Living with Cancer: Endings and Beginnings

Dorset County Hospital NHS Foundation Trust
This pamphlet voices some personal responses to the experience of being diagnosed with cancer and going through treatment and its aftermath.

**Six people (two men, four women) who had recently been treated for cancer at Dorset County Hospital met with writer Rosie Jackson for some creative writing workshops in October 2012.**

We shared feelings and responses to the experience of cancer; discussed what is helpful and not from medical staff, family and friends; talked about coping mechanisms and changes in lifestyle and outlook; wrote some poetry and prose. The group gave very positive feedback about the sessions, acknowledging how valuable it is to share and compare personal stories and how beneficial it felt to do some creative writing.

We hope that by sharing these thoughts and ideas, we will convey a sense of the reality of the experience of living with cancer, give some support in dealing with the emotional challenges of a potentially life-threatening condition and make anyone with similar diagnoses feel less alone.

Pen and watercolour images by Steve Phillips ‘Views from the treatment chair’.
Cancer’s a tough journey.

Few know how you feel unless they’ve been there.

I’ve found this a lonely journey, going through this with very young children.

It’s so unfair. I’ve led a nauseatingly healthy life... why didn’t I just live like a hedonist? Why do my innocent children have to be punished this way?

I look for reasons. I find myself trying to understand it and of course I can’t. There’s nothing fair about it.

I just didn’t believe it would ever happen to me. I had to keep saying why shouldn’t it be you? You’re not special. But I wouldn’t let myself believe it, I think because of the children.

I don’t know how much of me getting cancer in the first place was to do with stress.

Having cancer was not in my grand plan. Maybe it was just in my genes, all that family history of cancer that I never fully understood. Maybe I didn’t do anything wrong.

I didn’t want to have cancer. I wouldn’t have chosen it. But it’s not been an altogether negative experience.

It’s always in the centre of my consciousness. It swoops up all the time.

I enjoy those moments when something else completely takes my attention. Then it suddenly comes back. Something in me wants to block it out and play music very loud in the car. I can’t even see a film where it’s not in my face. Then when you watch TV there
are all these ads for cancer charities, and Stand Up to Cancer. I don’t want to be reminded all the time.

The only time I think about it is when I look in the mirror. I had an anxiety dream last night where I went out without a headscarf.

I remember when I first lost my hair and every time I wore a wig, I wondered if it would blow off in the high street. I didn’t know if I could face it. I didn’t know how to keep the public side of me going.

I try to avoid looking it up on the Internet, but sometimes I Google images. It doesn’t help at all.

The cancer has given me permission to live life differently. For some people it’s right to go back to where they were, but for me it was an opportunity and challenge to change. It’s not always easy to translate that for the people you love. It’s hard to tell them there is no going back.

Strangely enough, cancer absolved me of responsibilities for a little while, let me be me, let me do some of the things I wanted to do at home. I wanted to work hard at making something good come out of it.

The most helpful thing for me throughout my diagnosis, treatment and after-effects has been to be understood. ‘Lay people’ that is family, friends, others, even often medics, find it difficult to know what to say or how to help. They tend to think, for example, that if you have survived the treatment and are in remission that you should be back to ‘normal’. Family and friends want that, of course. But everyone I have spoken with
who has had cancer knows that can’t happen. Cancer changes everything, and I firmly believe it is meant to change you radically, and that is a symptom of being out of balance. It is not a gift, but it does bring gifts: raised awareness, including more empathy towards others, the necessity to live more in the present and to enjoy small, often unnoticed things, such as lying warm in bed listening to the wind.

It’s hard to explain or encapsulate what I mean by understanding. It’s empathy rather than sympathy. It’s being met, recognised by another person on all levels as one goes through all the changes that the illness brings. It’s as if one’s whole being gives a sigh of relief.

‘It’s hard to explain or encapsulate what I mean by understanding. It’s empathy rather than sympathy.’
When you get a diagnosis, you stop taking for granted all the things you previously took for granted.

The day will always be firmly imprinted upon my memory. I’d returned to work that morning after a week’s holiday, was really busy and felt stressed trying to get to Dorchester in time for the appointment. I felt slightly curious about the tests having never had them before, then the technician spent a long time examining me and I knew she’d found something serious, though part of me was in denial. When I went back and was shown the mammogram image of breast cancer, it didn’t feel real, as if it was happening to somebody else. I couldn’t stop thinking that I don’t get ill; I was strong, fit, healthy, resilient, impervious to disease! I’d always believed I’d enter old age as a fit and healthy person with very thin medical notes because illness happens to other people. I was far too busy to be ill; when was I going to fit in time for treatment? I was in a daze, half listening and smiling that I understood, half disbelieving. And then on the way home I was thinking how to tell the children, how much would I say. That evening we pretended to the children that nothing was wrong, but both of us were quiet and my husband kept disappearing upstairs and coming back with red eyes.

Of course, when I’d found the lump, I knew there was a possibility it could be cancer. But that sort of thing doesn’t happen to me. I was breast-feeding at the time and thought it must be something to do with that. So, when I went to my appointment, I didn’t take anyone with me. There’d be a scan, they would drain the lump, end of... I returned to see the consultant. ‘Is there anyone with you?’ ‘No.’ A nurse came into the room...
with us. A shiver went down my spine. I knew what she was about to say, practically word for word...

I was almost home before thoughts of my children forced their way into my mind. ‘I don’t want my boys to grow up with no memory of me, what I look like, who I am, my smell, the things we do together, a sense of me.’ That came just before the end of the dual carriageway. I had to force myself to concentrate on my driving. I must get home safely and dry eyed.

I’m a teacher and my major fear was that I might bump into my students. I don’t want to have to explain something so personal and private, it’s too exposing.

The woman who did my ultrasound scan walked past and wouldn’t meet my eye... I felt a little hurt as we’d talked for ages about our children... at last I was called in. I got up feeling excited, keen to be rid of the choking anxiety that had been creeping over me those past few days, and I walked in smiling. There were several people in the room, but I assumed this was normal. The consultant looked down and said that unfortunately they’d found ‘some cancer.’ I leant forward, frowning and said ‘What?’ I felt as if my hearing had done something odd, and the room seemed to shift. He repeated what he’d said. I said, ‘I feel as though I’m in a film.’ What I meant was that the situation felt so weird, I wouldn’t have been surprised if they’d all turned into cartoons. He said a few more things that I didn’t hear and suddenly I was watching him draw a crude diagram of my breast and nipple,
‘I wish I’d had a blood check before... but being a man, I’d been too proud that I never went to the doctor!’

Being diagnosed felt completely surreal. There was a lack of information from the start: it seemed to be a policy of gradual disclosure so I fired questions at people, I went into hyper-vigilant questioning till I got answers. ‘It’s a grade 2 and it won’t go down, it will only go up.’ I’m divided about whether this policy of slow disclosure is good or bad. I think I appreciated it being dribbled out a bit at a time: it would have been too much to take in all at once. It would have overwhelmed me. It’s a coping mechanism: if I don’t know too much I can’t scare myself too much. But there came a point when I just wanted to know everything.

When the haematologist gave me his diagnosis, it seemed just the confirmation of what I’d thought for some weeks, but I think had hoped against hope wouldn’t be the truth...

I wish I’d had a blood check before... but being a man, I’d been too proud that I never went to the doctor!

I was dealing with the information quite well until I told my youngest daughter. That was when I cried. I had 75 years of appalling good health and it’s hard then finding yourself in a medical environment. I found that a shock. It alters the way you perceive yourself. The worst thing is when people say ‘Well, you’ve had a good innings.’
I just want the cancer out of my body. I can’t wait to have surgery. It’s strange to know I have it when I don’t actually feel ill. It was only the chemo which made me ill. I didn’t mind the radiotherapy. In fact it isn’t the cancer that makes you feel bad, it’s the treatment. That’s the hard thing: coping with being really ill from the treatment. You need to be prepared for the side-effects. It’s useful to have the booklets to refer to this.

I was very unwell and did think I might die… I railed silently against God and tried to bargain. I asked for a few more years to see my young daughter through school and into the world. I planned my funeral in my head, something for everyone. I rested a lot and listened to music of different kinds according to my moods, and I saw an open door with a light beyond it. This ‘vision’ or whatever it was stayed with me for quite a while, something I held onto and wrote a poem about. It faded as I became more well or at least less ill.

When I relapsed this year, it was fairly devastating, though I think I’d been aware for some time that things weren’t quite right. My mother had the same illness, but never talked about it or her treatment. I come from parents who treated doctors as gods, and believed every word. We live in a society that doesn’t seem to prepare for death.

My body is not what it was. It feels old and scarred, stiff and achy. I can’t reach as high as I used to. Gone are the days when lying in the sun felt effortless; now I have to carefully choose what I wear. I look wistfully at women with curves.

I’ve become more attached to my body as it’s begun to fail me… it’s a stiff old thing and doesn’t always
‘I enjoyed the company and the exchange of experiences with fellow patients.’

respond as I’d hope. But it’s also amazingly resilient to cope with all that’s been done to it over the past three years, both seen and unseen, inside and out. I’m not at all vain these days, living through no hair and dreadful nails and losing weight - what does it matter? So I wear what I like, and don’t worry what others think.

The side effects of treatment are complete shit. George V, on his deathbed, said ‘Bugger Bognor’. I shall say ‘Fuck Cancer’... not really, but right now, cancer stinks.

I defied the side-effects. They said I’d put weight on but I didn’t; they said I’d be less physically fit but I’m not; they said I’d experience depression during the radiotherapy but I didn’t - I enjoyed the company and the exchange of experiences with fellow patients.

We’re so lucky to have the NHS. I’m supporting a project to fund medical care in Tanzania because I realised that if I was living there I would be dead by now. That humbles me when I think about the cost of some of the treatments I’ve had - that amount of money would feed people for a long time and that’s humbling. I’m undergoing new treatment for non-Hodgkin’s lymphoma, which involves stem cell collection and blood tests every week. I’d always been very healthy before this, so it was a big adjustment.

The medical system is quite difficult if you’re not used to it. But the most difficult thing for me was dealing with my daughter, my younger daughter. It was hard for her to accept my illness.

It’s the little things that hit you. Being told, for example,
that I could never have a sauna again. I burst into tears. I went away wishing I knew more. I asked what my odds were of surviving. I was told I had a 34% chance of still being alive in 10 years time. And having that awful prognosis made me take it seriously, make me make strong changes in my lifestyle. I found it useful to motivate me, to change my diet etc, even if this didn’t make any actual difference. It made me feel empowered to do those things and that helped me. I did everything I could to be around for my children who are my main priority.

My body is in better shape now than before I got diagnosed. (I am not ill!!) There have been huge fluctuations in my appetite since I started treatment and I lost some of the weight I was carrying. I would not recommend cancer as a weight control method, but this has been a positive side effect for me. If it wasn’t for my hair loss, I would probably feel better about my appearance than I have for some time.

So the treatment made me feel bad. So what? That is a sacrifice I am prepare to make to defeat you. I can’t wait for the surgeon to cut out what remains of you from my body. You will end your days on a microscope slide in a lab, whereas I will grow old with my children, husband and grandchildren without sparing you a second thought.

‘It made me feel empowered to do those things and that helped me.’
Outside the room with the huge machine primed to radiate,

I sit in a wheeled chair, wait, and study a painting:

a tall sky
of matt, myosotis blue, seeps
into waves
sea grass
seaweed
sea-glass worn thin
above dull old gold.

All the layers
rest on fine-ground
hot sand.

My eyes search
form
deepest
substance
tissue
bones
radiance.
‘It takes courage to name reality and face it. That’s the most important thing to me, facing the reality, not avoiding it.’

**What Helps You Cope?**

My coping mechanism is to get outside myself and not think of myself. I’ve always done a lot of walking. I used to take groups of 20 to 30 out on long walks. I’ve lived in the country all my life, nature is so important to me. I need to see things like the first primrose and the first butterfly.

I find writing poetry is quite cathartic, whether it’s about how lousy I’m feeling, or something funny.

I have always defined myself by my physicality and I fight the illness by staying extremely fit physically. I do what I can to keep fit knowing that everything adds to the odds. Not that it will cure the cancer, but it will help me if only in knowing that I’m doing the most I can do myself. I always believed in the joy of winning... You’ve got to do everything that is within your power.

I find the doctors very approachable. For me the six-week wait in diagnosis was the hardest thing to deal with. It was better once it was quantified. One nurse said ‘You’ll die with it, but not from it.’ I found that a helpful phrase.

I find that facing cancer is like when I was called up to the Army. It takes courage to name reality and face it. That’s the most important thing to me, facing the reality, not avoiding it. I never want to duck my fate. I generally adjust by being humorous about it. We all need to find our own path.

I need someone with me when dealing with doctors. When you are in shock is hard to take in what other people can take in. I like my husband to come with me because he’s more of a scientist and there’s so much technical stuff around cancer. He understands...
I cope by talking about it all matter-of-factly so that everyone knows. My first diagnosis triggered grief, a grieving process, but having my relapse was a different kind of disappointment, wondering what will they put me through now?

Faith helped me and sustained me, but then I had faith before the illness (Quakerism) and it has always helped me through everything.

It’s easy to blame the cancer for everything, especially when things go wrong with the children. But those things could be happening anyway. It’s easy to take on a burden of guilt about not mothering well while going through treatment; it is hard to cope with everything at once. It helps to be reminded of all this.

We all deal with things in our own way. Some people need a friend or relative with them when seeing a consultant or getting the diagnosis, but I don’t take anyone with me. I like to face whatever they tell me on my own.
‘I felt **humbled** and **moved** by people’s thoughts and experiences.’

Sometimes I do visualisations of myself at the Penny Brohn Centre in Bristol, and I’m giving a talk of how I cured myself of Stage 4 cancer, inspiring others.

For me, cancer has made me easier on myself. It’s calmed down that critical inner voice. In fact it’s really surprised me. I would have predicted I’d take all this very badly, but to my amazement I haven’t. I’ve managed to enjoy life more, to have an extra nice time, because the nearness of death puts life in focus. The little worries I had no longer matter. It’s really strange. I wasted so much time worrying about inconsequential things, and yet I turned out to be really good at dealing with something as big as cancer.

I found these writing workshops really helpful. I felt humbled and moved by people’s thoughts and experiences. It was so good to be able to be honest and to be understood.

Attending these workshops was a rare opportunity to explore and express my deepest feelings about my cancer journey alongside other people who understood how difficult this can be. It got me writing poetry again which I find cathartic and life-affirming.

I found it interesting and therapeutic to write down my thoughts about my cancer, I surprised myself with some of the things I came up with. It helped me to better understand how I want to be treated by those around me. Most of all, though, it was the pure creativity that left me feeling I had achieved something worthwhile, and that isn’t something I feel very often at the moment.
There are two things going on inside simultaneously: the determination to do what I can to cure myself; and at the same time being at peace with the idea of dying. I have these two things running parallel - they don't cancel each other out, they're not mutually exclusive, rather I feel they both need to be given equal weight.

I found reading Dr David Servan-Schreiber's book 'Not the Last Goodbye' very helpful. It opened up questions and a sense of spiritual awakening. I wanted to feel comfortable that if I die in the next two years, as is possible, I would feel okay about going. And I do feel that. The fear of cancer shouldn't stop you living. My sense is that we need to feel okay about our journey to wherever it is.

Letting go of fear is a daily struggle. I practice meditation, have a wonderful counsellor, my Quaker faith, and loving family and friends. The best people are those who have a special capacity for listening, a combination of intelligence (non-academic), intuition and perception, with whom I can also share their own problems. And shared laughter is balm to the body, heart, spirit and soul.

Music becomes incredibly important.

‘The best people are those who have a special capacity for listening’
Cancer forced me into a re-examination of my life. It made me take a year off from work and I’m really enjoying not working, despite all the drugs and the side-effects. I’m loving time with my children, time to do things to the home. I take more pride in my home life now and realise I was missing out on it. Before the cancer, I was trying to be a wife/mother/professional and not feeling I could do them all well. At least now I can do the first two really well.

In this roller-coaster, I’ve learnt that I’m strong, that I can keep going in spite of pain, fear and physical disfigurement. I’ve learnt to play, to allow myself to do nothing, to relax, to indulge in gardening, pottery, hat-making. I’ve learnt I’m surrounded by wonderful people. My husband has been a rock, a shoulder to cry on, cook, nurse, friend and father. I’ve learnt that work isn’t everything: that all those deadlines and targets and politics don’t really matter in the great scheme of things. Faced with the stark reality of your own mortality, the important things come into sharp focus. I keep more of a sense of proportion and humanity at work...

It’s been a journey of discovery about how to lead a healthier life, learning about some inspirational people who have also faced cancer. This has led onto thoughts about spirituality and dying, and allowed me to feel strangely calm and peaceful about my own future.

I’ve learnt that day to day chores still don’t get done, the house still isn’t tidy and it’s Ok to live with some muddle! I’d rather meet a friend and have a coffee (herb tea!) than do housework anyway!

New Beginnings
I’m waiting for a time when the other important aspects of my life return to the centre, and cancer is filed away in a corner... this may never happen, but if there is some minor good news, I’ll settle for that.

All my school reports used to say the same thing: ‘she has so much potential’. I don’t want that to be my epitaph as well. I want to do things I daydream about, to do what I feel passionate about, to try and to be OK with failing.

Having completed treatment, I’m now well recovered and enjoying life. I can get back to country walks and the garden, enjoy writing my poetry, see life through a new meaning. Many things have ceased to be important; my family and their well-being is now my first concern. I want something positive to come out of my illness which can be used for the good of others. I work for Hands, the group which supports people with head and neck cancer in the Dorset area, and I sell copies of my poetry to produce funds for cancer charities.

Doing something creative definitely helps. It makes me feel more optimistic. We’ve drawn on our own experiences to set up a new cancer drop-in centre in Bridport, called The Living Tree. And now I want to do more for others with cancer and that gives me hope that life can be meaningful.

The cancer has given me more courage to make positive changes in my life. Before, I was so busy, I had little time to stop and be. Now being has become the miracle of my life.

I’ve found, or am beginning to find, a way to live with myself, with my cancer, a new path forward which opens up new possibilities as each week passes.

‘And now I want to do more for others with cancer’
Aftermath

There needs to be more support for what happens after treatment. This side of things isn’t given much attention - the fact that even the relief of feeling better physically can be stressful and make you feel low and depressed. Going back to work after treatment is something of an anti-climax, you lose the care, the focus, the time, the attention of the professionals. You don’t know how you’re going to cope.

Once my treatment was over, I felt very down, resuming the responsibilities of my daily life. There was no more contact with professionals, no more personal attention. There was a sense of flatness, of anti-climax. This is one thing you’re not warned about. Fear about the future creeps up on you and the offers of help recede. You wonder if you can cope on your own.

The expectation is that you’ll go back to normal. People seem to want a kind of pay off for their help, there’s a subtle pressure to be happy, to be grateful that the treatment is finished and if you can’t show this you’re failing your part of the bargain. But you don’t want your whole experience, which was so life-changing, to be negated.

They ask ‘Is it all over now?’ They want you to just forget and return to normal. But that’s the thing about living with cancer. It’s never over.

Have I changed? I’m still a wife, mother, friend, sister, daughter, aunt. I still like chocolate. I still enjoy watching period dramas, walking in the countryside, the company of friends. We’re still planning to do the alterations to our house, have a dog, organise outings, trips and holidays.
Who am I
this body
moving skeleton
clothed in water
elements
what we call flesh
I thought I knew
for all these years
of growth and
change
of walk and talk
of children born
and parents gone
I thought I knew
until the day
I caught my breath
and fluid drained
and I lay face to
face
with death
and then I knew
that I was
something
more than this
much deeper
far beyond
the sentence passed
the words or pain
and I can be that
me
despite the shadows
on the screen
live my life
inside the silence
know well
the path within
this moment’s goal
Oh God, is this then
my soul

Contemplating me
What More Needs to be Done?

The trouble is that wherever the cancer shows itself in the body that’s the department where you end up in hospital. It’s not dealt with in a holistic way.

I had wonderful medical care, but there is very little input on how to live with cancer, information on changes in diet, relaxation, meditation, doing creative things, complementary therapies. It’s very frustrating spending a lot of time sitting around in hospitals, it would be good to have a place there to go to learn about these things. The books that are available are in a very busy corridor, it would be good to have them somewhere else.

Dorchester Hospital has a completely different feeling from other hospitals. This is because of the art work, the light and the gardens. The art is everywhere, it’s fantastic, it has so much variety. It’s inspiring. Everywhere should be like this.

I definitely prefer hospitals with lots of art work and gardens, other than endless long corridors.

It would be good to have counselling, but the word counsellor carries a lot of baggage, it still carries a lot of stigma, implies you have problems. It would be good for everyone to be offered ‘chat’, meaning counselling, as part and parcel of the treatment. And it should include the chance to learn about related things like diet, relaxation, other tests, complementary therapies, money and medical insurance - for example, if you have critical illness cover you can pay off your mortgage.

It’s important that carers receive acknowledgement and support. I want people to ask my husband how he is as well as how I am. I want him to be acknowledged
‘You don’t want to have to pretend that the glass is half full when it isn’t’

for all he is doing.

There aren’t any words that will make you feel better or be better. Everything everyone says feels like a platitude. What you don’t want is stupid enthusiasm or an over the top response. You don’t want people to say how ill you look but, on the other hand, it’s hard when people say you’re looking well because that puts a certain expectation on you to be well. You don’t want to have to pretend that the glass is half full when it isn’t.
‘Please Don’t’

Tell me to ‘be positive’
‘expect the best medical outcome’
say you couldn’t do this
tell me how brave I am
treat me as a victim
wrap me in cotton wool
hide the facts
avoid the word ‘cancer’
try to cheer me up
stay away because you are too embarrassed
make jokes about my wig
say you ‘know how I feel’
or ‘things could have been worse’
or ‘everything will be fine’
or ‘you’ve had a good innings.’

‘Please Do’

Talk openly with me about my condition
ask me how I am and really listen to the response
be honest about how you feel
allow me to feel bad sometimes
ask me to do things, share joyful things
treat me normally
introduce yourself if you’re touching my body
help me stay in touch with the person I really am
ask my partner how they are
offer your help, the more specific the better
make me soup, buy plants instead of flowers
remember I am not my cancer
send me a card to say you’re thinking about me
hold me in your thoughts or prayers
keep in touch, e-mail is best
A Letter

Dear cancer, do you realise what awful timing you had, coming whilst I was still breast-feeding my baby son? Were you there, growing stealthily, whilst he suckled and I thought smugly about how breast-feeding reduces a woman’s chances of getting breast cancer? I looked up a picture of a breast cancer tumour on the Internet and there it was, stellated, star-like. Were you like a star, too close to my body and burning into me, or like a fallen star, no longer bright but darkly, deviously spreading, multiplying to make milky ways in my blood, and black holes in my bones? My life can never be what it was before I knew you.

You have changed my life in many ways, not all bad, some good. You challenge me daily in the little things of life and frequently in the big. You touch every corner of my world and make me assess and re-assess continually all that I do and say. You’ve changed the people around me, my family and friends, in subtle but perceptible ways. I’ve met so many special people through you. I talk about you a lot, maybe too much, but it’s the only way I can tame you.

Healing images

The sea: hearing it, smelling it, being out on the cliffs looking down on it, through all the different times of year and seasons, fish and birds, sun on the water, yachts gliding, sitting on pebbles, writing poetry on the beach, surf on the shingle like lace, the clouds like angels.

Silent meditation.

Listening to Ravel’s String Quartet.

A trickling stream within a cool wood: dappled sunlight, the sound of tinkling water, the feel of warmth and light upon my face, beautiful leaves moving gently in a soft breeze, stillness and calm all around, with intermittent bird song.

Lying under a tree next to a burbling river, burying my feet into the warm sand on the riverbank, bright sunshine warming me.

Fresh spring flowers gathered from the garden.

My sleeping children: peaceful, calm, tranquil, beautiful, full of promise, in their bed, soft toys surrounding them, safe, warm, loved and loving, soft light falling on their faces, the sound of their breathing and the funny little noises they make as they stir.
Laying the Table

A woman filled with cancer and the gladness of living
put her elbow on the table.
She put her children and husband on the table,
put her whole family there,
even those she disliked in the past.
Her hopes for a long life,
for a point to the everyday sacrifices she made,
her newly vegan food, she put on the table.
The woman put a book on the table,
then another.
She laid down her children’s need for their mother,
for her quirky, flawed but loving hand in their lives.
She put down whole kilns full of pottery,
ticking as it cooled.
She put down the long exhausting walks to remote places
and the meals which followed them.
Her pain and fear she put down,
as well as her ease and her pleasure.
She put down the loving companionship of friends old and new.
She put down her secure loving home,
all of it.
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