

Living with Albinism in Fiji:

Information for Children and Young People



Fiji Albinism
PROJECT

Acknowledgements

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Why is my skin pale?

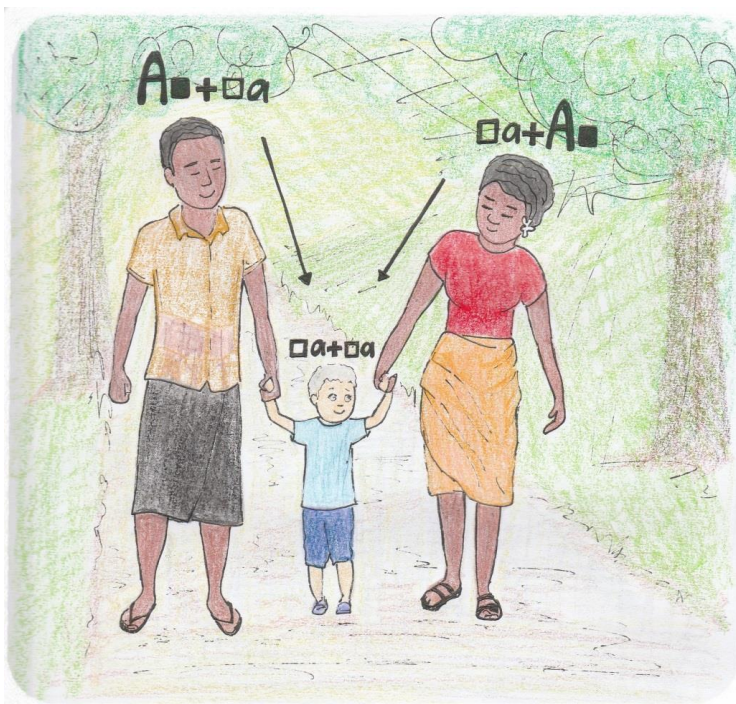
You have a condition called albinism which means you do not produce dark pigment (called melanin) in your hair, skin and eyes.

In others ways you are just like others. Both boys and girls can have albinism. In Fiji the iTaukei word for a person with albinism is “rea”.



My parents both have dark skin. Why is mine white?

Albinism is inherited from both parents and is no one's fault! 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), one from our mother and one from our father, which produces melanin.

There are two forms of this gene which are “A” which produces melanin and “a” which does not.

How did I inherit the albinism genes?

We all carry two copies of an inherited unit (called a gene), one from our father and one from our mother, which produces melanin.

Melanin is the pigment that gives colour to our hair, skin and eyes.

There are two forms of this gene. The “A” form produces melanin but the other “a” form does not.

Your parents are both carriers of the “a” gene but also carry the “A” gene which is the main and so they can produce melanin and have dark skin, hair and eyes.

You inherited the “a” gene from both your mother and father which does not produce melanin, so that is why you have albinism.

Albinism is a genetic condition that you are born with and will last all your life. It is not related to anything bad that happened during pregnancy. It is not a sickness or a disease and so cannot be passed on to others by contact or touching.

People are born with albinism in countries around the world.



I have brothers and sisters who are brown. How is this?

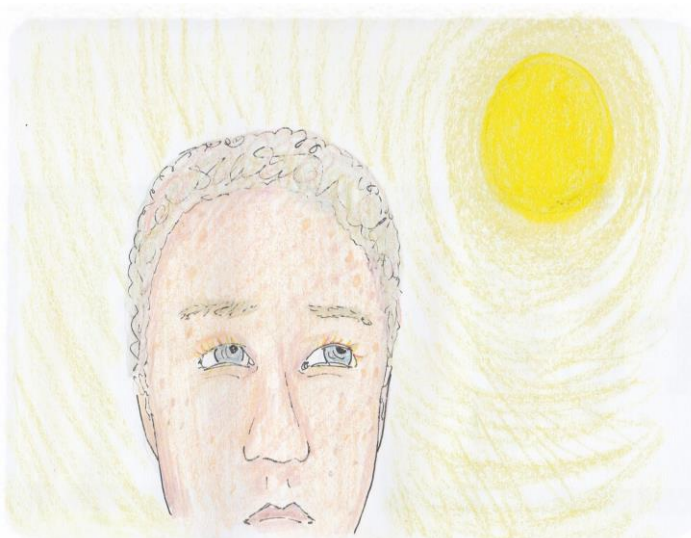
They have received at least one copy of the gene “A” that produces pigment from your father or mother or both. They may also carry the “a” gene like your parents.



In this family two of the children have dark skin and two have albinism.

Is my eyesight different from others?

Yes, your eyes lack pigment and this changes the structure of your eyes. They ‘wobble’ from side to side which makes it difficult to see detail.



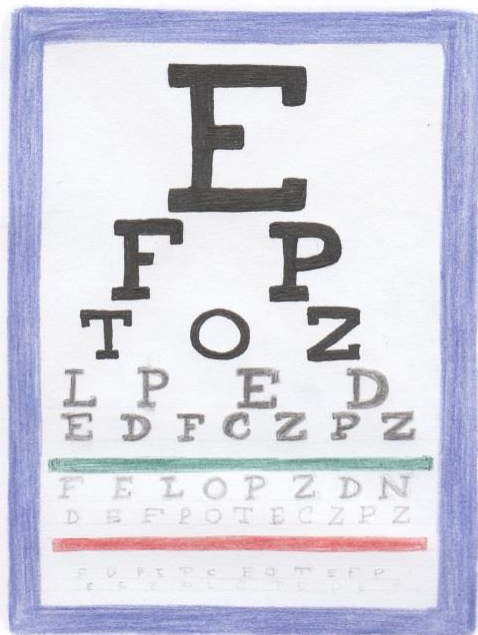
Your eyes are very sensitive to bright light.

How does my eyesight differ?

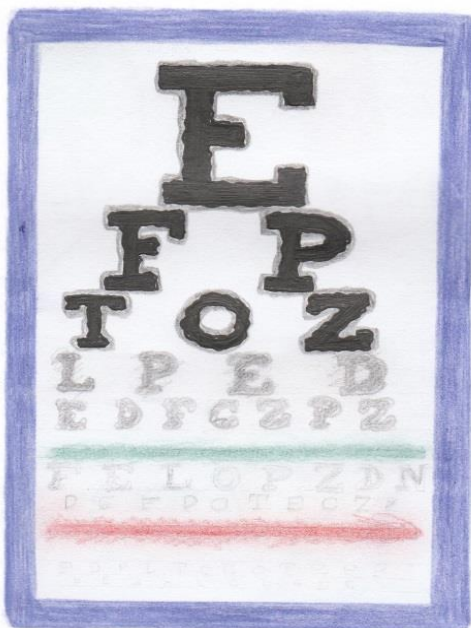
You will find it more difficult to see things at a distance. You may find it difficult to judge movement and speed, for example when a ball is thrown or a car is travelling towards you

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

People with albinism all have reduced eyesight, which will vary from person to person, just as in people without albinism.



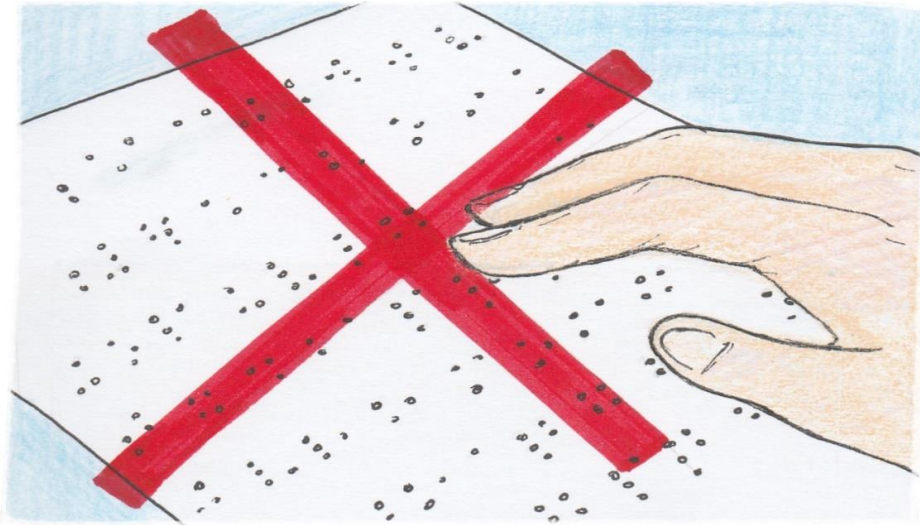
This is a picture of a chart used to measure your eyesight. People with 'normal' vision can read these letters on the chart.



If you have albinism you will have difficulty reading all these letters at a distance.

Will I go blind because I have albinism?

No, your eyesight will change as you get older, but you will not lose your sight.



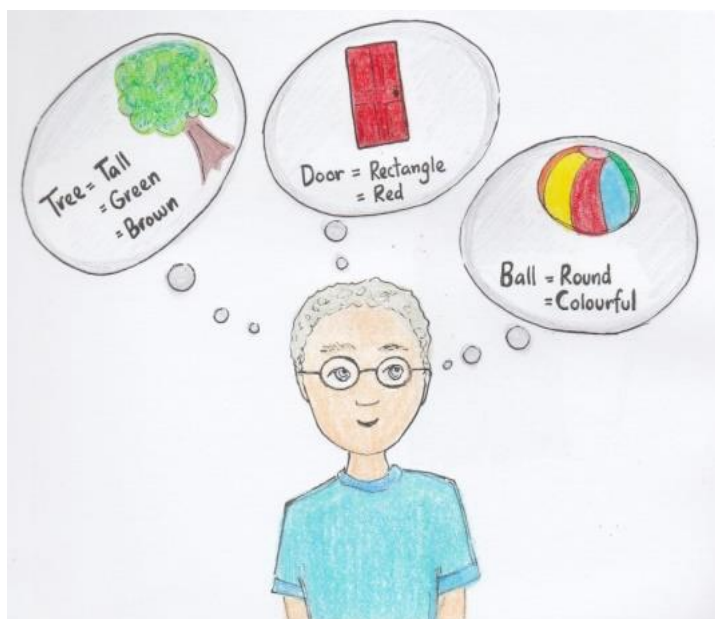
Albinism causes low vision, not blindness

Should I learn Braille?

No. If you can see when you hold the book or an object close to your eyes you do not need to be taught Braille.

How can I manage with reduced/poor eyesight?

Here are a few tips, which you probably know already:



**Use colour, shape or patterns to help identify and find objects*

**Ask people to speak so you can recognise their voice and can follow lessons in class*

**Do tasks like reading early, when you are fresh, rather than later in the day*

**Some people with albinism find that their eyes 'wobble' less when they tilt their head.*

Is there anything that can help me seeing better?



Mere has albinism. When she started school she did not realise her friends could all see the board while she could not. She asked for help from her teachers and now she is a teacher herself.

Prescription glasses can help you read.

Magnifiers that you hold in your hand will make letters and numbers larger.

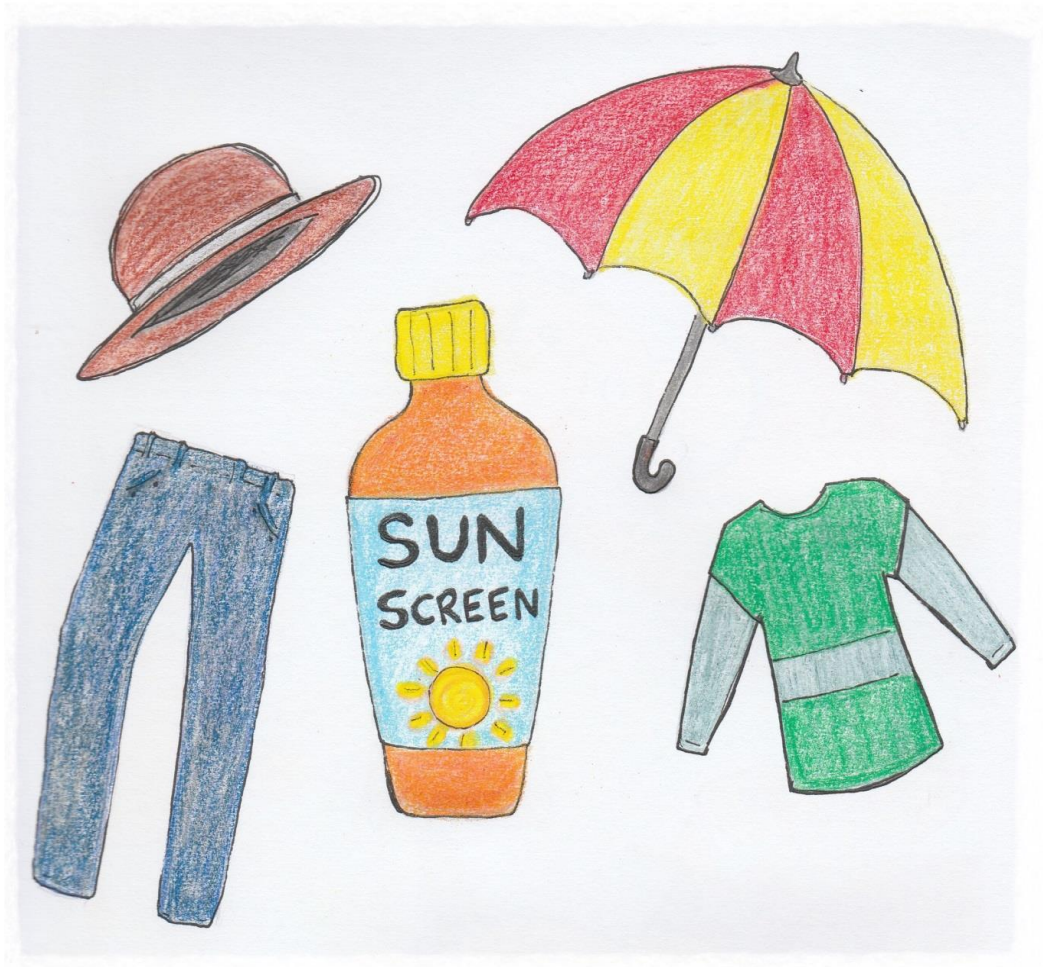


Remember the most important thing is how you use the vision you have!

Why am I so sensitive to the sun?

Having albinism means that you do not have brown pigment that helps protect your skin and eyes. This means the sun's rays cause damage and discomfort.

How can I protect myself from the sun?



- Wear long sleeved shirts and 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.

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 clinic or hospital.***

How does the sun damage my skin?

- UVA are ultra violet (UV) sun rays that age your skin
- UVB rays cause your skin to go red and burn
- Both damage your skin and cause sores.

How does sunscreen help protect my skin from the sun?

It contains ingredients that help protect your skin from the sun.

How do I use sunscreen?

- If affordable, use sunscreen that protects against UVA and UVB, with an SPF (sun protection factor) of at least 15, preferably 30
- Apply this to all parts of your skin not protected by your clothes, especially your face, neck and hands
- Apply to dry skin at least 15 minutes before going into the sun
- Apply more than once each day, especially after swimming or sweating
- Apply during the day; at night you can use any cream or Vaseline to soften your skin
- Even if you use sunscreen you should still wear clothes to protect your skin from the sun and try to avoid the sun during the middle of the day!

When should I protect my skin from the sun?

Every day!
All year round!
Even on cloudy days!



Damaging UVA rays reflect off water, sand and concrete and pass through glass.

This means your skin can burn if you are out on a river or lake, even if you are wearing a hat.

Is there any special food I should eat?

No, you can eat the same food as everyone else.

I go red when I have a bath in hot water. Should I use cold water?

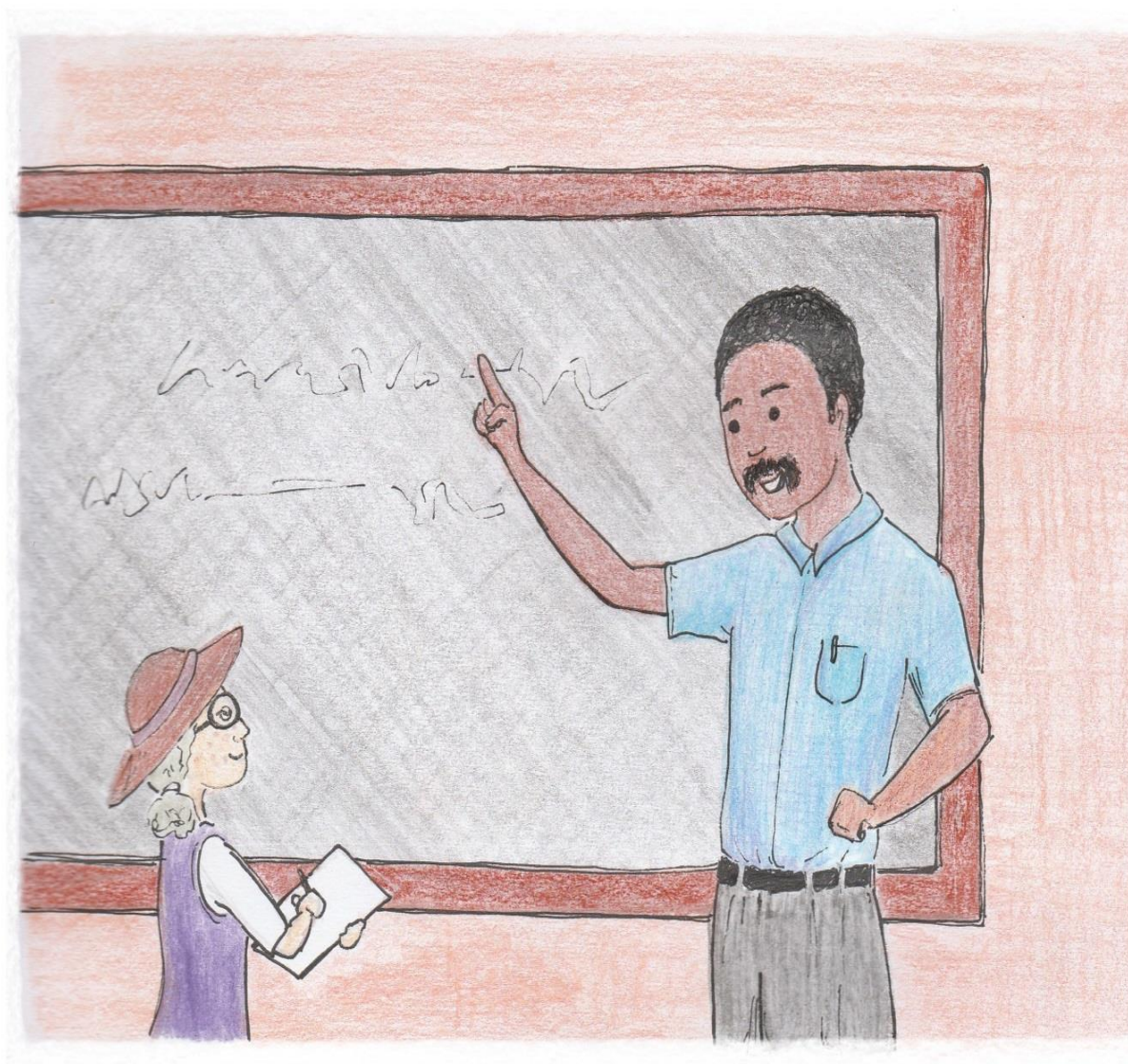
No, the redness is temporary (it is not the same redness as you get when out in the sun!). You can use hot water to wash.

How can my friends help me?

- Join you playing in the shade or indoors rather than out in the sun
- Walk with you so that you are safe crossing the road and help you learn how to get around at school and in the community
- Call you by your name when they see you, so that you recognise their voice, even if you do not see them clearly
- Read out loud to you
- Help you copy notes from the board in school and share their notes with you afterwards.



How can my teachers help me?



- Allow you to sit at the front of the class, in the middle so you can see the board
- Let you wear your hat indoors, to help protect your eyes from the bright light
- Let you move to the board to see more clearly what is written
- Give you your own book to read, rather than sharing, so you can hold it close to your eyes
- Write in big, clear letters on the board and speak aloud while writing
- Provide tests and exams in large print
- Help you to avoid being in the sun as much as possible
- Give you indoor duties
- Explain to other pupils what albinism is and why you are treated differently e.g. always sit at the front because you do not see as well as others.

SHOW THIS BOOKLET TO YOUR TEACHER!

How can well - wishers help me?

- Give you a hat with a wide brim, long trousers or skirt or a shirt with long sleeves
- Give you sunglasses
- Provide you with sunscreen lotion (although this is expensive and may not be freely available)
- Give you a magnifier to make letters and numbers easier to see
- Tell others about albinism to help educate the community.

Plan your day:

- Make sure you are wearing clothing to protect your skin and have your hat or umbrella before leaving home
- Do reading and learning earlier in the day when you are fresh rather than later when your eyes are tired. It is ok to rest your eye if they are tired.
- Plan outdoor activities such as sport, gardening, and farming for early in the morning or later in the evening when the sun's rays are not as strong
- Plan every day to try to avoid the sun and make sure your clothes cover as much of your skin as possible.



Does albinism make me different?



***No, you
have the
same
ability and
potential
as others.***



***Remember:
Everyone
has the
right to a
good
education.***

Where can I find more about albinism in Fiji?

Families with a member who has albinism may want to join The Fiji Albinism Project, which promotes the welfare of people with albinism in Fiji. For information about the project, this booklet, or the **albinism eye and skin clinics** you can contact:

The Fiji Albinism Project

Email: fijialbinismproject@gmail.com
Tel: 3320066
Address: GPO Box 16346 Suva, Fiji Islands

