

Airing Pain Programme 71: Protect Our Girls

Persistent pain and the fight to end female genital mutilation.

Over 100,000 women in the UK have been affected by female genital mutilation (FGM) with devastating long-term consequences including persistent pain. Janet Graves hears from FGM survivors and the healthcare professionals treating them about this culturally-embedded practice and how to uproot it.

Hana Gibremedhen and Valentine Nkoyo speak about the impact being cut as children has had on their psychological and physical health as well as their relationships. Nkoyo also explains how her Mojato Foundation is working to mobilise opposition to FGM from within the communities affected.

Gilbremedhen's experience of undiagnosed chronic pain after FGM highlights the lack of knowledge among healthcare professionals. Clinics with experience in seeing women with FGM are vital, says Specialist Midwife Juliet Albert, if they are to get the care they need. Midwife, 'fighter' against FGM and founder of the Hope Clinic Aïssa Eden shares her story and stresses the importance of education in ensuring the safety of the next generation.

Valentine Nkoyo: When the entire clitoris and the labia minora and labia majora are cut off and everything is sealed together and a very tiny hole is left, you know, like the head of a matchstick. And that's only to allow urine or the menstrual period to go through. Can you imagine a woman having sex with a man in that tiny hole?

This is **Airing Pain**, the programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain and for healthcare professionals.

I'm Paul Evans and this edition is supported by a grant from Rosa, the UK Fund for Woman and Girls.

Nkoyo: On the day of their wedding, that is when the man is supposed to open up, they have to force themselves through that tiny hole – you can imagine – and sometimes if they can't do it, they have to be cut up and the man has to sleep with her on the day of the

wedding. That is *torture*. Childbirth, *how* can a child come out of there? These are the terrible consequences women are having to live with.

Paul Evans: Female genital mutilation FGM refers to all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs for non-medical reasons. In the UK it is estimated that over 100,000 women are living with the consequences of FGM and sixty thousand girls are at risk.

For this edition of *Airing Pain* Janet Graves talks to survivors, clinicians and those working to eradicate this culturally embedded practice.

Juliet Albert: My name is Juliet Albert. I'm a specialist FGM midwife. I work at Queen Charlotte Hospital, which is part of Imperial College Healthcare NHS Trust and I'm also project lead for the Acton African Well Woman Clinic.

There are four different types of FGM. Overall, FGM is defined as any procedure that is harmful and has absolutely no health benefits, so a procedure that's done to the female genitals. There are four different types of FGM: type 1 is where the hood of the clitoris or the clitoris itself is has been removed or cut; type 2 is where the clitoris and clitoral hood and part of the labia and the anterior part has been removed; type 3 is where the clitoris and clitoral hood, sometimes, and most of the labia has been removed and then the area is stitched up to form an anterior scar, leaving a *very, very* small opening with which to pass urine and menstrual blood; and type 4 is any other procedure, so that includes any pricking, piercing, stretching of the labia, basically, anything else that's done to the female genitals.

Valentine Nkoyo: My name is Valentine Nkoyo and I'm originally from Kenya, from a community called the Maasai. I was 11 years old when one morning my mother called me into the kitchen, she had just finished milking the cows and she said 'there's something that I want to speak to you about'. And she said to me, 'it's time for you to become a woman'. And I didn't know what that meant. And then I asked her 'what do you mean, I need to become a woman?' She said 'it's time for you to be cut. You and your sister are big girls enough now'.

So that evening there was a *big* celebration, a lot of food and alcohol and the men and women were singing and my sister and I and two other girls in my village were going to be cut at the same time. And in the evening, my sister and I were taken away and we were shaven because we needed to be clean and we were given new clothes that we were going to wear during the entire process. We were given presents that evening by the elderly ladies, by our aunties and then we were to be given presents in the morning after FGM by our uncles.

And then in the morning around six o'clock we took off our clothes and we were given tiny blankets, we call them *lessos* and they were wrapped around us. And we were so cold, *really, really* cold. My sister and I and the two other girls from the village, were taken to the bushes where they were going to carry out the operation and they had like a big piece of cloth that they laid out on the ground and then there was hide on top.

So my sister was on the left and the other two girls from the village were on my right and two women grabbed my legs and opened them, and there were other women who pinned me down from the back, so I couldn't move. I couldn't move my hands and I couldn't move my legs and it was the tightest... I've never felt so spread out like that.

I remember looking up and I saw the cutter and – my God – I can remember *everything* that she wore. I can remember the jewellery she wore, the colour of her clothes... her face has never left me. Every time I talk about it, it's still there. It's not something that will go away, because this is someone who is going to punish me for a lifetime, someone who is going to take a piece of me away. And I remember, I closed my eyes because I didn't want to see her until the operation was done.

So, I closed my eyes. And when I closed my eyes I could feel my sister moving but she couldn't make any noises and the women were saying 'Don't be a coward! Don't be a coward!' And I can't remember the amount of time it took but I could feel her struggling with them but she couldn't cry. And then that stopped and I opened my eyes and then saw the woman again and then I closed them again, I didn't want to see her again. Then I felt a very sharp pinch on my clitoris and immediately I started feeling the razor. She actually used the same razor she used on my sister. And I started feeling each and every cut she was making. I felt it.

[Tearful] And the women behind me were saying 'You are a brave girl. Keep strong, keep still and this will soon end.' But it felt like a lifetime. And the anger was... I didn't understand why I had to go through FGM. It's such a painful thing – you can't even explain the pain.

And I remember, they were saying 'Don't cry!' But I was crying from the inside, but I didn't want to shame my family because once you scream or cry, that would be a mark forever. And even for the man that will marry you, they will know that you cried when you were being cut. It's such a psychological thing that you can't live with, so you just cry from the inside.

To make things worse, after she finished cutting me, she took salty water and poured on the raw... the raw wound. And that was hell. I can't even explain how it felt, it was so bad. Imagine if you had a tiny cut and someone put some salt on that, absolutely horrendous. It's

the same pain. And if I imagine another child is about to go through that, it makes me really upset, it makes me really angry.

So they cut the other girls. I was so weak, they helped me to stand up and then we went and stood outside the room we were supposed to heal from. Our uncles were supposed to give us presents, so we were offered cows, sheep and, you know, money. And I remember looking down [sobs] and I was standing in a pool of blood of my own blood, I could see it flowing. [Sobs] I couldn't understand why I had to go through that pain, yet there were people there still saying it was a good thing. But it wasn't and the pain was absolutely... it's not something you can explain.

To me the presents didn't count, because immediately I was cut I knew something about my life was taken away. So after we were given the presents, we were taken back to the room and I passed out. I remember when I regained consciousness they were pouring coke down my throat. They couldn't take me to hospital because that would have been bad and they would have been caught for cutting me. But I was so weak for the whole three weeks we were supposed to heal.

I kept getting flashbacks and just seeing these people who were running after me, maybe to cut my throat or to take something away; and then I would try running away and when they were about to cut me I would wake up. Then the pain is when you wake up quickly because you still have the wound and then it would just make it even worse.

We had to be looked after for three weeks and every day they would use the salty water and Dettol, the disinfectant, and the smell of the disinfectant, I hate it. Even if the doctors recommended it [very distressed] I can't take it because it brings back the memories. I think for me the psychological impact has continued. It's not something that anybody should go through.

Albert: There are unfortunately multiple long term pain problems as a result of FGM. We see women in our clinic with long term pain, complex perineal pain as a result of FGM, for example, pain passing urine, pain during sexual intercourse, sometimes just constant continuous pain. We also see women who are having pain, again during sexual intercourse, because, for example, if they have a very severe type 3. Some of the women, their pain is from having had children, which is a consequence of having children and their FGM. So it does vary considerably. And then a lot of women have a lot of emotional pain. So we see women, for example, who may have had the less severe type 1 perhaps, but they will have all the memories of being held down, bleeding, the pain, no anaesthetic being used. And, as a consequence, their psychological pain is very extreme, very severe.

Hana Gibremedhen: My name is Hana. I'm coming from East Africa, Ethiopia, but originally from Eritrea. I was probably about nine years old when I had FGM. And it was early morning that I was told to go in the room, an empty room and then the lady – not a proper midwife but [a] traditional [practitioner] – she told me to sit there. And the other two people, they were holding my legs and then after that it was *really* painful.

Normally they do it in early age, [when you are] a little girl after you are born – 18 weeks or something, that's when they normally do it. But for some reason mine was late, when I was nine years, so I should have it. In our country they believe having FGM is like protecting the woman – not to go with different men, protect you, to make you calm, but they don't realise that after you have the FGM what are the consequences – it is very painful.

After they did it, it's more painful because they treat you with traditional things, because you're not going to hospital or you not being treated with proper things. They just use herbal [remedies] and then they put it every morning on your private area. It really burns, it's really painful. I can't forget it.

Albert: A woman with type one, who's had perhaps a less physically limiting type of FGM, might have very severe psychological consequences, which may not even arise until she is pregnant. So there are women we have met who have buried their FGM and haven't thought about it, haven't spoken about it and suddenly, during pregnancy and childbirth, they suddenly have flashbacks and the whole thing comes back to them, because you can imagine obviously during a vaginal examination, it suddenly reminds of the place where they were as a child when their FGM was carried out.

So, it doesn't necessarily matter what type they had, it may be that childbirth has a lot of severe emotional consequences. And then of course we have the women that have the more severe physical types, like type 3 in particular, where they may have even struggled to get pregnant, because if they have a very small opening – if it's about half a centimetre diameter – sexual penetration is incredibly painful if not impossible. We do have three or four women every year who come to our clinic who are pregnant, despite having a very tiny opening like that. And I always say, 'don't be naive and think it's not possible because it can be possible'.

Gibremedhen: Since I am pregnant, I had pain most of the time. And most of the delivery time, it was a nightmare for me. It was four nights and four days for delivery, because the

doctor who assessed me said I'm going to have to stitch because of my FGM. It's not easy to open properly and then to have a normal delivery.

Albert: For those women with very severe type3, they need to be opened, preferably in ante-natal – before going into labour – because actually doing a vaginal examination is very painful, also very difficult for the person trying to do it. Putting in a urinary catheter is extremely difficult and if the woman arrives in labour, for example, very late on perhaps when she's already in the second stage, she's already pushing, then it may be an emergency procedure to open her by somebody who perhaps has never even seen a woman with FGM before and perhaps doesn't know what they're doing. It may mean the woman will end up with a caesarean section because the birth attendant doesn't really know the best way to deal with it.

Then after the birth there's also lots of problems, with very severe tearing because they have a lot of scar tissue in the area. They're much more likely to have post-partum haemorrhage, extra bleeding and then as a consequence, obviously, lots of physical pain.

Gibremedhen: The nurse, they don't have any knowledge of FGM. And after I had my baby, after a month... I got really four months of pain and when I went to hospital and said to them 'I've still got pain. When I stand I feel that something is pushing me down.' It was like I was shaking in my body. And when I went to my GP all the time, they said all the stitches are dry and you don't have any problems, but they're not realising inside what's going on.

Albert: Sometimes when women go into hospitals, I think – or perhaps even to a GP – and they're going to be examined, for the first time genitally, it may be the person has never seen FGM before. You hear stories from women and there is also research, actually – Forward did a piece of research called 'The Peer report', where women described healthcare professionals' shock at seeing them, their FGM and bringing other healthcare professionals in to have a look. Sometimes even exclaiming loudly how shocked they were and *really desperately* upsetting the women themselves.

So I think it's terribly important to have FGM specialists that woman can be referred too. So that, for example, if a woman does go for a smear test, if that practice nurse or GP hasn't seen FGM before and has noticed that it doesn't look the same as it normally looks – I don't like to use the word 'normal' because I know it can upset women – that they would then refer them to a FGM specialist. And in London, there are several specialist FGM clinics, but most are hospital based or linked to maternity services and clinics, so it's quite unusual to find a community clinic like ours, which is open to non-pregnant women as well.

There is a clinic in Bristol which opened last year which is GP-led, which is based on our model in Acton, but there aren't many services similar to this. And, although London has got other clinics, as I said, where women can access... there is a very well-known FGM clinic in Birmingham, one in Oxford... So there are centres of excellence, but there are also places where there is literally nothing really for women. There may be community groups or third sector organisations, but they don't have access to specialist NHS services. And this is a problem for a woman who lives in Newcastle to see me in London is obviously very, very difficult.

We had a lady come from Northern Ireland a couple of months ago. She said she left home at four o'clock in the morning to fly over to London to come to our clinic because she didn't know where to go and she had had three children by caesarean section. Two of them were born in Newcastle and one in Northern Ireland and she said not once during her caesarean sections did anybody mention her FGM. Now that's at least three people who have placed a urinary catheter and not mentioned she had a severe type 3 FGM. So there are definitely problems with healthcare professionals not knowing how to help women with FGM.

Aïssa Eden: My name is Aïssa Eden. I am a midwife but I'm also a specialist midwife on FGM matters and I'm also what we call 'a survivor of FGM', but I would like to call myself 'a fighter'.

If you look at the background of the practice of FGM, it's done by family members, grandmother or mother – someone you trust, who will take you to a place, where you will have the most horrible pain in your life, the most horrible situation in your life. So, trust issues can be one of the psychological impacts of FGM.

I was done when I was six years old and I was with my little sister, she was only one year old. And I did carry the guilt because, for me, my sister shouldn't have had that done. It was performed on both of us because I was in the process of going away to France. So it was not planned for her at this time – they just did that because I was the one that was going. They just thought, 'oh, let's do both of them together'. So I did have the guilt for a long time for my sister because I thought it was my fault.

I developed a clinic – I called the Hope Clinic – to offer holistic care to the women and their family. We work with the ladies and we've a project, we've a plan for *this* lady in particular, like very individual care. But it's also education and prevention because when you have to go for the care, I think it's too late. So education and prevention is more important. We don't want anybody to go through FGM.

Albert: For women who have had type 3 FGM – the most severe type – there is a procedure called de-infibulation or ‘opening’ really. We actually cut open the anterior scar, so that we reveal the vaginal opening and the urine hole underneath the scar tissue. And then we stitch the edges of that opening to stop that fusing back together. Sometimes historically, this was called ‘a reversal’ but we try not to use that term because you can’t put back what has been taken away. So for the women with type 3, there is actually a physical procedure that can sometimes be done. Sometimes it’s not possible to do it, so for women where it’s more complicated, for example, where they have a cyst as well as their type 3, or sometimes where the scar tissue has fused with the urinary meatus [opening], it makes it very difficult to de-infibulate. So for some women we can’t, but this opening de-infibulation procedure is actually quite a minor procedure and can be done under local anaesthetic in an outpatient setting.

We had a woman recently who’d been closed for nearly 40 years and she was actually exclaiming loudly with delight that she was finally open [laughs]. Other women who’ve had several children, who’ve been what we call ‘re-infibulated’, or closed, between children and then, again, who’ve come to see us because they want opening.

For those women who have had other types of FGM, there isn’t actually a physical procedure we can do. Really, they need a lot of counselling and psychological support. We had a woman recently – a young woman – who came to see us, who wanted to know what type she had. When I had a look, I explained to her that she had had type 1 and I explained that we couldn’t put anything back that had been taken away – she had had some of her clitoral hood removed and her clitoris removed. And she was terribly, terribly upset. She said ‘I want you to make me normal again like everyone else, I want you to put back what they took away.’ And she was really distraught as she was wanting something we couldn’t provide for her.

Nkoyo: I made a commitment that I would not dare to sit and watch any of my nieces go through what I went through. So I started talking to different family members and, only last year, my mother, sisters and brother made a commitment. And it took a lot of time of me, picking up the phone and just excusing myself and saying ‘I’m going to talk about something we normally don’t talk comfortably about’. And I had – this was actually my brother – because I said I wanted to him to know what was done to me and what I’m living with. And I said ‘I want you to tell me if you want your daughter to go through that.’ And when I explained everything, he said ‘I will never let that happen. And if I know of anyone who is willing to do that, I will take a step forward.’

So for me, I've managed to deal with the psychological part of that by helping others. So the Mojatu Foundation is a not-for-profit organisation. We are based in Nottingham and we mainly work with African and Caribbean communities. We produce six issues of our community magazine called *Mojatu* and we use it to raise awareness of issues affecting African and Caribbean communities.

The most important thing is to actually help people understand where the help and support is. So what I've been doing personally is going round and talking to survivors and encourage the women that have gone through FGM to seek medical support. And that will not only help their health condition but it will also help with data collection, to understand the magnitude of the problem locally and also nationally, so that this can be managed in a much better way. But we need to have coordinated efforts from the police, from the city council, from the communities and also engage the survivors.

And now we have a Nottingham FGM steering group. And I'm part of the board as a community representative. And I think this is so powerful, bringing all these people together and have everybody's voice. And, for me, what I've been trying to do is to inspire the survivors to know that it's actually ok to talk about what happened to them and it's ok to share with other people, because that's the only way people can connect with what happened and also take steps forward to support girls. And, for the vast majority of the staff I've been working with, they say it's been very empowering for them to feel they are part of this decision making process on how FGM can be tackled. And for me, I strongly believe that they are a powerful force in helping themselves to deal with the pain of what happened and all the consequences and to protect our girls.

Evans: That was FGM survivor, Valentine Nkoyo. For more information on the Mojatu Foundation go to her website valentinenkoyo.com. And 'Nkoyo' is spelt 'N' 'K' 'O' 'Y' 'O'. Other organisations mentioned are The Hope Clinic and their website is fgmhopeclinic.co.uk and there's a comprehensive list of FGM clinics and resources at forwarduk.org.uk. All these links are on Pain Concern's website from where you can download this and every edition of ***Airing Pain*** as well as transcripts and further information on FGM and other pain-related topics. You can read about FGM in this month's edition 62 of ***Pain Matters*** magazine and, as I say, all these details are available on Pain Concern's website painconcern.org.uk.

And I'll just remind you that whilst we at Pain Concern believe that the information and opinions on ***Airing Pain*** are accurate and sound, based on the best judgements available, you should always consult *your* healthcare professional on *any* matter relating to your health and wellbeing. He or she is only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

Albert: I feel very positive, actually, that a lot of the women we see in our clinics and particularly the women who have gone through years of pain themselves, have absolutely no intention of doing their daughters themselves and, in fact, feel very strongly about not doing their daughters and other family members. I think that women are being educated about the health complications of FGM and really now understand the link between the two.

I think, historically, you can imagine if a woman wasn't educated about her anatomy, didn't know anything about biology and everybody else is the same as her, they wouldn't even make the connection between the FGM and the physical pain she is having. And I think now that women who are being educated in this country and are seeing their children going through the education system... I think it also to do with equality and higher expectations are really against the practice and men as well – we really do see families that understand that FGM is a bad thing.

Now, of course, I mustn't be naïve because I'm sure there are small pockets where there are people who still want to go ahead with the practice. And my concern is that sometimes they may practice a less severe type of FGM, because they believe this is a cultural tradition that we need to continue and if we do a less severe type, that's ok. So we do also spend a lot of time explaining to the women that even the least severe type, will have a really bad psychological impact and that they understand that's a human rights violation as well.

Nkoyo: I am very hopeful that we can actually end FGM in a generation. I was the last girl in my family and I made it a priority that I will not stand and see anybody in my family go through it, so four of my nieces were saved last year from going through FGM. A lot of work is still needed and I know there are fantastic people out there, someone like Lynn Featherstone [former Liberal Democrat MP] has been very supportive of the campaign and doctors... there is Dr Comfort Momoh, there is Forward, there is Mojatu Foundation... all the work we're doing to raise awareness... It's not going to happen tomorrow, it's a gradual process, but we will be able to tackle FGM and it's everybody's business to look after our girls.

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