# STORIES FROM MENOPAUSE MANDATE SUPPORTERS.

MENOPAUSE SERIOUSLY

## **IT'S TIME TO TAKE MENOPAUSE SERIOUSLY.**

"Through my involvement with Menopause Mandate and the subsequent support we've given to produce this book, I've grown to better understand and appreciate the importance and severity of the issues that women may face when dealing with the challenges of menopause.

The business community has a significant role to play here, in socialising and supporting female colleagues, whilst at the same time encouraging the introduction of effective menopause policies. We also need to educate all employees and remove the taboos and embarrassment that prevent open and honest conversations.

Reading the stories, it's shocking that so many women leave their employment during this time. That surely has to stop."

Nina Wright, CEO, Harmsworth Media

# HARMSWORTH MEDIA

i NewScientist

# IT'S Beyond Joke

#### MENOPAUSE MANDATE

# **CONTENTS**

FOREWORD Mariella Frostrup, Chair of Menopause Mandate Carolyn Harris, MP	06
CHAPTER ONE Patrons' Tales Everybody has a story	11
CHAPTER TWO The Mirth of Misdiagnosis It's anything but amusing	33
<b>CHAPTER THREE</b> <b>The Ridiculous Roundabout of Symptoms</b> Why are women going round in circles?	45
<b>CHAPTER FOUR</b> <b>The Merry Mismanagement of Early Menopause</b> Difficulties in delayed diagnosis and treatment	57
<b>CHAPTER FIVE</b> <b>Ludicrously Losing Jobs</b> The urgent need for legislation and support in the workplace	71
CHAPTER SIX Farcical HRT Shortages	85

Three years of shortages, and still not resolved

CHAPTER SEVEN The Absurd Cost of Menopause	95
We can't all afford to pay for treatment	
CHAPTER EIGHT	105
<b>Laughable Vaginal Dryness</b> A dry sense of humour is great. Vulvasnot so much	
CHAPTER NINE	115
<b>Riotously Awful Treatment</b> It's a wonder we don't take to the streets to protest	
CHAPTER TEN	127
Genuinely Happy Endings It's not all bad news	
CHAPTER ELEVEN	137
<b>Three Cheers For The Chat</b> Let's keep up the campaigning	
CHAPTER TWELVE	151
Supporter Statements We'll all shout out	

# FOREWORD

#### Mariella Frostrup, Chair of Menopause Mandate

am honoured and delighted to be Chair of Menopause Mandate, working with such an extraordinary group of supporters: politicians, campaigners, grassroots organisations and our patrons. But whilst we make a merry team, we didn't form this group for fun. We came together because of the way in which women have been, and continue to be, treated during menopause.

Some 50 per cent of the population will have to navigate this period of hormonal turbulence, which is a key part of our biological journey. And yet menopause is by no means near the top of any agenda and is still not taken seriously. That's what we're here to rectify.

This isn't about politics. We are fortunate enough to be supported by a crossparty collection of inspiring MPs. It's about women's rights. Menopause Mandate is going to be around until we've achieved the changes that are necessary to improve the quality of women's lives in midlife.

When we launched our website, we asked women to send in their accounts of menopause, so that others might read them and realise that, although every experience is unique, we all go through this liminal time.

Hundreds of you got in touch. Thank you to everyone who took the time to share your story. I'm beyond proud to present a selection here today. From years of terrible symptoms to awful misunderstanding and unfair misdiagnosis, to some of the incredible GPs and brilliant healthcare providers in the UK, every single one of these anonymous stories represents thousands of women.

There are those who are suffering in silence, those who haven't been given the right treatment, those who've been dismissed or mocked and those who still aren't sure that their anxiety, headaches, aching joints, dry vagina or night sweats are signs of menopause. And there are also those who have had a good experience; these are fewer in number, but every single one of us ought to be in a position to celebrate our excellent education and treatment during this important transitional phase.

When we read the stories, some clear categories emerged. The chapter

headings are mostly ironic, and verging on the highly sarcastic. Many anecdotes refer to HRT. We fully accept that not all women wish to or are able to take it, but it's a large part of the struggle for many.

There is clearly still a great deal of fear around HRT, despite the fact that it is widely accepted by experts to have more benefits than risks for most women, especially body identical HRT. The truth is still not out there. Those for whom it's not an option point out that other treatment is seriously lacking.

One of the most appalling themes is the cost of menopause - and I don't mean the metaphorical cost. Lack of NHS resources means that women frequently end up paying for private treatment.

Many cannot even afford NHS prescriptions. Support during this period should never be a socioeconomic choice. Another shocking chapter is about premature menopause - whether natural or medically induced - and the fact that it's too often overlooked and under-treated.

There's no question of blaming an underfunded and understaffed medical profession who are trying to manage an unprecedented workload. This is about a systemic and societal failure of education and information, and there remains the continued influence of the historic flawed research into HRT, which has now been re-evaluated.

The stories often mention other groups and individuals who are not part of Menopause Mandate, and we celebrate them all. We are a broad church and grateful to anyone on the quest to improve women's health. On a personal note, having spent the last seven years raising awareness for better menopause provision, it's disappointing that there's even a need for campaign groups!

After making my BBC programme, The Truth About...The Menopause, in 2018, I hoped that the subject was laid to rest. Clearly not. Writing a book about the subject in 2021 simply highlighted the need for education for all, an end to the scaremongering, the right treatment for everyone, and affordable and accessible HRT.

Finally, there are the stories celebrating the fact that the conversation has started and that it's going to continue. Menopause may not be a laughing matter, but we're here to ensure that future generations don't have to suffer in silence and shame.

#### **Carolyn Harris, MP**

n October 29, 2021, Parliament Square was filled with jubilant women. Women who felt their voice had finally been listened to and were overjoyed with the commitments that the Government had made that day in the House of Commons.

These were for a single annual charge for NHS HRT prescriptions in England – saving women hundreds of pounds a year – and a promise to form a UK wide Menopause Taskforce in a bid to improve access to support, services and treatment for women right across the UK.

Five months later the picture was somewhat different. There was a Government announcement that the promised Annual Prepayment Certificate would not be introduced until April 2023 – some 18 months later than promised. In addition, there was a nationwide shortage of a number of HRT products.

Women were outraged, and so were campaigners, all feeling let down by a Government which had promised so much. Out of this outrage, Menopause Mandate was born. It's a campaign to bring everyone together, to share experiences and to use our collective voices to demand that women's health be given the respect it deserves.

A year on from those triumphant scenes, it feels as though menopause support and services remain undervalued by the Government. The HRT Tsar was gone in four short months – her legacy merely a list of recommendations.

Stock levels of many HRT products are consistently low – despite promises from the Department of Health and Social Care that these would be resolved by early summer. The single charge for prescriptions in England is still six months away and every day we hear from women who are still struggling.

But together we can make a difference, and by sharing our experiences we can ease each other's struggles. Thank you to everyone who has been brave enough to get in touch, to share their lowest moments in the hope of supporting other women. Your stories have made this book possible, and they will help others when they don't know where else to turn.

Menopause Mandate isn't about the famous faces that we are absolutely privileged to have as supporters – it is about every person who deserves to be able to easily access the support and treatment they need.

- 8 -

# CHAPTER1 PATRONS' TALES HASAQTADV

e are extremely grateful to our patrons, who are so generously giving their time to support Menopause Mandate. Below are their stories and the reasons why they're enthusiastic about campaigning for change.

#### Carol Vorderman, presenter, author and campaigner.

Every cell in my body is filled with confidence, and there's no challenge I won't try and tackle. But when menopause hit, it floored me. I'm not argumentative, but the anger I feel about how women's health is treated in this country makes me want to attack like a tiger. For two days this year (and for many years in the recent past) we had a female Monarch and a female Prime Minister. Why should we still have to beg for menopause support as though it's doing us a favour? It's not rocket science!

I was born in 1960 into absolute poverty. We had one tub of bathwater a week between my mother and us three kids, and we were cold for many months of the year. My mother was 32 when she had me and in her 40s when I was a teenager. In those days if you were 40 that meant that you were middle-aged, and women had to behave in a certain way. Success in life was still measured by whether you had a male partner.

So, on my 18th birthday, here I was, this supremely bright young woman from a comprehensive school and on free meals. I was full of confidence, driving rally cars in my spare time and had just started to study engineering at Cambridge, but I was given hell about how I should think about settling down with Ricky, my chicken farmer boyfriend, or 'I'd be left on the shelf'!

My ambition was to be either an RAF fighter pilot or an astronaut, never a TV presenter, and I've still not let go of that second ambition. At that time, I wasn't even legally allowed to join the RAF as a pilot. It was a different age, and I have fought to change that ridiculous attitude towards girls. It seems extraordinary that I'm now knocking on 62 and there are continuing issues around women's position in society and - especially - their health. It's utterly outrageous, and a subject on which I'm quite happy to fight.

I've never been scared to face controversy head-on. In 2000, when I was 39, I wore a short dress to the BAFTAs. You'd have thought I'd committed a violent crime. TV presenter Robert Kilroy dedicated an entire show to it, and the vitriol that came my way was unbelievable. The headlines screamed: SHOULD

A WOMEN THIS AGE WEAR A DRESS ABOVE THE KNEE? Even then, it was thought that by the time you were 40 you ought to consider going grey and stop exercising.

Back in 2012, only a decade ago, when I was presenting Loose Women, I hadn't yet gone through menopause. Whenever the subject was mentioned, there had to be a joke made or an excuse. 'Oh, I'm having a bit of a crazy moment,' you might say. Or: 'I was a bit crazy yesterday.' We weren't told to do so by our bosses, it was just how society defined women when their hormones were out of kilter, and this seemed perfectly normal.

Then, without realising, I started to have symptoms. As I headed further into my 50s, I began to get anxious about things. When I had to go to London for work, I'd worry about how to get there; would I take the train, would I drive, would I book a driver...? Then I'd worry about timings. I knew that it was all in my head and that it wasn't logical, but on a couple of occasions, I felt that I really couldn't cope.

It's important to stress that there was no other issue in my life; I didn't have financial problems and the kids were happy. Everything was amazing, and yet there was all this stuff in my head. And there was no literature about menopause at the time, so I thought to myself - because that's how I'd been programmed to think - oh, I'm just at that age, that's what happens to women. Next stop dementia.

In 2014, suddenly, having never been depressed, I started to feel very low. This went on for months and was like being in a very bleak, dark hole, with a constant sense that nothing mattered. I bought a book about depression, but I didn't want antidepressants and somehow, deep inside, I knew that it wasn't clinical depression.

The one piece of advice I'd give to women is to keep a record of your periods. That's what I did, and when I looked back, I could see that I'd been living in this blackness for about nine months, but for two weeks of every month it got even worse. There was never time to recover completely, and I realised that it must be hormone-linked.

I had a look online for doctors and a Professor John Studd came up. When I saw him, he just went: 'Yeah, I know what this is, it's hormonal depression.' He did blood tests, although he didn't need to, and he gave me oestrogen gel,

progesterone and testosterone. Literally within 48 hours, that dark feeling lifted completely and has never returned.

In 2016, I finally talked about the subject on Lorraine. I'm driven by logic, so didn't want to discuss menopause until I had an answer. I knew that HRT, ideally alongside a health check, was the way forward. I did this interview and my goodness, it hit all the front pages. The editor of the show said that they'd never had a reaction like it. Everything exploded - I got email after email from women, and from men asking what they should do to help their wives and girlfriends. That's when I realised that surely the government ought to be funding the NHS to do all this - half the bloody population are going through it, and all most of us want or need is a bit of HRT.

You go through different chapters in life, and menopause is just one of them. Yes, it's a huge one, but it's important to remember that it doesn't end once you've passed through that final moment, 12 months after your last period. This is also a time when you don't care what people think and you're not frightened to express your opinions. I don't want my daughter to have to put up with this rubbish. Are we, or aren't we equal? If anyone wants to have a go about menopause, I'll have a go right back! Just algorithm the situation. Give us a health check every year and chuck us some hormones.

#### Carolyn Harris MP, Deputy Leader of Welsh Labour.

As a former school dinner lady and barmaid, my route to Westminster was somewhat different to many of my colleagues. But having had a fascination with politics since I was a little girl and a deep-rooted desire to help others, I have always been determined to use the platform I have. I am so fortunate to be a voice for those who are not being heard.

So, when the annual World Menopause Day debate came round each October, I would dutifully add my name to the list of speakers and talk about the devastating impact the menopause was having on other women's health, wellbeing, relationships, and lifestyles.

I felt so fortunate that I was one of the lucky ones who had 'sailed through' my menopause, that it was important that I spoke up for all those that were suffering. And then somewhere along the journey of speaking up for others I started to look at the list of symptoms that women were beginning to share

with me and something clicked.

There was my self-diagnosed nervous breakdown in my early 50s which had led to me being on antidepressants for more than ten years. There was the extreme fatigue that I had put down to the long hours, working weekends and travelling between home and Westminster every week. There were the aching bones and joints that I thought would get better when I found time to exercise more frequently. And there were the headaches that I explained away as a result of being a bit stressed or not getting enough fresh air.

I wasn't depressed, or overtired, or any of the other countless things I had diagnosed myself as – and clearly, I hadn't 'sailed through' my menopause either!

Without a doubt, taking myself off to get a prescription for HRT was one of the best decisions I ever made. I hadn't actually realised how much of Carolyn was missing until I found her again. HRT isn't the answer for everybody - there is no one-size-fits-all solution for menopause. But it works for me.

And having realised how naïve I was about what was happening to me, and how with the right help I have seen such an improvement in my own wellbeing – I am now more determined than ever to ensure that everybody who needs it has fair and equal access to support and treatment right across the UK.

Davina McCall is one of the UK's most prolific and well-loved presenters. Her documentary programmes include the highly acclaimed Sex, Mind and the Menopause, and Sex, Myths and the Menopause. She is the author of many books, including the just-launched Menopausing.

I've recently been quoted as saying that I enjoy partying until 2am. Outrageous!!!! And true!! I don't know if I'm on the other side of menopause, because I have the Mirena coil, but I am happily full to the brim with HRT, 30-years sober and revelling in my second spring, which is how I like to consider the second half of our lives. This is a time of energy, self-love, ambition, power and huge gratitude for and appreciation of family and friends. Here's to all of us!

Insofar as it's possible to have a famous menopause, mine has been pretty well documented over the last two years. Since making my first documentary about the subject - Sex, Myths and the Menopause - with Kate Muir, menopause has been a key topic of conversation both in and outside my home and has given

me a huge sense of purpose. Who knew the impact the programme would have, or how many women so desperately needed to hear that they weren't alone in their menopausing journey?

After it aired in spring 2021, I was inundated with messages from women and men, telling me how much they had enjoyed watching it, and how it had opened their eyes as to what actually happens to women in midlife. I couldn't buy a box of tea bags in the local supermarket without someone sharing their own story or getting a lovely hug or having a cry with someone. It was very humbling. I have wept in frustration, anger and utter despair at the awful stories I've heard. It beggars belief what women have had to put up with.

There have been so many brilliant books and programmes about the subject. All the amazing menopause warriors before me gave me the courage to speak out. This is a space that will never, as far as I'm concerned, be full, and certainly not until all women know about perimenopause and menopause. Not until they are all told what the symptoms are, given a good once-over by a GP and then offered the treatment that's appropriate for them. Ideally all for free. (I literally cannot believe this isn't already happening). Much as I'd like to think this is imminent, we all know that there's a lot of fighting left to do before we reach the heady heights of good menopause provision across the UK.

In my case, menopause sidled up to me and took me by surprise, just like so many women out there. I assumed that menopause happened in your 50s, yet I was only 44 when I started to have those classic signs of what I now know to be perimenopause. I had no idea what was going on, even though I was a one-woman walking checklist of symptoms, with hot sweats and then the cold feeling that follows, the 0-60 mph flash of anger, which sometimes made the school run miserable for us all, brain fog and palpitations.

But menopause isn't the same every day; it comes and goes like a bad boyfriend. One day I'd feel awful and the next day I'd be absolutely fine. It was other women who opened my eyes to the fact that it was my hormones going insane, and I realised I needed to get some help.

I began using HRT, which restored me to my former self almost instantly, but I was ashamed about this for years, only 'fessing up quite recently. That's the other problem with menopause not having been talked about. It means that there's still shame attached to the subject - even though it happens to 50 per cent of all humans. Say that out loud, and yes, it's clearly ridiculous that it's not given more importance, but it's true.

It seemed to me that choosing HRT was somehow cheating or failing, which of course isn't the case at all. We need to firmly lose sight of the idea that women's bodies and biology are a bit shameful, and that HRT is for the wimps who can't put up with a natural process. Menopause is not something that should be 'got through'.

These days, of course, I'm no holds barred and absolutely no shame. I'm proud to be on HRT. It's simply replenishing what's lost, and we're increasingly aware of the benefits - for the heart and for bones, and, according to emerging evidence - possibly protecting against dementia, though more research needs to be done.

The above explains why menopause has become such an important part of my life, and why I wanted to make my two documentaries and then write my book with the lovely Dr Naomi Potter, who's there for all the medical stuff. Because we should be told about all this stuff, so that when we start questioning our sanity in our 40s, we know what's going on, rather than floundering in misery, sometimes for years.

I've heard so many heart-breaking stories, especially when researching my book. Thank you to all the women who've contacted me - all of you have touched my heartstrings, and I hope that I've been able to be there for you. And thank you to the women who took the time to write to Menopause Mandate your stories have so much impact. You are all very brave for telling your tales.

It's wrong that women have to put up with this, and I'm staggered that menopause is still not taken seriously, in spite of all the noise we're making. I'm proud to stand with Menopause Mandate and fight for what women need. And I'm not going anywhere until we get it.

## Gabby Logan, MBE, prominent sports broadcaster and presenter of The Mid Point podcast. Her book, The First Half, is just out.

The day after Carolyn Harris's success in Parliament in October 2021 (when we were promised the one-off payment for HRT), I interviewed her on BBC breakfast. The same day there was a Wales rugby international match and my husband Kenny went down to Cardiff to watch. He sat down and two old men, who had clearly watched me earlier in the day, looked over at him and asked: 'Do you really believe in the menopause?'

You don't get puberty deniers and you don't get pregnancy deniers. Menopause? Well, apparently that's still up for debate.

That's the sitcom approach, isn't it? The bloke at 50 suddenly feels as though he doesn't understand his wife, so he goes off and has a separate life, plays golf every day and doesn't feel he can relate to her. He is a bit squeamish about finding out something more than the very basics of the mechanics of a woman's body.

When I was asked in the past how women's football could grow, I always said we needed men to watch and support. Now, the crowds are more diverse and the game is growing, and that's partly because we have male allies. It's a game for everyone, not just women. It's the same with menopause. We need men to be on board in terms of pushing the menopause agenda, again, as our allies. We are all in this together. After all, menopause affects everyone, not just women.

When interviewing consultant gynaecologist Sara Matthews for my Mid Point podcast the other day, I suggested to her that there needs to be a PR exercise around the whole subject. We could do with an HRT 2.0 reboot of the whole story and narrative.

I feel like I've got all high horsey, but it's still not taken seriously even though it's a third of our lives. That's the third where, as a woman, you've traditionally done the hard stuff with your body, and it should be a time to pursue your passions and further your ambitions. You also want to be well and healthy and not feel completely redundant and a washed-up hag who needs to go off and live on an island. We want a woman of 50 to think she's going to have a great life till she's 80, not just exist.

I don't think it's too dramatic to say that HRT could be as big an influence on women's lives as the pill in terms of the ability to keep going at the age of 50. But we need that reframing and that revolution. I read stories about the HRT shortages and realise that they're like a postcode lottery. It reminds me a little of going through IVF. Women's health issues always seem to be left to the vagaries of various authorities and the distribution chain. There's no cohesiveness. And for those not on HRT, they don't necessarily get the full picture because there isn't that central source of information that would encourage them to take it.

Personally, I didn't have catastrophic night sweats or embarrassing flooding,

I just felt completely unlike myself. I've never been prone to dark moods or depression, yet all the things that would previously give me a lift, like exercise or being in nature weren't producing the same results.

Although the hormones eventually grind to a halt, it's a gradual process. You don't go from 'oh! I'm jolly, happy Gabby' one day to 'oh! I feel like shit,' the next. If you look back over a year, then you might say: 'Hang on a second. I have been getting increasingly ratty, I have been getting increasingly short-tempered with my kids, more moody and feeling a bit rubbish.'

The most distressing symptom was brain fog. I didn't associate word loss with my time of life. I thought that perhaps all the thousands of hours of live telly I'd done were coming home to roost, that I was like a computer that had filled its storage. Once I realised that hormones were part of the whole thing, then I understood that thankfully there wasn't an end date to my career.

I was very aware of all this when I spoke to Mariella Frostrup about menopause on my podcast - and then asked her for Sara Matthews's number! I knew that I needed some help. When I decided to use HRT I wasn't looking for the elixir of eternal youth. There's still a perception that it is for those who are simply hoping to look younger. Don't get me wrong - HRT is great in terms of skin, hair and libido, and it does make you feel younger. But for me, it's about mood and anxiety rather than the physical.

In my day-to-day working life menopause doesn't come up massively. We have conversations in the make-up room with Denise Lewis and female athletes, but you don't get many women competing in sports age 50, though who knows, with the rise of the use of HRT, we might see it more often! However, there are certain blokes who definitely would not flinch at the conversation compared to 20 years ago.

We all need to understand our bodies - not just women. Kenny only found out about his prostate cancer in February this year because he listened to my Mid Point podcast and asked what was going on with HIS hormones. I explained that men's hormones change at a different pace. He said: 'If your libido is going to go crazy because you're on HRT, I don't want to be left behind. I'm going to find out what's going on with mine.' Thank goodness he did.

Kids need to know as well. It's not a daily conversation with my teenagers, but they know I'm on HRT. I don't give them a reason to say: 'Is this the menopause?'.

They know what it is and when it comes, and that in itself is great.

Talking is how we're going to make the changes, and it's important where the information comes from. Kenny is an avid listener of The Mid Point, so he said to those two men at the rugby match that yes, he did believe in menopause and that it's really important to know what's going on with your wife and in her world. Otherwise, how can you have a lovely relationship with her?

And they both said: 'Oh, hm, yes, you might have a point.' Then, maybe, they'd have gone down the golf club the next day and said: 'Oooh, you'll never believe who we sat next to yesterday and what Bob said to him and what happened.' And another of their group might have said: 'I knew, and it's improved my sex life.' Suddenly, you've got four middle-aged blokes talking about menopause.

Continuing to communicate is vital, and thanks to all the women who have shared their stories with Menopause Mandate. Reading those shows how much still needs to be done.

# Lavina Mehta MBE, founder of Feel Good With Lavina, personal trainer, wellness coach and mum of three. Honoured for services to health and fitness during Covid-19.

My involvement with menopause campaigning is down to a number of factors. Some are because I've educated myself and some are because of fortuitous circumstances! I've realised that everybody has a menopause story, and everyone's is completely different.

In May 2022, I went to the paperback launch of Mariella Frostrup and Alice Smellie's Cracking The Menopause. I thought OK, this is the week I've gone public with my perimenopause journey, so being here is fate. I'm going to stand up at the end. And I did. I stood up and said: 'I'm South Asian, I've just started HRT and I'm opening up because I want to help my community. They don't understand menopause or know the solutions.' Whatever your skin colour, you need to see someone who looks like you going through it. Otherwise, how can you identify with something?

Many people don't realise that South Asian women tend to go through menopause aged 46 or 47. It's such an under-explored area in this country, and we stick to the oft-quoted 'average age of 51' without questioning it. There's no doubt that more work needs to be done on the subject to make it more inclusive for all populations.

Personally, I think that I started to be symptomatic when I turned 40. My once regular as clockwork periods went haywire, but I was told I was too young for it to be menopause! Then I had Covid very badly in July 2020. After that, I think that I mixed up the symptoms of perimenopause and Long Covid. I was experiencing anxiety, disrupted sleep and brain fog - to the extent that I worried about Alzheimer's, especially as my late grandmother had it.

At the same time, I'd just started on a new career path as a PT. Pre-Covid I launched a national campaign called Get UK Asians Fit! I'm a British Asian and am passionate about promoting the health benefits of exercise to treat and reduce the risks of such conditions as type 2 diabetes and heart disease, which are so prevalent in Asian communities.

During Lockdown I started to do free workouts on Instagram and this became far more successful and widely viewed than I could have ever dreamed! At the same time, I had these ongoing symptoms, but they came and went. Sometimes I'd worry about them, and the rest of the time I, like most women, just got on with things.

My lightbulb moment was watching Davina McCall's Sex, Mind and the Menopause documentary, when I was 44. In the first few minutes I burst into tears. My husband and my son came to see whether I was OK, and I said to them both: 'Just sit with me.' They watched the whole thing holding my hand and the next day I went on Instagram - very emotional, in tears, no make-up, wanting to share and say to women in my community - this is what's happening.

I had a huge response. Thousands of my followers are South Asian women like myself, and there is so much that's not discussed in our community; pregnancy, sex, periods, mental health and, of course, menopause. My mother says that in her day you just got on with it (this seems to be what most mothers say, whatever their ethnicity)!

Everything happens behind closed doors, and nobody wants to put themselves out there. Many women have sent me private messages about feeling at rock bottom. Generally, women's things are seen as a bit taboo, but we urgently need to be aware of the possible symptoms; the hot flushes, the hair loss, the anxiety and aching joints. Let's normalise the conversation and stop suffering in silence. I now have more than 120,000 Instagram followers, and perimenopause and menopause are a big focus of the work I do.

Also, as women, we believe that we should always put ourselves last. For many South Asian women with large family responsibilities, going to the gym or working out can be seen as selfish. I understand this as I lived in a joint family with nine people, including my in-laws, for five years. I argue that it's about our physical and mental health! My motto is: 'Exercise for Sanity not Vanity!'

Investing in our physical health, whether it's working out, eating a healthier diet or using HRT, is beneficial for us, our families and our colleagues. I am on HRT via the NHS, but I'm still struggling. It's important to remember that it's not the be-all and end-all. I have done my best to get the facts out there and the solutions - not just HRT, but the other ways of looking after ourselves. Here, again, more research needs to be done. I've read that if you eat a more plant-based diet, you don't suffer as much with hot flushes, and I've not yet had one. I had one night sweat, but I think that was Covid!

Cost and education are strong factors. There's no word for perimenopause in Gujarati. If you don't have a word for your symptoms, how can you possibly justify spending money on solving them? It excludes thousands of women from asking for HRT or even seeking medical advice. And, of course, there is huge socioeconomic disparity within the UK.

I'm thrilled to be involved with the campaign. There's a great deal wrong with the way in which all women are being supported through this time, and I hope I can be part of the change. Let's hope that as time goes on the stories told become far more celebratory.

#### Lisa Snowdon, TV and radio broadcaster, host of Midweek Menopause Madness on Instagram with Dr Naomi Potter and recent winner of Celebrity MasterChef.

On a train to Devon recently a women sidled up to me and said: 'Thank you for talking about menopause.' This happens sometimes - I'm cornered in toilets at festivals or whispered at in queues, and I'm proud that we can collectively support each other. But menopause needs to be a healthcare priority, and women should be automatically given information and support once they reach their 40s, so that the heart-rending stories in this book don't continue to happen.

I look back over my own 40s and feel sad that I didn't realise what was going

on, and that I didn't need to have experienced the evolving symptoms that plagued me for years. Had I known they were perimenopause, they could have been eased with informed medical advice, HRT and lifestyle changes. I know that my story is similar to that of many of the women who have written to Menopause Mandate.

There were a few things going on in my early 40s, when I was exhausted from work and unhappy in my personal life. I burst into tears easily, my sleep was affected, and I had very low dark moods. I've always been positive, no matter what obstacles life threw at me, but I simply couldn't get to a happy place. In retrospect, of course, this was the start of perimenopause. When I went to my GP, I broke down. He said that I was clearly depressed and prescribed antidepressants. I felt as though they were a bit of a Band-Aid but gave them a go.

Some months later my now fiancé George and I were getting together, and he saw me taking them. I explained, and he said: 'I honestly don't think you're depressed.' They certainly weren't making any difference, so I decided to wean myself off them during a holiday to Ibiza with him. We had a wonderful time, staying in a beautiful remote finca in a pine forest and I felt truly happy. On our return, I didn't plunge into darkness as I'd feared, but then things changed again. That's what happens with perimenopause - you deal with one symptom and then another pops up.

I started to experience extreme nausea before my period, as though I had food poisoning. Sometimes, I couldn't get out of bed and would lie there feeling utterly hideous. Then I got terribly heavy and painful periods, where I was literally haemorrhaging blood. Within five minutes, I'd bleed through a super plus tampon. I couldn't travel to work or take the bus. If I bled, I leaked through all of my clothes, even onto chairs at work and in restaurants. It was excruciating.

This meant that I avoided leaving the house. If I had to go out, I'd take spare clothes. My once-regular cycle went from 28 days to 23 to 40. Even then, I didn't realise it was down to fluctuating hormones. With periods we're so used to managing them on our own and juggling that you just deal with it.

Over the course of the next two years, I gained three stone in weight. I didn't notice it creeping on as I didn't have scales. I just knew that my jeans were a bit tighter, but then I went on a trip and weighed myself and was astonished. It accumulated in places I'd never worried about like my back and arms. I

remember going to Japan with George and saying take a nice picture of my back with a beautiful background, then doing a double take at the result.

Next, the hot flushes began. It's as though you're suddenly being set on fire and there's nothing you can do - whether you're in a presentation or talking on telly. Night time became hideous and debilitating. George would come to bed for a cuddle...he started calling me Furney - as in 'Furnace'! I'd throw off the blankets, shiver with cold and then I'd need to pee every hour. When I woke up I'd feel exhausted and anxious and have a coffee, which didn't help! It was a vicious circle, and I was a horrible person. I said terrible things to George - I can see why relationships fail.

Now, I am on HRT, but I look back and wish that I'd known what was going on.

And oh yes, over the years, there's been plenty of sniggering, and: 'Don't ask her, she's not functioning right at the moment!' I know that I've used it as deflection myself - like a disclaimer. 'Oh, it's menopause brain! Silly me!' You feel as though you have to laugh about it. The irony is that during pregnancy, people understand that it's a time when hormones change dramatically. But when they dwindle later in life, people can be dismissive and derogatory.

As Mariella says, we need a menopause specialist in every surgery. We need education, not just about puberty and periods and pregnancy, but also about menopause. That way, people will understand it's just a stage of life and won't fear it. It's the same with work - menopause policy needs to be in place so that if women need support, it's available.

Menopause has become a huge conversation for me this year. I helped to launch the This Morning Bus and then went on Loose Women. At last, everybody is sitting up and paying attention. Once we've got support, we can continue to do the amazing work that we do every single day; being ambitious, looking and feeling fantastic and being present with our family and our friends.

Chair of Menopause Mandate, Mariella Frostrup, is one of the UK's most respected broadcasters and columnists. Co-author of Cracking the Menopause (2021), she made the ground-breaking BBC1 documentary The Truth About...The Menopause and currently presents her own daily show on Times Radio.

My menopause - in retrospect - was almost without event. I didn't have 30 hot

flushes a day or migraines that crippled me for days out of every month. My joints didn't ache so badly that I could barely move, and I managed to maintain (and retain) my relationship with my husband and my children. So, I am aware that - in the scheme of things - I had an easy time.

However, for two years, I was desperately miserable, stressed to my back teeth and barely able to sleep. And for that entire time, I had absolutely no idea what was going on. I wondered whether I was developing early-onset dementia, whether I might just be going a little bit mad, and whether, perhaps, this is what ageing was going to be like. I wasn't happy about that prospect at all.

For many of you who have been through menopause and are out the other end, you'll recognise those months or years of feeling below par but without any tangible reason.

And with the symptoms comes the self-loathing. Nobody chooses to feel irrational anger, and I still remember that rage when I get home and the dishwasher isn't emptied in spite of there being three other sentient beings in the house, all watching telly (though when it comes to dishwashers, it's entirely justified).

My daughter swears that I once threw a book at her in a fit of temper, but I have no recollection of having done so. I am sure - I hope - that she is just trying to make me feel guilty. I was - apparently - unreasonable on occasion with my husband, which I find far easier to believe. But I mostly remember that constant feeling of not being right, of not being myself and genuinely having no idea why.

I recently read the most brilliant description of hot flushes by an American writer, Kathryn Baecht, on mcsweeneys.net: 'A mildly uncomfortable sensation that feels like a new star is being born in your abdomen and all the heat from the explosion is radiating out of your face. Only hotter.' I had two, and I can testify that her description is accurate. Though if I remember correctly, it was a little hotter than that.

Eventually, in my late 40s, I sought help from a GP, who offered me antidepressants. A second GP suggested that I might be coming up to menopause, but then decided that I was postmenopausal. Finally, I saw an expert, and she firmly pinpointed perimenopause and prescribed HRT - oestrogen gel, micronised progesterone and - a little later - testosterone. That was nine years ago, and I feel I have been incredibly fortunate to have stumbled

#### on the right care.

But that makes me all the more determined that women and healthcare professionals are educated to recognise the symptoms of perimenopause, and that the tools - HRT, CBT, lifestyle advice, whatever is necessary - are available to all. It's certainly not the case at the moment.

## Michelle Griffith Robinson, former Team GB triple jump Olympian, campaigner, life coach and mentor.

We talk about menopause in my house. My kids are 19, 15 and eight - and they're aware of it and the work I'm doing around the subject. They call any outbursts my 'peri-meni moments'. It's great. We also talk about periods and pregnancy and unhealthy relationships. That means they're aware of things before they get to a certain age or are in certain situations. These days we're so much more open with our kids and vice versa, and all these things ought to be normalised conversation.

I'm still having 28-day cycles, but I'm certainly perimenopausal, and at the moment the biggest symptom is brain fog. Yesterday, I couldn't remember my bloody name! I've got my HRT, but even so, it was one of those days - I couldn't remember what day it was either! And I was bone tired, which makes my brain worse. Menopause is such a moving target when it comes to symptoms. About three or four years ago it was lack of libido that was the problem, but that's returned.

I check in with my husband a lot and try to be open about all these subjects, and I think that's important for keeping a relationship strong. At this time of life you're more vulnerable, you aren't who you were ten, 15 or 20 years ago, but that's ok. Why should you be? We are all evolving and changing daily. As someone once said to me, ageing is a privilege. But we also need to own what's going on with ourselves, get support in the right places and understand that one size doesn't fit all, and of course communicate with our loved ones.

I think the one great thing that I've had in my toolbox is being a life coach so I'm a lot more aware of how humans can behave. When I was younger, I might think that someone was behaving like an arsehole. Now, I'm by no means a psychologist, but I'm also looking at what's going on behind the situation. I'm not that tolerant the entire time - but I'm more tolerant than I used to be! Menopause is holistic. We need to look at a change in lifestyle, which is a full 360° approach. Yes, I have my HRT, but I have to be eating well, sleeping well and moving well to feel good. We need to look at a shift in terms of celebrating life, as well as the change. My glass is always full and spilling over and I feel fortunate.

I aim to be the best version of myself. It's about empowering other black women to do the same. I know that I'm on my game when I'm doing the right things lifestyle-wise and that applies to all of us. You don't have to do a long workout, you can just put on your music and blare it out. It's about making better choices generally and making sure you put aside a bit of time for yourself every day. One of my best friends is on HRT and has just got testosterone. I'm thrilled for her, but I said: 'Those beers you're having during the week, they've got to stop as well.' We need to put in the work too.

When I did interviews for Black Lives Matter, I said to a white friend, if you are ever in a situation where a white person says something derogatory about someone of colour, then you must take them aside. It's the same with menopause. It needs calling out. I feel so strongly about the subject. If someone says dismissively: 'Oh, she must be going through the change.' I'll respond: 'Ok then, how are you helping her?'

Personally, I've not experienced menopause discrimination, but I was once privy to a conversation where someone said: 'They're all getting at each other in that top office because they're all going through the Change.'

I couldn't help myself. I replied: 'Perhaps they need to look at their HR and be supported. Perhaps it's not the women's fault?'

He said: 'But there are so many up there though.'

I said: 'If there are so many, where's their support?'

The person went from being utterly flippant in tone and comment to admitting: 'I never looked at it like that.'

There has historically been an appalling lack of diversity in the menopause conversation. Black women have not always been treated fairly when it comes to health, childbirth and, of course, menopause. There need to be voices and perspectives from all communities and ethnicities. Everyone should be given the same standard of treatment, whatever their economic situation or location. As a campaign, let's push knowledge, kindness and empathy, as well as a comprehensive approach, to hopefully improve things for all women.

## Penny Lancaster, freelance photographer, model, actor, TV panellist and special police constable.

I have a very strong sense of duty, which is why I work in the police force. Equally, I think that if you have a voice, it's your duty to speak up. I feel privileged that women listen to me about the subject of menopause. Lots come up to me and say that they've heard me or my fellow campaigner Lisa Snowdon speaking, and that's how they realised that their symptoms were menopausal. Sometimes the two overlap and women want to chat about menopause when I'm in uniform, though I use my discretion, and people are very respectful! As an aside, the police are excellent on the subject of menopause. They have a very strict code of ethics and they look out for their employees.

For me, the first signs of perimenopause were during that first terrifying Lockdown in March 2020. The fear factor was huge as nobody knew what was happening. We were in the United States and brought the kids out to stay with us.

One evening, I started to burn up with heat and thought: 'Oh God, this is it, I've got Covid.' I was lying on top of the bedcovers dripping wet, then panicking and thinking I couldn't breathe properly. But within ten minutes I was absolutely freezing cold and back under the covers again, thinking to myself: 'Hang on a minute, that's not Covid!' It didn't even dawn on me that it might be my hormones. These sweats came and went over a few weeks and then tapered off. I did at one point wonder when I'd had my last period, but pushed it to the back of my mind because there was so much else going on.

However, later that spring I wasn't coping well. I assumed things were getting on top of me because I was home-schooling. There was the pressure of trying to keep everyone calm and ensuring the children didn't worry too much. I am quite an emotional person - I always wear my heart on my sleeve, and the kids know that Mummy gets teary now and again. But this was far beyond occasionally welling up.

There was one moment when I lost it completely. I'd called them all for dinner and they ignored me. I screamed, threw the dinner plates across the kitchen and then crumpled on the floor. Rod ushered the boys out of the room, saying: 'Boys, give Mummy a minute.' It was terrible. For them it was like: 'Oh no, Mum's snapped, she's broken.' I was crying uncontrollably, thinking I can't deal with this, and if I can't cope, how am I going to look after everyone else? It was such a vulnerable place.

Rod gave me a hug and the boys came in and hugged me and said it was going to be OK. We all worked through it together. That's when it dawned on me that I needed help. I got in touch with my doctor and was prescribed antidepressants. But two months later I was still struggling, and I was having hot flushes during the day as well.

One day, I was speaking to the girls at Loose Women, and they were sharing their menopause experiences. They said: 'Penny, you don't need antidepressants darling, you need some hormones.' I was staggered - I'd got to the point where I thought I was really in trouble if even the antidepressants didn't work.

Fortunately - and I know that this isn't available to everyone - I found a specialist and was prescribed HRT. It was like night and day. The hot flushes stopped and I could sleep at night. I was clearer in my mind and the depression lifted. I'm able to laugh and have my highs and also get upset about stuff, but in a place where I can manage it all.

There are many who don't want to or can't take HRT, and I totally respect that. But I've been on thyroxine for an underactive thyroid since my early 20s, and I know that my body needs it. I feel the same about HRT. I'm simply replacing what my body isn't able to make.

In retrospect, perhaps I ought to have realised what was happening. My mother went through a terrible time at the same age, and I remember it vividly. Her periods became erratic and very heavy so she had surgery, which was supposed to help, but it accelerated a lot of the symptoms, and she wasn't given HRT. She left my dad and suffered emotionally with that - we all did. At the time we thought it was part of life, but perhaps her struggle might have been avoided had she had the right support and knowledge.

Rod and I even discussed the subject. He asked: 'How old was your Mum when she had that bad time?' So we knew there might be a link. But when it happened, it simply didn't dawn on us. Symptoms don't just happen overnight, they creep up on you. And you've got kids and a house and businesses, and you just put it out of your mind.

I am so proud that Rod is happy to speak out and encourage men to pay attention and be supportive. The fact is that 50 per cent of the population

will go through menopause and 100 per cent will be affected by it. That's why everyone needs to be taught about it; schoolchildren, the medical profession and men as well as women.

Menopause has to be taken seriously, and the stories in this book show the awful depths to which some women plummet. I found my experience hard, but it pales in comparison. Enough of the depression and divorces...and worse. Of course, there's so much pressure on the NHS and so many needs that have to be addressed. But we can't shout from the rooftops once and feel that's enough. We need to keep the pressure on and the awareness going. I know women need help here and now but it won't happen overnight. We're edging forward and we will maintain that momentum.

# CHAPTER 2 **ANTROF** MISDIAGNOSIS BUT S

A lack of education, for both women and healthcare professionals, means that even common symptoms of perimenopause and menopause are often not recognised. A huge number of the stories sent to Menopause Mandate detail years of symptoms and suffering before women finally realised that their problems were linked to hormones and sought a diagnosis. Sadly, many were misinformed even after they tried to get help.

Research suggests that around 30 per cent of those who consult a GP for low mood caused by menopause are offered SSRI antidepressants, yet National Institute for Health and Care Excellence (NICE) guidelines recommend that first-line treatment should be hormone replacement therapy (HRT).

Again, we emphasise that this is not about blaming healthcare professionals. They are desperately busy. There is a shortfall of around 4,000 GPs, and besides, menopause hasn't been a vital part of the GP curriculum, so it's unfair to expect them to all have specialist knowledge.

There's hope on the horizon; menopause was introduced to the school curriculum in 2020, and the government has pledged that from 2024 all graduating medical students will have mandatory training and assessments in women's health. But for hundreds of thousands of women it's too little, too late.

#### I had no idea what was happening

I honestly didn't know what was happening to me. I'm now 51 and when my symptoms started at 451 thought that the grief of losing my brother was to blame.

I was rushed to the hospital with a racing heart and told it was a panic attack. I was referred three times to the GP and a heart specialist, and everything was found to be normal. I carried on while suffering with terrible anxiety. Although I was referred to counsellors, at no point did anyone say that this might be perimenopause. It was only when I spoke to a friend who was on HRT that I realised it could be my hormones. Now I'm on HRT and most of my symptoms have gone.

#### 20 symptoms - but each treated individually

I had 20 symptoms of perimenopause for more than 18 months, including the feeling of electric shocks, sweating, mood swings, monthly UTIs and palpitations, with my GP treating each symptom separately. Eventually I wrote to the practice with my list of symptoms and said I wanted HRT.

When I was finally prescribed oestrogen gel it was such a relief. However, my local pharmacies have now run out of this, so the GP prescribed a spray instead, which is also not available. I have now been given patches which are not working as well and I am struggling with my job as I am so exhausted and stressed.

#### GP doesn't want to 'dabble' in meds with me

I was offered antidepressants three years ago as it seemed that my low mood was likely to be depression. I pushed for a follicle -stimulating hormone (FSH) test but was told it wasn't necessary as I'm so young - only 39.

I have now had menopause confirmed. It hurts. It hurts my head. It hurts my family, my work and my mental health and I have suffered for three years thinking I'm going mad. I'm still awaiting HRT as I have been referred to a consultant. The GP doesn't want to 'dabble' in meds with me.

I should hear in the next 12 weeks, during which time I'll slowly lose myself a bit more. So, it'll be four years since I've felt missing in my own body, but hopefully I will finally get some help.

#### Antidepressants didn't work

I started to notice symptoms about four years ago at the age of 41. The main ones were severe anxiety and suicidal thoughts. I was put on antidepressants which seemed to be effective in helping with the anxiety, but while on them I noticed a variety of other changes. These might have been symptoms of perimenopause or side-effects of the antidepressants; vaginal dryness and loss of libido, weight gain, sore and dry eyes, headaches and difficulty concentrating.

It took two years to finally wean myself off the antidepressants. Once off them it was clear that the changes I had been experiencing were not caused by the medication, but must surely have been hormonal.

#### Sent to a cardiologist but it was menopause

I went to the doctor with anxiety, breathlessness, tightening of my chest and an overwhelming feeling of imminent doom. I just felt terrible and in a constant state of panic. I saw a female doctor, who you would think should have been able to help me, but all she said she could do was to have me checked out with regards to my family history of heart disease.

I was then sent to a heart consultant and ended up having an angiogram which was, of course, fine. It was watching Loose Women on telly that told me all my symptoms could be connected with the menopause and I went privately to ask for HRT. It was as though my doctor hadn't ever heard of the menopause and at the time I had no idea panic attacks could be caused by falling hormones. Thank you so much, Loose Women!

#### **Pressurised to try antidepressants**

I contacted my GP to ask for help and advice when my menopause symptoms were getting worse and was offered antidepressants! I collected my prescription, even though I knew I wasn't going to take them.

However, I felt slightly pressurised by my GP to at least try them. It seemed to me that she was only focused on my low moods - which weren't that bad - and completely dismissed my other symptoms. I felt brushed off and it put me off speaking to any other health professional.

#### More training is needed

Generally, I have been shocked at the lack of training in the NHS. I'm 49 and have been taking HRT for six months. My GP initially wanted to prescribe antidepressants for my symptoms of insomnia and low mood. I had also skipped two periods over the last nine months and had put two and two together. I refused. I was insistent that I wanted to try HRT.

The GP clearly had no idea what oestrogen gel was and offered me tablets. He then reluctantly prescribed me patches and dismissed micronised progesterone. Despite my telling him how much better I felt on HRT, it seemed like he was only concerned with getting me to stop taking it as soon as possible. He told me that antidepressants helped with hot flushes, even though I have never suffered with them!

A couple of weeks after starting HRT I felt that a light had been switched back on in my head. I don't think I realised just how low I had felt before taking the HRT. I'm now under a new GP who is far better informed.

#### I took the NICE guidelines to my GP

Due to a partial hysterectomy at 42, I knew I wouldn't have the signs of

stopped periods to alert me to menopause, but knew it was likely to occur within five years.

I didn't have any idea what the wider symptoms were, so I didn't recognise the signs of perimenopause. In retrospect I realise that all those joint aches and intense bouts of ennui were almost certainly connected.

I finally went to the GP when I couldn't stop crying at work. I always cry easily but this was something else entirely. I knew it just wasn't me. She was very sympathetic, but also keen to point out my stressful job and the recent loss of my father-in-law and suggested that my symptoms might be stress related, recommending that I take time off work or an antidepressant.

However, I had done my homework and gone in armed with the NICE guidelines - thank you, Mumsnet, for linking them on your menopause forum - and was prescribed oestrogen.

Once we had tweaked the dose - I needed a lot - I felt myself again. Regular exercise, minimal sugar and minimal alcohol are also essential. Damn you, menopause!

#### I had no idea that my symptoms were menopause

I started to experience intermittent hot flushes aged 49 whilst working as a paramedic. Initially, I purchased some herbal medicine from a high street chemist, and that seemed to help.

Life went on for about two and a half years and then I started to have problems sleeping, restless legs, poor concentration, memory loss, brain fog, terrible hot flushes, low self-esteem, lack of confidence - the list seemed endless. I spoke to my (female) GP. Her response when I mentioned the menopause was: 'Well you're about the right age.' She prescribed antidepressants.

After taking some time off sick from work with stress, I made the very difficult decision to take early retirement. I was only 52, but I was terrified my poor memory and brain fog would cause me to put a patient in serious jeopardy or worse. I was also terrified to voice my symptoms to my managers or to occupational health because I thought they would have no option but to sack me.

I had no idea my symptoms were due to menopause and feel that I was extremely vulnerable. I don't think there will ever be a time when I don't regret leaving the ambulance service. I wish there had been someone I could have turned to who understood what I was going through.

#### I was sent to a psychiatric nurse

Three years ago, I went to see my GP struggling with symptoms I couldn't really understand; brain fog and hot flushes. My GP told me I was depressed, despite me reassuring him I absolutely wasn't. He insisted on referring me to see a psychiatric nurse, which I did to shut him up. However, the psychiatric nurse wondered whether I might be perimenopausal, and asked why on earth I'd been sent to her as I was clearly far from depressed.

#### I bled so much I needed an iron infusion

I suffer from polycystic ovary syndrome (PCOS) and have always had problems taking the pill. At 40 I started to suffer with perimenopausal symptoms. I fought to get to my local menopause clinic, who decided to prescribe me the pill. When I started to bleed, their answer was to up the progesterone content. Every time they upped it, I bled more. I ended up on an extreme amount of progesterone and needed an iron infusion to recover from the bleeding as well as a hysteroscopy to investigate the cause of that. The more progesterone I was given, the more my mental health suffered.

I have a lovely GP and in desperation I went to her and asked about HRT. This doesn't make me bleed, but the progesterone content most definitely affects my mental health. The minute my ten days of progesterone kick in I feel low, empty, and sometimes suicidal. I feel my only option now is to have my womb removed.

Why is so little known about progesterone sensitivity in women and its links to mental health? This should be talked about so much more.

Urgh... the continual frustration.

#### Six months for a prescription – then it was out of stock

I was initially told that I was too young to be perimenopausal and was put on antidepressants. I put on two stone in two months, which made me feel worse.

Three years later, I had a total hysterectomy and was discharged with no advice or HRT. I contacted my doctor a month after the operation, only to be told they wouldn't give it to me and that I had to go back to the surgeon!

It took me six months of going backwards and forwards to finally get a prescription. Then, once I went to the pharmacy, I was told that it was out of stock. I'm tearful, not sleeping, having night sweats, losing my hair, my skin has gone

dry, and the brain fog is so bad that I go to bed because I cannot cope with anything or remember anything. Why is it so hard?

#### I had no idea about perimenopause

I'M 53 now and I feel amazing.

I wish someone had sat me down when I hit 40 and told me how to look after myself in the coming years.

At 43 I just fell apart. I had no confidence, did a lot of ugly crying, didn't know how to dress and felt so unfeminine. My GP put me on antidepressants.

I had NO idea what perimenopause was until I hit menopause at 47.

That's when the penny dropped and I realised that the baffling symptoms I'd been experiencing were the support act to the main show.

If I had known better, I would have tracked my symptoms and asked for transdermal HRT. Had I started taking it in my early 40s, it would have saved me a lot of misdiagnosed conditions and referrals to specialists for unexplained and very distressing UTIs.

I know better now. I have still not been offered HRT, but I know how to manage my symptoms better. Keeping a health diary, and reducing external stress are the two biggest things I would recommend. And take your diary to your GP so you're not sitting struggling to remember it all.

#### Lack of support for women with learning disabilities

My story is not about me, it's about the women I work with. I work as a relationship counsellor for adults with learning disabilities. Some of the women tell me how they are feeling, and it's clearly related to the menopause! However, they don't seem to know or understand what is going on. Their support staff say they are being difficult or have challenging behaviour! It's sad to hear this, when it's clearly not the whole story.

#### **Diagnosed with anxiety disorder**

At the age of 51, I started to suffer from brain fog, depression, crying and panic attacks. I quit my highly paid job as I could no longer cope. However, I didn't have any hot flushes and my periods were normal. Hormone tests came back in a very good normal range. My FSH was even surprisingly low for my age.

After being referred to a psychiatrist and psychologist, I was diagnosed with Generalised Anxiety Disorder (GAD). I had six months as an outpatient in a very expensive mental health clinic and was prescribed anti-anxiety medication which I stayed on for five unhappy years.

So, I got on with it. I had no choice. I got on with my diagnosis, my medication, my sad little life with a poorly paid job, as I felt I was worthless.

Then I saw Davina McCall's TV programme: Sex, Myths and the Menopause. I phoned my GP the next day and explained that I thought I was suffering from menopause and not GAD, and she fully supported me.

I'm now off the anti-anxiety medication and am thriving on oestrogen patches, micronised progesterone and testosterone. There's no brain fog, no panic attacks, no crying for no reason and no depression, just a balanced woman looking forward to her new life with her hormones back in kilter.

#### I was repeatedly told to lose weight

At 39 I started to have symptoms of perimenopause, although I didn't know it at the time. My face would be dripping with sweat for no reason.

I was very tearful and low in mood, I was already on antidepressants following postnatal anxiety, but I remember realising that they weren't working any more. I contacted my GP and they changed my antidepressant. It made no difference.

I got recurrent UTIs - one every six weeks - and was told I was wiping incorrectly, back to front, but I wasn't.

My joints ached so badly. I was told to lose weight.

I complained of awful fatigue. Again, I was told to lose weight.

At one point I was asked if my periods were regular. They were, so I was told it wasn't menopause.

Then I didn't have a period for three months. Then I bled for six weeks. After I'd suffered these symptoms for a whole year my GP finally said I might be perimenopausal. That was it.

No tests, no referral, no: 'Would you like anything?' Nothing. I've had to go private.

#### We need more support for those who can't take HRT

I was diagnosed with breast cancer twice in my 20s. As part of my treatment, I am on medication that has put me into a chemically induced menopause to reduce the risk of the cancer returning.

Being thrown straight into a postmenopausal state, skipping out the 'peri' part, has been very difficult. The symptoms have been incredibly intense and extreme.

HRT is not an option due to my cancer being highly oestrogen driven (oestrogen receptor positive - ER+).

My debilitating symptoms were dismissed as just being part of my cancer treatment. After several attempts at stressing how much I was struggling, I was offered some antidepressants to try and help alleviate the night sweats. But what about the rest of my symptoms?

It took a consultation with another specialist to refer me to a menopause clinic for support, which I'm still waiting for. Whilst there may be little they can do to help, being heard is a start. More support for those who are unable to have HRT is absolutely needed.

#### My daughter's wedding was a blur

I am 66 and I would say I have been suffering with menopausal symptoms for at least 16 years. I started having heavy periods, and by heavy, I mean afraid to go anywhere because of accidents. I had a dilation and curettage (D&C) which removed part of the lining of my womb and that helped for a while. I then found out I was severely anaemic and had to take iron.

I was extremely moody, angry, violent and throwing things. My children now tell me that I was a different person. I eventually went to the GP when my mood became so low that I didn't want to leave the house. My daughter was due to get married and I wanted to be happy and enjoy the day. A nurse friend said I was probably menopausal and to go and ask about HRT.

So, when the GP said I needed antidepressants rather than HRT I went for it. They took a while to kick in and my daughter's wedding was a blur. The night sweats, hot flushes, palpitations and muscle aches were just some of the normal symptoms I learned to live with. My work and my sex life suffered due to constant tiredness and low self-esteem.

These symptoms eventually passed and have been replaced with postmenopausal symptoms such as bleeding because of dryness, severe itching, and, obviously, no sex life. I went back to the GP to get advice, as menopause had now become a buzzword and everywhere you turned it was talked about.

So, I asked about HRT once again and was told that the ship had sailed. I came off antidepressants of my own accord after taking them for several years and I don't think I will ever feel normal again. I also worry about my risk of osteoporosis, heart problems and dementia. I hate complaining because I know people suffer much worse things, but I have two daughters who will go through menopause, and I don't want them to suffer as I did.

Fortunately, menopause is now talked about, but it's too late for thousands of women who have suffered in silence. I had a friend who took her own life, and I am convinced she was severely affected by menopausal depression but couldn't talk to anyone at a time when menopause wasn't discussed, and women just got on with it. Let's pray this silence has ended for good.

#### It's a fight to even be seen

I have had perimenopausal symptoms for a few years. I was fobbed off by the doctor several times, yet I was over the age of 45 and presenting with low mood after ovulation, low libido, worsening allergy and asthma symptoms and joint aches. I was eventually offered antidepressants which I was reluctant to take, so I asked for a referral to a menopause specialist. I am now on HRT but feel that I would benefit from testosterone, as I still have issues. But I am reluctant to push for this as it's such a fight to even be seen. We should not have to suffer like this.

#### I was told that my lifestyle was stressful

I'm in my 50s and have been using HRT patches for just under two years. When I sought help for the lack of sleep, brain fog and terrible anxiety, I was fobbed off or misdiagnosed. I was told my lifestyle was stressful and offered antidepressants and sleeping tablets, both of which I refused. I was a single mum and felt I needed to be awake and alert to be a decent parent!

When I asked about HRT, I was warned about a high risk of breast cancer, which frightened me off. I tried over-the-counter remedies for the hot flushes, sleeplessness and aches and pains. Through trial and error I tweaked my diet and changed my exercise routine.

After my sister managed to get prescribed HRT patches in Lockdown, I spoke to a GP over the phone. I told him about my sister and said that I wanted patches too. After a few questions, he prescribed me the same ones. It has made a huge difference, but I cannot believe that such important treatment is not free and readily available to all who need it. My experience was pretty unpleasant, but nowhere near as bad as that of many others who I know are really struggling.

Then throw in the added expense of HRT, especially now, when many are choosing between heating and eating. How can we stand by and allow women to suffer like this?

#### I continue to suffer

Four years ago, when I was 57, I was feeling down and anxious. I had been through the menopause but didn't realise that low mood could be part of it. I went to the GP and saw a locum doctor, an older man. When I burst into tears, he was so busy looking at the computer that he had trouble understanding what I was saying. Without really looking at me he gave me a prescription for antidepressants and suggested self-referral for counselling. I came out embarrassed and felt like asking the receptionist if he really was a doctor!

I threw the prescription away; I didn't want medication. But I had counselling, where menopause wasn't even discussed.

About a year later, I went to the GP on another matter. This time I saw the female practice doctor and I thought that she would understand. I mentioned that I had low mood at times and wondered whether it was menopause. She just looked at me, smiled and said nothing! I left the surgery upset that even she didn't seem to want to know. So, I continue to suffer and at 61, it looks like it's too late for HRT.

#### **CHAPTER 3** FRIDICULOUS OF BOU SY L 6 ARE IN CIRCLES?

hese stories exemplify the distressing, sometimes dramatic and often devastating range of perimenopause and menopause symptoms and the effect that they can have on women's lives. It's thought that most women will suffer from at least one symptom of menopause. One in four will experience severe symptoms that will affect quality of life.

There are oestrogen receptors around our entire bodies - from the heart to the skin, bones and brain – and the range of symptoms is quite extraordinary. It's said that there are more than 50, though the number is probably even higher, and they include joint pain, muscle pain, anxiety, depression, brain fog, headaches, hot flushes, night sweats, dry eyes, dry skin, gum problems, itchy skin, dry vagina, increased UTIs and decreased libido. The list can seem endless and daunting.

#### I had pain in both hips

After visiting two GPs who couldn't decide whether I had arthritis or bursitis in both hips, it was agreed I'd try steroid injections to see whether they helped. They didn't. After some personal research I asked my GP whether I might try HRT. He agreed, and within three weeks the pain was gone, as were many other symptoms I hadn't even recognised as menopausal. That was two years ago, and I've never looked back!

#### I thought I had Alzheimer's

LAST year was a massive turning point. I found myself researching symptoms of dementia and Alzheimer's disease. I was terrified and convinced that I had early onset dementia or Alzheimer's disease because my memory had been getting worse by the week. I couldn't focus on anything. I couldn't even read a book – I would read the same page over and over without it registering. My work was suffering, and I'd sit looking at a screen wondering what I was supposed to be doing. I ended up going off sick for two months and was seriously considering giving up a job I loved because I felt completely useless. I was supposed to be supporting people with mental health issues. How could I do that when I couldn't even remember their names half the time?

One day I was pulling onto a big roundabout and had complete brain fog. I couldn't remember the rules of the road for what felt like a minute but was

probably only a few seconds. It was the most frightening experience, as I could have killed someone or myself.

I'd been researching menopause and after this I made an urgent appointment at my GP surgery. I explained all my symptoms and my GP agreed I might be right and asked what I would like to do about it. I suggested HRT, and she told me to go away and think about it first, then make an appointment for the following week to discuss it. I had been speaking to a colleague in work who was going through the same thing, and just talking to her made my mind up. I realised that what I was going through was not just me going mad, I felt validated.

The following I week I started on HRT and over the next month I began to feel better than I had in five years. It's left me so angry, but also determined to ensure that all women and girls are made aware of all the different symptoms of menopause and are brave enough to demand to be taken seriously. I honestly believe that if I didn't have such a good support network around me, my kids might have been left without a mother.

#### I left my husband because of my depression

When I hit 42, I started to experience debilitating depression. It came out of nowhere and I couldn't understand what was going on.

I left my husband the following year. We had been together since I was 19, but I couldn't continue with my up and down moods, and neither could he. I thought something was missing and couldn't understand where I had gone. It was as though someone had unzipped me, and I no longer felt like me anymore. I was still having infrequent periods and at times these were so heavy I didn't want to leave the house.

I met another man after the break-up and he turned out to be a narcissist, although I wasn't aware of this until it was too late. He would often ridicule me when I had a heavy bleed and said my body odour had changed. I now know this is a side effect of the menopause, yet at the time I didn't even know I was going through it. I had always been told you have to have no periods for a full 12 months.

#### The skin on my hands was split, infected and bleeding

My periods stopped at 48. In the previous five years I'd suffered several

unpleasant symptoms, including UTIs every few months, but I carried on, thinking this has got to stop at some point. Then, 15 months ago, aged 51, I developed chronic eczema on my body and especially on my hands. It has been the most painful and debilitating condition I have ever had, from washing myself, to cooking and cleaning. I work with my hands.

In the back of my mind, I realised that it was something to do with the menopause. All the skin on my hands was split, infected, swollen and bleeding. I was on a continuous cycle of steroids, antibiotics, antibiotic cream, ointments and washes from the GP.

I reached breaking point last month and then managed to get a face-to-face appointment with my GP. I now know my eczema is caused by lack of oestrogen causing my skin to become very dry. He prescribed me three months' supply of HRT patches. I've only been wearing them a couple of weeks, but my skin is already starting to heal. It's been life-changing.

#### I've had two frozen shoulders

I am 47 and started HRT six months ago – I am fortunate because my nurse practitioner has been very helpful and the prescribing of HRT for me has been the smoothest part.

Initially, the worst symptoms were a high level of joint pain, severe headaches, flushes and not feeling like myself – I'd often feel stressed and low. On certain days the headaches affected my ability to work efficiently.

I'd love to know if there is research on joints, inflammation and oestrogen levels. I have a right frozen shoulder. Five years ago, the left one became frozen and resulted in two steroid injections and surgery. I've just had the first steroid injection on the right one. This causes so much frustration and pain. I have no risk factors other than age and being a woman. Until I started this journey, I never even knew joint pain was a symptom of the menopause.

#### Three doctors said I am too young

I am 43 and believe I am suffering many perimenopause symptoms. I have severe shortness of breath but not asthma, I have extreme joint pain, itchy feet, insomnia, migraines, brain fog, lack of sex drive and now irregular periods, and feel like I could just sit and cry. I have now seen three doctors, all of whom have dismissed what I say as I seem too young. I have explained my mother was a similar age when she started with symptoms, and whilst acknowledging that this did have a bearing, they said it was still unlikely that menopause could be causing my symptoms. I have been prescribed an antidepressant for my migraines.

I don't know what do now as I don't have the energy to keep arguing the point, and I can't face being dismissed again. It is affecting my whole life and it feels as though no-one cares.

#### HRT made me bleed

My periods had completely stopped so I was put on HRT. It stopped all my menopause symptoms and I was happy again. But this was only for a few months until I started bleeding. This would last for weeks. I went for scans time after time but nothing sinister appeared. I stopped using HRT and the bleeding stopped, but menopause symptoms soon came back, and I could not cope with them. Doctors tried me on all sorts of HRT, but every time I would bleed constantly. I am still in this situation now. I have recently had to stop HRT again and, yet again, can't cope with the symptoms.

#### In agony from joint pain

I started having hideous joint pains 18 months ago. My elbows and wrists were constantly painful and it really affected my work and life. I was in pain when I slept and often in agony when I was awake. I had six months of physiotherapy, an MRI scan, X-rays, and everything came up fine. It was relentless. I could barely walk my dogs or use a phone or computer mouse.

I eventually heard Dr Louise Newson's podcast talking about joint pain being a symptom of menopause and it clicked! I am 52 and my periods had stopped. Why did nobody think that it might be menopause? A load of reading by me, a great discussion with my supportive doctor, and HRT almost totally got rid of the pain as well as some of the other symptoms that I just thought were a part of ageing and had to accept.

#### **Crippled by five-day-long migraines**

I have suffered from migraines since I was in primary school - they run in my mother's side of the family. I get the classic sort with one-sided blindness,

hypersensitivity to light and noise, vasodilation of blood vessels in the brain and a stiff neck.

Despite being used to excruciating pain, nothing could prepare me for what lay ahead during menopause. Migraines that once lasted one to two days at most during childhood were now up to five days long, and the pain was infinitely worse. Much of the time I was bed-ridden. They were accompanied by extreme nausea, loss of balance and at one point I began to think I was suffering from some form of early onset dementia, as I was struggling to think coherently. One thing I've seemed to escape has been the hot flushes. Hopefully, it will stay that way.

I'm medically trained as an NHS physiologist specialising in neurological disease, and when I had my medical head on I realised that my symptoms were most probably the product of menopausal changes. However, it made the sudden memory losses no less exasperating.

Fingers crossed, I am now emerging from the worst of it and I feel more like my old self again. This whole experience has lasted around three and a half to four years, and hopefully I am now making a full recovery and will be able to do the humble things I enjoyed before the storm arrived, such as walking in the park, meeting up with friends, being able to sit at my computer or simply relaxing with a book.

I wouldn't wish this on anyone. If you are suffering, seek help.

#### Lack of information meant I chose not to take HRT

I am 63 years young, a mother to three amazing children and I have four beautiful grandkids. I also have sweats night and day which are sometimes accompanied by heart palpitations. They are debilitating to say the least. I also suffer from brain fog - that feeling of, 'Wait a minute, what was I doing?'

But there seems to be so little information out there, even on Google or social media. I have had days when the exhaustion is so overwhelming, I just give up and either lie down or retire to somewhere in the house where I can have a good cry.

From choice I am still working, as otherwise I would actually climb the walls! I should mention I chose not to take HRT – again, because of lack of information. I just accept this as a way of life.

#### It felt like every bone in my body was broken

Most mornings, I struggled just to get out of bed. My job entails walking round and round a massive supermarket and some days I felt as though I was walking in slow-motion.

One day, I struggled out of bed when my usual 4am alarm went off and felt as though every bone in my body had been broken. I remember thinking the sensation was as if I'd been crushed or hit by a truck. This horrible pain became my new normal.

I seriously thought I had cancer of the bones. My husband said he couldn't stand to see or hear me in pain anymore and begged me to go to the GP. I saw a female doctor that week and she told me it was perimenopausal and she wanted me to have HRT patches.

I swear that within a week I felt no more bone ache and within a month I was truly back to my youthful self again. I hadn't realised the slow decline I'd been in, and I feel as though my oomph is back to the brim again.

#### I lost everything

I will be 50 this coming Saturday and it's a birthday I never thought I would see. Just over a year ago, I transformed from an intelligent, life-loving, confident and professional woman to an absolute wreck of a human being. I lost the job which I had been in for 10 years. I lost my home. I lost my partner. I lost all hope and I lost my mind.

I stayed in bed last summer for four weeks and couldn't speak to a single soul. I went from being a busy, respected professional who was brilliant at what I did to a walking zombie. I was terrified that my brain - which has always been the tool of my trade - would never recover. I couldn't even make a cup of tea.

I had heart palpitations for five months solid. I didn't sleep for three weeks, despite sleeping tablets. And as for those so called 'hot sweats', well that's a ridiculous turn of phrase. I was on fire and having simultaneous panic attacks - I thought I was having a heart attack at least three or four times a day and had to lie on the kitchen floor until it eventually passed.

But I'm still here. And so, so thankful that I am. The reasons I am still here are that, firstly, I couldn't work out a way to take my life. I wrote suicide notes. I researched it. But couldn't find the right way.

Secondly, I have the most wonderful sister, who was on suicide watch every day for months. She always kept at least half an eye on me, and when she couldn't she subcontracted the job! She is a truly wonderful person.

Thirdly, when I was finally made to go to my GP, my doctor was empathetic, kind, completely understanding and recommended a seriously high dose of HRT without any hesitation.

I recognise I was lucky. Nobody had prepared me for the absolute devastation menopause can cause in your life. My mother died by suicide aged 45. She was a wonderful, loving, brilliantly talented person. But she unexpectedly took her own life when I was 19. For a long time, despite therapy, I struggled to wrap my head around how someone who was a selfless, loving mother of three children could just do this. Then, last year, I completely understood.

Every day during that dark, dark period was torture. And I never thought it would be any different. I could not locate a glimmer of joy in anything - despite all the efforts of the wonderful people that surrounded me. And they tried hard, believe me.

I have a wonderful grown-up son but despite knowing how my mother's suicide impacted on me it simply didn't matter. I had shut down completely.

But here I am. Still alive. And embracing life in a way I never thought I would. And I don't know if this rebirth is completely down to HRT. I've also taken up yoga (after vowing I never would), open water swimming - which has been excellent for sorting my nervous system and ridding me of palpitations - and had more therapy.

And I am now loving life - more so than before my breakdown. I've started my own business, which is gong ridiculously well, and my brain is properly motoring. I have more freedom than ever in my life, more purpose, more stimulation, much more confidence, and more satisfaction than I think I've felt for decades.

I get that menopause impacts on different women differently. For me, HRT is not a 'lifestyle choice' or a 'nice to have'. It is medication I know I need so that I don't return to the desolation of last year.

I am hoping the supply chains get sorted. If this condition happened to men, I have no doubt that every town fountain across the UK would be pumping out free oestrogen gel. But it isn't a male issue. And I am so grateful for this campaign to make it an issue for the whole of society. Even the capitalists have to recognise that losing half your workforce at 50 is bonkers, especially when they represent the most experienced, skilled, patient and smart half!

Finally, just to say, if you're in that dark place just now, know that things really will change. I know this is hard to believe. But it is true.

#### I need help

I am 46 and suffering debilitating anxiety and physical symptoms because of perimenopause. I've had to take time off work and am struggling at home. I'm unable to pay for a private menopause specialist. Please help.

#### My partner looks at me as though I'm inhuman

At 43 I was diagnosed with breast cancer and received chemotherapy and radiotherapy treatment. Because of this, I entered menopause and I've been suffering ever since. I'm unable to have HRT like most women and feel that I have been left out by not having any help. I've had years of suffering from depression, anxiety, mood swings, flushes and night sweats, as well as suicidal thoughts. I have been prescribed a high dose of antidepressants but am finding they're not working as well now. My partner does not listen to how I'm feeling and looks at me as though I'm inhuman. I'm crying most days, feeling frustrated that no one is listening to me. I feel alone and that I can't live my life, I'm just existing.

#### Even if Tom Hardy was interested, I wouldn't be

I went to see my doctor 11 years ago, when I was 53, about my hot sweats, lack of sleep and feeling tired all the time. His reply was: 'I have patients that have far worse symptoms than you and we don't prescribe HRT at this practice.'

All these years later, I still have the same symptoms, but added to that is a four-year long lack of libido. My poor husband is an absolute saint. I tell him that even if Tom Hardy was available and interested, I wouldn't be. We get by with lots of humour and love, but why should we? There need to be dedicated menopause practitioners that woman can access, without being made to feel that we are being a nuisance.

#### **GP** guffawed at my self-harming

I was plunged into hellish symptoms aged 43. I was all over the place with every

symptom going. Worst of all, one day a month I would feel such awful rage at myself that I even self-harmed. I was terrified and had had enough. I went to various GPs over the next four years. The one who I told about my self-harm attempt just guffawed at me! I stopped going to the GP and tried many natural approaches such as homeopathy, acupuncture and yoga, none of which worked.

I ended up back at my own GP and demanded that she refer me to the local menopause clinic. She said: 'No need, I work there one day a week.'

I nearly grabbed her, both screaming and celebrating!

I was put on HRT and am now on four pumps of oestrogen gel and taking micronised progesterone tablets every day.

I honestly believe HRT has saved my life. I still have mild symptoms and bad days but feel the need to share my story with all my friends in their 30s and 40s in the hope they don't go through the same experience as me.

Thank you for sharing and helping support each other and change!!

#### I remember whole conversations which never happened

The worse symptom for me is what I would describe as 'Mindstorms'. I've had whole conversations with my husband, where I remember exactly what he said, and where he was standing when we were talking. Then it turned out that they NEVER HAPPENED.

On one occasion, I'd dropped off one of his drawings and had been paid in cash. The person paying me had rolled up the notes and kept them together with a rubber band like some kind of dodgy drug deal. He asked for the money, and I told him I'd already given it to him. I specifically remembered, you see, because he'd chuckled when he saw the rolled-up notes. That chuckle came back to haunt me when I found the money tucked away safely in my cycling bag. I'd never given it to him. It was all in my mind. We now have a family gag, where they can challenge anything I say by chanting: 'Was I chuckling when I said that?'

I've unknowingly sent random texts that mean nothing and that I don't remember sending. I've thought that I've seen messages from people that have never happened, but which I've responded to. I have huge holes in my vocabulary; ordinary words that I've used regularly for years that I just can't find in my head. Don't even get me started on names. I've consistently dreaded the horror of talking to clients or my team, and then simply failing to find the words. Embarrassing and humiliating are the first words that come to mind, if I haven't lost them, that is. But it's the spread of cold fear that really took a hold in the beginning, which definitely exacerbated the problem. The desperate grasping for an alternative word, while trying to keep my poise and professionalism, rather than just wanting to curl up in a ball and make it all stop.

## **CHAPTER4 AMERRY** ISMANAGEME NTOF **RLY MENOPAUSE** 17G Π H 1 ΑΝΠ

his chapter is for the thousands of women who go through menopause before the average age of 51 and tells just a few of the many stories we received about it.

Menopause before the age of 40 is called Premature Ovarian Insufficiency (POI) and affects one in every 100 women. Between 40 and 45, it's called early menopause and affects five per cent of women. This can occur naturally, or it might be as a result of surgery or cancer treatment. As well as often being psychologically devastating, untreated premature or early menopause can have severe and lasting physical effects.

The official recommendation is that you should take HRT until at least the average age of menopause for the sake of bone and heart health. In reality - as these stories reveal - women often have to fight for a diagnosis....and suffer the consequences of such delays.

#### Told to get HRT privately

I had a bilateral oophorectomy [removal of both ovaries] at the age of 33 along with a hysterectomy. I left the hospital with HRT, but my GP then told me that because of my young age they could not prescribe it to me and I would have to get it privately. They did not offer a referral to the local menopause clinic and refused to do my blood hormone levels.

I have never felt so ill, so unable to function and so let down by the NHS. I had a one-year-old and a three-year-old and was unable to leave my bed due to menopausal symptoms which I was being told were 'normal'.

I have had to fight so hard to access HRT and wonder what happens to those women who do not stand up for themselves and fight.

#### A man wouldn't be treated like this

I am 34. I believe I've been experiencing POI for at least three years. I had never heard of perimenopause until two years ago when Caroline Hirons shared her experience in an Instagram video. Every word she said was so relatable that both myself and my husband cried listening to her.

I had thought I was losing my mind. I began going to my GP every three months listing my symptoms, taking in NICE guidelines for POI and requesting

they investigate or prescribe HRT. They refused repeatedly, despite my seeing every GP and healthcare professional at the surgery.

Eventually, a locum referred me to the only menopause specialist for our area in October 2021. I saw her in November, and she ordered six lots of blood tests every six weeks and informed me she'd do a review once the blood results came back.

By the following February my symptoms had me seriously suicidal. I wrote to the specialist begging she see me sooner, quoting the NICE guidelines for POI, as these recommend just two blood tests. I heard nothing. Eventually, I got through to the gynae secretaries who informed me that my calls weren't being returned as the specialist had had no secretary since December. In addition, the specialist had gone off sick the previous month and wasn't expected to return before the end of the year.

I have now paid for private treatment. I have got to credit card my health, because not going poses a real threat to my mental health, I feel like a shell of who I once was, as if I'll never again know the person I used to be.

My life feels as though it has been stolen from me and I feel like a slave to my hormones, or lack of them! I have evidenced repeatedly that I've done my research, I'm making informed requests, and that I know my body better than anyone. I have done everything I can to help myself.

It is a systemic failure that I have been battling for two years with no end in sight, and nobody listens.

Even the private menopause specialist, when I asked what I should do to cope between appointments, simply said 'keep doing what you're doing'. What is that exactly? Barely holding on? Experiencing serious health effects from the lack of hormones? How is any of that ok?

To top it off, my husband requested testosterone testing for himself in February 2022 for symptoms of testosterone deficiency. Within a week he'd been tested, it was confirmed, and he has been referred to urology for further investigations and likely testosterone treatment.

But my life, my suffering, my symptoms, my mental health, my responsibilities, my quality of life, my tears, my fight, my future health and life expectancy means nothing! How is this OK?! How many of us are being failed? Things MUST change. Women make up 51 per cent of the population, and right now it feels as though we mean absolutely nothing.

#### Why isn't there NHS support for us?

Even though my GP knew about my early menopause symptoms, no help was offered to me and I didn't know enough to push for more.

Thankfully, I found a wonderful menopause clinic through a friend. I read lots of their online posts and started to educate myself. I realised that I was at risk of osteoporosis and requested a bone density scan after which I was diagnosed with moderate osteopenia - the stage before osteoporosis. Thankfully there is still time to put things in place to guard against full-blown osteoporosis.

The menopause clinic is helping me to get my life and mental health back on track through HRT. I wish I had known about this support before I had resigned from my senior position at work and started to work part-time because I didn't feel like I could cope with the pressure anymore.

I honestly feel totally let down by the NHS. Why isn't there support in place for us? It's glaringly obvious to me that a woman aged 45 who hasn't had a period in over two years has something going on and it needs checking out.

I'm so happy that women are starting to speak out, so that in the future no woman should have their symptoms ignored through lack of medical training, or through the idea that menopausal woman don't matter.

#### I was 'too young' for menopause

I was 28 when I started having problems with my periods. I saw so many doctors, and most of them said that it couldn't be the menopause as I was too young. One actually said: 'Have a hysterectomy as that will solve your problems'. They just prescribed me antidepressants to try and help with the symptoms.

It took another five years before it was confirmed that I had had an early menopause and I was given HRT. Although this has helped with my symptoms, I still suffer from low energy and mood so take antidepressants alongside my HRT. I'm 49 now and still feel as though I am palmed off rather than being listened to.

#### I know it's menopause but nobody believes me

I had an ovary removed whilst pregnant 11 and a half years ago. I had a benign tumour and it was an emergency operation.

I'm now 42. I find myself having massively heavy periods that are irregular

and painful, making me ill and generally miserable. I have sweats that make me feel as though I'm burning up, I forget what basic items are called, I mix up names and have a massively decreased sex drive, which is causing issues in my relationship, and dryness.

I approached my GP practice, but they insisted I was too young for menopause. I calmly explained I only have one ovary, my mother went into early menopause and there must be something that can be done to check. Again, the doctor insisted I was far too young. They decided the best course of action was an internal scan as there must be something else wrong. I had the scan which I found traumatic.

#### Needless to say, it came back clear.

I approached the doctor again, who insisted that I was too young but eventually agreed that I could have a blood test. I then had to wait for my now irregular and horrid period to have the test. The results, the doctor tells me, are those of someone who is menopausal. Great, I thought, finally we are getting somewhere. But no! I am still too young, and I need a second test with the same results before they will do anything.

It is so upsetting as I have jumped through many painful, undignified hoops to get to this point.

#### We can't all take HRT

Approximately ten years ago I had a fibroid and had to have a hysterectomy, I then went into menopause. My GP was excellent and prescribed HRT which worked well and reduced all the symptoms. Then six years ago, I was diagnosed with breast cancer and my consultant would not let me continue with HRT. My life has been heavily impacted with serious hot flushes and night sweats; I am currently prescribed a drug which has helped with the hot flushes. My frustration is that not everyone can take HRT - please consider us.

#### Family history of early menopause

My periods became irregular about five years ago when I was 35, and for a few years this was the only symptom of menopause I experienced. At the time I went to my GP, who sent me for blood tests and a pelvic scan to rule out anything else.

The results came back normal, so I was told there's nothing to worry about.

I'd explained from the start that my mum and nan both went into early menopause.

After a few years I started to experience other symptoms like hot flushes, hair loss, inability to lose weight, itchy skin, insomnia and anxiety, to name a few, so I went back to my GP who again sent me for blood tests and a pelvic scan.

The bloods showed changes in my hormone levels, so I was told to have regular blood tests every three months to monitor this. They weren't happy to prescribe HRT as I was quite young.

After much fighting I was referred to a private clinic that specialised in women's health, but I was discharged after only one appointment with them which produced normal hormone levels - possibly because I was going through a good spell and the hot flushes had subsided. We were at the start of the Covid pandemic, and it wasn't an emergency.

This was the start of two years of utter struggle. The menopause symptoms started getting worse, my periods had pretty much stopped, and I was dealing with stress, sleep deprivation, serious money worries, and was also home schooling a five- and 12-year-old. I was experiencing what I can only describe as blind rage and no patience - another charming menopause symptom - and feeling awful, with no help whatsoever!

Then, in January this year, a week before my 40th birthday, I got a longawaited appointment with a consultant at the hospital who prescribed me HRT with no further testing. He just listened to me and what I was going through.

I'm feeling loads better and have a follow-up appointment next month, but it really shouldn't be this difficult to get help! Menopause training for all GPs should be mandatory.

#### Only 59 and now I have osteoporosis

I went through early menopause in my 30s, but this was over 20 years ago. At the time I was told that I couldn't have HRT as it caused blood clots. Now I have osteoporosis. I am only 59 years old, and it's shocking. I wish I could have had HRT.

#### Ten years to get a diagnosis

I was told at 19 that I'd likely go through early menopause for medical reasons,

but it took until I was 29 to do a simple blood test and see where my hormone levels were. I had endured about seven terrible, horrible, horrendous years of symptoms, and all my GP would prescribe were antidepressants.

Finally, after a breakdown at 29, they agreed to a blood test. My partner and I had been trying for a second baby with no luck for over five years and I hadn't had any periods since I'd had my son at 22.

I was given three blood tests over six weeks and then asked to come in to discuss the results. I knew what was coming but it was still a shock to be told I was fully menopausal as I was only 29 and my partner was 26. I had the quickest discussion with my GP who said that I needed to start HRT straight away. I left with no other knowledge, support or care.

I think I had to wait a year and a half to see a menopause specialist. He saved my life. He listened to all my symptoms, and that day I left the appointment with a testosterone and oestrogen implant. Unfortunately, that doctor retired before my next appointment, and I was then referred to his nurse-led implant team and things turned bad again.

At last, I have a new GP who seems friendlier and has not tried to force me on antidepressants. I'm hoping this is a turning point in my menopause journey.

#### Told it was my imagination

I'm 44 and have been perimenopausal for seven years. Despite the risks of early menopause, it's taken me until this year to get a GP to stop saying it's in my imagination, and to prescribe HRT. Even now, I'm living under threat of it being taken away because of the mantra of 'as low a dose as possible for the least amount of time'.

However, I've gained two stone in the four months I've been on it despite changing nothing about how I move and eat. Part of me is resigning myself to going back to the hormonal, irrational, desperate person I was and just giving up my job. I honestly can't be bothered to fight to be normal anymore.

#### At last someone listened

I was one of the unlucky ones and went through early perimenopause. Three generations on my mother's side of family had suffered with hot flushes, anger, tears and anxiety since their early 30s. Now I'm 43.

Getting a diagnosis was very difficult, as I kept telling the GP surgery it won't show on blood tests, please look at NICE guidelines. They said you're depressed and you're too young. No, I am not! I was close to breaking down, and the final straw came when I lashed out at a loved one.

Then I was blessed to come across the lovely Louise Newson to whom I explained my symptoms. She advised me that I was perimenopausal and suggested I keep on at the GP.

Finally, I saw a lady GP and it was like a happy firework display! Someone listened, didn't belittle me or disbelieve me and put me on an HRT plan.

#### No advice after cancer treatment

I snowballed into perimenopause following chemotherapy and radiotherapy for lymphoma at the age of 39. My hormones were only considered as part of my fertility; I was asked before treatment whether I wanted any more children. I presumed that meant I would be in a menopausal state afterwards, which I thought wouldn't be a problem as my understanding was this would just mean no periods. I had never been taught or told otherwise.

Three years after treatment I was unrecognisable to myself. I experienced an accumulation of symptoms including anxiety, suicidal thoughts, crippling foot and joint pain, weight gain, hair loss, palpitations, UTIs, three metatarsal stress fractures, lethargy, erratic moods and more. At one stage, I remember saying to my husband I feel as though I shouldn't have bothered having chemotherapy, as I felt pointless, worthless and a burden to my family. The irony was that chemotherapy and radiotherapy were a doddle compared to the hormonal state I was in, not least because of the support and understanding which was available to me at the time of my lymphoma treatment, but which doesn't exist for perimenopause.

My own extensive research and subsequent understanding of perimenopause and menopause empowered me to keep going and somehow muster the energy to seek help. Unfortunately, I saw many GPs who were lovely, but just too scared of the implications of my cancer back story.

An NHS referral resulted in a 'no appointments available at this time' and I ended up paying to go privately. There was some reluctance to prescribe here as well and I was told I could only be on HRT for a short time. I took the

prescription and within three days my life started to change for the better. I was no longer crippled by joint pain in the mornings, my anxiety began to reduce and I had the energy to help myself in other ways - such as exercise.

Nearly a year on, I have found another consultant privately, who has explained I fall into the POI category and that HRT is imperative for my future long-term health.

Finding an informed health care practitioner has taken time, patience, emotional energy and money. All women going through cancer treatment that affects hormones should have a care plan in place. Having recently moved counties, I am also now aware of the postcode lottery in terms of care and hormonal support following cancer treatment. My experience shouldn't be happening.

#### I felt hit by a bus

AT 38 I went through medical menopause due to cancer surgery. I was shocked by the lack of help or advice. The symptoms and issues that I was experiencing were almost an afterthought, yet I felt as though I was being hit by a bus. My prescriptions are super expensive and the medications often unavailable when I go to collect them, so I am left waiting while my unbearable symptoms increase day by day.

#### This menopause malarky is real

I had an elective total hysterectomy aged 41 because of cancer elsewhere. No one talked to me before the operation about the effect of surgical menopause this kicked in two days after surgery. It took the doctors five weeks to prescribe the HRT that I am now struggling to get. Good luck ladies. This menopause malarky is real.

#### Postcode lottery wouldn't allow an HRT implant

I was in my early 30s when a full hysterectomy threw me into menopause. I left the hospital with a leaflet and a box of HRT, was told my recovery time and that I'd probably be on HRT for the next 20 years

I had suffered two decades of endometriosis and adenomyosis and trauma from 19 surgeries. At no point did anyone sit me down and explain 1) What menopause would really feel like, 2) The proper after-care I should experience, 3) How I should be supported going forward being so young. Nor did anyone offer any mental support.

As my body healed from surgery, the symptoms of menopause started. I experienced hot flushes and night sweats and they started to affect my sleep. My body shape began to change and I felt fatigued easily. My exercising slowed down as I tried to save energy to run around after the children and go to work.

Then something happened that I really wasn't expecting. I felt as though the plates I would usually juggle were starting to fall. I forgot things; the kids' club timings, things my husband had told me, conversations I'd had about projects at work. It was like my inbox was full. I became so irritable. I was angry and explosive at times, hiding my anxiety, had a feeling of not belonging and all of this whilst not having a clue why I felt this way. I honestly felt as though I was losing my mind.

With relationships starting to crumble, I felt I wasn't any good at my job, and wasn't a good mum, wife...or person! I was lost.

Driving the kids to school one day, I remember not being able to hear the music. I was numb to their usual squabbling, and as the sun shone in my eyes, I remember thinking that I just couldn't be bothered to squint, pull down the visor or press the brake...in that moment I wanted to die.

I was off work for six months after that day. With a phased return, it took almost a year to get back into the swing of things. In that time, I learnt that diminishing hormone levels, the wrong dosage of HRT and no support around my surgery were a huge part of what had happened.

That was a few years ago. Five months ago, I finally got to speak to an NHS menopause doctor through a new clinic at my GP surgery. I felt listened to and she wanted to know my history. Her diagnosis after blood tests was that my oestrogen levels were dangerously low and I wasn't absorbing oestrogen through any of the tablets, gel or patches I'd tried over the years. I needed an oestrogen implant. But what came next was a text message, like some sort of bad break up, to inform me that I couldn't have the implant, thanks to a postcode lottery, it wasn't on offer to me and that was it!

#### So where did that leave me?

By this point, I was a mess with physical symptoms including aching joints, severe

fatigue, brain fog and heart palpitations. I couldn't believe what I was reading.

My options were to go on an NHS waiting list for a hospital two hours away or go up the road to a private clinic and pay £500. I opted for private care, had the most amazing consultation and paid for the HRT implant to be ordered. I'm still waiting, five weeks later, for it to arrive.

I'm left physically and mentally at rock bottom. This is not living! Not only am I concerned as to when I'll get this implant, but I also question what happens when it needs replacing every six months? Will I even get it? What about support and care...it petrifies me.

I do not fit the usual box for menopause. People like me are often not seen or heard in the media. We're not recognised on medical forms, menopause checklists or HRT checks at GP surgeries. Often, we are the ones educating the professionals as to why we're menopausal at such a young age.

For me, menopause isn't just a natural stage or transition. It is a medical condition, a hormone deficiency that needs proper care, knowledge, support and medication.

#### Women like me barely get a mention

I had a hysterectomy which left my ovaries 13 years ago, and not long after that I hit menopause. It's been unrelenting since. I had a migrainous stroke, so I've been told that apart from beta blockers and antidepressants, that's it. HRT is not an option. A GP from my practice contacted the specialist team locally who said the same thing and that's been it. No discussion, no support, nothing. I've been left completely on my own.

In amongst all of this I had surgery for a grade four prolapse in 2013 and was diagnosed, coincidentally, with fibromyalgia in 2014. Whilst it's great that menopause is on the agenda, where it should have been a long time ago, it breaks my heart that women like me rarely get a mention. That only further exacerbates the isolation we feel.

#### My husband walked out due to lack of intimacy

I went through menopause aged 42, at the same time as being diagnosed with an underactive thyroid and nursing my mum through liver cancer. I also had two teenage sons and was working in a highly stressful environment. Fast forward 15 years and my husband walked out, saying that there was a lack of intimacy and he had felt resentful for the last 15 years! I was speechless.

I went to see a gynaecologist privately and her words to me were: 'If I had a pound for every woman who tells the same story as yours, I would not need to work!'

She wrote to my GP and finally got the HRT I needed, as well as testosterone. I wish all women the best of luck and hope their husbands, sons and healthcare practitioners listen.

#### If a man's private parts burned would he be told to go for a run?

I am a breast cancer survivor of seven years. I was thrown into surgical menopause at 40 and basically left to get on with it, which I did for five years as best I could. The last two years have been horrendous. My symptoms are vaginal dryness with burning sensations, a painful bladder, aching bones and joints, broken and restless sleep, anxiety, tearfulness, flushes, horrendous IBS symptoms, headaches, dry skin and dizziness. My male GP told me that menopause lasts for four years and I should go for a run. I've swapped practices but there's no continuity of care and I am floundering as to what I should do.

Not only do I have to survive breast cancer, I've also got to survive the menopause. I've waited 15 months to see a menopause oncology team. I wonder if a man's private parts burned, they'd be told to go for a run? I'm still here though! Half the person I used to be and hanging on by my fingernails!

#### I'd love to help any young woman suffering with this

I have been suffering with menopause since I was 23. I am now 32 and still struggling.

My 20s were very difficult. It was almost unheard of for someone my age to be going through the menopause. I suffered badly for three or four years without any HRT treatment. I had hot and cold night sweats, loss of libido, vaginal dryness, mood swings, foggy memory, insomnia, hot flushes, depression and anxiety.

I felt so alone. I felt fobbed off by my doctors and as if I couldn't speak to my friends as they didn't understand what I was going through. I suffered in silence.

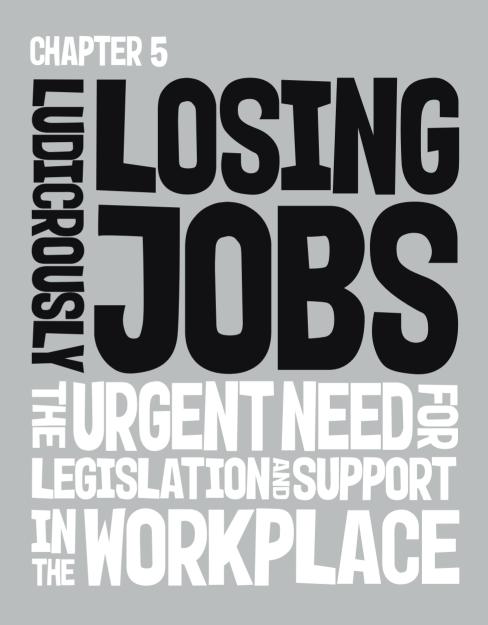
Now I have been on HRT for approximately five years and I'm also on tablets for high blood pressure. The HRT has helped with the night hot and cold sweats

but now I experience night terrors.

In my 20s I was embarrassed about this and never spoke up, but now I have done a lot of my own research. As well as HRT I have started taking different vitamins; magnesium, folic acid, Omega 3 to help protect my bones and skin, and B12 to reduce fatigue.

Since turning 30 it became apparent that I needed to change and think of myself. I keep myself busy with different projects around the house, so I don't sit and dwell on the fact that I'm different to other women my age.

I would love to be able to help any young woman suffering with this.



S o many of the stories sent to Menopause Mandate have been about struggles at work during this time. Women who have symptoms often don't feel that they can raise the subject in the workplace. Or menopause is treated, as has been the case historically, like a joke.

Many have written about how they had to reduce their hours, didn't go for promotions or even had to leave their job. This is reflected in the statistics which suggest that almost one million women have resigned because of menopausal symptoms. And yet, incredibly, there still isn't specific legislation to protect women in the workplace.

It's an inequitable situation. According to the Fawcett Society's Menopause In The Workplace report, 77 per cent of women experience one or more symptom which they describe as 'very difficult'. Some 44 per cent said that their ability to work had been affected, and one in ten women who were employed during the menopause have left work due to their symptoms.

Incidentally, the report also discovered that 81 per cent of employers don't have menopause training for managers and 84 per cent don't have it for any staff. This is far from ideal. As has been said so many times, this doesn't mean women can't do their jobs - of course they can. The only people likely to suffer are women themselves - struggling through. Here, as in so many other areas of society, there needs to be more support and acknowledgement.

#### People laughed at my red face

I felt embarrassed because I had flushes which made my face go hot and scarlet. I used to put my face in the freezer to try and not look so stupid. My confidence was totally undermined. I felt that everything I said looked like a lie because I kept on blushing. Naturally, I didn't want to have a flush in a difficult circumstance, yet the anticipation of having one made a flush inevitable. This affected my working role as I did not receive any support, just laughter at my red face.

#### The headteacher said I was being negative

I've probably been suffering with perimenopause symptoms for well over a year without realising it. Last year I had time off with stress, even though I'd never been affected by it before. I've suffered from anxiety, brain fog, night sweats, insomnia

and fatigue and had reached the point where I felt as though I couldn't do my school job properly. I was starting to hate it and thinking about leaving.

I went to the headteacher several times to tell him that I wasn't coping, that my workload was too much, and that I had reached a point where I was ready to walk out and not return. He said he didn't agree with me, he didn't think my workload was too much and that I was coming across as negative.

With no understanding or support, I felt as though I was reaching breaking point. I often sat in my office crying. I'm thankful that there were a few teachers who were also going through it; they really supported me and made me feel like I wasn't alone.

Then I had a bout of illness - fatigue, aches and pains - to the point where I couldn't get out of bed. My GP was great. They sent me for a blood test, then rang about a week later to tell me I was in menopause. I was immediately put on patches without question or delay.

I'm now almost 4 months into my HRT and starting to feel like my old self again. This has given me the energy to act.

I contacted the CEO of my academy trust directly, sent him information on the menopause and asked whether we might have a menopause policy with support in the workplace. I also directly contacted our HR department and asked for an appointment with Occupational Health to help me cope better.

It's hard to do these things when you have no fight in you and you just want to curl up in bed and not face the world. But now I'm starting to feel better, I feel able to bypass my unsupportive boss and go straight to the top to try to make change. We need support in the workplace for every woman going through this now, and hopefully make it a better environment for the next generation.

#### I need HRT to remain economically active

I am a 61-year-old woman who has been using HRT for the past eight years. Prior to starting treatment, the menopause symptoms I experienced were so debilitating that I was unable to function at work or drive safely.

I work part-time, run a small internet-based business from home and care fulltime for my partner who suffered a debilitating stroke three years ago. When I first started work more than 40 years ago, the retirement age for women was 60. I will not be eligible for a state pension until 2028, when I reach 67, and will need to support myself and my partner through work until then. We do not receive any state help or support.

I was unable to obtain HRT for nine months in 2019 due to shortages. My menopause symptoms returned with a vengeance, leaving me struggling with work and domestic life and I was forced to take sick leave from work. I resorted to sourcing my usual medication from overseas, at great expense, via the internet.

As long as women are expected to remain economically active until their late 60s, HRT is not a lifestyle choice, it is a life saver.

#### I had to leave my job after a total breakdown

I am a former HR Director, but I left my job as I had a total breakdown. I had what I now know to be perimenopausal symptoms and have had to go privately to get a prescription for the HRT that suits me. It's been more than four years, and while I feel so sad for myself that I've had every symptom and just got on with it, what I can't get back is the time with my family.

My 19-year-old was 15 at the time, and she witnessed her mum at her worst. The impact it has on relationships is so awful, and I'm fortunate that my husband is supportive.

I am so grateful to every celebrity who has highlighted this, along with amazing medical people. I still feel like a different person. I'm not me.

I still don't have the confidence to go back to work.

#### Colleagues laugh when my memory fails me

I am a partner in a large law firm and deeply experienced in what I do. My colleagues enjoy a laugh at my expense when my memory fails me and are completely oblivious to the impact perimenopause might be having, despite there having been various awareness-raising initiatives by HR. Disappointingly, even younger female colleagues join in with the mockery. I worry there's something wrong with my brain. It's humiliating and I am seriously considering leaving the law.

#### Pushed out of two jobs by my employers' attitude

I lost my mum 13 years ago to pancreatic cancer when she was just 67. She had gone into early menopause at 38 and was given HRT, which was considered

revolutionary back then.

I had a full hysterectomy ten years ago at the age of 47 and nobody spoke about what was coming. I struggled on, not wanting HRT due to cancer links and mum's history. My GP at the time agreed.

I moved house and got a new GP. She did a blood test and asked how I was coping with no oestrogen in my body, and whether I wanted HRT. She was happy to prescribe it. But because of what I'd read, I didn't.

I was an air hostess and had flown for 12 years, but I had to give up as I could no longer take the early morning starts and then have the energy to fly all day on little sleep.

I spoke to my employer who brushed it under the carpet, so I got a new job which was desk-based but included night shifts. Three years in, and I have asked for a slight adjustment so that I do not have to work all through the night, but they won't accommodate me.

Thankfully, I am now better informed about health risks, and have chosen to be on HRT. My life is much better, but I am having to move departments as I am still not able to cope with the night shift.

I feel as though nobody cares and that 'menopause at work' is lip service. This is the second job that I feel pushed out from due to the employer's attitude around menopause.

#### Had to step down from my NHS job of 30 years

I started having symptoms in my early 40s, mostly hot flushes at first, and then some dizziness with tiredness and lethargy creeping in. I had been reading up on perimenopause and menopause to get an idea of some of the symptoms and thought this was what I was experiencing. Little did I know that it was going to get a lot worse.

By 47 my exhaustion was so severe that even walking up the stairs was an effort and I had to sit down for a bit to recover. This was a type of tiredness that I'd never experienced before and not like anything I'd expect from exercising, which used to be exhilarating.

A work colleague mentioned that they had been the same and were now on HRT. I thought I'd give it a go. Initially, it helped, and for a couple of years I felt OK. But then I noticed more symptoms developing; memory loss and brain fog so awful that I was stringing a sentence together but not making sense, as well as feeling as though my brain was slowing down. This went on for a while and got worse, with anxiety coming to the fore.

I was failing quality audits at work, the pressure kept on and in September 2020 I had a breakdown.

At the time I had no idea that there were different types and doses of HRT. With all the information that's being put out, I now know this, and it's greatly helpful.

I've changed HRT this year, but it's still a process of getting it right. I started on oestrogen gel, but had to swap to a different form due to stock issues.

I have had to recently step down from my role at work as I'm still not able to perform at the level needed. I've worked in the NHS for 30 years. I tried to keep my chin up and work through this but failed.

#### A complaint was made against me

I have always been a high achiever in my career and was quite successful in my 40s. I was working in human resources and leading a service in a large organisation. This was rare as a black woman in the 1990s. After a while, I found the workplace very stressful, and it started to affect my physical health.

So, in my 50s I moved to a less demanding role and worked with another woman who was a similar age. We were vocal women, and our voices, opinions and suggestions were not welcomed. In addition, two of our male colleagues - one the line manager -negatively targeted us for attention.

One evening, leaving work, I was approached by one of the men. I lost my temper and loudly told him to leave me alone! He later took out a grievance complaint against me. It was humiliating to be in such a situation for the first time at this age and stage in my career. I defended the complaint but ended up with a warning being placed on my work record for my outburst.

In hindsight, I now recognise that I was experiencing mood swings from going through the menopause. I very much felt that the HR Director who chaired the grievance complaint had little awareness of the underlying issues; an older black woman, with a long unblemished work record, going through the menopause and being targeted and scapegoated by two men in the organisation.

I eventually chose to leave the organisation. I felt I held onto my dignity by making that choice. Even now, I still feel annoyed that that was the only option

I felt I had, due to the lack of support and knowledge about the menopause.

Thank you for raising the profile of the menopause in women's lives and in the workplace. At last, I feel that raising awareness of menopause and its many symptoms, will hopefully avoid other women going through a similar experience.

#### I can't cope with full-time work

I worked full time as a receptionist whilst suffering menopause symptoms, including awful hot night sweats, where I was awake at 2.30am and 5.30am and then got up at 6am to go to work and return 12 hours later. I also had daily anxiety, brain fog - I couldn't get my sentences out - and non-existent libido. I felt that I was going mad until I was prescribed HRT. It was literally an overnight transformation, and I was back to feeling me again.

However, I cannot cope with full-time work. I need time for myself and selfcare, so I handed in my notice. I'm lucky to be able to cope financially for the moment and am concentrating on looking after myself and trying to lose the weight that I gained by being unhappy in my skin. I'm relieved to learn that it's common with the menopause, as I have piled it on around my tum!

I saw Lisa Snowdon on This Morning about a year ago, and I identified with every word she said about how she felt. It was a great relief and comfort to know I wasn't on my own with these new body experiences that were all caused by the menopause. I feel heard now and that I'm not alone.

I wish menopause could be seen as a medical issue. The reality is women like me sometimes feel we must stop work. I also wish there was financial support for those of us who are unable to work. This is how debilitating the menopause can be. Thank you for highlighting the life-changing experiences of countless women. I hope Parliament enables us to have free prescriptions, as otherwise the menopause is expensive to treat.

#### I retired and lived in poverty for four years

I retired from working as a specialist nurse in the NHS because of my godawful menopause symptoms. I received no help from my managers, or even empathy. My matron told me: 'It's only the menopause.' One of my many symptoms was brain fog and my manager put me on a disciplinary action route. This was humiliating after an exemplary 20-year nursing career. I was on HRT, but I now know it wasn't the correct dose.

I had originally intended to work until my State Pension started so that I could save for my retirement, but I had to retire early, aged 59, as I simply couldn't cope any more. So, I lived in poverty for four years. I had so little money I bought no new underwear until I got my pension. I even stole toilet paper from cafes to make ends meet. I'm still angry about this and I've been retired ten years. I am also so pleased that you and others are pressurising the government and employers to finally acknowledge how awful the menopause can be. Thanks for letting me vent.

#### I had to take a demotion

Looking back, I had had symptoms for years; aching joints, fatigue, disturbed sleep, anxiety and loss of confidence.

I ended up having panic attacks and taking a demotion at work.

I had been to the doctor with various symptoms, but nobody mentioned that they might be perimenopause.

During the pandemic it slowly dawned on me that everything I was experiencing could be perimenopause symptoms.

The final straw was vertigo. I started to seriously research, found the menopausenotmad.co.uk website, and made an appointment at my GP.

I went armed with all the info and was prepared for being dismissed. Thankfully, I had an appointment with a younger female GP who was very knowledgeable and supportive. Within ten minutes I was picking up my prescription at the pharmacy.

That was nearly a year ago, I am a completely different person, I have my confidence back, my brain fog is gone, I sleep well, my libido has returned and I feel joy.

#### I was a senior leader but my confidence was crushed

With the benefit of hindsight and education from various websites, I realise I was going through perimenopause for eight years before my periods actually stopped. During that time, I had what I now know are typical symptoms, such as dry itchy skin, brain fog, increased migraines and joint pain. I visited my GP,

suspecting menopause, but was told I was probably overusing thyroxine, which I was taking because I had a total thyroidectomy in my early 30s.

I asked for a referral to an endocrinologist. The surgeons who had treated my thyroid had said this would be the right course of action when I was menopausal. Inexplicably, I was referred to a rheumatologist who couldn't understand why he was examining me but was at least able to prescribe drops for my dry eyes.

Six years later, suffering up to 40 severe hot flushes a day, I finally managed to get a referral to an endocrinologist, who confirmed my thyroxine dose should be put back up and that I was menopausal.

I struggled on, with the hot flushes and brain fog affecting my work decisions and my ability to perform, especially in meetings. If I was ever on the back foot or challenged, I found myself unable to think quickly enough to form a meaningful reply - something that had never been an issue previously.

This led to some very critical and highly personal feedback which crushed my self-confidence at work, despite being in a senior leadership role. The crunch came when I was in a meeting to dismiss a colleague and was so overcome with hot flushes – redness, sweating and breathlessness - that my colleague was more concerned about me than about the end of their employment.

Immediately after that meeting I went to my GP in tears to beg for HRT. I was given an appointment with an amenable doctor who prescribed patches.

They have been life changing, mostly because of the reduction in hot flushes and improved quality of sleep. My brain fog is better but not gone and my skin, hair and eyes are still horrifically dry. I haven't been able to wear contact lenses for seven years. I'm sure my hips have suffered from the delay in receiving HRT as I have constant pain. However, I can now function as a mother, in my new role as a manager and as a person.

#### I was constantly checking and re-checking my work

It began when I started to feel as though words got stuck in my head and wouldn't come out. I began to doubt I'd covered documents correctly at work and generally felt anxious.

My anxiety got worse and I lost an extreme amount of weight. The GP did tests and recommended antidepressants. I refused, because I've never had anxiety before in my life. They offered me Cognitive Behavioural Therapy (CBT) online, which I accepted, and I made adjustments at work and home.

My anxiety turned to ruminating, worrying and obsessively checking everything. I lost my confidence at work. I was constantly checking I was doing things right and needed reassuring.

I booked counselling with work, but that didn't help, and I did meditation, which did help, but didn't entirely resolve things. In the end I paid for a private appointment and was prescribed oestrogen patches and micronised progesterone. Now, 18 months later, I'm starting to feel like myself again.

#### Subjected to performance reviews

I am 47 and have worked as a nurse for 27 years. My career is unblemished, and there's not a single complaint or sanction against my name. I was previously a clinical lead specialist in a service that I had worked in for 17 years, leading a team of senior nursing sisters before I left my role to pursue a career in advanced nursing practice within a GP setting.

Six months later the Covid pandemic began. I worked tirelessly throughout with little in the way of formal support from my employer. But then I began experiencing symptoms of the menopause, including low mood, anxiety, brain fog, night sweats and insomnia so severe that I eventually went to my GP.

Carrying out the role that I do means that I am perhaps more informed about this than some people and that, coupled with the fact that I have an excellent GP surgery, meant I was started on HRT at my request. I was off sick for two weeks throughout this process and submitted a sick note supporting the leave. I have been open and honest with my employer throughout.

Despite this I have been subject to numerous 'reviews' of my performance, without clear statement or purpose, which compounded and did not support my difficult situation.

In response, I submitted a grievance to my management, in order to improve this experience for others and - in a female dominated workforce - prevent them from treating other staff members in this way in the future.

I am now awaiting a date for a formal disciplinary meeting with my employer. Despite trying to explain my situation on numerous occasions, the support remains lacking - I have been told 'I don't want to be responsible for you' and this was included in the minutes of a meeting! Also, two different GP partners in the practice told me: 'I'm not having it that symptoms of the menopause are having an impact on your ability to do your job.'

I am well supported by my union representative but decided that I needed to do something more to empower myself, whilst feeling extremely vulnerable (and extremely sad) at present. That's why I've told my story. I would like to see education for all to include employers, practitioners and patients and I passionately support all of this hard work. Thank you.

#### Sacked for 'fabricating illness'

I was dismissed from my job because of my debilitating symptoms. When I look back now, I am astonished how I pulled through it all. I was battling depression, such heavy bleeding that sometimes I had to sit in the bath, sleeplessness due to bleeding, night sweats and brain fog that was so severe I often forgot what day it was. I honestly thought my life was unravelling and nobody knew what it was or how they could help.

But I was told by my employer that I was 'fabricating an illness'. According to them, I had made it in to work and looked fine.

Luckily, I had backing from my trade union and a brilliant solicitor. They fought my dismissal and I won.

I know that it is not easy, but there is hope! We must fight for better diagnosis and better access to HRT.

#### Grave consequences if I declare myself unfit

I work in a male-dominated environment and the word menopause returns zero results on my employer's website. It doesn't even accept it exists.

I know that the symptoms I could suffer will potentially make me unfit to do my job temporarily, but I have no choice but to try and carry on. It's frightening. I can't declare myself unfit due to menopause symptoms without grave consequences.

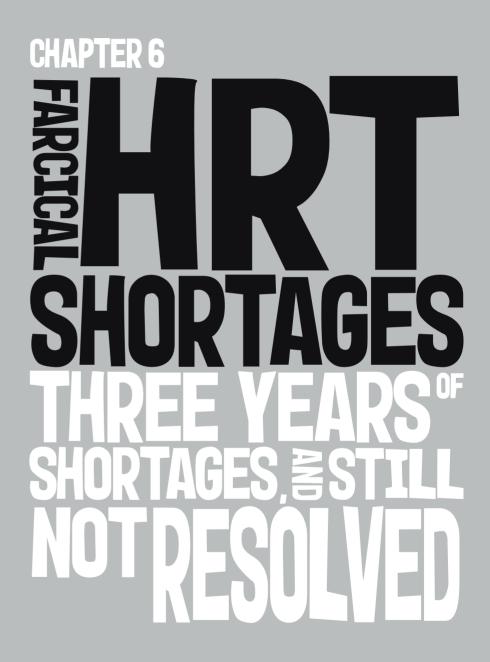
#### I couldn't cope any more

I had to give up my job of 17 years as I didn't feel I had the confidence to do it any more. I had always been a manager, in charge of upwards of 30 staff in a fastpaced environment, but I didn't feel I could cope any more due to increasing issues with concentration and anxiety. I was treated with antidepressants. It is still a struggle trying to get the correct HRT and the correct dose. I have been offered another management job but still don't feel able to take it on. Not when this anxiety is still out of control.

#### I was called a 'woman of a certain age'

I didn't know what was happening to me. My senior manager started referring to 'women of a certain age' and I assumed he just meant older ladies. I had no idea he was referring to menopause and the physical and mental impact it has on many women, until it started to impact on me in my late 40s. My symptoms culminated in hysterical crying and refusing point blank to do a presentation that I, along with colleagues, had been planning for months.

I had no explanation and felt so ashamed of myself but just felt so overwhelmed. I know now that was my first significant run in with perimenopause. I would love to go back now, nearly ten years later, to explain myself. Sadly, that was the beginning of the end of my career.



RT shortages have hit the headlines for the last three years and are the subject of many of the stories we've been sent. Around two million women are prescribed HRT in England alone - this number has shot up recently as its previously toxic reputation is finally being consigned to history's medical waste bin. However, the increase in demand - thanks to all the campaigning out there - hasn't been matched with an increase in availability.

Further reasons given for the shortages are manufacturing problems, supply chain issues and a lack of forward planning.

This has led to women having to change the type of medication they are on, which often means a return to symptoms for some time. Others are halving their dose - worried about being unable to get their next prescription. Some simply can't get hold of it at all. For those who need HRT - that is really anyone who is on it - it's incredibly stressful. It's particularly hard for those with very severe symptoms, or with Premature Ovarian Insufficiency. Women have even ended up bartering for HRT on Facebook groups or driving hundreds of miles to obtain it.

At the time of writing this, the HRT Tsar Madelaine McTernan has just returned to her role overseeing Covid boosters. Clearly this is a vital job, but the HRT shortages have by no means been solved. Read on, to see the impact that they are having on women every single day.

#### I have anxiety every month in case it's out of stock

This is my HRT story. I am 41 and have suffered with endometriosis for over 20 years. A few weeks ago, I had a full hysterectomy due to the severity of my condition.

I was discharged with no HRT 24 hours after having my uterus, ovaries, fallopian tubes and cervix removed and being plunged into menopause. The hospital was out of stock.

My menopausal symptoms were horrendous. So huge and so out of my control.

Eventually, after a few days and many phone calls, I was able to get some HRT. I couldn't believe how much better I felt. It was amazing.

My anxiety was gone, the bad thoughts, insomnia, sweats all gone.... until the second month and once again it was out of stock and I was plunged again into a dark place.

The national HRT crisis is real.

And the anxiety I will have every month for the next ten years is real. How can we be in this position? How many more battles do we as women have to fight?

#### Three hours trying to get through to the pharmacy

I am having an absolute nightmare trying to get my HRT. Today has been totally dreadful and I still don't have it sorted. I'm exhausted and stressed and it's not over yet - I've got to do it all again tomorrow! I was trying to get through to my pharmacy for three hours! My husband drove me there and, guess what, they don't have the patches I've had to swap to because I can't get the gel. I am absolutely sick of this, and it happens every time I try and get my prescription, although it's got worse! Please, somebody, make this better now? Thank you.

#### Finally given HRT... then it ran out

I have just started HRT at the age of 47, having had perimenopause symptoms for around five years. This recently came to a head with anxiety, lost confidence and really low mood to the point where I've been signed off work with stress.

My first doctor prescribed antidepressants via a phone consultation. I mentioned my age and asked could it be menopausal? He said yes, possibly, and sent me for a blood test. I was off the antidepressants within three days due to severe side effects and spoke to a female doctor who suggested HRT would be a more appropriate course of action. She also told me the hormone blood test was unreliable at my age and symptoms were a more accurate indication.

I'm now happily on HRT with no side effects so far. The only problem has been availability of the oestrogen gel! My very first prescription was for the pump bottle of gel, which the pharmacy didn't have, so the doctor switched to the sachets. The pharmacy could only fulfil part of the prescription and had to order the rest, and this also turned out to be unavailable! Fortunately, by this time the gel in a pump bottle was back in stock (although of course that required another new prescription).

At least I live in Wales where prescriptions for HRT are free. It's awful that we must face so many obstacles in terms of diagnosis and obtaining the necessary medication. The government needs to address this problem urgently!

#### Had to reduce my dosage to make it last

A shortage of the metered-dose oestrogen spray in the UK has meant that I have paid privately to receive a bottle which will hopefully last until it is back in stock. It costs £30 for one bottle and I need two per month.

Additionally, my existing spray has a fault and I cannot exchange it at my chemist due to no stock being available. As a result, I've had to reduce my dosage to make my medication last which has meant a return of symptoms. My mood is very low.

#### Gel on eBay at four times the cost

My husband has bought me some oestrogen gel using eBay, at four times the cost of a prescription.

#### I pray I don't run out of patches

I am 51 and I think it's vital that women of my age talk about the subject and know more about it, because our mums weren't generally given any help. Menopause was a taboo subject and resulted in a lot of them saying to this day things like: 'I was ok, I got by without it, what's the big fuss about running out of HRT?'

I am very grateful for all the forums we have now. Times are changing, and hopefully they can get this awful and unnecessary shortage situation sorted out ASAP.

My mum (who is 85) was on HRT tablets for a while when she was younger but didn't get on with them and I remember her always advising me against them.

I had several gynaecological issues over the years, including quite bad endometriosis in my 20s and 30s. The female doctor dealing with that told me, off the record, never to go on HRT. This would have been around 15 years ago, and most of us were too worried to take it because we were worried about breast cancer or other health issues.

I had a total hysterectomy four years ago and started HRT tablets a few months later. I wasn't offered it by the hospital or doctors. It was only through searching on Google and through a Facebook group that I realised I needed it.

I went through different dosages to try and get on top of symptoms, and they had to give me different brands of tablets due to shortages a couple of years ago. I had to drive around several pharmacies to get them and have always tried to get them a little while before I need them in case there's a problem. I don't want to be without the HRT. I went onto patches in August, and although I am starting to get a bit hot again and still don't sleep well, I feel like a different woman. I'm more positive, less angry, more energetic and have fewer mood swings.

I'm so pleased there is so much discussion about it now. It really helps. I don't have children, but I hope the next generations of women get a lot more help. I'm also hoping I can get more patches when I run out in a few months.

#### Shortages are nail-biting

I have wept talking to doctors' receptionists when trying to chase up replacement HRT when the prescribed one has run out. It makes me so angry that it's allowed and expected that women just need to get through menopause. Replacing depleted hormones can make such a massive difference to your health and quality of life.

I started taking HRT because I was feeling out of control, not coping with life at all and breaking down in tears all the time. I was forgetting the simplest things. Having worked hard in my career in HR while raising my son, suddenly I just couldn't cope. I was also having horrendous heavy periods and often had to go home during work hours to shower and change.

Fast forward a couple of years and many appointments later, and I remember a particular male GP, who was really nice. But when he told me I was perimenopausal and it was something I just had to get through, I broke down in tears. He said I could try over-the-counter remedies as they don't recommend HRT and to expect other symptoms such as a dry vagina. I looked at him through the snot and tears and said, 'Well thank you very much,' and I left, utterly despondent.

Two years on, I had taken redundancy at work, which was timed perfectly as I wasn't coping. I went for a walk along the river and started to listen to a podcast about menopause. I remember throwing my arms in the air. 'Wow! This is me!'

I called my new GP surgery and asked for an appointment with a menopause doctor, or one that specialises in female health. I informed her that I had been suffering for around eight years with perimenopausal symptoms and I wanted

HRT. I was calm, composed and determined because I was empowered with the right information. She immediately started the process of prescribing it.

Then came the shortages and the nail-biting anxiety when I've dreaded collecting my prescription because of the number of times the medication has been out of stock. I have often wept in the chemist in despair and even refused to leave until they told me what was available and liaised with my GP to get replacements. I know that HRT shortages aren't the fault of pharmacists, but I felt that my local one treated me as though I was an irritant.

#### Getting my prescriptions is stressful

My menopause journey started about a year ago. I had no idea about anything, and it was like a lightbulb moment when I started researching information on the menopause myself and realised what my symptoms were. I made a telephone appointment with a GP who gave me a website to go on and decide which treatment I wanted. I eventually made a decision and was prescribed HRT. It's been a very bumpy journey, trying several different treatments.

To start with I had no issues with getting my prescriptions, but it's got so much worse. It is so scary and stressful. I now dread trying to get my HRT. It should not be like this for us. All we're asking for is our hormones. We shouldn't have to fight for them - things are hard enough and we deserve better.

I continue my journey feeling grateful for all the tools and information we have these days to make decisions about our own health. We are all warriors, but the battle should not be this hard. Change needs to happen. I really, really hope that it does.

#### **Given tablets instead of patches**

I was put on HRT patches and they were great. I started to feel like myself again, with loads of energy. All my aches and pains disappeared. I'd been on them for about four years when they became hard to get (I know that some women were buying them from abroad because of shortages here). I was persuaded to go on the HRT tablets.

I'd been on the tablets for about ten days when I had a TIA (a mini stroke). The consultant put the TIA down to taking HRT tablets rather than my usual patches, which don't have the same small risk of causing blood clots. I'm now

on statins and blood thinners for the rest of my life. Women shouldn't have to go through something as scary as this.

#### Struggling to get patches

I had to have an early hysterectomy and so I need HRT patches. But now, months on, they're struggling to give them to me. The chemist doesn't have them, the doctor won't supply a prescription without an appointment, and I can't get an appointment. And all the time I'm suffering from hot flushes, feeling low and tired and generally unwell.

#### Only a shortage in the UK

I wanted to let someone know about my current experience in trying to source my usual oestrogen pump. I had read in the media that there were shortages so, despite not being that low on supplies, I decided to put in for an NHS prescription with my GP. Initially, my local pharmacist informed me that stocks would be in by the end of the week, then I was told they were out of stock and that all the alternatives were also out of stock.

I have managed to source some oestrogen sachets through an online private pharmacist and my GP has prescribed me oestrogen patches as an alternative.

However, I really don't want to change my prescription. I originally saw a private GP as I wanted time and a face-to-face appointment. I didn't want to discuss my menopause symptoms over the phone with a young male locum from the car park at work. The money I paid to sit down and discuss all my concerns with an understanding female doctor was worth every penny.

Yesterday, I jokingly asked a friend who lives in Luxembourg if he'd mind driving over the border to Belgium, to break into the factory where oestrogen gel is made and steal me some! Being a good friend, he phoned his local pharmacy to see how their stock levels were. There are absolutely no shortages in Luxembourg or, it seems, anywhere else in the EU. The shortage only seems to be in the UK.

We are told about huge surges in demand, which rather places the blame on us annoying women being awkward and demanding life-enhancing medications.

It looks like I will have to go and visit my friend if I want to get my gel. It's very tempting.

#### Scoffed at for trying to get it

I started taking HRT in 2020 after two years of chronic insomnia, restless legs and body agitation, night panics, anxiety and waves of suicidal depression. I began to see danger and threat everywhere and became unable to even swim in the sea. I thought I was just burning out.

Eventually the hot sweats started, and I was prescribed HRT by a male GP who made his clinical decision thus: 'It seems to help my wife, so I'll prescribe it.' Brilliant. All my symptoms were under control within weeks. Also, brilliant.

But this year I have found it initially very difficult, and now almost impossible to get HRT in Warwickshire. I have travelled from town to town in search of it. I've more than once lost my temper with pharmacists who appear to me to be dismissive and scoffing and seem to think it's a fun drug for the vain. I've subjected myself to public humiliation.

I've been given old-style mare's urine tablets

I am perimenopausal with mood swings, changes in digestion, palpitations, and low energy. I've seen two GPs. One initially said that I couldn't have HRT as my mum had had breast cancer. She showed me a medical book to try to prove this - but it turned out the statistics she wanted to show me weren't there. So, she reluctantly gave me a prescription for patches, saying: 'You won't get these anywhere.'

She was right, a year later and I haven't been able to get them, so I asked to see another GP who gave me a different prescription for gel and progesterone tablets. Again, I can't get them as they're out of stock and they can't order them.

A friend who is ahead of me in the HRT journey told me the tablets I've now been prescribed instead of the gel are made from mare's urine and aren't the most up to date HRT.

I need to go back to the GP again to try to get a different prescription. All of this means I have had to take time off work. I don't feel the doctors I've seen are knowledgeable about what is available. I have changed my job in the last year due to lack of confidence. I am 48, exercise every day, am not overweight, don't smoke, hardly drink, and I want to protect myself from future osteoporosis, dementia and heart problems. It's such a battle and it's just not good enough.

#### Refusing me HRT is belittling my symptoms

Asking for my second prescription of oestrogen gel, I was told it was out of

stock. My pharmacy said they'd order it in but had no idea when it would be available. I explained I was worried about not having it because it had helped ease my symptoms over the previous three months.

I asked for an alternative, only to be told there aren't any and that it will do me no harm to go without. I realise that there will be women whose stories are far worse than mine, but to be told it won't hurt me to go without is belittling my symptoms and making them sound unimportant. In fact, they are quite debilitating. Trying to explain this to a pharmacist in an open shop was embarrassing and I was made to feel I had to justify my need for help.

## **CHAPTER 7** D COST H OF FOR

Provide the end of the

There are 134 British Menopause Society recognised NHS menopause clinics in the UK. The number is clearly inadequate for the 16 million women or so over the age of 45, and many desperate women find themselves looking at private care. This can easily run into hundreds of pounds - which is simply not affordable for the majority of us.

The real cost of menopause is that women aren't getting the right care or treatment because of the price. It is possible to buy NHS prepayment certificates, but these are still over £100 a year. With the current economic situation, it's hard to see how this is going to get any easier (short answer: it's not).

#### I lost my income so pay for prescriptions from my savings

I entered perimenopause five years ago and suffered terribly with prolonged and heavy bleeding. This resulted in time off work. When it was at its worst, I couldn't even leave the house. Initially, I received poor advice from my GP, who was dismissive and unsympathetic. Eventually, after being persistent, I was referred to a consultant, and had an ablation to burn away the lining of my womb, which made a massive difference to the bleeding.

However, the other symptoms remained; night sweats, exhaustion, a total lack of libido and low mood. Due to Lockdown, I didn't feel it was appropriate to burden the NHS with this, but eventually I had a phone consultation with my GP and started HRT.

I was first put on combined (oestrogen and progesterone) patches but had a severe skin reaction. I came off these and was put on oestrogen gel and a separate progesterone pill.

The biggest issue for me is that I now have to pay every three months for this

prescription. As it's two separate items, I pay double.

I gave up my well-paid work due to menopause as I just couldn't cope with the symptoms and do a good job. I'm not on benefits so still pay for my prescriptions, but have no income and am relying on my savings. Why do women have to pay out like this just to feel normal? It's so unfair, and like contraception, HRT ought to be free or, at the very least, a one-off charge annually.

I really hope that the government can see the depth of desperation many women feel and will rethink their decision regarding both prescription charges and accessibility.

#### An expensive experience

My friends noticed my symptoms before I did, nearly four years ago. I suffered from debilitating brain fog, lack of focus, loss of confidence, low mood, poor sleep and, at times, chronic anxiety. I thought I was having a midlife breakdown. I sometimes wondered whether it was dementia. I left my job of nine years because I didn't feel I could function any longer. I've been on HRT patches on and off for nearly four years and need regular check-ups to see whether symptoms have got better or worse. I still feel there is room for improvement, but it's a very expensive experience and it just shouldn't be.

#### Paying high charges to online pharmacies

I have been unable to get oestrogen gel on my repeat prescription because of NHS shortages. My local pharmacy gave me an IOU slip to collect it later, which took six weeks. I was very anxious at the thought of my symptoms returning, so searched online and bought some gel from an online private pharmacy at a cost of £31. I have had to reorder from them, because once again I can't get my NHS gel from my local pharmacy. I spent three hours driving between three counties trying to find a pharmacy with stock. The online pharmacy accepted my order, but then emailed to say the item had increased in price by £10 due to difficulty sourcing stock.

#### I can't afford it but won't cope without it

I don't have the income to be able to pay for medication on a regular basis, but I have no choice as I cannot work, function or sleep without my HRT.

#### Shortages have doubled the cost

I have been on HRT for two or three years now and am currently on a dose of four pumps per day.

I requested my last prescription which went directly to my local pharmacy. When I went to collect it, I was given just one out of the six bottles and told to come back when it had run out. When I returned, they gave me another two bottles. I went back today to request the remaining prescription items, only to be told there can now only be a maximum of three bottles per prescription, effectively doubling the cost of my HRT treatment.

I am returning to college in September to retrain as a music therapist and have no idea how I will manage to pay for prescriptions or manage on half the dose of my oestrogen gel.

#### I'm having to pay for private treatment

I was unable to have my NHS prescription fulfilled in January. As a patient of a private menopause clinic, I had the option to get my HRT via a private pharmacy. So, I paid the recommended cost of my gel, which was approximately £14 per bottle. But there were also additional costs; £35 for the private prescription and then £15 for the postage and packaging from the private pharmacy. That's £50 extra on every prescription.

I recognise that I am in a very fortunate position and can afford to pay for my private treatment, but why should I have to? I work hard, I pay my taxes and I am not a burden to society. I feel the hormones I take are essential to my wellbeing, and a basic medical requirement that should be covered by the NHS for every woman that needs it. I cannot help but feel that if men needed HRT, then these shortages and the postcode lottery would never have happened. Thank you for taking up this issue.

#### Working overtime to pay for HRT

I was incorrectly, by my GP's own admission, given an endometrial ablation at 43 to deal with unbearable periods. I then suffered vitamin deficiencies, excruciating foot pain, could hardly get out of bed most days, extreme fatigue, memory loss, lack of sleep and was freezing cold all the time - no hot sweats for me. Meanwhile, I was trying to hold down a stressful, full-time job and look after three kids.

This went on for years. I asked the GP about my hormones and was told all was fine. By the time I was 50, I was at breaking point. I saw my GP again and was finally told that I was postmenopausal. My doctor admitted I should have been offered HRT at 43. No one had ever mentioned I might be in menopause.

I was finally prescribed HRT, but it was an old-style type, with higher health risks, and I was told I could only stay on it for two years. Three months later, I didn't feel any better and was then on a treadmill of 'try this' or 'try that' - of different cocktails of drugs, with the doctors effectively saying they didn't know what else to do for me, but they weren't open to a gynaecological referral.

In late 2021, feeling like a complete shell of my former self, I decided to take action. I paid to see a private consultant who has prescribed new oestrogen, micronised progesterone and - finally - testosterone. She's been appalled at the way I've been fobbed off. I am three months into the new meds, and finally feeling like I'm finding something of my old self.

But it's cost me £300 so far, plus all the money I spent on prescriptions for drugs that didn't work. I have another bill of £300 coming in ten days' time for my next consultation. I'm working overtime to pay for this but find it tremendously sad that I'm having to do extra hours to get the medication I need. This is at a time when I should be taking life easier to help the HRT get me back to my old self.

I don't blame my doctor's practice at all - they are general practitioners and not menopause specialists - but I'm frustrated that I have to pay for a drug I need when I've worked full-time my whole life.

I also feel huge empathy for other women, friends of mine who can't afford to take the private route. We should have access to the right advice and meds when required on the NHS.

#### I paid for a specialist clinic

I suffered classic perimenopause symptoms, particularly brain fog, anxiety and lack of sleep. I lost my resilience to cope and just tried to keep battling on in isolation, continually apologising for myself.

In the end, a friend directed me to a specialist menopause clinic which has been transformative. I know I am lucky to be able to absorb the costs of this and it is not right that so many women are not able to seek this level of specialist help. I am also concerned by the lack of knowledge of surgical menopause which is the other journey many of us have had to endure. We need significant improvements in female health, with funded research and education. In my experience women are being failed by our current system.

#### I bought testosterone privately

After no improvement in symptoms following six months of HRT, I saw a private specialist. Through blood tests I discovered that my testosterone was negligible, which exacerbated what I was already feeling.

Women do not have access to a testosterone product designed for women on the NHS. It is unacceptable that the only product available is one that is created for men. Given this, I have opted to purchase the women's product privately, which is costing me £80 per tube. I suggest that we aim to have a testosterone product for women and that is widely available to women.

#### I'm a fan of the NHS but feel let down

I went to my GP as I was experiencing night sweats, weight gain, low libido and was feeling sad. He said he would do a blood test, and when the results came back OK, he said that there was nothing he could do for me. I was frustrated and dismayed.

A colleague at work told me about her GP who is a menopause specialist. I looked her up online and found that she ran a private women's health clinic. I paid £250 to make an appointment. The doctor I spoke to was amazing and I am now on HRT. This doctor also wrote to my GP recommending that he prescribes me the HRT, which he is doing but only one month at a time.

I have always been an advocate for the NHS and the great work that they do, but honestly feel that I and too many others have been let down by the system.

#### The cost of premature menopause

My menopause story starts with my fertility story. I was diagnosed with bad endometriosis aged 31, not long after my husband and I had started trying for our family. I was told I would need laser treatment, for which I had to wait six months. In the meantime, I was given an injection to stop my periods with the aim of stopping the endometriosis from getting worse. Roll on ten years and I am now almost 40 with all those symptoms and signs we all know and love! I was living with hot flushes, night sweats and memory loss for over a year. But finding a doctor who would believe that I was menopausal was very difficult. I finally managed to get the blood test I needed to confirm what I already knew, and I was right - I was fully menopausal.

Early menopause affects one per cent of the female population. You shouldn't have to battle this hard to be heard. When I finally had the evidence I needed, I tried to schedule a call with the female lead or menopause specialist at my GP surgery to talk through my options, only to be told that there wasn't one.

This meant I had to make do with a five-minute phone call with a doctor at the practice who prescribed me HRT.

But instead of feeling better, when I started taking HRT, I found my mood dropped. I started to feel anxious, teary and low. I have now found out this is a sign that you may not have enough oestrogen, but by then it was too late. I'd ripped off the oestrogen patch and stopped taking the progesterone pills, deciding it would be better in the long run to deal with the side effects of menopause than depression.

I am sure that, in time, I may go down the path of HRT again, but I have resigned myself to the fact I will need to see a female menopause specialist, someone who will talk to me for longer than a routine five-minute appointment over the phone. Someone who will listen to my problems, ask me about my past situation and work out the correct HRT for me, because one size does not fit all women.

However, to do this I will have to pay around £300 privately. I can afford it, but so many others in my situation can't, so what do they do? It's just not good enough.

#### I had to go private

I have had to beg my GP for menopause treatment, despite several crippling symptoms which have affected my mental health, my marriage, all my relationships and my working life. Even when I have managed to persuade a GP to continue prescribing, I feel I have had to grovel to get my prescription renewed, with many comments such as: 'We'll have to see if we can wean you off this stuff.'

With HRT I can lead a full, happy, healthy and productive life, but without it I feel

as if I am struggling to go on, and I've sometimes had very dark thoughts about whether it's worth carrying on.

I eventually consulted a brilliant but private and expensive women's service that I found online as I was feeling completely desperate. I am now signed up with an expensive private GP, so at least I can get a regular prescription without being put through an interrogation every time I want to renew it.

For the first time I felt that I was in sympathetic and knowledgeable hands.

Now the problem is that I can't get the medication which has been prescribed. I feel scared every time I try to get a prescription filled; will they or won't they have my oestrogen gel in the pharmacy? I've been told that my prescription for oestrogen gel and micronised progesterone is the Rolls Royce of HRT treatment.

I feel that if it was men who were having these difficulties, something would have been done about it long ago. I've been made to feel like a fraud and a neurotic, complaining woman, for trying to lead a healthy life, without the most terrible symptoms.

GPs were quite happy to prescribe me antidepressants and sleeping tablets but not menopause treatment.

Thank you to Penny Lancaster – and her husband Rod Stewart for being so caring - for helping to put Menopause Mandate together. If women unite and make a big enough noise, someone, somewhere may eventually be willing to listen.

There is absolutely no reason why we should be written off at menopause or be made to feel guilty about getting treatment and making the best of the next phase of our lives. It feels discriminatory and misogynistic.

I don't want my daughters to have to go through the fear, anxiety and illness that I've suffered when their time comes.

I'll always remember the female GP who snapped at me, 'I can't think why someone your age would want a Mirena coil,' when another GP had recommended that I investigate this as a way of obtaining the progesterone I needed. I felt humiliated, and I don't want other women to feel the same.

#### My job is at stake, how will I pay?

I have suffered with gynaecological issues for years, with random perimenopausal symptoms that weren't fully recognised or confirmed, so I just

had to muddle through. On many occasions I thought I was losing my mind.

Now, following surgery, I've been plunged into surgical menopause. Recovery from surgery has included trying to handle menopausal symptoms, and it has not been easy. It's taking longer than expected, and this has developed into a situation where my job is at stake.

It's extremely stressful and draining. You worry how you'll pay your bills. Can you afford to pay for your HRT? Will you find another job and will other employers be supportive? You feel you've been abandoned, that your voice is not being heard and you are being penalised for a medical condition all women will have to face.

Well, it's about time we were heard. HRT should be free everywhere in the UK, and women should be understood and supported, both in our daily lives and within the workplace. Far too many women struggle and suffer in silence. We are not frail, unable to perform or achieve goals or work to high standards within the workplace, we are merely going through a natural stage in our lives.

### CHAPTER 8 AUGHABLE 50 IS b VULVAS

here's still such sniggering shame around the word vagina. But only too often it's the forgotten part of the menopause equation. Most women are likely to experience some symptoms of Genitourinary Syndrome of Menopause (the official name). It's also called vaginal atrophy and is most frequently Googled as vaginal dryness. And that's not funny at all.

As well as a reduction in lubrication, there is thinning skin and less good muscle tone, which can affect the vagina, vulva, bladder and urethra and there may be awful symptoms - frequent UTIs, dry cracked skin, itching, bleeding, burning and agonising pain as well as urinary incontinence and frequency. The effect on women's lives, particularly their sex lives, can be disastrous. The best treatment is local oestrogen in the form of a topical cream, a vaginal ring or a tablet inserted into the vagina. Yet embarrassment and a lack of awareness means that too many women who could benefit aren't receiving this.

In the stories we were sent, Genitourinary Syndrome of Menopause, vaginal atrophy, vaginal dryness - call it whatever you like - was often listed, among many other symptoms. We felt that it merited an entire chapter.

#### Local oestrogen changed my life

I'm now 56. At 39 I entered perimenopause. It took six months to persuade my GP to do a blood test, but they eventually agreed. Although I was told the risks of HRT, I wanted it. I had two little boys and was a single mum with a very demanding job. It was a lifesaver and enabled me to keep my job and be a decent mum.

I've had lots of UTIs during my menopause and recently, after being rushed to A&E because I was urinating blood, I finally got diagnosed with vaginal atrophy and now also use a vaginal pessary along with daily oestrogen and progesterone. It changed my life, as I'd been in a pretty bad way for a couple of years.

So, I guess my story regarding HRT is not too bad, but the shame of it! Especially the vaginal atrophy. One of the biggest issues for me is that since being diagnosed as perimenopausal at 39 I've not dated. I've now been single longer than I was married and can't imagine inflicting myself on anyone. Whoever would want me? The lack of support over the past 16 years has taken a severe toll, and while I feel it's all too late for me, I hope others can have a better experience. I'd love to think that there will be more support in the future to help women who are in a similar position to me, so that they feel they can date and be more comfortable in their skin.

#### I'm not allowed local oestrogen any more

I have a skin condition for which I receive treatment. After my periods stopped, I noticed that I was getting dryness, discomfort and itching in and around my vaginal area. A male GP attributed this to my skin condition but could offer no relief.

On my next visit to the surgery, a female GP suggested that my vaginal dryness may be due to the menopause, and she prescribed me local oestrogen in the form of cream. Hallelujah! After six years of using this, I had far less itching and soreness and sex was no longer painful.

But during a routine check-up last year, my male GP suggested that I could now stop using it as I am postmenopausal. A year on, despite my protests, my GP has gone against my wishes and removed it from my regular prescription. I am currently in the process of contesting this with my medical practice.

#### **Years of infections**

For years I've had problems with UTIs. After many visits to walk-in centres and the GP, I was sent to a urologist, who concluded that everything was normal.

I had to find out on a Facebook group that my issues were hormonal, and a dose of local oestrogen twice a week, costing me a few pounds a month, solved it all. It's shocking that the consultant didn't have a clue. I haven't had to seek medical advice on this issue since starting on local oestrogen, saving a lot of time and resources for the NHS.

#### Menopause is more than hot flushes

For roughly two years in my mid-40s I kept visiting the GP because of bleeding and vaginal infections after sex. They insisted on testing me for STIs every time, which was humiliating. They were negative, but it was suggested that this was because the bleeding had stopped. My smears were up to date, but I was very worried about cervical cancer.

Then I saw Mariella Frostrup's programme, The Truth About...The Menopause, and realised I had symptoms of perimenopause. So, I researched it some more.

What I found truly astonished me. Why hadn't anyone told me this? We all hear about vaginal dryness the whole time, but this does not describe what happened to me. The desire was still there. I'd feel turned on, wet and ready, but internally things were different. Once I had worked this out and introduced lube, the problem was solved.

Not one of my friends in their mid to late 50s knew about this. Some have given up sex altogether due to the pain and one had had to reduce the positions to avoid deeper penetration.

I get the feeling that women our age don't use lube as part of sex, whereas young women seem to have found the benefits much earlier.

I had thought I couldn't have HRT as my mum had breast cancer, but the protocol has changed, and I can. The GP offered patches or tablets. He didn't know about gel, but I asked for it and he prescribed it for me.

My despair lifted overnight when I started taking it.

After taking it for a few years, I started experiencing night sweats where I'd wake up with a cold, wet neck and back. As I usually apply my HRT gel in the mornings and had switched to getting up earlier than usual, I wondered whether the gel wasn't covering me through the night. So, I started having a pump at bedtime in addition to the morning pump and, hey presto, no more night sweats.

Had I not seen Mariella's programme, I wouldn't have been able to work it all out and get what I needed.

#### I was informed that I had an STI

Aged 32, I started to have horrendous hot flushes, my periods stopped and I felt as though I was having a breakdown. I didn't even know the word menopause. I suffered for two years before going to a well-woman clinic. Here, I was given a single blood test and then told by a GP that I had no hormones and 'you didn't want more kids anyway'.

I actually did, but it seemed my choice was made for me. I was then informed I had to have HRT or suffer problems in the future. So, I went on HRT. Every year I duly went for a review. There was no other communication. Despite suffering with further mild symptoms the dosage was still kept very low.

But when I was 48, I started to suffer severe menopausal symptoms along

with vaginal atrophy and extreme pain. I visited the GP, and wow, were my eyes opened about lack of knowledge. I was told I had thrush despite no swab being taken. Treatment for this did not work and I then had to get a further appointment which, as I was told my pain was not an emergency, took approximately five weeks.

I was then informed I had an STI, despite stating I had not been sexually active for over five years. A swab was taken, and unsurprisingly, I was informed a week later that it was clear. No other forms of treatment were given, and I was abandoned again.

I then had to book another appointment five weeks later.

All this time I was in such excruciating pain that I couldn't sit, stand or wear clothing. This severely impacted my quality of life and I felt suicidal. I visited the GP surgery to inform them of this and was told the on-call GP refused to see me but would call me on the phone. I then had to stand outside the door on the phone explaining in front of a crowded waiting room how and why my vagina felt as though it was on fire.

Another time I had an appointment with a doctor who promptly told me, 'we all know what a sore vagina feels like', which is very patronising.

I ended up with numerous scans, painful biopsies and visits to hospitals during the pandemic, so the anxiety that I was already suffering became horrendous. I was eventually given an appointment at a menopause clinic but feel this was only because of my persistence and wasn't offered freely.

My journey is continuing and I'm 55 now. I still have symptoms and painful vaginal atrophy and I'm still trying to get my levels correct. The menopause clinic has prescribed the next level HRT to me but straight away discharged me back to the care of my GP who has no knowledge. If this doesn't work, I start the process all again. My journey is going to be a long painful one still, but I refuse to give up as I deserve a life.

#### Such pain in my vagina I thought I had cancer

I work as a nurse and am surrounded by women but was completely unprepared when the menopause hit me. I was blissfully unaware of the signs until they overwhelmed me. I had sudden and extremely heavy bleeding and developed acne, amongst other symptoms. I only went to the doctor's when I was having such bad night sweats, migraines and pain in my vagina that I thought I had cancer.

My doctor examined me and thought there was nothing at all wrong, but advised that if I was worried I should attend the sexual health clinic. At 50 years old I thought I must have some dormant sexually transmitted disease, or cancer. So, I took myself off to the clinic, hoping nobody would see me, and had a full and embarrassing examination to be then told it was 'just' vaginal dryness as I was menopausal.

I was then advised to go back to my GP armed with this knowledge. I now have a Mirena coil (IUS) and use oestrogen gel. I have the old me back. I freely talk about the menopause now and hope my daughters are not met with the attitude of, 'well I got through it without help', which I have often heard from other women. Let's all help each other.

#### I have Lichen Sclerosus

I am 64 and I have been trying to solve various health issues since my mid-50s, when lack of oestrogen kicked in after a menopause in my late 40s. I was told HRT was dangerous, and I was further at risk because I suffered from migraines and have a family history of breast cancer. I did not find my menopause too bad as I had a healthy diet and lifestyle.

Then I began to get major muscle and joint problems including two frozen shoulders. After that, I experienced palpitations and tinnitus plus painful sex, anxiety, UTIs and cystitis constantly. I now realise it was lack of oestrogen.

I saw a load of specialists including urologists and gynaecologists who did all the tests and came up with nothing. I also had terrible constipation which was put down to IBS.

By this time my mother was suffering from dementia and caring for her meant I ignored my own health. I did try to ask a gynaecologist for HRT as a test showed that my hormones were non-existent, particularly testosterone. She said at 62 it was too dangerous and too late. Someone prescribed local oestrogen, but I was so sore that it burned on application. I stopped using it and the leaflets that came with it stating all the dangers put me off.

I had extreme anxiety and fatigue. My mum passed away of bowel cancer and at that point it dawned on me that the debilitating genitourinary symptoms dictated everything I did or couldn't do every single day.

I read about body identical HRT (transdermal oestrogen and micronised progesterone) and got referred by a GP to the menopause clinic. A year later they contacted me via a telephone appointment. In the meantime, I went private and got prescribed HRT. Even then, I was anxious about taking it due to the horrendous warnings on the leaflets and the warnings from the private doctor about the risks at my age. Finally last November I started and it has made a difference. Unfortunately, some issues of the vulva remain. But my GP has carried out several examinations and said that internally it looked OK, so refused to refer me to a specialist.

I finally saw a younger GP who has been working with a vulva skin specialist and she says I have Lichen Sclerosus [a skin condition which causes itchy white patches on the genitals and elsewhere on the body]. It means I'm at a slightly higher risk of developing vulval cancer, but I have to wait at least four months to see a specialist, and it could be much longer. The menopause clinic refused to refer me as it would take another year to see someone and told me to use emollient. I am trying to remain positive that it's been diagnosed in time and the treatment will prevent it progressing as it has already started to change the structure of the vulva.

I am telling my story to say do not be fobbed off, keep making appointments, push to see the right people and write to the practice manager if you are unhappy with the way that you have been treated. Write to your MP. I have a lot still to offer the world, particularly my grandchildren and I am going to fight for it!

#### Who can answer my questions?

I'm now 70, but I was prescribed HRT early on in perimenopause due to brittle bones. Unfortunately, due to some adverse research, I was strongly advised to stop taking it and was put on a different medication for my bones.

I then experienced symptoms such as night sweats, but feel they were probably reduced due to my having actually gone through the menopause on HRT.

While I was having periods in my earlier life, I suffered badly from PMT and was prescribed antidepressants. I assumed that this would disappear once my periods had been left behind. Sadly, this was not the case, so I stayed on antidepressants until fairly recently, and am now weaning myself off them.

#### CHAPTER EIGHT

My concerns are twofold: 1) can I go back on HRT to prevent dementia and other health issues? How long is one advised to be on HRT these days? Is it too late for me? 2) My libido is non-existent and has been since coming off HRT. I have an extremely dry vagina, but I do have local oestrogen that helps. Is there any other form of HRT that could help me now?

# **CHAPTER 9** RIOTOUSLY IΤ 1 WONDER

he stories sent to Menopause Mandate are mostly the worst possible experiences, and there is sometimes criticism about the reporting of menopause. The naysayers claim: 'Plenty of women are absolutely fine.' Of course, it is good to hear that some women do not have problems. But the way in which some women are treated is quite appalling; whether by society, partners, the medical profession or by ourselves. The self-loathing in many of these stories is utterly tragic.

Each woman who has been told that she's 'too young' or 'too old' to be menopausal or to have treatment, and every woman who is having their HRT stopped or is waiting months for an appointment, is a woman whose life is significantly and debilitatingly affected. Let's face it, we are only likely to seek medical advice when things are unbearable. It is vital that these stories are told.

#### Ended up in psychiatric hospital

Where to begin? Almost four years ago I was taken off the combined pill at 56. Within weeks, menopausal symptoms started, with insomnia, low mood and my hair coming out. Things escalated quickly, and I made several visits to the GP asking for HRT. I knew, after 40-odd years on the pill, I needed my hormones back.

I was given sleeping pills and antidepressants, but nothing helped. In three months, I lost more than three stone in weight and was so weak I couldn't walk. I made four visits to A&E and saw a private neurologist as I was convinced that I had dementia or cancer.

By the end of the third month I couldn't sleep, eat or drink. I started to hallucinate from lack of food and from medication and I made an attempt to end my life.

I was put in a psychiatric hospital for four months, which was worse than any horror film I've seen. I begged for HRT again but was given different medication. That year I tried to take my life two more times. It took me another two years of fighting to obtain HRT last June and it was by chance, as a new locum started at the surgery. He was a young man who had done training in menopause. He prescribed it and I've not looked back since.

I wish someone could help my story be heard. I don't want this for my daughters and granddaughters.

#### **Too many antibiotics**

I had UTIs which increased year on year until I had eight in one year and ended up on intravenous antibiotics. I saw 16 different health professionals, from urologists to gynaecologists, had lots of tests, spent many hours in A&E due to bleeding and no one ever mentioned that it might be related to menopause.

Eventually, I spoke with a private menopause specialist nurse who advised that all I needed was local oestrogen. The GP prescribed it and I've not had an infection since. This is great. However, I am now allergic to two antibiotics as I was given so much.

#### 13 years of my life wasted

My symptoms started around the age of 40 with an explosion of mental issues. I suffered extreme panic, anxiety and depression so severe that at times I no longer wanted to be around. I was constantly at the GP surgery where I was given beta blockers and antidepressants. These made me feel terrible, but I persevered because I was so desperate.

Prior to all this, I was at the top of my game with my career, having won a national award for my work. I became a quivering wreck, struggling to get out of bed every day and crying with the fear of getting through that day. I was suicidal at times at the thought of this being my life now, sapped of joy, enthusiasm and motivation.

I kept telling my GP I thought it was hormonal only to be fobbed off with, 'you're too young,' and, 'HRT won't help with things like that'.

Ten years later, and following much research, I decided to go private. It was something I couldn't really afford, but I was desperate and determined to change things. After just five months the improvement has been incredible. Blood tests showed I had extremely low oestrogen and testosterone, which are now both being replaced with HRT.

I feel so angry that I lost 13 years of my life to debilitating symptoms which could have been treated were it not for the lack of knowledge. Every GP practice should offer at least one professional who specialises in menopauserelated issues. It's disgusting to think that many women suffer because they don't have the option of paying privately! We have to keep the momentum going and get ourselves heard, in the hope it will bring around a muchneeded positive change.

#### Labelled a 'challenging patient'

I ran out of HRT after being on it for five years. My GP surgery was closed for staff training, so I had to call 111. The operator refused to give me an emergency repeat prescription and the on-call doctor wouldn't authorise one either. Their reaction frightened me so much I decided to stop taking it straight away. I then descended into a painful hell.

When I saw my GP some weeks later, he dismissed my concerns, prescribed me anti-anxiety medication and told me to stop ruminating. I was in so much distress, but I was labelled a 'challenging patient'. I felt every subsequent doctor was influenced by this label and that prevented them doing proper investigations.

I survived the ordeal and only now, five years later, are my concerns finally being heard. I just don't want what happened to me to happen to anyone else.

#### Apparently, I'm not menopausal

I had my last period in 2017. At the time I felt OK and lived a normal healthy life. But then symptoms started in 2018 and got worse by the month. I had daily dizziness and vertigo, lower back pain, no sex drive, loss of interest in life, depression, muscle weakness, drop foot, migraine and no quality of life.

I've gone from being a happy bubbly person to thinking 'what's the point?'. Doctors won't join the dots. Frequent nightly urination means I don't sleep, and dizziness leads to panic attacks.

I've been told to give it time, I'm not menopausal and I can't have HRT. Nowhere else to turn...

#### No help for late menopause

I'm now 63 and postmenopausal. But like many women, who are hardly mentioned, I had a late menopause at around 60. When I had my coil removed at 53, I was still having periods. I was prescribed the contraceptive pill and told I could take it continuously so I wasn't bleeding. My GP was advised by a hospital gynae to monitor the situation and I appeared to have gone through menopause just after my 60th birthday.

I was ok for almost a year before the hot flushes, night sweats, drop in libido, weight gain, skin infections, broken sleep and low moods began. I spoke to my GP, but it was during Covid so just on the phone, and the first thing she

told me was that as I was over 60 she couldn't consider HRT. She prescribed a vasodilator drug for the flushes, which hasn't helped; and was a bit dismissive of the libido and low mood issues.

So, I have just been bumbling along, trying to eat well and exercise (although I often don't have the enthusiasm for anything other than sitting reading with a big bar of chocolate). My husband has been supportive but is starting to think there are other things going on because, really, I should be over this by now.

#### My marriage ended

I started to feel different at 39. Initially I was just having hot flushes. When blowdrying my hair, I'd find that I needed to open a window. This escalated to flushes during the night, more headaches than normal and a sadness I'd not felt before. I saw my GP and mentioned that my mum had an early menopause but was told there was no way to diagnose it. I was given HRT for six months, but when I returned for a review, I wasn't sure whether it had helped and was taken off it.

Over the next year my symptoms gradually escalated, my sex drive diminished and then my marriage suffered. I was unhappy, maybe more so because of the sadness I'd felt for a year, and my husband withdrew from me. I think his ego was also flattered by someone else. We eventually separated a year later and then divorced.

In just two years my whole world had turned upside down. I saw my GP again and was prescribed antidepressants for my low mood. I asked about blood tests, or taking HRT again, but this time I was told that as I was only 41 it was unlikely that I was going through the menopause and that HRT would be more detrimental than beneficial.

I started to suffer with neck pain a year later, and now believing my bones were being affected, I pushed for treatment. I received a short course of physiotherapy and requested an MRI, which I received at 44. It showed moderate arthritis, which wasn't normal for my age. I also suffered with vaginal dryness.

After seeing four different GPs prescribing various treatments over two years, I saw one who mentioned HRT as my periods stopped aged 46. We discussed my story, and she explained that my body was ten years ahead of my actual age. HRT was prescribed again.

My story is not unique. However, I believe that had the initial GP recommended

I persevered with HRT in the early years, I might not be suffering as much with constant neck and shoulder pain as I do now.

#### I regret not fighting harder

I am now 66 and bitterly regret not fighting harder to go onto HRT after being consistently denied it over the years by my GP. I had crippling anxiety, palpitations, aching joints, hot flushes, loss of confidence in my job, mood swings, the lot. It's too late for me now, but I am advising my daughter to get onto it as soon as she can – she's 46 and getting severe symptoms.

#### Told I'd get breast cancer

I approached my GP to ask about HRT two years ago. I was told that if she prescribed me HRT, I would be coming to her in the future asking why I had breast cancer, and she would reply, 'because you had HRT'. I abandoned the idea and have suffered hideous symptoms.

#### My husband left because of my anxiety

My husband of 22 years left me in 2020 for another woman. He met her in Lockdown and moved straight in with her five months later. One of his comments was that I'd become 'far more anxious'. I'd say that was one of the primary menopause symptoms I suffered. Needless to say, the other woman is younger.

He told me the day after our wedding anniversary that he was leaving, having denied there was anyone else for months. I wonder how he'll cope when his new partner goes through the menopause.

#### **Finally treated in Spain**

I was over the moon when my periods finished but then the dreaded menopause hit! It's like, 'yay! Celebrate! No periods!', and then nature says, 'hold on a minute, we're not finished with you. Have some more, but this time we're going to make it a million times worse.'

I went to the doctor with every menopause symptom. It was awful. He denied me any kind of help and told me to try herbal remedies. I told him I'd tried them all with no luck but was still told there was nothing to be done.

I suffered for two years until I moved to Spain, went to see a doctor there and

got prescribed the right thing straight away! Within a few weeks it worked, and it continues to work.

I've heard so many similar stories from friends. This is so wrong on every level. No-one can understand how bad it can be. Why are we not getting the help we deserve? It's not like we asked to be menopausal!

#### 18 months to see a specialist

I have been waiting for a specialist appointment for 18 months and have had four hospital cancellations. I'm taking HRT but need specialist advice from the hospital as my GP does not have knowledge of adjustments. I currently still have severe problems that affect my working life and personal life.

We need more focus on women's health for older ladies.

#### **Refused HRT**

I was always aware of menopause. My grandmother married a widower whose first wife took her own life, which he felt was because of untreated menopausal depression. He arrived home and found her.

In 2008 I started to feel decidedly under the weather. My menstrual cycle was still regular, but I was suffering from insomnia, hot flushes, depression and painful joints with urinary incontinence and no libido or sexual sensations.

I went to my local NHS practice, but the GP was reluctant to prescribe without sign-off from the practice gynaecologist.

She immediately refused HRT, despite my wishes to try it. I was told to take a multivitamin and she scrawled 'no HRT' in my medical records.

Things ambled along for a short time. Then I became worse, crying and refusing to get out of bed. My husband was seriously concerned. He begged me to see a specialist privately.

Eventually I was prescribed HRT, including testosterone. Within a short period, I had my life back, and my sex drive improved dramatically.

My husband featured in a magazine talking about the subject from a man's point of view.

Now he is active in his government department helping to drive through new menopause-friendly policies. I have often advised other women. The treatment from the NHS is often atrocious, with antidepressants handed out like sweets.

#### **Told to drink milk**

When I started getting symptoms of the menopause, I went to see my doctor who did a test and confirmed that I was indeed going through the change. When I asked him whether I could have HRT he checked my notes and declined my request, because my mother had suffered from thrombosis in the past. This was on my notes, as it was a question asked when I went onto the contraceptive pill years before.

I asked him what I should do to help with my symptoms of hot sweats, sleepless nights and anxiety. He said I should look into natural supplements and to drink at least a pint of milk a day to help with maintaining my bones. I started to take over-the-counter sleeping tablets and ended up feeling I couldn't sleep without them. The pint of milk a day didn't help much either, other than making me put on weight. I feel I was left to suffer in silence.

#### I don't know where to turn

Things changed overnight, like a light switch. I was taken off the pill due to my age and have not had a period since. Then I started to suffer hot sweats at night, followed by broken sleep or no sleep at all.

My bones ache like I'm an old lady. I've no interest in anything, I cry uncontrollably at times, and my memory is just weird.

I have a very high-profile career and it's a struggle to get through the day. I've lost friends as they don't understand and just think I'm being mardy. My GP says my blood tests show I'm not in menopause so they can't help. I'm 48 and don't know where to turn.

#### Told too old for HRT

I have been on HRT for 31 years following a hysterectomy aged 38. Since then, I've had every kind of medication; tablets, patches, implants and lastly gel. I have tried to stop taking HRT twice before on my doctors' instructions and had very, very bad hot flushes. I had sweat dripping off my chin out in public and was constantly being asked if I was OK. So, I returned to using it, this time with my doctor's backing. I have been given all the information and made the decision it was doing me more good than harm, which has been borne out by recent research. But now, with the combined effect of the shortage of supplies and not being able to see a sympathetic doctor face to face, I feel I am being forced to wean myself off it as I've only been given eight weeks' supply.

This is really worrying after 31 years of happily using it and just short of my 70th birthday. I'm only ten days in and the hot flushes have already started. God knows how bad it is going to be further down the line, and this is at an age when other older age problems start to kick in.

#### I've given up

A few years ago, my GP practice invited me to a well-woman check. I mentioned to the nurse that I thought I was heading towards menopause. She replied: 'Just get on with it and next time come back as a man.'

In recent weeks I went to the doctors with a painful knee and decided while I was there to broach the subject of HRT. I just wanted a conversation about it. I'm managing my symptoms as best I can but am interested in the long-term benefits of HRT with regards to heart health and osteoporosis.

She suggested a phone consultation the next week and booked me in, as well as suggesting I get the Balance app and be ready to tell her exactly what my symptoms are. She said I would receive some texts about HRT so I could have a think about what I may want. These never arrived.

#### I still felt hopeful!

The day of the phone appointment arrived and I waited with my phone close by, not wanting to miss the call and having done all the preparation she had requested. My phone rang no more than twice and by the time I picked it up it had stopped ringing. I never got my phone appointment.

l give up!

#### Given cryotherapy on my cervix

I was misdiagnosed, sent to a sexual health clinic and had cryotherapy [the use of extreme cold to treat abnormal tissue] performed on my cervix. I was also denied HRT when I asked for it directly from my GP. I struggled with depression, brain fog and flushes and got no support at work. I cried and suffered for three years, and even after getting HRT, I had to take what was given without discussion and fight to keep my thyroid medication at the same consultation.

#### CHAPTER NINE

I stopped working as my confidence could not recover despite some benefit from the HRT. I felt that management had a poor opinion of me, that nothing would change. For the sake of my self-esteem, all I could do was leave. I could not look for alternative employment due to poor confidence. I am now unemployed.

## **CHAPTER 10** GENUINELY **FS**

t is by now probably apparent that many of the stories sent to Menopause Mandate are highlighting the appalling experiences suffered by hundreds of thousands of women. However, there are also those who have had an excellent GP, have done their own research, had fantastic support or simply sailed through menopause.

This chapter is a celebration of some of those stories - which highlight even further the need for mandatory education and access to treatment for all, so that everyone can call their menopause experience 'excellent'. Let's not forget that there's also liberation in menopause, with no periods, and not caring what others think of us! Thank you to all those who wrote in and reminded us that there is also a bright side.

#### I sailed through without noticing

I was one of the lucky ones. I sailed through my menopause without noticing it. So many friends have suffered and are still suffering. Thank goodness the world has woken up to the fact that HRT should be as available as contraception.

#### Menopause has been a time of reinvention

I have a very positive story about my menopause. It has been a time of reinvention. I changed careers in my late 50s, going from being a stay-at-home mother of four to a yoga teacher. Now, at the age of 60, I am Head of Yoga for an online wellness platform for women over 40. I am helping other women through their menopause journey - offering support that I did not have.

For me, menopause was a launchpad to a new career, to meeting new people and to doing fun things. I wish this for all menopausal women.

#### I'm one of the lucky ones

I'm one of the lucky ones! I have a mother who is a trailblazer when it comes to menopause matters. And yet I still felt the stigma of ageing and feeling that I must be too young to be menopausal, which put me off asking my doctor for help. When I eventually did, I was angry, exhausted, forgetful and not at all myself. My doctor was good and put me on oestrogen patches straight away.

I saw the benefits within three months, but they soon waned. My doctor did as much as she could and upped my doses, but eventually she had given me all that

she could under the NHS guidelines.

So, I had to scrimp and save and went private. I'm now on testosterone as well as oestrogen gel and I have a Mirena coil (IUS). And I feel much, much better, as though life is worth living again. I have two young children, and they need a mum who's there for them - not someone raging with anger who falls ill at the drop of a hat and loses her mind.

Now, I look at my friends, who are clearly going through the same, and they want to go natural. In the meantime, their marriages are at risk and their health is deteriorating swiftly. I believe they are going to cost the NHS so much money in the next 30 to 40 years of their lives. Or they refuse to join the menopause club because their doctors tell them they've not reached menopause yet, or because the shortages mean they think they won't get their prescriptions, or because of the stigma!

It's time that the UK started prioritising women's health.

#### **HRT** was amazing

Age 50 I was suffering from aching joints, headaches, insomnia, and was feeling low the whole time. My husband was worried about me. Then I saw Mariella Frostrup's programme about menopause and wondered whether it might be that - I knew I was the right age. So, I went to see my GP and said that I thought I might be menopausal. She agreed and asked whether I'd like to start on HRT, which I wasn't sure about, but she reassured me. Within a couple of weeks, the symptoms had gone and I felt back to normal. It was amazing.

#### Here's to the next 50 years

All through my 40s I felt like giving up, leaving my family and even taking my own life, as I felt anxious and worthless! Perimenopause? Never heard of it!

Fast forward 12 years and I am living my best life. At 48, I told myself: 'Enough is enough.' I started exercising with Joe Wicks and changing my lifestyle through diet, destressing and exercise. I educated myself as to what menopause is all about. At 49, I started yoga which sorted my head out completely.

At 50, I buckled up and found the courage to ask the doctor for local oestrogen due to having lots of UTIs and painful sex. At 51, I became a yoga teacher to help others feel the way it made me feel. At 52, I'm about to become

a menopause yoga teacher as both subjects are so close to my heart.

This whole process of investing in myself, educating myself and loving myself totally turned my life around. I love my life so much I very rarely need to take time away from it. Menopause can truly be a wonderful time. Here's to the next 50 years, as I'm not retiring any time soon.

#### I saw an understanding doctor

I am 53 and a few years ago I started the classic symptoms of the menopause, but at the time I didn't realise, just thought I was losing it! I had terrible mood swings, anxiety, paranoia, and felt tired and withdrawn.

I went to the doctors and explained I thought I was going through the menopause, hoping she would be sympathetic and give me advice. Quite the opposite, I was told to 'ride' it, I went away thinking that was my only option, as I had no one to talk to and no one was talking about it.

My symptoms continued and, as it was affecting my family, I returned to the doctor's, I saw another female doctor who again had no knowledge on how to help me so offered me antidepressants, which I refused to take.

It was only on my third attempt at visiting the doctor, about an unrelated issue, that I finally got the help I needed. A male doctor told me: 'You can't carry on like this, you need HRT.' He went through all the HRT options. He was amazing. We agreed the patches were the best option and I haven't looked back, I have my life back. The only sad part is that due to the previous doctors' lack of training and knowledge I didn't get HRT sooner.

#### My GP was wonderful

With all the negative press about menopause and HRT, I wanted to share the other side, to give women hope.

I had started with all the typical symptoms at age 51 and it was my husband who read an article in the news and suggested it might be worth a visit to the GP to ask about HRT.

I made the appointment, and having done lots of reading and research, I prepared myself for a fight. I could not have been more wrong.

My GP was wonderful, agreed with me, prescribed HRT and gave me lots of follow-up reading to do including the Balance app.

During the shortages of gel, I was quickly changed to the spray, accompanied by a phone call from the doctor to check all was ok.

I know I have been fortunate but want to let women know that help is out there. If your GP refuses treatment, then seek a second opinion.

Use all the resources that are available to you. There are so many help pages, groups and forums available - use them.

#### HRT changed my life for the better

I hadn't realised how much HRT had changed my life until a brief period without it. I was experiencing some bleeding and had some polyps removed. The gynaecologist told me to stop using my patches and wait two weeks before talking to the doctor about changing my prescription.

During that time brain fog descended and my anxiety went through the roof. My GP was thankfully brilliant and gave me a new prescription straight away. It took another two weeks, but I'm now back to my usual calm, cheerful self.

#### My GP reacted immediately

I sailed through the menopause – or so I thought. I'd had a Mirena coil (IUS) and hadn't had periods for a number of years, so when I had it removed at 52 and my periods didn't restart, I thought that was it. Hurray, over and done.

At 54 I started a new job. I work in a technical job in IT, which is very much male dominated, and most of those men were younger than me. I've always loved my job, and the best thing about it has been the continual learning. The new job was in a place I'd wanted to work for years and involved new technologies and a chance to add to my skills. I was overjoyed at the opportunity.

Except that I couldn't do it. Nothing made sense. My brain simply couldn't take in the new technology, and my confidence ebbed away. My anxiety increased. I would disappear to the toilet and cry. I couldn't sleep. I gained weight. I became snappy and irritable with my family. In addition, I had lots of physical problems; a frozen shoulder, hip and knee issues and migraines.

Eventually I contacted my GP, thinking I must be depressed. Immediately she suggested I try HRT patches. It took a while, but HRT did help. My sleep improved almost immediately, the fog began to clear and I began to understand the new technologies. The anxiety and lack of confidence persist to some extent but

#### I'm getting there.

It's a shame that I couldn't and never have talked to my manager about this. It was an all-male team apart from me. He is the kindest, most understanding person, and I'm sure he would have been concerned and tried to help – but I was just plain embarrassed.

#### Webinars helped me speak to my GP

Off the back of watching Let's All Talk Menopause webinars, I've been able to work with my GP to join the dots of all my perimenopause symptoms going back seven years and I am starting HRT in a couple of weeks! It is such a relief to know that I'm not a hypochondriac, which is how I felt, and I am so looking forward to feeling better.

#### I was listened to by family and doctors

My GP didn't know much about HRT but listened to the research I'd undertaken into body identical oestrogen gel. This was ten years ago, when HRT was still out of favour, due to a flawed study. My mum had sailed through menopause, and I was expecting the same.

But first my brain started to go - my memory was terrible, I couldn't think of words and I'd stop mid-sentence, forgetting my train of thought. I also had constant joint pain.

I completely lost my confidence and floundered at work.

I started to take HRT, but the bleeding was horrendous. I couldn't get it under control with medication. I paid for a private appointment with a gynaecologist who agreed that a hysterectomy was a good way forward and wrote to my GP who then referred me. I recovered from the hysterectomy quickly.

Now, I feel alive on HRT. I work and look after my grandchildren. I'm fit, with minimum joint pain, good sex drive and a healthy knicker department. I will take HRT until I die.

#### **Blessed with well-informed doctors**

I went to my GP at the age of 42 as I was having terrible periods and random bleeding. He did some blood tests and gave me the good news that I didn't have cancer. As it happens, I wasn't aware this was a possibility! But it was the 'storm

before the calm' and he sent me on my way. I sat in the car park and cried.

A house move - and a change in GP practice later - I went back to the doctor aged 45 because I thought I was depressed following the death of my dad. The GP said she didn't think I was depressed, but I was experiencing symptoms of perimenopause. Thank goodness for her and her absolute kindness. I left armed with information on HRT. I originally thought it would give me breast cancer if I took it. But the information she gave me changed my mind and I was happy to be prescribed it. HRT made an immediate difference and I felt like me again.

I'm 48 now and lots of my symptoms have returned. I've been back to the surgery, and I think I'm blessed because the next GP I spoke to was also well-informed and gave me new options.

I'm still not right yet, but I'm being supported at work so I'm coping. I feel sure I'll get the balance right again.

#### I felt great the whole time

I took HRT for 15 years and felt great. I had good skin, no mood swings and no hot flushes. HRT was a life changer, and I would take it again if I needed to. Very helpful to most women. I'm 77 now.

#### My quality of life improved

I suffered with symptoms for many years before realising that I was perimenopausal. In fact, I had not even heard of the perimenopause, in part because I was only in my late 30s. I had terrible anxiety, aching in my joints, brain fog, lack of libido, dry skin, dry eyes, tiredness and poor concentration.

I have been lucky that my GP has been supportive. I have been on HRT patches for four years now and my quality of life has improved immensely. I would hope that there is increased awareness of the perimenopause and menopause, so that women do not needlessly have to suffer in silence.

#### Alternative remedies and quitting alcohol worked for me

I would like to put it out there that I suffered from sweats, terrible mood swings, and all the other symptoms you can think of. With a few remedies from a homeopath and, perhaps as importantly, no alcohol, my symptoms went away. My energy came back and so did my brain power. Please consider this as an option.

#### Your sex will be on fire in a good way!

HRT is life transforming. I had low confidence, a fuzzy head, anxiety, and hot flushes. I remember seeing a photo of myself looking very middle aged! I spoke with a women's health GP who suggested HRT. I have never looked back.

Now I feel and look youthful. People comment on how good I look. I am 60 next year and have never felt so great.

So, please do not hesitate to go to your GP. HRT can be life-transforming and give you confidence. Don't suffer. Life is for embracing and to quote the famous song, your sex will be on fire! In a good way.

#### I feel capable and alive

I'm a singer and songwriter and I turn 50 this year. Two years ago, I lost all my confidence and my poor body was in a mess because of perimenopause. I started taking HRT and my life totally turned around. I jumped out of a plane for a sponsored skydive last week, put myself in the foreground in a new music video and feel capable and alive again! So, HRT matters. It changes lives.

# **CHAPTER 11** THREE CHEERS FORACHAT THE

hree cheers for the conversation. We were thrilled to receive stories celebrating the fact that menopause is finally being discussed openly, after millennia of it being treated as tedious, shameful and - frankly - disgusting. The optimistic tone within these tales shows the value of campaigning and open conversation. Women's health needs to be brought out into the open and discussed.

Some of the stories have thanked Menopause Mandate, which is very kind. Others mention some incredible campaigners who have made such a difference. Menopause has, at last, permeated our press, our social media and our day-to-day chat. Most importantly, every single one of the stories celebrates, encourages, starts or continues the conversations which we all need to be having.

#### I feel hope for the future

I am now postmenopausal. The first thing I would like to say is that I feel more hopeful for women approaching perimenopause, because of the raised awareness of the issues.

When I approached perimenopause around 12 years ago, I was ill-prepared. Honestly, I had never heard the term perimenopause. I had vague expectations of hot flushes and, perhaps, bad temper. In reality, I was floored by my symptoms. At the time I didn't seek help or explore HRT. There was much less information out there then and HRT was medically frowned upon.

I applaud the work that is now being done to increase awareness of menopause generally and particularly in the workplace. My confidence at work plummeted and I retreated into the background. As a result, I missed opportunities and promotions, for sure. Sadly, I look back at my 50s as a lost decade.

#### Social media helped me make sense of it

I felt abandoned and frightened by family and friends. I tried to explain how I was feeling but nobody seemed to understand. How could they when I didn't know myself? All I knew was that I was losing myself and I didn't feel like me. I wasn't sleeping, I was comfort eating to keep symptoms at bay, I was also losing my hair and my skin was dry.

I had some dark days that gave me flashbacks to my postnatal depression.

One day, driving home from the school run, I looked at the grass verge and wondered what would happen if I drove into it. Would it be serious? Would the police and an ambulance attend? Would my husband cope? These intrusive thoughts came in so quickly and at such speed they were scary, but they were also a wake-up call that I wasn't well.

I seemed to be the only person in the world to secretly welcome Lockdown. I didn't have to battle my symptoms at work or pretend I was OK. I didn't have to attend meetings in person, so no more seeking the seat closest to the door in case I needed to leave in a state of panic. Lockdown for me took the pressure off. I was in the comfort of my own home, and I loved it!

During this time, I contacted doctors on numerous occasions to describe how I was feeling. I was convinced I had something sinister wrong, and thanks to Dr Google I diagnosed myself with a number of illnesses and diseases. Then I saw the Davina McCall TV programme about menopause and it all made sense!

I eventually spoke to a brilliant doctor after yet another panic attack and vertigo episode while on a family day out. She listened, she nodded in all the right places and just told me to stop. Hearing the words 'you would benefit from HRT, let's get you started,' was like a weight being lifted. I could have given her a massive hug!

Months down the line and I am better. I can pop into a supermarket without feeling sheer panic. I can go to work without worrying about how I am going to cope, and the biggest thing is that I can take my little boy to the park without feeling fear! I have even joined our local gym. For someone who could barely leave the house, this is a massive achievement.

Thank you to people like Davina McCall, Lisa Snowdon and Penny Lancaster, who have raised these issues on social platforms.

#### I want things to change for my daughters

I had to change my job due to a complete loss of confidence in my abilities. The stress of this went on for months. I saw one GP who offered me antidepressants for my total loss of any joy in life and I felt completely flat for 18 months. I realised something had to change.

I went to see another GP who was also reluctant to give me HRT but at the second appointment finally agreed. Even then, the patches sat in my kitchen

for three months! I was scared to start! But once I did use the patches, it was completely and utterly life-changing. Within a week or two I could feel my mood lifting and I am now able to cope with life. I have been on the patches for eight months now.

I want things to improve for my daughters when they get to this stage in life, as it is utterly unbelievable in this day and age that there's so much lack of knowledge around the subject of menopause! Thank goodness there are people raising awareness.

#### Thank you to Daisy Network

I don't want other women to feel alone and sit in their bedroom wondering what to do like I did. If just one woman reads my story, and it helps then my work is done.

My menopause journey began with my fertility journey. After suffering from irregular periods after a year trying to conceive, I was diagnosed with POI at the age of 34. I was working as a specialist women's health nurse, but despite all the knowledge I had, I still sat alone in my bedroom wondering what to do and who to talk to. Looking back, I think I had started to suffer years before, with symptoms such as anxiety, irritability, fatigue and abnormal periods.

Sadly, our fertility treatment was unsuccessful, and my husband and I had to accept a future without children. I also had to juggle the symptoms of a premature menopause. These were so severe that at one point I thought I had early onset dementia, as I kept forgetting things, making mistakes and suffered severe anxiety. I even left a job because of an unsupportive employer.

Premature menopause means being out of step with your friends and family members - all of whom are having children - with no one to talk to or share experiences. Many friends just did not know what to say or couldn't understand. I had little support from my GP and my mum had to pay for private healthcare so I could see a specialist, have a bone density scan and get the right medication. A nurse's salary just wasn't enough to cover the costs!

It took many months of trial and error to get the right HRT regime for me. It has always felt like an uphill struggle, with few healthcare professionals having the knowledge to support my condition or willing to make a referral to someone who could help. Frequently, I have had to fight for basic treatment such as local oestrogen alongside my HRT - it took me three appointments and more than a year to get that via my GP. I joined The Daisy Network - a charity for women with POI - a few years ago. It was great to know there were others like me I could talk to and get more support from.

My tip for other women is, don't be afraid to talk to others or ask for help. It took me many years to find the courage to do so, and now I don't want to stop talking! I do feel more information is out there now, and many wonderful women have done a fantastic job talking all things menopause.

My mum's support continues, and she is now helping me self-fund my PhD which will be looking at women's lived experiences of early menopause.

#### 12,000 people joined my Facebook support group

After surgery to remove an ovary ten years ago, I was sent home with no information or advice other than to rest. What followed was years of suffering, as my lack of hormones hit me like a wrecking ball!

I was initially given antidepressants and the mini pill, but when I researched my symptoms, I realised that I was perimenopausal. My GP knew nothing about HRT but said I could try a combination tablet. This was disastrous, giving me horrendous anxiety and depression.

I felt lost, I had no lust for life and I finally turned to the internet where I researched patches and my HRT journey really began.

I started a support group on Facebook which, incredibly, has over 12,000 members and counting. I was affected by the shortages three years ago, and had to change HRT again, as well as having to endure a hysteroscopy and biopsy. I now have my HRT right, but now we've got shortages again, and I'm praying I have enough patches and gel to keep me going. I feel I have myself back, with patches, gel, testosterone and antidepressants. It's why I've not had to take time off work in over two years. We women deserve better, and this is why I've joined Menopause Mandate. Change is well and truly overdue.

#### Thank you for talking about menopause

I love how we're now all talking about menopause. Thank you to everyone who is fighting and making the world aware of it. You are amazing and thank goodness for you! I'm certainly out there promoting HRT and supporting women that I

speak to about perimenopause, knowing that it will help the next generation of fabulous women with their journey.

My perimenopause symptoms started in my early 40s but were masked by the contraceptive pill. When I came off the pill at 43, I suffered horrendous symptoms; night sweats, hot flushes, painful wrists, restless legs, insomnia, sensitive teeth, weight gain, dry skin and hair – even my eye lashes fell out. I didn't know what was happening to me and felt very alone. I started researching the effects of lack of oestrogen and discovered what perimenopause is.

I thought I was surely too young, and then realised that it's quite normal around my age and understood that coming off the pill, which gave me oestrogen, had given me a double whammy of awful peri symptoms.

The symptoms did ease with lifestyle changes and doing and taking everything recommended. I keep a spreadsheet and log everything and monitor my moods.

But really, I was surviving for about 18 months, until one day I just felt I couldn't go on anymore, what was the point? I realised that I was just existing, not living. I felt numb, felt nothing and didn't look forward to anything. My confidence was completely gone. I checked my log and could see how my mood had gone downhill over time.

I told my GP, and she was fantastic, though I did go armed with information from all my research. I knew I needed HRT to balance my fluctuating hormones.

I've been on HRT since September 2021 and feel that it has saved my life. I am back to living again, feel great in myself, and the weight is coming off at last as the HRT is working along with lifestyle changes. I'm back to me again and my husband is pleased, bless him!

Now, the oestrogen shortage is terrifying me. I can't go back to where I was last year - I never want to feel like that again. It breaks my heart knowing that women can't get hold of their oestrogen as I know how I will feel if it's not sorted.

#### We need to keep talking

I'm an Indian lady and topics such as the menopause are not openly spoken about. I became perimenopausal a year after I got married in 2016. I didn't have a clue about what was happening but saw my GP for a blood test which confirmed it. I was offered no support or advice. So, I educated myself. I talked to anyone I could, watched Loose Women and signed up to the magazine Menopause Matters. I recorded TV snippets where they talked about the menopause and made my husband watch them. I'm lucky that he has been very supportive, but the early years were difficult for both of us.

The other huge help I got was watching experts on You Tube which educated me about micronised progesterone. When I switched to this it stopped the bleeding which I had on the combined patch. I've just started testosterone this week. The oestrogen patch has been fantastic and again my dose has just been increased. It has been six years for me and I'm in a much better place. Please keep talking, find help, support and ways to alleviate your symptoms. There really is help out there.

#### Here's to all the fantastic people

HRT has given me a life of stability and joy. Previously, doctors talked about me having an emotionally unstable personality disorder. They gave me all manner of pills, but nothing helped. Being told that there was no cure for this condition, I became suicidal. In April 2021, I was hospitalised after a near fatal attempt. Now I'm on HRT, all of my symptoms have gone, and I can live again. From the very first night, I slept like I hadn't in months.

I would love to personally thank all the fantastic people who have brought attention to this topic. You are life savers.

#### TV and social media flagged my symptoms

Until 2021 I'd never heard of perimenopause. But thanks to the regular discussions on TV and social media, I realised that all the symptoms I'd been displaying for the last three or four years were likely to be the beginning of my perimenopause journey. I think I ticked off around 30 from the symptom list!

I first went to the doctor in early 2022 to discuss this and ask about going on HRT. He told me that there were antidepressants that offer the same relief for my night sweats and hot flushes and would help with the anxiety I'd been feeling, but without the risks of HRT. I believed him and took them for a month but noticed no change at all.

In the meantime, I read further into the research around perimenopause and HRT and knew that's what I wanted and, indeed, needed. So, at my next appointment I went armed with books and notes and said that I was aware of the risks but also the benefits of HRT.

I was prescribed patches and within one week my night sweats had stopped and most of my other symptoms are beginning to show signs of improvement. Hearing some horror stories about the lack of support from doctors I do feel like one of the luckier ones. I know this is only the beginning and there may need to be tweaks to things, but I am eternally grateful for the army of women who have begun to raise awareness of menopause.

#### I armed myself with the facts

At the age of 45, completely out of the blue, I had severe suicidal thoughts to the point that I was planning how I would end everything.

I had never experienced anything like it in my life before. I went to my GP and was offered antidepressants and counselling, neither of which I wanted or felt I needed. I asked whether it could be hormonal and was told blood tests were unreliable and the conversation ended there.

Fortunately, I have since armed myself with all the information I needed and asked another GP about HRT. She was far more informed, and I was prescribed oestrogen gel and progesterone capsules. I haven't looked back since and I thank the all the women in the world who are using their voices to fight for the cause - thank you!

#### I feel fantastic

I'm now 54. Six years ago, I sobbed to my GP that I couldn't cope and she offered me antidepressants. I said I wasn't depressed. I was menopausal. At the time she wouldn't prescribe HRT because I have a history of migraine with aura which is linked to strokes.

Since then, I have coped with exhaustion, more than 20 intense hot flushes a day, a heart attack, brain fog and sleep problems - all while running my own business.

Then I watched Davina McCall's programme and went back to the GP. She said I could now have HRT as it was safer. Why had nobody told me? I now have no hot flushes and feel fantastic. I'm ready to live my life instead of dragging myself through each day.

#### We need the information to make choices

I am writing this at 2.46am. Going through perimenopause and menopause was horrendous and lasted for years. I'd go to the doctor crying that I didn't know what was wrong with me and was given antidepressants. I wasn't aware it was menopause related. I had heavy periods where I would be soaked with blood at work and had to take in a change of clothes. On a flight from India, I was in the toilet unable to stop the bleeding – I ended up needing to change into spare clothes from my hand luggage.

Menopause was one of the worst experiences I have ever had, and I didn't know enough about symptoms. I suffered from exhaustion, sleepless nights and brain fog. Oh, and tiredness. Overwhelming tiredness.

I didn't go on HRT, as all I knew was that you risked getting breast cancer.

At 62 I was diagnosed with oestrogen-receptor positive breast cancer. The first thing they asked was: 'Did you take HRT?'

I felt like screaming: 'No, I bloody never, I suffered for years and still got bloody breast cancer'. I'm not sure which was worse, the diagnosis, or the realisation that I might have suffered for nothing!

Well now, two years later, I'm on drugs to reduce the risk of my breast cancer coming back. Bloody hell, I'm going through the menopause symptoms again.

Please, in your quest to raise the profile of menopause, also include us breast cancer patients. Let us have the information to make informed choices. I am so pleased you have raised this issue, and as we all live longer our daughters will benefit from what you are doing and raising the awareness.

Let's hope it makes a difference. Thank you.

#### The recent exposure encouraged me to see a nurse

I have a list of symptoms as long as your arm. A few years ago, I asked my GP to test me for diabetes, check my thyroid and had a 24-hour heart monitor from the hospital. I also had arthritis in my hands. I'm nearly 55 and it was never suggested that it could be the menopause. I truly felt like a hypochondriac, but just knew I didn't feel well.

All the recent exposure has encouraged me to see the nurse about it all and I will soon be starting on patches. I am really looking forward to getting my life back and feeling well again. Thanks for all the hard work you're putting into this campaign. I can't believe how many women out there feel just like me!

#### My instincts were right and I got guidance

I felt a shadow of the person I once was. I had no confidence and at times felt paralysed by unexplained anxiety. I thought I was losing my mind and it impacted my job in a senior role. The memory loss and brain fog were crippling and compounded the problem. But I had no physical symptoms. No hot flushes or night sweats.

A nurse wanted to put me on antidepressants and I told her it wasn't depression and anxiety, it was menopause. It got to the point where I really wanted to end my life, as I saw no future. But then I got support from the incredible Diane Danzebrink, founder of menopausesupport.co.uk. She reassured me that my instincts were right and gave me much needed knowledge and guidance about HRT. That helped me take control of my GP appointment. I started the patches and pills, and it changed my life. My old self returned within two weeks. I couldn't believe the difference in my energy levels, brightness and joy for life again.

Even my acid reflux disappeared. Bizarre! The benefits far outweigh the risks for me, and I would say to anyone considering HRT, don't give it a second thought, just do it.

Oestrogen is the glue that holds us women together and when we start to lose it, things can unravel in our bodies as a result. So, treat the deficiency and get yourself back on track. Arm yourself with knowledge and ask for what you want and need.

### The positive press is heart-warming

I am a nurse practitioner and have been passionate about treating the menopause for years. I am an advocate of positive women's health. The great positive press about the menopause and HRT is heart-warming. We just need the products to be available.

### I will keep fighting for what we need

My story started three years ago when I was 40. My periods got so heavy that it massively affected my ability at work. As a PE teacher in a primary school, I often had to abandon classes and go home to change, and my confidence was rock bottom. I spoke to my GP and over the phone she prescribed the mini pill without any discussion of the perimenopause. I naively thought I was cured.

Fast forward two years and symptoms started to creep in - I thought they were down to other factors - rage, anxiety, low mood, paranoia, tinnitus and hair loss. The list went on but I thought it was down to Lockdown and I did nothing. Then my sister-in-law pointed me in the direction of Dr Naomi Potter of menopausecare. co.uk and I watched and read her posts, often crying because I related to it all.

I contacted my GP immediately and they were reluctant to see me. Even though I said it was to treat perimenopause, they kept saying I was too young to have HRT for the menopause. They were looking at it as 'just menopause' and not the different stages. I found myself having educate them and finally after being prescribed antidepressants, my GP asked me what I wanted, which was HRT.

I instantly felt better, and some symptoms went altogether, but my low mood and loss of libido still lingered over me like a dark cloud. I wrote desperate emails to my GP after hearing about testosterone and its benefits. This was one of my lowest points as I was embarrassed and felt completely alone.

She said that there was nothing she could do apart from refer me to couples' therapy! My partner had been extremely patient, but this was not his doing and I felt completely let down. Why was there this drug available to some but not all? I sent more desperate emails and eventually they referred me to a gynaecologist who prescribed the testosterone!

However, now I'm fighting to get the prescriptions as my GP still won't prescribe it and I go back and forth.

All we want is to be happy, healthy and not lose ourselves along this path in our mature years. I have now made so many changes to my lifestyle to embrace this change, but I want help from the professionals too and I don't think that's too much to ask for.

It feels as though we are being left to become shells of our former selves and I don't want that for me. I will keep fighting. The evidence is there, we just need the right people to listen.

### So grateful to those making a difference

As an advanced nurse practitioner in general practice with a special interest in menopause and women's health, my heart breaks daily when I speak to women and they tell me how they are suffering with menopause symptoms

#### CHAPTER ELEVEN

but feel that they haven't been listened to and are unable to access appropriate treatment and support.

I am also a perimenopausal woman and am frustrated that my needs are not met by my own practice - I've been told that to be prescribed testosterone I will have to be referred to a menopause specialist.

The current HRT shortage has led to an increase in workload for both me and our practice clinical pharmacists to find alternatives for patients who are already settled on their HRT and must, once again, go through the struggle to find their balance. I have also personally been affected by the shortage and am unable to access my own HRT treatment.

I am passionate about advocating for women in menopause, and am grateful to the MPs, celebrities and clinicians who are making a stand and making a difference.

# CHAPTER 12 SUPPORTERS' STATEMENTS STATEMENTS BURGEDUCE

e asked our experts and advocates, who have a breadth of knowledge and experience across so many different areas, to each give us a few words about menopause, and the impetus behind their joining Menopause Mandate. Thank you for your voices. We appreciate each and every one.

### Consultant Gynaecologist Tania Adib, Lead Clinician for The Lister Menopause Clinic and co-founder of Luminosa London

As someone who spent her training specialising in gynaecological oncology, I didn't foresee then that the menopause would become my main interest.

Age 43 I had to have my ovaries removed and was plunged into a surgical menopause. I was not prepared for what was to follow! Hot sweats, brain fog and other debilitating symptoms, including vaginal dryness. It led me on a journey both as a doctor and a patient.

Because of my medical history I was initially determined to manage my menopause symptoms using natural strategies such as diet, exercise and mindfulness. I also developed my super-specialism: treatments for vaginal health such as lasers and radiofrequency.

More recently, I decided to add HRT to my regime. I can honestly say it has been life-changing. I am now passionate that all women get the best treatment available to help them through this challenging period.

# Karen Arthur, fashion creative and founder of Instagram account @menopausewhilstblack

I am glad that the world, with the UK seeming to lead the way, is finally talking about the menopause.

The biggest worry I have about menopause care is the glaring inequalities that currently exist for marginalised communities.

My biggest hope is that those who do have will actively reach out to those who don't have, so that every person who experiences this stage, across every demographic around the globe, is able to access quality care when they need and want it.

Things are changing, and whilst many are better off, there are so many, many more who have no idea what is happening to them or even what's to come. Intentional action - seeing beyond habitually elevated faces - will be needed to normalise equality in the future. This is necessary now.

#### Deborah Arthurs, editor of metro.co.uk

It's only over the last decade that menopause has become a topic frequently discussed in the media. Previously it was seen as something to avoid - unsexy and uninteresting. Thank goodness that has changed.

Menopause shouldn't be something we talk about only when we get there, and if all of us are talking about it, not just those experiencing it, we are more powerful. I'm a huge believer in celebrating midlife and beyond. That's why I'm so passionate about publishing articles about the menopause that both inform and represent women.

We need to continue to have these conversations, for more articles to be written and for all women to feel supported, should they feel they need it.

# Dr Meg Arroll, chartered psychologist, scientist and co-author of The Menopause Maze

The psychological and cognitive symptoms of the perimenopause and menopause are so often neglected, misunderstood and stigmatised, yet we know the significant impact anxiety and mood disorders have on women's lives. We must continue to raise awareness of these symptoms in order to reduce health inequalities and improve access to appropriate treatment.

### Dr Juliet Balfour, GP and British Menopause Society accredited menopause specialist. She runs the Somerset NHS Menopause Service

I have been a GP for more than 30 years and still remember the furore after the now-discredited Women's Health Initiative Study was published in 2002, leading to scary newspaper headlines about the dangers of HRT. Prescribing of HRT fell dramatically and the effects are still with us, leading to women being told they can't have HRT due to the perceived risks.

We now know that transdermal oestrogen and micronised progesterone (or the Mirena IUS) are safe options for many women who can't take oral oestrogen.

However, the prescribing of HRT is not always straightforward, and women with a complex medical history, such as a hormone sensitive cancer, need more help than is currently being offered. We desperately need more NHS specialist menopause clinics that GPs can refer to for advice, and where the more complex patients can have an in-depth consultation about their options. Every woman should have access to individualised and evidence-based advice and support.

# Emma Bardwell, registered nutritionist and co-author of The Perimenopause Solution

There's a lot of noise on the subject of menopause right now, which is much needed, but there's also a lot of misinformation. As a result, many women are left feeling confused and overwhelmed. I created my menopause platform to cut though the confusion and give women reliable, solutions-based nutrition and lifestyle strategies that get results. Menopause is inevitable, but it's certainly not insurmountable.

# Amy Bennie, psychotherapist and chair of The Daisy Network, the only charity supporting women with POI. Author of Our Guide to Understanding Premature Ovarian Insufficiency

Women of all ages, even those in their teens, can go through POI (premature menopause). We need more awareness of the symptoms and diagnostic procedures, as this happens to one in 100 women under 40. Yet most of us don't even know that it's a condition that exists. Without diagnosis and the correct treatment, women face developing serious health problems that may impact the rest of their lives. It's a sad fact that we need to campaign in order to ensure the subject is discussed and recognised as vital.

# Laura Biggs, co-founder and director of Menopause Mandate. Owner and CEO of Intuitive Events - the team behind Let's All Talk Menopause, Let's all Talk Mental Health and The Fertility Show

As someone who has struggled with fertility issues, menopause has always been a word I couldn't quite come to terms with.

When I hit my 40s, still unable to conceive our much-wanted second child, and with time running out for a pregnancy, either naturally or by IVF, I certainly wasn't in a menopause mindset. Aged 47, I was still having regular periods and was so grateful, as this enabled me to have a final attempt at fertility treatment with an egg donor.

Miraculously, it worked! Perimenopause was put on hold for me during this time but a few months after I gave birth, the rosy glow of the arrival of our much loved and wished-for baby girl wore off and it hit me hard.

I had heavy periods, rage, PMS, brain fog - you name it....and I had no idea what to do. I'd suffered from severe endometriosis, and the first GP I saw was very wary of prescribing me HRT suggesting that it might make this flare up. Finally, with some grit and determination, I got my HRT.

As I know from the stories in this book as well as through our Let's All Talk Menopause sessions, symptoms can come back and you have to change and adapt. Most importantly, we all need to be more educated about female health - right from the beginning of our periods to the end - so none of it is a shock!

# Professor Henrietta Bowden-Jones OBE, vice president, Royal Society of Medicine

I have seen many middle-aged women presenting to my clinic experiencing anxiety and low mood for the first time in their lives at the start of the menopause. These are women who have no psychiatric history but find themselves feeling overwhelmed and struggling to cope despite successfully navigating their careers and family commitments without problems until then.

Often they have not associated the menopause with the emotional lability, the anxiety and the low mood experienced and it is a relief to many to know that HRT is available and that their GP can prescribe it.

### Gwenda Burns, Chief Executive, Fertility Network

The menopause crept up and hit me with no warning, and I feel now I should have known what was happening.

I should have been more aware of the symptoms and just how hard-hitting it can be. I could just about deal with the hot flushes, insomnia, tears, itchiness, feeling low and loss of all confidence, but the daily anxiety and feeling of panic that something awful was going to happen were too much to cope with.

I felt I could no longer function. If it wasn't for my husband's support and my local surgery having dedicated menopause nurses, I can honestly say I don't know where I would be.

#### Darren Edwards, CEO, Sytner Group

It is so important that all organisations are more aware and more knowledgeable of menopause. As a nation, we consistently lose incredible talent from our workforce due to the effects of menopause and the lack of support provided, and this cannot continue.

Menopause not only has an impact on our colleagues but also upon their partners, and the more we can all understand about this stage of life that every woman faces, then the better colleagues, partners and employers we will be.

Sytner Group are proud to support Menopause Mandate and the work they are doing to raise the profile of menopause and help educate us all.

#### Jo Elvin, editor, broadcaster and CEO of Children With Cancer UK

I was 47 when, on a routine visit to the doctor, she asked me when my last period was. When I told her it had been two years ago, she said, 'Wow! You started menopause young!' It wasn't the first time I'd heard this from a doctor and to be honest, it irritated me. Because I knew, among my own friendship circle that plenty of women my age had also reached this stage of life.

I realised something: there are doctors out there astonished to hear that a woman under 50 is menopausal. But it's not because that's irregular. It's because we don't discuss it.

So other women like me have been bearing it quietly, convinced we must be the weirdo, when it's totally, utterly normal. When you grew up hearing only your grandmother discussing 'the change' in quiet, embarrassed tones, of course we feel like it must be odd to be going through it in your 40s. And so this is why doctors also believe it's unusual.

So let's talk about it. Let's make sure no one is embarrassed to ask questions about menopause. If we're all honest about it, fewer doctors out there will look at us like we're fish who suddenly learned to speak when we say we're young(ish) and menopausal.

#### Samantha Evans, director, Jo Divine

As a former nurse, sexual health and pleasure expert and co-founder of Jo Divine, I want people to know that your sex life doesn't have to stop when you reach menopause, it can get better. Using local oestrogen, irritant free vaginal moisturisers and sexual lubricants, skin safe sex toys and talking to your partner can really help.

# Thorrun Govind, pharmacist and chair of the Royal Pharmaceutical Society

The Royal Pharmaceutical Society has long been campaigning for better access to menopause treatments for women. We find it frustrating that there is still stigma surrounding periods and menopause.

As a healthcare professional, seeing the lengths women are having to go through to access menopause treatments is concerning, particularly with women being forced to seek treatment from unregulated sources.

The serious shortage protocols put in place by the government are unnecessary bureaucracy and don't go far enough to assist women. The government needs to work with healthcare professionals such as pharmacists, to ensure that women's health and the menopause is higher up the agenda. As a society, we need to do better.

#### Saska Graville, co-founder, hyldalife.com

We know from our global community of midlife women that menopause is both a challenge and an opportunity. Every woman's menopause is different. For many, the symptoms can be debilitating, and more education is needed. But menopause is also the start of a new life stage. At Hylda, we are here to take the brakes off midlife - we help women see menopause as the signal for their next chapter to begin.

#### Emma Hammond, solicitor and employment partner at gunnercooke LLP

In my time acting for women who are experiencing discrimination in the workplace, I see countless examples of mistreatment arising out of my clients presenting with symptoms of (usually) the perimenopause at work and suddenly being made redundant, or put on a performance improvement programme.

So often, it is glaringly obvious why these routes are taken and I fight for my clients for the best possible outcome.

However, there are also many great employers who are committed to doing the right thing and I support them in drafting policies, preparing training sessions and putting practical measures in place to educate the workforce (across the board, not just those directly affected) to remove the stigma and push for equality.

All women need to have this great experience - and that's why I'm happy to be a part of Menopause Mandate.

# Dr Shahzadi Harper, perimenopause and menopause doctor and GP. Director of the Harper Clinic and co-author of The Perimenopause Solution

In my opinion, we need to talk more about perimenopause, about those symptoms that can hit women five or ten years before their periods actually stop. There should be more education for all - men, women and children - starting at a young age so that we normalise this time of life.

And it's the same with healthcare professionals. By tackling women's symptoms sooner rather than later, we are improving long term health outcomes, reducing osteoporosis and heart disease, and therefore saving the NHS costs.

We need to see women before they fall off that cliff of menopause and help them to thrive. It doesn't have to be seen as a medical condition, but as a normal stage of life.

# Cathy Hastie, FCIPD, HR director, Big Four management consultant and author of Menopause Working

It still amazes me that for such a large part of the population and workforce, we find it so difficult to talk about 'women's things'. I've been in HR for nearly 30 years and I've seen far too many women – talented, capable women – leave the workplace or take a step back because of their menopause symptoms and a lack of support from their employers. That's why I wrote a book about the subject - it's everything you wanted to know about managing menopause in the workplace, but never dared ask.

The current flurry to create menopause policies is a great start, but it is just a start. We need to change cultures and educate managers and colleagues. We need to give women the adjustments that they need to manage their symptoms better and continue to thrive in the workplace. It's not just that it is the right thing to do; it's an economic imperative.

# Dr Anne Henderson, MA MB MChir MRCOG, Consultant Gynaecologist and BMS accredited Menopause Specialist. Owner and Director of Amara Clinic

Where do we start and how did we get here? Given that more than 50 per cent of the UK population aged over 50 is female, it is genuinely staggering that there has been such a dereliction of care and attention paid to the mental and physical health and wellbeing of this key population group.

The substandard care is undoubtedly due to the fact that HRT - which has overwhelming and life-changing benefits in women on long-term treatment has for far too long been perceived as potentially harmful due to the emphasis placed on any increased risk of breast cancer.

This was largely thanks to the highly flawed, misleading and subsequently discredited studies published in the early 2000s which resulted in millions of women worldwide stopping HRT abruptly. Combined with an institutional failure to ensure mandatory menopause training for all doctors, the result was a virtual tsunami against HRT which has taken decades to redress.

In recent years, largely due to the impact of mainstream and social media, with advocates such as the Menopause Mandate team amongst others, the situation is finally improving, and women are becoming more self-informed and aware of the benefits of HRT, thus driving the substantial and incremental increase in use. It is clear that the future provision of menopause care must change radically - and change soon - to provide equitable access to quality care in both the NHS and private sectors.

# Alex Hollywood, chef, blogger and author of My Busy Kitchen and Cooking Tonight

As a food writer, it was a shock to discover that what I ate had an impact on my menopause journey. There is little nutritional information readily available and what there is often unappealing and prescriptive.

Understanding how diet can impact menopause health is important. After some trial and error, I discovered some of the foods which triggered my symptoms and those with positive effects. I now incorporate proactive ingredients into the recipes I post but still believe we women need more information on menopause eating.

# Dr Ateh Jewel, HonDMedia, beauty journalist, broadcaster (This Morning, Good Morning Britain, CNN) and diversity advocate.

We stop the conversation with our mothers at periods and pregnancies, and I think it's really important to carry it on into talking about the perimenopause and menopause. In Chinese Medicine they call the time after menopause your 'second spring' - a time when you are stepping into power. We need to completely remove the shame and stigma around it!

# Dr Philippa Kaye, GP and author of The M Word: Everything you need to know about the menopause

We need more accessible and easily available information, support and treatment for every woman, no matter where they live or their background. For too long the menopause has been a taboo and it continues to be so for many groups of women. Even if they do come forward to discuss their health, the lack of a national formulary, menopause clinics and more still means that they may not get the help that they need.

### Millie Kendall, OBE, CEO British Beauty Council

My menopause journey started around the time our country Brexited and America elected the most dangerous man (in my opinion) in the world as President. I thought it was just the emotion, the sheer grief from all of this, plus David Bowie dying. My mum was sick at the time, and she couldn't tell me what menopause felt like or what her experience had been, so I went to my doctor.

By 2018 I was two years into desperately trying to get a doctor at my practice to take me seriously and give me something to stop me from crying, sweating and having heart thumping anxiety that woke me up at strange hours of the night.

I then bumped in a work colleague who told me exactly what I needed and sent me back to my GP to demand it. HRT. My doctor hadn't even sent me for a blood test at that point and I was two years down the line, having had around five or six appointments with various GPs at the practice.

I now think the experience of menopause has mostly made me realise how I am not alone. The minute I spoke about it to someone of my generation, I found a solution. They shared their experience, they had empathy, wisdom and support. We have had to self-soothe as a nation, because the government isn't capable of helping. I have found comfort in not being alone and listening to other people's experiences that mirror my own.

### **Alex Mahon, Channel 4 Chief Executive**

At Channel 4 we like to be ground-breaking and we live to challenge taboos. We also like to think that we understand the needs of those working here. Working with our brilliant women's network 4Womxn, I realised that menopause can be a difficult and debilitating time of life, and it often coincides with other intense responsibilities at home.

And this meant that experienced women, women who have worked for decades, who are rich in experience are quitting their jobs because they aren't given the support that they deserve and because people are scared of saying the word menopause. That felt like a taboo and a very unfair one.

So in 2019, Channel 4 was proud to launch the industry's first dedicated Menopause policy. Since that time, we have been made aware by our staff of the immense difference it has made. We made it free to other organisations a year later and now we see its impact across UK employers. Women's symptoms, discussions and needs are supported. And since we made programmes about it with Davina we have seen a tidal wave of positive impact across society.

It's extraordinary that there is still a need to shout about something that will happen to every woman, but until people can utter the word menopause in every workplace, I'll continue to do so!

# Dr Anjali Mahto, consultant dermatologist and author of The Skincare Bible

Most women don't realise how much skin can change during the menopausal years, as collagen levels suddenly plummet, leading to dryness, wrinkling and increased pigmentation.

Most importantly, these are years of hormonal fluctuation in which skincare conditions such as acne or rosacea might develop. They can be very distressing but are eminently treatable with the right skincare and lifestyle changes. Skin usually settles down after these years.

Education and information are so important so that we have the tools to deal with the turbulence

#### **Rosie Nixon, editor in chief of HELLO!**

In my role as editor in chief of HELLO!, and as an ambassador for the charity Wellbeing of Women, I have felt all kinds of emotion in understanding the range of symptoms and challenges women are experiencing as we go through the menopause years.

We have felt compelled to respond to this vital need, by using our HELLO! platforms to amplify stories about this life stage and advocate for change, most notably with our support for the Menopause Workplace Pledge.

Personally, as a woman entering perimenopause, this heightened awareness has enabled me to better support my own menopause journey. After gaining the confidence to find the menopause expert within my local doctor's surgery, I have recently swapped antidepressants for oestrogen and am already feeling the benefits.

But this is still not the case for every woman – the more we share our stories, the greater the impact we will have in improving life for all women. We need this to continue, along with adequate provision of HRT nationally, and a clearer understanding through education about this time of life, made available from the school years onwards. We are motivated, we won't 'keep calm and carry on', we will fight for the healthy and fulfilled life every woman deserves.

# Caroline Nokes MP, chair of the Women and Equalities Select Committee

What has struck me most during the committee's work on how the menopause impacts women in the workplace is the number of women who are still scared or embarrassed to let their employer know they are going through the menopause.

Even really senior women are frightened it will negatively impact the rest of their career.

We have to change that. We have to break down the stigma and the taboo, and make sure younger women have an easier journey than we all have.

#### Dr Uchenna Okoye, dentist and director of London Smiling

I am outraged at how overlooked the menopause is in all aspects of our society. I had a very difficult perimenopause and wouldn't wish my experience on any other woman. Part of the problem was that I simply didn't know what was happening to my body, and I am grateful to my friends and patients who shared their experiences.

But my interest is both personal and professional. Every day, as a dentist, I see women in midlife whose mouth health has suddenly - to their dismay - gone downhill. Dentists have little training about menopause and its effects, but lower oestrogen means less lubrication everywhere, including the mouth and this can lead to tooth decay, gum disease and a dry and burning mouth. Women and dentists need to be aware of this so that they can take steps to mitigate the situation.

I am a firm believer that menopause is a hormone deficiency and thank goodness for HRT. I am so proud to be part of the Menopause Mandate and helping others.

# Dr Naomi Potter, British Menopause Society accredited specialist, founder of the Menopause Care Clinic and co-author of Menopausing with Davina McCall

Despite the recent media publicity given to menopause, we still see so many women refer themselves to the clinic with symptoms not being recognised as being hormone related and it causes such distress. I'm sure that that the Menopause Mandate will help to change this.

# Michele Price, honorary counsel at Menopause Mandate, and partner at gunnercooke LLP

The opening up of this topic into mainstream awareness has been long overdue. The sheer variety and combination of symptoms that are unique to each woman have been the most important factor in my journey. It is this breadth of information that needs to be widely available and understood, so that medical professionals, as well as women themselves and those around them, can recognise and address the underlying, rather than just the presenting, symptoms in a timely and joined-up way.

#### Professor Dame Lesley Regan, Chair of Wellbeing of Women

Despite affecting half the population, the menopause has been shrouded in secrecy, stigma and taboo. But that is now changing thanks to a new generation of inspiring and candid women who are speaking out. Women will now live longer postmenopausal and they deserve to live this part of life openly, happily and healthily.

# Melissa Robertson, director of Menopause Mandate, CEO of Dark Horses. Creator of an open source menopause policy

Too many women consider giving up work during their menopausal years. This is because their symptoms are too awful to deal with, because they are woefully under-supported in their working environments, and because it's still a societal taboo that necessitates silence and resilience.

But we need these women. Without them, we lose a vast swathe of experienced, talented, brilliant practitioners, at the peak of their careers. Without them, the gender pay gap soars and boards struggle with gender imbalance.

If we don't get more people talking about it - I mean really talking about it - with understanding, empathy and support, then too many good people will be lost, and businesses will be all the worse for it.

# Alice Smellie, co-founder and director of Menopause Mandate. Co-author of Cracking the Menopause, health journalist and columnist for Marie Claire

Writing a book about menopause was an enormous eye-opener. I read a great deal about how it was perceived historically, with women basically seen as defunct and disgusting once fertility was over.

It was clear that for millennia, menopause has at best been a joke and at worst a reason to spend a bit of time locked up in an asylum or on a ducking stool. Thankfully - and thanks to all the campaigning that's been done by so many amazing women over the last few years - things have started to change.

But there is clearly a long way to go. The stories in this book starkly reveal this, and the fact that the right advice and treatment saves quality of life (and even lives).

I have personally had a very positive experience, with an excellent and knowledgeable NHS GP and local pharmacist. This ought to be automatically available for everyone. I'm proud to be a part of Menopause Mandate and campaign towards that end.

# Tim Spector, Professor of Genetic Epidemiology and Scientific Co-Founder of Zoe

It's great to see more focus and research on the menopause which has been hugely neglected since my own research on the topic. We now have research to show that the menopause causes metabolic and microbiome changes in women that are independent of age. It's an exciting time to be contributing to the evidence that can help women improve their health during the changes of the menopause and for the longer term.

# Clive Spence-Jones, consultant obstetrician and gynaecologist, former president of the Obstetrics and Gynaecology Section of the Royal Society of Medicine and a member of The UK Clinical Guideline Group for the use of pessaries in vaginal prolapse

Most women will experience some symptoms of vaginal atrophy after menopause and up to 40 per cent of women may experience prolapse symptoms which affect their quality of life. Again, these are particularly common during the menopausal years.

I've been a consultant for 27 years, and am still astonished at the lack of information given to women about possible vaginal and vulval conditions that can be highly distressing but are completely treatable. Local oestrogen, pessaries (to support prolapses) and systemic HRT are all tools that can be employed.

#### **Clare Stafford, Director of Communications, Holland & Barrett**

We need to pause and listen to women to make sure their symptoms are taken seriously, diagnosis is quick and advice is tailored to their needs – however they want to manage their menopause.

#### Dr Chris Van Tulleken, infectious diseases doctor and leading presenter

Obiously I haven't personally experienced any menopause symptoms, but I welcome the increasing awareness of the subject. We all need to be educated about it as a part of women's biological journey, so that understanding can be given, and support where needed.

#### Dr Tonye Wokoma FRCOG, MFSRH BMS/FSRH, advanced menopause

#### certificate consultant in sexual and reproductive health

As a menopause specialist, the whole state of affairs makes me very angry. I see women suffering; waiting months to see the right person (unless they can pay) and deprived of appropriate care because they live in an area without a menopause clinic or can't afford the prescription charges. Something has to be done urgently!

#### Nina Wright, CEO, Harmsworth Media

Through my involvement with Menopause Mandate and the subsequent support we've given to produce this book, I've grown to better understand and appreciate the importance and severity of the issues that women may face when dealing with the challenges of menopause.

The business community has a significant role to play here, in socialising and supporting female colleagues, whilst at the same time encouraging the introduction of effective menopause policies. We also need to educate all employees and remove the taboos and embarrassment that prevent open and honest conversations.

Reading the stories, it's shocking that so many women leave their employment during this time. That surely has to stop.

# RESOURCES

Balance website and app: balance-menopause.com British Menopause Society (patient arm): womens-health-concern.org Let's All Talk Menopause: letsalltalkmenopause.co.uk Menopause Mandate: menopausemandate.com/help Menopause Matters: menopausematters.co.uk Menopause Support: menopausesupport.co.uk Menopause Support: menopausesupport.co.uk My Menopause Centre: mymenopausecentre.com NICE guidelines: https://www.nice.org.uk/guidance/ng23 Pelvic floor health: gussetgrippers.co.uk Premature Ovarian Insufficiency: daisynetwork.org Rock My Menopause: rockmymenopause.com Samaritans: samaritans.org or call 116 123 The Menopause Charity: themenopausecharity.org Vaginal atrophy: mymenopausalvagina.co.uk

If you would like to contact or speak to anyone from Menopause Mandate, please email **info@menopausemandate.com** 

Edited by Alice Smellie With very grateful thanks to Dr Juliet Balfour and Lucy Shersby Designed by Dark Horses

**DISCLAIMER:** This book does not offer advice, medical or otherwise. It is intended to be about the subject of the lived experience of menopause. The stories have been collated in good faith, but because of their anonymous and voluntary nature we are unable to guarantee that the information published is entirely free from error or is factually correct. It is recommended that you should always consult a qualified medical specialist for individual advice. You should not delay in seeking medical advice, disregard medical advice or discontinue any medical treatment because of the stories in this book.

#### © Menopause Mandate 2022

H&B has been supporting women with menopause for over 50 years and has launched a Pause & Listen Pledge.

Listening is powerful, no one person's experience will be the same, that's why we're pledging to always listen and support.

We won't pretend to know how your menopause feels. We won't tell you to just get on with it. We won't say 'You're too young to be menopausal'. We will help you try to find ways to get through it. We will understand that your menopause is unlike anyone else's. We will show you that you don't have to do this alone. And above all we will always listen and support you.

It's so important that these stories are heard, and acted on by all – we're proud to co-sponsor this collection of powerful stories.

Holland&Barrett

# STORIES FROM MENOPAUSE MANDATE SUPPORTERS.

"This whole book has been shaped around the punchline of menopause. Our supporters have articulated the challenge of the journey through their own stories. They make it very clear that, despite the comedy material it's provided for society from time immemorial, menopause is no joke."

Mariella Frostrup, Chair of Menopause Mandate

"Put together we can make a difference, and by sharing our experiences, we can ease each other's struggles. Thank you to everyone who has been brave enough to get in touch. Your stories have made this book possible, and they will help others when they don't know where else to turn."

Carolvn Harris. MP

"As a menopause specialist, I see women suffering every day; waiting months to see the right person and being deprived of appropriate care. Something has to be done urgently!"

**Dr Tonye Wokoma** 

"Some of these personal stories are so sad, detailing the loss of quality of life, relationships, an experienced and valuable workforce and even lives."

**Dr Juliet Balfour** 

The production of this book was made possible with support from:

dmg::media

Š HARMSWORTH MEDIA

Holland&Barrett