

Vitiligo: My story



Young people talk

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Vitiligo is a long-term skin condition where white patches develop on the skin. It's caused by the lack of melanin, a pigment in the skin.

It affects about one in a hundred people. It can appear anywhere on the body but is more noticeable on the face and hands, and shows up more in dark or sun-tanned skin. There may be just one or two patches which soon clear up, but sometimes there are lots of patches which may spread to cover large areas. Vitiligo confined to one side of the body is called "segmental".

Vitiligo is caused by the body's immune system attacking pigment cells. Most people are otherwise healthy, but doctors may check for other "auto-immune" conditions like thyroid problems. Auto-immune conditions can run in the family. Not all white patches are vitiligo – there are other causes which your doctor can usually recognise. Many people with vitiligo experience hurtful comments or even bullying. Having vitiligo affects the way they see themselves even if others don't notice it.

In some cultures there is a stigma attached to vitiligo which makes people desperate to find a cure. They may resort to folk remedies which are unhelpful and even harmful, like excluding certain foods from the diet.

Dermatologists can treat vitiligo, but the options are limited and don't always work. We must at least recognise the psychological aspects and try to help patients cope with having vitiligo.

The people in this book all have vitiligo and have found their own ways to deal with it. Their stories inspired us and we hope they will help and inspire you.

Professor Celia Moss
*Consultant Dermatologist,
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Hospital*



Tommy



Tommy (right), roller-booting with his sister Isabella

Five-year-old Tommy has lots of white spots – that's what he calls his vitiligo. Tommy knows he has to take care to avoid burning in the sun. He loves being outdoors, so he makes sure to use plenty of sunscreen. He's a sporty boy and a keen footballer, and he plays 5-a-side in the Little Dribblers. 'I've scored 500 goals!' he says proudly. And Tommy loves roller-booting too with his big sister, Isabella.

When other children ask him about his white spots, Tommy jokes, 'I'm like a Dalmatian!' He and Isabella love the film 101 Dalmatians. 'We've watched it five times!' he says.

Tommy's first white spot appeared when he was a baby. His vitiligo has been growing ever since, with a big increase in the last year. 'I think 50% of his skin is covered now,' says his mum, Jennifer.

'He's confident in his skin, and we try to make sure it doesn't affect him psychologically,' she says.

He's confident in his skin

But Tommy was upset recently when he grazed his elbow, because he thought it might make a new white spot. 'We just try to keep things normal,' Jennifer adds.

Don't hide or cover up



Out in his Nan's garden one summery day, Tommy started drawing lines around his spots. 'So we joined in,' says Jennifer. 'We drew round all of them. It was fun! He said it tickled. He looks like an atlas, and he loved it.'

Jennifer's advice for other families? 'Don't hide or cover up. Just love them for who they are.'

Tommy has never met another child with white spots. 'It would be good to meet up with other families,' says Jennifer. She believes that children who are faced with being different become strong. 'They can learn a power that other children will never understand, without that everyday battle. I'm so proud of how Tommy deals with it, even at his young age.'



Drawing around Tommy's vitiligo patches

Siriah

When Siriah was 6 or 7, red patches appeared around her eyes. They were a bit sore, but not itchy. After a week the redness went down, but the pigment around her eyes had disappeared. Siriah had just been swimming, and at first her mum Sharlene wondered if it was an allergic reaction. Eventually a dermatologist said it was vitiligo. 'The diagnosis was a relief,' says Sharlene.

Siriah was offered treatments in the form of cream, but they preferred to focus on a nutritious, healthy and balanced diet to make sure little Siriah was getting all the vitamins she needed.

Siriah has to be careful as her skin is also sensitive to heat and cold, and can sometimes get painful welts after bangs or scratches. But that doesn't hold her back. Siriah loves to dance, and has tried all kinds of dance – ballet, street dance, lindy hop and contemporary dance.



If you're upset, tell



Siriah and
her mum



Siriah loves to try
different kinds of
dance

People are curious about Siriah's skin. Sometimes they look, and ask if she is wearing make-up. Someone offered make-up once to cover up the vitiligo patches, but Siriah and her mum weren't keen.

'It doesn't affect me,' says Siriah. 'It's no fuss. Let's just carry on! It's more important to be happy in yourself. If you're upset, tell someone you trust – family members, or Childline. And ask your friends to stand by you.'

'You're so beautiful!' says her mum Sharlene. 'We talk about it. Everyone is different, and you have to learn to be happy with yourself.'

Dad Curtis says, 'Siriah's a confident young girl growing up and learning about the world, learning respect and to be compassionate. Good things to learn.'

someone you trust. Ask your friends to stand by you

Pranav

Pranav is 13, and he's always busy with lots of interests. He likes K-pop, and he plays the drums. Hockey is his favourite sport, and he likes writing too, creating futuristic stories set in fantasy worlds. Recently he's enjoyed acting in school plays 'But when I grow up, I'd like to be an architect,' muses Pranav, 'or perhaps a game-designer.'



Pranav's vitiligo started when he was about four years old. When he was little, he says, no one bothered about it at school. But now that he's getting older, he's aware of people staring when he goes out. 'My friends don't care,' he says, 'and we don't talk about it much. When people are familiar with it, it's less of an issue.' But sometimes now it can feel like an effort to go out somewhere new.

Pranav has had some difficult times particularly when they have been to India to visit relatives. 'It's a different culture over there,' says his mum, Veni. 'People ask very direct questions, and they offer advice. It got very repetitive, and Pranav wasn't very happy. So now we go on holiday in Europe or the States, where we haven't had these problems.' Teachers at Pranav's school have been understanding and supportive. They put Pranav in touch with an older boy at his school who also has

If people judge you because you've got vitiligo, they're not a true friend

vitiligo. Together they've discussed the pros and cons of using camouflage to cover the lighter patches.

'Camouflage is not for me,' says Pranav. 'Everyone knows that I have vitiligo,' he says, 'so there's no point in hiding it. It would come out anyway.' He was also offered the chance to talk to a counsellor at school. 'But I didn't want to miss break-time with my friends,' Pranav grins.

What is Pranav's advice for living with vitiligo? 'Don't feel you should only stay at home. If someone stares, it's just for

Vitiligo helps you know your real friends

a couple of seconds, and then they're gone. You hope they'll think about it afterwards.

'And vitiligo can help you too,' he adds. 'If people judge you because you've got vitiligo, then they're not a true friend. So vitiligo helps you know who your real friends are.'

Pranav on stage, acting in a school play



Phoebe

Eleven-year-old Phoebe is a busy, outgoing girl, and she loves dancing salsa, cha cha and jive. And drama, and singing too. 'I sing all the time!' she says.

Phoebe has vitiligo, and so does her mum, Amy. But Phoebe's started earlier than her mum's did, when she was 5, and her patches are bigger.

The first symmetrical patches showed on Phoebe's knees. 'I called them my special freckles,' says Phoebe. Gradually patches arrived on her arms, legs, feet and on her face.

Phoebe and Amy both follow Canadian top model Winnie Harlow, who has vitiligo. Winnie Harlow has become a role model for people with vitiligo, speaking out and posting a YouTube video called A Skin Condition, Not a Life Changer. Winnie has been open about being bullied during her childhood, and about how she found her strength and individual identity.

'A skin condition, not a life changer'

Phoebe is a keen dancer – and singer too

'Winnie Harlow is my idol!' says Phoebe, following her on Instagram. She also follows April Star, a teenage model with vitiligo.

'Michael Jackson had vitiligo too,' says Amy. 'Some people say he had a patch on his hand, and that's why he wore gloves. And then he lightened his skin so it wouldn't show.'

Amy and Phoebe both feel glad that there is more awareness about vitiligo now. 'People don't feel they have to hide,' Amy adds. 'It's better now.'

Winnie Harlow is my idol!

Phoebe showing a photo of model Winnie Harlow on her phone



Olivia

Olivia is eight years old. She loves arts and crafts, and sewing. She likes swimming and going to the gym with her dad. And she loves reading and drawing, as you can see in her self-portrait (below right).

Olivia never met her great-grandmother, but she has her photo, which shows that she had vitiligo too.

Olivia's vitiligo started when she was four years old. Now she's a bit older, she notices other people with vitiligo, for instance she sees a lady at the gym who has vitiligo. Olivia doesn't speak to strangers, she says, 'but we saw each other, and we smiled.'



Olivia enjoys swimming,
reading and drawing



We noticed each other, and we smiled

Reaching out to people with vitiligo all around the world

'I'm glad when people ask about my skin,' says Olivia. 'Sometimes they ask if I'm in pain. I say no, I've had vitiligo since I was little, and it doesn't hurt me. And then we can make friends.'



Janae, Olivia's mum, says, 'Family support is a big deal for building confidence and happiness.' Janae posts photos on Instagram, tagging others who post about vitiligo too. Her main aims are to raise awareness, and to build and maintain Olivia's confidence, so that she is able to explain about her skin and help others to understand. 'People are more comfortable asking questions via social media,' says Janae.

Janae and Olivia live in Las Vegas, but this has put them in touch with the Vitiligo Society in the UK, and with others living with vitiligo. They have reached out all around the world, sharing information and advice.



Olivia posing as Wonder Woman, the theme of her 7th birthday party

Lucy

11-year-old Lucy first spotted white patches on her knees last year when she grew tanned on a summer holiday by the beach. It was vitiligo. Her skin is light-coloured, so when she has no tan, it doesn't show.

Lucy's vitiligo shows symmetrically, on her knees, elbows, back and armpits. Her granny had just the same at the same age – some families do show a genetic link.

Lucy's younger brother Alexander was a bit upset at the beginning. He was worried for Lucy that her vitiligo would get more extreme, or that it would show more if she got tanned.

Lucy, Alexander
and Granny at
the seaside

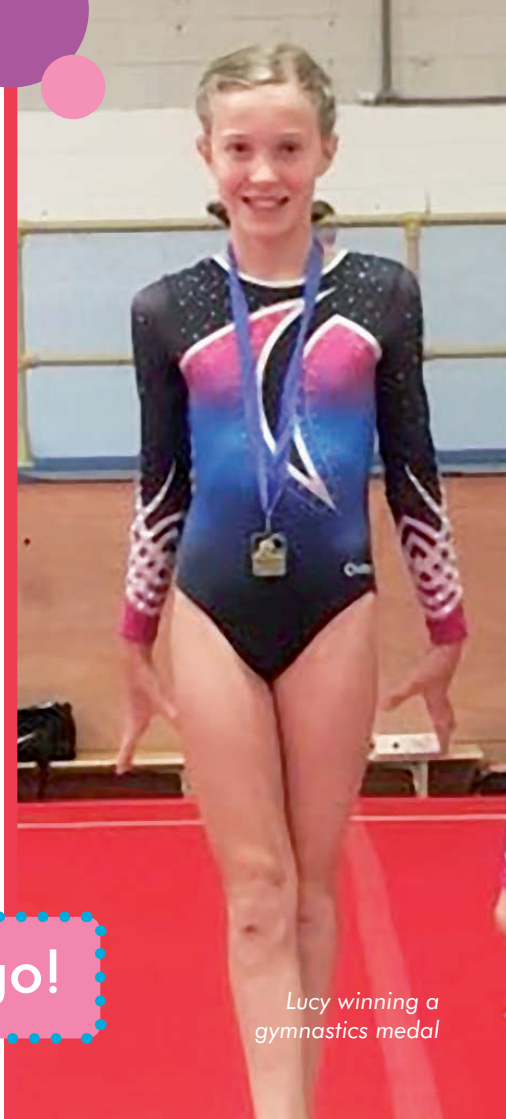


But Lucy loves spending time outdoors too – and vitiligo isn't going to keep her indoors! She's happy wearing shorts and T-shirts, and she doesn't feel she has to cover up. She's busy with all kinds of hobbies, including gymnastics, playing the clarinet, and writing adventure stories.

'Friends sometimes ask about my skin when they see it at gymnastics. I don't mind, I'm happy to answer questions if people are polite enough to ask. It's better than staring.' Lucy has been offered makeup to match her skin, but she's not bothered enough to do that.

'When the rain is drying quickly and the pavement looks patchy, I think it looks like vitiligo!' grins Lucy. 'Vitiligo doesn't change her,' says Lucy's dad, Matt. 'She's still Lucy and we still love her as she is!'

It looks like the pavement has vitiligo!



Lucy winning a gymnastics medal

An adult's perspective



Natalie enjoys expressing her love of fashion

Natalie

Natalie, now in her 30s, grew up with vitiligo. As a little girl, Natalie didn't realise she was different. Her parents didn't want her to be ashamed of who she was. They made sure she wore shorts, dresses and swimsuits in the summer.



Doctors prescribed steroid creams to try to re-pigment her skin, but nothing seemed to help.

During her teenage years, Natalie became more aware that her appearance was different from her friends.

'I struggled with my skin through my teens and even into my twenties,' she admits. She felt self-conscious, wearing long sleeves and long trousers even in the summer heat. 'I just wanted to look like everyone else! I tried to cover up with camouflage make-up or fake tan, but it was time-consuming and messy, and none of the colours matched my skin tone.'

In her twenties, Natalie undertook UVB light treatment. This treatment isn't always recommended for children, and not everyone opts for it. 'It's quite a commitment, twice a week or more for a year, and it's not guaranteed as a permanent solution,' she says.



But it has encouraged the re-pigmentation of Natalie's skin. Her natural skin colour gradually started to come back on her face, legs and arms. And so did her confidence. Finally she could wear shorts, t-shirts or a swimsuit on the beach. 'It felt like an absolute miracle,' says Natalie.



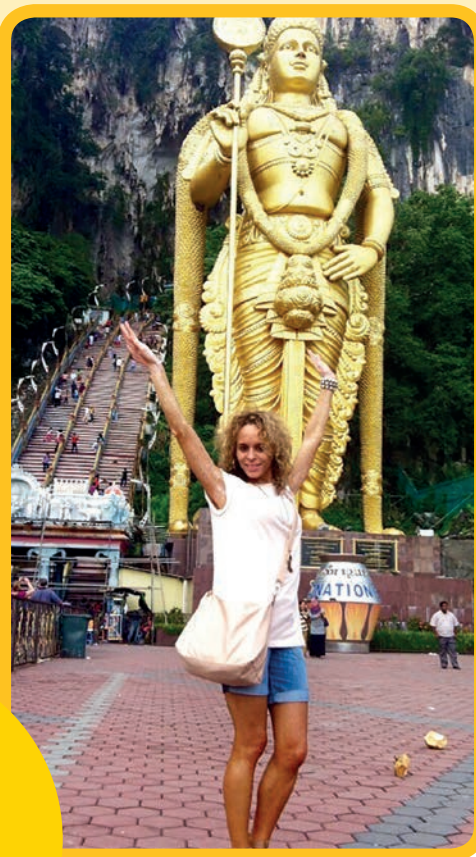
But in the meantime, Natalie has seen a real change in the way vitiligo is reported in the media. She got involved with the Vitiligo Society, first as a volunteer and now as a trustee. She has worked to help raise awareness and spread positive messages on TV and social media, encouraging people with vitiligo to embrace their skin.

Whilst everyone's journey with vitiligo is unique, she finds similarities. 'I love hearing the passion when people share their stories and how they have overcome the challenges they have faced. The important thing is to find acceptance. Some find it early, others later in life.'

'There is so much support and encouragement out there, not to feel embarrassed or ashamed, but to celebrate who we are,' Natalie says. 'This is the BEST time to have vitiligo!'



Natalie on holiday in Kuala Lumpur, the first time she had worn shorts since childhood



More information and support

The Vitiligo Society supports people with vitiligo, offering advice and information

www.vitiligosociety.org.uk

Skin Support's website offers advice and ideas for dealing with the emotional impact of living with a variety of skin conditions

www.skinsupport.org.uk/emotional-support.html

British Association of Dermatologists leaflet on vitiligo to download

www.bad.org.uk/shared/get-file.ashx?id=137&itemtype=document

British Skin Foundation's information page on vitiligo

www.britishskinfoundation.org.uk/SkinInformation/AtoZofSkindisease/Vitiligo.aspx

Changing Faces work with people living with unusual appearance.

They campaign for 'face equality'

www.changingfaces.org.uk

You can find people's real-life experiences of living with vitiligo and a wide range of health conditions, at **www.healthtalk.org** and **www.youthhealthtalk.org**

You can contact Childline online or phone **0800 1111** for advice and support

www.childline.org.uk

Vitiligo Society

Vitiligo Society is the UK's leading charity dedicated to supporting those with Vitiligo. Established in 1984, the society has become a leading source of primary information, actively campaigning for greater awareness of the condition which affects around 70 million people worldwide.

The Society supports people with vitiligo, sharing information, promoting research initiatives such as the Hi-light Trial, raising awareness amongst the medical profession and running an annual open day.

The Society has access to advice through their Medical and Scientific Advisory Panel (MaSAP) and is an active member of the Dermatology Council of England and the All Party Parliamentary Group on Skin. It participates in online skin clinics through Talkhealth, and has formed partnerships with UV Buddy and Ultra Inc., who offer products for people with vitiligo.



www.vitigosociety.org.uk

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Young people with vitiligo can feel very alone. It is good to know that someone else shares your experience and understands. This booklet is a collection of true stories and photos of real people with vitiligo, so you can read about how they cope with it.

Introduction by Professor Celia Moss, Consultant Dermatologist, Birmingham Children's Hospital

Written by Mandy Ross. Original design by Anne Matthews and Heather Blackham

If you would like a copy of this booklet, please email general@vitiligosociety.org.uk or write to The Vitiligo Society, 24 Greencoat Place, London SW1P 1RD, asking for a copy of 'Vitiligo: My Story'

Professionals can obtain copies (minimum 25) from bwc.bchcharities@nhs.net

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