It happens

A PoeTRY diary about breast cancer

Rajan Madhok & Helen Job

Denbighshire

2022

It happens

Cancer diary of Helen Job

Introduction

This diary charts Helen's journey through diagnosis and treatment for breast cancer.

It is Helen's story and whilst I recorded day to day events, she made some personal notes, and these have been added in various places (*text, in Italics*). This anthology is being shared in accordance with her wishes:

Helen Job on her proposed diary - YouTube

All cancer patients and their circumstances are unique, but what is common is the intense upheaval and the physical and mental toll it takes, despite all the advances in treatments. What gets one through is the focus on living each day, one day at a time. We did it and so can you if you are unfortunate to get a cancer and are reading this. We wish you the very best.

Background

Although Helen had surgery and radiotherapy too, the main treatment for her cancer was chemotherapy; one of the longest courses of some of the strongest drugs, given over months. Her care was coordinated by the North Wales Cancer Treatment Centre at Glan Clwyd Hospital, and you can see the detailed timeline at the end of the diary.

Helen is a painter, and when she saw the scan of her cancer it reminded her of the artwork on the front cover which she had made some time ago for her future exhibition entitled – Inside/Tu Mewn – at Theatr Twm o'r Nant, Denbigh. The artwork had been inspired by a poem I had written about depression:

Go away
And bang, he is back
Riding on shoulder
Bolder than before
Shake him off now
Longer he stays
longer will take
That black dog
can sense weakness

Helen lives in the tiny community of Peniel high above the town of Denbigh in North Wales and is very fond of the wild and rugged countryside around her and particularly the Denbigh Moors; the back cover is from her recent Outside/Tu Allan exhibition about the moors. I am a public health doctor and live in Ruthin; but stayed with Helen in Peniel when she was diagnosed.

We have tried to present a factual diary with its many mundane and repetitive entries in a more interesting way – it's not really poetry in the usual sense of the word (it is more about Rajan's aspiration to write poetry- PoeTRY!), and what seems boring on looking back was what got us through at the time. Living through cancer treatment is a roller coaster, with its ups and downs, and whilst we realise that our presentation may detract from its readability, we need people to understand that this is how it was - mistakes and all. You are reading how it was lived then, and not sanitised later for some artistic reasons. It is about 'normal' people, not important people and experts - cancer is a great equaliser; we are all humans. Everyone has to find their own way through their journey, and what you are reading is how we did it.

Life BC (Before Cancer)

September/October 2021 (on train to London to see son, Simon)

I don't feel young anymore. The skin on my upper arms tends to wrinkle when my arms are at rest and my hearing is not quite as sharp as it once was. My eyes, though, are better than they were ten years ago due to cataract surgery – a painless procedure but disconcerting in that being short sighted for many of my 64 years, I am now long sighted and need varifocal lenses. Threading a needle requires extra reading glasses on top of the other glasses to sufficiently magnify the hole in the needle so I can locate it. My sewing machine is idle these days, far too much trouble to thread that!

I get lost on train journeys and a trip to London is a thing of dread as I've always managed to get on the wrong train or the wrong part of the right train only to find it splits and I'm heading in a totally unexpected direction. The indignity of being rescued and put on the correct train, on the correct platform, by some slip of a young child is humiliating. Welcome old age.

And yet…I don't feel old. This last 18 months my life has exploded into colour and my horizons are limitless. I'm learning Hindi and have taken up Bharatnatyam (Indian classical dance) which I find has improved my body and my mind. So, my expectations of myself have been challenged. Slipping into my small, cosy, rural life has been diverted into a vast world of possibilities. Something I could never have seen as being available to me.

And just as this newfound life burst upon me, we were struck by a pandemic which, paradoxically, shut everything down. Literally. No travel, no socialising, no fun apart from that we could have in our own homes and local environment.

As I sit on a train, in the right carriage, going in the right direction, I look around and most of us, me included, are wearing face masks. Uncomfortable physically but acting like a sticking plaster on our confidence of not catching the Covid 19 virus. Double vaccinated and careful, we are not really immune but more immune than we were 18 months ago and not so likely to die of this invidious bug. Many succumbed. It was like a clear out of the very old and infirm. Our government emptied hospitals to make room for Covid patients by sending elderly and infected people to nursing homes to infect everyone else living and working there. Devastation.

Note: you can read about our experiences of living through the pandemic here RaMa Reflections (see under My Projects section)

Part 1: Nightmare starts

Making the discovery

Oh, what have we got here
as she self-examines
having had cysts in the past
Somehow feels different
Turns in bed with that look
What do you think
From lover to doctor suddenly
try long forgotten medicine
tender caresses to detached clinician
Bugger makes it easy, as no missing it
And no messing either, so onto GP
Horror stories of waits, patients dying
as NHS reeling from Covid
not making it easy, so shut it all out
No rushing ahead, take it slow
Will panic when necessary
and may be never

The wait

Two weeks' wait for cancers
no longer, more like six
Mind in overdrive
Pain in chest wall and
visions of her mum's myeloma
with dreaded chemo

Pester GP for more tests
Any way to speed up referral
ringing appointments, checking phone/post
being a nuisance
Another day passes
Anxiety mounts for both
My mum fading away also
not able to go back to India
thankfully had just seen her
Shitty situation all round
Finally to hospital, weeks later

It must be NHS

No other option
Private maybe for some things
but not when cancer

NHS at its best

Hello, my name is…..
And so introduces the nurse
the technician, surgeon and all
as navigate the system
frightened, unable to focus
Very calming and helpful
with scans and biopsy
Clearly nasty not nice
Will know more next week

The person

She is who she is
was and will be
She is not breast cancer
It’s something she has
along with other things
love, compassion, empathy
kindness and sense of humour
Don’t think cancer, think her
see her, the person

The intruder

Like an unwelcome guest
unannounced, unwanted
too late to shut the door
already in and settled
no way to chuck out
may go away in time
but when, anyone's guess

She may have it
but belongs to both
Which pain is worse
one felt directly
or seen helplessly
Sink or swim together
Join forces to see it off

NOTE: This picture is from the Internet, source unknown but thanks

Oh, we do like to be beside the seaside

Meanwhile, off to Whitby
whilst waiting for results
bit of sea, sand, fresh air
and fish aplenty
Up to the abbey and
down the pier
taking in Robin Hood's Bay
on the way back
The sun shone, good omen
life is for living, until it is not

- *It was later that I came across the famous Welsh song: Lawr, ar lan y mor*

Part 2: It is for real

Meet the 'intruder'

Invasive ductal cancer, high grade, receptor negative
(TNBC to the professionals)
Finally got a name for the unwelcome guest
as the cancer gives up its identity to modern science
with more tests to follow to see if alone or in company
Not likely to leave easily so filling syringes
sharpening knives and getting ready to zap the bugger
You have been warned, mess with me and
I will mess with you, let the battle commence

- *Helen wanted to add here that she is not a fan of using war terminology for something she feels is not a battle. She says she is more a passenger to the process.*

Boom

Just when thought light at the end of tunnel
after years of wilderness, found shelter
except it was the train coming, high speed

So, how long have I got?

Who can say
But good treatments
and known cancer
Time will tell

It's the journey now
not about how long

but how well lived
Make every moment count

Just as well

Yin and yang
Optimist and pessimist
Herself making light
Yours truly catastrophising
Cuts through in her own way
Not much rumpy pumpy then
Lowering the tone to distract

It’s everywhere

Like buses in threes
or Hyundais on road
as soon you get one
Everyone a story
Friends and family
Made it through and
going strong years later
At least know the bugger
and in good hands
One way to look at things

- *Within our immediate circle, there are five other women undergoing treatment at this time.*

Do not 'Poor you' me

Flowers and sympathy can do without
but laughter can do with
and give me cakes and chocolates

Life is a death sentence anyway
who knows when Grim Reaper calls
why fuss over this cancer

Life must go on

No point sitting, wondering, moping
Packs lunch and sends me off to hills
Fresh air, good company of ramblers
whilst doing her dance lesson
Takes minds off and both better for it

Rollercoaster

Has left the station, no getting off
At the mercy of the operator now
keep looking, screaming, crying
or hold tight, smiling, telling story after
Enjoy the ride for now, it too will pass

So many plans, much to do
spent last two years surviving pandemic
living in hope of better times
travelling, culture, friends and family
all gone may be, definitely on hold

Too early to talk of Swiss clinics
two drips, one double bed
find someone when gone, keep house
Stop nonsense, throw away tissues
get off backside and get on with life

Wise words

Always a shock, but why
Death inevitable yet unprepared
suddenly or slowly

Neither changes fundamental
All the time there is, is now
and all life is here

See the possibilities

Beauty everywhere
Do not waste a moment

Wake up call

Maybe better to get the reminder
to make amends for hurt caused
to do things not done and wished for
to appreciate beauty, to give thanks
Go in peace and leave them in peace

Amazing how it focusses the mind
The world suddenly shrinks
separates important from trivial
and yet grows as see love and
kindness of carers and well wishers

Unsaid

Will I cope
Will I do the right thing
Am I strong enough
Mind racing
Inevitable not insurmountable

Think different
Sent to test, make stronger
Sadness, grief, loss
there to appreciate joy
Life’s rich tapestry

Promise

Banish all negative words
Can’t do, sick, sad, death
What you think becomes you
It’s all in your head, use it well

Crying is OK

Dabbing eyes, sad
Why this, why now
You did not deserve this
Says she, but then who did
It is what it is

There will be days
when curled on sofa
watching rubbish tv
all that will be possible
But why let that destroy today

Thanksgiving

Getting into groove
Off for more tests
Family outing today
as own hernia appointment too
Pack the mutts in car
herself sings praises of staff
wonders how to thank them
best show gratitude as you go
every kind act needs recognition

And it gets to you

Like three in a marriage
or child with tantrums
It is there, beware

No getting away
from fallouts and shirtiness
each trying to cope

There will be tears
there will be laughter
and that is OK

Losing hair, prematurely

Should shave off head says she
Bit early, isn't it
Not even started treatment yet
The power of myths
Will deal when happens
And may join you
Always fancied Yul Brynner look

Making plans

Will it be isolation
Bit like lockdowns
Just the two, and the mutts
Will it be different and how

It happens

No visitors, no travel, and so on
and for how long
Making list of questions
as make another trip
to meet the oncologist
Look on the bright side
time to make decisions
About love, life and loss
doing things that matter
No excuse for not learning piano,
Welsh, writing and teaching now

Part 3a: Let us go get the bugger- Phase 1 (Chemotherapy)

The oncologist spells it out

Good doctor, no rush, listening
asking and answering
Open, honest and reassuring
no beating around the bush
Has to be chemo first
Describes the journey
over next six months
in two parts: scary stuff, start Tuesday
Not going to think too much
One day at a time

Morning after

Yesterday’s daze clearing
Going to be real soon
Talk practical stuff
Get ready for the long haul
Worry too much or
plan too little
Too many unknowns
Breakfast first though
Mutts to be fed, walked
Shopping to be done and
back to hospital for CT scan
What will it show
Not know for weeks
Constantly googling
Five year survivals
Mind up, down, see-saw

Fear

Do not want to die
and the tears start
What to say/do
Philosophical or practical
Bit early for that or
Is it ever too early
Biggest problem of humanity
Denial of the ultimate
Death not an abrupt event
Is happening all the time

Every minute gone is death
But maybe not a good idea now

Rather, do what it takes
Small things, daily
Be there when down
It's not duration but quality
Can pack a lot in short time
or waste years
Create space for grieving
and for laughter daily

- *Helen did not appreciate the book: Duck, Death and the Tulip by Wolf Elrbruch that I was reading and uttered a word that rhymed with duck followed by 'off'…oops*

Anxiety rules

Feel it in my bones
says she on walk
around Foel Gasyth
with mutts straining
Every ache
hips, elbow, ribs
due to the intruder
As waiting for CT scan
Every visit so far worse
Benign cysts to common cancer
local and small size
to TNBC with lymph node
Would CT break the trend
and show clear

Is there a God

- *Helen says: probably not*

And they are off - Part 1*

Bit different to dropping at shopping mall
as send her into the hospital, not going in self
to go and face the 'music' inside, all alone
for the first day of chemo
Who will come back, will it still be Herself
or bald, wizened, stooping woman
And bless her, comes out smiling
clutching bag of goodies, full of praise
and as usual takes charge at home
keeping busy, as if it was a shopping trip
The only way, the new normal
One done, 15 more to go…

- *Carboplatin and Paclitaxel (CP) – two cancer drugs*

The dip (1)

Halfway through first week
Blues, wobbly, tears
Trying to figure why
Could it be the drugs
causing facial swelling
Or something deeper
Mind playing games again
Thankfully friend's call came
to cheer up

And another one...

Not ready to die
much to do still
So, make a pact
To live each day fully
Go to bed peacefully
No regret if don't wake up
Not easy conversations
but essential
Meantime moors beckon
despite storm Arwen
Mutts come along too

It happens

Science to rescue….

Another stellar performance
as nurse sites the PICC line
No more pin cushion
Easier for all, except bugger
who will get frazzled now
You were warned mate
Not too late still, leave now

- *Peripherally Inserted Central Catheter (PICC) - makes it easy to give intravenous drugs*

Grab it while you can

Like the Scouts rule
Eat and evacuate when one can
Never know what next
and grab them forty winks

Patience

All bunged up
No scatological jokes please
Not funny, as no movement
sleepy nether regions
Fancy a depth charge, love
Nothing like a hot curry

- *Helen says: Really? I think that's between me and my bathroom!*

Being useful

Chatting with medical student
answering questions, explaining
Not just cancer but life
Everyone has to learn
and it passes the time
Hooked up on chemo
Seemingly mum was popular
for helping in various ways
Remembered by staff
Why waste an adversity
Learn and share, says Herself

Hair we go

Let’s cut hair before fallout
but why the rush
Wait and see what happens
Same as why worry
about second phase
Take things as they come
Overplanning as bad

Cake walk

Almost, like girlie outing
Full of beans
after second session
Paclitaxel alone bearable
Dashed around the house

Tidying, readying for Christmas
But taste going, and is face drawn?
Avoid unanswerable questions

There is a God

Loud crying downstairs
whilst at desk
as she comes up running
tears running down
Heart sinks, unable to stand
to find, of joy, relief
as CT scan clear
Doctor rang to give news
More to do still
but lot easier now
Dance practice resumed
though not formal lessons
Got to keep fit

Another stellar

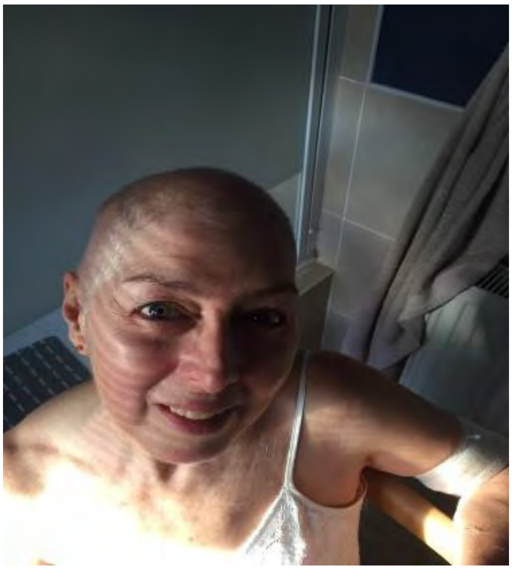
Comes out happy
from seeing nurse
at Denbigh Community Hospital
in time for next chemo
Slowly getting into rhythm
Big worry due to Omicron
but one day at a time
And leave the hair alone
no need to cut before time

My girl

Very doable says she
after one quarter of first round
Three done, nine more to go
Focus on diet, exercise, hygiene
Leave medicine to experts
Help them to help you
Don't think second round yet
In best hands now

Hair today…..

As with everything else
Not waiting for the slow loss
So out with the shears
In with the new look
Better for showing off earrings too



And the son is up

Like the sun
brings light and joy
Much needed, for both
as he comes from London
Mum and son together
If not now, then when?

And so is the tree

Bring out decorations
collected over the years
remembering each one
as put them on the tree
Watch and listen
and share their joy
Made more precious
with all else going

Hard to believe

Fourth session already
One third of first round
Time flies……
as goes off to centre
Bag, check, phone, check
Book, check, water, check
Oatcakes, check and so on ….
New life, routine formed
Not easier but bearable
Got the bugger's measure now
Only worry if beanie matching

Humans after all

Mix up about which chemo
So wait and looong session
Ended up with extra drugs
to counter side effects

It happens

But Nepalese nurse was great
impressed with her Hindi and dance
These things happen says she
Paying price three days later
with flushing and trouble swallowing
as getting ready for Christmas
So the nurse has a look
sorts it out, and all set
for the best Christmas

And it's Christmas

All the must haves
though fish not turkey
and pigs in blankets
for the carnivores
And why not as
Mum and son slave
to get it all right
with presents galore
Kindness and generosity
the best Christmas ever

How do they do it?

Christmas and holidays
Omicron on top
Not just patients but
self, family, friends
Juggling as nurse calls
trying to fit it all in
over long breaks
to avoid disrupting care
NHS at its best, again
Respect+++++++++++

28th December 2021

Since writing the last piece (at the start, Life BC) I have been diagnosed with breast cancer. (Triple negative invasive ductal breast cancer). I am one month into a six month chemotherapy treatment. It has come as a complete shock though the initial trough I fell into has lifted and I hope that we have caught it early enough for the chemo to work its destructive magic. Lumpectomy and radiotherapy await some months down the line but I'm hoping this is not what will see me off.

No HRT even though this cancer is not hormone driven. The fewer things my body has to process, the better for now. Some hot flushes but I think if I keep off the alcohol, sugar and caffeine it might be bearable. We'll see.

The way this chemotherapy works is carboplatin and paclitaxel for twelve weeks. Four cycles of three weeks. Each cycle consists of one week of carboplatin and paclitaxel together followed by two weeks of just paclitaxel. The second half of the treatment consists of four three weekly cycles of EC which is a combined chemo of Epirubicin and Cyclophosphamide. I believe the second half of the treatment is harder than the first. The first half is not that easy anyway.

The staff at the N Wales cancer treatment centre are amazing. Very caring and professional. They seem more like a family than colleagues so supportive are they of one another. They look after me so well. And the soup…delicious! I'm not sure how I feel about the whole thing yet. Rajan is so kind and looks after me without fussing. As does Simon. A lovely week with him over Christmas.

All this is against the new variant – Omicron – which is raging. For chemo patients whose immune systems are compromised, it's a scary time. It complicates everything. No contact with friends – the weather is too cold to meet out of doors.

Blwddyn Newydd Dda

Dips and bounce backs
Keep going the only way
next few months will pass
just like the last three
and before you know
it will be another and
a much better Christmas
Goodbye annus horribilis
Welcome annus mirabilis

It happens

Nadolig Llawen a Blwyddyn Newydd Dda*

Joy to remember friends
Give thanks for company
On life's journey
Each year more peaceful
When count blessings
More vivid with covid
And various setbacks
As one gets older
Knowing time limited
But ready for everything
Stronger due to you
Always in our thoughts
Joining in spirit on the day
Will raise a glass (or two) 😊

With very best wishes
Rajan and Helen

- *Our Christmas 'card', photo from times BC*

31st December 2021

New Year's Eve and in bed at 9.30pm after having tried and failed to set up a Wi Fi device so that the internet is available in the spare room where, sadly, but of necessity, Rajan is sleeping at the moment. He's not pleased by my purchase of the small Wi Fi device which needs to be charged daily. So, I've retreated to bed tired and cross. This on top of having thought I'd left my phone at home earlier when we went to the hospital for my blood tests – I couldn't ring him to let him know to come and pick me up so I had to ask someone to ring my friend Pamela so she could ring him…after having a lecture earlier for not zipping my bag up. And yes, the phone had been in the bag which he passed to me in the car emptying the phone into the picnic basket as he did so….

*We are both cognitive function f**ked at the moment. Both trying not to be cross and actually succeeding. Off to Rhos on Sea and the delightful St. Trillo's Chapel, tucked away below the Marine Drive, looking out to sea. Well worth the walk even if I am completely exhausted by it. Another day of the 24 weeks gone. Thank goodness. Let's hope 2022 will be OK.*

This too shall pass

No taste, says she
Eating for its sake
And the brain fog
Forgetful and tearful
Thankfully aware
Insight and sight of
big party and travels
at the end of it
Picks herself up, again

And how is it for you (carer)? - I

How are you coping
They all ask afterwards
knowing background
with recent loss of mum too
It is what it is, the only answer

It happens

Some days good, others not so

giving up not an option

so draw on the reserves

and replenish regularly

Life is still beautiful

Checkpoint (1)

Halfway through first phase

Can hardly feel bugger

Happy doctor, happy patient

Time standing still one hand

As ground hog day ……

And flying on other hand

As already 7th chemo

Keep going, soon be over

17th January 2022

Strangely calm after my consultation with Dr Julie Jones. The tumour has shrunk so much she can't measure it manually. The horrible chemo is working. I had no idea it was developed after a doctor treating gassed soldiers in World War I noticed that their blood cell production was affected by mustard gas. So, I'm being mustard gassed! Sort of, but nothing like those poor soldiers and horses. Better not to think about that too much.

Still a bit prisoner-ish here though we did have a grumpy outing to Prestatyn. Both in a bad mood. Well….tomorrow is another day. At least the dogs enjoyed it a bit.

*Rajan struggles with his Congruent Depression; his baseline S**tometer is high and he starts his days with the black dog, whereas my base line is maybe a bit too jolly sometimes. After the initial diagnosis and the thought that my life was about to be snatched away from me, I'm now more positive of a good outcome. Nothing is ever guaranteed but we can only hope that this is not going to see me off just yet.*

We come into this world on our own and we leave on our own. Book of Job. Jolly, eh?

Teacher's pet

Likes going for chemo
as if seeing friends
Loves the food, banter
Discipline and practice
with diet and exercise
and busy with housework
Reports she, on how's it going
Very impressed, says doctor
Full marks, bound to ace it
Comes out smiling after consultation
like a happy kid from school

Do not forget

Chemo brain, says she
making her forgetful and repetitive
But what's your excuse
for being curmudgeonly
Maybe it's sadness or helplessness
But do not compound the misery
Get help to help her if needed
Be patient with the patient

The Dip (2)

Low energy, no walking dogs
Lying on sofa, falling asleep
partway through film
Tingling feet, small nosebleeds

Old medical issues resurface
Taste gone too, but……
it’s eighth session, two thirds done
So puts on brave face
Trots off to bed early
Tomorrow another day

Solidarity

Good chat with fellow traveller
as her friend rings up finally
Was trying to get head together
and now feel able to talk
Acceptance important, though takes time
and each one has their own way
Nice to hear both chatting
and laughing about it
Do whatever works but clamming up
self-pity and anger no use
Plenty in same boat
Problem shared, problem halved

Getting there

Tenth session, last of double drugs
in first phase of chemo, with two left
before the big un’s in second phase
This too shall pass, though may be rocky
But no getting ahead, will deal when it comes
For now, ten done, six more to go
Have done, can do and will do

Penblwydd hapus

Special date 2-2-22!
Muted celebration so no different
to last year in lockdown
Had practice but still not easy
as poor taste and swallowing
and lacking social contact
But if the pain means more birthdays
then worth the temporary setback
Will do a proper celebration next time

The Dip (3)

Getting more difficult as builds up
tastes like washing up liquid
Starts doing something then collapses
Huffing walking to upstairs lounge
Gut misbehaving, bunged, bloaty
All adding to anxiety about second stage
Supposed to be worse
And Welsh opening rugby game no help
No match for the strong Irish squad
as lying on sofa under blanket
Double misery

- *Six Nation Rugby tournament*

Them steroids

Good for two days after session
Comes down with a crash after
Best and worst, round after round
Maybe easier in second stage
As three weekly rather than every
Clutching straws, may be
but something to aim for
What else is the choice
Says she on way to 11th chemo
And then there is the soup
after the lovely pre-med
See-saw, roller-coaster, runaway train
All at once, some ride, hanging on

On the one hand….

Tingling feet and hands worse
but one more dose to go
Should I or not
On top of worry about next stage
EC* worse than CP or is it
And should it be 3 or 4 cycles
No universal rule as centres differ
How to decide
In too difficult bucket
Pain now or pain/regret later
Naughty bugger this TNBC
wait till talk to doctor next time

* *Second part of chemotherapy*

Some relief

As Simon comes back
Mother and son quality time
Had saved lots of jobs (*sic*)
put him to work straight away
Stacking logs, cutting hedges
Whilst yours truly recharging
Important for carers to have breaks
And some change for patients too

And then it happens

Going for last chemo in first stage
Drat – test shows neutrophils too low
Sent home to recover and back next week
Just when coming to terms with it
having had some low periods
and psyching up for second part
Will the setback delay treatment
Will these episodes recur
What to do or not to do
Is there more risk of infection
Mind reeling but sit tight
Seeing doctor next week
At least got this far with no hiccups

Mind your language

No point battling cancer
Fights are tiring and draining
More like on train in bad weather
Diversions and dodgy buffet
Sitting tight, hoping will arrive

Not being passive and
in no rush to embrace death
But also not denying it
It has to do its job
I will do mine, by surviving

- *Helen started following Liz O'Riordan – https://liz.oriordan.co.uk/ - who also calls out the Fighting/Battling metaphors.*

Generosity continues

Finding ways to make a difference
As e-gift cooked food voucher arrives
in case not up to it or want change
Others offering social distanced teas/lunches
Opening up homes, making favourite dishes
Friends watching, caring, stepping in
Feel blessed and give thanks

And they are off - Part 2*

Day of anxiety
Blood test today
Will it be OK

It happens

Have missed dose or press on

Two camps among expert friends

Less is more versus

give it everything now

Listen to all but make own mind

Trust the treating doctor

And so on to stronger stuff

- *Epirubicin and Cyclophosphamide (EC) – cancer drugs. Helen could not have the 12th session of CP drugs and was moved onto EC drugs.*

It would have been a miracle

Stuff happens even with best systems

as blood tests slip through, notes not up to date

Decisions made by default and variable evidence

Herself grateful for everything, blind faith

Self questioning, knowing things do go wrong

Not about blame but about learning and preventing

No need to be defensive, glad things are still working

knowing the state of NHS and problems elsewhere

Going to have some blood transfusion and

keeping medicines under review

Dejected but then perk up and give thanks

Feel lucky and grateful to have got this far

2nd March 2022

Things they don't tell you about chemo until you're in the middle of it. Taste. Everyone is different. No actual nausea but on the different chemos you get different reactions. EC makes food during the first week of the cycle taste of soap and has the texture of cardboard.

Brain fog. No focus at all! Short bursts of energy which fritters away. Even jigsaws are an intellectual mountain I can't climb some days.

It happens

It's soooooo boooorrring!!!

Even really good friends must get fed up listening to my steroid infused witterings.

It's a very emotional journey. On Monday I watched my dance teacher's daughter perform online at the Nantanjali festival through a complete fog of tears. Such a beautiful dancer and a wonderful performance. Two years of hard work for me and I can't even remember the basic Adavus (steps). My neighbour, Paul, tells me that my muscle memory won't let me down once I get my strength back. I hope he's right. Maybe I was a bit ambitious trying to learn this complex dance form at 63. But age is a number if you're fit, which I was. Keep the faith, Meera!

I feel calm, happy and blessed which is a huge surprise to me.

No appetite. Eyes are no good. Hearing is rubbish. Thinking gone. Ah well, another ten weeks. God help us through this. If there is a god, which I don't believe there is. I couldn't be better supported. The day I took Rajan as my partner was a blessed day indeed. We are now focussed on our future together and I hope it will be long and healthy.

On high alert

Scary stories of febrile neutropenia
Bone pain and tiredness
hair loss not just eyebrows
nose also, cold air, runny
swallowing hard, food tastes soapy
and the hot, stinging wee
Trying soups and copious fluids
Resting, making jigsaws and watching TV
Though Welsh rugby performance sad

- *1000 piece jigsaw*

Boring is good

Got up, ate, pootered, slept fitfully
Did whatever to fill the time
Nothing on to do list today
Just like yesterday and one before
Not rushing to save mankind
make millions and impress folk
Just being, at home, with mutts
looking after each other
watching hills, clouds and stars
Cries of new born lambs wafting up from barn
And if same tomorrow then wonderful
Every day that passes one step closer
Boring maybe but still here
Times to get up and go and
times to sit and rest
Could be in a worse place

Febrile Neutropenia

Is it or is not it
Suddenly deflated in morning
after not so bad days
Evening temp goes up
High but not enough for hospital
Take advice from friend
very calming manner
explains slowly and clearly
what to do and look for
Day eight after chemo
Already on G-CSF*
Stressful but not to panic, yet

- *Treatment to stimulate growth of important blood cells, which get destroyed with cancer drugs.*

And it is

Good night and breakfast
Felt rested, and then wham
Backpain, fever, shivering, burning wee
all happened over two hours
Nurse says come over
so rush to hospital
Just as well in afternoon
when cancer centre open
did not fancy trip to A & E
Super busy but take her in
Tests and rest till results
Filling her with antibiotics
Blood counts in boots
Staff searching for bed
Finally find one

Why me?

Doctor says unlucky one
But were there signs
Could it have been
detected early or prevented
Hindsight but still useful for
how to avoid in future

as three more cycles to come
No over analysis
but be watchful
Help them to help you
Ask questions and listen
Together we know best

Home alone

Leave her in hospital
and head home
Mutts to care for, clingy
following everywhere, looking

Lost in thought, sleep elusive
Listening out for phone call
But thankful, at least in safe place
they know what they are doing

Hospital stay (Day 2)

Drifting in and out of sleep
Passing time on YouTube
and thanks to iPlayer
Oh is that a painting
the view from bed

As always cheery and
thankful to the staff
Says first class service
Clean linen, towels, food
No news yet re when home

Wednesday to Sunday in the Cancer Unit in-patient department

For three days I felt as if I was made of gossamer wings. A puff of wind would blow me away. I had no weight, no strength, no will, no joy, no sorrow. A sort of limbo between living on earth and being in heaven. A wraith, a will o the wisp. A shade, a ghost. I hope this doesn't happen again.

Neutrophil count 0.05.

Back home

Four nights in hospital
Thank the staff
Hopes not to see them again!
What next, for another day
Quality of life
now vs in future
But need to get fit first
so hunker down in bunker

Passing time

Extra careful now
no mixing with people
just me and you
And dogs named Ifor and Delyth

Up in the hills in windy Peniel
remembering, planning
getting on nerves (not)
Dogs named Ifor and Delyth

Gardening, cooking, reading
gentle walking when able
and watching them frolicking
Dogs named Ifor and Delyth

It happens

- *Apologies for mangling the famous song, Me and you and a dog named Boo!*

Looking the part*

Finally says she
With loss of eyelashes too
Sunken eyes, bald head, drippy nose
Not cachexic but weight loss, cancer patient

- *After hospitalisation for FN*

Pandemic fears

Really short memories
Or life must go on
As all precautions to wind
no thought of pandemic
even as numbers high and rising
Worrying, but what else to do
Only what's in own control
Do not outsource personal safety

Life is for living

Break in weather
so pack lunch and
mutts in the car
Off to explore
history and nature
Up Denbigh moors
through Ysbyty Ifan
Harlech here we are
Glorious day, admiring beauty
giving thanks, enjoying small things
Makes a big difference

Anxious night

Nurse rings about session tomorrow
Come early as need another blood test
today's shows high platelets
And the mind goes berserk
Googling, sending messages to friends
What does it mean and what to do
But mostly in dark, as not enough info
Need to wait till morning when see doctor
but worry about not having enough time

to digest and make informed decision then
Her life but not in her control, system takes over
For first time rocked, usually unflappable
Still reflecting on last session
If not preventable then predictable?
Hindsight and foresight, need both
Not looking forward to visit tomorrow

Much ado about nothing

Turn up in hospital, apprehensive
and calmed by the doctor
Listened and explained well
Yes, unlucky and yes, platelets high
but go ahead with next chemo
Safeguarded by lower dose, better G-CSF
Felt more assured, keeping fingers crossed
Wait and see what happens this cycle
Also clearer about options from now on
Lesson, mind in overdrive inevitable
Very important to talk to doctor
Question but also trust them

- *Helen was switched to Long-acting G-CSF; a personal, and painful, reminder of my time as a medical director when I was responsible for making NHS decisions about which drugs to use and when*

Bounce back

Says felt lot better last few days
even forget that have cancer
especially when went to Harlech
Drove there and back, long walk

As if in old days, can beat this
And life will get back to normal again

Totally different

EC nothing like CP says she
Hard to describe, as if something gnawing
Snaking, whacking inside and making tired
Not as much chemo brain as physical

Worst the pain on peeing
Despite gallons of water, vicious cycle
As drink more, pee more
Finally cranberry sachets some use

But every day that goes, closer to end
So finds the reserve and carries on

Gotta keep moving

Quick, a chair
As she wobbles
making pancakes
to get back taste
and do something
Wrecked yesterday
when felt like giving up
Woke up, determined
Life is for living

making an effort

Do what you can

So she tries

PS: The pancakes were yummy

20th March 2022

Gorgeous day. Made higgledy piggledy pancakes. Two hander, sitting down and in three episodes. Poor Rajan. Have I got some repaying to do after this! That man is just lovely. I'm so lucky.

Joys of small things

Sunny, dry, clear, watching hills

and fields full of life

As birds and animals perform

playful lambs, occasional hare,

Tell-tale signs of elusive mister moley

To remind of life as sit with low energy

Nights like days with full moon

Makes all the difference

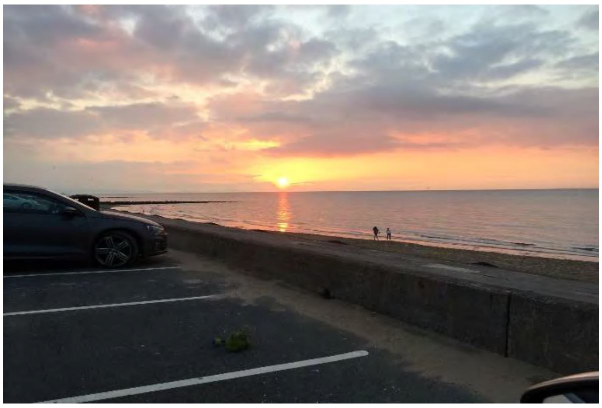
It happens

Looking ahead*

Already forgotten first part of chemo
Never going to look at the past
Waiting to find out more
Scan tomorrow to check bugger
wonder what it will show

Strange stuff EC, says she
Hit, down, up, only to be hit again
Anyway, two more cycles to go
Having bounced back after wretched days
Full of energy, so off to seaside we go

- *The third week in EC cycle seems OK, the worst period being 4-12 days post chemo*



1st April 2022

April Fool's day and not much fooling going on.

Another lovely day here. Snow yesterday but cold and sunny today. I have reasonable energy considering but dread next week. Third of four EC chemo. Each time is different but we'll get to see the consultant and see the results of the latest scan. I just hope we've got the better of this horrible disease. I want to live and love and enjoy some time with Rajan and one day, one day, grandchildren.

Simon and Megan are in Iceland and having a great time. It looks a bleak old place – not for me! (I later learned that they had contracted covid whilst there but were isolated anyway so it didn't spoil their holiday).

We went to the Wirral on Wednesday as Rajan has just been offered a position as a non executive director of the Wirral University Teaching Hospitals NHS Foundation Trust. Good that his experience will be fully appreciated. Let's hope this year brings some real rewards for all our hard work together and all his struggles will pay off. I feel calm, blessed and happy and I hope he can get the same. He's been running in his head for too long.

Yesterday we heard that his dear friend, xxx, has had a TIA. He and his wife sound a lovely couple and have been very supportive of Rajan over the years. I have not met them but hope we can meet up soon. I don't want to miss them as I think xxx has had a huge impact on Rajan and is a sort of mentor.

Covid is still here. More and more people we know have got it. My 96 year old sister in law has it. She's not physically affected much, just cross and affronted! Eileen is indomitable. I'm very fond of her.

Others have fared less well with Covid. Neighbours in Llanbedr have been very ill and very tired afterwards. They are feeling weak and tire easily if they do any walking etc. This virus is so strange. I hope I don't get it. I don't want to fall at the last hurdle of my chemo.

Wobbly

Do not want to go for session today

Very unlike as usually up for it

Running out of steam

Tries to get out of fourth cycle also

Esp as needing another transfusion

But then buoyed by news of clear scan

with surgery planned for May

Really hard this stuff, longest chemo says doctor
but nearly there, hang on, not long now

- *Day of third EC session*

Wobbly+++

Day six, third cycle EC
Absolutely knackered, fed up
Can’t stay in bed but can’t get up either
Comes down after lunch but not for long
Thankfully no burning pees or bone pain
Tired yes but more than that, weary
Old nail infection flares up
Antibiotics from the GP to rescue
All made worse by phone scrolling
reading about TNBC, thinking worst
Can not be cheered, just have to survive
Be there and do what you can
Hopefully will bounce back soon

Not quite but…….

Start gaining strength
Danger of overdoing, so go slow
Small things and enough rest
Patience patient!

Musing

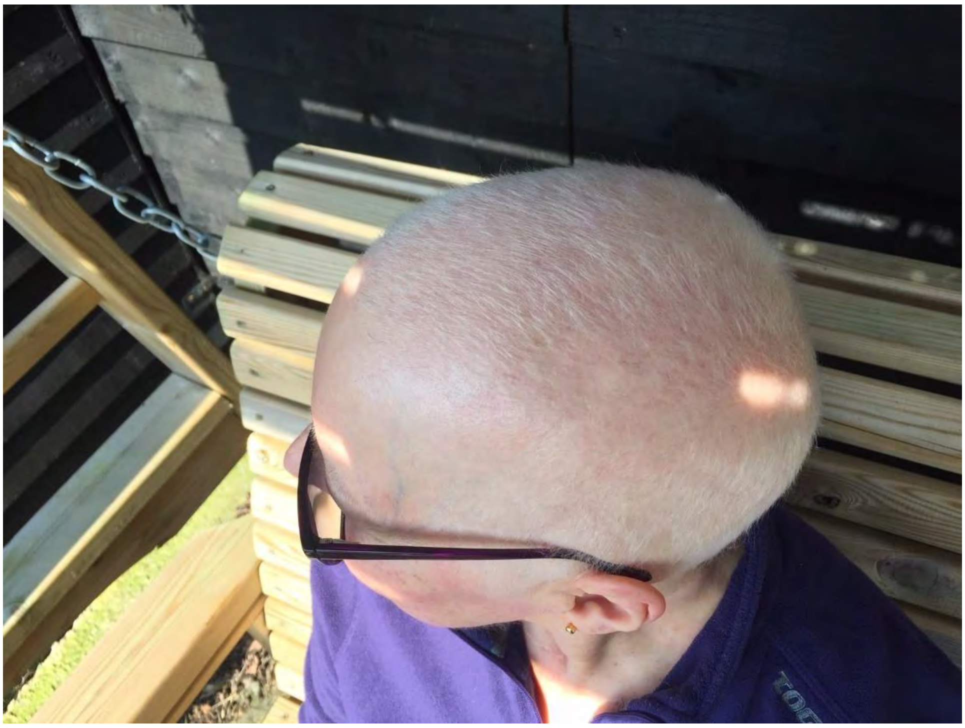
The worst things about this cancer

Side effects known and expected
but the duration of chemo surprise
and brain fog most challenging
Not in control anymore, no concentration
Learner driver (patient) with instructor (chemo) controlling
Was the time wasted, just surviving
Could have spent it working in studio
catching up on painting, readying exhibition
In theory yes, in practice not possible
says she, in reflective mood
Focus daily on getting through day
There will be time later, hopefully
as on home stretch, one more chemo to go

Not wobbly!

Cheered by growth on head
Life coming back
though says just as well no hair
during chemo with PICC line
Hard to wash and one less worry
Two more days before last session
Enjoy small things, sunshine helps too
For now stop thinking what next
Still some way to go
Surgery, radiotherapy and the rest
Que sera, sera , live the moment

It happens



BIIIIIG DAY (last session)

The final EC chemo today
Happy but also reluctant
Wish did not have to do this
Afraid and what ifs on mind
Also need to find out what next
Keen to get the operation
and know where we stand
Whole lotta of living to do
What with pandemic and then this
Need to catch up, and hopefully will
So off we go…………

BIIIIIG DAY (2)…..

It happens

Not personal, but won’t miss seeing you
as meet her for the final chemo session
operation to follow, rest after biopsy
but for now, over to the surgeon
says the doctor, and yes, get the PICC line out
Yippee…………

BIIIIIG DAY (3)………

Comes out smiling, bouncy step
No more chemo, no more PICC line
Sings praises of staff, will miss them (*sic*)
Says like leaving a happy job
Messages pour from friends on milestone
Too much excitement, so crashes to bed early
Focussed on surviving next few days

It happens

[Helen Job finishes chemotherapy - YouTube]

Onto the practical stuff

Planning future, life been on hold
Can not wait to get going again
parties, friends and travel
For now a walk on the beach
But hang on, passport runs out soon
and how to take a photo with no hair
maybe that wig after all, she reckons
Hey ho…………..

Not quite, yet

And messages start pouring in
with invitations for bubbly and brunch
to mark the end, from friends
as word spreads about last chemo

Not quite, sadly, not over yet
But nice to know, and not too long now

On the home stretch, ….slowly

As before, wham, days after last chemo
Not so good, no energy, no patience
unable to stay out of bed for long
Every meal brought up, tasteless but must
with snooker to keep company
Wary about things going wrong
Never again, prolong life at what cost
Hopefully turn corner next week

- *Ronnie O'Sullivan won the world snooker championship for the 7th time!*

Profound

So what have you learnt from the experience
Me: Stuff happens, tough, suck it up
Her: You Tube is good

12th April 2022

Rajan asks, frequently, what is the meaning of life?

So, after some thought, for me it's…

Love – for all creatures and life.

Respect – for all creatures and life.

Honesty – with everyone and particularly with yourself.

Kindness – in all our dealings. Remember the days you were weak or troubled.

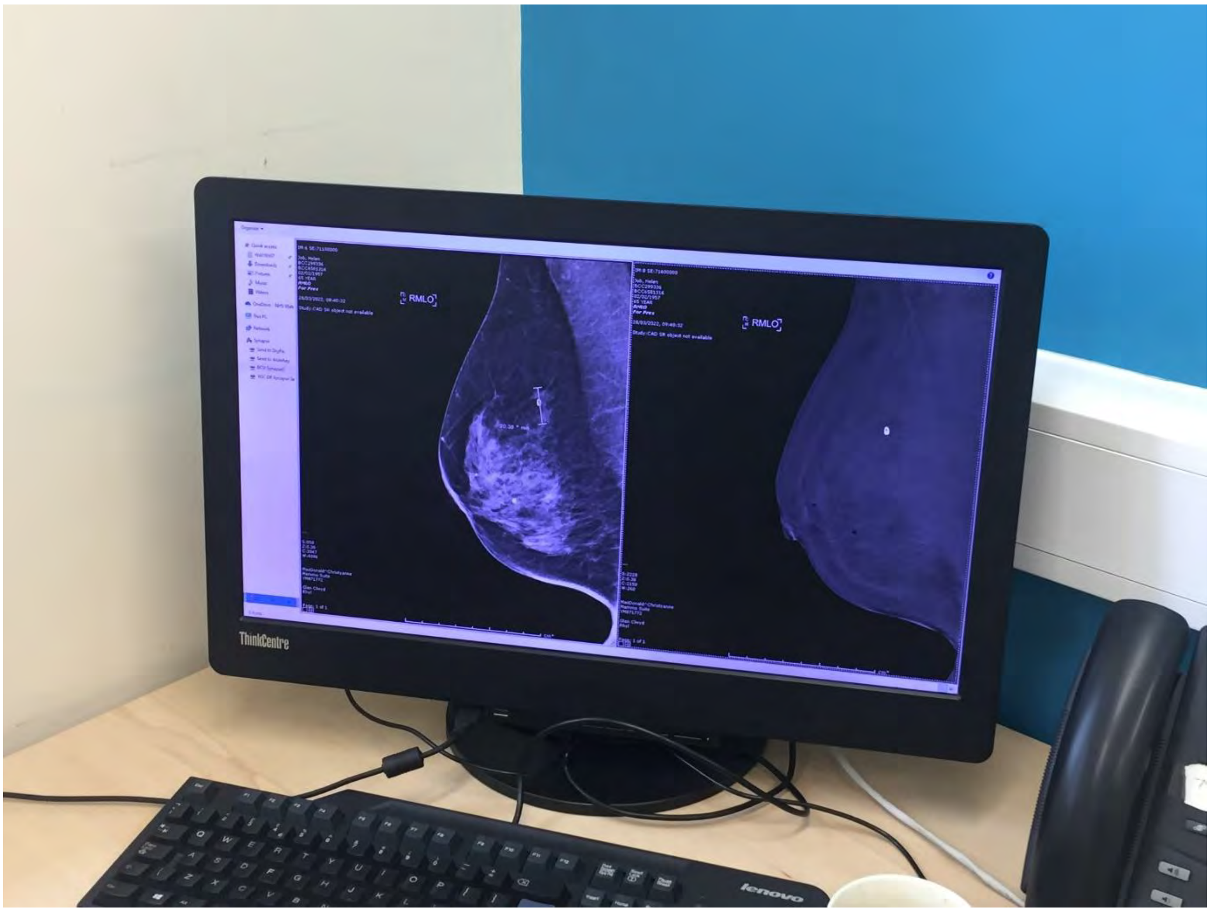
On way………

The day finally
Seeing the surgeon
Wonders what is in store
Says last session has drained
Cumulative effect of friendly poisons
Worries of longer term effects
heart problems, cancers
Will never be same
But enjoy now

Part 3b: Let us go get the bugger- Phase 2 (Surgery)

And we have a date…

Happy surgeon, looking at scans
Should be straightforward operation
Takes his time, explains everything
Ready for the knife in 4 weeks
Comes back clutching more info
with dates for pre-op and operation
and falls into bed, tired
Every bit of effort hard, says she
But should be ready by then
……Hope so



Voila

12 days after last chemo

Been feeling wrecked lately

Finally found the energy

to get going in studio

Even walked up local hill

first time in 3 months

Mutts happy to have her back

Tired after 300 yards

but it's a start and sun shone

Not long to surgery now

gotta be fit for it, says she

3rd May 2022

After several months of chemo, feeling scared, tired and upset what have we learned?

Rajan says "Stuff happens" but we knew that already. I've learned that You Tube is pretty bloody useful and very entertaining. It's so egalitarian. People put up the most amazing videos. Some are trying to save the planet etc but most are hilarious. You can lose yourself in it for days. From the Royal family to dog rescues, Johnny Depp defamation trial to useful domestic gadgets that will transform your life, apparently! The audio books and films have been a life saver for someone whose brain has gone into survival mode and is addled by chemicals. At three in the morning there is a whole community out there commenting, posting and generally awake and alive. But whatever you do, see it for what it is, a bit of fun, don't take it too seriously.

Another day trying to get on with things, getting dizzy and falling back to bed. Grey skies overhead but the weather is OK. On days like these it's hard to have faith that you won't always feel this fatigue. Faith in the next day is something that's seen me through so far. And faith that I'll recover from this.

Chemo is a perilous journey. Infection looms large, a tightrope walk between reaching the next cycle or falling off and ending up in hospital again

And the collateral damage years down the line. I'll probably find out (if I'm alive!) what damage has been done to the heart, liver etc. My brain has taken a hammering also, but I hope I'll recover that. In the time I've been under chemo Ukraine has been going on, Covid has continued and all sorts of catastrophes have befallen *family, friends and strangers. I haven't been oblivious but I haven't been able to engage at any meaningful level. I've been in limbo on a horrible journey of my own.*

But, Rajan has been here and made it all possible, if sometimes in silence! As Covid restrictions are gradually lifting people are getting on with their lives and some have forgotten about me, I'm sure, and why not? People are busy.

Yippee…. Whatever turns you on (10 May 2022)

Finally, off to shops for groceries

Not been for six months to isolate

Relying on yours truly, not a keen shopper

Been missing some of her favourites

Comes back smiling, and so is yours truly

Over to you from now on, my dear

Both happy, a win : win

Reasons for living

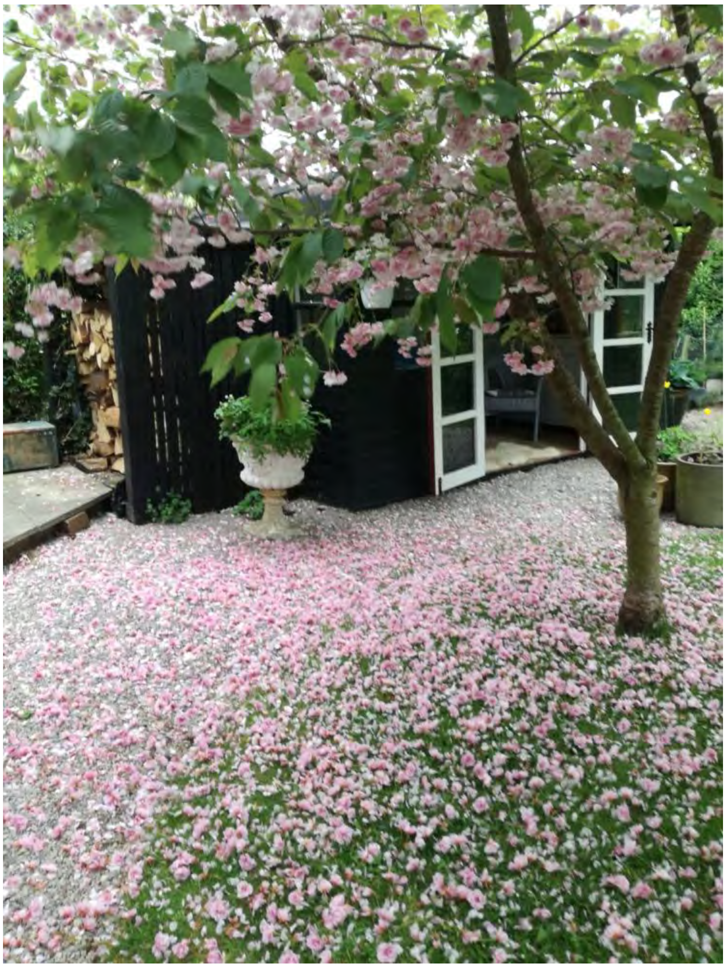
Let me count, says she

Beautiful days in Peniel

Garden in full bloom

Friends, family, skies, beaches,

hills, nice wine, meals
Having a bloody good laugh
And do not forget Me!



Countdown (1)

Worried about operation
More what If’s
What will biopsy show
More treatments, when
But for now, get to first base
So off for ‘Magseed’ to mark site

making it easy for surgeon
Quick but sore procedure
but comes out happy
as radiologist impressed
Can not see the bugger
Next stop pre-op assessment

Countdown (2)

Relief! Letters arrive
after pre-op yesterday
Covid test Tuesday
Then isolate till operation
Report at 7:30 on Friday
for day surgery
after six months of chemo
But time dragging now
Drawing on last of reserves

Pushing out the boat

Even a big birthday party
First one in long time
Offer could not be refused
So dressed to nines
with the must have new frock
Strange but pleasant
being around people
Cake and fireworks to finish
Worked wonders for soul
Trailer of life to come, energised

Countdown (3)

Up at crack of dawn
Bag packed, off to hospital
Excited though daunted
and ready for the op
Surgeon says all well
No sign of the bugger
Checked with scans
Zapped, nuked, kaput
Comes back with blue tit

But not so fast

BP low, sugar up
So observe for a while
and then bye-bye hospital
Except not quite ready
Collapsed in heap at door
SOS to neighbour, arrives fast
Not so fast with ambulance
3 hours wait says 999
Draw on long forgotten medicine
Check vitals, slowly comes around
Manhandled to bed somehow
Pasty, grey, but less dizzy
What if neighbour not there…..
In for an interesting night

It happens

- *Thanks David*

New dawn

Exhausted completely so slept well
Resumed Depp Heard case
as if preparing for Mastermind
Well, whatever helps
Feel revived next day
after scare of last evening

28th May 2022

Operation yesterday. 7.30 start but once there your feet don't touch the ground.

Radio active injection to locate the lymph nodes with a Geiger counter. Blue dye in the breast to see which way the lymph nodes drain. Anaesthetic then oblivion while they retrieve the sentinel node and send it off for biopsy. Whilst waiting for the result they take out the tumour site and some margin. The biopsy came back clear so no more nodes removed. Hurray!

Recovery room. Low oxygen so a mask on and then up to the ward. But my blood pressure was very low and I tried to get up but failed. Then we discovered my blood sugar level was high, 18.4. Bad news! Drank lots of water, reduced to 17.1. BP up a little bit.

It happens

Wheelchair to the car. Felt terrible but got to Peniel OK. However, I passed out and Rajan had to get help. Lovely David came and I got upstairs on my hands and knees having realised I'd wet myself! Mortified! But Rajan says that can happen when you pass out and sometimes the rear lets go, too. Luckily it didn't!

Here I am in bed. Watched the Depp/Heard closing arguments. That woman needs locking up! She lied and lied and lied on the stand and then her lawyers did a masterclass in gaslighting.(That's my opinion, and probably millions of others) but Johnny Depp's lawyer, Camille Vasques, was amazing. Verdict next week.

Note: He won! And in some style.

Upwards and onwards

Excitement, long overdue, finally
Resuming life, visitors lining up to come
Booked trip to Islay, for whisky tour
And planning Freedom party

- *Rajan's brother coming over from India at the end of June for holidays, and few other visits lined up*

Cor Blimey

Like hit by cricket bat
Bruised all over, day 3 post op
Must have bled afterwards
Setback as was raring to go
Realises need to take it easy
and let it all settle down

It happens

Not so fast

Cancer centre nurse says come over

to check out bruising as unusual

Blood transfusion as low haemoglobin

Ultrasound scan and attempted aspiration

Known complication, but why me

- *Fifth post op day, ended up in Glan Clwyd for the day. Second unplanned visit; first being febrile neutropenia.*

31st May 2022

Slump! I feel I've climbed a mountain, got to what I thought was the top only to find it's not. But that probably speaks more about my personal expectations of my body. Surgery is not the easy bit as I had imagined it to be. There's extensive bruising and some pain and swelling but my blood response has taken me by surprise. Still dizzy several days after surgery. Could I be a little anaemic? Certainly frustrated at not being able to achieve what I want each day.

Me and tech. Tried to ring the dentist. Line busy all day. Tried to speak to a doctor at my surgery, no chance as I had missed the slot to book an appointment. Tried to book a blood test, line busy then the time slot for booking ran out, 10am until 2pm.

It happens

Tried to connect the printer to scan and email, one and a half hours, no. Internet going on and off all day. Tried to send pictures of the form I was trying to unsuccessfully scan and send, via my phone. File too large to send. Ironically the form I'm trying to send is to get the grant to improve our internet. They only respond to email….Grrr! No reliable internet to send the damn thing!

In the end I printed off a hard copy (via Rajan's phone which actually talks to my printer, unlike my computer which seems to be on nonspeaking terms with the printer at present….don't ask me why…they fell out a few weeks ago) and sent it to the IT people in Ruthin for them to scan and send via email….why oh why???? The dentist responded as did the breast care nurse. Blood line people again this morning, hey ho.

Everything I touched yesterday turned to dust. Shopping this morning. One of life's small pleasures and Simon tomorrow, smiley face, thumbs up!

By the way, the reason for my feebleness and muddle headedness was a massive haematoma. No wonder I passed out on the drive arriving home from the hospital. North Wales cancer unit again, blood tests, ultrasound, inspection of surgery – bruised all over both breasts and beyond – more blood into me and felt instantly better. I should learn to listen to my body when it tells me all is not well.

And how is it for you (carer)? - II

Knackered physically, mentally

Being alert all the time, at a price

Days like yesterday, so near yet so far

Compassion fatigue compounded

Just about hold it together, as one must

Do not under-estimate, and be careful

This too shall pass, keep remembering

Getting there, slowly

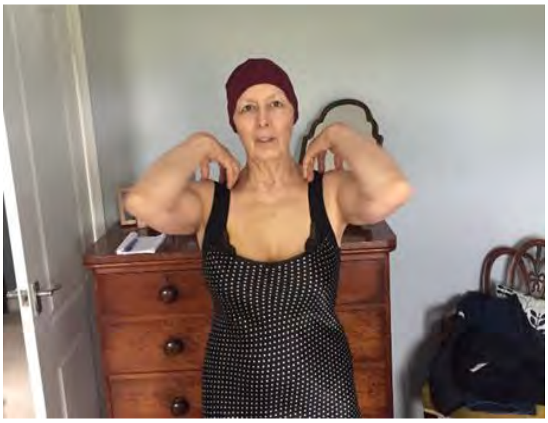
Day 8 post op, black and blue

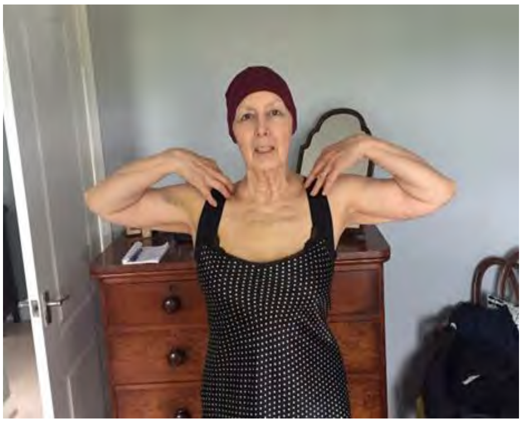
Bit tender but bearable, says she

Gotta keep going, do what you can

Exercise gently, not easy for impatient patient

It happens





Getting there, very slowly

And the waiting goes on
with spectre of another transfusion
Bank holidays may delay biopsy report too
In limbo…………….

And the final answer is………..

Got the bugger, mostly
The poison worked its magic
Smidgen left, but down graded
Nothing extra needed
just some rays and bone protection
says the oncologist
But first a break and to recover
Time off for good behaviour
By chance, cousin drops in, sun shines
and all is well with the world, for now

Sod's Law

Unusual to begin with, TNBC much less common
as are febrile neutropenia and surgical heamatoma
Happens to doctors and near ones, common saying
Not sure as can happen to anyone, but hope not often
Come back deflated, after another attempted aspiration
10 days post-op, wonder what else in store
How much more reserve in 'mental' tank, 8 months later
Need to dig deeper, reminder: this too shall pass

Look on the bright side
Can have proper shower, says she

I fyny ac i lawr

Up and down, finds reserve then goes empty
Short exertions ok, but tired with longer
Frustrating for active folk, getting fed up
Constantly feeling haematoma, heavy, achy
Google helpful earlier now source of anxiety
As keeps reading RCB and survivals

No one knows what else to come
All we have is, here and now
So sit on garden swing, up and down
Listening to sheep, cows and birds
Nature's symphony, what joy, priceless
Glad to be alive and that's enough today

- *RCB- Residual Cancer Burden, indicator of how likely to come back. I have been learning Welsh, apart from piano (both badly). I fyny ac i lawr: up and down (Welsh)*

Yippee (21 June)

Finally lap of Foel Gasyth
Her daily 3 miles hilly walk for years
restored after six months
Bit slower with some stops but made it
Happy, gotta keep going, up and at ‘em

And the surgeon says….

Coming along, should resolve
Feels not so hard and smaller
One more check may be
Confident surgeon, happier patient
Different matter that Covid booster
and broken tooth taking their toll
Slow and steady to build strength
says he, may listen to him
And beanie ditched, hair sprouting!

It happens

22nd June 22

Hot weather again today. Had my fourth vaccine yesterday and feel a bit rough. In fact I had a bit of a wobble – broken a tooth, toenails are disgusting, breast still sore and now the vaccine injection site is very sore making it difficult to sleep except on my back – snoring! This makes my mouth incredibly dry and must annoy the life out of Rajan. However, aren't we lucky that people have developed and delivered vaccines? And people have trained to be dentists, surgeons and GPs?

Rajan and I had a chat the other day about the end of life (Rajan is on the Clinical Advisory Group of My Death, My Decision Campaign). We often do ruminate on such subjects irrespective of the present circumstances. It must come with the territory of being in our sixties. I reckon there are several things to be considered when thinking about a planned end of life scenario:

1. *How much love surrounds you? What holds you to this earth?*
2. *Have you done everything that you can do? Is there anything you can put right that you put wrong? Is there anyone you need to help before you go?*
3. *Is the pain too much (including mental anguish, which I think is probably the worst pain available to humans) and unlikely to abate?*
4. *Have you settled your affairs? Never leave a mess for others to sort out when (we'd like to think) they might be in grief (but only for a respectable amount of time before they get on with living and living well and happily),*
5. *Are you really ready to go?*

So many elderly friends seemed to have no quality of life and yet didn't want to die just yet. Others have died suddenly and shockingly. What actually holds us here? I felt suspended between heaven and earth in hospital with neutropenia. I couldn't understand how my organs continued to function. How did my heart carry on pumping the blood? How did my lungs and my brain function? Such extreme *weakness and yet everything continued to work. Eyes, ears, mouth, nose, all the senses worked and yet even my finger tips felt weak.*

The blood circulated even though it was devoid of neutrophils. I do wonder what damage the chemo might have done. What are the long term effects of neutropenia?

So I need to stop complaining, enjoy the lovely weather and look forward to our trip to Scotland (rain forecast). It's time we started living since we are actually alive.

And some R & R

So off to Islay, Scotland

Long drive for a short visit

Herself being designated driver

during visits to distilleries

of which plenty on the island

But all happy, so she says

Driving three Indians to drink (*sic*)

Much needed break, with visitors

Part 3 c: Let us go get the bugger - Phase 3 (Radiotherapy -RT)

More to come (1)

Not over yet
Gonna give it all
Drugs, knife and now rays
Not taking any chances
So, turn up for radiotherapy planning
only to find haematoma a problem
Needing another surgical review
Deflated, no end in sight yet
but not defeated, buoyed by holiday

More to come (2)

Better but not quite, says surgeon

So booked for scan and aspiration

failing which minor operation

Still within 90 days window for RT

Though sooner see the end, the better

In limbo, but thankfully not laid up

So up and at ‘em, says she

11th July 2022

Emotional energy. BBQ with friends on Sunday and it was great fun. Hot sunshine but as always in Peniel, a breeze. Very pleasant.

Completely knackered in the evening. I’ve been feeling a little nostalgic and sad about my life recently. I suppose it’s tiredness which brings me low. During chemo I protected myself from negative news and anything or anyone with high emotional energy needs. I restricted my interaction with people so as not to drain my own emotional energy.

I’m gradually getting back into the swing of life now. I still don’t want to know about situations I can’t do anything about. I’ll give money to help but I don’t suppose the people in Yemen, Syria and Ukraine will be aware of my angst for them but will be pleased to have some financial support. We engage in too much hand wringing in our comfortable, pleasant, peaceful countries. We watch TV and cry when practical help is required in fact. Causes become fashionable because they are reported. The Ukrainians look like us Europeans so we identify with them more. But the children of Yemen, Syria, Afghanistan, Africa are in equally bad situations. Worse in some cases.

Do we accept that war and conflict, political exploitation, are just part of human nature? The world is always in turmoil, we now have the means to know more about it with moving images and more detailed information, all at our fingertips.

On the home front, the haematoma is still very hard. I’m hoping this won’t delay the radiotherapy too long. I just want all this to be over now. We had a good five days together in Scotland. Haggis was elusive but we had plenty of fish. And the boys had a good share of whisky! We were lucky with the weather and the ferries.

Covid is everywhere. XX and YY have both got it. It’s worrying for people like me with a compromised immune system. Off into the garden now, lovely sunny day.

The Dip (4)

Waiting for call, for scan and aspiration
and mind goes berserk, down and sad
Background app running, what if……
Thankfully picks herself up again

Be there and support, all one can do
Beware the black dog, comes up quietly
Don’t let it stay, see it off fast
It is what it is, and this too shall pass

Don’t overdo it

Up and at ‘em
(getting ready for an exhibition)
But too much, too fast
Gone in at deep end
Paddling back to shallow
Pace self, still recovering

The Dip (5)

Not easy, has to be said
Outwardly calm but mind racing
Just need RT to be over
Counting days, hoping not another op
Filling days to stop thinking
well knowing, not the end
as then bone treatment and reviews
Cancer is for life…………..

- *Helen says: So is living*

It happens

And we wait…….

Smaller than before but haematoma still 5cm
Solid, can't aspirate, says clinician
Provisional booking for RT later in month
pending surgeon's review next week
That's how it goes, as heatwave adds misery
So want this to be over, been a long time
Keep breathing, keep going…….

- *Hottest day ever in UK, 19 July 2022*

Green signal

Ready for RT, says doc
and marks the spots
Comes back happier

Nearly there
On the bridge, finally
Going across safely

- *We went to Hull for a break; yes, it's not Hull, Hell and Halifax, there is lot going for Hull. Declaration: Rajan used to work there.*

First things first

So off doing the rounds
of places and people
saying thanks for help
and the loving care

The Dip, again

Though not quite
with foreboding and low mood
Feeling bored with it all
Getting tiring, after months
Wishing it all over
Never to revisit
No denying its hard

And then it was the day

Patient radiographer
taking time and trouble
to explain all
In the true Welsh way
Herself finds a connection
with the young fellow
Same area, knew his school
Forget six, more like one
degree of separation
Get blasted with rays
for five days and
That will be it
Cannot come soon enough
And look, hair is growing

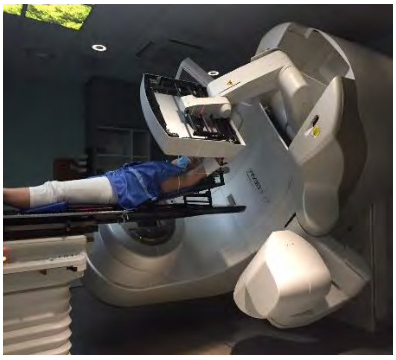
5th/ 6th August 2022

Radiotherapy day. For some reason I'm in a bad mood. It's been a heavy (in terms of physical exertion) few days staging and hosting an exhibition of sculptures at Nantclwyd y Dre, Ruthin, which I enjoyed. Tiredness creeps up on me and I don't recognise it, mistaking it for low mood.

It happens

Slightly anxious about the radiotherapy. It's a permanent thing – rather like a tattoo. The three dots they put on you to line up the machine are slightly disappointing. No anchors or skulls and crossbones, alas.

In the event it wasn't an unpleasant experience. The staff, as always, were lovely. Courteous, respectful, professional and humane. And the machinery…well, I'm gobsmacked. For the tech-challenged individual, like me, it's as if you're on the set of "2001, A Space Odyssey". And now it's Saturday. Sunny and beautiful. A filthy house to clean, lovely dogs to walk and left-over Indian food (home cooked by himself) for lunch. Luverly!



Oops

Almost missed second session
as timing mixed up
Had been brought forward
but not been told
Just as well decided to go early
No harm done but any hiccup taxing
Tiredness taking its toll
Both struggling, herself getting brunt
continuing worry, ten months on
little sign of end, haematoma still there
no news re bone treatment
Try and park it all, focussing on RT
How we long for days BC

Not quite…yet

Not out of the woods
says clinician on review
RT can burn, so watch out
usually see after two weeks
and months before strength back
Chemo, knife and rays take toll
Gotta keep going……………

And so she does

Back in the studio
getting ready for exhibition
Full steam ahead
Stuff fighting to get out
of head onto paper
after months of cogitating

My girl

All set for the big day
Girl must have a hair-do

Gotta look your best

First one since the start

Thanks to friendly neighbour

Off to last session in style

The BIGGEST day

Red letter day

Been there, done that

got the T-shirt

not quite, but rung the bell

Was hard to imagine this day

ten months ago when all started

Somehow got there, in the end

It happens

She is back!

Turns her head
to more important issues
saving hedgehogs from speedsters
as not just young ‘un’s but
oldies too flash past for thrill

Part 4: And they lived happily ever after

What now?

Back in land of living
Picking up from where left off
seemingly years ago
Trying to figure future
looking for signs
making sense of life
Comes back from break
Says the answer is obvious

- *We went to Lake Vyrnwy for a break to celebrate the end of treatment, via Chirk Castle (below).*

Yn fwy ac yn iach*

And it is 42, as the penny drops
Everything and yet nothing changed
Cancer now a constant companion
But why should anything be different
One starts dying the day born
when, how, unknown and so it remains
Wish it did not happen, but it did

It happens

Now in the past, future who knows
All there is is here and this moment
Make the most of it and enjoy
Today is the first day of rest of life

- *Welsh- Alive and well*

Goodbye and good luck

Not hundred percent yet
Gets tired easily
but determined to get on
and put all this behind

So, it is goodbye from her
and goodbye from me
Thank you for company
Love, peace and joy

- *Tiredness remains an issue two weeks after last RT but she is learning to pace herself, and we await further treatment.*

Patient's perspective: some final words

I asked Helen to make some final comments:

How has it been for you? Your feelings?

At a physical level the experience of chemotherapy and the length of the therapy was gruelling, particularly the second twelve weeks. The side effects were varied, unpredictable and all unpleasant. On an emotional level it had highs and lows. After the initial shock and then disbelief, then, briefly, anger, I felt an overwhelming and profound sense of gratitude. Gratitude to my partner, my son, my family, my friends and neighbours and to the people who looked after me in the NHS. The oncologist was straight talking and didn't patronise me in the slightest but explained everything and at a pace I could follow. She gave me information gradually as I needed to know it. I felt empowered and in control. The chemotherapy suite staff at the North Wales Cancer Unit were caring, professional, delightful and knew exactly how to keep me going through a difficult treatment. It became almost a pleasure. I had complete confidence in them and was treated like a film star. I felt that my life mattered to them. I became ill with low neutrophil counts and had to spend some time in Enfys Ward at the Centre. It was a bizarre experience, surreal. But the staff were humane, kind, funny and I felt safe and supported. Surgery was ok. I wasn't at all worried by it and from the moment I arrived at the hospital I felt everyone there knew their job and was completely dedicated to getting me through the process as safely as possible. I include the behind the scenes technical staff, cleaning and catering staff in this, they all played their part.

I didn't want this cancer, no one does, but it has taught me a lot about life, my potential end, and about my friends and family, their worth and my own worth.

How did you manage? The good bits and the bad bits.

Not sure how to answer this. I thought I managed quite well most of the time apart from the days when the steroids stopped. The steroids are a necessary part of having chemotherapy as they protect the body from inflammation. Those days were very difficult, and I felt I had no control over my mind. Part of my brain told me that it was all due to the drugs and the other half was panicking and thinking the world was coming to an end and I was a weeping wreck. This would last a day then I was back to normal. Chemo brain is a thing, a horrible thing and it gives an insight into what early stage dementia must feel like. Awful. It made me feel very guilty about being a burden on my partner and my family but they understood and even thought it was funny at times…...

What about the future? Do you worry that the cancer will come back?

I wouldn't be human if I didn't worry that it might come back. However, other cancers and other life-threatening diseases are available. No point in anticipating any of *those. The risk of secondary cancer through having chemotherapy is real, but the risk is low and anyway untreated, the risk of dying from triple negative breast cancer is 100%. So, no contest. People can die from complications after tripping over their tea cosies, think about that and worry.*

What advice would you give to others in similar situations - to patients/carers.

Don't buy tea cosies. I wouldn't dream of giving advice. Each one of us is unique and each body reacts differently to each cancer. Treatment options are many and varied, doses are many and varied, reactions are many and varied. We all approach life in different ways. All you can do is keep going. The alternative is unimaginable and permanent.

I would like to add a few words about being a carer. To be a carer is to render service to another human being when they are in extremis or in long term need through illness. It is often physically and mentally exhausting. It can rob you of your life, almost, as the time you have to pursue your own interests diminishes in direct correlation to the needs of the person you care for. But it also has benefits for the carer. There is the satisfaction that comes from doing one’s duty. Having spent many years as a carer for my late husband, mother and father, I can honestly say that it improves us as a person. It gives us insight into the suffering of another and makes us kinder. I feel that carers are often overlooked when it comes to help but without the thousands of carers in this country I don’t think our social services and NHS would be able to function at all. The one thing that carers desperately need is time off from the relentless sense of responsibility. To know that someone is looking after a loved one so that a carer is able to rest properly can mean the difference between them maintaining their health or collapsing mentally or physically and therefore presenting the NHS or social services with another patient or client. Having said that, I would not change my life including the years of being a carer.

Carer’s perspective: some final words

There is never a good time to get cancer, but Helen’s came at a rather difficult time; she discovered her lump three days after I had got back from India to see my mother who was not well with a view to returning there quickly but it was not to be. Mum passed away soon after my return and I was not able to see her again, and sadly she did not get to meet Helen. So, it was not a good place mentally for me anyway and then the fact that Helen got the ‘bad’ type of cancer, with one of the longest chemotherapy regimens and ended up with the known but serious side-effects, meant that it has been a real roller-coaster.

What helped me as a carer? I am very fortunate, and my job was easier since Helen is a very resilient and practical woman. Seeing a loved one suffer is not easy, the feeling of helplessness is over-powering, and so how the patient copes can make a big difference. It is of course a two-way process as each supports the other, and we realised that we needed to be very open, talk about feelings as we navigated the turbulence with her treatment, and try and not be downhearted and especially not both at the same time! There is no getting away from the fact that there will be lows – sometimes quite bad when things would be bleak – but we always reminded ourselves that these will pass, that there was a better tomorrow. Crying and ‘shouting/swearing’ was OK! We took each day as it came, and focussed on getting through, trying to make light, no big plans but finding joy in the smallest things. It was really about living in the moment, dealing with here and now, and avoiding unnecessary worries about what next. Having already been through a long period of social isolation with the pandemic worked both ways; we were partly used to being alone (as we had to be extra careful during chemotherapy to avoid infection) but partly we were also tired, and just when things had started easing with the pandemic and friends had re-started their lives we were again restricted.

But I did recognise that I was vulnerable and took some actions. Helen and I had just become friends when the pandemic started and were trying to make sense of our relationship, and then we got hit by cancer. Having to deal with some deep personal issues was an additional challenge, and hence I spent a lot of time making sure that I remained fit- physically and mentally. I took regular exercise, partly of necessity to look after the two Jack Russell’s, ate well, avoided (too much) alcohol, and spent time learning Welsh and piano among other things. Apart from physical aspects of caring, which to be honest was easy with Helen who tried to be as active as possible, the mental stress is the problem. I also had help from Simon, Helen’s son, who came regularly to stay and give me a break.

Whilst it may seem that we had it easy in one sense, being older, retired and without many of the obligations others have, we also faced difficulties including coping with the loss of a close family member and the challenges of undergoing treatment during the Covid crisis. My professional experience as a former surgeon and public health doctor was helpful in many ways but also presented its own challenges as things are very different when viewed from patient and carer perspectives. But the latter is a story for another day.

Although I would not recommend cancer to get a perspective on life (*sic*), the experience does focus the mind, makes you appreciate what you have and learn to live in the moment.

Bottomline: Look after yourself, do not neglect your own needs; unless you are OK you cannot help the patient. It is not easy being a carer but it is worth it, and very doable.

Helen’s cancer treatment journey -timeline

Helen was diagnosed with Invasive Intraductal Triple Negative Breast Cancer (TNBC) at age 64. Helen’s lump was small size, 2.5cm and grade 3 on initial diagnosis, this was downgraded to grade 2 after biopsy of surgical resection which showed a small 0.5mm residual tumour but clear margins and vessels.

Key Dates:

2021

07 Oct: Right breast lump discovered

08 Oct: GP referral

14 Oct: Private consultation

06 Nov: Initial assessment including Biopsy

18 Nov: Results – TNBC confirmed so more tests and start with chemo

22 Nov: Contrast mammogram and stapling of tumour

25 Nov: Oncologist consultation

26 Nov: CT scan for staging

27 Nov: Covid test and isolation

30 Nov: Chemo starts in two parts: part 1 with CP (Carboplatin and Paclitaxel) regimen, to be followed by part 2, with EC (Epirubicin and Cyclophosphamide) regimen over six months

06 Dec: PICC line inserted

09 Dec: CT scan clear

13 Dec: First visit to Denbigh Community Hospital for bloods and PICC line check

15 Dec: Shaves off hair

24 Dec: Unscheduled visit to hospital to deal with side-effects, in time for Christmas

2022

11 Jan: Clinical check-up, doctor happy as lump shrunk, can hardly feel it (clinical response)

15 Feb: Chemo session cancelled as blood count low

22 Feb: Started second part with EC, having missed 12th paclitaxel will forego now says doctor, haemoglobin low also and needs transfusion next day.

02 March: Unscheduled visit to hospital due to fever – Febrile Neutropenia, blood count very low, admitted

06 March: Discharged after 4 nights in-patient stay, on oral antibiotics

14 March: High platelets, await further tests/info – no panic, switch to different G-CSF, EC dose reduced

28 March: Enhanced mammogram to check progress

05 April: Scan clear (radiological response)

06 April: Another blood transfusion

12 April: Antibiotics from GP for foot infection

26 April: Big Day, last EC chemo and PICC line out

04 May: Surgical consultation to plan operation

17 May: ‘Magseed’ insertion for surgery

19 May: Pre-op assessment

24 May: PCR test pre-op

27 May: Operation as daycase

01 June: Unexpected visit to cancer centre for haematoma

07 June: Out-patient (OP) visit for biopsy report (Pathological response)

09 June: Post op surgical OP visit, another attempted aspiration

23 June: Review surgical OP visit

06 July: Radiotherapy assessment visit; RT deferred

07 July: Re-review surgical OP visit, further scans and procedures planned

19 July: Scan, not drainable

27 July: Radiotherapy (re) assessment; decide to go ahead

05 Aug: RT commences for 5 doses

11 Aug: Last RT

To be continued………. As Helen will need regular treatments to protect her bones, and reviews to monitor her progress. Cancer is for life.

Summary of key elements of Helen’s treatment

- Biopsy, mammogram and CT scan apart from regular blood tests
- Weekly visits to community hospital for PICC line checks
- six months of chemotherapy in two phases with regular visits to cancer centre
- three blood transfusions
- one operation

- Radiotherapy
- Two complications leading to unplanned visits including one in-patient stay

We received very helpful written information about each stage of her journey from the Cancer Centre. In addition, there are many excellent on-line resources about breast, and other, cancers.

Declaration by Rajan

I am a non-executive member on the Board of Citizen Voice Body for Health and Social Care in Wales and a non-executive director on the Board of Wirral University Teaching Hospitals NHS Foundation Trust in England. For further background please see Rajan Madhok (nhs70.org.uk)

The views expressed are personal and are my responsibility. They are shared in good faith. If I have misrepresented anything then please accept my apologies, and if I need to do more to make amends then please get in touch: madhokrajan@gmail.com

Dedication

Dedicated to all the health care workers in North Wales – clinical and administrative - who have helped us during this very difficult time. We do not know where to begin in terms of thanking people who gave their expertise, and most importantly, time and kindness. There were so many of them and it is hard to name them all here but we want to mention Mr Walid Abou Samra, Surgeon; Margaret Moore, Designated Breast Care Nurse; Dr Julie Jones, Medical Oncologist; cancer treatment teams at the Heulwen suite, Enfys Ward, day surgery centre and radiotherapy unit at Glan Clwyd Hospital and at Denbigh Community Hospital; and GPs and staff at Bronyfynnon Practice in Denbigh.

Acknowledgements

Our friends and families sustained us throughout the journey, especially Simon – we are grateful for their love and support. Our thanks to Mr Gopal Mahadev, Breast Surgeon, Dr Sunil Upadhyay, Oncologist, Mr Chelliah Selvasekar, Surgeon and Dr Raj Kumar, Dr Tariq Chauhan and Dr Umesh Roy, all GPs who are personal friends, who provided medical support.

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Buddhdev Pandya has helped with the technical production of this diary, as part of his work to promote patient engagement in health care, we thank him for this and his general support over the years.