



Stories of life with chronic kidney disease

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)



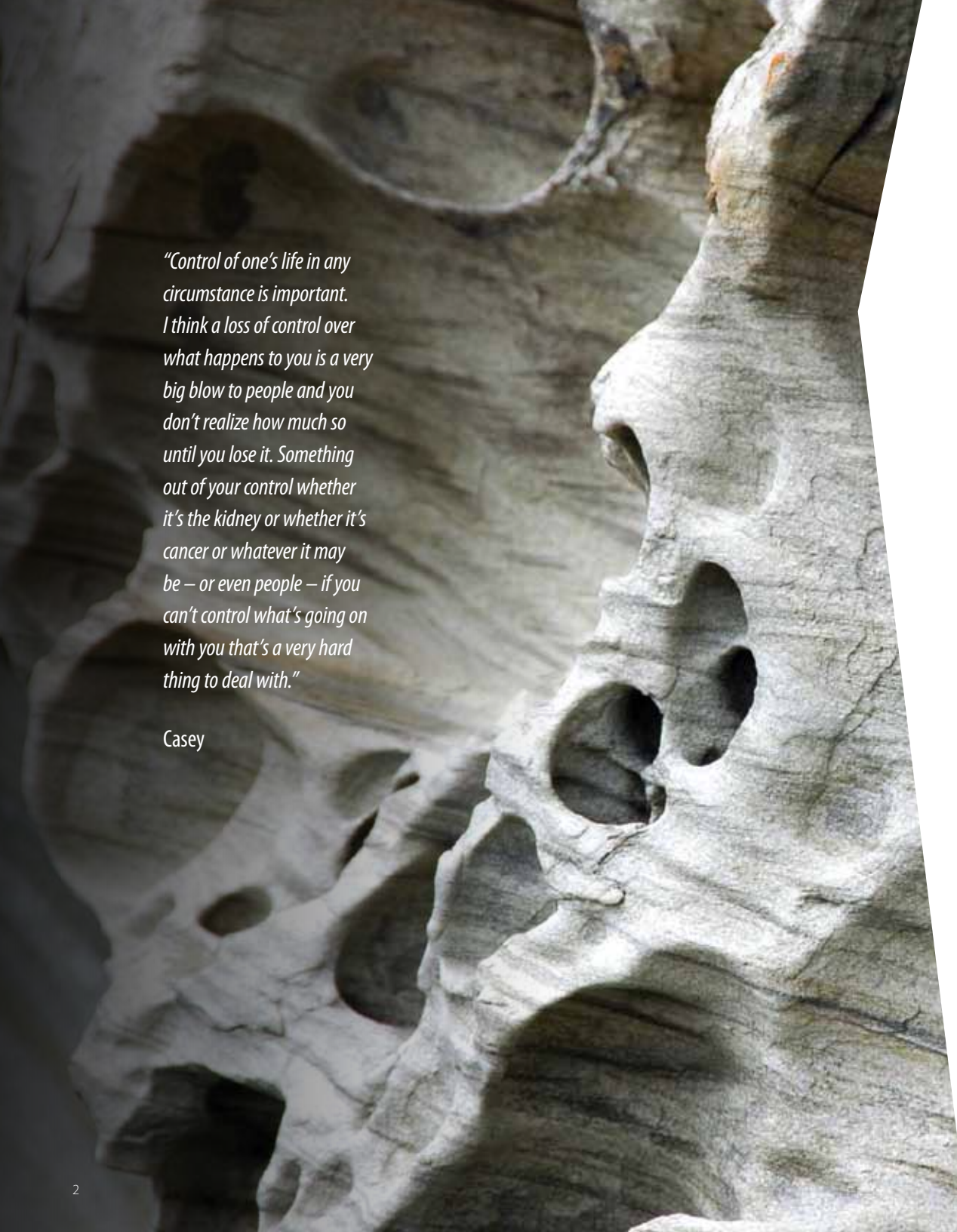
Living with uncertainty: Storying life within life-threatening illness

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 CKD 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

Stealthy beginning

"I was diagnosed with this now over 20 years ago I guess; I was diagnosed as it was high blood pressure and my kidneys were starting to fail. So I've known about kidneys since then." Leonard

Having CKD was generally marked by a quiet onset. Diagnosis was not instantly associated with life-threatening illness. Further, life in the early phase was largely free of symptoms and the medical treatment routine was minimal.

Transitions to complex care


"...following my transplant I'm still facing uncertainties cause I need to have more surgery ... it's shifted now to a new set of issues wrapped up in that disease." Elisa

People described increasingly relying on life-extending technologies that permeated daily life and required support from others. Dialysis marked a clear shift into an intensive phase of treatment, with life revolving around the therapy.

Management of life-threat while living with chronic illness

"He told me you can live with one kidney. What he didn't tell me was that life is not going to be the same eventually." Devin

There was a balancing act of managing everyday illness symptoms while managing aspects of life-threat. This was a process complicated by feeling poorly and not being able to readily find solutions or answers, for example within the medical and legal systems.



"I just want to be normal. But I know I won't ever be and it's always going to be this and that. Just strive to live a normal life."

Tara

Seeking normal

Illness symptoms and needs as guides of daily life

"Well there's a lot you can do with diet and you manage it, you learn to, by experience, because I didn't have a clue 10 years ago." Rory

CKD requires expansive changes to one's basic daily life, including diet. For those doing dialysis, people structured a new normal around the routine of medical treatments.

It could have been worse: Finding oneself being grateful

"Generally my luck's been good. I mean I've had... some problems – I've had a heart valve put in and that almost didn't work and so on, but this seems to be working out." Stu

Many individuals found themselves feeling fortunate, particularly in comparison with the stories of others. For example, some people felt fortunate to have good care at home.

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 . . . and I won't do it."

Tegan



Facing dying and death

Being on "life support"

"That's what I think comes to my mind, how much longer will this kidney disease or whatever medicine I'm getting, keep me alive you know?" Sandy

Over time, it was often recognized that medicine provides a means to live with CKD – rather than imminent death. This awareness was heightened when people had "close calls" or medical events that brought them close to death. People were also aware that they had the option to withdraw treatment, allowing for end of life.

Awareness of other people becoming seriously ill and dying


"I was appalled at how many died last year, at the renal clinic. 35 people had died from kidney disease – 35 people – that's a lot of people" Daniel

During dialysis treatments, people were exposed to situations where others had died, both on dialysis or not. For example, they described death notice postings and the absence of fellow patients at the clinic. These were reminders of their own mortality, but common occurrences that became expected.

Preparing for death while living life

"So now I've got 27 pages of information in my file drawer with "Passing Away" as the title and I've highlighted it all in red so it's very easy to find." Marcel

Preparations were part of life and included advanced directives, estate planning, discussions with family about last wishes, and recording important life moments for others.



"There are a hundred other things I could think of that I would rather not have, so if you have to have something . . . I've had a very good life despite kidney disease. I've been very blessed."

Morgan

Exploring life questions

Reflecting on beliefs

"I do find myself - talking to somebody - to myself really, but in prayer form, sometimes. But like I say I don't know whether it's an ultimate being." Kieran

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

"I didn't ever think I'm going to die. . . again my kids just motivated me to keep going, like. . . they need me." Sadie

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, with things happening for a reason. Further, that they were fortunate in comparison with others.

Beyond words

"Nearly dying was kind of like on some of those spacey shows, they show the swirls and stuff in it - I've thought long and hard about it. I just can't put words to it." Irvin

Many aspects of living with life-threatening illness were beyond words or unsayable; people were unwilling or unable to discuss them. These experiences were 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...

Felt experience of dialysis:

"Yeah it was almost like having a... extra job you know, a part-time job and I used to get pretty tired. By the weekend I was very tired."

Scotty

"It's kind of funny to say but dialysis is kind of a happy place, you know. I think of that once in a while because before I couldn't eat this, couldn't do that." Marlo

Treatments becoming part of life:

"I've been on meds for so many years that it's just part of my life. I remember at first it was like, oh I'm going to be tied to this for the rest of my life, taking drugs, but it just becomes part of your routine." Kai

"I have to live with myself. It's not being heroic; it's not being anything specific. It's putting to one side what you cannot do anything about. Why let it take over your life and stop you enjoying the time you have free to enjoy things with this right in front of you all the time?" Kris

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.

Notes:

*“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

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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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