

Frequently Asked Questions By Martin Lang

Albinism Fellowship (<http://www.albinism.org.uk>)

Frequently asked questions are just that. The Fellowship has publications explaining about albinism and there are detailed references for people to read to find out all they want to know. The Frequently Asked Questions and answers here are intentionally not repeating what others have already done so well. Instead, these questions attempt an approach from a different perspective. The questions listed here are questions that have been asked of our family and people with albinism in general. I have tried to give simple, straightforward replies that could be given for others to use and adapt. Of course, everyone will answer questions differently because everyone is an individual. I have written most of these answers as a parent of child with albinism. These are the sorts of Frequently Asked Questions that we have been asked and this is how we have answered them.

If you have a 'Frequently Asked Question', whether or not you are able to answer it at the moment, why not send it to the fellowship. It is likely that you may have a very different answer on some of the questions and the answer you give may be very different. If so, why not share your experience with us and pass on the benefit of your experience.

I have divided The Frequently Asked Questions into three groups. First, those concerned directly with the condition of albinism. I have purposely kept the language simple and straightforward. If you want definitions and detailed descriptions then go to the articles page or visit some of the sites on our links page.

The second group are social and emotional questions and the third, a catch-all of responses to odd questions and comments that don't really fit into either of the first two groups.

- Questions about Albinism
 - Can't she see properly?
 - What can she see?
 - Will her eyesight stay the same?
 - What colour are her eyes?
 - Why is she wearing sunglasses indoors?
 - What is Albinism exactly?
 - Why do her eyes wobble?
 - Why is her head wobbling?
 - Isn't there an operation she can have?
 - How does the Nystagmus affect her eyesight?
 - Why is she always wearing a hat or a cap, even in winter?
 - Can she read books?
 - Does the light hurt her eyes?
 - Why does she sit so close to the TV?
 - How do you stop her burning, getting sunburnt?
 - Don't you go on summer holidays?
 - Don't you go out in the sun?
 - What is melanin?
 - Which is the best sun cream?
 - Why is her hair blonde and where did it come from?
 - Will her hair always stay that colour?
 - Could she dye her hair?
 - Does she go to a special school?
 - Do you get lots of help?

- Does she have lots of friends?
 - Does she have to go for lots of tests?
 - How did you find out she had albinism?
 - Does she have any special things to help her?
 - Can she ride a bike?
- Social and Emotional Questions
 - Is it hard for you as parents?
 - What benefits can I apply for?
 - What was it like when you found out that she had Albinism?
 - Does it bother her that she can't see very well?
 - What should I do if my child gets called names?
 - What do you do when people make comments that aren't meant to be hurtful?
 - Other Questions
 - Is that a wig?
 - Should I register my child as 'partially sighted'?
 - Are there any things that she cannot do?
-

Questions about the albinism

Can't she see properly?

No, she can't see clearly things that are far away or some distance away. That doesn't mean she can't see them at all, it may be that she can see an object, but not very clearly. Good contrast helps her to understand what she sees. From a distance she may see you, but she might not recognize you until you are close up or speak.

What can she see?

She sees in a similar way to normally sighted people, apart from the fact that things that you see in focus are blurred or out of focus for her. If you see a person at the opposite end of a football pitch from where you are, you probably can't see their face clearly. However, you might know who it is because of their clothing or because they shout to you or because you expect them to be there. If that person is stood in white clothing against a dark background it is easier to see them. Clear contrast helps. If the sun is in your face the glare makes it more difficult for everyone.

Will her eyesight stay the same?

Yes, it is unlikely to get any better, but like everybody's eyesight it may get worse as you get older. Many children will quickly learn how to make the best use of the sight that they do have and compensate by developing all sorts of different strategies. When she was in nursery she knew if I had walked in the room by the jangling of my keys, before I had even spoke.

What colour are her eyes?

They are just pale, sort of grey and lack colour. They aren't pink or red, except on flash photos.

Why is she wearing sunglasses indoors?

The sunglasses reduce glare from bright lights making it more comfortable for her. Not all people with albinism wear dark glasses. You have to find what best suits the individual.

What is Albinism exactly?

It is a condition that you're born with, that you inherit from your parents, where for a variety of reasons your body has no or very little melanin. This is important because it affects the way in which your eyes develop before you are born and your ability to see clearly objects close up and at a distance.

Why do her eyes wobble?

It is a condition called Nystagmus. People with albinism will have some degree of nystagmus.

Why is her head wobbling?

Her head wobbles just very slightly sometimes to counteract the nystagmus, something she does automatically to help improve her vision.

Isn't there an operation she can have?

No and experts have advised us that is very unlikely that an operation could be done in the foreseeable future because of the nature of her condition. Some people may have an operation to correct a squint but this does not generally improve their eyesight (significantly?)

How does the Nystagmus affect her eyesight?

People who have albinism tell me that it stops them being able to focus clearly on things in detail e.g. sometimes it is hard to read phone numbers as all the figures blend into each other. Reading vertical lines on a graph is difficult, they either turn the paper around or tilt their head to one side. This is the same as reading the spine of a book on a shelf, you have to turn your head to a ninety-degree angle to read what is written. If you are tired or stressed the Nystagmus may get be worse, making you a little clumsy and unable to judge the distance of things away from you.

Why is she always wearing a hat or a cap, even in winter?

The cap reduces glare and it is more comfortable for her, particularly if the sun is low down in the sky. In summer, it shades her head.

Can she read books?

Yes and often these are large print books or she uses a magnifier to read them.

Does the light hurt her eyes?

Imagine coming out of a cinema in the middle of a bright afternoon. Until your eyes adjust to the bright light it is uncomfortable. People who have albinism have told me that if the sun is piercingly bright, it can be very painful. They can't see anything when this happens

and if they are walking down a busy street, it can be very scary when you have no clue where you are going. They have described bright sunlight as like the reflection from glass or a mirror from the sun.

Why does she sit so close to the TV?

To get a better view, if she were to sit further away, the screen wouldn't be in clear focus for her.

How do you stop her burning, getting sunburnt?

We use a high-factor sun cream, hats, long sleeves, long dresses and staying out of the sun in the hottest part of the day.

Don't you go on summer holidays?

Yes we do, we just have to be a little more careful than most other families.

Don't you go out in the sun?

Yes we do, but we take precautions to protect her skin.

What is melanin?

It is the substance that the body makes and gives colour to hair, skin and eyes.

Which is the best sun cream?

Different people like different sun creams. The best thing to do is to try them out for yourself. Look for a 30 SPF (Sun Protection Factor) as a minimum.

Why is her hair blonde and where did it come from?

It is white because it has no pigment, melanin gives most people colour in their eyes, skin and hair.

Will her hair always stay that colour?

Yes! But she won't have to dye her roots!

Could she dye her hair?

Yes, the results may be a little unpredictable and temporary dyes may not washout. Her hair does tend to take on a colour /dye very easily, when face paint or poster paint comes into contact with it, the colour is there for a while!

Does she go to a special school?

No, she goes to a regular mainstream school, but she does get extra help where she needs it in the school. Some people with albinism may go to a school that has a special VI (Visually Impaired) Unit. Others may go to a special school. This varies.

Do you get lots of help?

Yes, it's just a case of knowing who to ask and how they can best help you. There are lots of people and organizations that are willing and able to help. It is just a case of knowing how to contact them and how they can help you.

Does she have lots of friends?

Yes just like every one else.

Does she have go for lots of tests?

In the first five years or so there were lots of tests by lots of different professionals. Now that she is older there are less tests and examinations. Now it is just regular eye tests and examinations.

How did you find out she had albinism?

An eye specialist confirmed the diagnosis that other professionals had suspected.

Does she have any special things to help her?

A monocular, magnifiers, a large print Dictionary a laptop for class, are examples.

Can she ride a bike?

Yes, she of course has the balance to ride a bike. I ride right next to her to give a commentary of all possible dangers. As for adults and older children, it really depends upon the individual and where you cycle. A few are more courageous than others and cycle on roads, some people with albinism prefer not to cycle.

Social and emotional

Is it hard for you as parents?

Initially, in the beginning it was very hard because we did not know what we were dealing with and there were lots of 'unknowns'. As parents, it is the not knowing what to do, in the early stages, that is the most difficult time. After 10 years it becomes second nature and giving a commentary of hazards on a walk with her or juggling for a position to view the TV around her are just what we do as a family.

What benefits can I apply for?

Most people with albinism can apply for Disability Living Allowance. There are several components to this and it is awarded at several levels. The form filling takes a while and it can be difficult to understand. A good idea is to keep a diary every day for a while and note all the things that you do over and above that which you would do normally, for a child of their age.

What was it like when you found out that she had Albinism?

For us it was easier. When we had the condition diagnosed we learned how to take practical steps to as to how best to help her. Meeting others overcoming the same issues was a great help as parents. Meeting adults we albinism was very reassuring.

Does it bother her that she can't see very well?

She doesn't know any different.

What should I do if my child gets called names?

If it is in school, contact the school and tell them, discretely if necessary, what has happened. All schools should have procedures to deal with such incidents and hopefully it can be nipped in the bud. Give your child answers that they feel confident in giving when they are asked questions by their peers. Gently prepare them and talk to them about how they might deal with situations that might occur. Attempt to teach them to have confidence. Be open with people and answer other people's questions if they ask about her condition.

What do you do when people make comments that aren't meant to be hurtful?

On the spur of the moment it is often difficult to know what to say in reply. We often get the comment "cool shades" from shop assistants because of her dark glasses. My daughter's favourite reply to this is "yea, I'm just back from Hollywood" with a sneaky grin. Obviously, I'm not suggesting you use this line, but just that you have something ready.

On another occasion as a 4 year old she was running around playing a game of chase with some other children. A lady commented rather loudly about her white hair. Not pausing from her game she informed this lady "that's because I don't have any melanin", as she dashed passed. This lady's face was a picture and it was her who was lost for words.

Other Questions

Is that a wig?

She has been asked this on several occasions! A smile and a gentle tug of her locks is the way we have dealt with the situation. It would be easily to regard this as rude and react angrily, but we see the funny side.

Should I register my child as 'partially sighted'?

There is some reluctance on the part on some parents and people with albinism to register as partially sighted. Some people prefer not to be labelled or pigeon holed. However, there are advantages in that it defines her sight to a particular level so that others, perhaps in authority, have to take note. Concessions are available to some places if you are registered as partially sighted. Once registered, it is up to you whether or not you choose to disclose the information to anyone else.

Are there any things that she cannot do?

Legally drive a car in Great Britain on the road is the only barrier we have found so far, and she isn't old enough to do that anyway! People with albinism can go to hot sunny countries and even go skiing. Most things she has a go at. We were advised that the Cello would be too difficult because the music would be too far away! The 'can't do' list is small, squash, tennis, badminton, driving legally, unless you know different....