

Living Alone with Cancer Explorations

An arts for health enquiry into the physical, emotional and financial implications of facing cancer while living alone.



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Cover image

‘A little bit broken but still a beautiful thing’

This painting was inspired by a photograph of a butterfly someone else had taken when it landed next to her, and her observation of how it was broken but still beautiful, like her. It really spoke to me. For my painting, I switched over the broken wing to the left side, to represent my cancer and mastectomy side. The drops coming from the broken wing are blood and tears, representing the physical and emotional brokenness I have experienced through breast cancer. I wanted to try watercolour for this painting (even though my paints are mouldy they are so old and unused), because of the delicate and fragile nature of both a butterfly and my emotional state.

Adriana Ford

About the project

This project formed part of a wider enquiry into the unique physical, emotional and financial implications of facing cancer while living alone (Tenovus Cancer Care, Innovation grants, 2016-2018). Eleven cancer patients took part in Living Alone with Cancer Explorations, an arts-for-health initiative where they produced creative pieces that reflected their diverse experiences. This involved writing poems, making drawings, paintings and sculptures, collating images and writing a narrative about which parts of their cancer journey these creative pieces represent. These pieces were then collated into thematic clusters on receiving a cancer diagnosis, going through treatment, resilience and life after discharge. We are using these posters in these images in teaching, research and public engagement events to start a dialogue with cancer care students, healthcare professionals, patients, carers and members of the public about living with cancer. We have found that art offers a unique starting point in engagement because healthcare professionals, relatives and members of the public initially connect with the aesthetic element of the art and then dwell into the message it conveys, thus creating a strong emotional reaction that triggers self-reflection as well as a wide range of conversations.

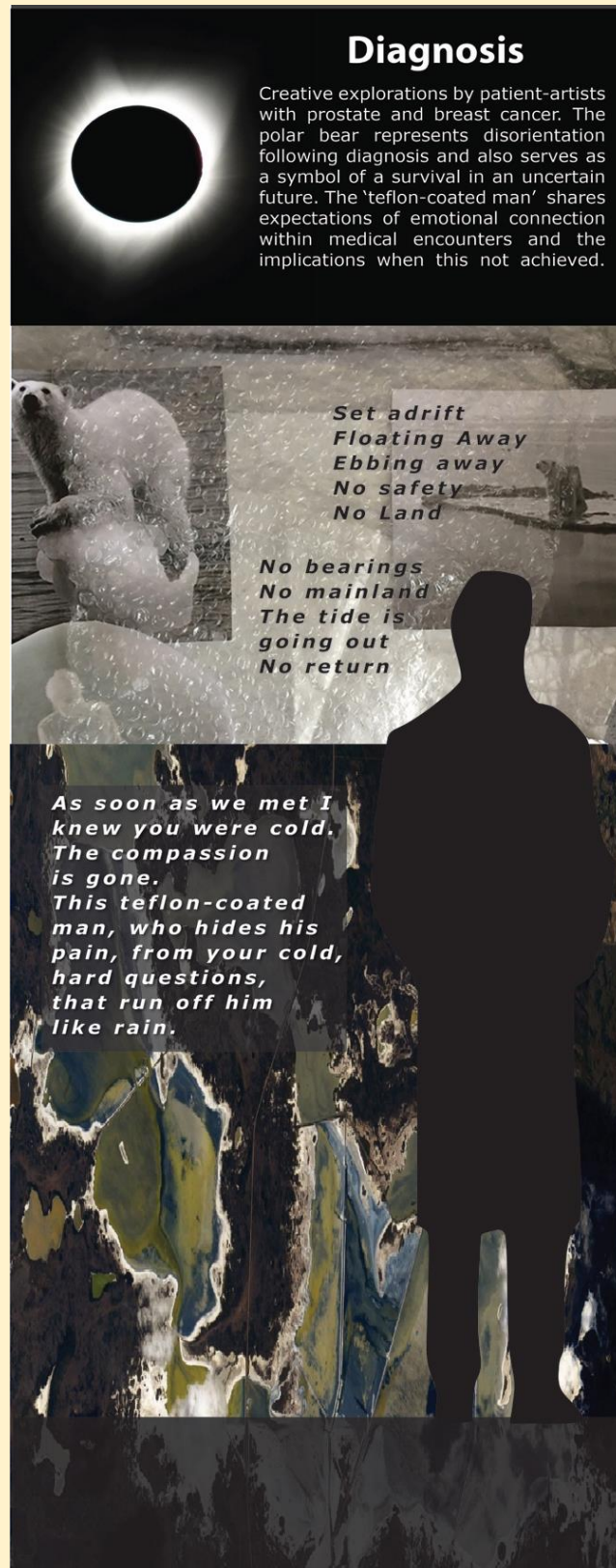
Cancer diagnosis and treatment often have significant negative impacts on people's lives long after the end of the medical treatment. Partners and families are often seen as the main source of support for people living with cancer however little is known about how people cope when living alone, particularly in areas of high isolation and deprivation. The aim of this study was to examine the effects that cancer diagnosis and treatment has on people living without co-resident carers. This group of patients includes single people, single parents, people who are divorced and those who have been bereaved.

Our study participants had experienced kidney, breast, prostate, ovarian, thyroid or oesophageal cancer. Their age ranged from 35 to 71 years of age. Years of living alone (without co-resident carers) ranged from 2 to 38 and four participants were single parents. Communication with oncology healthcare professionals regarding diagnosis was reported to be particularly problematic. The main physical implications reported were fatigue, difficulty in doing household chores and preparing meals. This was particularly acute shortly after surgery. The main emotional implications reported were feelings of loneliness, depression and anxiety about the future. The main financial implications reported by people in employment were reduced income as a result of reducing hours of working to cope with fatigue. Participants reported resilience regarding the new reality of 'living *well* with cancer *and* alone' and had developed coping mechanisms for dealing with fatigue, depression and reduced finances. Cancer healthcare professionals working on cancer patients' holistic needs assessments could pay particular attention to the psychosocial needs of those who live without co-resident carers and signpost them to appropriate sources of support.

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Diagnosis: the importance of communication



Am I going to die?

When you are told you have cancer you are reminded of your own mortality: the first question you ask yourself is am I going to die?? You can see that same question being asked on the faces of your family and friends-- and so you take on this fight this battle you never wanted because you have no choice. That's what it is a battle for survival the road ahead is littered with pain, doubts and sometimes grief: the uncertainty of the outcome invades your mind, sometimes peace of mind is hard to find - amongst the drugs, chemotherapy and the surgery, the things you have to do to win a fight against an enemy you never see.

This poem is about a medical folder that was left on the side of the bed.

*I didn't want to look
I didn't want to view
The different scenarios
That could come into view*

*There lying there
Upon the bed
Daring me to open them
To run around
Inside my head
To cause chaos
To cause dread*

Once released out side

The box

No control to take

The knocks

The knives are

Blunt

The wounds not

Deep

Just deep enough

To cause me pain

That I can live with

And get up again

The loss of blood

Not too great

The blood congeals

The scars don't

Heal

The space where fear

Normally resides

Is empty now

No tourniquet can stop

The flow

No Compromise

'It's almost certain you have CANCER'

*I sat in the consulting room
With my red socks as company
'It's almost certain you have CANCER'
Is what the doctor said to me*

*There are tigers; there are pussycats
Mine is the aggressive kind
On hearing this, my world collapsed
I momentarily lost my mind*

*I'd been SUPERMAN, personified
Invincible - or so I thought
Everything I'd achieved
Seemingly, reduced to nought.*

To trust a doctor or not?

Denial

I was in denial the moment I felt the pea-sized lump. I was too stressed at work to deal with it and it came and went with my cycle, so it was only once I had quit my job a few months later that I found the time to make a doctor's appointment. Denial then went into overdrive.

My world collapses in

We are told we should trust doctors, but having finally experienced a number of them on my cancer journey, I have discovered that most of their hearts are in the right place but their knowledge is not. Are they trusting what they are taught or questioning it? What system have they been sucked into?

Percentage This, Percentage That

You are bombarded with so many percentages you are repeatedly told that your five year survival relies on you doing as you are told. I knew no one with cancer and those I knew who had loved ones die from it, they were at the six year point - so I didn't understand why FIVE years was the figure bandied about. I wanted a percentage for FORTY year survival.

Information Overload

The doctors can tell you as much as they want and you come home with a bag full of leaflets from Macmillan. Reading it all and looking for the straight facts that you want listed out for you is impossible to achieve alone as I discovered. You keep wanting to find the leaflet that just tells you straight what you should do. As none of them were answering my questions, just making more questions, I became even more confused.

I am a Person, not a Disease

From my pre-op for the lumpectomy, I discovered I had a hole in my heart. I discovered that that cancer didn't worry me, the hole in my heart didn't worry me, but the fear of lymphedema in my arm was petrifying. At no point did anyone want to help me with my fears. Percentages were just thrown at me to confuse me more. Not once was I given help that helped me.

Learn to Listen to Yourself

I remember my instinct was to not have the lymph node surgery as that was my biggest fear. I had no counselling to see if I would be able to deal with the aftermath, I ignored my intuition, as that is what I had learnt to do, and convinced myself I would be fine and that no nodes would be removed. I later found out that even the one sentinel node removal for testing could cause lymphedema. Why was I not told this?

Avatar

Paramhansa Yogananda explained that the term avatar refers to a soul who has been freed from maya (delusion) and is sent by the will of God back into manifested existence to help others. An ex friend, when I said that they would inject blue dye into me to highlight the lymph nodes, said I would be an avatar. A bit more sexy than a smurfette I think. I was told I would be blue for 12-18 months. I am still blue nearly 3 years on.

One Lump or Two?

After having a mammogram, an ultrasound and a biopsy where they couldn't get the needle in the tumour, eventually leaving me black and blue, I was told I had one tumour and a lumpectomy would be done. They get you in for surgery before you have time to look into options. A target to hit perhaps? You discover on waking that you actually had two tumours. A grade 2 invasive mucinous carcinoma and a grade 2 invasive ductal carcinoma were discovered. So was the mammogram wrong or did the biopsy spread the tumour? Because I had quit my job a month before, I was much happier, eating better and exercising more, was my tumour encapsulating? Is that why they had a hard time doing the biopsy? Was the mammogram correct and did the biopsy spread the cancer cells? I am learning that no one knows, so why do they try so hard to convince us that we should believe what they tell us. I was told because of my age, breasts are dense, so mammograms are not accurate, in which case why is this inaccurate, outdated technology being used? So my smaller breast is now even smaller!!

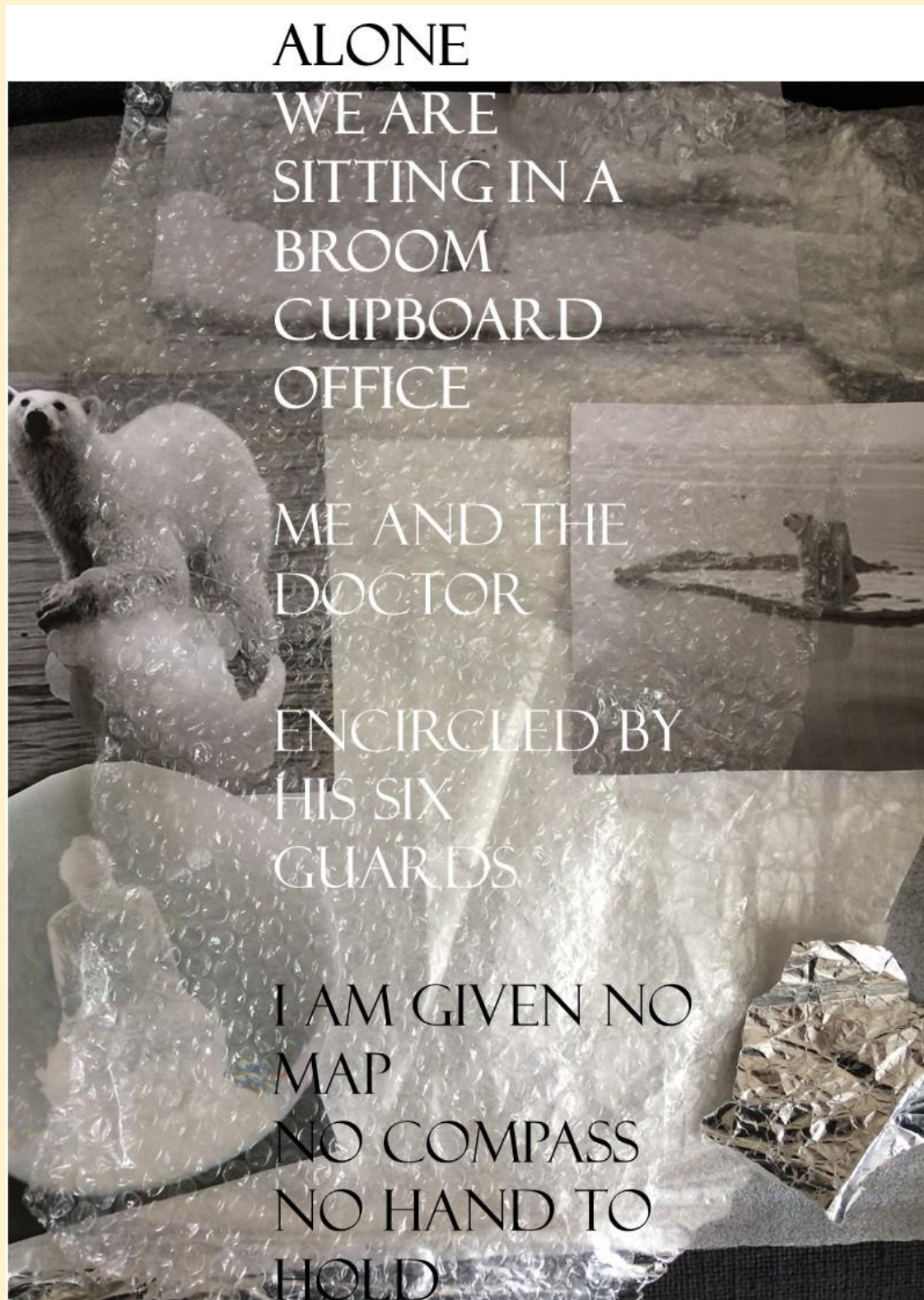


The GP, The Life Saver

The GP role is a really important one. For me, if my own GP hadn't been so good and I had listened to his colleague - who I saw while he was on leave and was really dismissive - I probably wouldn't have got my early diagnosis. I have met many people since then who had been turned away, their symptoms dismissed, by their GPs - some on several occasions - whose cancer as a consequence was more advanced and so less easy to treat. I have also talked to many people affected by cancer who - because of the pressures of life, work etc. - only went to their doctor because their partners insisted they did so. If you live alone there is no-one else there who sees you day to day to make you go.

*Thank you doctor
For listening to me
For showing understanding
For treating me like a person,
Thank you doctor
For taking me seriously
For looking me in the eye
For ordering the tests
Thank you doctor
For not giving me
Empty reassurances
And platitudes.
If not for you,
I could have carried on
Accepting the symptoms
Until it was too late!*

So alone



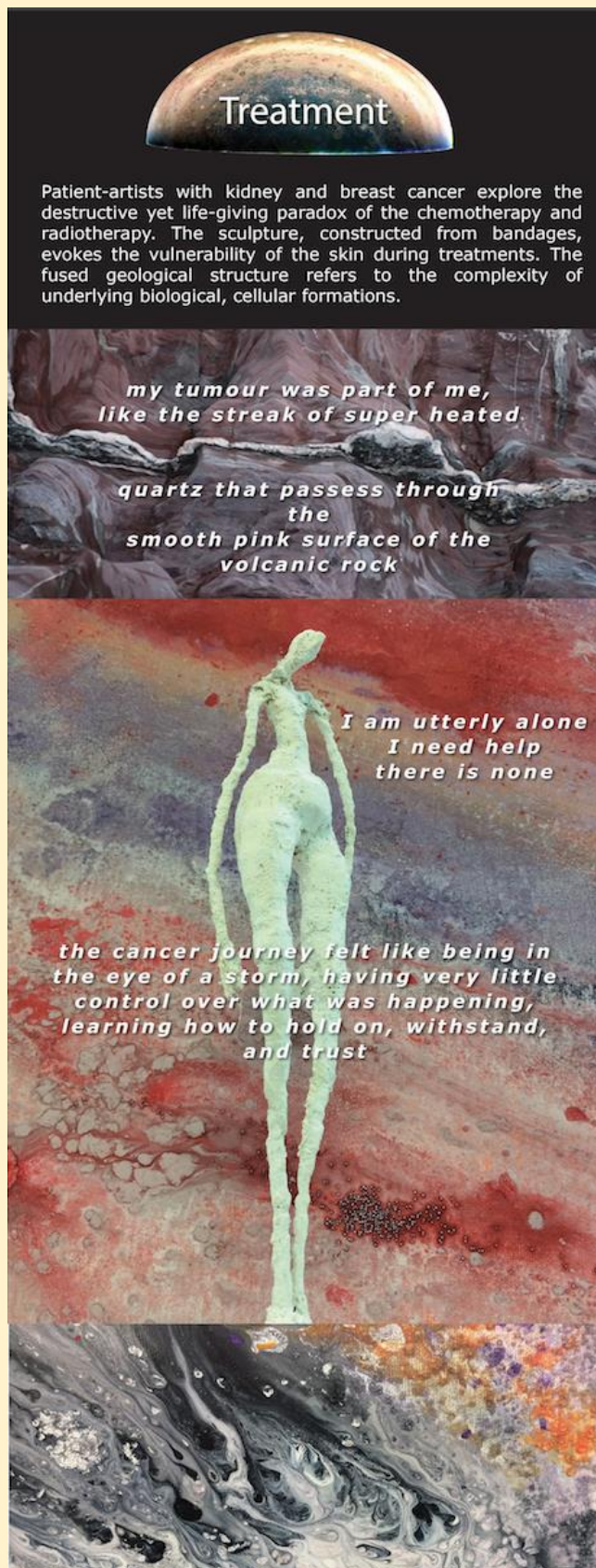
I was alone at the diagnosis appointment in a very small room (think a broom cupboard with a filing cabinet...). The other 5-6 people were leaning on the walls. One was a breast care nurse from the card she gave me in whispered words when I left the room. It was a kindly gesture but seemed she had stepped out of normal protocol. More information on options would have been much more useful.

I don't remember anyone introducing themselves or much eye contact. Who were these people and why were they there? I could see the consultant was uncomfortable. The only question I could think of was 'Am I going to die?'. He said none of us know when but that he could walk under a bus tomorrow. That throwaway comment was the single most unhelpful response at that moment. If it is supposed to show how we are all in the same boat it didn't help.

It could have been an opening to some sort of information about grades, stages, treatments etc which I would have really appreciated but I was ignorant of these and so didn't know what to ask. He did attempt to be human and ask if I had children. Despite the weirdness of the meeting I am grateful that I was operated on 2 weeks later. Luckily, I had to be referred to another hospital as this consultant was going on holiday so I had a much better experience afterwards. I can thank him for the quick referral. I wish I had had someone with me at the meeting as I felt very alone.

The image of the polar bear came in a conversation I had with a loved one when I was trying to explain how I felt. I felt I was drifting away from someone I loved and who loved me, no longer counted among the general population on land. This illness was separating us. It was borne of a deep sadness. This was in the days after my operation and before I had the results of the analysis of the tumour they removed.

Going through cancer treatment



Oh cancer what are you doing to me?

*Oh cancer, oh cancer
What are you doing to me?
I'm told I can't get rid of you
How? - do we live in harmony?*

*You're always there, inside of me
When I'm asleep, or, wide awake
It's as if we're joined at the hip
Being together, without a break*

*So - what's the point in having cancer
If not used in a positive way
Since then, my mission has been
To have men tested, for their PSA*

*I've done the watching and waiting
I've received Hormone Therapy
But - now the time has arrived -
It's onto Radiotherapy*

*Before I had Radiotherapy
Some thought me - rather superior
Well, now, it's fact, I can confirm
The sun shines from my posterior!*

*'You've always been a shining light'
A friend made such a remark
'Now it's true, for all to see
Your derriere glows in the dark'!!*

I had no battle with cancer



This volcanic rock is beautiful because of its colour; the smoothness of its surface and the shapes that have evolved with heat, time and the sea.

My body is the same.

My tumour was part of my body's evolving nature.

I had no 'battle against cancer'. My tumour was a part of me, like the streak of super-heated quartz that passes through the smooth pink surface of the volcanic rock.

I was gentle to my cluster of abnormal cells and worried for my body because it had gone astray. I needed to go inside myself and gently enquire why things were going in that direction.

I chose treatment because I didn't have the space and time to talk to my body.

The poison that was pumped in to my vein became sweet nectar that bathed the millions of cells in golden light before it ultimately destroyed them.

I am grateful to my tumour. It made me stop, evaluate myself, my son and my life. I was not living a life suited to the health of my mind and body. It has taken four years of 'stopping' to delve ever deeper in to my very existence in this universe.

I am stardust after all.

Ups and downs



Looking back 8 years on April 29th 2009 my life had a blowout. I was diagnosed with oesophagus cancer. Life is like the board game snakes and ladders. Life began again for me at square 1 on the 29th of April 2009. The photos are of my achievements since then as you don't take photos of your failures...The mental mountains I had to climb and the many ways I tried to adjust to a new me and a new way of life. The things I've learnt along the way and the random snakes and unexpected ladders that presented themselves.

The ones at the funerals show funerals at different times, I kept losing friends, people that had been with me on the journey. So they disappeared...If you survive and you survive it, you want to thank your lucky stars because I didn't fight any harder than the others. We all fought just as hard too, somehow my body and the chemo and everything worked, and for them it didn't.

SQUARE 12 - *Things aren't always what they seem, a situation that looks boring and ordinary can be the jewel you need or the key to a new life if you just see it in a different light, this picture is actually a plain grey cotton vest top which cost a £1, under a black cardigan, but in the photo, which I took by accident, it looks like a glittering necklace. When I saw the image a few days later it made me realise that situations have silver linings if you just see them differently.*

Worry and depression: an inward scream



The image in my mind trying to cope with issues in the period after surgery was Edvard Munch's *The Scream*. It captured my anxiety, the chaos and inner turmoil. However, I didn't have the energy to scream. Instead I felt bowed down, deflated, manipulated by events.

The figure is part human body and part artist's mannequin which can be twisted into different shapes representing the feeling of being manipulated by others and by events. The background relates to that of *The Scream* with constant white noise added. The twisted wire and cord is the tangle of thoughts and worries to be battled with. The crystal in the drawstring bag represents the spirit or life energy trying to emerge from the tight grip of the darkness within.

Being able to see what's happening



The scan is my internal landscape. It's important to me to know what's going on in my body and because I'm a very visual person, to have a scan, to actually see the cancer, made a big difference. I'm not sure why - but it makes you more comfortable about what's happening. If a consultant shows you that and explains everything it puts your mind at rest to a certain extent. I mean you've obviously still got cancer so that's pretty bad, but to know what's going on and to see, actually see what's going on in your body, to me is really important.

The value of caring to people affected by cancer

Thank you to family and friends for your faith in us, for your help, support and love at the darkest of times: my poem is called My Gift to You-- because you are a part of the gift we have been given - the greatest gift of all - life.

This timeless peaceful place

Washed over me

My mind set free

To say the words that means so much to me

Feelings kept close to my heart

About the present and the past

The doubts and fears I have gone through

That brought me to this Majestic place

You think of me when I'm not there

You wonder how I am

You care if I'm all right and doing well

Your gentle thoughts reached out to me

At a time in my life when chaos showed its hand

You helped to set me free

To talk about the things

That means so much to me

A value that seemed lost

Is once again restored

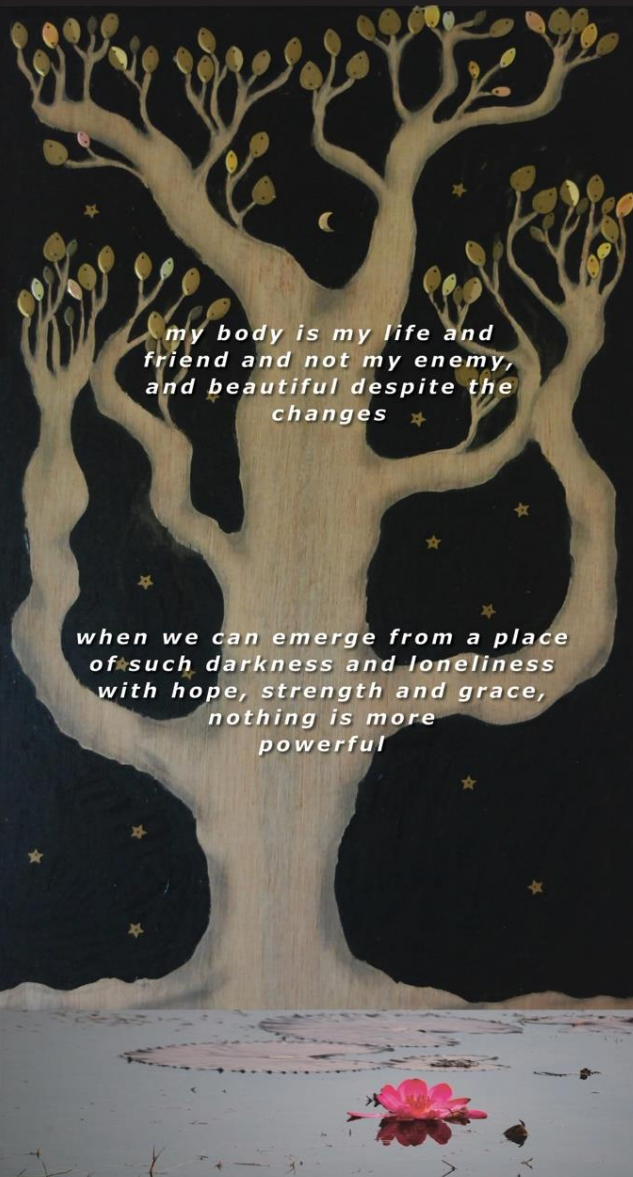
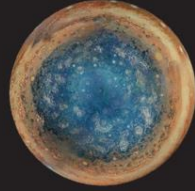
*I really am so proud of you
The things you say and do
The times you've helped me*

*Battle through
You took the time to listen
To understand
You reached out a hand
To stop me falling
If I am down you
Help me up
And brush me down
With words and deeds
That helped me see
How much you mean
To me*

Life post-discharge: changed bodies, changed lives

Post - Discharge

Patient-artists with breast cancer connected powerfully with natural forms. The stark tree with luminous leaves depicts physical and spiritual nourishment. The lotus flower arising from mud represents resilience. Artists also shared a cosmic perspective by exchanging images of Jupiter from the recent mission and photographs of Earth taken from outer space.



Feeling grounded, not free anymore



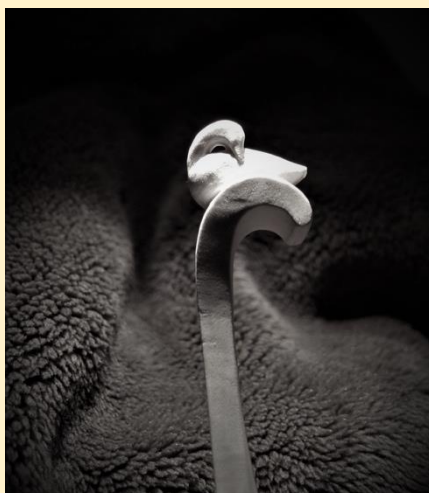
Before my diagnosis and treatment I spent a lot of time with ravens on the mountain ridges of Snowdonia.

I would soar high above the crags, catching the wind as it was lifted up the dark cliffs, diving, flipping, feeling the wind with every outstretched feather.

After my treatment I was grounded and could only watch from a distance as my majestic friends flew the high ridges. I could no longer join them in their free flight.

My four year check-up found no trace of cancer, and since my last clear results, I have felt a shift in my outlook.

A pair of ravens fly in to my garden and I hear their call. For the first time since my diagnosis I believe that I will, once again join them.



Going back to work after treatment

I was put under intense pressure at work, my fears, worries and depression got deeper and deeper, and self-doubt and lack of self-worth took hold. I felt trapped – alone – trying to fight my way out of this morass, but powerless to do so. My world felt like it was caving in, my whole life felt worthless, everything I'd done, everything I had strived for was thrown back in my face, I felt useless, a waste of space! This wasn't just the cancer, but the effect the cancer was having on my way of life as a whole.

Loneliness and pain



The sculpture is all about loneliness and pain, it speaks for itself by its demeanour, by the way the shoulders are slumped and the head is down... made with plaster and plaster bandages.

Eating away at my inside



The 'rotten' light-weight form of this driftwood spoke to me of not-knowing if the cancer is there - eating away at my inside.

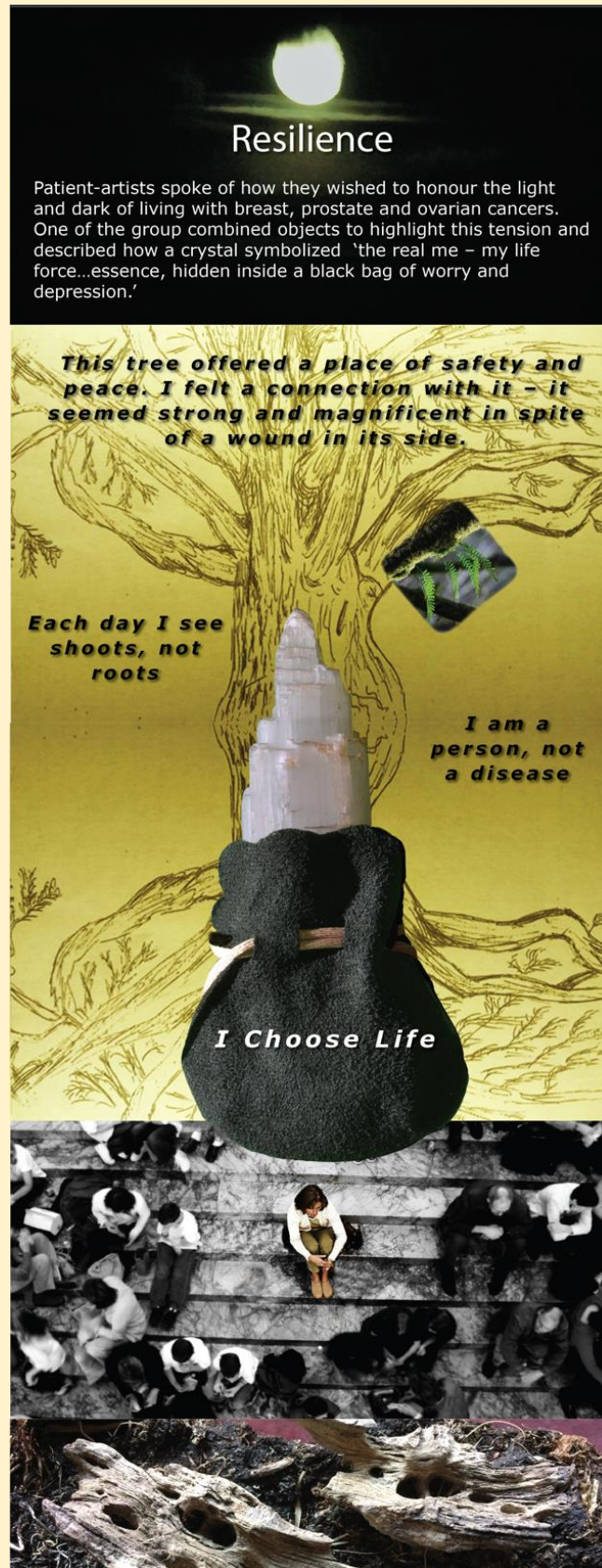
The essence under the hard and ugly cover



The acorn cups resonate with me, from the outside they are hard and ugly but those golden cups are the very heart of the tree - they hold the seeds of her life together, until they fall and start again as we all do.

We live in a world where everything is so quick and fast-moving we can miss the small detail. You don't need a hammer to crack a nut, but sometimes people need a little bit of help or a nudge to help them focus.

Resilience: learning to overcome adversity



My body Is my life and my friend, not my enemy



Healing with Gold

*I didn't hate my left breast, I still loved her.
She was part of me and I dreaded losing her forever.
She would be resurrected from the ashes, like the Phoenix.
That's what I called her, the new one, Phoenix.
My spirit had to become the Phoenix too.
From being broken down I had to rise high.
Well, I didn't have to, but I chose to. I chose to look to the light above me.
I'm being healed with gold, like the art of Kintsugi.
What was broken will be more beautiful.
I love my new body, she tells the story of a warrior.
My body is my life and my friend, not my enemy,
and beautiful despite the changes.
I was given a second chance,
And I'm in awe of how strangers mended me.
They are forever a part of me now.
As I grow from the broken cracks, healing with gold,
There will be a day that I will be at peace,
The pain an echo only.
It's a day I long for.*

The healing journey



The natural world became an important part of the healing process for me – being close to nature became a way of releasing some of the emotional turmoil and stress that resulted from my diagnosis. This tree offered a place of safety and peace. I felt a connection with it – it seemed strong and magnificent in spite of a wound in its side.

Invincible no more



Image 1

Before diagnosis I felt healthy and did not realise there was anything wrong.

When I heard the news I was shocked, anxious and low.

A friend helped by arranging a second medical opinion for me.

Image 2

Following surgery I was anxious about the symptoms I was experiencing such as loss of voice from temporary vocal nerve bruising.

Once I started recovering I became anxious about the scar on my neck.

Friends and family came to the hospital and helped me at home initially.

Image 3

I was conscious of my scar for a while, worrying people would notice it and judge me as an unhealthy person.

I started covering my neck with scarves, necklaces and polo necks.

Friends even bought me scarves.

Image 4

Feeling better again, scar fading, not covering neck and health less on mind.

Back to normal life and time with friends and family. Although not feeling quite as invincible as I was prior to diagnosis and treatment.

I'm never alone with my treatment, I belong to the club

*I have FAITH in those who treat me
I have HOPE, that a cure can be found
Those cancer research CHARITIES
Value every donated pound*

*I'm never alone with my cancer
I belong to such a big club
Living well to the end, is my motto
It's not easy - and there's the rub*

*But each day I see shoots, not roots
Things still make me laugh and smile
Diagnosis was eleven years ago
But - I'm 'Staying Alive' for a while.*

Grateful for being alive



My picture shows the tree in colour against black because the feeling of trees that night was of warmth. They were in silhouette, but the nature of them was bright. I painted this picture as a memory came to me concerning trees and cancer.

I was lying in a wood on a cold, damp, late autumn night. My son was digging for spruce roots to finish a birchbark pot he was making. He had climbed up the mountainside to a spruce plantation and all I could see was a small pool of light from his head-torch as he knelt down. I lay on my back and listened to the many birds coming into roost, squabbling and restless in the fading light. Droplets of rain fell on my face as I watched the trees turn to silhouettes against the slate sky. The black web of twigs clung to their droplets of rain, they glistened as chinks of light caught them; I lay captivated and dazzled by transient diamonds set against the black velvet of the night.

As I looked up at the tangle of dark branches, ever fading in the darkening sky, I was so enraptured by the beauty of where I was that it made me rejoice at simply being alive. Cancer had made me think of death, but the damp moss, the earthy smells, the twisted shapes and the luminous beads of rainwater had made me think of life.

When I die these trees will still be here in all their magnificence and my son will still come here and scrape the rich earth with his strong hands in search of precious roots.

Life will continue in the wood.

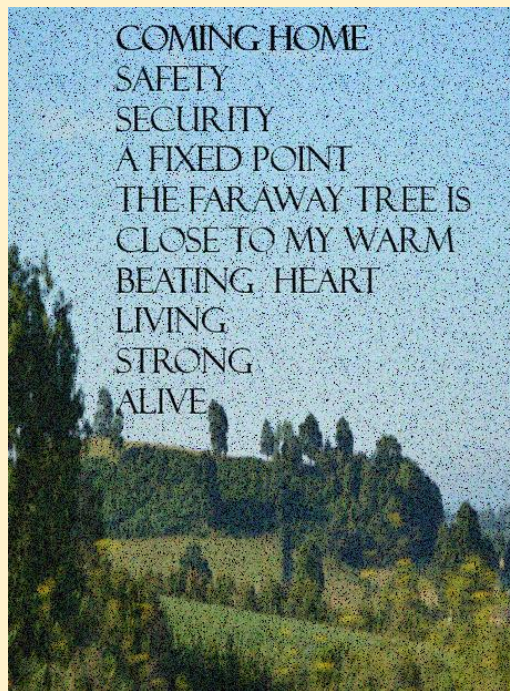
Emerging from the eye of the storm



A personal connection with the vibrant lotus flower emerging from the mud inspired the choice of this tattoo: when we emerge from a place of such darkness and loneliness with hope, strength and grace, nothing is more powerful.

To me, the cancer journey felt like being in the eye of a storm. Having very little control over what was happening, learning how to hold on, withstand, and trust, until eventually the storm is over, and we are left to pick up the pieces that remain and figure out how to put them back together again.

Arts engagement has introduced me to alternative ways of sharing experiences and making connections, relating to the world playfully and spontaneously and developing confidence in visual languages.



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For electronic copies of the booklet and educational resources please visit our website: <http://blogs.cardiff.ac.uk/cancerservicesresearch/art/>

