

Time is running out

The need for early diagnosis
in ovarian cancer



TARGET
OVARIAN
CANCER





Alison's story

When Alison first experienced symptoms of ovarian cancer, she knew something was wrong. An experienced nurse, she visited her GP and pushed for diagnostic tests. An ultrasound scan revealed a worrying mass, and after an operation Alison was diagnosed with stage I ovarian cancer.

Target Ovarian Cancer wants to see a future where all women recognise the symptoms, get sent promptly for tests, and are diagnosed early.

Thanks to her early diagnosis, Alison is still here to tell her story 18 years later.

About ovarian cancer

Ovarian cancer can be devastating. It kills 11 women every single day and survival rates are among the worst in Europe.¹ Over 7,000 women are diagnosed every year and more women die as a result of ovarian cancer than all other gynaecological cancers combined.²

It's time to

TAKE OVAR

Target Ovarian Cancer's campaign 'It's time to TAKE OVAR' aims to accelerate change and transform the futures of more than 25,000 women who are living with the disease and thousands more yet to be diagnosed.

Early diagnosis of ovarian cancer saves lives. The earlier a woman is diagnosed the greater her chance of survival; 93 per cent of women diagnosed at the earliest stage survive for at least five years compared to just 13 per cent of women diagnosed at the most advanced stage.³ But one in five women diagnosed with ovarian cancer are already too ill to receive any treatment.⁴

NHS England is committed to ensuring that three quarters of cancers are diagnosed at an early stage (stage I or II) by 2028. We want to see the same commitment across the rest of the UK. It is an ambitious target. To achieve it for ovarian cancer, we must act now.

Time is running out.

It's time to TAKE OVAR and demand earlier diagnosis.

What needs to be done?

The reasons behind late diagnosis can be complex and challenging. But we have the solutions:

- **The postcode lottery must end**

In some parts of the UK ovarian cancer survival rates are world-leading; we now need to extend this to the whole of the UK. We're calling for government-funded clinical audits of ovarian cancer to track progress in diagnosis and treatment and to identify areas where more can and should be done.

- **Women need to know the symptoms**

Women need to be aware of the symptoms of ovarian cancer and feel empowered to go to their GP as soon as they notice something is wrong.

- **GPs need to understand ovarian cancer**

GPs should be trained on the symptoms and diagnostic pathway to ensure that women are referred as quickly as possible.

- **The diagnostic pathway should be as short as possible**

Ovarian cancer should be diagnosed or ruled out within 28 days. The pathway must be shortened, with a CA125 blood test and ultrasound carried out at the same time.

If we achieve the recommendations set out in this report, every woman diagnosed with ovarian cancer will have the best chance of survival.

The postcode lottery must end

Regional variation

Where someone lives can make a substantial difference to how early ovarian cancer is diagnosed.

In England the percentage of women diagnosed at stage I or II varies from 56 per cent in the best performing Clinical Commissioning Groups (CCGs) to 29 per cent in the worst.⁵ In Scotland 46 per cent of women are diagnosed at stage I or II, in Wales 43 per cent of women are diagnosed at an early stage and in Northern Ireland 45 per cent.⁶

These are unacceptable inequalities that must be addressed now. Areas with high rates of early diagnosis should be empowered to share learnings and best practice with those with less favourable outcomes.



Learning from cancer data

In order to address this postcode lottery, we need to get a clear picture of what is causing it. In England the cancer dashboard breaks down performance across local areas so CCGs and local Cancer Alliances can better understand how well they are doing. At the moment, the cancer dashboard is only available for the most common cancers (breast, lung, bowel and prostate) and excludes ovarian cancer.

To provide more in-depth data Target Ovarian Cancer is jointly funding **the ovarian cancer audit feasibility pilot**, alongside the British Gynaecological Cancer Society and Ovarian Cancer Action. The current pilot is due to run until autumn 2020 and will demonstrate what data it is possible to produce for ovarian cancer and the richness of information available. The pilot will release data on regional variation in incidence, stage at diagnosis and survival, helping to identify where a greater focus is needed in improving early diagnosis.⁷

In order to ensure this learning is not lost, and that progress can continue to be made in addressing regional variation, it is essential that the government commits to funding the audit beyond the pilot.

In Scotland, a slightly different approach offers detailed ovarian cancer monitoring data through Quality Performance Indicators (QPIs). These are a series of measures which report on Health Board performance across areas such as access to specialist surgery and review by a multidisciplinary team. While not always offering the same level of analysis as a full audit, QPIs provide a reliable indicator of how ovarian cancer treatment is delivered in Scotland.

In Wales and Northern Ireland, Target Ovarian Cancer is currently working with our audit partners on exploring options for delivering an ovarian cancer audit or equivalent.

What needs to change?

- Ovarian cancer should be available on the cancer dashboard in England broken down by CCG and Cancer Alliance.
- There must be a government-funded audit of ovarian cancer diagnosis and treatment in each UK nation.



Target Ovarian Cancer's work to end the postcode lottery

Starting in England, Target Ovarian Cancer is already working with CCGs to address the postcode lottery. We will develop interventions in local diagnostic pathways to increase the number of women diagnosed at an early stage.

Women need to know the symptoms



Sharon

Sharon knew the symptoms of ovarian cancer. After suspecting something was wrong, she quickly made an appointment with her GP and was sent for diagnostic tests. She was soon diagnosed with stage I ovarian cancer and was able to start receiving treatment at the earliest opportunity.

Amy

For a long time, Amy had been feeling unwell but didn't know the symptoms she was experiencing could be a sign of ovarian cancer. She visited her GP several times when she experienced bloating, abdominal pain, needing to wee more often and feeling full very quickly. Amy was only diagnosed when she moved GP practice, two years after she had first started experiencing symptoms.



There is no effective screening tool for ovarian cancer so it is vital that women are aware of the symptoms if ovarian cancer is to be diagnosed early. Target Ovarian Cancer research found that 86 per cent of women diagnosed with early stage ovarian cancer had presented with at least one of the symptoms as set out in

National Institute for Health and Care Excellence (NICE) guidelines, demonstrating that awareness of the symptoms has a critical role to play in catching the disease early.⁸

There are four key symptoms of ovarian cancer: persistent bloating, pelvic or abdominal pain, feeling full and/or loss of appetite and urinary symptoms (needing to wee more often or more urgently). Occasionally there can be other symptoms, which include changes in bowel habit and extreme fatigue.

Women do not always recognise the potential seriousness of symptoms. Of those women who experienced symptoms and visited their GP, 27 per cent waited three months or more before booking an appointment.⁹

There is also widespread confusion between cervical cancer and ovarian cancer with 31 per cent of women believing that cervical screening also detects ovarian cancer.¹⁰

Awareness of the symptoms of ovarian cancer across the UK¹¹

Bloating

| England | Wales | Scotland | Northern Ireland |
|-------------|-------------|-------------|------------------|
| 21 per cent | 17 per cent | 17 per cent | 25 per cent |

Tummy pain

| England | Wales | Scotland | Northern Ireland |
|-------------|-------------|-------------|------------------|
| 20 per cent | 18 per cent | 20 per cent | 27 per cent |

Needing to wee more

| England | Wales | Scotland | Northern Ireland |
|------------|------------|------------|------------------|
| 1 per cent | 1 per cent | 5 per cent | 4 per cent |

Feeling full

| England | Wales | Scotland | Northern Ireland |
|------------|------------|------------|------------------|
| 3 per cent | 5 per cent | 3 per cent | 4 per cent |

Awareness campaigns

Efforts to increase knowledge of the symptoms of cancer have focused on public awareness campaigns. Public health campaigns are devolved across the UK, and there have been some campaigns featuring ovarian cancer symptoms but these have been of extremely limited duration.

England

Be Clear on Cancer is a government-funded programme, launched in 2011, which aims to improve early diagnosis by raising awareness of the symptoms of cancer and encouraging people with symptoms to see their GP early.

Be Clear on Cancer ran a local pilot on ovarian cancer symptoms in 2013 and a regional pilot in 2014. The final results of the regional pilot in the North West of England found that the campaign was successful in raising awareness of the symptoms of ovarian cancer with an increase in the number of women going to their GP about symptoms, increases in referrals to secondary care and increases in the number of CA125 blood tests carried out.¹²

Ovarian cancer was included in a Be Clear on Cancer pilot focusing on abdominal symptoms in 2017. This was aimed at both men and women and included bloating as one of the main symptoms. Initial results found that there was an increase in women being referred for further ovarian cancer tests.¹³

Despite the promise shown by these pilots, funding for the Be Clear on Cancer programme has been reduced and there were no campaigns planned for 2019.¹⁴ If the government is to achieve its ambitious target of diagnosing more cancers at an early stage, public awareness is vital and the expansion of public awareness campaigns is an essential part of reaching this goal.

Northern Ireland

There has been limited awareness raising activity in Northern Ireland. In 2014, the Public Health Agency ran a standalone ovarian cancer awareness initiative in partnership with Target Ovarian Cancer and a local campaigner, Una Crudden. In 2015, the Be Cancer Aware initiative was launched to raise awareness of all cancers. While some focused activity has taken place during Ovarian Cancer Awareness Month, there has yet to be a specific ovarian cancer awareness campaign.

Scotland

The Detect Cancer Early programme in Scotland is a government-funded programme to improve cancer survival in Scotland. A key objective of the programme is to increase the proportion of people diagnosed at stage I.

Detect Cancer Early has featured ovarian cancer as part of the #mysurvivor cancer awareness campaign and as part of the Get Checked Early website but it has not yet been the focus of any standalone activity.

Wales

In 2017 the Welsh Assembly Petitions Committee produced a report calling for a public ovarian cancer awareness campaign. However, to date there has been no specific campaign in Wales.¹⁵

What needs to change?

- There must be publicly-funded ovarian cancer awareness campaigns in every UK nation.



Target Ovarian Cancer's work to raise awareness of ovarian cancer

In 2018-19 Target Ovarian Cancer helped 931,269 people learn the symptoms of ovarian cancer through our award-winning symptoms leaflets, posters and video.

GPs need to understand ovarian cancer



Seema

Seema's mum, Savarn Lata, visited her GP on several occasions experiencing symptoms of ovarian cancer, including bloating and tummy pain. After finally receiving a CA125 blood test, ultrasound and biopsy, she was diagnosed with ovarian cancer nearly three years after first visiting her GP. Despite undergoing treatment, Seema's mum sadly passed away.

Dr Alison Wint

Alison is a GP in South Gloucester, clinical lead for cancer in her local commissioning group and a member of Target Ovarian Cancer's GP Advisory Board.

"Diagnosing ovarian cancer can be a challenge for GPs as most of us will diagnose between eight or nine cancers a year. Most of them will be more common cancers, not ovarian cancer. It is very easy for guidance to describe symptoms of ovarian cancer, but patients rarely present with textbook symptoms. Information for women on which symptoms to report and guidelines for referring women can make a real difference. The earlier ovarian cancer is picked up, the more effective the treatment is. It's that simple."



When a woman visits her GP with symptoms that could indicate ovarian cancer, it is essential to access diagnostic tests as quickly as possible.

There are clinical guidelines on how GPs should assess women who present with symptoms of ovarian cancer (see flowchart opposite).

GP understanding of ovarian cancer

Clinical understanding of ovarian cancer, including symptoms of the disease, has progressed rapidly in the past decade. But there are still outstanding gaps in

GP knowledge with 44 per cent of GPs believing that ovarian cancer symptoms only present in the later stages of the disease.¹⁷

Ovarian cancer symptoms can be confused with irritable bowel syndrome (IBS). Guidelines are clear that IBS rarely occurs for the first time in women age 50 or over and women this age presenting with new symptoms should be referred for ovarian cancer tests. However, Target Ovarian Cancer found that 21 per cent of women over 50 who visited their GP to discuss symptoms were told they might have IBS. Eight per cent of women visiting their GP with symptoms were told these might be down to mental ill health.¹⁸

Variation in practice

Target Ovarian Cancer has found significant variation in the number of CA125 blood tests carried out in different areas, with some areas carrying out 90 times more tests per 1,000 practice population than other areas. Additionally, there is significant variation in the time taken to complete ultrasounds with 80 per cent taking place within two weeks in some areas, where other areas fail to complete ultrasounds within two weeks.¹⁹

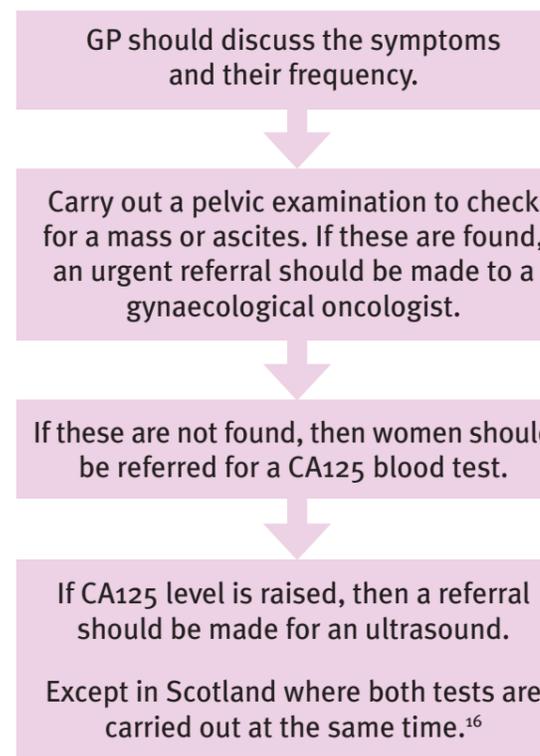
What needs to change?

- Every GP in the UK needs to be trained on the symptoms of ovarian cancer and the referral pathway to reduce variation in practice.



Ten years of primary care education and support from Target Ovarian Cancer

Target Ovarian Cancer is at the forefront of improving GP knowledge of ovarian cancer. Through our expert online learning and face-to-face seminar sessions we have educated thousands of GPs on the symptoms and diagnostic pathway for ovarian cancer.



Shortening the diagnostic pathway



Diane

Even though she was experiencing common symptoms of ovarian cancer, Diane went back and forth between her GP and the hospital before receiving a diagnosis. She was initially sent to A&E by her GP, where she was misdiagnosed and sent home. She then visited the hospital for three more months on numerous occasions as an in-patient and out-patient with the same symptoms. Diane was eventually diagnosed with stage III ovarian cancer.

Rosalind

Rosalind had been experiencing some symptoms she was unsure about, including abdominal pain. She thought it might be due to the menopause, and made an appointment with her GP who quickly arranged for tests. An ultrasound found a mass doctors couldn't explain, and after an operation Rosalind was diagnosed with stage Ib ovarian cancer. She feels extremely fortunate her GP knew to investigate further and the cancer could be detected early.



Once a woman has been referred by her GP for tests, it is vital that ovarian cancer is either diagnosed or ruled out as soon as possible, but there can still be unnecessary delays in diagnosis.

Speeding up diagnosis

The new Faster Diagnosis Standard is being rolled out in England to ensure that all patients who are referred for the investigation of suspected cancer find out if they do or do not have a cancer diagnosis within 28 days.

In order to achieve the Standard, the current cancer pathway needs to be reviewed and shortened. In Scotland, women with suspected ovarian cancer are referred for a CA125 blood test and an ultrasound at the same time, a shorter pathway than the rest of the UK where an ultrasound can only be conducted after a CA125 comes back showing a raised result. Bringing the pathway in line with best practice in Scotland would lead to a reduction in the time women wait for a diagnosis.

This Standard will be introduced in England by April 2020. We need to see the same commitment to faster diagnosis rolled out across the UK for all women with suspected ovarian cancer.

Another key step in achieving early diagnosis is the roll out of Rapid Diagnostic Centres (RDCs) in England. RDCs provide a pathway for GPs to refer patients to when symptoms are non-specific (ie could indicate a number of possible cancers). In order to be referred to an RDC, patients must also have a series of core tests which includes a CA125 test for women.²⁰ If their CA125 is elevated, women will be referred to the ovarian cancer diagnostic pathway. If it is not elevated, women will then be referred to the RDC. A similar model is also being piloted in Wales and should be considered in Northern Ireland and Scotland.

Better diagnostic tests

There is no screening tool for ovarian cancer and the current combination of a CA125 blood test and ultrasound has limitations. The CA125 protein is elevated in 80 per cent of women with advanced disease, but no more than 50 per cent of women diagnosed with stage I ovarian cancer will have a raised CA125.²¹

To see a step change in early diagnosis there must be significant investment in research to develop screening and diagnostic tools as well as developing better targeted treatments. Ovarian cancer research funding has dropped from a high of £12.9 million in 2010/11 to £8.6 million in 2017/18.²²

What needs to change?

- In England, Wales and Northern Ireland the diagnostic pathway must be shortened to bring it in line with best practice in Scotland.
- There must be significant investment in research to develop more accurate diagnostic tests and eventually a screening tool for ovarian cancer.

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Symptoms of ovarian cancer



Persistent bloating



Feeling full quickly and/or loss of appetite



Pelvic or abdominal pain
(that's your tummy and below)



Urinary symptoms
(needing to wee more urgently or more often than usual)

Need someone to talk to about ovarian cancer?

Contact our nurse-led Support Line

Phone: 020 7923 5475

Website: targetovariancancer.org.uk/supportline



Target Ovarian Cancer is the UK's leading ovarian cancer charity. Our campaign 'It's time to TAKE OVAR' aims to accelerate change and transform the future of more than 25,000 who are living with the disease and thousands more yet to be diagnosed.

Ovarian cancer can be devastating. It kills 11 women every single day in the UK and survival rates in the UK are among the worst in Europe. Yet, it faces chronic underfunding compared with other cancers.

Join us to raise awareness, fund research and save lives. Enough is enough. It's time to TAKE OVAR.

www.targetovariancancer.org.uk

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