THERE IS NO CURE: 10 small essays on my cancer by Tor Fosnæs



"If you remember, I did mention possible side-effects."

1. The militarization of cancer as euphemism for what is feared

Fear isn't real.

You have seen them, obituaries that say "after a courageous battle with cancer". The dead must roll over if they could hear such foolishness. What part of cancerous our behaviours are considered courageous?

Speaking from personal experience, now 12 years since diagnosis, there is little courage involved, better to describe it as acceptance, there is nothing you can do except get your head around it and as for battle, you take the therapies, the pills, the miseries of side effects and wait for the inevitable.

So what is it people mistake for "courageous battle"? Nothing more than their own doubt that should they be the afflicted they would do battle, never go out easily, strive to survive, and it is a euphemism for a normal inability to understand what cancer is when you don't have it. We, who have it, simply wait it out, relishing the small remissions, cursing the return of symptoms, suffering the side effects of drugs.

Ask any cancer afflicted person if they feel courageous, if they are involved in a mighty struggle. 'No', most will say, 'it is what it is.' 'I am grateful for every day I have left.'

Even the doctors occasionally militarize cancer, but mostly they simply state the worst-case scenario and try to boost the patient's *attitude*. Attitude doesn't cure or alleviate cancer, but it can help a patient accept with some humour the inevitable fall to entropy.

One fellow sufferer was telling bad jokes about his cancer Well, I remarked, you haven't lost your sense of humour, a trait for which he was well known 'No', he replied, 'what's the sense in having a terminal disease if you can't have fun with it '.

Now, that's attitude. Not courage.

A positive attitude is not about curing cancer by some autonomous exercise of willpower. That doesn't work. There is no cure.

A positive attitude is how to make the best of what time you have left after the agony of therapies. I don't live with cancer, cancer lives with me.

Those who don't have it (wait, they say everyone gets it eventually) try to put their own brave face onto the afflicted because they cannot understand the inevitability of the process.

Everybody dies, was the watchword of Game of Thrones. *Valar morghulis*. When the un-afflicted speak of courage and battles they are showing they think nobody dies.

They say your cancer is somehow more easily cured or set into remission because if they ever got it that's what they would want to have happen. The reality is there is no cure, suck it up.

2. Questions and answers

Ignorance doesn't help.

The big C, cancer, is feared most by people because of their inability to ask and understand the right questions; because of despair; denial; or dis-belief. And all those things. Or in some combination. Many people can't even say the word, always using a euphemism.

You are sailing along and suddenly there are Gleason Scores, Stages, adenocarcinoma, acinarcarcinoma, the litany of drugs with un-spellable names, procedures named after their inventor, statistics and probabilities, actuarial tables, recommendations about certain doctors (he has a good record), stated compassion, a certain amount of expressed sorrow, knowing looks, and ...

My doctor told me, when I kept apologizing for asking questions, possibly making him run overtime, "Not at all, you ask good question, most people don't ask any, most people don't understand the answers."

I would discuss the matter with friends and loved ones, write out a list of questions. I would cross examine on points I didn't understand, seek other references for information (but not Dr. Google).

How else can you cope if you don't have understanding. When you understand the problem the 'woe is me' syndrome ceases, you get to curse fate instead of making up things that (might have given) 'gave' you cancer. Life gave it to you and you can't give it back.

Patient informed decision making, he said. Then listed three or four approaches. Hey, I reminded him, I am not the doctor here. What do I know? What would you do?

This.

Ok, let's go there, I said. I am yours, I said.

Some questions the doctor can't (or won't) answer:

How bad is it?

How long have I got?

Will the treatment work?

Doctors always state the obvious worst case scenarios. There is never false hope, no this will get better, no this will certainly work. You get the sense they are guessing.

As everyone with cancer has a cancer unique to them, the best the doctors can do is put you in a category and make guesses as to what will work. Fortunately, their first guess seems to be efficacious. As things get worse, and they always will, they have 'more tools in the toolbox'. Comforting, not.

I remember his comment once we had a plan for treatment, 'If to do this treatment the cancer won't kill you, you will die of something else before.'

He also said the treatments would never stop, 'If they do you will die.'

He said most people 'tolerate' the treatment at hand well, but they tend to gloss over the effects of cutting, burning and poisoning. Those effects come only after you are cut, burned or poisoned.

There are people who don't want to know. Who deny treatment. They usually are first to go.

There are people who are so freaked out they can't talk about it or understand what is happening, they go more slowly always in a

state of disbelief and confusion. As one relative said, 'They sent me home to bleed out.'

If you are diagnosed with cancer, first thing, regardless, get your affairs in order, establish an exit plan, it is too late when you are in extremis.

3. Doctors' Dilemmas

Those with cancer would do well to follow the teachings of Armand Gamache of the Surete de Quebec, the protagonist of Louise Penny's books.

Penny, through Gamache, offers four sentences that lead to wisdom: 'I'm sorry', 'I was wrong', 'I don't know' and, always said after a long pause, 'I need help'.

These should be applied generally in life, with cancer, especially the last two. You have cancer? You need information and help!

What doctors say isn't always comprehensible, their casual use of medical language and the cancer patient being overwhelmed by having cancer makes for a lot of near-failed communications.

Doctors are usually encouraging and positive. If also quick to say afterwards, if things are going south, 'well I told you to expect that'.

They are caught in a middle. They can't destroy you with doom. And they can't lie about rosy outcomes.

If you ask sensible questions and make sure you understand all the ins and outs, it can take time, but, hey, an hour, a day, a week isn't going to see you out, not usually. They often have to tell people there are no more tools in their toolbox and there is nothing more they can do. In Newfoundland this is commonly referred to as being sent home to bleed out.

Some people go on for years.

There are two kinds of cancer, acute and chronic. Pray for chronic.

The conversations with the oncologists are required but given the two views (theirs and yours) of the cancer inside you, you need careful parsing and attention. Patient-informed decision making means the patient has to know what is going on. A patient who doesn't want to know is committing self-harm. This attitude also wearing on the medical team.

Finally, doctors don't always tell the truth about the effects and side-effects of therapies. You ask, 'What are the side effects'?

'We have good results with this, there may be some of this ... or that ... blah, blah'.

'Most people tolerate it well'.

'It works differently in different people'.

Regardless, your oncologist is your best survival chance, you can't be friends, but you talk as often as needed. They promise.

4. Effects – the good, the bad and the really ugly

Tools to control cancers. Pills. I haven't had the joy of chemotherapy but have several close friends who reported many miseries.

Chemotherapy is for metastatic cancer. It is spreading. It is systemic poisoning of your whole system. Everything dies and comes back to life, mini death, repeatedly, the idea being the cancer dies as well, thereby reducing the load.

Prostrate cancer is dealt with through the use of hormone based tools. Prostrate cancer cells proliferate in the presence of testosterone. First, reduce and finally eliminate testosterone production. Then they use a testosterone 'blocker' so the cancer cell receptors are fooled up and 'found' testosterone can't be used.

Doctor told me that if prostrate cancer cells can't get enough testosterone from the host body, they make their own. Those dirty buggers.

So no testosterone as a result of chemical castration brings on many changes. Man breasts, loss of body hair, emotional reactions, a certain lethargy (more about tiredness later), there are others.

Other organs and glands that use testosterone are also affected. Long term testosterone deficiency is a disease on its own.

The hormone blocker makes sure that testosterone naturally occurring in your body, perhaps some made by the cancer cells, has limited take up by cells. Double whammy.

In ten years, with various tools, it seems to work, my cancer grows very slowly, a controlled growth. The drugs are working. Stay the course.

The needle for the testosterone killer is about 1200 CAD every three months, Blue Cross covers it. The first blockers I took were sort of normal priced but the last one (three years now) is provided by the manufacturer. It costs 146,000 CAD a year. 400 a day.

They are effective. But, here is a side effect, repeated trips to the cancer clinic.

They know that when the current tool fails it happens fast, so I get a blood test every 28 days. Go to the cancer center, give the blood, wait for the results, meet the doctors and nurses, answer the standard 20 questions for the guys paying the 146k.

Then there are the side effects printed in the little fold out paper that accompanies the bottle of pills.

Most significant in my case are fatigue and diarrhea. If you want to curse someone for life, wish chronic diarrhea on them. It really messes up your life, literally and figuratively. Fatigue and tired are often thought of as synonyms but there is a fine line.

Tired is what you get when you work too hard, stay up too late, overdo stuff. Fatigue is constant, not alleviated by rest, and it isn't rationalize-able.

Radiation and powerful cancer drugs, and chemotherapy, cause deep, total fatigue. I asked for uppers but the doctor said it wouldn't do any good. The cancer drug grabs ahold of your systems and wears you out.

Of course, cancer takes an enormous amount of energy as your immune system tries to get rid of it. Eventually your immune system collapses and/or the cancer finds ways to ignore your immune systems.

Cancer, no testosterone, the blocker, and being 75, it is difficult to determine what is the biggest contributor to needing a lot of naps.

Tired plays on your physical system, your joints hurt, your head hurts. You rest and eat well and tired goes away.

Fatigue plays on your mental state and can result in bouts of depression. If you are inclined to depression, make sure you have someone who can say, 'you are depressed, go get help'. If you are depressed, you can't have a good attitude and you become a cranky asshole.

Fatigue ruins your interests, things are out of focus, you lose your appetite and become short-tempered. Your hobbies become boring. Work intolerable. You must force yourself to do housework and cook.

It is covered by the word desultory; marked by lack of definite plan, regularity, or purpose. That is fatigue explained.

Of course, there are other less obvious side effects, my thyroid is screwed up (take Synthroid) my skin gets a strange rash (use betaderm, a topical steroid, or in my case B12 from Marmite), my sinuses are more sensitive and I sneeze a lot (stay off the antihistamines), my joints hurt (wait, is that from the drugs or because I am 75?).

While these effects are my experience they are generalities to all cancer treatments.

Make sure your doctor explains clearly what to expect and be prepared.

It feels sometimes the treatment is worse than the cure, and in short term that is true, but in long term, you can live forever, or die trying, thanks to the tools of modern cancer management.

5. Humour and good will

The modern human condition might be readily summed up as, 'If it wasn't so funny - it'd be pitiful. If it wasn't so pitiful - it'd be funny.'

Old hippies are often heard mumbling, 'Fuck 'em if they can't take a joke.'

Appreciating (and being able to express) the humorous in life, in others and in yourself can't cure cancer. It can make everything easier. This is also true if you don't have cancer, of course.

The opposite, not having a sense of humour, you know them. When they get cancer they suffer greatly from having it, add the side effects and you have true misery.

Laughter is the best medicine applies to cancer as to any other malady. Of course, you have to have something funny in order to laugh at and there is little in life funnier than your own self. Really!

And reading books is rewarding to having an active sense of humour. The foibles of others (real or fictional) is always entertaining.

Always look on the bright side of life. Maybe that's a bit too far. Sorry. I too have some trouble with that one, of late, but I am getting better at looking at a future without hope. If that I ever had any hope, but back then I didn't ponder the future, it hadn't happened yet. Nor the past, it was over. Nor the present because I didn't get you one.

See, a joke. Pretty funny. Laugh.

Beware of forced humour, stand up comedians especially. They are not funny, with one or two exceptions.

If you can't say something funny, say nothing. Especially if you don't have cancer and are talking to someone who does. Always applies if you have cancer.

Tied to good humour is good will, I can't have one without the other. Good will keeps you young. Being polite and compassionate to others helps your recovery and is a solid mental practice. Good will always adds up. There isn't anything that can't be done by people of good will working together in common purpose.

I think I made up that last one but I stand to be corrected.

Practicing and demonstrating good will and good humour is healing but it can't cure cancer. There is no cure.

All this preamble and aphoristic blah blah is meant to guide a new cancer person. You will have cranky, emotional reactions to the diagnosis, impossible not to. You need to recognize or have someone point it out when you lose either you good will or your good humour, then you must correct as fast as possible using the tools of laughter and attitude.

Booze will not help, nor tobacco. Fruit smoothies and a little cannabis works for me.

I don't think I have any conservations that don't have pithy remarks, absurdities, exclamations or other humorous asides. Besides which, lightening the conversation lightens the non-cancer person's unease, things that don't need saying are not said.

My high school yearbook editor wrote next to my name, 'He thinks too much, such men are dangerous'. Really, I was just confused, but I had a wicked sense of humour. Now I am 75, with chronic cancer, am thinking too much, and still haha-ing along.

Practice telling jokes so other will tell you more jokes.

Laugh at them all.

Keep marching.

6. Other people, with or without cancer

So you got a diagnosis, presumably in the presence of a loved one. You are in shock. Information overload is instant, and information blank-out is common.

Anyway, after a while you accept, and surrender to those who know more and who are trying to offer you a quality of life instead of just curling up and dying. I suppose there are those who choose to curl up ...

You wrestle with the process and, of course, you tell anyone who will listen. Most reactions start with, 'I am so sorry you have cancer'. Thanks, but there is little or no comfort there. Then there is, 'What can I do'? I always say, send money.

You cannot get mopey, playing the woe is me card, the why me card, or the fear card. You got it, you got to live with it, however long you have left, and try to enjoy every day left. There is no alternative, well, perhaps, curling up and ... which is a poor and unacceptable alternative.

Mostly people will continue to ask how you are doing, mostly your close friends. New acquaintances will often say, 'Well you look fine, you'd never know'.

Things you don't want to hear, 'O that is the easiest cancer to cure (if caught early)'. 'My uncle had that and lived to 90'.

Those who have cancer are a great comfort, they know what they are talking about. Those who have not cancer, don't listen to a word they have to say, unless they are your doctor.

In the early days my beloved convinced me to try alternative options, I went to a naturopath 80\$ for a scan and 400\$ for homeopathy ingredients that were absolutely useless against cancer growth.

I wen to a blood analysis lady, another 80\$. I can't find any cancer she said. Okay, thanks, I guess the entire medical profession has it wrong, the operation was a mistake. We can cure cancer, she said in parting. I assumed she had a pharmacopeia in the basement but I didn't ask.

I went to a lady (another 80\$) who made me hold electrode things in my hands while she ran a machine that hummed and beeped (I think it beeped) and printed out a long chart of data which she reviewed. The cancer is receding, I can help, just buy these expensive concoctions and ointments, it can be made to go away.

I said to each of them, if you could cure or make cancer go into remission how come you are not rich beyond belief. All three wrote me off as non-susceptible to flim flam, snake oil and quackery. Stay away from them.

Medical people are mostly sympathetic, caring and compassionate. At least they don't promise cures [THERE IS NO CURE, remember]. But you are just another, one of thousands, slab of meat with a condition. There is no love. If you balk they will turn on you in a flash. Taking drugs means you deal with a pharmacist doctor. They are concerned and will support your attempts to understand and deal with your conditions. The oncologist, says, 'Everything is working, stay the course, see you in three months'. He is just waiting for the metastases to start, until then he has sicker people to help.

The cancer clinic mantra is, 'If there is anything we can do for you, just ask'. So far I managed to get a referral to the cannabis doctor, but all other questions, like, can I get psilocybin, acid or uppers, to deal with the continual tiredness (you got to ask otherwise you get nothing) are met with, well, nothing.

Because the drug I am on can have deleterious effects on the liver, I have not taken alcohol for nearly three years. I had a

double Sam on the rocks for my birthday and a sip or two of Scotch at my buddy's house, two glasses of port about 8 months apart, and four or five half glasses of white wine also well spaced out. I don't miss it as I thought I would, so I think I was never an alcoholic.

But people who knew you as a sociable drinker are not the same when you are a teetotaller. It sets you apart at parties and dinners. You explain about not wanting to add stress to your liver. They don't really understand unless they are undergoing similar reasons for not doing something. I think people who turn to AA must get the same reaction.

If you have a dog handy, they are great listeners, understand everything you talk about, and are pits of empathy, all for a little attention. This may work for cats.

7. Cancer time

The statement of a cancer diagnosis plays havoc with your time sense.

Suddenly things are moving way too fast, no, wait, now far too slow. Which is to say you lose all sense of time. The initial six-week period of tests, meetings, considerations and decisions seem interminable. You want everything to go faster.

Faster is what causes errors. Therefore, the whole medical system is slowed purposively. You have to switch time sense to accommodate them. Otherwise, you become anxious and miserable.

Remember, the doctors wouldn't space out the weeks of this and that if they thought you were in imminent danger. If you were, they would tell you. I believe that.

The process of radiation, for example, is usually 7 weeks. Radiation must be parcelled out a bit at a time so your body can deal with it.

Then you must recover from the radiation before the next steps can be implemented. More time.

The fatigue caused by cancer and its treatments also make time crawl slowly, mostly because you are super-attuned to everything and because you unwittingly and naturally expect immediate improvement in your prognosis. Of course, we do, it is normal.

Another scan, another scope, another biopsy, are all time consuming but you must ask if you have any other appropriate choices. No, you don't.

I am 75 and I am not worried one more scan will overload me with X-rays, what is it going to do? Give me cancer?

The curling up process, refusing treatment, being in denial, takes a lot longer than you'd expect and more misery than you'd like, of this, I am sure.

Look at each part of the process with some interest, track your progress or lack of it, I have a spreadsheet of all my PSA scores, calculating my doubling rates and noting current therapies.

Some people keep logs or diaries, in fact the cancer crowd promotes this to deal with having cancer, along with support groups and counselling. All this stuff takes time, they tell you, and they are keen on ways to get you out of panic mode and into a more relaxed mode. There is no rush to the inevitable that makes any sense.

I am now 12 years since diagnosis. 144 months. 724 weeks. 5058 days. So far I have lived a little over 3900 weeks and am under cancer treatment for about 20% of them. For me, that time has just slipped by as most of us older folk find time passes faster and faster. In reality, it is a long time. A slow time. You have to resist the urge for rapidity. There isn't any.

Cancer treatment is boring, a lot of waiting for the team, a lot of waiting for tests, a lot of waiting for information, a lot of waiting for results.

You can't push rope, is an old sailors' saying. When the rope is metaphysical, invisible, and inscrutable, like cancer and its treatment, good luck even getting your hands on it, let alone pushing it.

We are not trained medical people, we can only understand so much, the rest we have take on faith they know what they are doing, hope our case is somehow 'better' than the other people. Do not pray for miracles, it is time wasted when you could be having fun. Patience rules. Otherwise, frustration will lead to anxiety. Anxiety is dangerous. I am convinced anxiety will give you worse cancer.

When you have cancer you have a limited future, regardless of the prognosis, the end is the same, you die of cancer or with cancer. All you have left is time. Enjoy it while it lasts.

We all know we are going to die. Some of us get a warning about when and how. If it takes years, you die an old person. Regardless, there is nothing else to do but eat, drink and do some items on your bucket list.

Man makes plans and the gods laugh, remember.

8. Waiting protocols

First of all, practice WAITING while you are waiting. Mindful waiting. Gautama said if you want to meditate on life, do it in a graveyard. I am convinced that the cancer clinic waiting room is good substitutes for our times.

I find reading is hard in public. There are so many distractions you find it hard to get up a rhythm. A lot of people are on social media while waiting, I expect they are on social media always if they are awake. Lam not on social media.

The cancer clinic has a great collection of local, that is Newfoundland art, it seems to grow occasionally. I often look for my favourites, the rhubarb by L. Doody in Clinic C, and study them as if I was at the AGO or some other gallery.

The collection covers every style of painting, just about. If you have to wait, go wander about, look at them twice, you get some movement in and the time goes faster. In the exam rooms there are posters and notices and those anatomical dissection drawings showing cancer and organ placements. They are not so interesting but surprisingly catch my attention.

Don't go get coffee and sit in dejection sipping bad coffee and fret over the future. Many do this and they are noticeably depressed and withdrawn. They won't engage in conversation.

Count things. How many pairs of Birkenstocks are there? Jeans? What is ratio of male to female? Any old hippies? Goths? You hear a lot of birthdays being said, who is older than you, younger?

How many are worried near death? How many seem to not give a fuck? That alone can take time from waiting.

I am usually in dread of the results. If they are ok, I relax, but I always expect the worse. It has gotten loose, we will see what we have to do next, after a CT scan, blah blah. I will resolve to

take that conversation in stride, but like the initial diagnosis, will be a blow, a shock, a gut wrencher. It is coming eventually.

There is no cure.

9. The great leveller

It doesn't matter if you are rich and famous. Or just famous. Or just rich. Or an old retired dockworker, cab driver, municipal labourer, a jock or a couch potato.

If you have cancer, every other person who has cancer is your brother and sister. Instant family. Huge family. Even if you don't know them, never meet them, never notice them, you are family.

I suppose any group of people suffering the same disease would be equally united in suffering. I have cancer and can only speak for and to that family.

If you want to know how big a family it is go look at https://www.canada.ca/en/public-bealth/services/publications/diseases-conditions/fact-sheet-cancer-canada.html

Note it says half of all Canadians alive today will get it. That's like 18 million people. But treatments are getting better in helping people live longer and reducing the cancer effects.

Some treatments for a particular cancer work in one person but not in another. Some work equally for everyone. This tells us that some things about cancer are universal but individual cancers are unique to the individual. Each person's cancer is unique. That's why, sadly, there is no cure.

How each person deals with cancer is different and unique as well, although the bromides are universal and mostly wrong headed. For example, encouragement to improve one's attitude can be helpful or irritating.

A good diet and quitting bad health habits are essential to a good life whether you have cancer or not. But if you have cancer, you will suffer more and die faster if you continue with the stuff that is bad for you. It only makes sense.

10. Remission and control

Lest you think I am all dark, harping there is no cure and you must not waste time praying or hoping for a cure, there is a sensible hope - for remission, defined as 'Abatement or subsiding of the symptoms of a disease and the period during which the symptoms of a disease abate or subside'.

I haven't any symptoms to abate, my cancer continues to grow and I am so lucky, because for 12 years my cancer has been controlled through slashing, burning and poisoning. Because it doesn't go away, I am not in remission, but under control.

It feels like waiting for a blind date. A sort of continual nervous anticipation.

The light at the end of the cancer tunnel can be the light the end of the tunnel or it can be the headlamp of the approaching locomotive. In the cancer tunnel it is always the locomotive. Like the Monty Python boot, it hovers and then crushes us unexpectedly. Of course, this is true of all life, not just cancer.

We pray for remission but it is granted to only a few. Ask them and they will all say they know it is never over. Often remission depends on continued therapies and drugs to abate symptoms. Remission is not cure.

Remissions of five, 10 or even more years are known, but unless Lady Luck gets you killed somehow else meantime, it seems cancer always comes back, often in another part of your body and most often metastatic.

God bless those whose path has been free of cancer or treatments for years, for the rest of us, we continue to pray for remission but must settle for control.

When controls fail, we must pray for grace.

At least that is my plan.