



**Making
more
health**

ALBINISM

**A training binder to raise
awareness on Albinism.**



www.makingmorehealth.org



**POSITIVE
EXPOSURE
KENYA**



What is Albinism?

is it...

... a disease?
... contagious?
... a curse or punishment?



or is it...

... a condition?
... non-contagious?
... genetically inherited?



What do you call me?



1

Avoid use of derogatory language e. g. Zeruzeru, Albino, Mzungu, Pesa.

2

When dealing with any condition, it is better to use person centered language.

3

Saying person with albinism considers the person before the condition.

How is Albinism characterized?

The colour of their skin, hair and eyes is lighter compared to that of community members from their ethnic background.

The exact colour depends on the amount of melanin produced by an individual (if any).



Challenges experienced by people with Albinism

Low vision is the primary challenge experienced by people with albinism. It affects their education (especially reading), socialization (including sports participation and peer acceptance), and mobility.

1

Socialization:

- ▶ Stigmatization
- ▶ Discrimination
- ▶ Rejection
- ▶ Abandonment
- ▶ Name-calling

2

Psychological abuse:

- ▶ Social injustices
- ▶ Human rights abuse
- ▶ Poverty
- ▶ Neglect

3

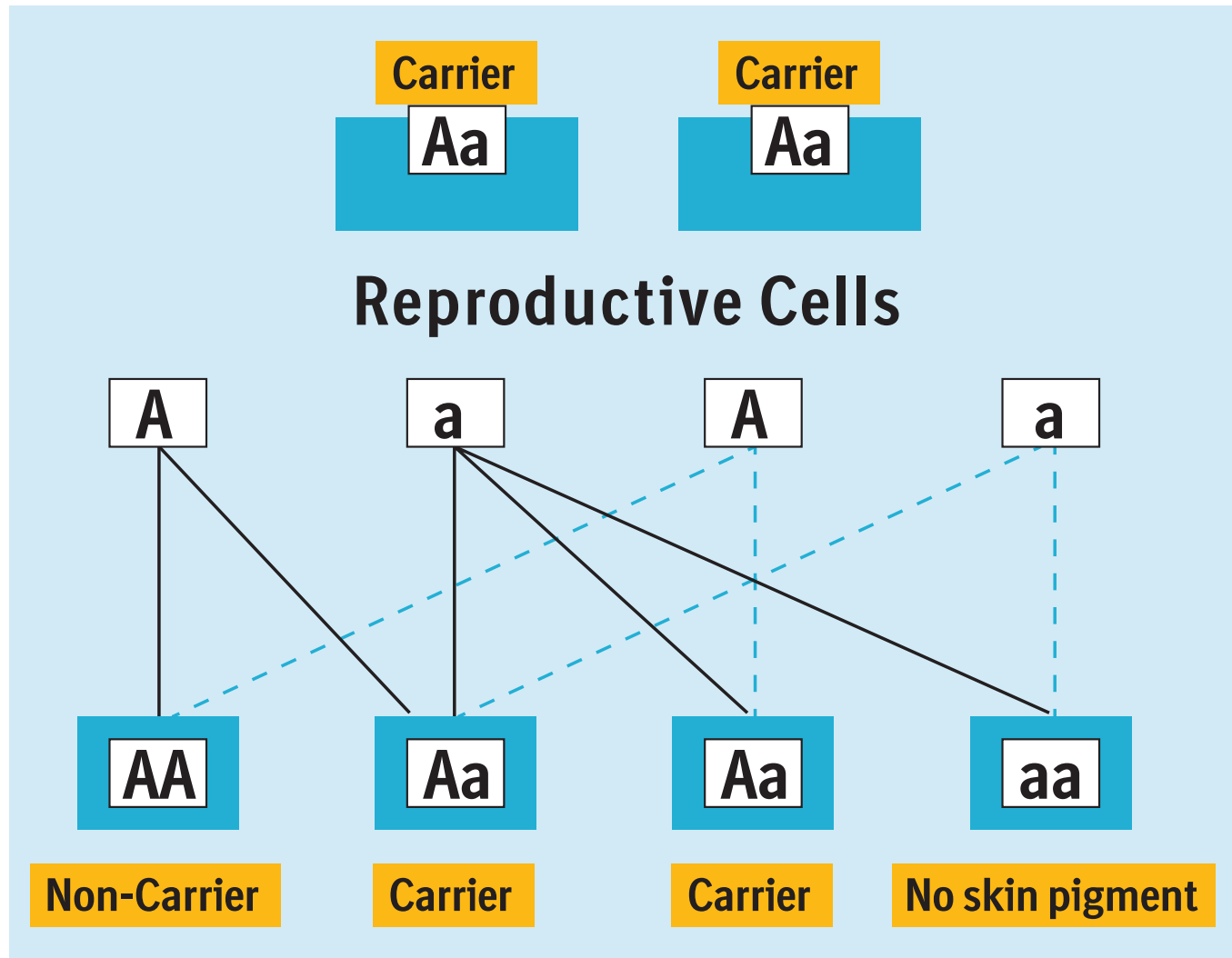
Social insecurity:

- ▶ Violence and physical attack
- ▶ Denied opportunities for growth
- ▶ Medical cover

?

What other challenges can you think of?

How is Albinism inherited?



Albinism is inherited when a set of parents who are carriers of the albinism gene get a child.

For every pregnancy, the resulting probabilities are

- ▶ 25 % chance for a child with albinism
- ▶ 25 % chance for a child without albinism and not a carrier
- ▶ 50 % chance of a child without albinism but a carrier

Albinism is associated with poor vision from birth, but not blindness. Low vision refers to insufficient vision to be able to do the desired task.

Why is Albinism considered a disability

The degree of visual impairment ranges from mild to severe and differs between individuals.

Production of reduced amount of melanin affects the eye with reduced visual acuity. Simply, the student can see from 20 feet (6 Meters) what students with normal vision can see from 200 feet (60 Meters).



Persons with albinism are classified as persons with a disability according to the Kenyan constitution and therefore are eligible for AGPO affirmative action by the Government.

What are the visual difficulties for people with Albinism?



Reduced pigmentation in the eye, increases sensitivity to light and decreases the ability of the pupil to absorb light.

As a result, people with albinism can experience discomfort in bright light and can often appear to be squinting or closing their eyes.



Albinism is associated with several eye conditions such as

- **Photophobia (extreme sensitivity to light)**
- **Nystagmus (involuntary movement of the eye)**
- **Myopia (Short-sightedness).**



The front and back of the eye also develop differently resulting in a lack of precision or detail in their vision.

Proper eye care for people with Albinism?

Approximately half of all students with albinism need strong prescription glasses that improve vision but do not completely correct it. With or without glasses, most people with albinism have to hold text very close to read it clearly and comfortably.



Tint reduces discomfort from glare, but it also reduces clarity and detail. People with albinism may resist using sunglasses at times because they feel they do not see as well when wearing sunglasses.



Routine visits to an ophthalmologist and vision therapists are highly recommended for persons with albinism.

Proper skin care for people with Albinism?

Bodies of people with albinism produce no melanin. Therefore their skin have no natural protection from ultraviolet rays and are vulnerable to sun burns, as well as skin cancers.



Any sun screen with an SPF factor of 30 and above offers adequate protection. The higher the sun protection, factor the better.



Even with the use of sun screen, persons with albinism are advised to wear protective clothing such as wide brimmed hats and not to stay too long in the sun.



Routine visits to a dermatologist are highly recommended for persons with albinism.

Why do some people with Albinism develop moles and freckles on their skin?

The skin of people with albinism has almost no way to protect itself against the sun rays.



The dark spots are a sign that the skin is not protected well enough from the sun.

It burns badly after long exposure to the sun. The skin itches and hurts.

After long exposure to the sun, the skin tries its best to protect the body but as it has only small quantities of melanin it can only create some dark spots, freckles or moles.

Is there a cure for Albinism?

YES or **NO** ?

Albinism is a genetic condition that occurs at birth and lasts throughout life. Currently, no treatment can cause the body to produce melanin and lessen the symptoms of albinism. However, with proper eye and skincare albinism can be efficiently managed.

Can children with Albinism attend mainstream schools?



Yes, children with albinism can attend mainstream schools.

However, schools should strive to create an inclusive and safe environment that provides reasonable accommodation for children with albinism to thrive.



How can I create a conducive learning environment for students with Albinism?

1

- ▶ Learners with albinism should follow classroom rules and school discipline codes just as other students would.
- ▶ Do not be uncomfortable to use the appropriate terminologies associated with the condition.
- ▶ Learners with albinism easily get fatigued while reading or writing. Offer frequent simple breaks, e. g. a few moments for the student to look around the room.
- ▶ High contrast while writing or reading is best for learners with albinism e. g. white chalk on blackboard or dark pen(cil) on white paper.
- ▶ Develop a positive attitude towards differences among all children to avoid teasing and bullying.

How can I create a conducive learning environment for students with Albinism?

2

- ▶ It is particularly difficult for students with albinism to change focus repeatedly, so copying from the board to an exercise book will be much more difficult.
- ▶ Allow a fellow student to share notes. If possible, photocopy teaching notes for the students with albinism .
- ▶ Write in big, bold letters on a clean board and organize text clearly.
- ▶ Always describe with words and in detail what is being done so that the students with albinism can follow the lesson.
- ▶ Keep in mind that it may be difficult for a student with albinism to see facial expressions or hand gestures from a distant.

How can I create a conducive learning environment for students with Albinism?

3

- ▶ Orient the student with albinism to the school.
- ▶ Ensure that students with albinism are positioned in the classroom where they are most comfortable. This usually aligns with the position of their head that makes their nystagmus or shaking eyes slow down.
- ▶ Do not attempt to alter the head position of students with albinism as the tilt reduces their eye movements.
- ▶ During emergencies, an adult should maintain responsibility for children with disability including those with albinism.
- ▶ During school trips, keep an eye on the child with albinism as they may be at a greater disadvantage in new environments.

How can I create a conducive learning environment for students with Albinism?

4

► Allow the student with albinism to use low vision devices while reading regular print text.

► Allow extra time for tasks, including tests, to allow for additional time needed to read the questions.

► Glare is a distinct problem for children with albinism. Teachers should take care not to stand with their back to the window in the classroom otherwise; glare from the window makes it difficult for the child with albinism to look at the teacher.

► Keep in mind that distant objects and extremely bright areas usually will present the most difficulty for a child with albinism

Should children with Albinism be involved in extra curricular activities?



- ▶ Art, music, physical education (PE), library, and other extra-curriculum activities are appropriate for the child with albinism.
- ▶ In outdoor activities e. g. physical exercises (PE) the student should wear a cap, sunglasses and sunscreen.
- ▶ Games with larger and slower-moving balls may be more appropriate.
- ▶ Be mindful of activities as some students with albinism struggle to judge distances and speeds.

Are people with Albinism normal?

prejudices



- ▶ People with albinism are ghosts with magical power.
- ▶ Body parts of people with albinism make potent charms for wealth, success and fertility.
- ▶ Sexual intercourse with persons with albinism cures HIV/AIDS.
- ▶ They melt in the sun or they disappear when they die.
- ▶ They are not normal.
- ▶ People with albinism are a result of inbreed or incest.
- ▶ People with albinism have a lower IQ compared to their counter parts.
- ▶ It is difficult to teach children with albinism.

facts



- ▶ People with albinism are normal people. They have the same feelings, needs and abilities.
- ▶ They only differ in appearance by the colour of their skin, eyes and hair.
- ▶ They deserve and are accorded same rights as any other human being.
- ▶ For a child with albinism to be born, both parents must carry the albinism gene.
- ▶ They do not melt in the sun but they have to be protected against direct sun exposure.

Are people with Albinism destined for poverty?

Society's superstitious beliefs shun people with albinism from accessing opportunities for empowerment, particularly education, which is a primary factor for welfare and development.

Even with the limitations of low vision, individuals with albinism can live normal productive lives when they have appropriate support and reasonable accommodation. As adults, they have families, friends and jobs and participate in community activities.

In many societies, education has been a way to escape poverty. Since people with albinism are born with poor eyesight, it makes it difficult for them to see.

Schools should strive to create inclusive and safe environment that provides reasonable accommodation for children with albinism to thrive.



Lady Justice Mumbi Ngugi, Judge of the High Court of Kenya. She is an example, that a career for people with Albinism is possible.

Final thoughts

