



Praise for  
Stephanie Butland's

*The*  
**CURIOUS**  
**HEART**  
*of AILSA*  
**RAE**



'I **loved it so much**, I couldn't put it down. I wish I hadn't read it so quickly, really, then I'd still have it to read! It felt completely authentic and was really interesting as well as **moving, funny and romantic**. I also want to take up tango. **Utterly engaging** from the first line to the last . . . **impossible to put down**'

KATIE FFORDE



'It completely **knocked my socks off** – I devoured it in a single sitting! **Wow. Just wow**'

CLAUDIA CARROLL

'A **funny, heart-wrenching and life-affirming** story that's **brave and beautifully written**. And made me want to dance the tango. **Bravo!**'

ZOË FOLBIGG

'If you loved *Lost for Words* you'll be pleased to know that Ailsa Rae is exactly as **warm-hearted and compassionate** as you'd expect'

CARYS BRAY





**‘Utterly wonderful . . . quirky, heart-warming and emotional . . . loved it!!’**

**LIZ FENWICK**

**‘I loved it so much . . . the thing that most struck me was the sheer human-ness of that moment *after* the crisis . . . It rang incredibly true’**

**SHELLEY HARRIS**

**‘A lovely, heartbreaking story of given second chances. Her characters are so vulnerable, so unsure of themselves and at the same time so lovable. I love this unusual story’**

**BOOKSELLER REVIEWER**

**‘Butland writes with great wit, sensitivity and insight . . . It’s a love letter to life . . . A bittersweet story of love and loss, hopes and dreams, life and death – and what can happen when we dare to take a chance. It’s a joyously life-affirming tale that’s full of heart – balm for the soul, and utterly unforgettable’**

**GOODREADS REVIEWER**

**‘A delightful happy read’**

**AMAZON REVIEWER**

**‘I could empathise with so much of [Ailsa’s] story and wanted to help fight for her, defend her, hold her hand, guide her . . . I have cried, laughed and loved every moment of reading this book’**

**GOODREADS REVIEWER**

**‘Her characters are so raw and real you become truly engrossed in them’**

**GOODREADS REVIEWER**

**‘This book left me tingling in a way that only happens when I know I’ve just read something special’**

**GOODREADS REVIEWER**



*The*  
**CURIOUS**  
**HEART**  
*of AILSA*  
**RAE**

Stephanie Butland

ZAFFRE



*Part One*

*October 2017*  
*Night's Candles are Burnt Out*



[www.myblueblueheart.blogspot.co.uk](http://www.myblueblueheart.blogspot.co.uk)

6 October, 2017

## **Hard to Bear**

It's 3 a.m. here in cardio-thoracic.

All I can do for now is doze, and think, and doze again. My heart is getting weaker, my body bluer. People I haven't seen for a while are starting to drop in. (Good to see you, Emily, Jacob, Christa. I'm looking forward to the Martinis.) We all pretend we're not getting ready to say goodbye. It seems easiest. But my mother cries when she thinks I'm sleeping, so maybe here, now, is time to admit that I might really be on the way out.

I should be grateful. A baby born with Hypoplastic Left Heart Syndrome a few years before I was would have died within days. I've had twenty-eight years and I've managed to do quite a lot of living in them. (Also, I've had WAY more operations than you everyday folk. I totally win on that.) OK, so I still live at home and I've never had a job and I'm blue around the edges because there's never quite enough oxygen in my system. But –

Actually, but nothing. If you're here tonight for the usual BlueHeart cheerfulness-in-the-teeth-of-disaster, you need to find another blogger.

My heart is failing. I imagine I can feel it floundering in my chest. Sometimes it's as though I'm holding my breath, waiting to see if another beat will come. I've been

in hospital for four months, almost non-stop, because it's no longer tenable for me to be at home. I'm on a drip pumping electrolytes into my blood and I've an oxygen tube taped to my face. I'm constantly cared for by people who are trying to keep me well enough to receive a transplanted heart if one shows up. I monitor every flicker and echo of pain or tiredness in my body and try to work out if it means that things are getting worse. And yes, I'm alive, and yes, I could still be saved, but tonight it's a struggle to think that being saved is possible. Or even likely. And I'm not sure I have the energy to keep waiting.

And I should be angrier, but there's no room for anger (remember, my heart is a chamber smaller than yours) because, tonight, I'm scared.

It's only a question of time until I get too weak to survive a transplant, and then it's a waste of a heart to give it to me. Someone a bit fitter, and who would get more use from it, will bump me from the top of the list and I'm into the Palliative Care Zone. (It's not actually called that. And it's a good, kind, caring place, but it's not where I want to be. Maybe when I'm ninety-eight. To be honest, tonight, I'd take forty-eight. Anything but twenty-eight.)

I hope I feel more optimistic when the sun comes up. If it does. It's Edinburgh. It's October. The odds are about the same as me getting a new heart.

My mother doesn't worry about odds. She says, 'We only need the one heart. Just the one.' She says it in a way that makes me think that when she leaves the ward she's away to carve one out of some poor stranger's

body herself. And anyway, odds feel strange, because even if my survival chances are, say, 20 per cent, whatever happens to me will happen 100 per cent. As in, I could be 100 per cent dead this time next week.

Night night,  
BlueHeart xxx

P.S. I would really, really like for one of you to get yourself a couple of goldfish, or kittens, or puppies, or even horses, and call them Cardio and Thoracic. My preference would be for puppies. Because I love the thought that, if I don't make it to Christmas, somewhere there will be someone walking in the winter countryside, letting their enthusiastic wee spaniels off the lead, and then howling 'Cardio! Thoracic!' as they disappear over the brow of a hill intent on catching some poor terrified sheep. That's what I call a legacy.





9 October, 2017

Ailsa is alone when it happens.

‘We think we have your heart.’ Bryony, the transplant coordinator, is smiling from ear to ear, for once. Given that her usual message is No News Yet, that’s hardly surprising.

Ailsa feels her hands fly to her chest, as though to protect what’s in there, hold it before it dies. She makes herself move them to her lap. They are shaking. So is her voice.

‘A new heart?’ And then she feels the patched-up heart she has summon up the life to expand with hope: with permission.

Her head is a scramble of thoughts, the practical and the terrible. She needs to be nil by mouth, so when did she last eat? Where is her mum? If she’s getting a heart, that means someone, somewhere has died.

Ailsa’s mother rushes in behind Bryony, breathless, bringing cold air and cigarette smoke with her. They fight the stuffiness of the room for a second before being absorbed. ‘They told me at the nurses’ station to get along here fast. What’s happened?’ She steps across the room; her hand is in her daughter’s. All Ailsa can do is nod at her, squeeze her fingers, because her throat has tightened and her mouth is drier than usual. She wants to say: I wish you had been here when Bryony came in. You deserved to hear it with me. But that’s silly, and unimportant, and anyway, you don’t get to choose these things. You get to accept them.



‘We need to have you prepped and in theatre in three hours,’ Bryony says. ‘Hold onto your hats.’ She flips open the file in her hand, picks up Ailsa’s notes from the bottom of the bed, and so it begins.

Or ends, depending on which way you look at it.

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9 October, 2017

## **I'm Going to the Theatre!**

It's here! The heart is here! So it's going to be a while until you hear from me. (Don't panic. For the next couple of weeks, no news equals good news.)

I'm about to wrestle myself into my surgical stockings and say something that is Definitely Not Goodbye to my mother. I'm not going to tell you how I'm feeling, about the risks, about what's about to happen, or about the donor family, or about anything to do with Mum, because if I even look at those feelings I don't know what will happen to me, but I know it won't be good.

I wrote this poll a month ago and I've been saving it. Posting it before today felt like tempting fate. But now, the dice have rolled. So here is the first poll of my NewHeart life. I'll see you on the other side, my friends. Thank you for the voting, and the comments, and for cheering me on here.

What should I do when I'm well?

1. Climb something high. Not a ladder. A little mountain, or a big hill. A Munro, maybe. Somewhere I can see for miles and there are clouds and craggy bits and the odd sheep. Sometimes when I'm really poorly I close my eyes and think about those views.

2. Get a shock. I'll jump into cold water or go on a roller coaster. I'll watch some awful horror film or bungee jump off the Forth Bridge. My new heart will not be scared of anything. The heart I have now, on the other hand, took ill when I typed 'roller coaster'.
3. Learn to dance. I've wanted to tango since I first watched *Strictly Ballroom*.
4. Switch my phone off. For hours. I'll be fully equipped. No one will need to be worried about me. Don't get me wrong, phones are great. But before I had to come into hospital, I did actually have to be glued to mine, in case of an incoming heart.
5. Queue for something. I might go to London and stand for six whole hours waiting to get ground passes for Wimbledon. I'd be the only person who was in it for the queueing rather than the tennis. The important thing is – I'll trust my heart to keep me upright for as long as it takes.

I thought there would be a thousand things I wanted to do when I could, and my list would be full of Eiffel Towers and Taj Mahals. But those things feel too abstract right now. I don't even have a passport.

I suppose what it all comes down to, really, is one thing: I'll do what I feel like doing. I won't worry about whether I can, what might go wrong, or what the implications are. I'll be impulsive. Unmanaged. (As far as anyone on anti-rejection meds can be impulsive and unmanaged.) I'll be normal.

My question is – which of these will make me feel most alive?

- 1 Climb a high thing
- 2 Get a fright
- 3 Dance, dance, dance
- 4 Switch off my phone
- 5 Queue

I'll leave the poll open for a week, and look at it when I'm back from transplant-land. Because, mark my words, I'm coming back.

See you on the other side.

BlueHeart xxx

*32 shares*

*256 comments*

*Results:*

1	<i>Climb a high thing</i>	25%
2	<i>Get a fright</i>	19%
3	<i>Dance, dance, dance</i>	36%
4	<i>Switch off my phone</i>	14%
5	<i>Queue</i>	6%



12 October, 2017

Consciousness, it seems, is liquid behind glass: moving, ungraspable. Closing her eyes doesn't stop the fairground-ride heave of it, but it makes it easier to bear. She sleeps again.

'How do you feel?' people ask, what feels like every fifteen seconds or so. 'Ailsa? Ailsa? Can you hear me? How do you feel?'

She wants to say: I feel as though I've been kicked in the heart by a horse. I want to get out of here. Pass my shoes. Pass my eyeliner. Get me a five-year diary.

But her tongue is too tired to move and her teeth are heavy and gummed together, impossible to separate. Something hurts her throat. A tube? She tells her arm to move, to find out if there is a tube going into her mouth. Her arm ignores her.

She opens her eyes. Her vision fills with faces, smiling or questioning, and just the thought of trying to focus on them, to remember who the eyes belong to or to try to make sense of the words coming out of them, seems more impossible than flying. Flying, in fact, feels like something she can remember, something that she could do: if she could just untether herself from the blankets and the noises, she could float. She thinks she was floating, a little while ago.

Her fingers, back to babyhood, grasp involuntarily when other fingers touch her palm.

And she goes back to sleep, for what feels like no time at all, and when she wakes, it's the same thing, over.





15 October, 2017

‘Fucking hell, Ailsa,’ her mother, Hayley, says, the first time she opens her eyes and doesn’t immediately feel them drawing themselves closed again, as though her lids have been replaced by bulldog clips. ‘I thought you were never coming back.’ Hayley’s smile is bright but she’s paper-pale; her eyes have the horribly familiar I’ve-been-crying-but-if-you-ask-me-I’ll-deny-it look. Ailsa can only see her mother’s face, her hair and the scarf around her neck, which is one of Hayley’s favourites, a yellow-gold silk rectangle that Ailsa chose for her the Christmas before last.

‘Is it . . . ?’ she asks. Her voice is whatever the opposite of silk is, harsh and scraping.

‘It’s all good,’ Hayley says. ‘Six days since the operation. You were out for the count for the first forty hours, and you’ve been drifting up and down ever since.’

Ailsa nods, or at least thinks about nodding, but it doesn’t seem that her head moves. Her hair feels damp against the pillow. ‘Mum,’ she gets out.

‘I’m here, hen. I’ve been here all the time.’ Her mother’s tears are coming now, and she starts to talk, quickly, as though her voice will drown them out. ‘I told people not to come but they didnae take the blindest bit of notice. It’s been like Waverley Station in here some days. There’s a stack of cards for you, and chocolate, and somebody brought gin, but you’ll not be wanting that for a while, I should think—’





'Mum,' Ailsa says again. They are here. Finally, after all the years of illness – breathlessness, pain, caution – all the health checks and operations, all the conversations about the eventual need for transplant, all the ways their lives have been trimmed away at the edges because of all the things that Ailsa couldn't do, they are here, in the wished-for place. She feels as though she's going to cry; doesn't dare, because if she heaves a breath, who knows what will happen to her new heart? But Hayley is at her side, and she takes Ailsa's hand, and then she reaches over and presses her lips to her daughter's forehead, and it's all there, every hurt and fear they've shared, every hope.

Ah, here's the nurse. Hayley steps away, and there are lights and tappings and questions. Someone wets her lips. There's no tube.

'Did I have a tube?' Ailsa asks.

'For the first couple of days,' Hayley says.

'My throat hurts.' It's a ludicrous thing to say, because every single part of her, inside and out, hurts. Her ankles seem weighted, her legs are stiff. The downward force of the bed-clothes on her toes feels unbearable. Her stomach is surely full of some dark, thick liquid, tar or sour yoghurt, and if she moves, she knows it will spew from her. Her neck is pinched into place by tight muscles, her head sharp with pain, her eyes suddenly allergic to light. And as for her chest . . . She can't even think about her chest. It feels – well, it feels exactly the way she had imagined it would feel if the sternum had been separated, her heart removed, another attached in its place, and then the bones wired back into position and the flesh sewn together again over the top.







Except that the imagination isn't really equal to the reality. There is pain, yes, but confusion too. A memory drifts in: some reading Ailsa did about early transplant experimentation, the head of one dog attached to the body of another. That's her. She's that dog. Her heart – the heart – knows something has happened, but it doesn't know what, and that sense of confusion is moving through her body with every pulse and beat. Her chest, her bones, are crying out: that wasn't meant to happen. I didn't sign up for that. I am solid. I am not to be opened. I am designed to be sealed, to keep what is inside me safe. You can't just put another heart in here.

'Don't try to move, Ailsa,' Hayley says, and she puts her palm against Ailsa's forehead. 'Breathe. You're safe now. You've done it.'

But breathing feels like the worst kind of moving. Every stitch feels as though it's stretching to the point of snapping whenever she inhales. She tries to breathe more shallowly, but the monitors give her away.

'I feel as though I might break open.' Her words barely scratch the air, but she's heard. There's quiet laughter from her mother and the nurse. It's Nuala, the roses in the perfume she wears sweet enough to cut through antiseptic and cleansing gel. She thinks about saying that she's not joking, but that would be a waste of what little power she seems to have. So she closes her eyes.

'Everything is just as it should be,' a voice says, in the night. Although Ailsa knows it's a nurse – can even tell it's Frankie, from the clipped clarity of the Highlands in his voice – in the darkness, she hears Lennox, beloved and oh so missed, who





waited for a saviour who never came. She thinks about how she has lost six days, or rather traded them for something like a normal life. She was weeks from death. Now she has almost as good a chance as anyone else of seeing sixty. Well, fifty, at least. It's as though she has been given permission to look out of a window that has always been forbidden to her before: she cannot believe how far away the horizon is, how beautiful the view.

The next morning, Ailsa sits up, and eats a banana, and Hayley beams. She throws it up again.

'Ah well,' her mother says, 'you cannae win them all.'



*www.myblueblueheart.blogspot.co.uk*

1 November, 2017

## **A New Friend**

Yesterday, Mum and I packed up my hospital room and got into my honorary-auntie's car and brought my new heart home. I've had a couple of day trips and popped in here – hospital is not prison, though they do sometimes tie you to machines so you can't really leave – but this was Official Discharge. Which is way nicer than it sounds. I'll be back at the hospital three times a week for the next wee while, and I'm not out of the woods yet, but there is cause to be pleased.

The moment we got back to the flat, we all three looked at each other and sighed, and it did feel a bit as though we had been holding our breath for – I don't know how long. We were going to get a takeaway, but I took my meds and went to bed, and Mum and Auntie T drank wine and kept waking me up with their laughing. It was a good sound. (They shared a flat in their uni days and sometimes I think they've forgotten that they're not there anymore.)

So, I'm home. The hospital residency part of my BlueHeart/NewHeart life is done.

Now let the living commence.

Thank you for hanging on in there with me! (And for never, ever making me eat jelly when I asked you to vote

on menu choices.) Especially during all those compelling posts about my strange post-operative body and how weird it is to be growing a beard. The facial hair remover is working just fine. And the nurse assures me that it's a temporary side-effect of the drug regime, and won't be forever, and neither will the moon-face and the extremely erratic bowels. Here's hoping. There's still a likelihood of a vote on cures for constipation.

While I was out for the count, you all voted. Dancing and climbing a high thing came out on top. (Do you see what I did there?) And those are absolutely in my plan. But not for a wee while, because of all the getting better there is still to do.

Some getting better is easy(ish). Get enough sleep. Take enough exercise, within reason. Eat the right things. (That one needs a bit of work, to tell you the truth. The major side effect of steroids seems to be an insatiable need for cake.)

And some getting better is different. It's hard to explain. All I can say is – I wonder whether this new heart is having to learn me like I'm having to learn it.

I know it's not logical. I know it's not science. But we also know that science used to think that deoxygenated blood was actually blue. It isn't. Veins look blue (I looked blue) because of light hitting the skin over them and scattering into the wavelength that we see as blue. So there you go. Just because something looks true today doesn't mean it will still be true tomorrow.

I just – I don't trust this heart. Maybe it's because it's a new-to-me muscle, untried, untested, and so I'm

not going to use it to do any seriously heavy lifting until I know what it's capable of. I don't know anything about the person this heart came from. Mum and I talk about them, most days, even if it's just to say, 'Thank goodness for them' and 'I wish they knew what they did'. I do wonder how their heart feels, in this new body.

I was thinking about that this morning, as I was walking, walking, because whatever happens in Edinburgh, rain or sleet or wind or sun or all of them at the same time, I am going to walk every day. At the moment it's ten minutes, five there and five back. Next week I'll up it to fifteen. (Fifteen minutes in Edinburgh can be hard going. Edinburgh used to be a volcano, geology fans.) And I was thinking – maybe I should make friends with this heart. And making friends starts with a name.

I've chosen two, but I'm leaving the final decision to you.  
I'm giving you three days.

APPLE: Plump, red and good for keeping the doctor away. What better name for a heart?

AMBER: An amber traffic light means take care, and I need to take care of this heart in all sorts of ways or it will end badly for us both. Amber balances emotion and clears stress.

*102 comments*

*Results:*

APPLE: 64%

AMBER: 36%

2 November, 2016

*This Time Last Year*

'I win the Most Colourful Hands contest,' Lennox says. They've got into the habit of starting Ailsa's visits with a comparison, though she wishes they hadn't, now that Lennox is getting more jaundiced by the day.

'You win this round,' Ailsa says. 'I'm the winner overall, and you know it, because I've got years on you.' Her nailbeds are always bluish, and sometimes the skin on her fingertips has the same unhappy hue. She takes her hand from where it's been lying next to his on the hospital bedclothes, side by side, so that they could compare. Lennox moves his hand too, and their palms kiss, part.

He's diminishing, as well as yellowing, his athlete's body lacking exercise, his appetite gone. She tries not to show that she's noticed. He shuffles along the bed so that she can perch next to him, puts his left arm around her to keep her steady.

'How's life? Tell me things that aren't to do with hospital.'

Ailsa laughs. 'I've been watching *West Side Story*,' she says.

'OK. Tell me things that aren't to do with hospitals or *West Side Story*.'

'You're an ungrateful sod,' she says, and looks down at his right hand on the blanket, but her eyes slide away from its pal-lor and the cannula taped to it. She's understanding, more and



more, what it's like for her mother, her friends, when she's ill enough to be hospitalised and they come to see her. She wants to do to Lennox all the things she hates when people do them to her. She wants to tell him it will be all right, that he's brave. She wants to squeeze him and say she loves him. Hell, she wants to have sex with him, just to see if it will make either of them feel better. The usual rules for ex-boyfriends and girlfriends cannot possibly apply here.

'I know,' he says, and he rests his head against hers. 'What's what with the blog?'

'Oh.' Ailsa jumps with the surprise of remembering it. 'I've got to ten thousand hits.'

'Fantastic.' And though he's tired there's genuine pleasure in his voice. 'That's amazing for, what, six months? I hope you're proud of yourself.'

'Seven. I started it when I went on the transplant list,' she says. 'But it's weird. I mean, some people leave comments, and share things, so I know people are reading it, but it's a bit – one way. I've been trying to think of a way to make it more . . .'

'Interactive?' Lennox asks.

'Yes.' Ailsa snuggles closer, breathes him in – he's been wearing the same aftershave for almost as long as she's known him, and he still smells of it, even though he gives off the strange, sweet scent of his illness too. 'Whatever I think, or do, or want, is irrelevant, because it all comes down to getting a heart. Or not. I want to show people that.'

'And you want to keep it anonymous?'





‘I think that’s best. Folk can hear all about my ups and downs so long as they have no idea who I am.’

Lennox shifts his weight so that he can move towards her, and hold her with both arms. ‘I know exactly what you’re getting at,’ he says. ‘We’ve got to hang in and hope. And it’s shit. It’s out of our control. So you need – how about some sort of poll?’

Ailsa still fits against him so comfortably, so well. ‘You mean if I ask people to decide things any normal person would decide for themselves, I’m making that point, aren’t I?’

Lennox laughs, holds her at arm’s length, then kisses her, his mouth a little sour. ‘Genius, Rae,’ he says, and his smile has never changed, not since the first day they talked to each other when they were sixteen and working on an after-school project in a church hall. ‘This time next year that blog of yours will be winning awards.’









*Part Two*

*February 2018*  
*More Care to Stay Than Will to Go*



*www.myblueblueheart.blogspot.co.uk*

3 February, 2018

## **Behind the Mask**

Today, Apple is dealing with out-of-the-ordinary excitement.

Mum works most days, now that she's not on permanent Heart Alert, and so I've the flat to myself most of the time. I write a post, maybe wade in to some discussion about transplants or waiting lists online. I think about jobs I might apply for, once I reach the magic six-month milestone where Apple and I should know each other well enough for me to be able to protect her in the wide world, and her to be able to meet the odd germ and bug without losing her beautiful rhythm. (To be fair to Apple: it wouldn't be her fault. I'm going to be on anti-rejection meds forever.)

When I got back from my walk today – eight thousand steps (yes!) – and fired up the laptop, I thought I was going to be in for everyday ordinariness.

But it turns out you lovely people have nominated this blog for the Best Patient Experience Blog in the UK Health Blogger awards.

Wow.

Thank you. (No, YOU'RE crying.)

This is a big big BIG deal. On the off-chance that this is the only blog you read, let me tell you – there are more blogs than there are stars in the sky (probably). Being

chosen is a huge honour and I cannot tell you how much it means to me.

The fact that I'm here at all is fifteen sorts of miracle, and that's before you get to the transplant. If you're a regular here you'll know that, until the 1980s, Hypoplastic Left Heart Syndrome meant a baby dying while its mother watched. I had three operations before I was four years old and even if there hadn't been a healthy heart to replace my patched one, living until I was twenty-eight would have been considered not bad going.

I'm alive, thanks to a freak set of circumstances, which includes someone else's misfortune. And I think of that every day.

It still seems strange to me that others would even read this blog, let alone come back, and vote on the non-heart related elements of this life that's not my own. I did think that my coping might help others with their coping, and that any HLHS folk, a little behind me on what we've learned to call the patient pathway, might benefit from my experience, and avoid – or at least be a little bit prepared for – some of the things that have knocked me for six. I hoped (still hope) this blog would help the families and friends of HLHS patients to understand what it's like. Being ill is a pain. Being ill and explaining yourself is exhausting. If I have helped, I'm glad.

So – thank you. Truly. With BlueHeart bells on.

I can't go to the awards ceremony. I'll tell you why another time. If I can manage it. The organisers were kind and I'm recording a video just in case I win.

And I really want to. But – if I do – I won't be BlueHeart anymore. I'll be me, un-anonymised, and if I were to show my face there, then of course I have to show it here too, and be me, the real person, in real life. (The one who, coincidentally, isn't blue anymore.) And that's scary. Here's something I didn't expect. Since Apple arrived in my life, I'm not completely sure who I am.

You know what's coming, don't you?

Voting closes in two days.

Should I make the video, and come out from behind BlueHeart?

YES – This is a new phase in your life, and it's good to make it different.

NO – Protect yourself, physically and emotionally, for a wee bit longer. Send a message. Hide your face.

Until next time,  
BlueHeart xxx

*2 shares*

*10 comments*

*Results:*

*Yes*                      *87%*

*No*                        *13%*

6 February, 2018

‘Do you want me to make some of those cards to hold up? What do you call them?’

Ailsa laughs. ‘Idiot boards? No, I think I’ll be OK. I know what I want to say.’

They have spent an hour working out the best place to make the film, with a non-distracting background and good light. Now, Ailsa is sitting on the armchair near the window in their living room, and Hayley is perching on the coffee table with the iPad. A mini microphone trails its cable from the audio socket to the floor at Ailsa’s feet. She picks it up and holds it in her lap.

‘You’ve only got my head and shoulders in, aye?’

‘Down to here,’ Hayley says, drawing a line with her finger across her own chest, from armpit to armpit.

‘Good.’ The test run, filmed from further away, was depressing. Ailsa knows she’s gained weight – has to know, because she has to weigh herself every morning, alert for the gain of three kilos overnight that could be a sign of rejection – but hadn’t realised that, if she’s filmed when she’s sitting, there are three rolls of fat where her waist should be. Still, as Hayley says, she could have been a worm’s picnic by now. She shouldn’t be bothered about her appearance.

‘Ready when you are, hen.’

‘OK. Press the button.’

Deep breath. Big smile!



Hayley gives a thumbs-up and then watches the screen. If she was looking at Ailsa directly, she'd cry, and Ailsa would cry too. At least that's what happened the second time they practised this.

'Hello. My name is Ailsa Rae, though you might know me as BlueHeart. I'm honoured and overwhelmed to have won this award. Thank you to everyone who has voted for me – and, even more, thank you to everyone who has read my blog, and voted in my polls.

'Waiting for a transplant makes you feel powerless. My blog showed this in the best way I could think of. I had a life-saving operation two days after I was born, another before I was two years old. My childhood was almost normal, but I lived on the edges of what everyone else took for granted. I tried to do all that I wanted to, but by the time I finished my degree, which took a year longer than most people because I had a wee spell or two in hospital, it was obvious that my heart was failing. So I spent almost four years becoming more and more unwell, until I went on the donor register. And then I got lucky.

'This is bittersweet for me, because the person who helped me with the blog in its early days died less than a year ago, waiting for his own transplant. He should be here. He should be –' Hayley makes a gesture towards the iPad, ready to stop recording, but Ailsa takes a breath, deep – and oh, what it is to feel how good that feels – and steadies herself. 'He died. I wish he was alive. If more people were on the organ donor register, if more people made their wishes known to their loved ones before they died, he might be alive.





‘Thank you for voting for me. My name is Ailsa Rae. I’m the recipient of a transplanted heart. Please, when you die, when someone you love dies, help to let someone else live.’