

SARAH BENWELL



THE LAST
LEAVES
FALLING

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About the Author

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About the Book

I am going to die.

In a hospital, hooked up to a million machines.

Piece by piece, my freedom will be taken and my body will shut down.

What kind of an end is that?

But maybe there is another way . . .

This is a story of life and death, of finding friendship and finding courage.

THE LAST
LEAVES
FALLING

SARAH BENWELL



RHCP DIGITAL

For Malcolm, and for Mark -
I wish you were both here to see this

Glossary of Terms

Bah-Ba -

affectionate name for grandmother (obaasan)

bakeneko -

catlike supernatural creature

Benzaiten -

Japanese Buddhist goddess; goddess of everything that flows, including the arts

bonsai -

'tray plantings'; miniature trees, cultivated in pots. The art of bonsai is complex and revered

gagaku -

ancient Japanese court/dance music

jūnihitoe -

traditional, elegant, complex kimono; the 'twelve layer robe' (although it's not always twelve layers)

Ojiisan -

grandfather

Otosan -

father

Okaasan -

mother

raccoon dog -

indigenous East Asian canid species, named for its resemblance to a racoon (to which it is not closely related)

sake -

alcoholic beverage made from fermented rice

-san -

a suffix to names, which indicates respect. A little bit like 'sir' or 'ma'am'

yürei -

ghosts or supernatural creatures

A Note on Names

The use of names and honorifics in Japanese is complex and steeped in respect. People will often use full names or the suffix *-san* in everyday conversation, and there are different names for (for instance) *your* grandfather, and someone else's. It may also be useful to know that in Japanese, names follow the pattern: family name, given name (e.g. Benwell Sarah).

The names and honorifics in this book nod towards these patterns, but do not entirely follow them, because the complexities are lost in translation and can be confusing or overly formal and *different* to foreign ears. And ultimately, this story is about a group of teenagers not so very different from ourselves.

1

USERNAME

TAG-LINE

AGE GENDER

INTERESTS

If you could be anything in the world, what would you be?

UPLOAD A PROFILE PIC NOW

I stare at the cursor blinking expectantly at the top of the page.

Who do I want to be?

There are so many choices; honest, funny, brave. A superhero with a tragic past and bright, mysterious future; with superstrength or telekinetic powers. I could be anyone and they would never know.

People say that is the problem with the internet; paedophiles, murderers, conmen, the internet makes it all too easy to hide. But I like it.

I type 'SamuraiMan' into the first box, then my fingers come to rest against the keys again. I know I'm overthinking this, but it has to be right. Put all these boxes together and you'll have a picture: a picture of *me*.

Outside the computer, nobody sees Abe Sora any more, they only see the boy who looks weird, the boy who cannot walk, the boy who needs assistance.

The boy who's going to die.

At first, they thought that the aching in my legs was flu and nothing more, but the weakness grew, and one day, out on the baseball field, I fell. My legs stopped working. The tests seemed to go on for ever. Nobody knew what was wrong with me. They probed and prodded and asked a million questions. Every theory proved wrong, every disease and condition crossed off the list, until finally they found an answer.

I knew as soon as we opened the door. The doctor gestured to the empty seats, his face so serious, and I *knew*. They say that a warrior must always be mindful of death, but I never imagined that it would find me like that, in a white room with strip lights buzzing overhead.

'The good news is we *have* a diagnosis,' he said quietly. 'Amyotrophic Lateral Sclerosis.'

My mother shifted her chair a little closer, curled her fingers around my balled fist then said slowly, deliberately, 'What is that?'

'That's the bad news,' he sighed. He was staring somewhere between us, as though he could not bear to look at us.

I remember thinking, *Is what I have so terrible that he cannot even stand to say it? Will looking at me make him sick too?* I imagined germs flowing from my fingertips, infecting everything I touched. I tried to pull away from Mama's grasp, but her fingers were tight with fear.

I glanced across at her, watched her eyes desperately searching the doctor's face for clues. She looked tired. I noticed it for the first time that day. She has been tired ever since.


'It's rare,' the doctor continued. 'That's why a diagnosis took so long; it is not something you would expect to find in someone your son's age.'

My mother did not wait for him to continue, and when she spoke her voice was hurried, desperate. 'But what *is* it?'

The doctor stared over my right shoulder as he recited symptoms, using big words which meant nothing to me then - *atrophy* and *fasciculations*, then *neurodegeneration* - in what should, I'm sure, have been a reassuring tone.

His words rushed at me full force and then receded, like the flow of waves. 'Gradual deterioration . . . limited movement. No cure . . . average prognosis of two years, but in some cases it is more, or less . . . I am sorry.'

No cure. And since then, even to my mother, I have been the boy who's going to die; but here, here I can be anything.

USERNAME	<input type="text" value="Samurai Man"/>			
TAG-LINE	<input type="text" value="Farm when it's sunny, read when it rains."/>			
AGE	<input type="text" value="17"/>		GENDER	<input type="text" value="Male"/>
INTERESTS	<input type="text" value="Literature, history, reading, swimming, baseball"/>			
If you could be anything in the world, what would you be?				
<input type="text"/>				

Anything?

My mother's voice interrupts my thoughts, calling, 'Coming!' as she shuffles down the hallway. I hear the latch

and the soft creak of the door, polite voices, too quiet for me to recognize.

Who *is* it?

I glance at the clock, as if that will hold the answers, even though neither my mother nor I have very many visitors these days. It's . . . difficult. Embarrassing. No one wants to be around us any more.

I listen for any sign of who the visitor might be; a cough, a laugh, the rhythm of familiar steps. Nothing. I can't tell.

I wish they'd go away.

Holding my breath at every sign of company has become almost a ritual. Every time I hear the door, the telephone, a stranger's voice I wonder, who else is going to know my shame? Who else will stare, not knowing what to say?

Finally, the door closes and my mother's gentle footsteps move back along the hall. I rest my head against the monitor of my computer and breathe a long sigh of relief as the cool glass spreads its calm across my skin. They've gone. I'm safe.

'Sora?' Mother knocks at my door.

'Uhh,' I groan, turning my face towards the door. The cool of the glass shifts a little. I imagine that the cold is an iceberg, that I'm alone in a desert of ice where everything is clear and fresh and quiet. But I am not; my mother speaks again.

'Sora, your friends are here. Can we come in?'

'We?' I panic, sitting upright and pushing away from my desk, suddenly aware of how small my room is, how intrusive the large wheels of my chair are in this little space. There is nowhere to hide.

Who would visit unannounced? I never really had friends at school, more like acquaintances. People you could joke with in the classroom, but no one special. I preferred my own company and the quiet of the library, especially in the last months.

'Sora?'

I grunt, and the door slides open. My mother smiles at me and steps aside, ushering in the school's baseball captain, Tomo, and a girl I think I might have seen in the corridors of school, hunched below a cello case. I squint at her. Yes. Just before I left she caused a ruckus, leaving her first chair in the orchestra to start a rock band. They look odd together, short and tall, gutsy and clean-cut, the musician and the jock, but she's clinging to him tightly.

What are they *doing* here? Neither of them has ever been to my home before. We're not friends; we've barely even spoken.

They stand in the doorway for a moment, exchange glances. And I know: someone *made* them come. And neither of them wants to be alone with me. The cripple. The sick. The dying.

'Hey,' I say.

'Hi,' they say in unison, still not stepping over the threshold.

For a moment we just stare at each other, until I cannot stand it any longer.

'Come in, make yourselves at home.' I force myself to smile as I speak.

They step forward, one step, two.

'This is Reiko.' Tomo shrugs himself from her grip.

I gesture to the bed, with its neatly turned sheets. She sits, fiddling nervously with her plaits, but Tomo paces, swinging his arm like he's warming up to pitch a ball.

He stops and stares at the wall above my bed, the poster of Katsuhiko Maekawa, pitcher for the Tigers in the 2004 match against the Yankees. Below that, the shelf with my catcher's mitt, my limited edition silver bat, the ball signed by half the current team. And my baseball cards. Most of them are kept neatly in folders, organized by team and season. One, however, showing the face of Yoshio Yoshida, sits alone on the shelf looking out at me. It is a duplicate;

he's safely stored away with the rest of his team as well, but I like to think that he is watching over me.

'Wow!' Tomo nods towards the ball which takes pride of place beside Yoshio. 'Is that Tomoaki's signature in the middle there?'

I nod. The signature is barely recognizable; wonky and left-handed. Tomoaki Kanemoto had smiled at me and signed the ball even after playing through the game with a torn cartilage. That day, every boy in the bleachers learned about determination.

He frowns at it for a moment, squinting. 'Is this from 2004? *That* game?' he asks, eyes wide.

I nod again.

Games like that are not forgotten. Every pair of eyes is glued to the action, every heart longing to be down there on that green, soaking up the glory.

Tomo might actually make it there one day. He's good. I always wished that I could pitch like him.

'Awesome!' he says. 'You know, you should come to a game —' He stops, his eyes now on my chair. 'Well, y'know. If you find the time.'

'Yeah, maybe. Thanks.' I have no intention of watching the high school games, the team I should be on. I will never step onto the field or sit in the bleachers and cheer again. I know it, and Tomo knows it, and an awkward silence eats up all the air again.

'Actually, that's why I'm here.'

'Oh?'

'Yeah.' He shoves his hands into his pockets. 'Coach wants to dedicate the season to you.'

'To *me*?' I was only ever a B-team, after-school-club player.

'Uh-huh. He thinks, er . . . he thinks it might inspire people. Remind them what they have . . . sorry.'

I'm glad he has the decency to look ashamed.

‘Anyway. He sent me to tell you, and to invite you to the last game of the season. If you want. He thought you might do a speech. To motivate the others.’

What does one say to that? I am not a circus lion. I can feel an angry heat rising up my neck. It should not matter what the people of my past think. But it does.

I am nothing but the sick boy.

The unfortunate.

A puppet.

It is always like this. And suddenly a hundred awkward pity-moments flood my synapses, hit me all at once. Tomo and his girlfriend need to leave now; I need my room back. But as the seconds tick by, neither of them move, they just stare, and suddenly there is not enough air in here for three of us and I want them to leave *right now*.

I swallow hard, try not to sound desperate as I say, ‘I’m sorry, I am very tired.’

‘Oh. Of course.’ Tomo nods curtly and shuffles to the door.

Reiko gets up to follow, but she stops halfway. ‘We’ve missed you in class.’ Her eyes shine too brightly, as though she’s going to cry. ‘All of us. Hayashi-san is organizing everyone to sign a card.’ She falters. ‘We’d have brought it today, but a few people were absent and we know they’d want to send their thoughts.’

I do not want to think about my classmates, sitting at their desks as though everything is normal. Has someone taken my seat, or is it empty, a reminder that last term there was one more eager student? I look away from Reiko’s heavy gaze, tap the mousepad so my computer whirrs to life. ‘Thank you. I’m OK.’

She stays just for a second, then sighs and follows Tomo out. I hear them walk down the hallway, thank my mother. And as the door clicks shut behind them, I breathe.

Slowly, the air clears, and after a few minutes alone I turn back to the boxes on my screen.

If you could be anything in the world, what would you be?

I imagine myself passing Tomo in the hallway, sliding clumsily into fourth base, sitting in a classroom without thirty-five sets of eyes on me.

Healthy.

But then I think, *I'm more than that. I want more than that.* So I write:

I would like to be a professor when I grow up. Does that count? Or are you looking for something more abstract? In which case, I should like to be a fountain pen, expensive, elegant, belonging to a writer of beautiful calligraphy, or novels, recording truth and wonder for the years to come.

I am not exactly lying. I would love to spend my days in lecture halls until my hair is as white as the chalk dust floating through the air. I just . . . will never get the chance. But they did not ask me that.

I read the words again from start to finish and try to picture what someone else would see; what do I look like to a stranger? But even *I* struggle to see myself without this disease.

At the bottom of the screen are two buttons, *save* and *post*. My finger hovers over *post* but those shocked, sad faces from the school halls and the streets flash right before my eyes, judging me, and I do not click. I can't. I'm not ready.

2

My mother and I sit on either side of the table and eat in silence. She steals glances at me over her bowl of noodles, and I hope she does not see the tremor in my fingers. It is new, and I do not want her to know, yet. Once she sees it, she will do what all good mothers would, and fuss, but I want more time to do the little things myself.

I catch her eye, and she smiles her oh-so-tired smile. It is me who's done this to her, and I hate it. I wish that I could turn back time, change something, take her hand and run and run and run in another direction so that ALS can't find us.

She's curious, I know, but it takes her a moment to ask about my visitors. 'I don't think I have met your friends before.'

'No.'

'They seemed nice.'

I nod, picking up my chopsticks.

'Will they come again? Perhaps you should invite them for a meal.'

'They are very busy, Mama. I do not think they'll have the time.'

She hides it well, but I imagine I can see the longing in her eyes. I should be busy too.

'Perhaps we *should* apply to that other school.'

That 'other' school is a place for children who have disabilities. I am *not* a special student. I don't need help to tie my laces, yet, or to read, or manage my emotions.

Even if I am around for long enough, no one graduating from a special school will get a place at university.

We declined. But now I think my mother's having second thoughts.

'Are you going past the library tomorrow?' I ask, to change the subject.

'I could.'

'Great. If I write you a list, could you pick me up a couple of books? I can study on my own, Mama. You don't need to worry.'

'You know, we could go to the library together. Or the park? We could go for ice cream?'

I shake my head, and she sighs.

'Well, you have a session with Doctor Kobayashi tomorrow, don't forget.'

I nod. I can avoid the park, social trips and errands, but weekly meetings with my counsellor are compulsory, part of the terminal package. Every week, instead of going to extra classes alongside my peers, my mother drives me to the hospital and I sit for one stifling hour in that airless room, watching the seconds tick by until she will drive me home again. Doctor Kobayashi seems pleasant enough, but I do not know what to say to her. That I'm scared? That I wish it was someone else sitting in this chair? That I don't deserve this?

If I were a child, I'd cry. I'd scream. I'd throw my Hanshin Tigers baseball through the window as hard as I could.

But I'm not, and I cannot say these things.

I am so tired that my eyes itch, but every time I close them, fragments of the day flash into view. The look of pity on Reiko's face as she leaves. Tomo, in his baseball uniform, sliding into fourth base. An empty desk. A bustling classroom filled with people who don't fit into the real world. The lines around my mother's eyes.

When I can't stand it any longer, I swivel my hips so that my legs flop out of bed, and I sit, haul myself into my chair, and turn on the computer.

It is late. My mother is probably in bed asleep by now, but I listen tentatively for a moment anyway, before I type into the search bar:



Amyotrophic Lateral Sclerosis prognosis

The first page of results is all highlighted blue; all sites I've visited before. It doesn't matter, I need to read it again. Somehow seeing it written down makes it easier to process, as though I've unloaded part of the burden from my brain onto the screen.

I click on the first link, a simple wiki page.

Amyotrophic Lateral Sclerosis is a progressive neurodegenerative disease, usually presenting in patients over 50. The disease is always fatal, with most affected patients dying of respiratory compromise after 2-3 years.

The bit that always gets me, every time, is 'over 50'. I have an old man's disease. The doctors tell me that there are others, that I am not the only young sufferer or the youngest. But they cannot show me anyone else except sick old men leaving behind their grown-up children.

And if it is so rare, why me? Jealousy is an ugly emotion. It is not the warrior way. But I will never be that old man, never have children to sit upon my knee and teach about the way of things. And it is not only me I'm jealous for. I try not to think of my mother left alone, exhausted from two years of physical and emotional strain.

I try not to think of everything that comes between now and then, or rather to think of it, but as though it won't be happening to me. Because although my brain works fine, eventually I will be exactly like the kids at the disabled school. Unable to button up my shirt or raise a spoon of

food up to my mouth. Unable to master the simplest of skills.

It has started already. The aching in my hands, the intermittent trembling. Subtle now, but not for long. Months, perhaps, if I am lucky.

Legs, hands, arms, one by one they will give up on me.

If this were the olden days, I'd take a trusted friend and a sword out into the yard and perform the last ritual. Quick and final. No mess except the blood to sluice away. But it is not; we don't operate by that code any more, and no one speaks of the honour which flows through our veins. And I am stuck inside this failing body.

3

Doctor Kobayashi's office is on the third floor. You can see the tops of the trees through the window, laughing gently in the breeze; a stark contrast to the clean white walls of the hospital.

In here, the air is still, and there is nothing to laugh about. Doctor Kobayashi has placed a bonsai on the glass-topped table. Intended, I imagine, to calm her patients: a touch of green, a symbol of the essence of life. The cycle in perfect miniature.

Tiny yellow leaves spill across the table between us like curls of caramel. Nothing lasts for ever.

She watches me, her expression unreadable.

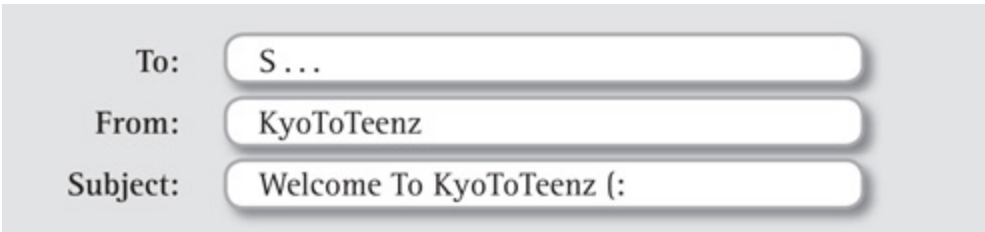
Judging me. They always do. Everyone.

Finally, she breaks the silence. 'Have you had a good week?'

I shrug, stare at the table rather than look at her. I know she wants me to speak, but I don't know what to say.

She cannot help me anyway.

4



Dear *SamuraiMan*,

Congratulations and welcome on becoming a member! We hope you will be very happy here.

Some features include:

Open forums - discuss anything and everything with the KyoToTeenz community.

Contacts - add your friends to a list; find their posts with ease.

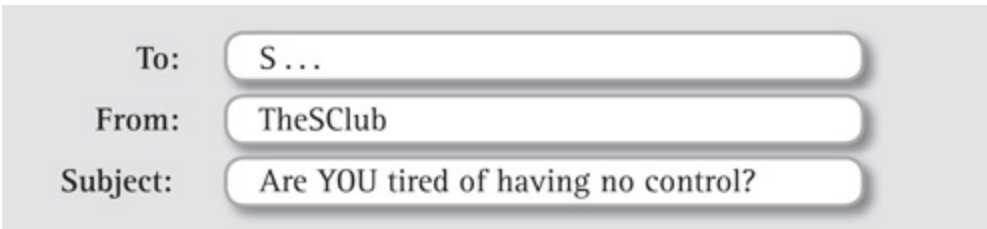
Private chat - some things you don't want to share. Private chat lets you talk only to the people who you want to see.

Ready to jump in? Your username and password will be with you shortly.

I flick through my emails one by one: a 20% sale on textbooks, and a message which reads:

**WE THINK YOU WOULD LIKE THESE MAGAZINES:
TRY ONE FREE TODAY.**

Then this:



Are you tired of adults being in control?

Want to take it back?

We will SHOW THE POPULATION, taking one last stand.

If we can't live our lives the way we want we won't live them at all.

Join us, for the biggest ending that there is.

The S-Club (can you guess what the s stands for?) is a new movement which plans to unite unhappy teenagers in their final moments and send out a message to the adults of the world, shocking them into change. WE CAN DO IT. We can make a better future.

Share with your friends! Join us!

Click the link below to find more info.

I read it again, because I cannot quite believe what it seems to be asking, and then quickly press delete. My heartbeat's pounding in my fingertips as though I have just handled stolen yen; if my mother saw this, she would take my computer into the street and burn it, ban me from the internet until the end of days.

But now she'll never know.

I stare at the unopened messages before me, more offers and one more from KyoToTeenz; nothing to suggest what I've just read. I'm safe.

5

‘How are you today?’

I shrug, barely, trying not to think about this morning’s physiotherapy and my awful performance on the walking bars. Last month I had been able to shuffle awkwardly down that runway, half using my legs. Today, they were bent and cramped and useless, and for the first time, my wheelchair felt like freedom.

‘It’s difficult for me to help you if you will not talk to me.’ Doctor Kobayashi sighs a practised little sigh which I am sure is meant to lay just the right amount of guilt.

I stare hard at the bonsai. It is almost bare now, only a few leaves clinging to the branches, and the yellow curls which spread across the desk at our last meeting have gone, swept into a garbage can somewhere.

She tries again. ‘How have things been since our last appointment?’

I do not answer. For a while she sits, studying me, then she breaks the silence. ‘Your hand is shaking.’

I want to turn away, to hide my hands in the folds of my sweatshirt. To deny it. But there’s no denying what is in plain sight. I nod. She cannot gather anything from one small gesture, right?

‘That’s new. I’m . . . it must be difficult.’

I’ve heard those two words so often these past few months that it surprises me when she does not say them. And I’m grateful. *Sorry* does nothing.

I nod. ‘Sometimes.’

A tiny flicker of a smile crosses her face, and she waits, expectant.

I wish I could retract my words, suck the sound back into my mouth and stay silent. But now it's out there, and she's waiting for more.

And she didn't say those two terrible words.

'Sometimes I—' And then I stop, because I don't know what to say. I take a deep breath. 'What will happen to me?'

'You mean your symptoms? Didn't your neurologist explain all that?'

I blink the Google images away, of end-stage patients, all pillows and trachea tubes and desperate eyes. Trapped.

I shake my head. 'No, I mean—'

What *do* I mean?

She watches me, waits, but I do not have the words.

'Life is full of mysteries,' she says sadly. 'Things which are only answered in the doing. I cannot tell you what it will be like, only that many have gone before you.'

We sit, neither of us saying anything, but it's different now.

I listen to my breath, strong, unlaboured. I let the instinctive rise and fall of it calm me. I do not have to think about that yet; in, out, in - it happens automatically.

The clock ticks by, counting the seconds, and I breathe, letting myself just *be*.

Is this what it will be like?

Not if the textbooks and search pages are right. It will be ugly.

'It's not dignified.' The words are out before I hear them in my head, and they sound bitter.

'No,' she says. 'The body rarely is . . . The *mind*, however, *that* you can control. That's where you keep your dignity.'

She sounds so sure. Profound. And yet . . .

'I don't know how.'

The clock is fast approaching the hour; two minutes left, but Doctor Kobayashi does not hurry. She sits, watching me, and for a moment there's a question in her eyes, then she shakes it away, apparently satisfied. 'OK.'

She stands, crosses over to the bookshelves behind her desk, and pulls down a slender volume.

'Here.' She presses the book into my hands. 'I want you to borrow this.'

Making sure my bedroom door is firmly closed first, I pull the book from my backpack. The deep grey paper of the cover is soft and warm. Inviting. Calm.

I hold it for a moment before my eyes slide across the title. *Death Poems: Last Words of the Samurai.*

6

I blink, surprised for a moment by the bold black print, no different from any other book. These are words of age and wisdom from the best of men, not written with a delicate brush, but typed onto a screen so long after they were first formed. Still wanted.

I skip over the long introduction; I will read it later, but right now I want *their* words, I need the stillness and the gravity of men who knew The Way. At the first poem I stop, let my fingers glide over the page to feel the words before I raise the book to read.

*I cannot mourn, for I have lived
a life
of mountain air and cherry blossoms, steel, and honour.
(Tadamichi, 1874)*

I feel the words float around me, settle on my skin and then sink slowly into me. It is a while before I turn the page.

*On journey long
I stop to rest and watch
the end of days.
(Kaida, 1825)*

I imagine leaning on the gate at the end of days, looking back, the sun warming my face.
I turn the page.

The whistle of the sword, sings;