

Sun and skin care for people with albinism

Why do we all have different coloured skin? - Nature provides us with skin to match where we live. Cooler climates have fairer skinned people, while tropical hot areas have darker skinned people due to the melanin in their skin. Melanin is the skin's natural sun filter. (Note: indigenous Australians have dark skin. The Europeans who moved here don't.)

What is the deal with melanin? – (People with albinism are unable to produce melanin) The melanin producing cells in people with albinism could be compared to “ghost factories” - All the cells (parts) are there and perfect, there's just nothing (no staff or equipment) to get them moving. Most people (those without albinism) have active working “factories”. Those with vitiligo don't actually produce melanin at all. They don't even have the factories built!

What is UV? - The ultraviolet radiation emitted by the sun. There are two types, UVA and UVB. UVA is penetrated deeper in the skin than B. You cannot repair UVA damage. An easy way to remember the way they work (damage) is:

UVA **A**ges (long term damage), UVB **B**urns (immediate / short term damage)

90% of UV rays penetrate clouds. UV is strongest between 11am and 2pm, so stay out of the sun between 10 am and 3 pm to be safe.

What types of skin cancer can affect us? - Basal Cell Carcinoma (BCC) are more common in the general population with squamous cell carcinoma (SCC) not so prevalent. However, in people with albinism, the ratios are reversed, and SCC are more common.

When should we worry? - Don't go by the brochures you see in doctor's surgeries and other places. If your skin cancer looks like the brochure you are in big trouble! In people with albinism, the colouration won't necessarily be a key, you'll need to go by other signs (people in attendance mentioned itching, flaky skin, indented and red / pink colouration, also non pigmented)

Have your skin “partner-assisted checked” (ie have someone else look; you can't see your back and other spots)

Do you have a smartphone? Take a photo of any spot you're concerned about and then retake a photo a few weeks later for comparison. Show them to your medico. Be persistent in getting it checked out if you're concerned. Ask for a dermatologist's second opinion.

What about kids? - Have your children with albinism see a dermatologist in primary school. This is mainly to educate them and you about their skin care. Schedule appointments when they are tweens or teenagers for skin checks.

TAKE-AWAY TIP

The skin on your face is the same age as the skin on your bottom.

The difference in the two is caused by the sun.

Sun protection 101



Hats: Don't count a baseball cap - you can get skin cancers in your ears. Check the width of brim material, check the colour, the weave and the lining (a brim width 7.5 cm provides SPF up to 7)

Note – as fashionable as they may be, not ONE of the hats pictured (left) gives adequate protection.

Clothes: if you're using clothing as extra protection, denim is best!

Colour - the darker the better.

The thickness and tightness of the weave - hold the clothes against the light. If it lets light through, it will let sun through. How often has it been washed? Does this affect its thickness?

Loose vs fitted clothes - loose is better, as wearing fitted clothes has possibly stretched the weave.

Sunglasses: Sun and glare will get in, so ideally wear 'wrap arounds'. The size and shape can block up to 90% of UV. Under dark glasses, your pupil dilates, so therefore lets more light in.

Sunscreen: All sunscreen is not equal. Double the SPF number isn't double the protection. Also, SPF doesn't protect against UVA rays. While SPF 15 ideally means fifteen times more time before burning, it's not a standard or easy equation. Numbers can be subjective. (ie SPF30+ . Does this mean 31 or 39?)

You need sunscreens labelled "broad spectrum" to get both UVA and UVB protection.

Some of the chemicals can actually degrade in sun exposure.

"Water resistant", "water proof" and "Sweat resistant" calculations are done under perfect research conditions, ie slathered appropriately, no gaps in sunscreen cover, etc. Most people don't use sunscreen this well, so it is a loose guide.

Using sunscreen

it can be difficult to say "use x amount" as it depends how big you are and how much skin you expose at a given time. Generally though, 2 mg / square cm is considered adequate. As you aren't likely to carry rulers and measuring equipment with you, try:

1/2 teaspoon for each part of your: arm, head, neck.

1 teaspoon each part of: leg

Use sunscreen anytime the UV index is over 3. Remember, even though you are using sunscreen you're still getting reflected rays from sand, surfaces, etc and hats and shirts can't cover that.

TAKE-AWAY TIP

"Safe tanning" is about as safe as
"safe speeding". It isn't safe.

Notes from session by

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