



Dear Carly

by Carly Findlay

Australia

Dear Little Carly,

I'm remembering you at twelve years old.

You've lived with a rare, severe skin condition called ichthyosis all of your life. It means you have scaly red skin, and it affects the whole of your body. You're just starting to take care of it without the help of your parents; you know the deal with applying ointments and seeing a handful of specialists. Even though you've got a handle on the medical stuff, the social aspects are really hard to manage. The constant stares and questions get you down. It's hard being ridiculed and excluded. And you just want to look like everyone else. But not even your mum's Clinique will cover up ichthyosis.

You've just started high school. Mum said you would have a different time at high school compared to primary school, in terms of making friends, but I know it feels pretty similar to you. The kids are still scared of

sitting next to you in case they catch something. You are lucky to be able to spend a lot of time in the school library; books are your escape.

At twelve, you are still tiny. Mum bought you a school uniform so big that it will last you until you finish year ten. So embarrassing. At least your socks are the cool slouchy ones, designed to effortlessly concertina up the ankle. Some kids at school have an undercut – a shaved scalp under their hair. Your hair is always sparse, you're embarrassed that your silly scalp means you too have an undercut of sorts, because your brittle hair breaks off.

You've been reading *TV Hits* magazine for years, cutting up the song lyrics each month, alphabetising them in a pile and securing them with a rubber band. I know you're so proud of this pile, and your ability to memorise song lyrics. This pile is the neatest thing in your very untidy bedroom. Recently, you've started to read *Dolly* and *Girlfriend* magazines, too – the two main Australian mags for teenage girls. Every girl at school is reading them. Cover girls are white women, sometimes famous, but often 'girl next door' modelling competition winners too. Kids at school enter these competitions but discourage you from doing so. This discouragement only further confirms the othering and isolation that you've

felt since you realised you were different to other kids. Even playing with Mum's Clinique make-up samples won't make you look like them. Your red, scaly skin will still exist underneath.

Really, Mum should ban those magazines for their ridiculous beauty standards, which I know contribute to you feeling like a freak. Those articles tell teenage girls how to get the perfect skin to attract the perfect guy – only, your skin is not like anyone else's in *Dolly* or *Girlfriend*, which, to you, confirms you'll never have a boyfriend. Or girlfriend. Adverts for acne wash and pink razors convince you that you need them. But, Carly, you don't have any acne and you have zero body hair. I advise you to stop dragging Dad's (unused) razor up those hairless legs of yours, otherwise you'll get another skin infection!

Summer sport in your first year of high school is swimming. You can't do swimming, so you get to choose an indoor sport with the older kids. You choose roller-skating, at the Village Rink. The soundtrack is the same every week – mostly eighties music with a few new songs in the mix. In the future, you'll think of speed skating at the Village every time 'Real Wild Child' by Iggy Pop comes on the radio.

I know at your first skate session, just last week, you met the boy you'll be crushing on for two years. You're slow but confident on skates, but while you were skating to Bryan Adams' 'Summer of '69' you felt something strange happen to your left skate, like a wheel was working its way loose. Suddenly a boy, one year older than you, glided up to you on his sleek black rollerblades – definitely not hired from the rink! Your hire skate's wheel had come off, and this dreamboat was here to save you. He had shoulder-length blond hair and a wide smile, as cool as any boy in *Dolly* magazine. He smiled and handed you the wayward wheel, and he let you hook your arm around his to get off the rink safely. Carly, his name is Adam, and you are in love.

So here's how you're going to play it. You'll play it cool. Week after week, that's all you'll do. You'll never have a proper conversation beyond that first engagement; you'll just exchange 'hellos'. You'll refer to him as 'Ahem' to the few friends that you have, because you don't want anyone knowing your crush's name. If anyone got wind of your crush's identity, you know they'd tease both you and him. The crush has to stay in your imagination, because based on what you've learned in magazines, a boy like him would never go for a girl like you.

Carly, soon you'll miss a fair bit of school because of your skin. Hospital stays always feel like a reprieve for you because the other kids on the ward understand what it's like to be sick, even if they don't have the same disability as you. You will develop strong friendships with these kids, and the nurses too. However, the hardest thing about being a patient with a rare medical condition is the medical conferences. I know you've been doing these since you were six – pitched to you as an opportunity for doctors to find a cure by looking at your skin, but I also know it's weighing you down. There are always doctors from all around the world at these conferences. Some just look at you, without even speaking to you. At these conferences you are freezing, sitting in the hospital room wearing just your undies and one sock (the doctors really have to look at your feet!). At this point, your breasts are starting to bud, and you're self-conscious too. I know you're starting to feel like you can't do this anymore, that you're sick of being a medical exhibit. And I know you're thinking about saying this to Mum and Dad. You should say it, Carly. Don't worry, they'll listen to you, and, after that, you'll be able to keep your body to yourself.

Would you like to know more about your future? In a few

years, when your school dress finally sits above the knee, you'll develop a huge obsession with the band Savage Garden. This will lead to lifelong fandom. At high school, you will develop a strong friendship with another Savage Garden fan, which finally makes you feel like you're a part of a group at school. You'll dub VHS tapes so that you each have copies of Savage Garden on *Jay Leno*, and you'll sneakily use the school library to search for Savage Garden on the internet. Your fandom will consume you. Years later, Savage Garden's frontman Darren Hayes will tell you 'what makes you different is what sets you apart' and you'll never forget this.

The stern school librarian will discourage you from searching for Savage Garden and, instead, she will suggest you look up ichthyosis. You may think she's just being strict, but much later you'll realise she knows how alone you feel, and that she wants to see you connect with others who understand what you're going through. It'll feel like you're being told off, but it's her way of showing you love. She's pushing you towards finding a disability community. And you will, Carly. You'll find an ichthyosis message board, and you'll realise you aren't alone: there are others out there, like you. You will have waited so many years for this.

In the future, your parents will be strict. You already know they're strict, even though you're a straight-laced kid who gets good grades, and that isn't going to change even when you continue to do well at school – and even when you don't get drunk until you're twenty-three! They won't let you listen to Alanis Morissette because of the swearing and relationship references, and they'll steer your education towards a 'sensible' university course that you'll hate, so you'll get a 'sensible' government job that you'll stick with for fifteen years. This will be difficult, but they'll do all this because they love you, and because you're the first in their families to reach such a high level of education. Later, you'll learn this is part of being a child to migrant parents – they sacrificed so much by moving to Australia, and so many of your friends who are also children of migrants will say they had a similar experience. But please know that it is OK to follow your own path, to grow up and be your own person, even if that's a different person to the one your parents imagined.

In many years' time, a move from your tiny home town to Melbourne will open your mind and give you so many opportunities, Carly. You'll study media and

work on your writing as a side hustle at night after your government job – this will be your passion. And you'll be speaking on many stages – at the Sydney Opera House, in Bali and in the UK – focusing on disability rights, access and inclusion, and how, for you, disability now means community, cultural identity and pride. Standing on stages in front of so many people will be a world away from not wanting to be looked at, which is (I know) how you feel right now.

Your parents will be proud of you, whatever you do, even if it's not what they'd choose for themselves, and even if Dad doesn't tell you so very often. You'll write a book in the future, and Mum will carry it around with her everywhere. She'll even show it to the Conservative prime minister at the Country Women's Association conference – he's not really your target audience, but could do with reading about disability rights!

When you're in your thirties, you'll really start living. That's almost two decades away – but I promise that you'll be thriving, so hang on in there. You'll have incredible friends, be a published writer and take up roller-skating again. You'll marry a funny and kind man who finds joy in your skin. But marriage won't be your greatest achievement. Your greatest achievement will

be finding love for yourself, and accepting your skin and facial difference, after so many years of wanting to be like those girls in *Dolly* and *Girlfriend* magazines. It will be such a relief!

You'll find out it's so much easier to love yourself than to hate yourself.

Your hair will never be thick, but it will curl past your shoulders, after you find the right (respectful!) hairdressers, and you commit to conditioning it every day.

You'll wear incredibly colourful clothes – people will stop you in the street, telling you they love your dress, instead of asking you if you've been sunburned.

You'll use social media to educate others. You'll be in magazines and on TV. You'll change the media for people with ichthyosis so they'll see themselves represented. And high school kids (and adults) will google ichthyosis and find you online, like when you searched for ichthyosis as a teen. Imagine that!

You'll even be in your school hall of fame – your photo hanging up alongside someone who bullied you!

One night in the future, you'll be at a restaurant and a

twelve-year-old girl will come up to you and ask: 'Excuse me, are you **the** Carly Findlay?' And you'll giggle shyly and say yes, inviting her for a selfie.

So, hang in there, twelve-year-old Little Carly, the world's not ready for you yet. But it will be, just you wait.