# Helen Swan’s rare cervical cancer missed by smear tests highlights urgent screening gaps



Helen Swan's journey through an unexpected battle with cervical cancer epitomises the critical importance of proactive health management and awareness. Despite years of negative smear test results, Helen, a 54-year-old mother of three from Aberdeen, discovered that she had a rare form of cervical cancer—endocervical adenocarcinoma—often undetectable by standard screening practices. Her experience highlights significant gaps in early detection methods, underscoring the need for women to remain vigilant about their symptoms even when routine screenings yield normal results.

Helen's ordeal began with alarming symptoms such as weight loss, extreme fatigue, and irregular vaginal bleeding, which persisted from 2017 to 2019. Each smear test returned negative, contributing to a sense of false security as her health deteriorated. After persistent advocacy for her own health, a biopsy revealed tumours in her vagina, leading to a diagnosis of stage two B cancer. The delay in diagnosis speaks to a broader issue in cervical cancer screening; studies show that relying solely on Pap tests can result in missed diagnoses. Research from Australia’s National Cervical Screening Program has shown that modern HPV testing identified an additional 90 cervical cancers that would have been overlooked by traditional methods within just two years, showing the heightened sensitivity of this newer approach.

Feeling dismissed by the initial smear tests, Helen remarked, "I have never had a positive smear test. The cancer I have was not picked up on the smears because it tests for cancerous cells on the outside of the cervix." This revelation illustrates the limitations of conventional testing and the necessity for further advancements in cervical cancer screening protocols. Even in Scotland, where recent errors led to approximately 13,000 women being incorrectly excluded from check-ups, the need for thorough and accurate screening is paramount.

Despite the grim prognosis after tumours were discovered in her lungs, Helen opted for alternative treatments after declining standard palliative chemotherapy. She pursued Transarterial Chemoembolisation (TACE), a therapy generally reserved for primary liver cancer, illustrating her determination to explore every possible avenue for her health. TACE is an innovative approach that directly targets tumours with chemotherapy and has shown promise in Helen's case, as her doctor noted a 10 per cent reduction in tumour size after her initial sessions. The fact that she had to seek this treatment abroad speaks volumes about the limitations of current NHS protocols, which only approve TACE for specific cancer types.

Helen’s fundraising efforts for ongoing treatment demonstrate not only her resilience but also the broader struggle many face when navigating healthcare systems and looking for alternative therapies. As she continues her journey, she urges other women to advocate for their health: “Regardless of the smear test, you should have them and if you have any concerns, research, look it up online, and go and get help." Her experience resonates deeply against the backdrop of various cases of missed diagnoses linked to cervical cancer due to misread tests or administrative oversights, including a notable review in Ireland revealing tragic outcomes for women who were not correctly diagnosed.

In light of Helen's story, it becomes crucial for the medical community to enhance screening methods and raise awareness surrounding the risks associated with cervical cancers that traditional tests do not catch. Women are encouraged to actively monitor their health, remain assertive in their medical consultations, and seek second opinions if they feel that their concerns are not being adequately addressed. The shift from Pap tests to HPV testing in other countries exemplifies the evolving landscape of cervical cancer screening and the potential for improved patient outcomes.

As Helen stands firm in her resolve, she embodies the spirit of advocacy that many women may need to adopt in an era where the advancement of medical technology must meet the urgency of health disparities. Her enduring optimism shines through her pursuit of treatment and with each new step forward, she conveys a powerful message: Women must know their bodies, trust their instincts, and, above all, be their own best advocates in health matters.

## Reference Map:

* Paragraph 1 – [[1]](https://www.dailyrecord.co.uk/news/health/scots-mum-negative-smear-tests-35287097), [[6]](https://www.irishtimes.com/news/health/cervicalcheck-review-12-women-die-as-chance-to-prevent-their-cancer-was-missed-1.4103348)
* Paragraph 2 – [[2]](https://www.cancer.org.au/media-releases/2022/hpv-testing-picks-up-cancers-missed-by-pap-tests), [[3]](https://www.cancercouncil.com.au/news/hpv-testing-picks-up-cancers-missed-by-pap-tests/)
* Paragraph 3 – [[4]](https://www.pearsonlegal.co.uk/blog/case-study/missed-cervical-cancer-diagnosis/), [[5]](https://www.bbc.com/news/articles/cx2pglwpz3jo)
* Paragraph 4 – [[1]](https://www.dailyrecord.co.uk/news/health/scots-mum-negative-smear-tests-35287097), [[7]](https://news.stv.tv/scotland/thousands-of-women-who-missed-smear-tests-in-scotland-by-mistake-to-be-invited-for-check-ups)
* Paragraph 5 – [[1]](https://www.dailyrecord.co.uk/news/health/scots-mum-negative-smear-tests-35287097), [[6]](https://www.irishtimes.com/news/health/cervicalcheck-review-12-women-die-as-chance-to-prevent-their-cancer-was-missed-1.4103348)

Source: [Noah Wire Services](https://www.noahwire.com)

## Bibliography

1. <https://www.dailyrecord.co.uk/news/health/scots-mum-negative-smear-tests-35287097> - Please view link - unable to able to access data
2. <https://www.cancer.org.au/media-releases/2022/hpv-testing-picks-up-cancers-missed-by-pap-tests> - A study by the Daffodil Centre, Cancer Council NSW, and the University of Sydney found that the new HPV testing approach in Australia's National Cervical Screening Program detected 90 cancers within the first two years that would have been missed by Pap tests. The analysis led by Associate Professor Megan Smith revealed that 546 cervical cancers were detected during this period through routine screening, highlighting the increased sensitivity of HPV testing over traditional Pap smears.
3. <https://www.cancercouncil.com.au/news/hpv-testing-picks-up-cancers-missed-by-pap-tests/> - Research by the Daffodil Centre, Cancer Council NSW, and the University of Sydney demonstrated that Australia's updated National Cervical Screening Program, which replaced Pap tests with HPV testing, identified 90 additional cancers in the first two years. This study, led by Associate Professor Megan Smith, found that 546 cervical cancers were detected through routine screening, underscoring the enhanced effectiveness of HPV testing compared to traditional Pap smears.
4. <https://www.pearsonlegal.co.uk/blog/case-study/missed-cervical-cancer-diagnosis/> - A 31-year-old woman received a substantial settlement after her cervical cancer was undiagnosed for over a year due to medical negligence. Despite reporting irregular bleeding, her initial smear test was reported as normal. It was later revealed that abnormal cells were present but not reported by the laboratory. The delay in diagnosis led to the development of cervical cancer, highlighting the critical importance of accurate and timely reporting in cervical screening.
5. <https://www.bbc.com/news/articles/cx2pglwpz3jo> - An independent review of cervical screening tests in Northern Ireland found that eight women developed cancer after their smear tests were misread. The review, which examined cases of 207 women previously diagnosed with cervical cancer, indicated that earlier diagnosis and treatment could have been possible if the tests had been correctly interpreted. This underscores the importance of accurate smear test readings in preventing cervical cancer.
6. <https://www.irishtimes.com/news/health/cervicalcheck-review-12-women-die-as-chance-to-prevent-their-cancer-was-missed-1.4103348> - A review of Ireland's CervicalCheck programme revealed that 159 women's cervical cancers were missed, representing 15% of the 1,038 cases examined. Of these, 12 women died as a result of missed opportunities for prevention or early diagnosis. The review, led by the Royal College of Obstetricians and Gynaecologists, highlights significant shortcomings in the screening process and the need for improvements to prevent such oversights.
7. <https://news.stv.tv/scotland/thousands-of-women-who-missed-smear-tests-in-scotland-by-mistake-to-be-invited-for-check-ups> - Thousands of women in Scotland were incorrectly excluded from cervical cancer screenings due to a mistake, and are now being invited for check-ups. Approximately 13,000 women who had hysterectomies were removed from the national cervical screening programme, but it emerged they may have been excluded 'by mistake'. This issue came to light in 2021, leading to a review of the Scottish Cervical Screening Programme and the re-invitation of these women for screenings.