

A lush green forest scene with ferns in the foreground and trees in the background. The text is overlaid on the upper left portion of the image.

# Stories of life-threatening illness

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 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

## Balancing act

*"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 thing then looms for me, so it's where to find the right balance."* Bev

All the people we spoke with described living with serious illness as a delicate balance of living their lives while having an awareness of death. This balance was sometimes hard to find, but was a pathway for living with unpredictable illness.

## Beyond time of diagnosis


*"Live in harmony, yeah; low, smoldering harmony... low and smoldering... when I think of that phrase it's like something ready to - burst into flames."* Carol

Living with uncertainty extends beyond the intensity of diagnosis and initial treatment. Experiences vary greatly, however uncertainty does not resolve after diagnosis; uncertainty becomes an undercurrent of daily life.

## Accepting that not all uncertainties are resolvable

*"You need an 'aha' moment when you understand that there's only a certain amount of information that you will ever know."* Jordan

People described efforts to resolve various issues that arose in their life with serious illness. Part of moving from an understanding of having an acute condition to a long-term illness was easing away from the need for certainty.



*"The longer I live with it the less it affects my life. Can I say that? . . . When I was first diagnosed with the illness . . . it was more on my mind . . . it's not like that anymore . . . it's just something I have, like somebody has diabetes. It's no more, no less. It's a disease that you're living with and managing as best as you can."*

Fran

# Seeking normal

## Coming to terms with the wish to "return to normal"

*"And so now cancer is a part of me where I'm aware that I had cancer, I'm aware that the surgery happened and this sort of thing. I'm aware that I go for checkups. But it's not who I am. It's not . . . it's just a part of me now." Tina*

People described the desire to return to their old life and how this changed over time as they came to terms with their illness. Illness became part of life, which was a new way of living.

## Learning to live in the "new" day to day

*" . . . my HIV medicines need 12 hours break between those two other medications, which I told her, I said, nobody eats supper 12 hours after they had breakfast. So it gets in there as best as I can do." Debbie*

Realizing their illness meant a new way of life, people made adjustments to daily routines. These could include relocation of where they called home and changing work status.

## Living in your body

*"I never felt ill. I mean, yes, I had associated symptoms like joint pain. There were times I couldn't get out of a chair, the pain was bad. I feel fine. I'm doing OK. I wasn't doing OK. It was real denial. You can look back and say that." Shay*

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 know I'm going to die. I live with that every day. I know every time they hook me up I might die. But you know every time I go and get into a car I might die too. So you know you can't dwell on it and I don't."*

Tegan



# Facing dying and death

## Raising questions about the nature of life

*"I'm quite at peace. I realize – I really am, I really am. I don't worry about stuff anymore. I don't worry about stuff. I don't worry about death. I don't worry about life."* Leon

People diagnosed with a serious illness often have an increased awareness of their own mortality, that they could die and someday will die. With this, people reflected on their mortality in new ways, sometimes living with less fear and anxiety.

## Who do I talk to?

*"How much longer will this kidney disease or whatever medicine I'm getting, keep me alive you know? I don't have anybody at the renal unit that I talk to intimately."* Sandy

Although over time individuals became more comfortable in facing their mortality, there were few people in their daily lives with whom they could discuss their thoughts and feelings about death and dying. Loved ones were often well-meaning, but the topic of death was difficult to discuss.

## Focusing on living

*"Dying with dignity I think is important with all of us. Living with dignity is even more important – to put it in a positive light – which we should do all the time – I really think."* Alicia

Preparations for end of life, for example estate planning, were reminders that people were living with life-threatening illness in their day-to-day life; and reminders that there was still life to live.

A photograph of a forest path. The path is covered in fallen leaves and ferns. Several tree trunks are visible, some of which are covered in bright green moss. The background is a dense forest with many trees and foliage.

# Exploring life questions

*"... it's not always easy getting that purpose in life back though, you know, but I still think that if you go after it, if you can ask the universe for it, it will, it's there to provide it. But you have to ask. It doesn't push it on you."*

Morgan

## Reflecting on beliefs

*"Celebrate this particular moment. I think it's more where I am and how I feel is more about who I am and the way I deal with things."*

Corey

Facing illness, people openly talked about their values and their spiritual and religious beliefs. What was important, was having personal 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 life, such as people or mementos. Many expressed how 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, you know, like people don't bother ..."* 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...

*“Well people who know me, know that I've been in hospital recently react kind and then I'll tell them you know that I'm feeling better and coming along. But if people don't know, then I don't go there. I just say I'm doing okay or... I try not to get into it. I'm tired of it. Tired of talking about it and... and I don't want people to, you know, sometimes they just turn sympathetic once they hear and I don't really want that either. So if I can get away with it I say as little as possible.” Nell*

*I did think to myself, have I erred ... in sharing my story with your research team? Is this dredging? And is it making me obsessive and is it making me self-obsessive cause I don't want to do that. Or is it helping me – it has to help me to make sense and there was a wee while there where I wasn't sure which part of the seesaw it was on and I'm – what I want is for what has happened around my treatment and health to be helpful in the greater field, but I don't need to know how it's helpful in the greater field. And then I think to myself, yes well you know maybe something will come from that.” Camilla*



This booklet is dedicated to all people living with life-threatening illness and their families.

We want to extend special acknowledgment to the 32 people who participated in this research and their loved ones.

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*"Dignity.  
Dying with  
dignity I think is  
important with  
all of us.  
Living with  
dignity is even  
more important."*

Sidney

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

*Front row:* Rosanne Beuthin, PhD Candidate; Dr. Kara Schick Makaroff & Sheryl Shermak, PhD Student



Funded by:



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

[uvic.ca/illnessnarratives](http://uvic.ca/illnessnarratives)



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

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