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Week 8 Reading

APA referencing

Kofman, L. (2019). *Imperfect: How our bodies shape the people we become* (pp. 90–111). Affirm Press.

Referencing for family history

Lee Kofman, *Imperfect: How our bodies shape the people we become*, Affirm Press, South Melbourne, 2019, pp. 90–111.

Chapter 5

When Gods Laugh

'Every time I was teased ... I was good at not listening, at pretending I hadn't heard, but I could sense myself changing, becoming more fearful.'

Lucy Grealy

'Don't write a sad, soapy story about me,' Mia messaged after several weeks of my courting her. Burnt by recent media exposure during her short-lived campaign to advocate for people with her condition, she took her time to trust me. We'd had email and Facebook exchanges, a phone conversation and silences. Finally, she'd said yes, but with reservations. I responded that, of course, I didn't want to write a soapy story either. I wasn't lying. But then, I'd read the articles that had so upset Mia and, knowing from her that they were factually true, I wasn't sure how to go about granting her request. In any case, I booked a flight to Brisbane, her hometown.

As I waited for Mia at GOMA, whose art collection we both loved, the sad, soapy stuff I'd read about her kept revolving in my

head. I knew she was wary of crowds, and I worried she might arrive in a flurry of commotion even though GOMA's café was almost empty that morning. Nevertheless, I'd prepared myself to get up in arms and fight Mia's fight if the need arose. Then, if I'm to be really honest, there was another reason for my growing discomfort: I, too, wasn't free of prejudice when it came to Mia's condition. As I tried to process all these anxieties, Mia finally walked in.

It was a sunny morning and she was wearing tight-fitting glossy black slacks and a pink singlet that revealed a delightful cleavage. Long, dark hair framed Mia's open, subtly made-up face. I wasn't surprised by her glamour, as I already knew she was enamoured with fashion. I stood up to greet her and only then did our difference truly strike me ... I am of average height but near Mia, who rose up to all of about 120 centimetres, I felt obscenely massive. She was about to reveal intimate things to me and here I was, an awkward stranger, towering over her. I froze, trying to figure out how to minimise myself, but Mia gave me such a warm smile that I just followed my instincts, bent down and kissed her on the cheek.

In our correspondence, Mia had emphasised and re-emphasised that she was 'a person like everyone else'. It upset me that she'd needed to state something so obvious, but I understood why she did. People have been perplexed by Mia since she was born. Soon after we began talking, she told me a story that happened at her mother's Philippine–Australian Catholic church (her father was Irish Catholic) when someone asked Mia's mother to take her toddler daughter out, saying Mia was a demon. 'My mother had to teach herself to get rid of the stigma, because she had that

mentality too, that if you have disability it's a bad spirit or you've been punished. And she had to fight for me within her circle,' Mia said calmly, as if this story concerned someone else.

Superstition around dwarfism and other congenital imperfections isn't particular to Philippine communities, of course. In past centuries, the birth of an imperfect child was a mystery. Storytellers, priests, medicine people and other myth-makers around the world resorted to tales of magic to give shape to the disturbing unknown, to what was considered then an affront to the natural order.

Some such folklore is pure poetry, like the Maori belief that people with albinism were fathered by supernatural men from a tribe of fair-haired mist dwellers. Some Ancient Greek and Medieval medical texts suggested that babies' imperfections were caused by a fright their mothers experienced during pregnancy, whether from nightmares or from an encounter with a wild animal. Most often, though, the myths were sinister. Imperfect babies originated in maternal transgressions, and were potentially evil, perhaps even endowed with supernatural powers. The theory of imaginationism popular in Medieval Europe (it persisted until the 18th century) proposed that imperfect infants were punishments for the lewd longings of their mothers, and sometimes the fruit of a real intercourse – with an animal or a nasty spirit. Such explanations pleased the crowds; they titillated them, and also soothed their anxieties by implying that 'good' mothers would bear no such calamities.

Today we know better how bodies work. Yet stories, once

released into the world, aren't so easily retractable. Certain congenital imperfections still inhabit the mystical space in our imaginations. Albinism, my child's often misunderstood genetic disorder, certainly does. People with this condition have a reduced amount of the pigment melanin responsible for the colour in skin and hair, and for the development of vision. Melanin levels vary among people with albinism: those with the least amount have snow-white skin and hair, and their eyes (usually blue or grey) are so pale that under certain lighting they can seem pink. The involuntary eye movement typical of this disorder, nystagmus, adds further to the unusual look. (My boy has some pigment, and so his hair and skin are merely fair, but his darting eyes are his imperfection to bear.)

Pronounced albinism brings to our minds often-sinister visions of ghosts, vampires and other otherworldly beings. Circus performers with albinism are described in Angela Carter's novel *The Infernal Desire Machines of Doctor Hoffman* as 'dancing albinos whose pallid gavottes were like of the luminous undead'. Even today some believe that people like my son can conduct electricity, read minds and, most bizarrely considering their poor vision, see in the dark. In popular literature and film, characters with albinism are often sociopaths and assassins, no matter that in real life most cannot drive a car let alone shoot with precision. But such minor obstacles don't stop the hitman Mr Joshua from *Lethal Weapon* and the henchmen twins from *The Matrix Reloaded*. Nor do they pose difficulties to Silas, the monk from Dan Brown's novel *The Da Vinci Code*, who begins his murderous career aged seven and who, to cement the association between albinism and the undead, says in the film adaptation, 'I'm a ghost.'

People with dwarfism (for variety I'll also refer to them as little people, another term acceptable by many in communities centred around dwarfism, but when describing fictional magical characters I'll use the term 'dwarf') have been endowed with magical qualities since antiquity, but often in more benign ways – perhaps because of their childlike size. In Ancient Egypt, the god Bes and his wife Beset were depicted as dwarfs. Bes was a popular god, the sun god Ra's supporter and a household protector, a champion of everything good and defeater of all evil. Real-life people with dwarfism were also believed to be patronised by Ra and welcomed in the Pharaohs' courts to perform Ra's ritual dances.

Some other cultures also associated little people with the divine. One of the avatars of the Hindu god Vishnu was a dwarf. In Celtic mythology, dwarfs belonged to the other-world inhabited by people of the goddess Danu and were portrayed as gifted dancers, poets, musicians and sometimes even prophets. In Scandinavian myths some dwarfs perform the honourable job of supporting the corners of the sky, and others are exceptional craftsmen, like the one who made Thor's magical hammer.

In medieval folklore, dwarfs had more varied representations. In fairytales you can find kind friends of Snow White, but also the vicious Rumpelstiltskin. In Arthurian tales, they range from supernatural villains to esteemed kings. But the magical association persisted. And today, David Lynch's cinematic oeuvre fond of mystical dwarfs pays homage to past beliefs. I happen to be a fan of Lynch, and of fairytales, and here is my uncomfortable truth: before I met Mia, I'd always been partial to little people in some visceral, and othering, way. On the rare occasions I caught

sight of somebody with dwarfism, I felt an eerie thrill, as if, like the protagonists from the stories I wrote as a child, I'd just crossed the threshold between reality and make-believe. I cringe as I write these lines.

Mia was born in a body burdened by age-old fantasies, but the stories she told me of her upbringing by her hardworking parents were prosaic. She and her two younger siblings (both of average height) had a 'nice childhood' with outdoorsy family holidays. Mia was a tomboy, riding bikes and skateboards, running around with the boys. I was surprised to hear this as now, aged thirty-four, she exuded the kind of femininity I'm very fond of, a femininity I associate with *Sex and the City*, with perfumed baths, Negroni cocktails and shiny long nails.

Mia's tomboyish past also surprised me because I knew of the physical challenges achondroplasia, the most common type of dwarfism, the one Mia had, presents. People with this condition have average-sized torsos, but their limbs don't grow to their full potential, and the burden on their spines is considerable. They may suffer chronic neck and back problems, arthritis, rheumatism, sleep problems, weakness of limbs – the list goes on. The range of the individual impact is wide. Some are wheelchair-users, while others lead lives restricted only by height, struggling to carry grocery bags or reach for shelves in shops. Mia suffered occasional leg and back pain but was physically active and well-travelled.

The older Mia grew, the more her Body Surface (as opposed to her health) made itself known. At her private all-girls school some students assumed dwarfism was an illness you could

'catch' and shunned her. Her teenage years were, predictably, even tougher as boys began swirling around her girlfriends, but regarded Mia as un-dateable. She went alone to her formal. 'My mum wanted to pay someone to take me, but even for money nobody wanted to.'

'And what was it like, to go by yourself?' I asked, feeling somewhat sick imagining adolescent Mia's vulnerability.

'I know my parents felt sad for me, and I felt so sad that *they* felt sad,' Mia looked away from me.

There had been times in her youth when it was so tough that Mia had openly raged against her mother for bringing her into the world. Sometimes she felt suicidal. Yet there had always been another Mia inside her too: the Mia who loved novels, who pursued her interest in psychology, who adored jewellery and bright colours. She dreamed about working in fashion, but in high school when students were being allocated work placements, her teacher would only give her office positions. 'Every time I put my hand up for where I wanted to go, something arty, my teacher said "no".'

That same teacher had told Mia that she could only do work that required sitting behind a desk. Mia believed her. Now she knows of people with dwarfism who are lecturers, and surgeons who cut into people's bodies while standing on a stool. But then, unaware of anyone else with her condition, she discarded her dreams. 'I opted for choices that were safe, thinking I'm not going to go for this job because they won't give me the opportunity because of my height.' She became a public servant working in policy, a job she described as 'dry'. To satisfy her yearning for knowledge, Mia also completed a degree in sociology.

Mia was twenty-three when she first met other people with dwarfism, at the Little People of America convention, which was also open to international attendees. 'I was so proud meeting people who were accomplished, educated and successful.' She also met her first boyfriend there, a Californian man with dwarfism, and enjoyed the attention of other, average-height, men on that trip. Only in America, Mia said, men asked her out. In Australia, 'they just laugh at me!'

Congenital imperfections can inspire laughter, just as largeness does. In Samuel Johnson's *A Dictionary of the English Language* published in 1755, secondary meanings of the word 'deformity' include 'ridiculousness' and 'the quality of something worthy to be laughed at'. In *The Iliad*, when Odysseus brutally clubs Thersites, a lame and hunchbacked soldier, for calling Achilles 'a coward', everyone laughs. Even divinities aren't exempt from mockery: the fate of Hephaestus, the Greek god of fire, is that of ongoing ridicule. Elsewhere in *The Iliad*, his fellow gods jeer as he hobbles breathlessly through the room in his role as the cupbearer at their banquet. (Perhaps inspired by this tale, the Roman emperor Elagabalus used to organise banquets with imperfect waiters and 'guests', just to have a laugh). And when Hephaestus's wife Aphrodite cheats on him with Ares and he traps the beautiful lovers in a net for the other gods to see, the joke is yet again on the deformed husband. They laugh and laugh, these divine beings, and the peals of their laughter drop down from Olympus, reverberating throughout the centuries in our mortal lives …

Little people, in particular, amuse us. The respect they once commanded in Ancient Egypt and old Ireland, where they were said to bring luck to those they served, was nowhere to be found in later times. If the archetypal person with albinism is a psychopath, the one with dwarfism is a clown. In Carter's circus, while 'albinos' danced, 'dwarfs wrestled together in arenas of mud …' And Woody Allen once remarked that dwarf is one of the four funniest words in English.

The tradition of wealthy people employing little people as playthings dates as far back as the Ancient Greeks. In Rome, the patrician ladies couldn't get enough of them; to match the demand slave traders deliberately stunted the growth of some children. European royals were also fond of their small-sized 'fools', often treating them as pets; Queen Henrietta Maria of England, for example, took her 'dwarfs' along with her on her travels, transporting them in the same cart as her monkeys and dogs. At the same time, people with dwarfism serving in courts were often allowed unprecedented freedom of speech, yet again on account of their supposed inferiority and insignificance.

This sense that reduced size equals reduced humanity endures. 'It's easy to dislike Arbus's photographs. Dwarves, nudists, transvestites, looming faces lit by flash, identical twins who seem poised for horror: they are the opposite of discreet, and can feel like a provocation,' writes Gaby Wood, in 'Incest, Suicide – and the Real Reason We Should Remember Diane Arbus' in *The Telegraph*. But why would she see dwarfs as belonging to the realm of the provocative? Perhaps it's difficult not to be influenced by the grotesque spectacle that unfolds on our screens where people with dwarfism often perform a slapstick-type

comedy, just like larger people do (if the latter break chairs, the former fall from them). The pervasive dehumanisation may somewhat explain why even the suffering of little people is more likely to evoke amusement than compassion. Some years ago, for example, then-AFL CEO Andrew Demetriou had a grand fit of laughter on the *Talking Footy* show, along with the other panellists, at the news that during the club's end-of-season celebrations a footballer had set a performer with dwarfism on fire.

Laughter was the soundtrack of Mia's life. 'Dwarfism is the only known disability where it's okay to make fun of people in public,' she said. Just recently she'd walked into a frozen yoghurt shop and the shop assistant had got down on her knees, imitating Mia's walk to the delight of her co-worker. Around little people many let go of their manners. But then, how could I sneer at others, when only two nights ago *I* had read a book to my boys, at which we'd all chuckled, where dwarfs had been stuck upside-down inside a chocolate cake? This moveable feast on someone else's difference in which I also partook …

'Every day I get up to deal with the way the public treat me,' Mia said. By now the café had begun to fill with people. I noticed a pre-teen girl lurking around our table, wide-eyed. 'Every single day … I get out of my car knowing everyone will be like, "Look, there's a dwarf!" There are good people around too, but so many are just trying to hold back laughter when they see me.'

The laughter is occasionally tinted with violence. One day in a carpark a driver threw ice-cream on her car, yelling 'Fucking

midget!' On several occasions Mia has had bottles thrown at her. Sometimes strangers snapped photos of her without asking her permission. 'And,' Mia said, 'I've had a few people come up saying, "Can I pick you up?"'

'Probably men …' I said stupidly, not knowing what else to say and betraying my own prejudices. I was trying, yet also afraid, to imagine what it was like to be Mia, to live as an unintended one-person show for everyone's free consumption.

'Oh no, it's both.' In one disturbing episode, two drunk young women in a bar had tried to lift her. She escaped to the bathroom, but they followed her there, kicking her stall's door until Mia's friends arrived.

In a way, Mia blamed some in the dwarfism community for 'degrading themselves in public'. 'When you watch television and there is someone with dwarfism there dressed like an elf or running around in a nappy … Young impressionable people see this and think it's okay to degrade us.'

She told me about an Englishman with dwarfism who was picked up by a stranger in a bar and thrown across the room. The attacker had apparently seen something about 'dwarf tossing' on television. The assaulted man ended up paralysed.

Dwarf tossing … The disturbing phenomenon, or so-called 'sport', usually played in bars, where people compete to see who can throw a person with dwarfism the furthest onto a mattress, or at a velcro-coated wall. Little people are paid to participate and usually protect themselves with padded clothing and helmets.

There are heated debates among people with dwarfism about participation in dwarf tossing and other debasing entertainment.

Many feel like Mia, that this encourages the view of little people as lesser humans. But those who do this work argue, not dissimilarly to sex workers, that they can use their bodies any way they like. Intellectually I understand their arguments. Yet when I watched some videos of dwarf tossing, where massive guys handled people with dwarfism as if they were inanimate objects, the cerebral understanding receded and only emotion remained. An emotion of visceral horror.

I found it overwhelming to think of just how much of Mia's life was dictated by her Body Surface – the anticipation of the next sneering, the practical adjustments she always made in order to retain her dignity. In Brisbane's CBD, where she worked, she always tried walking in the middle of crowds, to make it harder for potential abusers to notice her. She never used public transport or went out alone in the evenings, and would only meet her friends in places she considered to be relatively safe for her. She shopped on weekday mornings only, as soon as the shops opened, to avoid people, and even then sometimes she'd park her car in the shopping centre, sit there for a while, then drive away, unable to face the world.

Even when she didn't experience direct harassment there was the subtler process of exclusion to contend with. 'A lot of the time I need to sell myself, to convince others I'm just like everyone else.' One day at work a colleague brought in her newborn and passed the baby around for everyone to cuddle – everyone except Mia. 'She probably was thinking I was incapable of holding a baby,' Mia said, then added, 'When I met my friends, I didn't feel I was different in their eyes … I love [when] they come

to me for advice. It's like, wow, they see me as a person with knowledge.' These last words disturbed me. Why would this intelligent woman not take it for granted that someone could seek her counsel? But then, the world around her did look at her as if she was a joke.

'Some of my friends with dwarfism want to commit suicide. Like, what's life when you're so alone in a world with so many people around? And I've been there. I got to the point where I was really down, sick and tired of being laughed at, sick and tired of guys never asking me out ...'

Mia's craving for intimacy couldn't be quenched by her loving friends. The relationship with the Californian boyfriend, who had no profession or even ambition, lasted just a year of back-and-forth travel. After that she tried online dating, but 'that was hell'. Once she messaged someone and he replied with 'I'm not interested in someone like you.' Another man contacted her to say he found her attractive but couldn't take it any further because she was so short. Those who did want to 'take it further' happened to be several decades her senior. When Mia challenged them on why they approached her, the common response had been because she must have a good heart.

'But I could be a bitch,' Mia said, looking at the shimmering river across from the GOMA café. 'They defined me by what they saw, but I don't want to be defined by dwarfism, to be thought of as this angelic person submissive to others' needs ... The only reason dwarfism defines me is because I have to adjust myself to the way people treat me, not because I think, I'm going to act like this because I have dwarfism!'

No one is going to act in a certain way just because they have dwarfism, or one arm only, or a larger body. But, while it's difficult to generalise about the individual impact, being read regularly in damning ways can mould you too. People whose imperfections are publicly visible often cite harassment as the major hazard in their existence. Conferences for people with albinism I attended always feature talks with titles such as 'Dealing with negative comments' or 'Stares, smirks and shout-outs'. Some people with skin conditions, for example, internalise the prejudices against them so that they may feel themselves unclean as they're often told they are.

I did meet imperfect people who seem to be indifferent to all that, but they're a minority. Quantitative estimates of inner states are never precise, but across many studies of people with visible differences this population shows higher-than-average levels of mental health problems, and major psychosocial difficulties – shame, self-consciousness, social anxiety, problems with intimacy. One study of people with facial disfigurements, for example, found their rate of social avoidance to be similar to that of people with phobias, while another study of this population suggests some exhibit symptoms of post-traumatic stress disorder not because of an exposure to a specific trauma but because of the cumulative impact of ongoing harassment.

Even Lucy Grealy, who was a natural raconteur and charmer, suffered from social anxiety. As soon as she'd leave the safety of people who loved and even worshipped her, gawkers would assemble like hounds at the smell of fresh blood. When she

was younger, Lucy occasionally took her audience on: 'I stared right back at these strangers … I played games with them in stores … pretending I was absorbed in examining some piece of merchandise, only to turn my head quickly and trap them as they averted their embarrassed stares.' But as Lucy became a young woman, the attention grew more and more vicious, particularly from men. Once a pack of drunks called her 'the dog girl'. Eventually Lucy lost her nerve. One time she was so scared of walking alone to a grocery shop that she stayed home hungry. The looks, the taunts, intruded more and more, altering the structure of her. She honed her 'self-consciousness into a torture device, sharp and efficient enough to last me the rest of my life'.

'Dwarfism shapes the soul as well as the body,' Ginny Foos, a woman with dwarfism, says in *Far from the Tree*, Andrew Solomon's study of families with 'different' children. Solomon also cites research suggesting that little people tend to have lower self-esteem, are less educated, earn less and are less likely to marry, although these findings may have more to do with life chances than with the soul. A better example of soul-shaping might be the cliché of the feisty dwarf, which has some truth in it according to Solomon. He suggests that the feistiness typical of some might be a defence mechanism against the extraordinary amount of public attention they attract.

Mia, as far as I could tell, was more gentle than feisty. But it seemed to me her Body Surface had shaped her worldview in some ways. 'I'm angry,' she said at some point. 'I don't like the human population. I like the people in my life, but I find that

people in general are shitty, selfish, unaware that their actions are hurting others. It's hard for me to trust people.'

This soul-shaping is of course not particular to dwarfism or to any other imperfections. Any appearance is likely to become the weather, or soundtrack, of our lives. Maggie Nelson writes in her memoir, *The Argonauts*: 'Having a small body, a slender body, has long been related to my sense of self, even my sense of freedom.' Imperfect Body Surface, though, possibly shapes us most profoundly. Even Mia's entry into motherhood was shadowed by her appearance.

By the time Mia's colleague snatched the baby away from her, Mia was already an experienced single-parent of Ethan, who now was nine years old and 70 centimetres tall. Ethan's conception wasn't planned. Mia realised she was pregnant shortly after breaking up with his father, the Californian man. At only twenty-four, and single again, she felt deep ambivalence about her pregnancy, but her mother convinced her to keep the baby, telling Mia it could be her only chance, as she might never find another partner.

Mia's father had a different view. 'If the baby comes out with dwarfism, he's going to have the horrible life you did,' he said.

'How did you feel about your father's response?' I asked.

'I cried … I didn't want my baby to have dwarfism either. During my pregnancy I found out he had it, but everyone else said he's going to be cool, he'll be just like you … I decided to go with that, but I knew what to expect for him because I lived that life. Like, bring it on! Bring on the bullying.'

I was finding it difficult to continue our conversation, as I already knew that the bullying had indeed come on. I was also

thinking about my own child. Since he was diagnosed with albinism, the possibility that he may be bullied because of his difference had become my recurrent nightmare. Mia, in her straightforward manner which I liked, told it like it was – life was tough for her boy.

Ethan couldn't be as physical as his classmates. Playing contact sports, like football, isn't safe for people with dwarfism, and anyway he couldn't ever be fast enough. Instead, he painted. His artistic inclination wasn't in his favour at school either; he was pushed around and had no friends. Often he didn't want to leave home, anticipating ridicule. At the sight of other children on the street he'd often hide behind Mia. When they were out together, Mia put on a brave face for Ethan's sake, telling him people paid them all that attention because they were famous. It's not about giving him a false sense of identity, she said, but to make him think we're actually cool. At home he sometimes yelled and threw stuff. 'I let him do this,' Mia said matter-of-factly. 'It's a release for him. I used to do this too as a child.'

Some researchers, like Solomon, believe children with dwarfism whose parents share their condition have an advantage over their peers whose families are of average height. Any children with congenital imperfections are at a higher risk of poor bonding with their families. Robert Hoge, an Australian man born with a facial tumour and deformed legs, writes in his memoir *Ugly* that his mother, a loving parent to his four older siblings, refused to even look at him for some days after his birth. She'd been so embarrassed by him that for his first months she'd mostly kept him inside the house. Mia's mother cried for a year after her birth. Eventually, both Robert and Mia's families moved

on and raised their children lovingly. But such a happy ending isn't in store for everyone; psychological development of some congenitally imperfect children can be compromised from the very start.

Mia felt that Ethan benefited from their shared condition: 'He looks at me and knows there is nothing he cannot achieve.' Ethan was also the main reason for Mia's venture into activism earlier in the year. Previously, she had little involvement in the dwarfism community, preferring to think of herself as being beyond her Body Surface, even if most people she met were obsessed exactly with that aspect of her. But one day, when Mia and Ethan were at Brisbane Airport and she was struggling to get her luggage off the carousel, it struck her how not only did nobody there offer her help, but many stood by staring at her and her child, sniggering. The heightened aloneness Mia felt that day, coupled with her perpetual worry about Ethan, prompted her to launch a social media campaign to try and normalise dwarfism.

Mia began blogging about her life, showing photos of herself, Ethan and her then-partner, another American man with dwarfism, doing 'normal stuff' – walking the dog, hiking, attending a sports game. Journalists caught up on Mia's activities and it was then that a series of upsetting articles appeared. 'I was adamant that my story wouldn't be sensationalised and of course it was.' The press focused only on the most disturbing aspects of her life. Ironically, the more Mia tried to show how like everyone else she was, the more she felt defined by dwarfism. So she ended her campaign.

In the images Mia had posted she always looked striking, whether she was playfully made-up, or wearing sunshine-yellow

shoes or a wide-brimmed hat. While many saw her as diminished because of her appearance, Mia seemed to be using the same medium to fight back, attuned to the expansiveness of self-definition fashion offers, adding layers to herself with every new outfit. Fashion seemed also to be her means to stamp herself onto the world as a sexual being – an identity, Mia believed, nobody wanted to afford her. 'I feel like I'm not expected to be attractive. People with disabilities say you should accept yourself as you are,' Mia said.

Last year Mia had botox and breast augmentation surgery. Her natural breasts had the tubular shape typical of achondroplasia, which can stunt breast growth too. Mia thought this symptom had been overlooked by professionals, consistent with the perception of women with dwarfism as asexual. Despite her conviction (and, as I kept saying, mine too) that having that surgery was the right thing for her, she kept justifying her decision. 'I didn't feel womanly. I thought, how would I be with a man when I have dwarfism and I also have breasts that look like that? Like, c'mon give me a chance here! I shouldn't be a martyr.'

Mia's confidence in her new body was palpable in the ease with which she wore her revealing singlet. In some ways, though, she was at a low point now, after her relationship with the other American man had ended recently. 'I'm an ultimate romantic. My relationships define me in a way. Maybe put it down to low self-esteem, but knowing that someone finds me attractive lifts me all the way up and when it's taken away, I crumble. I also want my dad to see me get married before he passes away, to see that despite everything that happened there are good people in the world ...'

Mia now hoped to meet an average-height man. 'I don't feel like I always have to date a little person. It's about connecting with somebody. And when we're out in public, we're really at the centre of attention if there are two of us with dwarfism.' She added, 'Not to be rude, but I find that average-height guys are better looking.' This last remark made me think of my own preference for good-looking men. It seemed even we, the imperfect ones, weren't free from judgement on Body Surface matters.

The Brisbane sun was ripening as the afternoon approached. We were reaching the end of our long conversation, and I still hadn't worked out how to avoid letting Mia down in my writing about her. I felt drawn to her. On some very basic level she was my kind of person – intellectually and emotionally restless, someone unafraid of jumping into new waters be it a long-distance relationship or sunshine-yellow shoes. Her singularity was powerful, and the more time we spent together the easier it became for me to discard my fairytale-fuelled fancies. Yet, if I thought of our hours together as a symphony, then despite its richness one note dominated, possibly amplified in my ears by my worries about my youngest child: *What is life when you're so alone in a world with so many people around?*

I decided to come clean. 'You've told me some tough stories,' I said, 'but I know this isn't how you want your life to come across. What do you suggest I do?'

Mia considered my words carefully. Eventually she said, 'I want you to write it the way you want to write it, but I don't want to be pitied. That's the one thing I can't stand.'

I knew viscerally what she meant, even if our experiences of being imperfect were so different in other ways. I also knew

that, by this point, pity was no longer what I felt. I felt another emotion, an emotion I was normally wary of – anger. Anger at what Mia had to cope with on a day-to-day basis.

Just before we finished, I asked Mia about her future plans. She said she was thinking of doing a PhD, and travelling again, maybe to Japan. 'But really,' she said with that honesty of hers I so liked, 'I'd like to get married. I've seen the world, had a child, I have a career. But one thing that seems to come so easily to a lot of people, I haven't had it. I haven't even been on a proper date, something that's not like, "Come to my house at 11pm so my roommates don't see you," all this degrading stuff. So even just going out on a date – a date with somebody who won't be embarrassed about me and is interested in me as a person. I'd never be able to get rid of the fact that people treat me like someone with dwarfism. But … I just want someone who will be like, "Oh, you're so cool …"'

Later that afternoon, I stood in GOMA in front of a sculpture of a distraught-looking, middle-aged woman lying in bed. Australian artist Ron Mueck's work has been devoted to rendering the familiar human body strange. He often achieves this goal by skewing proportions. Some of his almost-alive sculptures were very small, others enormous. That was all it took – a size change à la *Alice in Wonderland* – to shake up our deepest convictions. I was looking at this woman, who would have seemed unremarkable had she not been looming so large in this almost-empty room, trying to recompose myself. Mia's voice kept replaying itself in my head. *Here, they just laugh at me …*

I thought how much Mia and my mother's dimensions, as starkly different as they were, also minimised their inner differences, at least in the eyes of the onlookers. People felt they *knew* who they were on account of their limbs' length or diameter. But Andy Jackson, he was unknown.