

Voices of women with ovarian cancer: the coronavirus pandemic and its impact

Ovarian cancer can be devastating. It kills 11 women every single day and survival rates in the UK are among the worst in Europe. Over 7,400 women are diagnosed with ovarian cancer in the UK each year, and more women die as a result of the disease than all other gynaecological cancers combined.¹

The coronavirus (Covid-19) pandemic has had a significant impact on the diagnosis and treatment of ovarian cancer and on the support available to women living with the disease. Target Ovarian Cancer has surveyed women to understand how they've been directly affected by the pandemic. Many have also shared their stories and experiences with us through our Support Line.

We have heard from women who are worried about visiting their GP with symptoms, who have had their treatment disrupted and who are coping with the mental and emotional impact of being advised to shield.

From their stories, it is clear that urgent action needs to be taken to ensure that the coronavirus pandemic does not set back recent progress in ovarian cancer and that diagnosis, treatment and support are returned to pre-pandemic levels as quickly as possible.

7,400 women are diagnosed with ovarian cancer in the UK each year

Ann's story

Since the pandemic, there has been a dramatic fall in the number of people contacting their GP because they're worried about cancer symptoms. Ann, who was diagnosed in November 2018, has been living with ovarian cancer during the pandemic and was told she needed to shield. She's passionate about raising awareness of ovarian cancer symptoms.

“It took me ages to get diagnosed because nobody had even heard of ovarian cancer, myself included. So raising awareness of the symptoms of ovarian cancer, particularly during the pandemic, is really important to me.”

1. Diagnosing ovarian cancer

Early diagnosis of ovarian cancer saves lives: the earlier ovarian cancer is diagnosed, the easier it is to treat. However, even before the outbreak of coronavirus, only 33 per cent of women with ovarian cancer were diagnosed at an early stage.²

In England, the pandemic has had a drastic impact on urgent referrals for suspected cancer (the two-week wait pathway) which is down 60 per cent from pre-pandemic levels.³

It is vital that the impact of the pandemic on early diagnosis of ovarian cancer is mitigated so women have the best possible chance of survival.

“I went to GP late January, I think if it had been a month later I may well have delayed going for fear of overburdening the GP, as well as coming into contact with Covid-19”

Woman diagnosed with ovarian cancer

Only 33% of women with ovarian cancer were diagnosed at an early stage

Awareness of symptoms

Women who are experiencing ovarian cancer symptoms should be encouraged to contact their GP. The recent awareness campaigns across the UK are welcome but there must be sustained investment in public awareness campaigns with a particular focus on ovarian cancer symptoms. We know that pre-pandemic, there was poor awareness of ovarian cancer symptoms with just 20 per cent of women able to name bloating as a symptom of ovarian cancer. We need to see new campaigns as the NHS recovers.⁴

Access to diagnostic tests

Ovarian cancer is diagnosed using a CA125 blood test, followed by an ultrasound if the levels of CA125 are raised. In Scotland, these two tests are carried out concurrently. We know that pre-pandemic, women with ovarian cancer were experiencing delays in diagnosis – the average waiting time from referral to ultrasound test being carried out had been 31 days.⁵ The pandemic means that women will face even further unacceptable delays.

There must be a diagnostic recovery plan which focuses on restoring and increasing diagnostic capacity. This should include reviewing existing diagnostic pathways to see where they can be shortened.

Recommendations

There must be a sustained investment in public awareness campaigns in each UK nation to encourage those with ovarian cancer symptoms to contact their GP.

A diagnostic recovery plan must be put in place, and in England, Wales and Northern Ireland this should include a shorter diagnostic pathway with a CA125 blood test and ultrasound done at the same time.

Amy's story

Because of the pandemic, Amy faced disruption to her treatment and a huge amount of uncertainty. Her treatment plan came to an end at the start of the pandemic. A meeting to discuss next steps with her doctor scheduled soon after lockdown began couldn't go ahead.

“It felt like I was in limbo. I didn't know what was coming next. I couldn't go into the hospital because it was too risky, so it felt like I had finished my treatment. I was left not knowing if I needed further treatment at this time, when it was going to start again, or even if it was going to start again.”

2. Treatment of ovarian cancer

Treatment for ovarian cancer is primarily through surgery and/or chemotherapy. The pandemic has caused significant disruption to both with 54 per cent of women reporting that their treatment has been affected by coronavirus.

Disruption to surgery

Surgery for ovarian cancer can be complex and can require a significant amount of surgery time and critical care support. This has meant that surgery for ovarian cancer has faced significant disruption throughout the pandemic. Women with ovarian cancer reported having their surgery postponed and having additional cycles of chemotherapy while waiting for surgery.

“I was not given the option of surgery following the outbreak”

Woman with ovarian cancer

The introduction of dedicated Covid-free treatment sites is welcome. But it is essential that these sites have sufficient critical care capacity to ensure that in the event of a resurgence of coronavirus cases, ovarian cancer surgery can still go ahead.

As access to ovarian cancer surgery is restored, it remains vital that ovarian cancer surgery is performed by a specialist gynaecological oncology surgeon as evidence suggests that overall survival is improved by 45 per cent for women treated at specialist centres.⁶

“I've been unable to speak to an oncologist yet about my diagnosis - this is partly due to the Covid situation. The gynae-oncologist was unable to do the surgery as he is currently not allowed patient contact. But I've had no opportunity for a phone call or video consultation yet. Info from the MDT meetings has only been briefly relayed to me by the specialist nurse in a phone call. As time progresses I have more questions about the type and grade of cancer, and options further down the line.”

Woman with ovarian cancer

54%
54% of women say their treatment has been affected by coronavirus

Changes to treatment and communication

Other treatments, including chemotherapy, have been disrupted. Many women have told us their chemotherapy has been postponed, cancelled or that they are having fewer and shorter cycles.

The majority of women with ovarian cancer reporting changes to their treatment feel these decisions have been taken in partnership with their treatment team. However, there are cases where women with ovarian cancer have not had clear communication about delays and their future treatment plans.

“I believe eight weeks is far too long to wait to begin treatment. My cancer progressed during this time. I had to kick up a storm to be seen and I’m still kicking up a storm to make sure I am receiving the best treatment available.”

Woman with ovarian cancer

“I had no approach from my medical team about the delay to my scan or about the possible risks to me from the virus. I had to take the initiative and ask directly for information.”

Woman with ovarian cancer

It is vital that changes to treatment regimens are accurately recorded and appropriate safety netting is in place. Where treatment has been changed or postponed reviews must take place regularly and there must be clear and regular communication about treatment.

Visiting hospital

We have heard from women concerned about accessing treatment in case it puts them at risk of catching Covid-19.

“It makes cancer so much harder. It’s already stressful but with coronavirus, even a routine appointment at the hospital is extra stressful as you are constantly worried about picking up the disease and what it would do to you on top of having cancer. It puts you off having surgery or chemo in case you catch it.”

Woman with ovarian cancer

“Having to go to the hospital and oncology centre for scans, treatments, blood tests etc., has been quite worrying in case I catch the virus. I would have liked more information from the hospital about how they are keeping cancer patients safe.”

Woman with ovarian cancer

Information and support should be made available to all those who need to attend a hospital setting about the infection control measures in place and what they should expect from their appointments.

Recommendations

There should be protected sites where complex surgery can go ahead, even in the event of another surge of Covid-19 cases.

Women with ovarian cancer should have their surgery carried out by a specialist surgeon.

There must be clear communication both regarding changes to treatment and the measures being taken to prevent Covid-19 transmission for those who need to attend hospitals.

Gill's story

Gill, who lives on her own, really struggled with changes to her treatment and the impact of having to shield. Her mental health has been severely affected since the start of the pandemic.

“My mental and emotional wellbeing has been a lot worse since I started shielding. When having regular treatment, you can focus on the next thing. But now that everything's stopped because of pandemic, I now have the headspace to think about it. I've really struggled with it.”

3. Support for women with ovarian cancer

The coronavirus pandemic has had a significant impact on the support available. 27 per cent of women with ovarian cancer told us that they are not able to access the same care and support as before the pandemic. This has been compounded with the challenges of shielding – 79 per cent of women with ovarian cancer were advised to shield. For many women, this has meant increased loneliness and isolation.

“It's lonely, but I do have a garden so that helps. I feel very vulnerable which is something I've not felt before.”

Woman with ovarian cancer

“I feel cheated that my life experiences will now be even less, having to stay at home. Our family holiday was cancelled in April; I don't know if we'll have time to go again.”

Woman with ovarian cancer

80 per cent of women with ovarian cancer have told us that the pandemic has had a negative impact on their emotional or mental wellbeing. Due to shielding women with ovarian cancer have not been able to see friends or family or take part in activities that they enjoy. Many women are also facing uncertainty after their treatment has been postponed or changed. For some women this has been compounded by difficulty in accessing psychological support.

“There was very little emotional or psychological support on offer prior to Covid; I was told by my GP to access this through charities as the wait time was prohibitive.”

Woman with ovarian cancer

“I had been seeing a clinical psychologist. Although face to face appointments were suspended, she did offer me telephone sessions if I wanted.”

Woman with ovarian cancer

27%
27% of women aren't able to access the same care and support

Recommendation

Support services, including psychological support, must be a key part of recovery plans for cancer.

Target Ovarian Cancer

Target Ovarian Cancer is the UK's leading ovarian cancer charity. We improve early diagnosis, we fund life-saving research and we provide much-needed support to women with ovarian cancer. We're the only charity fighting ovarian cancer on all three of these fronts, across all four nations of the UK.

**Raise awareness.
Fund research.
Save lives.**

targetovariancancer.org.uk

020 7923 5470

Need someone to talk to about ovarian cancer?

Contact our nurse-led Support Line

Phone: 020 7923 5475

targetovariancancer.org.uk/supportline

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