



ALWAYS SMILE

CARLEY ALLISON'S SECRETS FOR LAUGHING,
LOVING AND LIVING

BY ALICE KUIPERS

SEVENTEEN-YEAR-OLD CARLEY

Allison was reaching for the stars. She was on the edge of fame as a singer and songwriter. She was competing at an elite level as a figure skater. She had a bright future waiting after high school. Then she was diagnosed with a rare form of cancer in her trachea — so rare that it affects only one in 3.5 billion people.

That diagnosis changed her plans, but it never changed Carley. Through treatments and setbacks, Carley remained fearless and optimistic, dreaming big and smiling. Always smiling.

She was the kind of young woman who didn't let cancer stop her from falling head over heels in love. The type of person who sang for an audience of millions, when doctors said she might never sing again. Carley helped and inspired others until the day she died.

Now Carley's memory lives on in the countless people she touched with her courage. Bestselling author Alice Kuipers weaves their stories with the blog Carley kept in the final months of her life, sharing Carley's secrets for staying strong and facing life's toughest challenges head-on.

ALWAYS SMILE

CARLEY ALLISON'S
SECRETS FOR LAUGHING,
LOVING AND LIVING

BY ALICE KUIPERS



Text © 2019 Alicenotes Limited

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system or transmitted, in any form or by any means, without the prior written permission of Kids Can Press Ltd. or, in case of photocopying or other reprographic copying, a license from The Canadian Copyright Licensing Agency (Access Copyright). For an Access Copyright license, visit www.accesscopyright.ca or call toll free to 1-800-893-5777.

Many of the designations used by manufacturers and sellers to distinguish their products are claimed as trademarks. Where those designations appear in this book and Kids Can Press Ltd. was aware of a trademark claim, the designations have been printed in initial capital letters (e.g., Dairy Queen).

Kids Can Press gratefully acknowledges the financial support of the Government of Ontario, through Ontario Creates; the Ontario Arts Council; the Canada Council for the Arts; and the Government of Canada for our publishing activity.

Published in Canada and the U.S. by Kids Can Press Ltd.
25 Dockside Drive, Toronto, ON M5A 0B5

Kids Can Press is a Corus Entertainment Inc. company
www.kidscanpress.com

The text is set in Minion Pro and Pompadour.

Photo credits:

Every reasonable effort has been made to trace ownership of, and give accurate credit to, copyrighted material. Information that would enable the publisher to correct any discrepancies in future editions would be appreciated.

Page 10, 19, 34, 59, 62, 81, 129, 177, 180, 208, 209, 211, 216, 227, 235, 263, 271, 277, 286, 300, 341, 348, 350: Mark Allison

Page 27, 60, 102, 134, 155, 156, 182, 259, 335: Riley Allison

Page 183, 273, 287: Ioannis Servinis

Page 179, 312: Carley Allison

Page 298: Sarah Fisher

Edited by Kate Egan

Designed by Emma Dolan

Printed and bound in Altona, Manitoba, Canada in 1/19 by Friesens

CM 19 0 9 8 7 6 5 4 3 2 1



Library and Archives Canada Cataloguing in Publication

Kuipers, Alice, 1979–, author

Always smile : Carley Allison's secrets for laughing, loving and living
/ Alice Kuipers.

ISBN 978-1-5253-0040-0 (hardcover)

1. Allison, Carey, 1995-2015 — Juvenile literature. 2. Trachea — Cancer — Patients — Canada — Biography — Juvenile literature. 3. Cancer — Patients — Canada — Biography — Juvenile literature. I. Title.

RC280.T5K85 2019

j362.19699'4230092

C2018-904422-5

It's not about how long you live,
but how you spend the time
while you are alive.

– Carley

ALICE KUIPERS, author

I never met Carley Allison. In fact, I didn't even know her name until it showed up in my inbox one day, a story in search of a writer. I did not know that she was a skater or a singer. I did not know that she had a magical life, filled with people who loved her and everything a girl could ever wish for. I did not know that she'd been diagnosed with a rare cancer, that she'd fought it bravely or inspired countless people or that she'd died too young. But I have come to know these things about Carley — and so much more — from spending many months immersed in the life she left behind.

To tell Carley's story, I drew heavily on the blog she wrote over the years of her illness. I've added the occasional word or sentence to clarify, but these are Carley's own words and own writing style, and her real thoughts on living with her diagnosis and treatment. Carley began her blog as an assignment because her illness meant she was missing so much school. She quickly realized that people found inspiration from her words, and so she kept on writing.

I also drew on the time I spent with Carley's family, who opened their doors to me and shared everything they could of Carley's: her videos, her songs, her photos, her texts, her posts. They introduced me to Carley's wide circle of friends and to John, the boy Carley loved. You will hear all their voices here, edited for length and clarity, telling all the facets of Carley's

story and showing the wide range of lives she touched. You will also experience the world through Carley's eyes in scenes I have constructed from stories her family told me.

At the moment of her diagnosis, a vibrant and dynamic — but ordinary — young woman became extraordinary. Carley took the terrible thing that was happening to her and managed to keep her spirit and joy alive. She showed everyone around her how to live life to its fullest.

Carley lived according to simple rules that come up again and again in her blog or in the memories of the people who loved her. Above all, her secret to a happy life was this: Always smile.

This book begins with Carley's voice, just as it sounds in an interview she recorded with her father when her cancer was in remission. Carley and her dad set this up as if it were a media interview — it was a fun way to hang out together, but also an important record of how far Carley had come. After months of uncertainty and fear, they're relaxed in their living room at home. Carley is elegant in black, and you'd never guess what she's just been through. Because she is smiling. Always smiling.

CARLEY

Hey, everyone. My name's Carley Allison, and I'm going to tell you a little bit about my cancer story.

My everyday life before I was diagnosed was very busy. I was a competitive figure skater, musician and full-time student in school. My schedule was always very go-go-go. Then I got sick. My pathology was a clear cell sarcoma in the trachea. I was the second known case of this in the world — a one in 3.5 billion chance. Might as well buy a lottery ticket.

So, for me, one day I woke up and was like, Oh, wow, this is my reality now. I had to be pulled out of school, I wasn't skating and I couldn't sing. Singing was my best outlet, and I couldn't imagine my life without it.

My illness greatly affected my family. I'm just so grateful for all the things they did for me.

I'm grateful, too, for John.

My illness changed me 100 percent. My eyes have been opened. Before, if I was to see someone going through cancer, I'd say the typical things: Keep your head up. There's always light at the end of the tunnel.

But after going through it, I can say I know it's hard. I know it seems like there's never an end. Especially chemo. It feels exhausting. But never, never put doubts in your mind. Never think, Oh, well, I'm really, really not feeling well. Always think, Tomorrow I'll be better than I was today.

I still don't look up and think, Oh, I have cancer. It's not something I think about. When someone says it, it catches me off guard. Because I feel okay. In fact, I feel strong. And you never know how strong you are until strong is your only option.

CHAPTER ONE

Always be the best you can be.

— Carley

CARLEY

I'm just back from a fun day at the lake with Kat, Sydney, Denzelle and Jill. Those girls kill me — I never laughed so hard. On the drive back today, I played Taylor Swift and we all sang out the open windows, the wind through our hair, me dancing even while I drove, with shoulder shimmies, the open road before us filled with possibility.

Now I'm working on a song in the music room in our house. I scribble:

“Oh, I don't want you to go.

I want you to stay here, stay here with me.

*Seems like every day we're coming closer to the day
when you will pack your bags and say ...”*



always smile #maketodayyourbestday

This music room is one of my favorite places to be. Dad built this house — he’s a contractor with his own business — and Mom did all the interiors. Mom and Dad met when they were in high school. I can’t even imagine them young like that, getting married. I love thinking about what I’ll wear when I get married one day: a white bikini on a sandy beach, perhaps.

Mom has gorgeous taste — think a home-and-decorating magazine and you’ve pretty much got a picture. Except, our house always smells like muffins — Mom makes twelve every day to feed us and our friends and our huge extended family, who love to swing by, especially my cousins, like Jeffrey. Mom makes these daily muffins just after she heads out for her

morning run and just before she goes to work. Mom used to take me to her car dealership when I was a baby — maybe I'd like to work there one day. It's in my blood.

I pick up my guitar. We have five guitars — I know, we have a lot. We're lucky. I strum a few chords and open my mouth to sing.

I can never decide if I love to skate or to sing more. I sing a song I wrote recently:

*“So I can wake up and feel if this is real.
Even when I'm gone, I know you'll think of me,
so hold me close and tell me that you'll always love me.
I'm just not good with goodbyes.”*

My boyfriend messages. Well, my on-and-off boyfriend. Right now, we're off. I delete his message without reading it. Whatever he has to say, I don't have time for it right now. Denzelle messages me a photo of us smiling together.

I message her:

Young, wild and free hahahahaha

She messages back:

Exactly

I check the time — if I fit in a quick run now, maybe tonight I can do something fun with Den. Or maybe I'll just see if John wants to go to Dairy Queen.



I'm singing as I pull up to John's house. I'm always nervous when I wait outside in Ricky — that's the name of my white Jeep. John isn't my boyfriend or anything, but still I want his mom to love me — she's just the sort of person you want to impress, and I stress about coming up to the house and knocking on the door, or just waiting in the Jeep. I message John to let him know I'm here. I'm not even sure why I care what his mom thinks, anyway.

The song finishes on my stereo — “Girls Just Wanna Have Fun.” And John comes out. He's wearing a shirt and jeans, clean-cut as always. He lifts his chin and climbs into the passenger seat. I smile at him. “How's it going?”

“I'm ready for ice cream.”

His voice is low, soft, but steady. I like his voice. He'd sound good if he could sing. Which he can't.

“You? Skor?” he says.

“Always.” I drive up for the best view in Toronto. Every time we go there, he tells me it's the best view in Toronto at least once. As I drive, I tell him about skating today. Shin, my skating coach, was super hard on me — I get that he wants me to be the best I can be. I do. Because I want that, too. But sometimes I wish he'd be a bit less stern. Except, then Shin gives me a smile, and I know we both want the same thing — in those moments, I know I may not be there yet, but I'm closer than I was yesterday.

At Dairy Queen I order a Skor Blizzard and go to our spot. John is checking his phone, while I leave him inside waiting for our ice creams. I sit for a moment on the bench outside, looking

out at the evening light over the valley beyond. It's so beautiful here — and as I sit, I start thinking in song lyrics: "*It's hard to see your face when it's a million miles away.*"

John sits on the other side of the picnic table, opposite me.

"Are you messaging a girl?" I ask.

He shakes his head and laughs.

"You just need to find ... No. Even better, I'm going to find you the right girl."

"Carley, stop."

He laughs again. I look at him critically — he's handsome, for sure. Dark hair, dark eyes. His eyes are kind. He is kind — the sort of guy who opens a door for someone who needs it, who helps a stranger with a heavy bag. You can see when you look into his eyes that he's smart, too. A book guy — I mean schoolbooks, not stories. He's too rooted in reality to have time for made-up stories. One of the best things about John is how real he is.

I lean forward earnestly. "I'm gonna introduce you to someone perfect. And I'll be so mad at you if you don't take her out."

"I'm not even interested," he says. "Let's look at the best view in Toronto, instead."

"I knew you'd say that."

He opens his arms out wide. He's right — exactly here is the best place to be. We're quiet watching the sunset.

"*I care about you. I loved you.*" More lyrics float into my mind. I'll write them down later, sing them perhaps at my piano, share them with my older sister, Riley, who I often call "Ri." Sure, we haven't been hanging out as much as usual this

summer. I'm so busy with skating and my own friends. It's weird — we've always been more like best friends than sisters. I've always looked up to her, wanted to do everything she does. But she's been doing tons of stuff without me this summer, and I guess I'm mad at her. Not that I'd tell her that. Anyway, I'm too busy with my own life to care what she does with hers.

My ice cream is melting. I eat it quickly, chatting with John about the end of summer, about going back to school. Grade twelve is going to be the best year ever.

I'm so excited about skating and sectionals and prom — I'm going to get this dress with one shoulder on, one shoulder off, in silver. Can't wait.

As we get back in the Jeep, I start coughing.

"You sick?" John asks.

I shake my head. "Just this asthma. I'm on an inhaler. It's a bitch. Whatever. I'm not gonna let it stop me."

SAM SERVINIS, John's mom

That was the summer of Dairy Queen and Carley.

LYNDSAY REDDICK, Carley's friend

Carley and I first met when we were eleven years old, at a sleep-away camp named Saddlewood. We were assigned to the same cabin and immediately became friends. I still remember, over ten years later, watching Mark and May move her into our side-by-side bunk beds and thinking, Wow, this girl is way cooler than me. I'm going to make sure we become friends! From then on we were pretty much inseparable!

We became even closer when our older sisters, Riley and Jenny, became close friends. The four of us became this sort of sister gang — we considered one another family — we fought like sisters and loved one another like sisters.

SARAH FISHER, Carley's friend

The first time I saw Carley we were at Coffee House at our school, where people would regularly sing, dance, do anything that they liked to do and perform. And the first time I really saw Carley was in front of whoever was there at Coffee House. She was two years below me, and we hadn't really met yet. Carley was wearing her school uniform. And she was singing a Taylor Swift cover, and there was just this beautiful, gorgeous, perfect little blond girl with a guitar and this huge voice. Everyone was just cheering and was so in love with her, and she was such a small person, and she had such a big voice. And that was the first time.

HOLLY DE JONGE, family friend

In 2002 I started working as the nanny with the Allisons. I became part of the family, and now the family and I will be friends forever. They nicknamed me “Hol-Hol.” I didn’t spoil the kids a lot — it was tough love. I wanted to make sure we didn’t spend lots of money. We’d walk to a cheaper parking spot. If the kids made crumbs at lunch, they would have to vacuum, and I’d get them to do chores around the house. I made little games of it.

I knew Carley all through school, junior high school. I’d see her for lunch and after school. We had lots of adventures together — we loved walking the family dog together. Jack was an incredible dog. We used to do lots of arts and crafts, and we were always making things for their parents.

Many days, I’d get to the house and Carley would mimic me and put on the same clothes. She was a really happy kid, and she had a really natural athletic talent. She loved running and skating. At track meets she’d always be way ahead of the other kids, and she was very competitive. Her natural talent shone, and I think she got that from her mom, who was an Olympic marathon runner.



success will happen when you want it as badly as you want to breathe

SHIN AMANO, Carley's skating coach

When she stepped on the ice, she started to smile. Always. I could see through her face that she appreciated being on the ice and being able to skate. People forget how amazing it is to be on the ice and how amazing it feels, but her smile — I'll never forget it.

MAY, RILEY and SAMANTHA ALLISON,
Carley's mother and sisters

RILEY: There are two scores in skating. It was impossible to get a 50/50 split between your Components score and your Technical score. Carley would almost always achieve a 50/50 split because her skating skills were so high compared to the girls at her level. She could skate beautifully. And if she landed all her jumps, she'd win. It's hard. You've got to land — you've got to leave the ice, do two to two and a half to three rotations and land on the size of a dime. That's all you have.

SAMANTHA: And if your foot is even a little bit not straight, you fall. Carley was amazing. She was very expressive, a very good skater. But if she ever didn't land all the jumps, I'd try to say, "That was beautiful."

Carley would be, like, "Yeah, okay."

But she's giving me a look.

I was just, like, "What did I do? Who did I kill?"

MAY: In skating you have to do these athletic things, thinking about what's next, how you will land it, if you did it correctly, all the while making it look as if you are dancing effortlessly to music.

RILEY: I think that's why she loved it.

CARLEY

Kat shows up at my door and holds out a wrapped gift. She says, “I got this for you!”

Kat is tall, dark haired, athletic. We love to talk about running or skating or volleyball, or just hang out post-workout. None of our other friends ever want to talk about anything to do with sports, so I just adore hanging out with her.

“What’s this for?” I ask her.

“I missed your birthday while I was away at training.”

I rip open the pretty package. It’s a beautiful white sweater from Aritzia. “Oh, it’s gorgeous, Kat. Thanks!” I hold it up against myself. “I should wear it tonight. It’s perfect.”

“It suits you. Good. I thought it would. We should get ready. We’ll be late for Jill and Den. Except, I don’t even know what to wear.” She heads into my bathroom to try on both the outfits she’s brought as options to wear. I hear her sigh.

“You okay?” I join her in the bathroom and start to put waves into my hair. I watch in the mirror over my sink as she changes again.

“Wow. I don’t look good in anything.”

“That top makes you look great,” I reply. I hold my curling iron and wink at her in the mirror.

“*Urgh*. This is putting me in a bad mood. I don’t even want to go anymore.”

“We’re going to have a great time. You’re beautiful,” I say. I place the curling iron on the edge of the sink and turn to her. “You know what, Kat? This sweater you got me would look SO good on you. You should wear it.”

“Really? No. I just got it for you.”

“Seriously — it’s going to be perfect.”

KAT TSIOFAS, Carley's friend

Although the sweater was a little small because Carley was a lot shorter than me (she was a figure skater and I was a volleyball player), I did like it and ended up wearing it to the party. It was a small gesture, but that's just the type of friend Carley was. She was always looking out for everyone else.

CARLEY

By the time I get back from my run, I'm full of energy. I love the feeling running gives me. Love it and hate it — running competitively made me push myself so hard it made me feel sick, so I'm not competing as much anymore. I have some cross-country stuff coming up in the fall, but I've mainly decided to focus on skating.

I eat one of Mom's banana-chocolate-chip muffins and grab my stuff for skating. I'm due on the ice pretty soon. I message Sarah to see if she wants to hang out later. My big sister, Ri, is home for the weekend, and she glances up from her computer to smile at me.

“Good run?”

“It's nice out.”

“Do you miss it? Running, I mean.”

“Not really.” She's talking about when I used to run in stuff like the Ontario Federation of School Athletic Associations — OFSAA. I was twenty-first in Ontario in cross-country. You'd think that doing so well would make me want to keep up with running, but I don't love it the way I love to skate. I'm about to tell Ri all this — I think about the millions of conversations we've had, curled up together in our den or on the couches that run like wide train tracks from the kitchen to our huge fireplace. After family parties or when Lyndsay and Jenny come over. I miss all that so much.

She's already looking back at her computer. I get the same feeling of irritation I've been getting recently every time I see her. I know it's partly my fault, but I wish we could go back to how we

used to be. Ri and I did most things together — as if I was the same age as her — but now that she’s at university there’s a hurdle between us. I can’t do what she’s doing. And I hate it.

She interrupts my pity party.

“Do you remember when you were cast as Annie when you were little? Remember how it was a group of kids my age doing the musical, but you had to participate, ’cause we had to do it together? And you got cast as Annie over everyone in my grade?”

It’s like she’s read my mind. I have a flash of connection to her. I know she misses me, too. Weird how we miss each other but we’re in the same room. “I remember.”

“You remember how some of the other girls were mad, but you were so good at being Annie that in the end you won everyone over.”

“Why are you being so nice?” I kid. “Aren’t you too busy to head down memory lane with your little sister?”

“That’s right, Car. I’m always too busy for you. That’s why I’m home now and seeing if you want to hang out today.”

I head over to give her a quick hug. “Instead, it’s me who is too busy for you. Right now.” I pull a goofy face. “Sorry. I have skating. But maybe when I get back, we could do something.”



I step onto the ice for my practice, and I know people are looking at me — I’m in the fishbowl, and they are watching me while they eat in the snack bar. I love this opportunity to

perform. Love it. Skating is all about the lines you are creating with your body — how pretty can I make it look? I do stroking first, two rounds of Russian stroking — step on the ice, one step left, one step right, ending up on the short side of the ice. I go counterclockwise, take a few steps, then I do some crosscuts, walking-to-skating to get to the long side. I stretch out and do crossovers, heading left. I hold and pause, then do one crossover to the right, hold and pause. My mind and my body become one as I repeat continuous cross steps to make a shallow S pattern, then I do a U and start over.



every battle of a thousand miles starts with a single step
#figureskating #love ♥♥♥♥

I'm warm now, and my body is no longer fighting me. I need to warm up my edges next, and I work on my slalom — beginning with a two-footed, which I don't always do. But today I feel like everything is coming easily to me. I do a bunch of simple turns, thinking again of the people watching, then I do brackets, rockets and counters.

I think about the jump I want to do: my double axel. Shin shows up as I'm simulating the air position I'm going to need when I start jumping — two backspins in the center of the ice. He watches quietly. I'm too busy focusing to look up, but I picture his dark eyes upon me, weighing up what I need to work on, and it makes me want to work harder.

"Carley, hold," he says, as I finish my single axel.

I grit my teeth in frustration. I don't want to stop in this moment — I'm very square, and I'm perfect to jump. But I force myself to stop so I can listen to him.

By the time I get home, I'm stewing. All practice, Shin was on my case. Every step, every turn, every jump. *Urgh*. I feel like punching something. I slam into the kitchen, where my dad sits reading a John Grisham novel. He's at the wooden table by the windows, the one with the built-in bench, where all of us gather to eat family meals.

"I am so done with Shin," I say.

"Right," Dad replies. He hardly looks up.

"I mean it, Dad. I fired him today."

This is enough to get Dad's attention. He puts his book down.

"He went to the Olympics, Carley. And you fired him?"

I plop into a chair across from Dad and fold my arms across my chest. "Shin refused to let me fire him."

“What happened, exactly?”

“Just that. I told him, ‘Shin, I’m done.’ And he said, ‘No.’”

Dad smiles broadly. “He’s fired students. Good students, Carley. That’s how it goes in skating.”

“I know, Dad. I feel like screaming.”

“But he won’t accept being fired by you. Doesn’t that mean something to you?”

“It means I’m super mad.”

“It means that he really believes you can be good. That’s why he pushes you.”

I shove my fingers through my hair and pull a face. It’s a goofy face — my mood is softening. “I’m sick of getting it wrong.”

“You’re not getting it wrong, Carley. The whole idea of skating is that you make it look effortless and easy, but it isn’t.”

“Kind of like Shin,” I grumble. “He seems so quiet and mild, but he’s a bear.”

Dad grins at me and puts his hand over mine. “A bear you’re going to have to apologize to.”

I stick out my tongue. “Not now.”

“No. Maybe now you’d like to have supper with your old dad — everyone else is out. Sound good?”

“Sounds great.”



The next morning, on my way to class, I see John. I call out to

him, and as he turns to say *hi*, I swipe his hot chocolate and take a sip.

“I should start bringing you your own,” he says good-naturedly.

The rush of other kids around us is loud, but for a moment everything stills. I suddenly see John, his dark eyes, his smile. I actually kissed him a couple of times when we were younger, way younger, but nothing has worked out between us. I remember when we were cast in the school play together as girlfriend and boyfriend and we held valentine hearts with the words *I love you* on them. A bolt of electricity arcs between us, and I feel my stomach quicken. I’m being so dumb right now. John and I are friends. We’ve been friends since we both started in a group together in the grade ten trip. It was hiking trip, and we must have hiked twelve miles. I have a great picture of me piggybacking on John, both of us laughing. So, John and I were flirting even then. That’s what our friendship is — it doesn’t mean anything more than that.

JOHN SERVINIS, Carley's friend

In November 2012 Carley had a skating friend from Finland who had moved to Toronto, and they became very close friends in a short amount of time. I met Carley's friend at a party, which somehow led to her getting in my car and me driving her as well as all my other friends home. When driving her home, she asked me, "So you are just best friends with Carley? I don't understand. Haven't you ever thought of dating her and having her as a girlfriend?" At the time I blew this aside, saying, "No way! That's Carley. She's my best friend. She would never date me. It would ruin our friendship."



Carley thought it would be a smart idea to set me up with this girl. Carley's friend and I had a very short relationship that lasted three weeks.

RILEY ALLISON, Carley's sister

We would go over to visit Joni — our grandmother. She spoke Farsi. I was the oldest grandchild, and I had trouble with the Farsi word for *grandmother*. So, I used to say “Jon M,” which sounds like a word in Farsi that means “my love, my sweet.” My way of saying it turned into “Joni,” which ended up being what we all called her.

Joni lived across the street from the Granite Club, where we skated, so during the summer we went all the time. Then in the fall I'd come home from university for a long weekend, and we would go over and watch *The Price Is Right* with Joni because Carley had a spare. Or Car would go before or after school with Mom, after Carley had swum at the pool in the building there. Joni's home was beautiful, a big apartment, with beautiful Persian decor — lots of rugs and gold. It was very grand.

Joni had surgery on her pancreas, and after that point she didn't really recover. As the fall went on, she was in bed a lot. Sometimes she'd get up and walk down the hallway. She loved it when we visited.

CARLEY

After school I head to visit Joni, my grandmother. Mom lets me in, and I kiss her on the cheek. She is busy cleaning out the fridge. Mom says, “People have been so generous with casseroles she can’t eat them all.”

“How is she?”

“She’s in bed. Maybe we can get her to walk a little.”

I walk through the gorgeous sitting room, over the rich rugs, and I run my hand on a golden figurine that I love. I remember when this apartment used to smell of these cutlets that we called “koobi” — meat, potatoes and onions, all panfried. They were frigging delicious. My mouth moistens as I remember, although now the place smells slightly antiseptic, and of cleaning products.

“Model Girl,” my grandmother says from the bed. She is smaller, frailer, and this makes me slow my step. Just a little. I don’t want her to see my expression. It’s just hard because I remember my grandmother being so full of life all the time. Her dark hair is pulled back from her face, and her eyes are bright and full of life. Suddenly, I feel comforted. She is going to get better. I know she is.

She assesses me. “You know, I looked like you when I was young. I know you don’t believe it.” She adds in Farsi, “So pretty, so pretty.”

The words sound something like *Khalie-ghashang*, and they are words she’s used for me for my whole life — so I know what she means. I wish I could speak her native language. I wish I could connect to that part of her life and her history. She was

born in Tehran. I can't even imagine what that would be like.

"But you're too thin, Carley Joon." Joon is her pet name for all of us; it means "my love."

"I'm eating just fine," I say. "Promise. I've been working out a lot to get into shape — I want to be able to do triples. And I'm going to record two songs for my audition to go to Berklee — imagine, me going to school there? It would be so amazing to study music and voice like that."

She smiles. "Ah, my Model Girl. Big dreams. You make me so proud."



love you and Papa more than anything.

KAT TSIOFAS, Carley's friend

I remember Carley was having some trouble with her skating. She wasn't landing some of her jumps that she had normally been able to do. Her skating coach, Shin, was getting on her case because he thought she was out of shape. Carley, being the competitive girl that she was, really took this to heart. I remember her saying that she was out of shape. She would note that she was getting out of breath just from going upstairs — this coming from the girl who had done the CN Tower climb in record time.

Carley and I were similar in the sense that we were both very hard on ourselves when it came to our sport. At first I just thought Carley was being hard on herself again. As her friends, we tried to support her, telling her there was no way she was out of shape and that she was one of the fittest people we knew. Then when things weren't getting better, Carley started with the doctor's visits. She was diagnosed with exercise-induced asthma. I think mentally this made Carley feel better. Now there was an actual reason that she was getting out of breath, and she thought this meant she could continue with her normal training schedule.

CARLEY

I went to the recording studio to record a few songs for my Berklee audition, and the recording engineer asked me if I could breathe quieter ... I didn't really know how to do that, because my breathing was always loud and that's just the way it was.

HOLLY DE JONGE, family friend

The family dog, Jack, would always sneak up to Carley's room and sleep by her side at night. It was almost like he knew first that something was wrong.

MAY ALLISON, Carley's mother

My mother, Joni, was in hospital for Christmas, but we were able to take her out for a night. I vividly remember forcing her out of the house, pushing her to go out. She so enjoyed being out. She sat in the car and looked out of the window at the Christmas lights. She loved it as we drove slowly through our neighborhood so she could see the lights. It was a big deal for her. Mark filled our yard with several blow-up toys and lights. The whole front lawn looked like Disneyland. She was very happy that night.

Joni was an amazing woman. I remember from her hospital bed she said to me, several times, "You make sure you find out what's going on with Carley. She's lost too much weight. You make sure to get it looked at."

Joni died on January 26, 2013.

CARLEY

My heart is breaking. But I'm not going to cry, no way. Our family arrives at the R. S. Kane Funeral Home, the same place we had Papa's — my grandfather's — funeral just two years ago.

Once we get inside there are pews as if it's a church; the place is all dark colors and lots of red. I think of my grandmother, her soft hands, the way she called me "Model Girl." My grandmother was so selfless. She was so kind. I make a promise to myself in that moment. If I can be kind to someone, I will. If I can do something to help someone, I will. If I can inspire someone, I will.

Sammy, my younger sister, leans into me, sobbing. I put my arm around her. I can start by being kinder to her. Uncle Glen finishes his speech, and it's time for me to sing with Ri. I'm trembling, but I won't cry. Not now. I have to do a good job for Joni. I have to smile.

This song is one that Ri and I wrote together, and during the chorus — "*Don't worry about us, we're good*" — my voice cracks. I'm struggling through the whole song with my breath. It must be heartbreak that is making it so hard to sing. I turn to smile at Ri as we finish our song; our voices fall silent, leaving a space for my fears to grow. In a few minutes I will sing alone, and I suddenly worry I won't be able to do it — my breathing is heavy, and my throat hurts. I just want to sit back and cry.

But I will sing my solo, and I will kill it for my grandmother.

LYNDSAY REDDICK, Carley's friend

Carley's grandmother passed away, and I remember going to her funeral, and my sister and I were both really concerned because Carley had dropped a lot of weight. I was more concerned about that than her breathing, because you couldn't really hear her breathing when she was just standing there talking.

She sang at the funeral, and then you could hear her difficulty in her breath when she sang. She had applied to Berklee College of Music around this time, and she recorded two songs for her audition. You could hear, when she was singing, the moments that she needed to take a breath. You could hear her labored breathing.

I remember we always used to Snapchat, and one day Carley said she was going for tests, and she sent me a Snap. She had all these probes all over her head and chest, and she was in a hospital bed in a hospital gown, being tested, and then she went home that night, but she couldn't breathe. She was having a lot of trouble breathing. So, her mom, May, rushed her back to the hospital.

CARLEY

My mom decided it was time to take me back to the doctor. They sent us to have a VO₂ max test. My results were above average, but that was expected because I was an athlete. So, it seemed like nothing was wrong. Finally, we were sent to see a respiratory therapist. He had me do a few different things, then he and my family doctor decided to put me on a five-day steroid medication.

The five days on the medication were the most alive and energetic I had been in over a year. I thought I was getting better at last. Once I got off that medication, things felt even worse. The respiratory therapist decided I needed to see an ENT (ear, nose and throat specialist). My appointment was made for a few weeks down the road. I went home that day and started choking on my lunch. My mom knew it was time to take me to the hospital. They diagnosed me with basically a hole in my lung. They told us to come back on Monday for a follow-up appointment in the pediatric ward. My mom was shocked that they were sending us home. I still could barely breathe. My mom stayed by my side for the weekend and slept right beside me at night. But I didn't sleep those three days. I felt like I was running a race, and I never reached the end and never felt any relief.

We went for my appointment Monday, and they admitted me to the hospital. I sounded like I had just run a marathon, and I was losing weight by the day. The ENT sent a camera down my throat to take a look inside.

His face turned white, and he left the room. I wasn't scared at that point. It was all happening too fast.

CHAPTER TWO

Enjoy those you love.

– Carley

CARLEY'S BLOG

February 4, the day my life changed

On February 4th, 2013, I was sitting in my hospital bed waiting for the results of the CT scan. We had no idea what to expect; as far as I was concerned, I had exercise-induced asthma. Within an hour or so my parents were having a pretty serious conversation with my doctor. At this time I was still pretty clueless as to what was going on. I was an elite athlete, I had a healthy diet, yet I was always short of breath, so we always thought I had asthma for sure. My parents looked pretty upset, and I saw a few tears running down my sister's face. Now I'm really curious, all I could see was their facial expressions through the glass door of my room. They came back in and no one really said anything to me. My dad just held my hand, and my mom kissed my forehead, and they said the doctors don't exactly know what it is yet. I knew that was only half the truth.

MARK ALLISON, Carley's dad

The doctors made it clear that something was really wrong. I think Carley could tell, but she wasn't crying. She was already looking at it like a fight, like something she could get through.

We were all being brave for one another. May and I were trying to understand what was happening, but everything was happening very quickly.

The doctors said Carley had to go in for surgery.

CARLEY'S BLOG

Day One – After Surgery

The next day, I was on a stretcher on my way to surgery. For a while I thought I was having surgery to remove the tumor, but my doctor came back with some shocking news. The tumor was too large to be removed right away. So, the game plan changed a bit, and the next thing I knew I was getting a tracheostomy.

It was all happening so fast, the next thing I knew I was lying on the operating table. I lay flat on my back with a towel rolled under my neck to give it leverage. They said they couldn't give me an anesthetic for the first part of surgery because my airway was so small, and the swelling could clog my airway. I was a bit scared, I mean who wouldn't be, and I was going to be awake while they cut a hole in my throat. But it had to be done, so I closed my eyes and tried to be as calm as possible.

I woke up very confused. I was hooked up to a few different machines, I had an ECG monitoring my heart, I had an IV giving me pain medication, I had a tube through my nose giving me food, and I had a tube connected to my neck giving my oxygen. I realized I wasn't going to be able to move much, but as long as I sat still, I knew I wouldn't be in too much pain.

The anesthesiologist came into my room the next day to ask me about the surgery. He had been testing a new drug, and he wanted to ask me how it affected me and if I remember anything from the surgery. I think it was safe to say I remember 99.9% of it. When I explained what I remembered about the surgery, he looked horrified, the drug was supposed to mix up my memory so I wouldn't be able to remember the surgery. My dad pulled out a piece of paper I had written on when I woke up, it read:

It was so scary yesterday
they started putting the tube down
while I was awake and I couldn't
breathe I felt like I was under water
they had to like hold my legs and head
down cause I was screaming I think.
I thought I was going to die.

The anesthesiologist joked, "Well, I guess we have to use a higher dosage next time." It gave us all a good laugh.

I realized after experiencing a tracheotomy operation with no anesthetic I could probably handle anything, but I had no idea what I had ahead of me.

RILEY ALLISON, Carley's sister

I didn't want to leave her room. It had all happened so fast — one day everything was normal, and then it was all hospital, and us trying to keep up. Carley was still able to make me laugh, even through all this. I don't think she was as scared as I was — it was happening to her, and we just had to watch. And we didn't really know then what was going on — the doctors really weren't sure, and they kept changing their minds about what they thought she had.

Carley's friends were all wanting to come and see her, and she was happy about that.

LYNDSAY REDDICK, Carley's friend

I went to the hospital the day after her first surgery. I didn't know what to expect. Carley was in the ICU — intensive care unit — and she couldn't talk yet. When I was told she was using a tube to breathe, I expected it to go down her throat through her mouth, but instead a small hole had been made in the front of her throat, and the tube had been inserted through that hole: an incision in her throat with the tube sticking out, with a breathing tube attached to that. I was obviously shocked to see her like that. Although I knew she'd had a surgery, before that moment I didn't really know what a tracheotomy was or what it meant. It was pretty shocking seeing her like that.

Carley was lying in bed, swallowed up by her blankets and surrounded by the beeping and buzzing of machines. The conversation I made seemed so mundane and meaningless. She was unable to really respond; her only means of communication were hand gestures and typing on her iPad, because she couldn't speak with the tube in her throat. I was scared to touch her; it seemed like any connection would be painful. She motioned for me to sit on the bed beside her, but I couldn't make out her figure beneath all the blankets and didn't know where to sit. The doctors weren't sure how long it would be until she could talk and if she would ever be able to sing or speak normally again with her trach in. But, although she couldn't talk, Carley was still trying to chat. On her iPad she was asking me how school was, and I was just trying to talk normally and tell her about my day and my friends, and then after she tried to suppress raking, excruciating coughs, she motioned for a button to be pushed. I

guess there was maybe an overproduction of mucus or something because her body was trying to heal the incision in her throat. A nurse had to come in and clear the tube.

Carley caught my eye and mouthed, “Don’t look. Turn around.”

It was all I could do not to cry then and there.

I turned away and stared blankly at the wall until the nurse left. When I turned around and looked at Car, her eyes were staring blankly ahead, refusing to meet mine, tears streaming down her face.



I have never in my life experienced anything more heart-breaking — to watch someone you love in pain and be unable to help them. Once I left, I only made it to the elevator doors before breaking down. I was so overtaken with confusion and sadness. I couldn’t understand why this had happened to her.

CARLEY'S BLOG

Day One continuation — My amazing sister Riley

My sister Riley has been my biggest support my entire life and no doubt my biggest support since I've been sick. My sister and I have a really special relationship, I'd say better than most sisters, and it has really showed in the past few days. Since I couldn't speak, sometimes I would mouth out words, my mom would sit there with a confused look on her face, but my sister always knew what I was trying to say. Riley said that for the first day most of my vocabulary consisted of "warm and fuzzies." My medication made me feel warm and I couldn't remember the name of my medication for the life of me, so I would just mouth out "warm and fuzzies," and my sister knew what it meant — that I wanted more meds!

Riley is probably one of the most amazing people I know. When she found out I was sick she came home instantly and spent the night in ICU with me. My parents would say, "Riley, go home and sleep and you can come back in the morning." But she insisted on staying with me. The night of my surgery my parents basically forced her to go home to sleep, so she went home, but she didn't relax. Riley and one of my best friends, Jill, were at my house making posters of my favorite quotes. The next day when I woke up they were all over my hospital room wall, it was incredible.

IF ANYONE CAN DO IT, IT'S YOU.

FEAR ABSOLUTELY NOTHING.

DREAM BIG.



Day Two — ICU

I woke up today a little less comfortable than the night before but I was quickly distracted from that. I have 74 messages on my phone: clearly the word got out. I read through the messages and started to realize just how lucky I am. I have amazing family and friends, actually they are better than amazing, they are incredible. I don't know if I spent more than ten minutes with less than one person in my room today. The love I am getting from my friends and family is just the most amazing feeling, and I know it will keep me strong. There is no way this group of people is going to let me give up.

The trach was still sore and I was still unable to talk but I had started on my way to recovery. My parents always said to me, "If you're going to start a task, you better complete it and you better give it 100%," so I knew that's what I had to do.

When I signed the paper for my first CT scan, I made a promise that I was starting a task and I was going to give it 100%.

Every day from now, I start to get better.

MAY ALLISON, Carley's mother

She's hit with this, and there's hardly a tear. There's hardly a "Why did this happen to me?" She has always been able to hold it together. There was very little shock with her. And she's what's holding us together.

She was exceptionally strong.

CARLEY'S BLOG

Day Three – Back on my feet

Today I was finally able to get out of my bed. Although I wasn't allowed to go very far or be up for very long, it was still pretty exciting. ICU was a pretty closed off place from the rest of the hospital, and if you were a patient there, you were definitely not allowed to leave. So I started my little walk around the ICU, and it wasn't as easy as I thought it was going to be. I was sore and tired, and I quickly realized that it was much more comfortable in my bed. Quickly my focus changed, as I walked around the ICU, I could see into some of the other rooms. My jaw dropped at the condition of some of the patients; it was truly frightening. My mom noticed me looking, and she took me back to my room. For a few minutes I was in shock. I had heard about what ICU was like, but I'd never experienced it firsthand.

At this point my spirits were really down, I felt like I'd been on an emotional roller coaster ever since I got here. And this just happened to be a down moment. I don't think I really know how to deal with this yet. One moment, I'm laughing with my friends, and the next I'm wondering how serious things are. But I know that everything I'm feeling cannot even compare to how my parents are feeling now.

We wait patiently as another day went on and we had no results. My doctor had given my parents a few ideas as to

what it might be, but I'm not so sure that was a good idea. I could see my dad pull out his laptop and start Googling all of the options, and I just watched his face turn white.

He came over to my bedside and said to me, "Carley, we are going to do whatever it takes to get you better. Whatever it takes." It was really breaking my heart to see my dad like this. He's always the strong one, always the rock. But not today. Today I could see him slowly falling apart.



Day Four — The Diagnosis

Today I woke up in good spirits. I was feeling much better and I finally had that annoying feeding tube out. Just like every other day, my room was filled with visitors and the wall of cards was growing.

By mid-afternoon, my doctor came to deliver the news about what they found from the pathology. The pathology had determined that I had Malignant Melanoma inside the trachea. My doctor didn't seem very confident with what he was saying though: he said, "This is so rare that it's almost impossible that [you] have this type of cancer."

My doctor said that it could also be a Sarcoma Tumor, but

the pathology reported a Malignant Melanoma. After a little more conversation, my parents stepped out of my room with my doctor. To me it really didn't matter what type it was, because whatever it was I knew I was going to beat it.

A few hours later I was talking to my sister, and she says, "Hey, Numba Seven." For a second, I just burst out laughing because when I was on my medication, everything seemed to be funny. But after I was done laughing, I asked her what number seven was suppose to mean. She began to explain that if I really have Malignant Melanoma outside the trachea, I would be the seventh in the world to be diagnosed with this type of cancer. We kind of just joked about it, and changed the subject, but although it sounded cool to be seventh in the world, it was terrifying. I'd make light of it in front of my friends and family, but I couldn't help think about what comes along with rare things. Is it treatable? what kind of treatment would they do, chemo or radiation? Will it come back later in my life?

But I guess all that doesn't really matter anyways, like my dad said before, we will do whatever it takes.



ALICE KUIPERS is an award-winning, bestselling author of five YA novels, two picture books and a chapter book series. Her work has been published in 32 countries. She lives in Saskatoon, Saskatchewan, with the writer Yann Martel and their four children. Find out more about her and join her free online writing course here: alicekuipers.com

ORDER
YOUR
COPY
TODAY

ALICE KUIPERS is an award-winning, bestselling author of five YA novels, including *Me and Me*, two picture books and a chapter book series. Her work has been published in 34 countries. She lives in Saskatoon, Saskatchewan, Canada, with writer Yann Martel and their four children.

Jacket design by Emma Dolan
Jacket photos courtesy of Max Agency
and the Allison family

www.kcploft.com



WATCH THE
ACCLAIMED MOVIE
KISS & CRY
FOR MORE ON
CARLEY'S LIFE

“Everyone who followed Carley’s story saw how determined, optimistic and strong Carley was through her cancer journey, but she was all of those things long before she was diagnosed. I can’t capture in words how much Carley means to me, but this book provides a glimpse into her extraordinary and inspirational life.”

— **SARAH FISHER**, actor and close friend of Carley Allison; Sarah portrayed Carley in the feature film *Kiss and Cry*

