Spokespeople

Dame Laura Lee

Laura worked as a clinical nurse specialist in Edinburgh, where she gave chemotherapy to Maggie Keswick Jencks, Laura shared Maggie’s vision of a cancer support centre housed in a non-clinical and uplifting environment where anybody affected by cancer could visit to access practical information, psychological and emotional support to help them build a life beyond a cancer diagnosis.

Laura commented: “It is really shocking that so many people aren’t aware their treatment will cause early onset menopause. “We know how traumatic an experience this can be for people on top of their cancer diagnosis with people experiencing loss of fertility and a range of debilitating side-effects. It is crucial we shine a spotlight on these issues and that information is more clearly available.”

Lisa Punt

Maggie’s Cambridge Centre Head, Lisa Punt, developed the Maggie’s menopause and cancer course. As a former Consultant radiographer in Gynaecological Oncology Lisa has a special interest in menopause and has spoken at numerous events and seminars on the subject.

Lisa has said: “Early onset menopause caused by cancer treatment can be incredibly difficult and more challenging than a natural menopause.

“Many people don’t realise that they will experience menopause as a consequence of their treatment, perhaps because they weren’t told or didn’t take in the information as they were so focused on their cancer diagnosis.

“People often describe their menopausal symptoms being as hard to cope with as the cancer itself.”
“Then there is the emotional impact – these are often young people who are a long way from a natural menopause. The impact can be far reaching impacting on long-term health, intimacy and relationships. It is a huge issue, but we can help.”

Liz O’Riordan

Liz O’Riordan is a former breast cancer surgeon and breast cancer patient. She now supports and advises people with cancer via her books, YouTube and social media. She has been supported by Maggie’s and is supporting the Maggie’s menopause and cancer campaign.

She has commented: “As a breast cancer surgeon I had no idea how hard the menopause was for my patients until I became a patient myself. We aren’t given specific menopause training and often don’t hear about it from our patients as we only have 5 minutes with them after surgery and then don’t see them again for years. That’s why it is so important that people know that they can come to Maggie’s for safe, trusted, expert advice.”

Alice MacGillivray, 40 from London, supported by West London

Diagnosed with breast cancer at 35. After treatment she had her ovarian tubes removed as a precaution because she has the BRCA1 gene and as a result went through medical menopause which she says hit her harder than the cancer itself.

Alice said: “The menopause for me was harder than the cancer, it was too much. I wanted to be out of my body. Because of the cancer, I’d had a mastectomy and my ovarian tubes removed but because I was a young woman, people would pass comments like ‘oh, that’s
such a shame, you're so young’. People are trying to be kind, but it does build up on you. Not having a partner or a job, or a choice to have children made me feel unmoored, but I found I could talk to the people in Maggie’s about that. They taught me that life itself is the prize – and that nothing else matters.

“Even though I was over cancer, the menopause made me feel like I was broken again. I’d come in to Maggie’s sweating, probably three or four times a week. I met others going through the menopause, there was a lot of perspective. I could find the funny side and laugh about it when I spoke to others too. I lived with other young girls in a busy area in a very transient flat, where everything was fast-paced and high energy, so the tranquillity and peacefulness just helped me to align and collect myself.

Katherine Crowson, 33, from Edinburgh

Katherine was diagnosed with stage 3 HER-2 hormone negative breast cancer just before her 30th birthday in March 2020 (just as the UK went into lockdown). Three weeks later she was having fertility treatment to freeze her eggs and preserve her chances of having a family. This was prior to 18 months of cancer treatment including chemotherapy, radiotherapy and surgery. Katherine was then put on a drug called Zoladex to shut down her ovaries and give her a better chance to stop the cancer recurring.

Katherine said: “The menopause for me came as a retrospective shock. I was initially put on Zoladex to shut down my ovaries with the hope of protecting them from chemotherapy, however, my treatment plan changed and I was to stay on Zoladex for four and a half years. I understood the risk of becoming menopausal during treatment, but it was incredibly hard to identify what was chemo and what was menopause.

“I had been told it would take about a year to recover from chemotherapy, so I was very confused about still feeling fatigued more than a year later.
“It wasn’t until I came to a Menopause Workshop at Maggie’s for young women that I realised that all of my mental and physical symptoms could be ticked off on a checklist for menopause.

“All of the young, thirty-something women at the workshop struggle with slightly different things from brain fog to hot flushes, anxiety and lack of libido. They are all very real problems.

“For me, the bone pain and fatigue are the worst of my symptoms and they are almost as bad as the cancer treatment. Instead of explaining to people that I’m in medically induced menopause as part of my cancer maintenance treatment, I just say I’m still in cancer treatment and still manage multiple side effects.

“Otherwise, many older women just think I’m the same as them going through menopause at a young age when it’s actually much more severe, sudden and debilitating.

“Menopause has affected me so much that I am currently reconsidering my career and I’m on a career break simply because the world is not set up for a thirty-something woman to be going through menopause.

“Whereas, before I worked in a fast-moving financial services position, I’m now looking for a job where I can use some of my softer skills because I was finding that having to sit on hour-long calls and hour-long meetings would mean I would then need an hour-long break, I felt so fatigued and exhausted. Medically induced menopause means that I am now considering doing something different. It’s yet another part of my life I’m having to relearn after cancer.”

Hannah (40) from Pontypridd, South Wales

Pic Cap: Hannah Walsh

Hannah Walsh was diagnosed with breast cancer in February 2021. In the beginning, it seemed straightforward and she was told she have need to have a lumpectomy to remove the cancer followed by radiotherapy, however, numerous biopsies proved the cancer to be invasive and she had to have her whole right breast removed.

Hannah was then given Tamoxifen a drug that would offer a better chance of stopping the cancer recurring. A few months down the line she was also given another drug to allow her to tolerate the Tamoxifen, ‘Zoladex’ – a drug that would shut down her ovaries. This is when she says ‘classic menopause’ symptoms kicked in.

Hannah said: “My consultant told me in the beginning that I would need to take Tamoxifen to try to prevent the cancer recurring. Even though the benefit was quite small. I embraced taking this drug, along with Zoladex, which allowed me to physically cope with it.
“I was made aware that I would maybe go through some menopause symptoms, however, when you’re told this at the beginning of cancer treatment, you’re just doing what you can in the hope you’ll never find yourself in this position again. I was certainly happy to try anything. Any thoughts about menopause were secondary.

“Once I started Zoladex, the ‘classic’ menopausal symptoms hit me like a brick. Hot flashes and insomnia have been, by far, the worst menopause symptoms for me. I now can’t have a hot drink after 6pm at night or I’ll burn up afterwards for hours on end – then I can’t sleep at night. I often go to bed with a chilled, cold water-bottle and huge amounts of water to drink.

“Then, when the insomnia kicks in, I’ll often lie awake ruminating over whether these additional Tamoxifen and Zoladex treatments are actually worth it, and should I keep persisting with them because menopause symptoms are beginning to impact on my quality of life. I am, inevitably, exhausted after terrible sleep.

“Older women will also say things to me like ‘Welcome to the club.’ The thing is, I don’t want to be in their club yet! It would have been different to have had a few years to adjust to it and get there eventually but to crash straight into menopause is difficult in many ways and it’s upsetting because I’m not ready for it. The weight gain is getting me down, too – it seems so much harder to shift. I’m too young for this.

“I feel that people think I should be ‘past cancer’ now and that I should now be getting better, but I’ve been through a lot and now I’m suffering side effects from these additional, preventative drugs. I try to explain that once you’ve had to have part of your body amputated due to cancer and been through what I went through in the lead up to it, you will do anything to stop it recurring. Even if Tamoxifen can only give me that extra 2-3% chance, it currently feels worth it to me.

“Having children was also part of the plan before I had cancer, but for now I’m just taking things one day at a time. If I’m going to persist with it, I really need to stay on the Tamoxifen and Zoladex for another three years. I know that I may or may not be able to have children naturally once I come off this treatment, and that there is help out there for me with this, should I need it, but that is not even something I can even consider right now. I’m just trying to get through every day as best I can and trying to get on with my life, hopeful I’ll never have to go through it again.”

Anna Cook, 54, Training Administrator from Cambridge.

Pic Cap Anna Cook

Anna was diagnosed with a hormone receptive breast cancer in June 2020 during lockdown. She completed treatment including a bilateral mastectomy, chemotherapy,
removal of lymph nodes from right armpit and radiotherapy by June 2021, and then she began taking Tamoxifen.

Anna said: “Before treatment I had recognised that I was slightly perimenopausal. I was a bit warm now and then and my periods were a bit irregular but I thought menopause was just something that would come on gently and I’d get on with it.

“After my cancer treatment and three weeks into taking Tamoxifen, menopause hit me like a brick wall. Between the effects of the chemo and the Tamoxifen which stops production of oestrogen, I felt completely exhausted. Tiredness came over me in waves but I couldn’t decide if it was because I’d just had lots of treatment or if I was in menopause.

“Then I found myself really tired but also unable to sleep and I had really bad joint pain in my hands and my knees.

“I’m a really practical person, I’d worked in the same place for fourteen years but then one day when I’d gone back to work, I burst into tears in a meeting and this was really embarrassing. That’s when my manager sat me down and I realised that ‘no, I actually wasn’t okay’ and I wasn’t ‘sailing through this’ at all.

“Coming to the menopause workshop at Maggie’s helped me to meet people who also had cancer and menopause and we could discuss symptoms and problems in a safe and supportive space.

“This was really helpful because when you’re a woman going through menopause and thinking that it’s something that every woman is going to go through, you do feel a bit silly when you have to admit that it really is difficult.

“The workshop was led by Lisa at Maggie’s and two GP’s who specialised in menopause and it helped me to see that what I was going through was normal. The biggest surprise for me was finding out the list of symptoms related to the menopause. It’s such a long list and I had no idea how much it could affect me mentally and physically.

“Coming to the menopause workshop was empowering. At first, when I suffered skin dryness for example, I just thought I’ll buy some moisturiser but then I found out that the PH of your skin is different down there. Who knew? I wouldn’t have had known this had I not come to Maggie’s. After the Davina Menopause programme on TV, people are definitely more open to talking about menopause and that can only be a good thing.”

Lizzy Hutchison, 39 from Edinburgh

Pic Cap Lizzy Hutchison

Lizzy was diagnosed with breast cancer just after her 37th birthday.
She said: “I was given the option of being put into the menopause to save my fertility and then got a little bit of a curveball in that I’m slightly hormone positive, so I didn't think I was going to get offered hormone therapy, and then I did so that short term menopause has turned into a longer term thing.

What was explained to me was that they’d just switch my ovaries off. No one ever used the word menopause or talked about it, so it's all been a bit of a shock, and a learning curve.

I didn't really understand the impact. I don't think you do because you’re going through chemo, so you feel crap anyway. I used to play the game, is this chemo or is this menopause?! You don't really know which is which at the time.

I finished treatment in April 22 but the menopause symptoms have continued as I’m on hormone therapy for two years, so I'll finish in July 24. I'm hopeful that my periods will return then, because, it's a bit of health nightmare being in a menopause so early, like the impact it will have on my bones. I've really forgotten about the fertility side of things, and kind of come to terms with that but I'm just hoping that it resumes. I'll just have to wait and see though as I had eight rounds of chemo and two years of hormone therapy, so I need to be realistic.

For me, the number one biggest impact it has had on my life is vaginal dryness. Because I'm young, sex was a big part of my life and I want it to continue to be a big part of my life. So that's been probably the worst thing. My partner and I had only been together a year when I got diagnosed, last week celebrated our three year anniversary.

Maggie’s secured funding for me to see a sex therapist. I've been doing that every eight weeks for about eight months and they secured funding right until I finish my hormone therapy. So we've been working on practical stuff and I’ve got support. It's given me the confidence to go to my GP and have that discussion with them so I use oestrogen moisturisers and all that sort of stuff.

The other side effect is that my brain seems to just have been completely rewired. I think in a different way, I even quit my job - I took voluntary redundancy - and I'm looking at completely different career paths because I can't make decisions like I did before.

I think those are the two main symptoms that bother me. I mean, I do get hot flashes and stuff, that I've kind of come to terms with and hair in places I didn't know you could grow hair!

Nancy Digueno, 53, a nurse from Southampton, supported by Southampton

Nancy was diagnosed with breast cancer just before her 50th birthday. After chemotherapy and radiotherapy were over, she began a course of tamoxifen which brought on the menopause and she experienced symptoms like hot flashes.
Nancy said: “When treatment finished, I just felt lost and scared. It felt no one was looking after me anymore. If something happened to me, what would I do? Would anyone know?

I never worried about dying until after my treatment ended. I would wake up in the middle of the night and be scared to close my eyes again.

Jo Saunders-Betts, 57, from Surrey.

Pic Cap Jo Saunders-Betts

Jo was diagnosed with primary breast cancer in 2005 and then has recently had a secondary cancer diagnosis.

Jo said: “On my first cycle of chemo (epirubicin and cyclophosphamide) I had a slight menstrual period. Nothing to write home about. It was lighter and didn't last as long as usual. I didn't think much of it. Not sure I realised during the months of debilitating side effects that I hadn't had another period and I most certainly wasn't pregnant.

Through the chemo fog I realised that I would no longer bleed. Periods were over. I can't say I was sad. In fact, I was a little pleased. No more period pain. No more sanitary products. It was white trousers all the way for me. A small win in the sadder scheme of things.

It was later, probably years later that it dawned on me that the demise of my monthly cycle was not such a bonus. Hello dry vagina. Good day low libido. Goodbye sexy me.”

I realised that I was angry, but not at the cancer – at how it had left me and the aftermath. I was angry that I was exhausted and finding life a struggle. But it helped to come to Maggie’s and say these things to people.”