choices. But, the bottom line is that I am doing ok, within these circumstances, I am not housebound or bedbound. There IS some joy in my life and I am grateful for that as it enables me to tolerate my present circumstances and remain hopeful for the future.



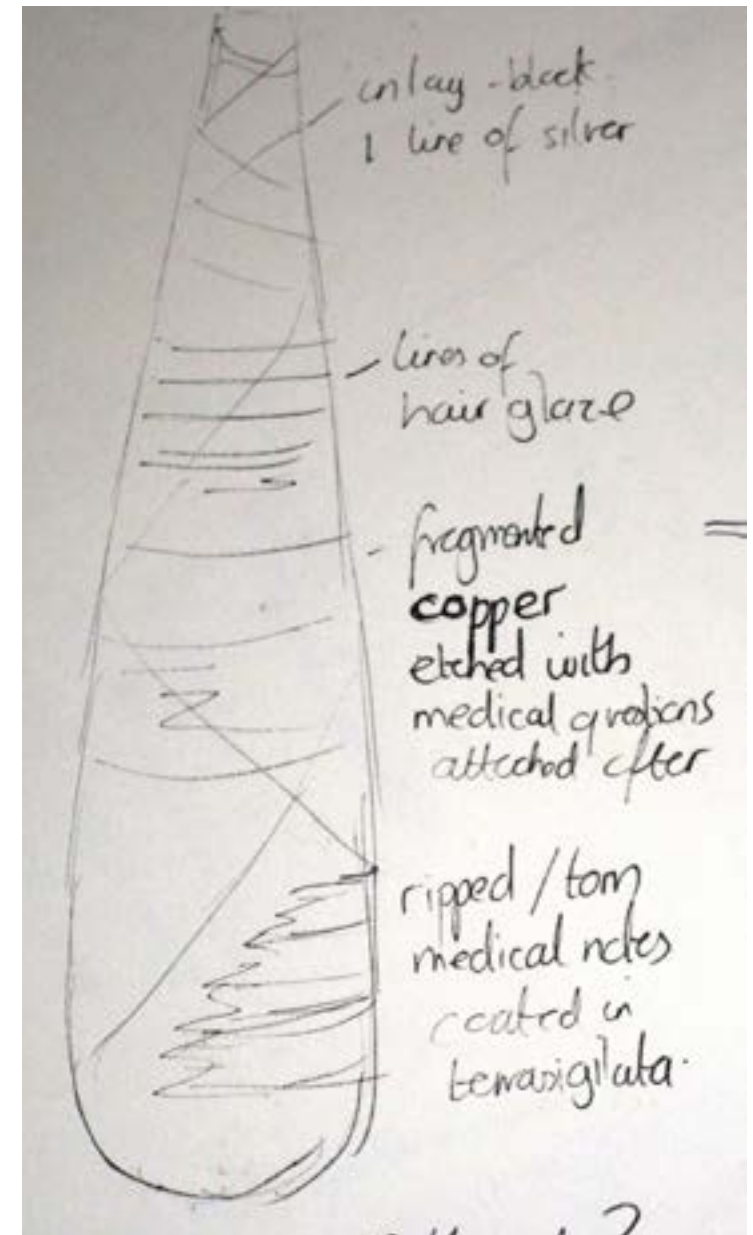
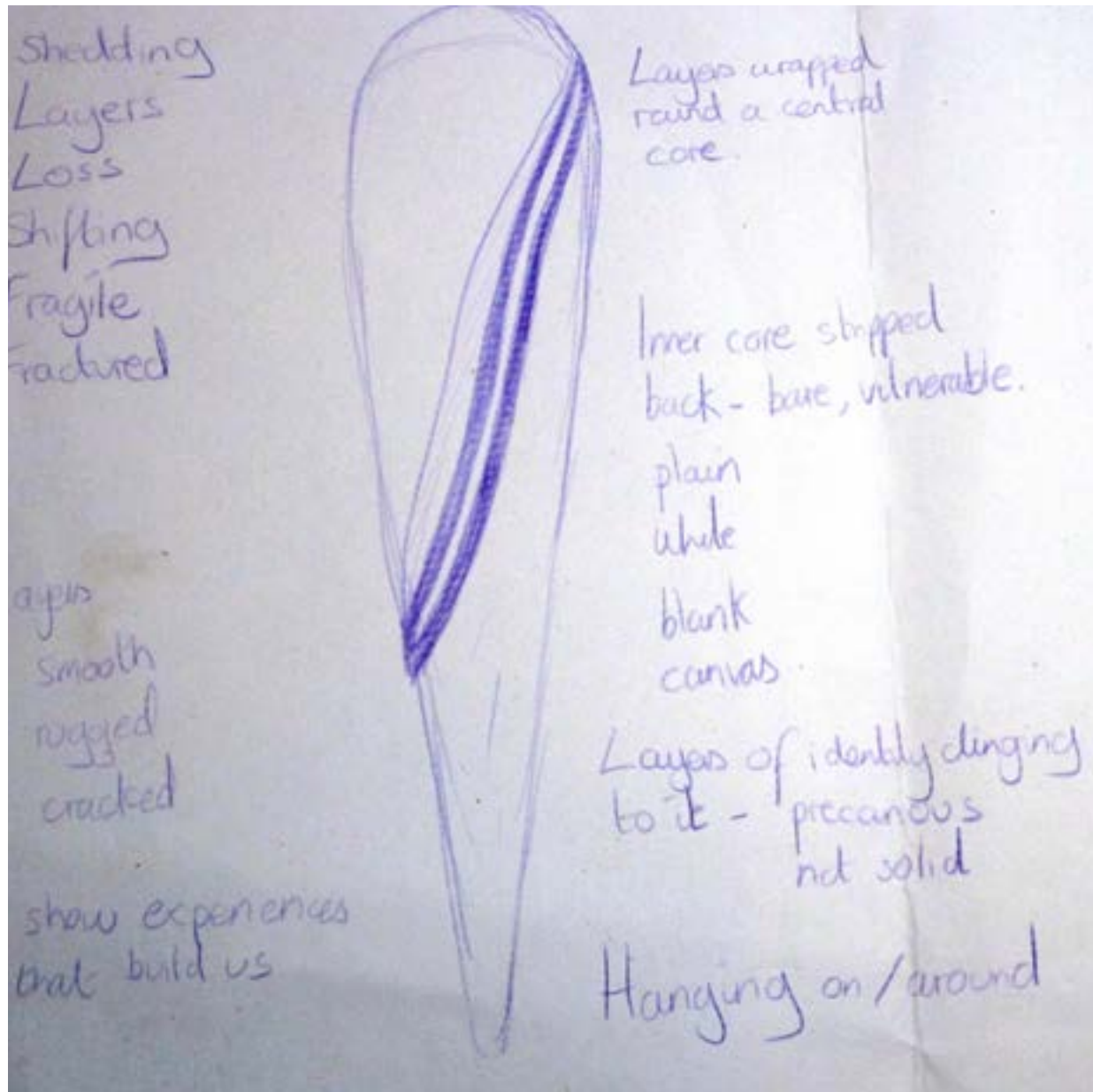
I felt that a piece on identity should somehow include an element that was personal, so began by exploring how I could leave marks and imprints by squeezing, holding and pressing wet clay - in particular using my hands to leave the impression of skin and fingerprints.



Owen Quinlan uses material inclusions to add texture and substance to his organic sculptures and I began to consider if I could incorporate significant materials in order to allow this piece to hold some of my own identity.

Owen Quinlan

I considered making a single form to represent my own struggles with identity and the many elements that I wrapped around myself whilst living with M.E.





I decided to make a tall, slender vessel to represent the body, to which I could include and attach materials. I made this form by throwing several large sections and then joining them together.



Burning My Hair

My illness lasted for 18 years, during which time I grew long dreadlocks. Towards the end of my illness I cut my hair off and kept it in a bag under my bed. I felt that this bag of hair held all the negativity and emotions that I had experienced whilst ill. It became a physical representation of the time which I felt unable to simply throw away. I decided that it was time to burn my hair and incorporate it into my work as a cathartic release and transformation from the negative to the creative. I mixed the ash with glaze and applied it to the vessel to create a textured ring around the piece



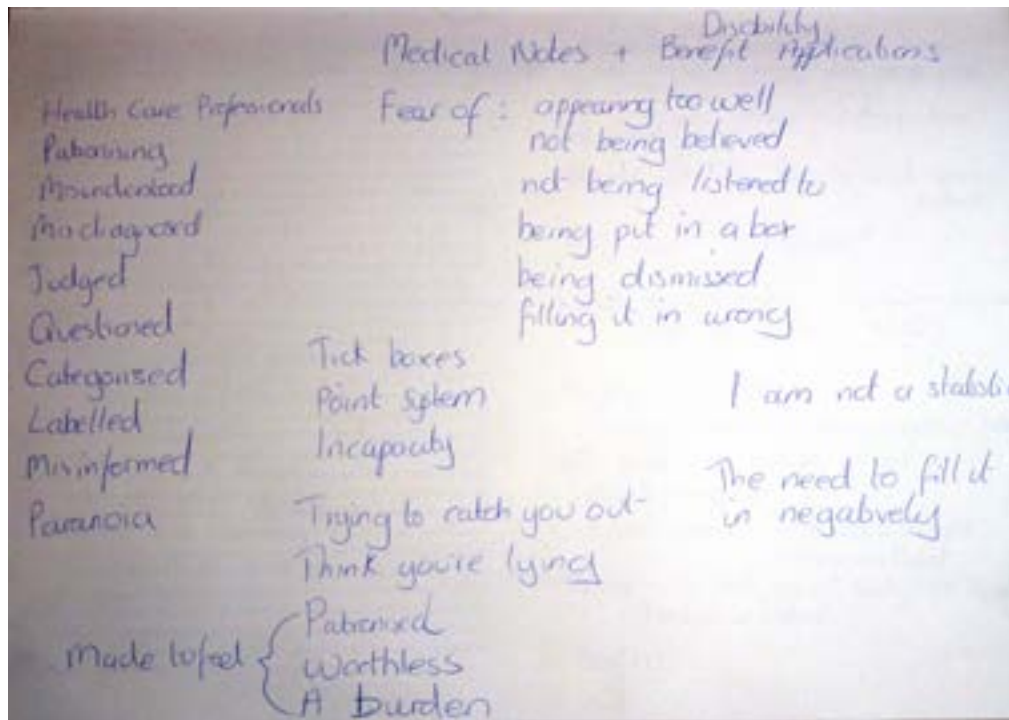
Burning My Hair
<https://vimeo.com/217544567>



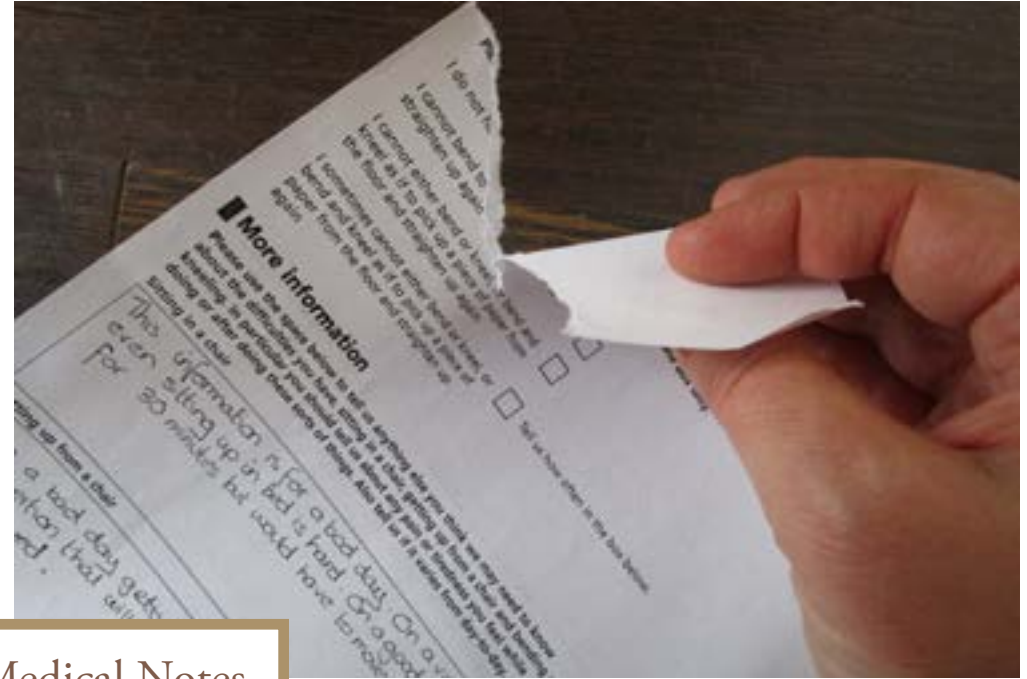
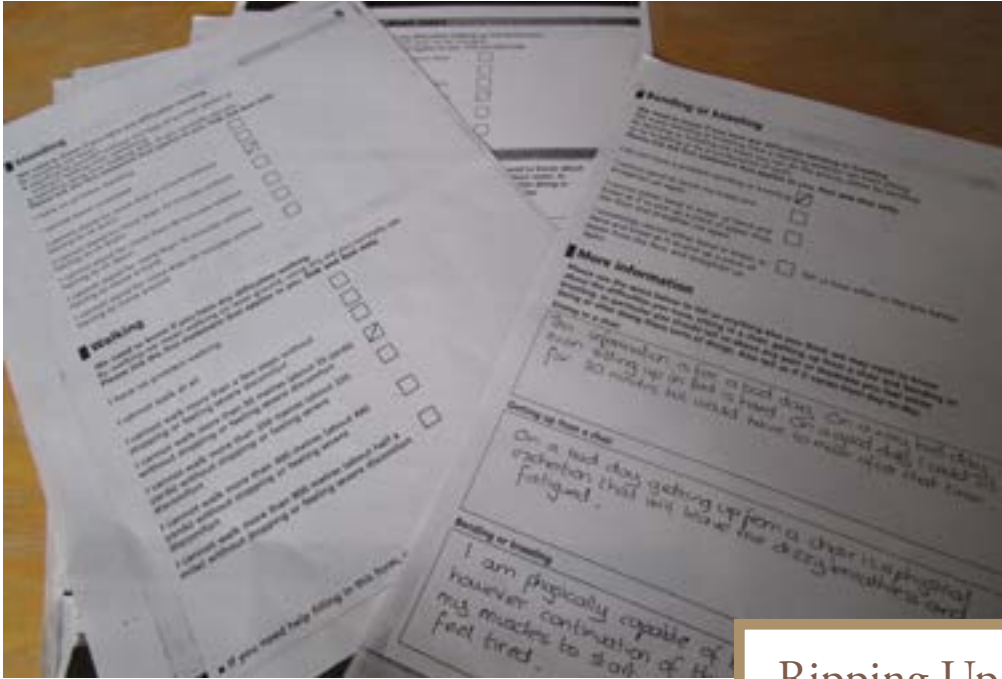


Ripping Up My Medical Notes

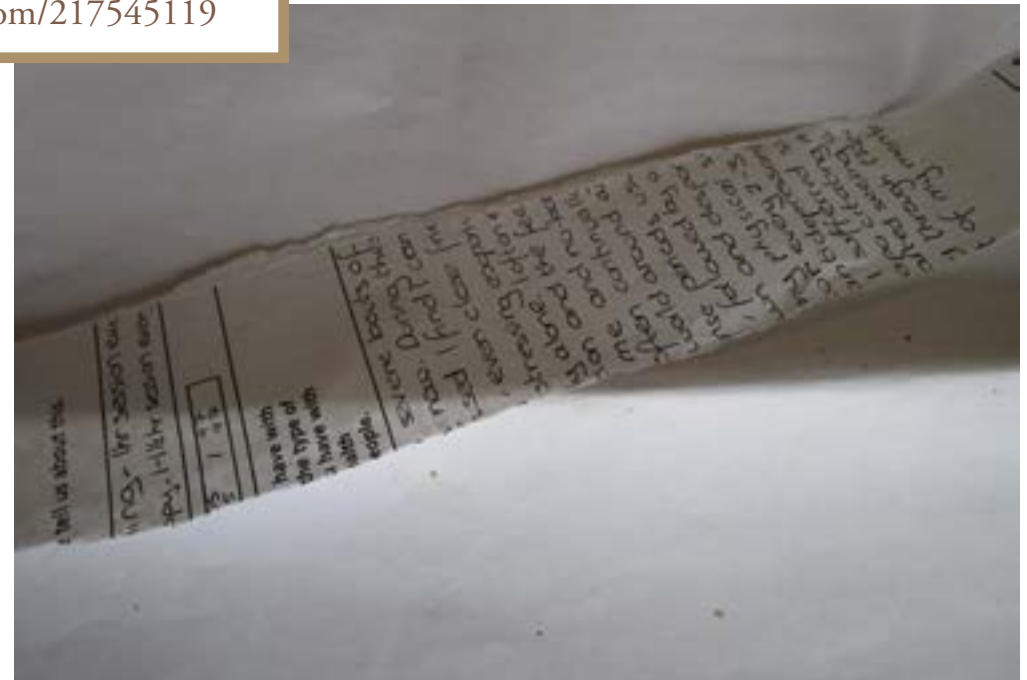
My medical notes from this period also held a lot of emotional baggage, in particular the questionnaires that I needed to complete in order to qualify for Incapacity Benefit. The questions asked always triggered a period of stress and tension due to the impact on my financial lifeline if I answered incorrectly, but also because they made me focus on the negative.



I collated a list of questions from the forms to use in another part of the process of making this piece, then I ripped the paper into shreds



Ripping Up Medical Notes
<https://vimeo.com/217545119>





I tested the effect of coating these pieces of paper with porcelain slip and firing them. The results were beautiful but extremely delicate and fragile.



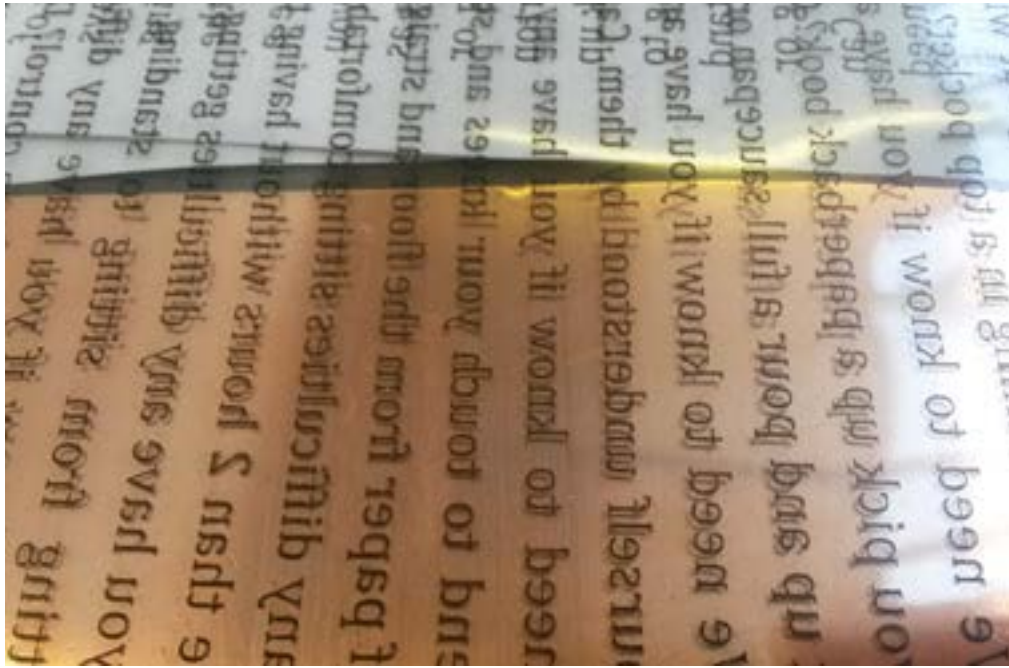


I wrapped the medical notes around the base of the vessel, coating them in slip, then sprayed a thin layer of glaze to strengthen the section. This had the unexpected and welcome result of making the print from the notes more visible. Although the paper itself had burnt away, it had left a still legible carbon residue which was accentuated by the glaze



I wanted to use the questionnaire information I had collated in a way that showed the impact these repeated questions can have on a person and the negative imprint they can leave. I decided to etch the text onto copper sheet, then wrap segments of the text around the vessel.

We need to know if you have any difficulties standing. Can you stand by yourself without the help of another person? Can you stand for more than a minute without having to sit down? Can you stand for more than 10 minutes without having to move around? We need to know if you have any difficulties walking. Can you walk more than a few steps without stopping or feeling severe discomfort? Can you walk more than 400 metres without stopping or feeling severe discomfort? We need to know if you have any difficulties walking up and down stairs. Can you walk up and down a flight of 12 stairs? Do you need to hold on to something, take a rest or go sideways and one step at a time? We need to know if you have any difficulties using your hands. Can you turn the pages of a book? Can you turn a sink tap or the control knob on a cooker? Can you pick up a 2 pence coin? Can you tie a bow? Do you have any difficulties reaching out with your arms. Can you raise an arm as if to put something in a top pocket? Can you raise an arm as if to put on a hat? We need to know if you have any difficulties lifting or carrying things. Can you pick up a paperback book? Can you pick up a carton of milk? Can you pick up and pour a full saucepan or kettle? Can you pick up a bag of potatoes? We need to know if you have any difficulty speaking to people or making yourself understood by them. Can strangers understand what you say? We need to know if you have any difficulties bending or kneeling. Can you bend to touch your knees and straighten up again? Can you pick up a piece of paper from the floor and straighten up again? We need to know if you have any difficulties sitting comfortably in a chair. Can you sit comfortably for more than 2 hours without having to move from the chair? We need to know if you have any difficulties getting up from a chair. Do you have a problem getting from sitting to standing without holding on to something? We need to know if you have any difficulties controlling your bowels or bladder. How often do you lose control? Do you think you have a mental health problem? Have you been treated for anxiety, mental health or illness? We need to know if you have any difficulties hearing sound? Can you hear well enough to follow a television programme with the volume turned up? Can you hear well enough to understand someone talking in a loud voice in a quiet room? Can you hear well enough to understand someone talking in a normal voice on a busy street? We need to know if you have fits or similar when you are



I used photographic etching to transfer the text onto the copper. The text is printed onto acetate, then transferred to the metal sheet which is coated with photographic paper. This is held under a UV light, exposing and fusing the areas around the text to the metal. The text itself is left unprotected and so erodes when the sheet is placed in an acidic solution.





I cut segments from the sheet to replicate ripped paper, then made small copper nails to attach them to the ceramic vessel. I wanted the copper text to appear wrapped and binding around the vessel, representing the restrictions I felt from this intrusive questioning as well as showing how we wrap fragments of our identities around ourselves.





The finished piece shows a single form, each segment significant to my own identity. Our life experiences are not always welcome but they shape us and make us who we are. Even those that seem cruel and harsh at the time can lead to building an element of ourselves that is stronger and more beautiful than before: beauty in the unpredictable, the broken and the mended.

Image References

All images have been photographed by myself except the following:

- Page 8 Postcards of Tea Bowls by Heads of the Raku family from the Raku Museum, Kyoto, Japan
- Page 11 Kintsugi: The Centuries Old Art of Repairing Broken Pottery with Gold: My Modern Met
<http://mymodernmet.com/kintsugi-kintsukuroi>
- Page 14 Photographed at Manifestations of the Mind exhibition, Kentish Town Health Centre.
‘Escape’ by Antonia Attwood
‘We Are Good People. We Are Struggling’ by Alisa Sinclair
‘Grief’ by Antonia Attwood
- Page 30 Sleep Positions: www.google.co.uk/imgres?imgurl=http://blog.downlinens.com/wp-content/uploads/2014/02/sleep-positions.jpg
- Page 43 Image from the #Millions Missing campaign. <https://millionsmissing.meaction.net>
- Page 53 Self Portraits by Marjolein Hoogendam <https://uk.pinterest.com/pin/384213411935402332/>
- Page 56 Image from the book “Stone” by Andy Goldsworthy showing ‘Clay Covered Rocks’ in the Haines Gallery, San Fransisco
Postcard collected from Art in Clay, Hatfield showing ‘Yunomi Stoneware Tea Bowl’ by Margaret Curtis
‘Deliverance’ by Emily Gardner www.emilygardiner.com
- Page 91 Unamed piece by Owen Quinlan. Photographed by myself at The Ceramic House, Brighton Open Houses, May 2016