

Advice and Support for
People With Albinism,
Families and Caregivers



COVID-19 Information



REMEMBER TO:

- ★ Wash your hands frequently for at least 20 seconds
- ★ Cover your mouth and nose with a bent elbow or tissue when you cough or sneeze. Dispose of the tissue immediately
- ★ Stay at home except for essential travel (buying food, work)
- ★ Avoid gatherings and crowded places
- ★ Maintain a safe distance, at least 2 metres, from people displaying symptoms
- ★ Stay informed using trusted sources of information



Standing Voice has established a **hotline number** where you can reach us for information about your skin, health, or any general concerns you may have.

The hotline will be operated by a member of our team and will be open from **8am - 5pm**.

HOTLINE NUMBER:
0990616149 | 0884293805

Email: malawi@standingvoice.org



What is albinism?

How am I different?

You have a condition called albinism, which means you do not produce dark pigment (called melanin) in your hair, skin and eyes.

In other ways you are just like others.

Both boys and girls can have albinism.

My parents are both black, why was I born different?

Albinism is inherited. Sometimes there is only one person in a family with albinism, sometimes there are more.

We all carry two copies of an inherited unit (called a gene) that causes this condition.

Your parents are carriers: they have one copy of this gene that is working to produce pigment (so they are black). The other copy is altered. It is not working and does not produce pigment.

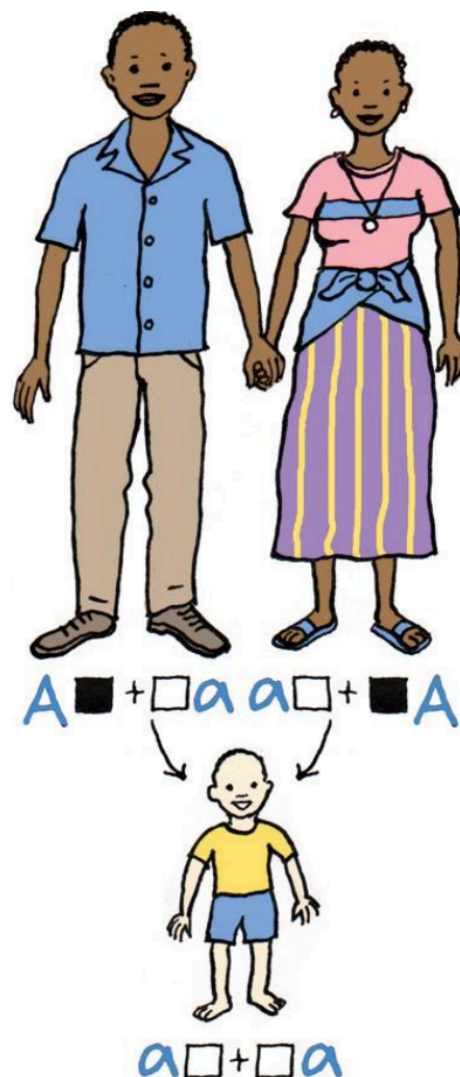
The mother and father each pass one copy of this gene to their child.

You have received an altered copy from both parents, so you do not have a gene that is working to produce pigment. This is why you have albinism.

I have brothers and sisters who are black. Why?

They have received a copy of the gene that allows pigment to be made. This could come from either the mother, the father or from both parents.

Some families have some children who are black, while others have albinism.



Sun protection

Why am I so sensitive to the sun?

Having albinism means there is no black pigment to help protect your skin and eyes from damage and discomfort caused by the sun's ultraviolet rays.

Will I go dark if I stay in the sun?

No. Your skin will go red, it will burn, blister and peel. This can be painful so avoid the sun as much as you can. If you have wounds on your skin that do not heal, ask to go to the hospital or call Standing Voice's hotline on **0990616149 / 0884293805**.

How do I use sunscreen?

1. Wash your hands and area of application with water and soap to avoid the spread of COVID-19
2. With clean hands, apply sunscreen with an SPF of at least 30 twice per day, or 15 minutes before sun exposure
3. Apply sunscreen thickly to skin not covered by clothes including lips, face, hands, and ears

4. Use two fingertips when applying sunscreen
5. Apply sunscreen every day of the year, even on cloudy or rainy days!

How can I protect myself from the sun?

- Wear a wide-brimmed hat every day to protect your skin and eyes
- Wear long-sleeved shirts or blouses, long trousers or skirts, and sunglasses
- Choose dark, tightly woven material, such as denim, to give good protection from the sun
- When buying clothes, hold them up to the light and choose ones you cannot see through
- Seek shade or remain indoors whenever possible, especially in the middle of the day, when your shadow is longer than you are. Use an umbrella where possible



Evolution of skin damage in persons with albinism



Sunburn



Precancerous lesions



Cancerous lesions



Advanced skin cancer

Sun damage is preventable if you take care of yourself



Apply sunscreen



Protect your eyes



Wear a wide-brimmed hat

REMEMBER

Check your body regularly for unhealed sores and wounds, particularly on your face, head and neck.



If you are worried that you have developed a cancer, don't delay and call Standing Voice's **hotline number** on **0990616149 / 0884293805**.

Low vision

Is my eyesight different from others?

Yes, because your eyes lack pigment, the structure of your eyes change. They 'wobble' from side to side which makes it difficult to see detail and means your eyes are very sensitive to bright light.

How does my eyesight differ?

You see things more slowly and may find it difficult to judge movement and speed, for example when a ball is thrown or a car is travelling towards you.

My sister also has albinism but her eyesight is better than mine. Why is this?

People with albinism all have reduced eyesight but this can vary from person to person, just like in people without albinism.

Will I go blind because I have albinism?

No, albinism causes low vision, but not blindness.

How can I manage with poor eyesight?

- Use colour, shape or patterns to help identify and find objects
- Some people with albinism find that their eyes 'wobble' less when they tilt their head
- Prescription glasses and magnifiers can help you read and will make letters and numbers larger. Sunglasses will protect your eyes from the sun
- Wear a hat indoors to help protect your eyes from bright light
- If you are a student, sit at the front of the class in the middle so you can see the board



Social impact

Albinism can bring social and emotional challenges.

Does albinism give you special powers?

No. The only difference in people with albinism is the amount of pigment you produce. You have the same ability and potential as others.

How can I support my family member with albinism?

Raise self-esteem and lead by example

Stigma can have a big impact on persons with albinism. They may have experienced trauma in their life which can have long-lasting effects including low confidence.

Women and girls with albinism face stigma because of their gender so may suffer from

low self-esteem.

Help to end name-calling and the use of disrespectful labels. Call persons with albinism by their name, not their condition.

Children with albinism

There is a myth that children with albinism will die young and it is not worth giving them an education. This is not the case. Every child with albinism has the right to a good education.

Parents and caregivers can help encourage young people with albinism to achieve by stressing they have the same potential as others.

If you are worried or concerned about someone, please call Standing Voice's hotline on 0990616149 / 0884293805.





Standing Voice is an NGO defending the rights of people with albinism in Malawi

Area 14, Plot No.63, Lilongwe, Malawi

Hotline Phone No. 0990616149 | 0884293805

Website www.standingvoice.org

Email malawi@standingvoice.org

Facebook @standingvoice

Instagram @standingvoiceuk

Twitter @standingvoice

Where can I find out more about albinism?

ASSOCIATION OF PERSONS WITH ALBINISM IN MALAWI (APAM)

P/BAG 512, Lilongwe, Malawi

Telephone +265 999 814 447

Email apam@apa-malawi.org

