everywomanChangemakers PODCAST: Why are women 'unreliable witnesses' to their own bodies?' meet the author challenging history's healthcare gender bias

READ THE TRANSCRIPT

Anna (everywoman) (00:06):

Progress, it's in the actions we take right now and in daring to think differently. Each one of us can do something to change things for the better, right where we are now, and 1,000 small things done with intent adds up to real change. For some people, that initial spark becomes a fire. Welcome to the everywoman:Changemakers podcast. I'm Anna, your host, and every month I'll be talking to inspiring leaders and activists who are changing outlooks, challenging perceptions and making a difference in the worlds of inclusion, business, the environment, sport, travel and more. We'll be discussing their work, motivations and vision, and most importantly how a revolution of one can lead to a positive, powerful change for the many.

Anna (everywoman) (00:52):

Today, we're talking to Elinor Cleghorn, author of Unwell Women, out this month, a fascinating journey through the misunderstandings, mystification and misdiagnosis of women's bodies, from antiquity to the modern day. In it, she discusses who gets to own and express women's health and their experience of it, and lays bare the historical male biases upon which modern medicine is founded.

Anna (everywoman) (01:12):

So welcome, Elinor.

Elinor Cleghorn (01:13):

Hi Anna, thanks so much for having me.

Anna (everywoman) (01:15):

Let's start with the premise that a body is not just a body, is it? Not if the only body that we're really looking at is a male one, in order to answer questions of a female one. So let's start by asking, how did men corner the market, if you like, in women's health and bodies? And, manage to consolidate themselves as the experts, in terms of women's health?

Elinor Cleghorn (01:37):

I think that this has a really long history, and it's really the history of who was allowed to perpetuate knowledge about bodies and illness over the centuries. And really, we're looking at quite a short history in terms of women's formal admittance to the hallowed halls of medical practice. It was only in 1876 that the UK government passed an act called the Enabling Act that meant that medical licences could be given to women, so that they were licenced to practise medicine officially. At that time in history, UK

universities could still legally bar women from entering so even with a government act, women still faced huge barriers to becoming professional doctors.

Elinor Cleghorn (02:26):

Considering the history, at least of means to what we would now call our mainstream Western medical cannon, we're looking at a history that goes back to the ancient Greeks. So for centuries before women were allowed to practise medicine with a licence, men have been building up a body of knowledge that has formed the historical context from which modern medical knowledge has evolved.

Elinor Cleghorn (02:54):

So I really think that it's got to do with who was allowed to practise, but also who was allowed to learn and who was allowed to create knowledge, and that historically has always been men. I mean, it's really difficult to know how women's literacy evolved over the earlier centuries, but when we're talking about the production of knowledge, it's really something that's owned by men. Even though women, of course, for centuries have been practising medicine, have been caring for bodies, have been creating knowledge of their own. As to do with how that knowledge is sanctioned and how that knowledge becomes part of an official history, and that unfortunately has been predominately male and male dominated.

Anna (everywoman) (03:34):

So your book Unwell Women covers all of this, and at its heart it's a really profoundly quite disturbing look at the way in which female health and the paradigms around that have maintained the patriarchal order.

Anna (everywoman) (03:47):

Tell me ... obviously, I'm asking you on a layman's terms to condense your entire book. But, how crucial a lever to the structural oppression of women was defining them as literally physically unworthy or unable to embody power? Through either not being the thing that you use to understand other things, or by disempowering them with this very reproductive paradigm of their being.

Elinor Cleghorn (04:13):

Yes, I think that's the perfect way to put it. I think it's been a crucial lever in the oppression of women historically. Ideas about women's biology, women's bodies, women's mental capacity have been sanctioned by medicine and by medical knowledge, and physicians have always reflected the social status quo. And before medicine became a science, or the science that we know it to be today, so from the 19th Century onwards, medicine was I think as much a form of social learning, and it really struck me as I was researching the book and I don't think I thought this was how the book would necessarily turn out. But, it really did strike me just how much oppressive medical ideas about women are wrapped up in oppressive social ideas about women.

Elinor Cleghorn (05:09):

It was really striking that every time there was a significant movement forward for women in society ... For example, in the 18th Century when Mary Wollstonecraft wrote the famous A Vindication of the Rights of Women. She was writing then partly against some ideas about women's nervousness and over-emotionality that were being used by physicians as reasons why, for the good of their health, women shouldn't participate in things like professions and why they shouldn't be educated. And why they

should be these happy, reproductive help maids to their husbands, and really confine themselves to the home, and the hearth and the childbed, so I think it's been crucial.

Elinor Cleghorn (05:57):

And similarly, in the 19th Century when debates put to the fore around the women question, so we're looking at questions around women entering the medical profession, but also women going into higher education on an equal footing with men. There was a huge backlash within the medical community using biological theories about how women were defective, how their bodies were defective, how their minds would be affected by things like learning, which would then lead to a detrimental effect on their bodies and reproductive systems.

Elinor Cleghorn (06:28):

So it's like every time there was a movement forward, the medical community or parts of the medical community would come in and argue back that progress was just not good for women's health. And, what was good for women's health was getting married and having babies, and being contented with a narrow, limited life.

Anna (everywoman) (06:49):

Your experiences of this with your own diagnosis of Lupus are discussed in the book. Did you write the book because of your experience of bias, or was it something that you were already interested in?

Elinor Cleghorn (07:00):

My experience of being diagnosed with Lupus was really fundamental to the early thinking that became this book, that became Unwell Women.

Elinor Cleghorn (07:09):

I was diagnosed with Lupus in 2010, after a difficult pregnancy with my second son and I got very sick. I had a heart condition that, at the time, was quite mysterious. I was diagnosed quite quickly after 10 days in hospital, but the awareness that I did have this chronic condition made so many things about my past medical history suddenly make sense. And since my early 20s, I'd suffered what I didn't know were actually symptoms of Lupus, so joint pain, swelling in my legs. Just really persistent chronic joint pain was the main symptom, but it also meant a lot of mental health issues because of the pain that I was in, a lot of other mysterious symptoms, migraines.

Elinor Cleghorn (07:54):

Every time I went to the doctor, I was either benignly told to stop worrying, I was probably hormonal. Some doctors even suggested I might still be growing at the age of 22, which is bizarre. One thought I might be pregnant, another had suggested I might have gout. It was either benignly or malignly dismissed, depending on what doctor I saw. And I think as women, even though as you said earlier, that often we're just not aware of these biases that might be rigged against women when we go to the doctors, we do feel and internalise the attitude that women's pain is to be minimised. That we will be thought of as fussy, or as attention seeking, if we complain too much about our bodies and our pain. I think we internalise these ideas that it's our lot in life to be in pain, but it's also our lot in life to be not taken seriously, or to be somehow diminished if we speak up about being in pain. Somehow, be taken less seriously as people.

Elinor Cleghorn (08:59):

So I think that even though, at that time when I was younger, I didn't know anything really about these sorts of biases in medicine, and I certainly didn't know that I should be searching for a better diagnosis or better medical care for better efficacy. I also had this embedded knowledge that that was just going to happen to me, because I was a woman. And sort of shrugging, "I can expect no better, really."

Elinor Cleghorn (09:26):

I was only until I realised that something serious was going on with me that I could look back and think, "Okay, that wasn't okay." And not only was it not okay on an individual level, it's also the experience of countless women I know, countless women that I read about, thousands, hundreds of thousands, millions of women across the globe. So the book really expanded the germ of an idea to really look into why this happens. And over the last few years especially, when medical bias and the way that it affects women has been coming into the UK and US press a lot, I think we've had a real reckoning of the treatment of women across all sectors of society since Me Too. I think the women speaking about their experiences has been really important in society as a whole, coming to understand that this is not just a trivial problem, but it's something that's actually damaging women's health and often destroying their lives.

Elinor Cleghorn (10:28):

And although this is really important now, it's crucial to the conversation now, the long history of this was really important. I wanted to know how it got ingrained, how did this thinking, these sorts of attitudes get embedded. So that when I go to a GP now who might go, "I don't know, the pain can't be that bad," there's something in that. He's not, I don't think, intentionally biassed towards me and definitely doesn't want to cause me harm, but yet there's something in the way, that knowledge has been transmitted across the centuries, that it's just a given that women will be always slightly distrusted, that there is always somebody else who's a better judge of, as you said earlier, of their pain, of their symptoms, the severity of what they're going through. And, that definitely is a feature of early medical knowledges, men trying to take ownership of women's pain and trying to name it for them.

Elinor Cleghorn (11:26):

It happens from the very beginnings of medical history, and it's something that we're only now really, I feel, beginning to reckon with.

Anna (everywoman) (11:34):

Historically, I have to say, one thing that really stuck which I quite loved was the story about Queen Victoria. She's had all these children without any kind of pain relief, and basically Queen Victoria insisted that actually, you know what, she was in pain when she was having childbirth and she was going to have chloroform. And, it took a monarch to push back against a male establishment.

Anna (everywoman) (11:59):

I just want to talk a little bit about the internalisation because obviously, there is a point that now women doctors are well represented in our medical establishments. Do women doctors still carry that internalisation? Or, is better representation and diversity going to change this in any way?

Elinor Cleghorn (12:18):

I think that better representation and diversity does go far to addressing these biases, but I don't think it's necessarily the case that women doctors would be on top of the issues of dismissal of pain. Anecdotally from my own experience and anecdotally from friends and relatives, I've heard of difficult treatment from both male and female doctors. But then, also some of the consultants who care for me the best since I've been unwell have all been women. I don't think it's a coincidence that these women are working on a really complex disease, Lupus, that affects 90% more women than men, that is as yet incurable, is manageable but there is no cure. And, that it also intersects with reproductive health and maternal health a lot, too. So I don't think it's a coincidence that women really at the top of their game in the field of autoimmune and immunology would want to get to the bottom of this kind of conundrum.

Elinor Cleghorn (13:21):

These biases that are present in medical culture that affect us on a day-to-day level, I think they really go above the level of individual prejudice. I think sometimes that it's just the way that the knowledge has been shaped.

Elinor Cleghorn (13:35):

There was a woman that I found in my research who was diagnosed with Lupus in the '50s, just after Lupus antibody was first discovered. She had actually tested positive for syphilis in a misdiagnosis with a blood test called the Wassermann that was given to people before they got married, before they could obtain marriage licence, to check they were clear of syphilis. But, there was actually a contraindication with this because the same antibodies present in Lupus are similar to the antibodies present in syphilis. So this poor woman was not allowed to marry, and she was also treated with an arsenic derivative, which was what was used to treat syphilis in the mid-Century, which is incredible. She underwent years and years of treatment for an infection she didn't have, while also at the same time battling with the symptoms of an undiagnosed serious, chronic disease, for which she wasn't being medicated or treated.

Elinor Cleghorn (14:36):

It really struck me that she was really, then, the victim of an era which was very concerned with maintaining sexual health and marriageable purity after the Second World War. But also, the victim of a lack of knowledge at the time, because there just was not the diagnostic protocols to ensure that her disease was properly managed and she suffered for years. This attitude is actually written in, so when this poor woman was being treated she was also being treated for mental health issues in a really brutal way in the mid-Century, so she was given electroshock therapy for example. When you think her undiagnosed pain, she was suffering undiagnosed pain, she was suffering the social stigma of being diagnosed with syphilis. And somewhere in the history of this disease called Lupus, this is written. This was a formative moment in the history of lupus.

Elinor Cleghorn (15:33):

So it's there, even if it's not articulated by doctors and consultants now. Somewhere there's an attitude, somewhere it's there, somewhere it's shaped, the knowledge. So I think when it comes to biases, the biases have to be found and actively searched out, rather than just, "Okay, we must listen to women," which of is so important. But, it's also about looking at how this knowledge has been framed with biases intricately written into it.

Anna (everywoman) (16:08):

Let's talk about women's voices, then. So you were talking about greater diversity within the medical profession, we're talking about really being active about seeking about biases, not just assuming that they're going to appear to you. But also, you get the other set of female voices who are speaking out about issues, things like endometriosis, childbirth and postnatal depression. Menopause is a massive one.

Anna (everywoman) (16:33):

Another thing that came through the book was very much this use of shaming and invalidating women's physical and mental manifestations, rather than seeing them as a very natural outcrop of whatever was happening. Do you feel that there is a big change in the way that women are speaking out now about all sorts of things? Not specifically things to do with our reproductive system, but it does all kind of seem to come back to that essential ground if you like, doesn't it, in terms of how women are understood in the health sphere. And, how important is it that people speak out?

Elinor Cleghorn (17:08):

I think the culture of women speaking out about their medical experiences, and also about their experiences of pain and illness, are hugely revolutionary. I think it's really radical and really important to hear the stories of women who are experiencing ill health, who are experiencing, who are experiencing medical dismissal. The bravery and courage I think that it takes to really bare those experiences, after centuries of being socialised to keep quiet, keep silent, and also to be ashamed of our bodies. And, so much of the gaps in knowledge that we have around female health at the moment I think can be rooted in a sense of shame in general, a societal and cultural sense of shame around women's bodies, around women's organs, around how we are allowed to speak about our own bodies.

Elinor Cleghorn (18:08):

So now that we're at a time when not only are women's body experiences part of something that is happening, women are speaking out, but we're also embracing this in our culture. It's becoming part of some truly incredible memoirs, brilliant websites, even films, in TV series, and just the visibility and acceptance of illness and ill health is I think crucially, crucially important. And, I think that's where change really comes from. From women understanding that they're not alone, they don't have to feel ashamed about their bodies. And if they do feel ashamed about them, that it's not their fault.

Elinor Cleghorn (18:47):

Yeah, I just find it truly radical and I think it's an incredible time. A time of learning, it's a time where medicine can learn an awful lot from the way that women are able to tell their stories outside of the doctors' office.

Anna (everywoman) (19:00):

And to reclaim that narrative. There were always female healers weren't there, throughout history.

Anna (everywoman) (19:05):

The other thing that I wanted to ask you was about this idea of medical facts and women fitting into medical facts. And how challenging the female state is, apparently, or has been, in medicine. So in the book, you talk about how our symptoms are the reality of our illnesses, and I'm going to quote here. "We mystify medicine because medicine isn't looking for answers in the right places. We mystify medicine because medicine isn't paying the right kind of attention. We mystify medicine because

medicine needs unassailable facts." Where should medicine be looking for answers? And, how do we meet this rigid system with female experience, which is cyclical?

Elinor Cleghorn (19:42):

I think that medicine as both a science and an art that's been based on male knowledge is shaped according to this idea of the unassailability of fact. So a symptom that's something that's experienced in illness, but a sign is a diagnostic marker that will be accepted by a doctor as evidence of a disease. Chronic diseases especially manifest in such diverse ranges of symptoms between individual people. A woman with endometriosis might have an extremely diverse presentation of symptoms to another woman in that waiting room.

Elinor Cleghorn (20:22):

I think that something I figured out from my research is that a lot of these diseases that are either specific to the female body or that have a very high female preponderance, like autoimmune diseases like endometriosis, their symptoms are so diverse across individuals that they'll rarely be a sufferer who fits into a very strict diagnostic criteria. I don't think it's any coincidence that the disease that medicine finds most difficult to treat, diagnose and cure are those which manifest so diversely in women. Because symptoms can change from day-to-day, especially in chronic diseases that are characterised by pain. Pain in itself is so subjective, and for women especially, the expression of main to a doctor is rigged against them from the start.

Elinor Cleghorn (21:17):

There was a really brilliant study done in the early 2000s called The Girl Who Cried Pain, about the way that women's expressions of pain are interpreted in medical settings, and how those different expressions go onto then affect their diagnoses and treatment. This was the famous study that showed that women, when they're in pain, are much more likely to be offered sedatives or antidepressants than they are to be offered pain medication, which men are. But, it was also a study that showed that the way that women talk about pain, women tend to talk about pain more emotionally. They tend to relate their pain more to the people around them.

Elinor Cleghorn (21:57):

I'm generalising but a man might say, "Oh, I've got a stabbing pain in my chest." Whereas a woman might say, "The pain keeps me up at night, I can't look after my children." They might relate it more to social and emotional settings. It was shown that when women do that, or when people do that, they're less likely to be taken seriously, or their pain is less likely to be regarded as something serious.

Elinor Cleghorn (22:21):

I think that what we need is not just the advice to healthcare professionals to listen carefully to women when they talk about pain, which of course is really important. But, it's also to accept that sometimes, women and people will not fit into a rigid diagnostic criteria, but they still deserve to be referred for further tests, for further investigation. If a person says they're in pain, the dismissal of that because they don't fit a rigid criteria is part of what holds up diagnoses of diseases like endometriosis for seven years, which is the average in this country.

Anna (everywoman) (23:08):

I actually just wanted to get your thoughts on, obviously a lot of health is now moving into a technological zone that there's going to be a lot more technology involved in diagnostics. We have lots of apps now that are trackers, providing services within the health industry. But, they've also come under criticism for being gender biassed. It's no secret that the tech industry is very male dominated and very male biassed. But, are they just the latest health paradigm? It's amazing that it's replicated itself. Can we stop that?

Elinor Cleghorn (23:43):

This is so interesting to me, because I was just reading about these new algorithms that are being designed, the kind of algorithms that can extrapolate from huge amounts of data and patient records, help improve diagnostic times and help guide treatment guidelines. I was reading about how, as you pointed out, they're often more likely than not created by men. The input and the way that they respond to data, these algorithms, is also based on that historical knowledge that's biassed against women, that the algorithm has its own embedded biases. So when the algorithms interpret data, they're still expressing bias even though the aim is supposedly neutrality. That's the point of these.

Elinor Cleghorn (24:31):

So I was reading about how this can be solved, and it's about going in and working out, and actually weeding the biases. Because if the biases already exist in the knowledge and creation of the tech, then you can't just expect the tech to not perpetuate those. It has to be made in order to redress its biases. I think this is really fascinating.

Elinor Cleghorn (24:55):

I think also, in terms of the health tech, it seems to be a really double edge sword, because so many health tech things that I've been reading about seem to have them narrative behind them. Especially in the femtech world, so the world of feminine health technologies. They have a narrative around them that they're solving some of the problems of medical bias. So for example, with some of the earlier period and ovulation trackers, and fertility trackers, a narrative of women being able to take back control of their bodies, and their fertility and their healthcare. But then at the same time, you're being tracked. You're producing data, and quite often the tech is a huge thing, you are a human being. So those two things can't marry, the tech cannot be that individuated.

Elinor Cleghorn (25:44):

So it's very interesting, I think the way that tech takes on these narratives. And not necessarily exploits them, because I think there's a genuine interest some femtech innovators to really provide better solutions for health management for women across menstrual cycle health, reproductive health. I was even reading about some really brilliant innovations in the developing world to do with handheld gadgets that help women take scans for checking for cervical cancer, for example. There's some really incredible, really fascinating innovations in global health. I think it's hugely fascinating, not unproblematic at all, but also something to really watch.

Elinor Cleghorn (26:33):

I just found out only yesterday that the femtechs, or the health and wellbeing industry for women, is projected to be worth $25 billion by 2025, which is extraordinary. It's just an extraordinary figure. I mean, the wellness industry itself is worth what, $50 billion or something. They're either creating a

problem and then offering a solution, or they're really is a market for this, women want to take back some control over their health.

Elinor Cleghorn (27:01):

I was interested too, in the fertility apps, marketing themselves as Contraception 2.0, so unmedicated contraception. I think that's an interesting language too, because there is a real distrust around pharmaceutical industries that exists. There's a real distrust especially around things like hormonal contraception. So it's intriguing to me that there is this keying in to these anxieties and offering something that is more reliable, more holistic. But yet at the same time, it's making you this object of data. Yeah, it's a really intriguing, fascinating area.

Anna (everywoman) (27:45):

I'd be interested to see how they deal with the point that you made earlier, about certain conditions present in so many different ways and how tech can deal with those nuances. It'll be a very interesting way to see how it moves forward.

Anna (everywoman) (27:56):

Let's just talk about where we are now, though. In terms of unconscious or conscious biases that women still have to deal with today around more mainstream medical approaches to health and wellbeing, what should all women bear in mind when they negotiate a medical environment, would you say?

Elinor Cleghorn (28:15):

I don't like to say that women should go to the doctors armed. It seems so counterintuitive that if you are concerned about your body, that you then build a case for yourself. But, in many ways I think it's a really good thing to, if you can, to be an advocate for yourself, to be an advocate for your own body. And to understand that, if you do have treatment that you are not happy with, if you feel that you're not being taken seriously, if you feel like your symptoms and your experience is being undermined, I think that there is always a way to address that, not necessarily in the room.

Elinor Cleghorn (28:57):

It's difficult with the NHS, because we get the GPs that we get. I think on the whole, those GPs do not want to hurt and harm us, but the pressures of the NHS, the pressures that the NHS are under can sometimes mean that we do feel it's a revolving door. And that if we have a non-specific pain that's concerning us, it might not concern them enough.

Elinor Cleghorn (29:19):

I think it can really, really help to keep diaries of your symptoms. I think it can really help to get your doctors to write down the advice that they're giving you, so that you have evidence of what's been said. I think it can really help to ask to explain to your practise manager, if you feel you haven't been treated adequately. And, to just understand as well that any treatment you encounter in that room, if it is negative, it isn't your fault.

Elinor Cleghorn (29:46):

That's not to say that you should go expecting a bad experience, but if you do get treated in a way that you feel isn't right, that's upsetting, or that is diminishing, that it isn't your fault. That there's often other

forces at work, in that room, that maybe even the doctor isn't aware of, the unconscious biases we've been talking about. But also, the external pressures of what is prioritised. What you can hope for is that we're moving towards a culture where women's health needs, women's diverse health needs, are going to be prioritised, which will mean a shift in priorities, a shift in knowledge, a shift in emphasis.

Elinor Cleghorn (30:24):

Also, if you don't feel comfortable advocating for yourself, maybe take a close friend, somebody who can speak for you, if you find that difficult. I think there are ways that you can navigate your own health experiences, to guard yourself a little bit against the possibilities that you may have an experience that is less than ideal.

Anna (everywoman) (30:44):

But, be a reliable witness to yourself. Don't discount your innate knowledge. It might not be medical, but you are still in your body aren't you, you know.

Elinor Cleghorn (30:54):

You're absolutely right. You know your body; your body is your own. If your doctor distrusts what you're saying, you are still the most reliable witness of your body regardless of what anyone says to you, or the attitudes that you encounter. Your body is your own, you can trust in your body. You know how you feel and you are the best narrator for what you're going through.

Anna (everywoman) (31:22):

So ultimately, is medicine still a critical frontier for women's equality? And if so, what is the change that you want to see and how can your book drive it?

Elinor Cleghorn (31:31):

I think medicine is a really crucial frontier for women's equality. I think that women deserve and need good health if they're to participate fully equally in society, in the workplace. They need to be able to know that their treatment, their bodies, their lives, their mental health is prioritised because health is just the beginning. If you have good health, then you're able to function in your life. Illness is not just in pain and not just isolated instances, they affect how you live, how you think, how you move through the world, how you feel about yourself. In order for us to gain full equality, I think that medical equality is really a crucial frontier.

Elinor Cleghorn (32:15):

I've been pleased recently to see that listening to women is being now a strategy that is being put forward by government. So on International Women's Day this year, the women's health strategy was launched, which is an inquiry into the ways that the NHS and healthcare providers might be failing women in the areas of reproductive, gynaecological, maternal health especially. But, what's so brilliant about this strategy is that there's a questionnaire to fill in, but there is also the opportunity to give evidence. So if you're able to and you want to, you can submit written evidence about your medical experiences.

Elinor Cleghorn (32:54):

So for the first time, I think this kind of subjective knowledge, of women telling their stories, talking about their pain, is something that hopefully will start to change policy. That's what we need. We can talk about this, share histories, we can share our stories, but what we really need is policy change, funding changes, funding priorities, and change to happen from the very top. Now what really gives me hope is that women's stories, listening to women, women's subjective knowledge is now being marshalled, it's being valued in a way I don't think it ever has been before. So just be hopeful for that, and hope that that really will be a driving force for change, and that that will help shape how we understand some of these really inexplicable diseases that are affecting so many women today.

Anna (everywoman) (33:45):

Elinor Cleghorn, thanks for joining us.

Elinor Cleghorn (33:47):

Thank you so much, it's been such a pleasure.

Anna (everywoman) (33:54):

everywoman is a global platform for women in business that drives positive change by empowering women to achieve their professional potential. Visit everywoman.com to discover how we're advancing women in business and inspiring a generation of future female leaders. For every woman, everywhere.