

Questions & Answers Booklet



for Albinos, their Families and Friends



This booklet was developed
in collaboration with
Tanzanian Albino Adolescents
and TGPSH - GTZ

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In collaboration with

Tanzania Albino Society (TAS)



Preface

The Tanzanian population is estimated at 41 million people. 10% of the total population or better/rather 1 out of each 100 people in Tanzania fall in the category of disabled¹, children, young people and adults included. Further available statistics show that people living with Albinism also referred to as Albinos are one out of 4,000. Disabled are often victims of segregation, stigmatization, and discrimination. Because of these and other factors disabled are faced with serious economic and social problems/disadvantages and are at a higher risk of health problems; problems that are fuelled by/through existing cultural beliefs and misconceptions within the community on the origin of the disability. This scenario especially so in the past made disabled people not able to air their voices/opinion or be heard leading to them being forgotten and not included in important socio-economic strategies.



Recently the government of Tanzania embarked on different strategies, recognizing disabled not only as people with special needs but also as people with equal rights like the rest of its nation. For example "The Strategy to Reduce Poverty" popularly known as

¹ *The Tanzania's National Disability Policy (2004) defines disability as "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical, mental or social factors"*.

MKUKUTA, expressing the importance of targeting specific groups with special needs in the development effort acknowledging contribution of each individual towards achieving development. Further the government endorsed and recognizes international and national agreements to protect the rights and dignity of disabled people. In addition to its commitment, the government through the Ministry of Labor has put in place "The National Disability Policy" (2004) that gives different guidance with regard to disabled people at all levels of the society. It also aims at sensitizing towards change in opinion, attitudes and political involvement to recognize and implement rights for those disabled. Despite all these efforts still the community has little knowledge on some of the disabilities which contributes to enhance existing misconceptions and beliefs.

This booklet is just one of the many efforts being undertaken by different players aiming at giving correct information on people living with Albinism. It is anticipated that correct information and knowledge will make people recognize Albinos as normal people with equal rights, feelings and needs and highly capable if given the same chance in a friendly and supportive environment. In this booklet the word Albino or people living with Albinism will be used interchangeably.

It is our sincere hope that this booklet will inform not only young Albinos but also their families, friends and the

community thus increasing the understanding, reducing stigmatization and still rampant killings of Albinos for witchcraft believes. The questions in this booklet were collected between July -August 2009 among Albino youths in Tanga, Dar es Salaam and Coast Region. The development of this booklet was done in a participatory manner involving young Albinos throughout the process. Through this booklet we hope to have contributed towards building in young Albinos acceptance of their condition, developing self-esteem, enabling them to claim their rights and to become responsible for their actions with regard to sexual reproductive health and rights and HIV/AIDS.

A handwritten signature in black ink, appearing to read 'Ernest Kimaya', with a stylized, scribbled initial 'EK' on the left.

Ernest Kimaya

Chairperson Tanzania Albino Society (TAS)

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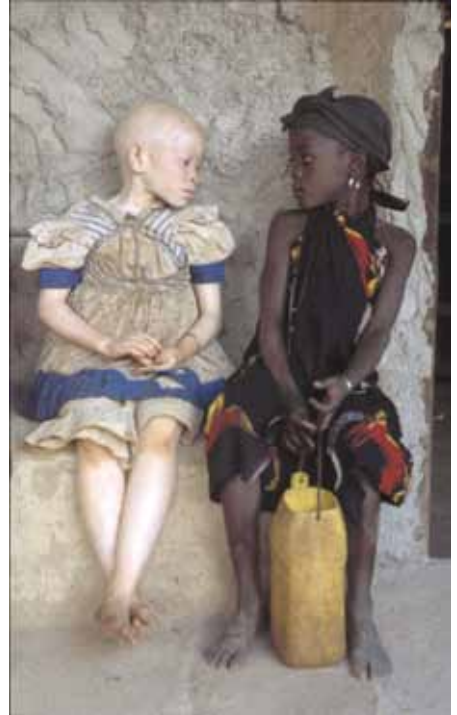
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1. What does the word Albino mean?

The word Albino means a white person. It is derived from the Latin word "albus" meaning "white". Since the 17th century the word Albino has been used to describe living creatures with Albinism, having little or no color in the skin, eyes and hair. For humans the term people living with Albinism is preferred by some because it emphasizes that these are people like anybody else who live with a special condition: "Albinism". We will use both terms interchangeably.

Language can shape ideas and create reality. Therefore, we should avoid using words like "zeruzeru" meaning a double zero or a worthless person. Using this word is very impolite and singles out Albinos in a negative and an unjustified manner.



2. What is Albinism?

People with Albinism have a white skin, blonde or reddish hair and brown, grey or blue eyes. Their skin is lighter than the skin of other family or community members without Albinism. The lighter skin is more obvious in black families; however, Albinism affects people of

every nation, ethnicity, and religion. We find Albinos in all continents.

3. What are the causes of Albinism?

The body of people living with Albinism has little or no ability to produce the color of the skin, hair and eyes. This color is called "melanin". Depending on the amount of melanin produced the color of the skin is more or less pale.

The ability to produce melanin is anchored in our genes. If the genes for melanin production are missing or altered little or no color is produced. Albinism is a genetic condition which means that it can be passed from parents to their children.

4. How is Albinism inherited?

Most children with Albinism are born to parents who have normal hair and eye color for their ethnic backgrounds.

Because the body has two sets of genes (one from the mother, one from the father), a person may have normal pigmentation but carry the Albinism gene. If a person has one gene for normal pigmentation and one gene for Albinism, he or she will have enough genetic information to make normal pigment. The Albinism gene is "recessive" which means that it does not result in Albinism unless a person has two genes for Albinism.

When both parents carry the gene, and neither parent has Albinism, there is a one in four chance at each pregnancy that the baby will be born with Albinism.

This type of inheritance is called autosomal recessive inheritance.

Inheritance of Albinism



Parents both black. They carry each the color gene for Melanin (M) and the Albino gene (a)

Ma

Ma



aa

Albino
two Albino genes



Ma

black
one color, one
Albino gene



Ma

black
one color, one
Albino gene



MM

black two
colour
genes

5. Do only humans suffer from Albinism?



No. Albinism is a condition which occurs in humans and other mammals. Famous are the white elephants in India which were honored at the kings court or white tigers, giraffes or lions which are highly appreciated by zoological gardens.

6. How many Albinos are in Tanzania?

The real number of people living with Albinism in Tanzania is not known because nobody has counted them. It is estimated - based on research in other countries like Nigeria and South Africa - that 1 out of 4,000 - 5,000 people lives with Albinism in Tanzania. The number is four to five times higher than in Europe or USA where we find 1 Albino in 15,000 - 20,000. In Tanzania we estimate that there are about 10,000 people living with Albinism.

7. Do all people living with Albinism look alike?

No, not all Albinos look alike. They differ according to whether they have complete absence of melanin pigment or an insufficient level of melanin pigment. Scientists

have identified different types of Albinism. According to the different types some people living with Albinism have a light brown skin and reddish hair, others have a white skin and blonde nearly white hair, some have many black moles on white skin, others have few.

8. Should an Albino use hair dye or wear a wig?

This is a question of taste. Some prefer to keep their hair natural, the way they are born. Others prefer to dye it blonde or black and others prefer a wig in black, brown or blonde. The most important thing is to feel comfortable yourself. The more you feel that you are looking nice the easier it is to behave in a self assertive way. If you love yourself, others will love you as well.



9. What is the problem with the eyes of people living with Albinism?

The iris in the eyes of Albinos lack the color pigment. Therefore, their eyes are highly sensitive to light. The iris normally protects the



inner eye from getting too much light. If the iris is not able to protect the eye from the rays of the sun, it

is difficult to get the contrast in a picture right. The vision is therefore blurred.

Therefore, it is of utmost importance for Albinos to avoid the rays of the sun with sun glasses.

People living with Albinism are often visually impaired. However, the type of disorder (short sighted, long sighted, blurred vision) differs. Also the effects of each person's poor vision on what they personally find easy and difficult to do varies. The fact is, people with Albinism participate in all kinds of sports, some are able to drive, and many can read normal print.

10. Why do some Albinos have rapidly moving eyes?

Some people with Albinism have rapidly moving eyes do not focus together. This is called nystagmus. The eye movement is not under the control of the person. If one eye focuses, the other might move. This makes it difficult to see properly.

11. What can be done about the eye problems of people living with Albinism?

Living with poor vision is Albinism's primary challenge, affecting education (especially reading), socialization (including sports participation and peer acceptance), and mobility. The problem starts if the impairment is not realized and no measures are taken by the family and the community to deal with it. If measures are taken either through the provision of glasses, books with



larger letters, magnifying lenses or simply sitting in the first row children with Albinism are able to perform like anybody else.

12. What are problems of Albino school children?

Although their intelligence is not impaired Albino children often do poorly in school and might be treated as stupid because they cannot read the blackboard. School age children with Albinism often find themselves left out of extracurricular activities and social events in school.

Teachers should know about Albino children and make a special effort to allow them to follow the lessons. Families and schools must make an effort not to exclude children with Albinism from group activities. Contact with other Albinos or with people who have Albinism in their families is most helpful.

Children with Albinism may learn to compensate for

their lack of self-esteem by striving harder in school and other activities. They tend to exceed at whatever they try. Many black people with Albinism have succeeded as technicians, legal assistants, entrepreneurs, computer programmers, college professors, etc.

13. Why are Albinos categorized as disabled?

Disability means a physical or mental impairment that substantially limits one or more of the major life activities of an individual. Since Albinism involves a visual impairment, they are legally categorised as disabled in Tanzania. This is specifically because of their poor vision. The signs of poor vision differs from one Albino to another some are far sighted and some are short sighted and some have blurred vision.

14. Why does the skin of Albinos look like the skin of white people?



The skin of people with Albinism lacks color. It looks similar to the skin of white people with low pigment. However, contrast to most white people the skin of Albinos does not tan in the sun, it does not get brown. In the same way as white people do, Albinos should protect their skin from the rays of the sun either by covering up with clothes or by using a sun protection lotion. The best option as reported of the late Queen Mother of the United Kingdom. It is said that she never exposed her skin to the sun and even at 100 years of age her skin was "like a baby's skin".

15. What should Albinos do to protect their skin?



An example of loved and well taken Albino twins

The lack of protecting pigment in the skin disposes

Albinos - in the same way as white people - to the risk of acquiring skin cancers. Therefore, every Albino is strongly advised to protect her/his body from the sun's rays by wearing long sleeved garments, caps or hats and if possible sun glasses. For those who can afford it there are special body lotions which can be used to protect them from the sun's rays.

In order to be well accepted young Albinos should make a special effort to dress nicely like these leaders from the Albino Society.

The skin is more fragile than that of black people's and therefore it is advisable to regularly put oil or to avoid drying. The lips are especially sensitive to drying out and need to be cared for with oil or fat regularly. If no special skin lotion is available cooking oil (coconut, sunflower etc.) helps to keep the skin smooth and soft.

16. Why do Albinos develop dark moles on their skin?



Moles on the face after years of exposure to sun

The skin of people living with Albinism has almost no way to protect itself against the rays of the sun. It burns badly after long exposure to the sun and the skin itches and hurts. The skin of an Albino tries its best to protect the body from the rays but as it has only small quantities of pigments it can only create some dark spots (moles). Therefore, the dark spots are a sign that the skin is not well enough protected from the sun. If a person living with Albinism is able to completely avoid the sun's rays, the skin will have few moles, or none at all.



No moles on the face of a 15 years old Albino due to consistent protection from the sun

17. There is the opinion that Albinos are normal people. Is this scientifically true?

This is very true. People living with Albinism are normal people and can be of all types like any other human being. They can be small or tall, fat or slim, beautiful or ugly, rich or poor, talented or average. They can be assertive or shy, friendly or rude, cooperative or hostile.

Remember they only differ in appearance by lack of color in their skin, eyes and hair. It is high time that

society learns to accept Albinos as normal human beings like the rest of them. They have the same feelings, needs, abilities and deserve all human rights like any other person.

18. How is an Albino affected by the stigma and discrimination prevailing in our society?

Many people treat Albinos differently from other people. They avoid contact. They may even cross in order not to meet them or in a daladala they avoid sitting next to them. Many believe the myths and rumours which are spread. Society isolates them in many events and thus reinforces the existing misconceptions about Albinos.

This leads to stigma and discrimination, putting Albinos on the margins of society.

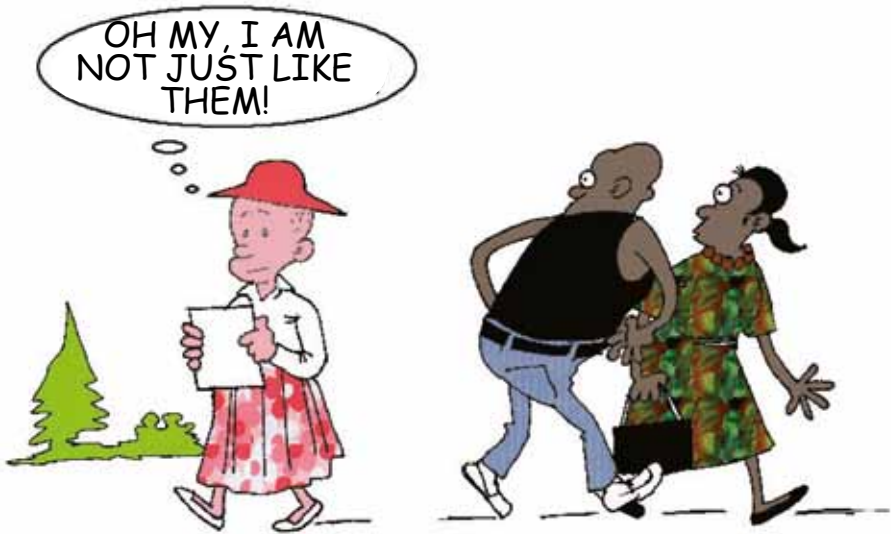
Worse is that this discrimination contributes to lowering the self esteem of young Albinos. With low self esteem it is difficult to be accepted or to get a job. Therefore, discrimination creates a vicious circle for Albinos.

A very basic human need is to be loved and accepted and cared for. Albinism often appears in a family unexpectedly. It can be a catalyst for acceptance and love involving siblings, grandparents and the parents.

Fighting stigma and discrimination and fighting for equal rights for Albinos is a big challenge for the Tanzanian society.

19. Why does the community hate us Albinos?

The community doesn't hate you. Some people might hate you but others love you for example your parents, siblings and friends.



Human beings often fear those who are different. In a white society many people fear blacks and run away if they see them. In a black society some people are scared of Albinos as they do not know what happened to them. They automatically fear them because they look different. The fear might be reinforced by rumors they have heard, e.g. that if you touch an Albino, you will be white as well, if you are pregnant and you meet an Albino your baby might be white. The truth is that these rumors are sheer nonsense. Albinism is a hereditary condition and not contagious. There is no reason to fear Albinos.

The negative attitude of the community changes when people know more and if they know a person living with

Albinism personally and have experienced that they are friendly and kind. You yourself can play a role to improve understanding if you address people frankly and in a friendly manner.

20. Why are we seen as a burden to our families?

People who need special attention can be seen as a burden as they might request help or special support which others do not need. Parents and other family members may need to face some unpleasant comments and have to cope with teasing and name calling. Siblings need to understand why their brother or sister looks different and why he/she needs special attention.



The family is the key to help an Albino child understand and accept himself or herself. A family able to accept and love their Albino child becomes rich and happy because this child creates a special bond in

a family - it gives the family the feeling of being strong and united.

21. Why are Albinos denied employment on the assumption that they are incapable?

Many people do not have sufficient knowledge of the skin disability and on eye problems affecting Albinos. That's the reason why sometimes the society segregates them on the conviction that they are protecting them from being exposed to further ill effects. They might even seek to protect them from tasks that they are capable of performing without seeking their opinions.

SHE CAN PERFORM BUT SHE LOOKS.....



People ought to understand the handicaps that people living with Albinism might have and give them tasks which suit their abilities. For example working in the sun for a long time is not appropriate or requiring them to read for many hours might not be possible. It is important

however for an Albino to realize their limitations and accept their abilities and to be willing to choose and perform tasks that are appropriate to their conditions.

22. Can an Albino have success in life?

The belief that Albinos are less capable is not valid at all. There are impressive examples of Albinos who have shown their ability and efficiency in various professions as teachers, scientists, lawyers and some participate actively in political leadership. People like the Hon. Al-Shymaa Kway-Geer (MP), the Bongo Flava female singer Keisha, the lawyer Abdallah Possi and Sizya Migila a Human Resource Officer at Tanzania National Audit Office are examples of impressive careers of Albinos in Tanzania.

The musical star Salif Keita is an internationally recognized afro-pop-singer-songwriter from Mali. He is highly appreciated in Africa and Europe as

the "Golden Voice of Africa". He is living with Albinism and is a direct descendant of the founder of the Mali



Sizyi Migila and her late father after the graduation ceremony at Dar es Salaam University.

Empire, Sundiata Keita. This shows that Albinism can occur in royal families as well as in a farmers family.

23. Are there laws in Tanzania supporting disabled people?

Yes, there are laws in Tanzania that support the disabled. Internationally, Tanzania signed the International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities of 2006. With this, Tanzania has expressed willingness and commitment to protect and care for the rights of people with disabilities. The Constitution of the United Republic of Tanzania of 1977² prohibits discrimination against persons with disabilities.

Many of the laws supporting the disabled are sector specific. These sector specific laws take care of the rights and privileges of the disabled in the areas of training, employment³, care and maintenance⁴ and general wellbeing⁵. However, there is also the Tanzanian National Policy on Disability of 2004. This policy aims at ensuring a conducive environment for people with disabilities to equally participate and benefit from social development and in receiving basic needs and services from society.

² *As amended from time to time*

³ *Disabled Persons (Employment) Act 1982 (No. 2). Disabled Persons (Employment) Regulations 1985*

⁴ *Disabled Persons (Care and Maintenance) Act 1982 (No. 3)*

⁵ *The Persons with Disabilities (Right and Privileges) Act no. 9, 2006. Applies to Zanzibar only. Source : ILO : Inclusion of people with Disabilities in the United Republic of Tanzania: Decent Work for People with disabilities: 2009*

BOSS GIVE ME A JOB AND
YOU SEE THINGS.....



24. Are there laws supporting Albinos and their rights?

There is no specific law that supports people living with Albinism. However, the Constitution and other sector specific laws prohibit discrimination of any kind, including discrimination that is based on race, origin, color etc. Further, the National Disability Policy defines disability as "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical, mental or social factors". The policy calls for equal opportunities for the disabled in receiving education and information, employment, care, health services, and mobility and accessibility in daily life.

However, since today Albinos are faced with many other

challenges, e.g. being hunted and killed for various reasons of which some relate to witchcraft. They can be protected using the available criminal laws that punish behaviors and offences that are directed against persons living with Albinism. Further, the Government's commitment towards supporting Albinos has recently been encouraging. Following the increasing number of Albino killings, the Government has initiated a census of Albinos and has established a police escort service for Albinos, mostly for children.



The topic of Albino has been put high on the national agenda for example this year the journey of the Uhuru torch had a message sensitizing people to reject the killings of Albinos.

Recent Albino killings have reinforced Government's commitment in further protecting Albinos by creating a special court committee to speed the hearings of culprits.

This has led to seven Albino killers being sentenced to hang.

Three albino killers to hang

BY CORRESPONDENT

24th September 2009

Comments Print Email

The High Court, sitting in this Shinyanga Region town specifically to preside over cases involving albino killings, delivered its first judgement yesterday. It convicted and sentenced to death three accused persons.

Reading the ruling, which lasted about an hour, High Court Judge Gabriel Rwakiballia said the court was satisfied that the evidence presented by the prosecution side proved beyond reasonable doubt the involvement of the three convicts in the killings.

He said the trio conspired and killed schoolboy Matatizo Dunia (13), an albino, on December 1 last year at Bunyhuna village in Shinyanga Region's Bukombe District.

Four more albino killers sentenced to death

BY CORRESPONDENT

3rd November 2009

Comments Print Email

The High Court of Tanzania sitting in Shinyanga region specifically to preside over cases of albino killings, delivered its second judgment yesterday by convicting and sentencing to death by hanging four accused persons.

Delivering the judgment which lasted almost four hours, High Court judge Gadi Mjemias sentenced Mboje Mawe, Cherenye Kishiwa, Sayi Gamaya and Sayi Maftzi, all residents of Nkindwabiye village in Bariadi district, Shinyanga region to be hanged to death.

He said the four conspired and killed Lyaku Wile (50) of Nkindwabiye village between November and December last year.



Bariadi residents who were convicted to death sentence by High Court yesterday in Shinyanga region, following the albino killing case they were facing. (Photo: M.A.A.P. Tanzania)

25. What does the Government have in place to curb the situation? How are we going to survive?

First of all the Tanzanian Constitution clearly states in Article 14: "Every person has the right to live and to the protection of his life by the society in accordance with law."

The President Kikwete in one of his monthly televised

addresses in 2008 said that “these killings are shameful and disgusting to our society” and “a senseless cruelty” and he added “It must stop forthwith”.

The government of Tanzania in collaboration with other non-state actors like civil societies and non-government organizations (NGOs) are working on providing the knowledge, skills and the right environment to enable Albinos to live as productive members of society.



*Al-Shymaa
Kway-Geer (MP).
Tanzania – a
politician advocating
the rights of people
living with Albinism*

26. Why do people believe that we Albinos do not have HIV?

This is absolutely not true. This may be an intentional distortion of the facts by a few members of society to propagate such wrong beliefs.

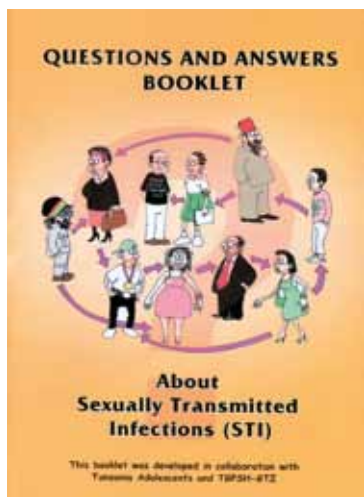
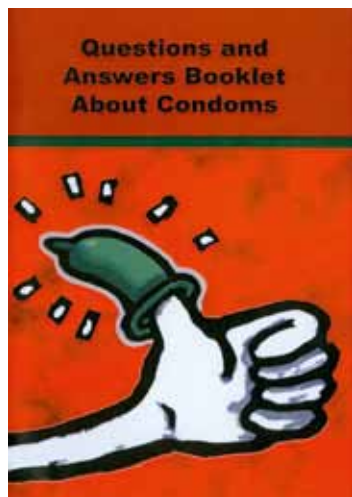
People are willing to believe all possible mistaken ideas in order not to face the truth about HIV. They hope to find a cure by having sex with a virgin, with a disabled person, with a person living with Albinism. All this is nonsense.

HIV is a virus transmitted through body fluids and especially through unprotected sex. The only secure way is to use a condom or for both sexual partners to be tested and to be faithful to each other. However, this is exactly what those people who spread rumours deny. They are searching for an easy way out.

It is in your own interest as an Albino to fight those rumours and to protect yourself.

27. Do Albinos get infected with HIV?

Yes, of course! The chance of getting infected is the same as for anybody else if in contact with body fluids from an person with HIV. This is most likely to happen during unprotected sexual intercourse. So use a condom whenever you have sex and if you are in a permanent partnership know yours and your partners status and stick to each other.



If you would like to know more on preventing HIV infection you can access: "Questions and answers on HIV and AIDS and on Condoms for young people". From Tanzania Printers Limited, P.O.Box 451, Dar es Salaam,

e-mail: <info@tanzaniaprinters.com>. The booklet "Questions and Answers about Sexually Transmitted Infections (STIs)" is available at Colour Print (Tanzania) Limited, P.O.Box 76006, Dar es Salaam, e-mail: <cptl@iwayafrica.com>. They are also available at www.tgpsh.or.tz

28. How will I know if I am infected with HIV?

The only way to know if you are infected is to take an HIV test; this test is widely available in Tanzania through health facilities or at counseling and testing sites like Angaza. The test involves taking a small blood sample and usually results are given within a few minutes. A trained counselor will speak to you about the test and will guide you on receiving the results.

29. Some say that people can be cured of AIDS by having sexual intercourse with an Albino? Is this true?

People are willing to believe all sorts of mistaken ideas in order not to face the truth about HIV. They hope to find a cure by having sex with a virgin, with a disabled person or, with a person living with Albinism. All this is non-sense.

The myth that one can be cured of AIDS by having sexual intercourse with an Albino is not true. Up to now there is no known cure for AIDS, although there has been great progress made in developing treatment with drugs called ARVs (Antiretrovirals). These drugs have greatly improved the lives of people living with the virus.

However, these drugs do not cure the disease. Therefore once someone becomes infected with HIV they will remain infected for life and they will not be cured by having sex with an Albino.

These myths also affect other groups in society, for example some people believe that having sexual intercourse with a virgin can cure AIDS. Those false myths have resulted into cases of child rape. It is important for young Albinos to know the truth and to protect themselves accordingly.



If you would like to know more on preventing HIV infection please ask for the booklet: "Questions and answers on HIV and AIDS and New Generation" available at Mkuki na Nyota Publishers, P.O.Box 4246, Dar es Salaam, www.mkukinanyota.com or at www.tgpsh.or.tz.

30. Supposed an Albino is infected with HIV are they treated with ARVs like black people and do they have their own hospitals?

As far as infection with HIV is concerned there is no difference between Albinos and other infected people. They get it by the same modes of transmission and they have the same need for social, psychological and medical support.

They get the ARVs if needed and under the same conditions as anybody else. If they face a problem getting their service, they should address a community leader or a member of the Albino society to successfully claim their rights.

There is no special hospital for Albinos who are living with the virus, but there are specialized hospitals to care for the specific problems of people living with Albinism. Those hospitals are specialized for early diagnosis of skin cancer (like Ocean Road hospital in Dar es Salam and KCMC in Moshi or like CCBRT for vision problems in Dar es Salaam).

31. Why are Albinos discriminated against love relationships by others (black people) in the society?

People have a tendency to fear or avoid things they perceive as different. The more you know about the facts and the better you are acquainted with Albinos the more you develop love and affection for them.

There are also many examples of people who have had love relationships with Albinos and there are many Albinos in Tanzania who are married. Each such example in the community helps to demystify the existing myths.

32. Many people believe that Albinos are hotter in sex than black people. Is this true?

This is not true, the difference between an Albino and a black person, as explained earlier on, lies in the color of their skins and hair and in their visual impairment. Other systems and organs are the same as those of black people.



Some like to spread rumors about others who are hotter in sex, e.g. Germans believe the French are hotter, many white people believe black

people are hotter etc. All this is nonsense. There are people who are hot in sex, who love having sex often and intensively, there are others who have only a moderate interest in sex and there are others who are not interested at all. This rumor tells more about the imagination of the one who tells it than about reality.

33. Why are black people afraid to marry an Albino believing that they will have an Albino child?

Albinism is a hereditary condition which means you get it from your parents. Two black people can give birth to an Albino child, if both carry in their body the gene for Albinism. This you cannot see or know. You only realize it after giving birth. About one in 70 people carries this gene but it is not possible to know who carries it.

If an Albino marries a black person the chance of giving birth to an Albino is low. Most Albinos who are married to a black partner have black children.



Young Albino mother and her child

On the other hand a couple who have already given birth to one Albino child has a high chance of having a second child with Albinism.

To give birth to an Albino the child must inherit Albino genes from both parents the mother and the father.

34. Why is it that in some cases the father denies that the child is his?

In many cases, after having seen that the baby has a light skin the father rejects the child blaming the mother for having had sex with a white man. This is pure

nonsense because everybody knows that children born from black and white parents are not Albinos, e.g. US President Obama who has a white mother and a black father.



This wrong idea is based on ignorance and mistrust. The more people know and learn about Albinism the less they will react like those fathers in future.

35. Why do people kill Albinos?

The killing of people with Albinism is a new phenomenon and it is by no means a traditional way of practicing medicine.

Some traditional doctors use parts of animals or humans in their ceremonies. For example human skulls are placed under the foundation of buildings to bring luck

or good business. Blood is believed to "boost" virility and placentas can be used to treat infertility.

But this has nothing to do with hunting and killing Albinos - a new business created by some greedy witchdoctors. They sell body parts pretending that they bring wealth and luck. However, these are criminal acts which society must not tolerate and which are prosecuted by the government and its police force.



36. How do the people who kill Albinos benefit?

There is no scientific study that has demonstrated any benefits relating to Albino killings. The allegations we hear of people getting rich because of such practices are mere rumors with no basis. It is unfortunate that these rumors are so wide spread in the communities and as a result many Albinos have been hurt and killed.

Killing and hurting are offences which are punishable by law and the government is currently highly committed to putting an end to these criminal acts by educating the communities and enforcing the law to the offenders when arrested.

37. Why are Albinos denied the right to life in this world?

Albinos have an equal right to live and to enjoy their presence on this planet as do other human beings. Killing Albinos for whatever reason is morally bad and is condemned by the government, human rights activists, the international community, religious institutions, other law abiding community members and every right minded and rational human being. The killings also contradict universal human rights and as such the perpetrators ought to be prosecuted.



38. What measures have been taken by the government to stop hunting Albinos?

The unfortunate bad development of the murdering of Albinos in Tanzania since 2007 has resulted in the positive effect of drawing much public attention towards protecting Albinos. The government of Tanzania has initiated several measures such as appointing an Albino to be a member of parliament, declaring in public that this murdering is nothing traditional but simply an appalling crime which has to be prosecuted. Calling in all regions publicly vote for the names of people who might be involved. Involving the police all over the country to hunt down the murderers of Albinos. Creating a special committees of judges to speed the hearings of Albino murderers, including top politician - condemning the killings in public meetings and events such as in the racing of the Uhuru torch, as ways of educating the society.

39. What does the police do to stop the harm and the killing?



The Police Force has taken stern measures to protect Albinos, to investigate matters related to crimes against Albinos, to arrest all those involved and prosecute them. The Police have also established a special task force to deal specifically with cases involving Albinos to speed up investigations and the finalization of their cases.

40. What should be done to those practicing FGM on Albinos and those performing the coming of age ceremonies for them under the open sun?

This question addresses two issues. First is on genital mutilation practices (FGM) on Albino women and girls. FGM is a criminal act punishable under the law; in addition, FGM goes against reproductive health rights for the affected individuals and has been a great cause of deaths and morbidity relating to reproductive health.

The second issue which is addressed here is exposing Albinos in the sun for a long period which can hurt their skin. It is also a kind of stigmatization because others stay inside and just come out on the graduation day for a few hours. This is for sure a misconception. Advice given here is, report such events to the community leaders so that they can take appropriate measures. It can be that such misconceptions are deeply embedded in the culture, therefore utilize people who can initiate change such as religious and opinion leaders in the community.

41. Are there effects for young male and female Albinos abstaining from sex until adult age, like acne, persistent headaches, shrinking penis and others?

The truth is that there are no known health effects for those delaying / abstaining from sex until adult age (or for a long time). The reproductive organs are also not affected in any way (they do not shrink or disappear).



There are myths claiming that people abstaining from sex for a long time may get acne and rashes on the face, or around the genitals and may even become confused mentally. There is absolutely no truth in such myths. Having facial acne is a typical problem of teenagers (from 13-19 years olds) attributed to the oils and fats on the skin. This condition usually improves as a person grows older. It often helps to do physical exercises which facilitates the opening of the skin pores.

There are no known health problems that may result from abstaining. On the contrary there are many health, emotional and physical problems which may arise from having sexual relationships at an early age for example:

unplanned pregnancies, sexually transmitted infections including HIV infection.

42. Why do some young Albinos engage in early sexual relationships?

There are many reasons for engaging in early sexual relationships, some of which include:

- Competition to have possessions, gadgets like mobile phones, watches and toys, or the need of money to pay for school fees.



- Pressure from peers may push young into engaging in sexual relationships. This is especially the case with young Albinos who easily feel marginalized and are tempted to share issues in common with their peers.

- Thinking that the real proof of a love relationship is sexual intercourse or feeling pressured to prove that it is “real love” even against the own will.

43. Some young Albinos deal with sexual urge through masturbation. Does this have any harmful effect?

Masturbation is a safe way for dealing with sexual urges, much safer than engaging into risky sexual acts. Masturbation is also very helpful if you do not actually have a sexual partner but feel distracted with a strong sexual urge. Scientifically there is no known harm from masturbation, neither for males nor females.



However, masturbation is not the only way to deal with sexual feelings. If you keep yourself busy and active, it is much easier to live without having sex than if you are hanging around idly.

44. I have an Albino girlfriend and we love each other very much, but why is she refusing to have sex with me?

Your girlfriend has the right to refuse to have sex. Perhaps she does not yet feel ready for it or perhaps she does not want to engage in sex before marriage. Her

decision may be based on fearing the consequences of early sex or she might have strong religious beliefs or she is not yet convinced that you can fully trust each other. If you really love her and value your relationship, give her the time needed, carefully listen to each other and then you will make the right decision. Whatever you decide, be careful in preventing unwanted consequences.

45. As a girl living with Albinism, I am afraid that a boyfriend only wants to try me out and dump me afterwards. How should I behave?

Sometimes being different creates curiosity and the rumours that Albinos are sexually somehow different nourishes this curiosity. Therefore, take your time. Like in any other friendship it is important to take time, to create mutual understanding, to carefully listen to each other and to understand each other. You can do many activities together and after a while you will find out how serious the interest in you as a person is. If you are sure that it is you as a whole person who is loved, then you can enter in a close relationship without fear of being dumped.

MY SWEET HEART
MY SWEET PIE
MY SWEET POTATO
YOU ARE NOT THE
OTHER GIRLS...
...YOU ARE UNIQUE!



46. Why do most Albinos not get married or involved in love relationships?

People who are perceived by others or themselves as being different (this may be due to race, religion, height and even Albinism) have difficulties in being fully integrated into society which makes it much harder for them to form relationships. So it is not correct to relate this experience only as relating to people living with Albinism.

Albinos may not have the confidence to form love relationships based on the experience of stigma and discrimination. They are often more worried than others of being refused by prospective love partners. Being loved first of all means being self confident and loving yourself.

It is a challenge to families with Albino children to build their self confidence and to educate them to believe that their difference is only on outside (skin and eyes), but they have all other abilities like other people.

As it is for all other people the more you develop yourself through education and training the easier it is to independently manage your life and to find a partner to live with.

47. Why is there a difference these days with men in the community being open to having love relationship with Albino women?

True love does not discriminate against religion, tribe or even race. It is usually based on the feelings of

attraction. In this case those men may be truly in love with the Albino women and are attracted to them. It is also important to be sure that the person telling you "I love you" is truly sincere and that they value the love that you are giving back to them. There is also a rumor within the community that being close to an Albino could also increase your fortune and help you to become rich.

48. Is there a test that can detect Albinism while the foetus is still in the uterus?

There is no simple test available to determine whether a person carries a gene for Albinism.

If parents have had a child with Albinism previously, there is a way to test in subsequent pregnancies to see if the foetus has Albinism. The test uses amniocentesis (placing a needle into the uterus to draw off fluid). Cells in the fluid are examined to see if they have an Albinism gene from each parent. However this test is costly and only available in industrialised countries or specialised expensive hospitals.

49. What are the effects of teenage pregnancy especially for an Albino?

Teenage Albinos are not different from other teenagers regarding effects of early pregnancy. It is strongly advised that girls should not become pregnant before 18 years of age. Before this age the female body



is not mature enough to go through a pregnancy without problems.

Young girls below 18 years of age have a higher likelihood of suffering complications during pregnancy and especially during delivery. The most common complication is that the baby does not come out and this usually requires an operation. The other complication is delivering an under weight child.

A very severe injury might happen, if the baby's head is too big for the birth canal: an injury called VF (vaginal fistula). In this case the tissue which separates the vagina from the urinary canal and the intestines is torn. This causes urine or faeces to be discharged uncontrollably through the vagina.

In addition to health problems, girls may have other problems relating to early pregnancy. These include being expelled from school, conflicts at home with parents and the community at large. It is important for young people to wait until they are fully grown up (above 18 years) and ready to take responsibility as parents.

50. How can one avoid pregnancy after having an unprotected sex, e.g. after rape or after having been forced?

If you have been abused against your will or forced to have sex you can get services to avoid pregnancy in hospitals, health facilities, dispensaries or from the community based providers.

There are pills which can be used to reduce your chances

of becoming pregnant, if you had sex without using contraception, you think your birth control failed, or you were forced to have sex. You can use them right away - and you have up to 120 hours (five days) after sex to take the pills and still prevent pregnancy. That means you don't have to wait until the morning after, and you can still use emergency contraception even if it takes you longer than the morning after to get it. But keep in mind that it is better to start using emergency contraception as soon as possible because it is more effective the sooner it is taken after sex.

Emergency contraceptive pills prevent pregnancy, so they are not inducing an abortion.

When you seek for this service do not forget to ask the service provider for Post Exposure Prophylaxis (PEP) to avoid HIV infection. You can get more information from government health facilities, UMATI and Marie Stopes Clinics and any other place providing modern family planning methods.

51. Is it true that disability can be observed in a child immediately after birth?

It is true that doctors can perform tests on women to determine whether a baby will be born with a disability or not. Some of the tests use ultrasound to visualize the baby in the womb. Other tests analyze the blood.

However, Albinism cannot be seen using these methods. After birth it is also possible for doctors to determine, if the child may have certain disabilities like heart problems, or blood problems like sickle cell disease.

Albinism may be observed after birth or in the weeks that follow.

52. Can parents who are both Albinos have a baby who is not an Albino?

Normally two Albinos will get a child that also has Albinism. Therefore, an Albino couple should carefully consider, if they would like to have a child together - having experienced themselves the problems of living with Albinism in a black society.

Albinism is a genetic condition and it requires the baby to carry Albino genes from both parents to demonstrate Albinism. However, there is not only one type of Albinism and not only one Albino gene. If parents of different types of Albinism and with different defects in their genes have a child, this child could be without Albinism. However, this is extremely rare. Only a few cases have been reported worldwide.

53. Can I get pregnant as an Albino by having sex only once?

Yes, a girl can get pregnant by having sex only once. This is by no means depending on the color of the skin. Black or white, people living with Albinism or people without Albinism are the same regarding the risk of pregnancy. What determines if she will get pregnant is the timing of the act as it relates to the menstrual cycle. If there is a mature ovum ready for fertilization then pregnancy

will occur after the man has ejaculated. This can happen even if the girl is still a virgin and this is the first time she is having sex.

54. Is there any strategy aimed at enabling Albinos to read the writings on a condom packet (example expiry date)?

Most people living with Albinism can read well, if the letters are big enough and bold, although in some cases they may also need to use glasses or magnifying lenses.



It is true that the writings on a condom packet may be small, but this should not be an excuse for people living with Albinism not to use condoms. You can request assistance from a close friend to read the packet for you.

When stored well condoms can keep for over five years from the date of manufacturing. To remain in good condition they need to be kept in a dry place away from moisture and direct sunlight.

55. Do sexual and reproductive rights apply for Albinos as well?

Basic rights - particularly the right of being valued and respected as a human being - are valid for all right from birth. The nations of the world have ratified the international agreements stating these rights and they are reflected in the laws of the country.

The most important sexual and reproductive rights are:

- The right to get information on sexual and reproductive health
- The right to have consensual sex, and the right to choose a sexual partner
- The right to decide on the number and spacing of children
- The right to access reproductive services
- The right to choose and decide on marriage
- Protection from harmful cultural practices like female genital mutilation (FGM)

All people including those with disabilities are protected by human rights. The challenge for people living with Albinism is to be vocal and advocate for their rights.

56. Can people living with Albinism have children without any problems?

The disability of people living with Albinisms does not interfere with the ability to have children. The disability is on the skin and not in the reproductive system, so Albinos can have healthy children. They may have children with normal skin appearance, if the other parent does not carry the Albino gene.

57. How many children can people with disability like Albinos have?

There is nothing special about Albinos that is different from the rest of the population when it comes to the number of children that they are able to have. They can have as many children as they plan to have; this is true for both male and female Albinos. The important consideration here is to plan to have children that you are able to provide for with all the basic needs.

58. Do people with disabilities get access to assisted deliveries particular caesarian operation during delivery?

Caesarian operations are offered to all women who are identified as needing it whatever their disability status. Every eligible woman will get the service if it is available. The problem in remote areas of Tanzania is that these operation services are far away and a woman in labour is not able to reach them in time.

59. What are some of the effects of drinking alcohol on young people especially Albino?

The effects of alcohol are the same for people living with Albinism and anybody else.

When under influence of alcohol one may become negligent in making the right decisions, for example risking ones life by riding a bicycle in zig zag lines, having risky sex without putting on a condom etc. In addition, people with an alcohol problem usually do not keep themselves healthy and this makes them more prone to getting other illnesses.

Alcohol may also interfere with the sexual life. At first you may feel exited and less inhibited, but later you become drowsier and some men have difficulties in getting an erection. You might be tempted to overcome your shyness by drinking but this rarely makes you attractive to others.

Excessive drinking over a long time affects some key organs like the liver and kidneys. This may lead to the failing of these organs and to death.

Drinking also causes irreversible destruction of brain cells which cause people to have memory problems.



Alcohol is considered to be an addictive substance. When the body has developed a dependency for alcohol, people may spend all their money on drinking and thus they fail to successfully manage their lives.

60. What are the effects of smoking cigarettes among young people especially Albinos?

There are many negative effects of smoking. The effects are primarily on the smoker by inhaling the smoke into the lungs which results in effects on many other parts of the body.

If you stay close to someone smoking, you could also be affected as you inhale the smoke (this is called passive smoking). Smoking makes your body absorb a toxic substance called nicotine which is mainly responsible for smoking related complications.

Cigarette smoking is responsible for a number of diseases; the first organ to be affected is usually the lungs. Smoking causes chronic coughs, pneumonias, eruption of tuberculosis (Tb) and eventually cancer of the lungs. Smoking also affects the skin. It makes the skin thinner and weakens the blood vessels at the top layers of your skin. In consequence this makes it more difficult for the skin to regenerate. As people living with Albinism already have a more fragile skin they should abstain or quit smoking.

Remember

Is Albinism contagious?	NO
Is it an illness?	NO
Is it a traditional curse?	NO
Are Albinos abnormal?	NO
Is Albinism only a black people's condition?	NO
Do people with Albinism have red eyes?	NO
Are people with Albinism superstitious?	NO
Do Albinos have supernatural power?	NO
Are people living with Albinism stupid?	NO
Is it the mother's fault to give birth to an Albino child?	NO
Should society change its negative attitudes towards Albinism?	YES!

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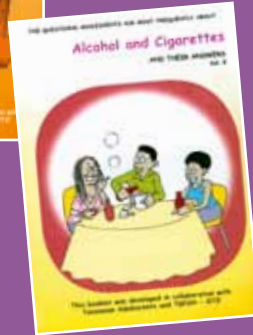
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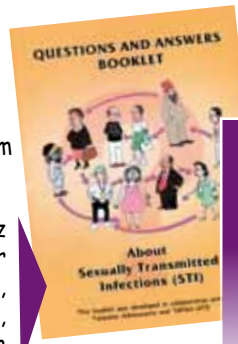
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