

## Facial discrimination: Living with a disfigured face

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American Richard Norris: left, in high school in 1993; center, after suffering a gunshot injury; right, after face transplant surgery.

- 1 Editor's Note: CNN.com is showcasing the work of Mosaic, a digital publication that explores the science of life. It's produced by the Wellcome Trust, a global charitable foundation that supports research in biology, medicine and the medical humanities, with the goal of improving human and animal health. The content is produced solely by Mosaic, and we will be posting some of its most thought-provoking work. The story was published by Mosaic
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"Take your ear off for me, please," Rosie Seelaus says to Randy James, who is sitting on a black exam chair in a special room designed for viewing colors in the Craniofacial Center on the Near West Side of Chicago.

- 10 He reaches up and detaches his right ear, which she created for him out of silicone seven years before. The ear is shabby, stained from skin oil and mottled by daily use. Viewed under various lights in the neutral, gray-walled room – daylight, incandescent, fluorescent – it remains a pasty beige.

James is a doctor with the Department of Veterans Affairs in Las Vegas – the fierce desert sunlight is also tough on his prosthetic ear. Seelaus is an anaplastologist, a clinician who sculpts artificial body parts for people who have lost them through injury or disease or, as with James, who never had them to begin with.

- 15 He was born 58 years ago with Goldenhar syndrome, a genetic condition that distorts the fetal face, sometimes severely. Some children with Goldenhar, like James, are born missing an ear or part of an ear (he had only the right lobe). Some have bulging eyes, or no eyes at all. James's jaw was undersized and skewed. He underwent 35 surgeries, including one to construct his right cheekbone using bone shaved from his ribs. He pulls up his shirt to show off slashing scars across his ribcage.

"I used to tell bullies I was mauled by a tiger at the zoo," he says.

*"I used to tell bullies I was mauled by a tiger at the zoo."* Randy James, doctor

- 20 The first time I walked through the corridors of the Craniofacial Center, on the University of Illinois at Chicago's medical campus, I had to sit down. Not that I was going to faint, but the immediate possibility occurred to me. So I filled a paper cup with water and carefully lowered myself into a chair.

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And that was before meeting any patients. Seeing the mute plaster molds of cleft faces, the blindly staring glass eyes and the little pyramids of false noses was enough. A baby's hand, made of silicone, grasped at the air.

- 25 That was 15 years ago. I'm not sure whether I was more or less scared of people with disfigurements than is average. As a child I had been terrified. Even of the small square picture on page 289 in the American Heritage Dictionary illustrating "contortionist," an early-20th-century photograph of a circus acrobat, her chin propped against the back of a chair, her body twisted impossibly above it, a foot planted on either side of her disembodied head. I would turn the pages of the Cs very slowly, steeling myself.
- 30 Most frightening of all, Cynthia Cowles, in Mrs Farmer's first grade class at Fairwood School, her eyes set too far apart, her nose flattened. We boys teased her relentlessly, so much that her mother phoned my mother, asking

her to make me stop.

"I felt helpless," my mother told me, years later. "The things you were upset about, you'd open your mouth about."

## 35 Misperceptions

Fear of people with facial disfigurements is a common phobia, yet, unlike other fears – of height, of water, of the dark – it is seldom discussed, perhaps because so much popular culture, from *The Iliad* to *Saw V*, pivots upon this fear. Perhaps it is assumed: of course you are afraid of the man without a face. Who wouldn't be?

- 40 Or perhaps because, unlike fear of high places, water or the dark, teratophobia – fear of disfigured people or of giving birth to a disfigured baby, literally 'fear of monsters' – has a living object: the injured, burnt, unusual-looking people themselves. Drawing attention to the flinching reaction they often receive, the stares and mockery that are a routine part of their daily lives, can seem an additional cruelty, the sort of vileness enjoyed by schoolyard bullies.

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- 45 Why are distorted faces so frightening? Freud classified certain objects as 'unheimlich,' a difficult-to-translate word akin to 'uncanny': strange, weird, unfamiliar. Waxwork dummies, dolls, mannequins can frighten us because we aren't immediately sure what we're looking at, whether it's human or not, and that causes anxiety. A surprisingly large part of the human brain is used to process faces. Identifying friend from foe at a distance was an essential survival skill on the savannah, and a damaged face is thought to somehow rattle this system.



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- 50 The psychologist Irvin Rock demonstrated this in his landmark 1974 paper 'The perception of disoriented figures.' Rock showed that even photos of familiar faces – famous people like Franklin D Roosevelt, for instance – will look unsettling when flipped upside down. Just as, if you tip a square enough it stops being a square and starts becoming a diamond, so rotating a face makes it seem less like a face. The mind can't make immediate sense of the inverted features, and reacts with alarm. A bigger change, such as taking away the nose, transforms the face severely enough that it teeters on no longer seeming a human face at all, but something else.

That isn't a theoretical example picked out of the air. On another visit to the Craniofacial Center, I enter Seelaus's examination room to be introduced to a patient. He turns in the chair, and is missing the middle part of his face. There are four magnetic posts where his nose will go, and below it, a void revealing smooth yellow plastic. My eyes lock on his eyes, I shake his hand and say some words.

- 60 A half-hour later, standing on the elevated train platform, I still feel ... what? 'Harrowed' is the word that eventually comes to mind. Why? There was no surprise. I'm no longer a child but an adult, a newspaper reporter who has spent hours watching autopsies, operations, dissections in gross pathology labs. I was expecting this; it's what I came here for. What about his face was so unsettling?

- 65 Maybe seeing injured faces compels an observer to confront the random cruelty of life in a raw form. Maybe it's like peeling back the skin and seeing the skull underneath. Like glimpsing death. Maybe it touches some nameless atavistic horror. That's as far as I get before the train arrives and I get on.

## School days

Randall H James was born in Ohio in 1956. His first surgeries were done over the next couple of years at Cincinnati Children's Hospital by Dr Jacob Longacre, a pioneer in modern plastic surgery.

- 70 "He was like a second father to me because I saw him so much," says James, who didn't celebrate a Christmas at home between the ages of 3 and 13. School holidays were for operations. Summers too.

"The teachers assumed I must be stupid." Randy James, doctor

75 When little Randy began school, his teachers in the city of Hamilton made a common mistake, the sort of automatic connection between inner person and outer appearance that has been the default assumption since history began.

"The teachers assumed I must be stupid," says James, who was put in a class with children who had learning disabilities – until teachers realized that he was actually very bright, only shy, and missing an ear, which made it harder for him to hear. He was allowed to sit in the front of the room, where he could hear the teacher, and his grades soared.

80 Doctors constructed him a large, puffy, vaguely earish appendage. It looked like a coil of dough, like a boxer's cauliflower ear. It wasn't much help.

As a student at the University of Kentucky, James applied to be a residence hall adviser, someone who assists other students in navigating dorm life. The supervisor who rejected him candidly told him that his odd-looking ear could put others off.

85 "You might make the students nervous," James recalls him saying, then paused, the pain still obvious after 40 years. "These were my classmates."

## History concealed

90 We are a society where people thrive or fail – in part, in large part – because of appearance. The arrangement of your features goes far in deciding who you are attractive to, what jobs you get. Study after study shows that people associate good looks with good qualities, and impugn those who aren't attractive. Even babies do this, favoring large eyes, full lips, smooth skin. Billions of dollars are spent on plastic surgery by people who are in no way disfigured, just for that little extra boost they feel it gives to them, gilding the lilies of their attractiveness.

95 How do people with unusual appearances fit into such a world? For most of recorded history, children born with disfigurements were wonders, portents or punishments. If they were allowed to live. "A couple hundred years ago, people born with craniofacial conditions, they were just putting them in a bucket of water," said Dr David Reisberg, an oral plastic surgeon at the Craniofacial Center.

100 But even then, astute observers saw beyond externalities. Michel de Montaigne in 1595 encountered a child conjoined to the half-torso, arms and legs of an undeveloped twin (what we would now call a parasitic twin), displayed by its father for money. Montaigne noted: "Those that we call monsters are not so to God, who sees in the immensity of His work the infinite forms that He has comprehended therein."

Read: Face transplant patients: Where are they now?

Adults were another matter. Those who came upon their distinctive faces later in life were seen as having been dealt their due, either through heroism in battle – dueling scars were so fashionable in 19th-century Germany that young men would intentionally wound themselves – or through the outward manifestation of inner sin. Plastic surgery began its first, faltering steps as a separate field of medicine after Columbus brought back syphilis from the New World in the 1490s, the injurious effects of which include destruction of the nasal cartilage. 105 Soon silversmiths were fashioning metallic noses, and surgeons were cutting triangular flaps from patients' foreheads and twisting them to form rudimentary new noses. Sometimes that even worked.



Face transplant patient reflects on life

The twin impulses, to conceal and to correct, have been competing ever since.

110 Perhaps the most surprising thing about the history of plastic surgery is how old it is. The use of the term 'plastic' to describe a type of medical operation was popularized in German surgical texts in the 1820s, long predating its 20th-century use for the synthetic material.

British doctors in 19th-century India advanced plastic surgery while trying to repair the noses and lips local

warlords cut off as a mark of disgrace. But plastic surgery truly entered the modern age after World War I.

115 Trench warfare created facial injuries with a grim efficiency. The trench protected your body and the helmet protected your head, saving your life but not your face. Historians estimate that 20,000 British soldiers returned home with mutilated faces after the War. Society wrestled with contradictory impulses: to seek them out and to shun them. The scarred faces of soldiers were highlighted in books and exhibitions, both to show off what was possible through modern medical technology and to act as a cautionary tale of the horrors of war.

120 Yet in Britain there were also schemes to segregate those with facial injuries in their own villages, to keep them out of sight.

In the 1920s, almost every café in Paris had its pensioned veterans. “Croix de Guerre ribbons in their lapels and others also had the yellow and green of the Médaille Militaire,” Ernest Hemingway notes in *A Movable Feast*. “I watched... the quality of their artificial eyes and the degree of skill with which their faces had been reconstructed. There was always an almost iridescent shiny cast about the considerably reconstructed face, rather like that of a well packed ski run, and we respected these clients.”

Sir Harold Gillies set up his famous hospital during World War I in Sidcup, a small English town, which soon found itself populated by servicemen having their faces rebuilt. Certain park benches were painted blue, as a code to the townspeople to brace themselves for the patients who might be sitting upon them, and thus not be startled as they approached.

130f This “startle” reaction is a cause of much distress, both for people with disfigurements and for those they encounter, who must compress the lengthy adjustment period that recovering patients themselves go through into a moment, and tend not to do it well.

135 Until not so long ago, those reluctant to see people whose appearances stray beyond the range of the usual actually had the law on their side. Many cities in the United States had ‘ugly laws’ designed primarily to reduce public begging. Chicago’s law read:

Any person who is diseased, maimed, mutilated or in any way deformed, so as to be an unsightly or disgusting object, or an improper person to be allowed in or on the streets, highways, thoroughfares or public places in this city, shall not therein or thereon expose himself or herself to public view ...  
The law was not repealed until 1974.

## 140 **Survivors**

“So Randy, can I take your bar off?” says Rosie Seelaus. James has a white gold C-shaped armature permanently fixed to the side of his head, anchored to his skull with gold screws. The prosthetic ear snaps onto the bar. “I’ll take your bar off so I can make the substructure. At lunch we can look at images we have.”

145 *“If this were fitting well we could use the same mold and just replace the silicone, but since it’s not fitting well, we’re going to be starting from scratch and redesigning ... Tomorrow will be mostly sculpting his ear.”*  
Rosie Seelaus, anaplastologist

It is Monday. James is in Chicago for the entire week, having his new ear created. Seelaus removes the screws and lifts the metal structure from the side of his head, the first time it has been taken off in seven years, since he decided to replace the crude ear surgeons had created for him with a prosthetic.

150 “If this were fitting well we could use the same mold and just replace the silicone,” she says of James, who has lost 24 pounds, which threw off the fit of his ear. “But since it’s not fitting well, we’re going to be starting from scratch and redesigning ... Tomorrow will be mostly sculpting his ear.”

This involves a range of high-tech gear. A CT scan is taken of his left ear. A computer then creates a mirror image of that scan, which a milling machine uses to carve a right ear out of a block of dense blue wax. Seelaus takes this prototype and makes a second, skin-toned ear from softer dental wax, which she puts on James to adjust its form and fit. A colorimeter and a spectrophotometer are used to gauge exact color values.

160 “Color is essential to having a successful prosthesis outcome,” says Seelaus, who spends hours matching shades, then fitting James’s ear to his head – even the most perfect, natural looking ear will fail if there’s a gap between it and the wearer’s head. When she’s done, the ear is then pressed into dental stone to create a mold that she fills with silicone to make the final ear. She mixes liquid pigments into splashes of clear silicone, colors she dabs into clear plastic, which she holds against James’s head, trying to match his skin tone. Seelaus doesn’t pour the colored silicone into the mold; she paints it in, layer by layer. To imitate tiny veins, she uses strands of red and purple yarn.

Matching the appearance of each individual is crucial. She has, for instance, created ears that were partially burned, to match scarring on a burned face.

165 “This is a full-life journey for these patients,” says Seelaus, who has done this work for 16 years. “I’m still learning from patients about what their life experience is and how it changes. Being born with a facial difference becomes a life journey that has a lot to do with acceptance. I’ve learned with patients who are burn survivors – not victims, survivors – initially their relationship with the prosthesis changes, too, throughout their lives ... What I try to tell them is, they’ve been through a lot already, it will also take adapting to the new way they look.”

170 How people fare on this journey generally depends on what they start with. “It’s about your self-perception before the incident,” Seelaus says.

And self-perception really matters. A Dutch study in 2012 looked at how well people with facial disfigurements functioned socially, finding that their satisfaction with their appearance was more important than the objective severity of the disfigurement.

175 *“People who sit in this chair are survivors. They don’t come to me in this chair without having survived something, and often it’s a lot.”* Rosie Seelaus, anaplastologist

Not that living with a face that is far beyond the mainstream is ever easy, or purely a matter of confidence. It isn’t. It’s a struggle, Seelaus says, requiring courage and endurance.

180 “People who sit in this chair are survivors,” she says. “They don’t come to me in this chair without having survived something, and often it’s a lot. It takes resilience to get through the treatment. And what they’ve been through living day-to-day in society takes a resilience we may never understand if we don’t go through that. Burn survivors have a resilience that is phenomenal. The reality is, it can happen to anyone. And so maybe that will bring about compassion.”

## “A Face for Me”

185 Is greater public compassion on the way? Stares and thoughtless comments are a daily part of life for people with disfigurements. But there are many groups that have long suffered abuse at the hands of society but are now better accepted. Is there any hint that those with damaged faces are traveling the same path that, say, people with Down’s syndrome are taking towards being more fully welcomed and integrated by society?

190 “People would really have to change a lot to make facial deformity the new normal,” says Kim Teems, Communications and Program Director at FACES, the National Craniofacial Association. “It’s a very hard thing to go through, not only being looked at strangely, but all the pain of surgeries.”

Based in Tennessee, FACES started in 1969 as the Debbie Fox Foundation. Fox has an important if forgotten role in the glacial social progress of people with disfigurements. She was born in Chattanooga, Tennessee, on 31 December 1955, with a massive cleft from her upper lip to her forehead, her eyes pushed to the sides of her  
195 head: basically a hole where her face should be.

“That was why I couldn’t play with the other children, go to school, go to church, run into the store to buy candy or ice cream. All these things had been forbidden to me.” Debbie Fox, author of *A Face for Me*

“Her parents resigned themselves to raising their youngest daughter as a hidden child – secluded from outside eyes,” a newspaper account noted.

200 Fox said she had never seen her own face until she was eight years old and found a hand mirror. She screamed in terror. “So that was what I looked like,” she wrote in her 1978 autobiography, *A Face for Me*. “That was why I couldn’t play with the other children, go to school, go to church, run into the store to buy candy or ice cream. All these things had been forbidden to me.”

205 By third grade she attended school via telephone hookup, standing to recite the pledge of allegiance with classmates she’d never met. When, at age 13, she was driven to Atlanta for reconstructive surgery, it was the first time she had left her hometown, the first time she had eaten in a restaurant – in the back, at off hours, but in a real restaurant.

It was also when “the girl without a face” caught wider public attention. The magazine *Good Housekeeping* ran a story about Fox in 1970 that showed her only from the back, a squeamishness that the media still struggle to  
210 overcome. Seeing people different from oneself can be a helpful step towards accepting them, but for people with disfigurements, public visibility has been slow in coming. Some progress has been made, though. *Esquire* magazine put a soldier missing both legs and an arm on its cover in 2007, and in 2010 featured inside a straight-on photograph of the film critic Roger Ebert with most of his lower jaw removed because of salivary gland cancer.





More on Roger Ebert and his remarkable life

## Educating the public

- 215 Randy James is not optimistic. As someone who not only wears an artificial ear and has sprays of scars under his jaw, but also is a doctor working with veterans whose faces have been damaged by war or illness, he doesn't see much improvement in how society views people with facial disfigurements.

"In some ways it's worse," James says. "With the rise of social media, you can be an anonymous bully. If you're not attractive, in many ways you're not going to be successful in society."

- 220 "I was working at St Mary's Medical Center in Huntington, West Virginia. I had just gotten my [prosthetic] ear right before I started there. Had I not had my new ear, which really changes my appearance, would they have made me one of their poster boys promoting their hospital? I can pretty much guarantee they wouldn't have done that if I had my old ear."

*"With our current conflicts, we're seeing injuries far more catastrophic than we used to see."* Captain Craig J Salt, plastic surgeon

- 225 Some disagree. Just as World War I injected people with disfigurements into the general population, so have a dozen years of warfare in Afghanistan and Iraq, and this new generation of veterans is having an impact on how those with a wide variety of severe injuries are viewed.

"With our current conflicts, we're seeing injuries far more catastrophic than we used to see," says Captain Craig J Salt, a plastic surgeon at the U.S. Naval Medical Center in San Diego, California.

- 230 "Massive tissue destruction, horrific burns ... The combination of the level of destruction with amazing lifesaving capability of the front lines gives you a patient population who would not have survived in the Vietnam era ... We have people entering rehabilitation horrifically disfigured in significant numbers."

Salt, who led the Navy's effort to begin treating facially wounded veterans with the same team approach used for treating cleft palates, says, "My impression is society is more accepting and more aware of the magnitude of injuries our soldiers and sailors, marines and airmen are coming back with. They're more accustomed to seeing disfigured patients because of media awareness, with social media ... people might be a little less shocked to

- 235 see a disfigured patient."



Bryan Adams captures the legacy of war

Soldiers in Britain echo Salt's sentiment. "Since I was injured five years ago, the profile of disability and injured service personnel has grown massively," says Joe Townsend, a Royal Marine who lost his legs to a bomb in Afghanistan.

- 240 "Unfortunately, a lot of that's down to the growing number of guys and girls coming back from Afghanistan with life-changing injuries, but the progress made by charities and the awareness on the television has really helped to educate the general public ... Before, I'd walk down the street and I'd notice people looking at me, but it's pretty much an everyday occurrence to see someone injured now."

Townsend says this in *Wounded: The Legacy of War*, a coffee table book of beautiful, fashion-style photographs of wounded British soldiers, taken by the rock singer Bryan Adams.

- 245 **Facial equality**

It is tempting to point books such as *Wonder*, and other popular culture treatments of disfigurement, and aggregate them into a sign of progress. *Wonder* by R J Palacio is a young-adult book that tells the story of August, a ten-year-old with severe facial differences trying to adjust to school life for the first time. "If I found a magic lamp and I could have one wish, I would wish that I had a normal face that no one ever noticed at all," August confides, on the first page.

And these works do have an impact. *Wonder* was on the New York Times bestseller list for 97 weeks. Even a decade ago, a child such as Mary Cate Lynch, three, might seldom have gone out in public. She was born with Apert syndrome, an extremely rare genetic condition that affects her head, face, feet and hands. But today, Mary Cate has her own cheery website, introducing her with photos and video. Her mother, Kerry Lynch, has taken her to 80 Chicago-area schools to present a program, often tied to the class reading *Wonder*, that explains Apert syndrome.

"Every parent does what they think best," says Lynch, a nurse. "I thought the best thing I could do is to educate others so they wouldn't be afraid of it. Fear comes from the unknown. I just thought if I could tell others about it, show them that, yeah, she's a little bit different, but she's more similar. If I could explain what these differences are, be very candid about it, that's what I could do to help her in her life."

*"I thought the best thing I could do is to educate others so they wouldn't be afraid of it. Fear comes from the unknown."* Kerry Lynch, nurse

Society takes a long time to accept people who look in any way different. Many Americans thought Irish immigrants, as a class, were ugly when they migrated in numbers to the USA in the 1850s, mocking them for their features, holding them up as signs of congenital inferiority. A few decades later, they marveled at how much these same Irish immigrants had somehow changed – "even those born and brought up in Ireland often show a decided improvement in their physiognomy after having been here a few years," Samuel R Wells wrote in the 1870s, making the common error of confusing a shift in one's own perception with a change in the object being perceived. Irish faces didn't actually change; the American public's antipathy did, slowly and without their even being aware of it.

Awareness of the challenges facing people with facial differences has not yet grown enough to smooth the path of any given adult walking into a restaurant or any given child showing up on a playground. But the seeds of improvement are definitely being planted. In Britain, the group Changing Faces put posters of disfigured people on the London Underground. Its founder, James Partridge, read the noon TV news in London for a week in 2009 to show that, while delivering information may be monopolized by the beautiful, it doesn't have to be.

"Are things changing?" says Partridge. "I think it's very much about where you look ... In 2008 we launched our campaign for face equality. We started public awareness, putting posters up, saying, 'Have a look at these characters, they're okay.'"

*"In South Africa, the message of facial equality is very easy for them to pick up. I think it's such a simple concept, the prejudices we need to attack."* James Partridge, founder of Changing Faces

"We definitely had an impact ... [though] outside of the confines of Britain, much less. Though in Taiwan there is a Facial Equality Day in May. In South Africa, the message of facial equality is very easy for them to pick up. I think it's such a simple concept, the prejudices we need to attack."

## Face to face

In 1998, the Italian fashion company Benetton ran a series of ads featuring people with disabilities. The ads awakened the guilt I still felt about Cynthia Cowles. I realized we had some unfinished business. I tracked down her phone number and called her, writing about our conversation in a Chicago Sun-Times column published at the time.

Talking to Cynthia was awkward for the first five seconds. Then we were old classmates, laughing and sharing stories. She said she had seen me interviewed on TV.

"You still play with your shoelace when you're nervous," she said.

I was nervous now. I told her I was sorry for being mean to her in grade school.

"If you were mean to me, there were so many other people who were so much worse," she said. "I recall you as being one of the kinder people. You were the one in eighth grade who came to visit me in the hospital – you told me your mother made you come, but you stayed a half-hour, very uncomfortably – and brought a box of stationery."

I have no memory of that, though spilling the beans about my mother's command was exactly the sort of dopey,

over-honest thing I would say, then and now. She recalled feeling sorry for me.

300 “You got teased for being fat, and got teased because you couldn’t skip,” she said, recounting how the gym teacher tried to drill me into skipping.

After we caught up – we both had got married – I asked her something I had always wondered about. What exactly was the cause of her disfigurement?

“I was basically born without bone in my nose, and the front of my forehead was not closed,” she said. “I’m hydrocephalic, which means my head is bigger than it should be, which put pressure on my brain.”

305 She had more than 60 operations. “Now I’m done,” she said.

We laughed a lot, particularly when she told a story about dealing with her tormentors. “My mother always thought if you ignored it, it would go away,” she said. But that only went so far, and one day she turned around and socked a kid who was teasing her, then was terrified because she realized the assistant principal had been standing right there and saw her.

310 “But he just gave me the thumbs-up sign, and said, ‘If you didn’t, I was going to.’”

## A matter of perception

On Friday, Seelaus heats James’s new ear in an Imperial V Laboratory Oven, then, wearing light green oven mitts, removes the cylindrical mold. After it has cooled, she pries the sections of the mold apart. “Look at that,” she says, brushing away excess silicone, then almost sings, “I think that looks pretty goooooood.”

315 She lifts out a startlingly human-looking ear. With a few trims and a touch of color here and there, she attaches it to James’s head. From two feet away you can’t tell it isn’t a natural human ear. James is delighted. “It looks a lot better, huh hon?” he says to his wife, who has come to see the final result. She later pronounces the new ear “sexy”.

320 Seelaus gives him some practical care tips. Keep away from solvents, small children and pets – animals like to chew silicone. The ear will sink. “If you go swimming, if you’re in the ocean, wear your old ear,” she says. “Don’t put it on top of a radiator or toaster oven.”

I estimate the ear costs \$10,000 – its fabrication took up most of Seelaus’s working week – and she does not contradict me. I also observe that Seelaus must be one of the few artists who hopes that her work goes entirely unnoticed by the public, and she doesn’t contradict me about that, either.

325 Happy though he is with his improved appendage, when I ask James if I could take a picture of him wearing his new ear, he refuses. He says he is worried, not about the photo’s appearance on Mosaic, but that it might later be lifted and included in some online “hall of monsters”. I ask several times in several ways, reassuring him that in my view this is highly unlikely. His answer is always the same: No. A reminder that looks are always relative, always only part of the story, and that our reaction to them fills in the rest.

330 There is no such reluctance with Seelaus’s next patient, Victor Chukwueke, a Nigerian-born medical student with neurofibromatosis, a disease of rapidly growing tumours that crushed his jaw, distorted his face, and left his right eye an empty hollow. He is here to get a new false eye and surrounding socket, to help put his future patients at ease. Even without a prosthetic, however, with a scarred void where his right eye once was, he smiles and poses as I click away.

335 Seeing people with disfigurements is important, because once a person, or a society, becomes familiar with them, apprehension fades. Just a couple of weeks before, I had needed to steel myself, sitting in my car in the parking lot of the Loyola University Medical Center, on my way to interview burn survivors, actually saying out loud, “If they can live it, I can see it,” to gather my courage.

340 But by the time I meet Chukwueke, that trepidation is gone. I had asked Seelaus to send me a photo of him, so I could prepare myself ahead of time, but she didn’t, and I go in cold. Hurrying into the Craniofacial Center, I spot a man who is obviously him, plop into the chair next to him and introduce myself, and we immediately begin to talk. His speech is sometimes hard for me to understand, because of his damaged jaw, so I have to lean in very close, our noses inches apart, as we talk to each other. It seems the most normal thing in the world.

Chukwueke puts his situation neatly into perspective.

345 “We all have an issue,” he says. “We all go through things in life, go through difficulties. You don’t have to let your challenges bring you down or let you be sad and depressed. It’s a matter of perception. How you see it.”