

ACCORD
Hospice

Registered Charity No SC013682

One person's practical, honest and heartfelt guide to 'living with' cancer.

I am

living with

(not dying of)

Cancer.

"You Have Cancer...."

My story

Those dreaded words. I sat in front of the Doctor, she continued speaking but all I hear is "You have cancer".

The next few days were a nightmare. Every pain and ache convinced me I was dying. I could not eat or sleep. I had a constant headache. My emotions were all over the place. I was

so frightened. 😞 How long have I got to live? Will I be in pain? Has the cancer got into my brain, heart? Is it all over my body? I

spent my time in bed crying 😭, did not talk to anyone. I had

some very black thoughts. I was so angry 😡. Why me? I don't smoke, drink to excess and I keep myself fit so why me? I don't know when I began to give some thought to this cancer that's got into my body.

So, I began the journey hospital appointments, blood test, scans, MRI scans, chemotherapy, radiotherapy, more blood tests. I used to say to the nurses "you must have a contract with Dracula!"

I wrote a list of questions for my oncologist, spoke to my GP, talked to my palliative care nurse. The more information I had the more in control I felt. I did not get my information from papers or the internet, I used the professional help around me. Everyone must find their own information as much or as little as you want or need, but remember, its your body, your illness, it belongs to you.

The Hospice



I began to accept the network of support around me but I still had some hesitations. My first visit to the ACCORD Hospice, arranged by the cancer nurse at the RAH was a scary, tearful experience. I thought "This is it. People come to a Hospice to die!"

I cried when staff spoke to me, I went to the loo and cried, I just wanted to go home. The only reason I went was to give my husband a break.

The staff were so caring and the counsellor over a good few sessions helped me to take control of my emotions and fears. I began to be honest with myself, talking and listening to fellow clients. I realised this is a happy place and you don't come here to die. The more honest I became the more control I felt I had of this cancer. Going to ACCORD every week helped me gain the confidence to talk to my family which I think helped them.

Family, Friends and Acquaintances

Every time I looked at my loved ones I could see their pain, big smiles, and dead eyes.



One of the things I noticed when I was diagnosed – family and friends stopped giving me a cuddle or a cheerio kiss. My husband tried to wrap me up in cotton wool. When we spoke they realised I would not break. Now, I give the kisses and cuddles and get them back. Physical contact is very important. Of course, they were getting their information from the internet so they became cancer experts. I let them explain to me what they have read – it gives them some control!

When people say silly things to you, such as “you look well”, when you look drained and pale, I think, “wish I had their glasses”. Or the one comment that used to annoy me, “Keep strong, you could go out tomorrow and get knocked down by a bus”, well, some days I thought “bring on the bus!”

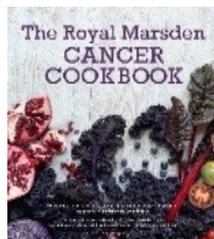
But remember, its hard for those around you. They have emotions, like you, fear, and sadness. So, when someone says something silly, smile and say “I’m ok, hope you can cope with my illness”its an opening to having the chat.

Eat and Drink Well

I am doing well. One of the things I learned was the importance of eating good food. Eat small meals, eat often. I find Tesco ready meals good, not expensive. Tomatoes , nuts , garlic , all good for regulating and keeping blood cells healthy.



Keep this in mind as healthy blood cells fight your cancer! Drink full fat milk, have a scone and jam with your cuppa. When you feel well, make a pot of soup and freeze some. A good guide to healthy eating is The Royal Marsden Cancer Cook Book.





I eat what I like now. If someone brings me soup or suggests we go out for a meal, don't say "oh don't bother with me", say "thank you" and enjoy!

I take a glass of wheatgerm grass (bought from Holland & Barrett for £9) every few days, I mix mine with cranberry juice but you can use any juice you fancy, it gives me an energy boost which allows me to exercise. I feel it's worth the money especially after chemotherapy, when I was tired and wanted to lie in bed all day. I would force myself to get up, drink my drink and do a little exercise which always makes me feel a bit better!!

Exercise

Daily exercise is so good for you. Breathing exercises are so important; I sit on the side of my bed every morning and take deep breaths. You can do as many or as few as you like but remember one is better than none! I try and get out for a walk if the weather is OK as fresh air works wonders, but if I can't, I walk in my hallway. I started with up and down 5 times, now I can do 30 – not bad considering I broke my hip only weeks ago!

So, you are eating well and exercising now – all very good to keep your body and more importantly those blood cells healthy.

Stress

If your white blood cell count is low, you will not be fit to receive your treatment. I became very stressed when I could not get my treatment. I then found out stress can cause your white blood cells to drop. You need to recognise your stressors and find ways to cope.

Stressors

For me, it was a worry about money. I found myself a bit skint at the end of each month. I had to have the heating on most of the day, I needed to buy good healthy food and I needed new clothes as I had lost a lot of weight. Palliative Care Nurse to the rescue money worries? You can get a payment as a cancer patient which is not dependent on income or bank balance and is confidential. I was given this number for a Renfrewshire Council Advice Worker who will come to your home:



0300 300 1238.

Another stressor was keeping track of hospital appointments. I bought a notice board from B&M (£2.99). When an appointment comes in I put it on the board! Also, when I leave the hospital and I remember an important question I did not ask I do not stress or worry, I simply phone either the Beatson Help Line: 0141 301 7000 or the RAH: 0141 887 9111 (general number). If or when you phone, have your CHI number to hand!!



There are many ways to help you cope with the stress. I write letters to my family , I talk to friends and professionals. Use the services at ACCORD. Get your hair done, try reflexology, Reiki, go for a walk, try some breathing exercises. Find your own way of dealing with stress, find what works and is right for you!

Looking Good

Now I feel better, have found ways of dealing with stress, it's time to start looking good and taking care of my skin, nails and hair. It does not cost a lot to look good, I have put together a shopping list of items I find useful:

Drink lots of tap water	It's free	😊
Coconut oil for face and neck	£1.00	
Vaseline coconut butter on body	£2.99	
Tea tree blemish stick	£2.99	
Coconut eye blemish stick	£3.99	
Lip moisture balm	£0.79	
Lavender stick (rub on wrist)	£3.99*	lavender helps you sleep
Lavender oil (sprinkle on pillow)	£4.99	

All of the above items can be bought from Holland & Barrett – not a lot of money to keep ourselves looking beautiful or handsome. Look good, feel good!!



“The Dreaded Nose Drip”



Do you find your nose dripping all the time? Can't leave the house without a dozen hankies, and if you do forget the hankies its back to childhood but a green sleeve is not a good look for adults!! The reason for the nose drip; Chemotherapy. Chemotherapy destroys the little filter hairs in your nose So the itch and drip WILL, in time, get better!!

I am now well down the road on my journey.

I have taken control of my cancer.

I am not dying of cancer, I am living with my cancer 😊

Written by Kathleen Stewart

Acknowledgements

Thank you to Emma (Occupational Therapy student) who asked me to share this project with her.

To the staff at ACCORD DTU for your care.

To Samantha for compiling this pamphlet.

To all the volunteers, including the drivers who give us their time.

To my fellow clients who have shared so much with me.