



Stories of life with cancer

Living with uncertainty

Stories move in circles. They don't move in straight lines. There are stories inside stories and stories between stories, And finding your way through them is as easy and as hard as finding your way home. And part of the finding is getting lost. And when you're lost, you start to look around and to listen.

Corey Fischer, Albert Greenberg
& Naomi Newman (1992)




Living with uncertainty: Storying life within life-threatening illness

Many people with life-threatening illness live longer and healthier lives with the support of medical advances and technologies. However, the outcomes of treatment are not certain and the possibility of the disease recurring or progressing is very real. What is it like to live with the uncertainty of life-threatening illness?

This booklet has come about from a research project where people living with life-threatening illness (cancer, chronic kidney disease or CKD and HIV) were invited to share their stories of living with illness. The research was carried out from 2007-2012, with thirty-two participants sharing their stories in multiple interviews. Growing out of that research, this booklet includes the major findings of the study related to cancer and the stories of participants in their own words.

*"It's been an interesting – a long haul – interesting haul.
But... who knew we would still all be here to tell you these things?"*
Oliver

Please note: Quotes featuring quotation marks are from the participants themselves. Names provided with these quotes are aliases to help protect the privacy of those who so generously shared their stories.



"Control of one's life in any circumstance is important. I think a loss of control over what happens to you is a very big blow to people and you don't realize how much so until you lose it. Something out of your control whether it's the kidney or whether it's cancer or whatever it may be – or even people – if you can't control what's going on with you that's a very hard thing to deal with."

Casey

Living with uncertainties

Negotiating turning points

"... let me tell you. Nothing prepares you for a cancer diagnosis. Nothing. No matter how much you think." Joanne

The first turning point was the abruptness of diagnosis, a sharp disruption of life events. From that point forward, diverse turning points marked shifts in life story and direction, such as surgery, beginning chemotherapy or finishing treatment.

Measuring life by trajectories

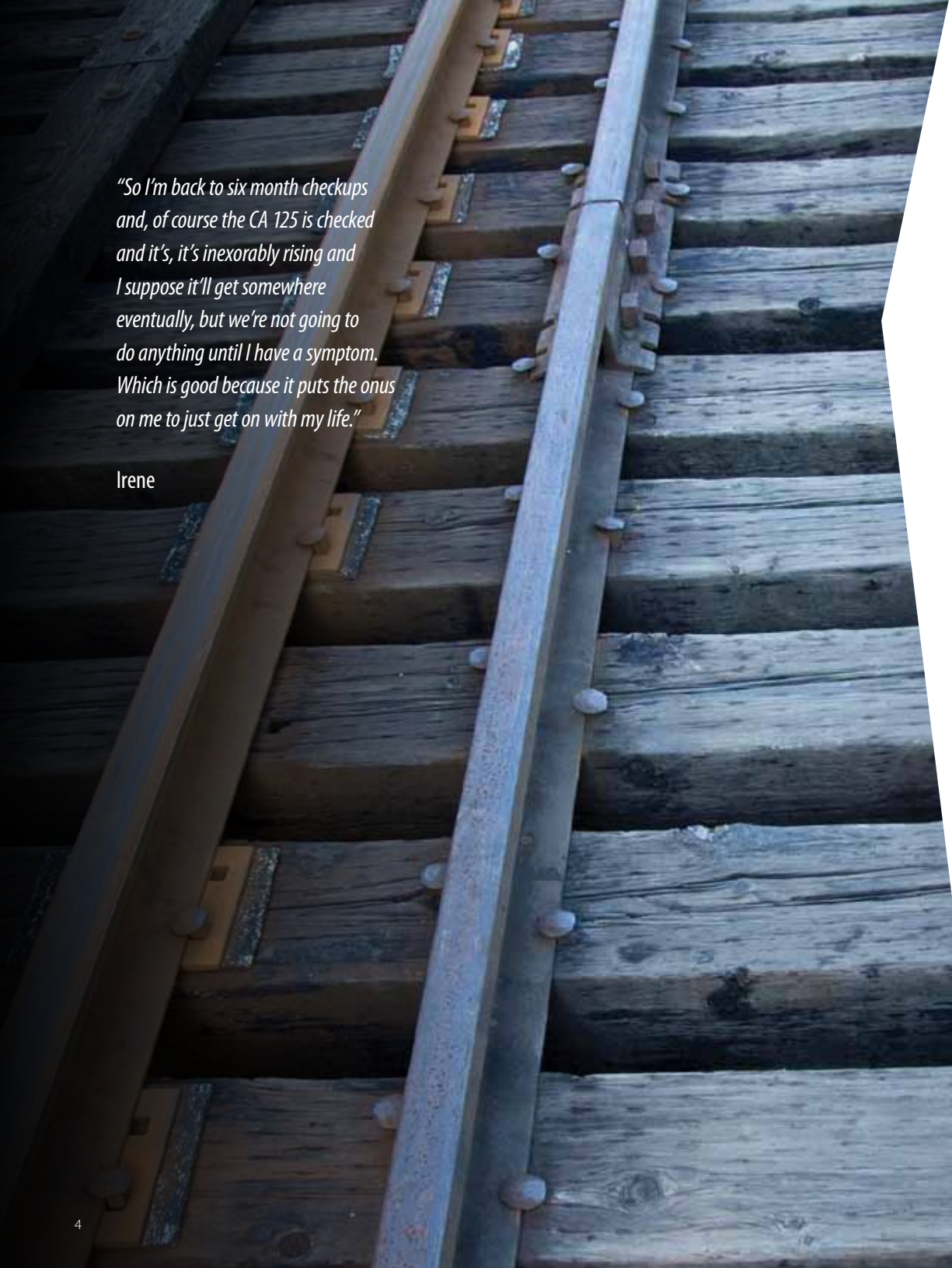
"Because I'm past five years does not mean I still don't have a higher chance of coming down with the cancer again." Diane

People described life with cancer as a series of medical events: notably diagnosis, tumour type and subsequent treatments. The cancer experience was highly individual, each person's illness path being distinct; often one of twists and turns, where expectations were turned upside down.

Finding ways to go on with life

After losing her hair, "I did think of going blonde and long hair and I tried all those on but really it's just such a farce ... you want to really look like yourself. So then they wash it and they cut it you know so that it is exactly like you." Lily

Living with cancer meant expecting the unexpected. It became part of finding ways to have a full life. As people learned to live with illness and the focus on the disease itself receded, uncertainties became blended into everyday life.



"So I'm back to six month checkups and, of course the CA 125 is checked and it's, it's inexorably rising and I suppose it'll get somewhere eventually, but we're not going to do anything until I have a symptom. Which is good because it puts the onus on me to just get on with my life."

Irene

Seeking normal

Accepting that life is not the same, but not entirely different

"The first big piece of normalcy was teaching again every week ... and just taking it week by week by week by week." Tom

At first, people had a desire to go back to life pre-illness. However, cancer was found to be a life-changing event. People described eventually settling into a new life that was different but not entirely removed from the one they had known.

Finding your feet, amidst change

"You've got to do what's best for you, you can't get too busy, you can't get too emotionally involved, because the depression then looms for me so it's where to find the right balance." Bev

Achieving equilibrium despite changes brought on by cancer was important. For some, turmoil was extended over a longer time period than for others, with the occurrence of adverse events such as depression or further treatments. For most, there was gradually a sense of readiness to fully live again.

Living in your body

"... you trusted your body and it's not what you thought it was. This friend of mine said, you know, you've seen the exit door. And you can't forget that." Sandra

Being ill is an embodied experience - it is felt in the whole body. Becoming comfortable in one's own body again meant finding peace with what they had physically been through with illness. Life-threatening illness was something people needed to come to terms with in mind and in body.

"I remember coming out of the doctor's office, looking at the world outside, and thinking, it's not changed at all for anybody else. The sun was still shining, people were walking their dogs, people were singing, people were – their life was just going on but my life was just all of a sudden not the same. And I don't know how I can describe the 'not the same' but it was from then on, life was different."

Charlotte

Facing dying and death

Increased awareness of your own mortality

"It's just - you know, you hear the 'c' word, you think the 'd' word. It's just - for me, anyway, it was just that automatic connection. I just went, 'oh my god.'" Sarah

Cancer is one of the most identifiable and frightening serious illnesses. The awareness of cancer in their own body, made people more attuned to the inevitability of death. Death was no longer something that happened elsewhere or to other people.

Life measured by the numbers


Regarding survival rates for some cancer, "The odds are fantastic. I mean they're going up and up and up." Jenna

People were keenly aware of survival statistics for their cancer type, tumour markers and other indicators of disease, and the public perception that five years equals a cure. However, they recognized that cancer was not entirely predictable.

Daily awareness of the realities of both life and death

"There comes a time ... when you have to say, there is a future, and yes it might be precarious but you can't say that every day." Marianne

Daily life offered reminders of both the possibility of death and the potential of a full life. For example, test results were not always clear in forecasting outcomes, alluding to many possible futures.



"I don't think I'd be the same person if I had never gone through this experience at all, even like 12 years ago I took a different fork in the road obviously, but between the two things which are fairly major to come out of it feeling, I think much better about myself than I did. And take very little for granted now. You know life is . . . life is precious."

Lori

Exploring life questions

Reflecting on beliefs

"There's something guiding us, there's something making sure we make the right decisions if we'll just listen to ourselves and just do the right things." Ivor

Facing illness, people openly talked about their values and their spiritual and religious beliefs. What was important, was having a personal system of values that guided daily life.

Finding meaning

"At my 60th birthday I really wanted to go to Paris and I did that, so you get to the point where you don't - well you do care about money but on the other hand you want the experience and the memory too so you put more focus on that." Bette

There was a renewed sense of what was important in their lives, such as people or mementos. Many expressed that there was purpose in life - that things happened for a reason. Many thought they were fortunate in comparison with others.

Beyond words

"I don't know why I'm doing this interview either 'cause I also don't talk about cancer. I rarely ever mention it." Pat

Many aspects of living with life-threatening illness were beyond words or unsayable; people were unwilling or unable to discuss them. There were experiences laden with emotion, memories, spirituality or even physical sensations of illness.



What

study participants would like healthcare professionals to know

In telling their stories, a number of people had messages they would like to share with health care professionals.

Give me a sense of the plan ahead:

"Umbrella support from somebody... here's how it is going to work, you know... nothing more terrifying than going into something like this not knowing." Carey

Relate to me as a human being not as an object or a disease:

"I had to know everything that was happening... for healthcare professionals to share what they were doing"... get down to the patient's level instead of standing over the patient's bed." Kelly

Choose your words thoughtfully as they have great impact and will stay with me:

"I'll never forget when he said..."

Be aware of and sensitive to the metaphors you use, as not all of us believe our illness is a battle to be fought:

"I don't like the word 'survivor' cause I don't like that, but no, I have a chronic illness that is in remission." Barbara

Overall, it's the human connection that matters, for example take time to sit with me, honor my vulnerabilities, and put kindness first.

"You feel very vulnerable and you feel you're only a number – I was 14-8-64 – that's all you are at the Institute because it's so busy." And, "Dr. C. was the doctor that really worked with me through the process. And she spent hours, oh yeah, hours educating me. Like I have a PhD in the disease." Louise

*Now I've learned, the hard way,
that some poems don't rhyme,
and some stories don't have a
clear beginning, middle, and
end. Life is about not knowing,
having to change, taking the
moment and making the best
of it, without knowing what's
going to happen next.*

Gilda Radner (2000)



Telling your story

Every person is unique. Every story is unique. There is no one “right” way to live, yet you are not alone. Other people have lived through these experiences. Facing life-threat is a part of the human condition and evokes “what is life about?” The following are such stories...

“Maybe it’s just (pause) – actually facing up to the fact that I do have cancer. I mean I don’t have cancer – well I do. You know, I’ll say I don’t have it and I don’t like the word ‘survivor’ cause I don’t like that, but ahm no, I have a chronic illness that is in remission, yeah. Like arthritis or something that goes into remission. Let’s hope it will stay there.”
Evie

“The balance of the whole living with, living with cancer. I mean you’re so frightened by the experience that it’s funny, it’s hard to get back to the life that you had before.” Lee

“Live in harmony, yeah; low, smoldering harmony ... low and smoldering. It’s there. It’s not active, it’s not inactive but it’s - low and smoldering... And I wonder ... if that’s what, what knocked me over - because then it becomes harder to do the harmony thing. And, that phrase, low smoldering ... is not exactly ... it doesn’t give you hope or confidence. When I think of that phrase it’s like something ready to - burst into flames.” Carol



This narrative research study was lead by a team of researchers at the University of Victoria and the University of Alberta. We began this research with the desire to listen to the stories of people living with life-threatening illness, with the intent being to improve understanding. Like most people, each of us has been touched personally and professionally by serious illness. Through sharing these stories we hope to improve the lives of people living with life-threatening illness.

Re-stor(y)ing life within life-threatening illness research project



Research team

Back row: Drs. Anita Molzahn; Laurene Sheilds (team leader); Anne Bruce & Kelli Stajduhar

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To learn more about the study and listen to the stories of people living with life-threatening illness please visit:

uvic.ca/illnessnarratives



Sharing stories to
improve the lives
of people with
life-threatening
illness.

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