

Supplementary written evidence submitted by Breast Cancer Now (CSV0058)

Sent on behalf of Emma Metcalfe.

Emma was campaigning for access to Trodelvy, a promising new treatment for secondary triple negative breast cancer. While the drug received its licence for use in September 2021 through the MHRA's Project Orbis route, a decision on whether it will be made available on the NHS is not expected until Spring 2022.

Working with Breast Cancer Now, Emma was calling for the pharmaceutical company, Gilead, to work with NHS England to put in place an interim access arrangement, like other companies recently have for other oncology drugs licensed through Project Orbis to support patient access to medicines following licensing and ahead of NICE guidance being published.

Emma died on Thursday 21st October 2021 before she was due to give evidence to the Health and Social Care Select Committee's inquiry into Cancer Services. She shared the following with Breast Cancer Now to inform their submission to the NICE appraisal of Trodelvy and as part of her involvement in the It's Time for Trodelvy campaign.

This written evidence submission highlights the importance of ensuring research and innovations reach patients as quickly as possible, and illustrates challenges in accessing optimal treatments.

What it is like living with secondary triple negative breast cancer?

"I got my secondary diagnosis in January this year, when I was still undergoing treatment for my primary. I had no idea what was going on as I've no family history of cancer, all my family normally live to a ripe old age, I'm never ill and never even broken a bone!

"I'm probably a bit different to lots of the other women because I'm so young and I don't have any children. Maybe this would have been different without getting cancer at 33? I have made my peace with it, it's a sad thing, but has been eclipsed by cancer. I met my husband when we were at school, we are 16. It took us 18 years and cancer to finally get married in January. Obviously it goes without saying that I don't want to leave him behind on his own.

"Every day I wake up and remember that I'm dying. I try not to let it get me down, and I'm actually a pretty cheerful person. I love my life and I love keeping busy and focusing on what I can do. I ran my first ever 10k run at the weekend and I'm bloody proud of myself!

"But I have tumours which I can feel, so when a treatment isn't working or stops working then it's mental torture. Knowing there are so few treatments available for metastatic triple negative breast cancer (mTNBC) is like holding a few matches in your hand and then striking another one out each time, knowing your hand will be empty soon. It's also very isolating. There are fantastic online support groups for women with secondary breast cancer but I find it hard to take comfort from women's stories of living 10 years with hormone responsive cancers as triple negative - it's just a totally different kettle of fish. Often it feels like it's a totally different disease all together. I am so envious of women who get to be declared "stable", or whose treatments keep on working for years rather than months.

"My cancer is fast growing and unpredictable, it scares oncologists. Previously oncologists have described my disease as "scary" and described my secondary treatment as "we're already chasing ghosts". It's so frightening as a patient to realise you have something where the usual platitudes and reassures don't apply.

“We all hope to be a cancer outlier, someone who dramatically outlives their prognosis. But that hope is in short supply with triple negative, women who have already been dealt a bad hand, and feel left behind while other women with other breast cancers live longer and longer. Trodelvy is the first real hope there has been in a long time, and to see that oncologists are excited about it is really powerful.”

What do you think of current treatments available on the NHS for metastatic triple negative breast cancer?

“The treatments feel very limited and it feels like a quick death sentence. I’m on my second line treatment and so far my treatments tend to only work for 2-3 months. At the moment I’m waiting for scan results and think my second line is failing.

“I’m aware I probably have one more treatment remaining, then we may be able to re-use something I’ve had before but with no guarantee of results. Maybe I can get onto a medical trial but accessing those is shrouded in mystery. I get the impressive assertive women who do lots of research, get second opinions and are willing to travel for treatment probably live longer and it seems to unfair to be expected to do “homework” as well as dealing with the day to day effects of cancer and coming to terms with the emotional and practical baggage of preparing to die young.”

What do you think are the advantages of Trodelvy?

“I see the advantages of Trodelvy as being that it can be used for second line onwards - some other treatments are only available for use earlier. For example, I believe immunotherapy is currently first line only for metastatic triple negative breast cancer.

“I understand that the way the drug works is different to more traditional chemotherapies in that it is more targeted, which can only be a good thing in terms of effectiveness and side effects.

“The main thing is means for me is HOPE and ANOTHER OPTION, when women with mTNBC have so few and feel left behind. For me, accessing Trodelvy means more time to live more, and to stay with my husband a bit longer. I would love to be able to go to my youngest brother’s wedding next year. It means time to set myself goals and make plans, rather than thinking “What’s the point?”.”

The importance of Trodelvy being recommended by NICE and becoming routinely available on the NHS

“mTNBC disproportionately affects younger women, more likely to be less financially secure. I am 35 with a mortgage and only a small amount of savings. I’m self-employed with no health insurance or anything else to fall back on. Trodelvy needs to be accessible to all women via the NHS to avoid widening the gap between those who can afford to pay for special treatment and those who can’t.

“It’s not fair to ask people to make that choice, and it’s not a choice for many of us. It’s just watching other women swap money for life which we all deserve a chance at and young women shouldn't be penalised for not having lived long enough to have savings. Life and the financial situation of someone in their 30s is very different to those of older women who have been lucky enough to have careers and take early retirement.”

Matt Turner, Emma’s husband

“If Emma’s hospital were able to access Trodelvy when it had been licensed, Emma may well have had a few more months to live. She had to work so hard to get that close. There was no one there to show her the way. It’s wrong. It shouldn’t have had to be like that.”