



Cervical cancer stories:

diagnosis, care, treatment and life beyond



Every day in the UK, nine women are given the news that they have cervical cancer. Jo's Cervical Cancer Trust, the only charity dedicated to women affected by cervical cancer, commissioned this landmark research, which brings together the experiences of 35 women who have been diagnosed with cervical cancer in the last two years. The views of three partners have also been captured.

This report

Here we show first-hand some of the issues women face when they are newly diagnosed, and how they cope during and after treatment, highlighting areas in which the care and treatment for cervical cancer can be improved and drawing attention to the varying experiences and needs of women affected by cervical cancer.

We are hugely grateful to all the women and partners who took part in this study for giving their time so generously and telling their stories so openly.

Cervical cancer in the UK

Each year in the UK, over 3000 women are diagnosed with cervical cancer, equating to nine women each day. It is the most common cancer in women under 35 years old, with 78% of those diagnosed between the ages of 25-64.

Out of 20 common cancers in England and Wales, tenyear survival for cervical cancer ranks 8th highest overall I. Cancer Research UK: http://www. cancerresearchuk.org/ health-professional/ cancer-statistics/statisticsby-cancer-type/cervicalcancer/survival #heading-Zero Accessed 17.08.16

(6th highest for females only) with two-thirds (63%) of women surviving for ten years or more.¹ These high survival rates can be attributed in large part to cervical screening (smear tests) which detects abnormal cervical cells, as well as detecting cervical cancer at an early stage when treatment is extremely successful. There are a number of treatment options for cervical cancer, with good clinical outcomes in terms of survival. However, other factors will affect decisions about which treatment is selected, including age, stage, fertility options, the long-term consequences of treatment and possible impact on future quality of life.

How we conducted this research

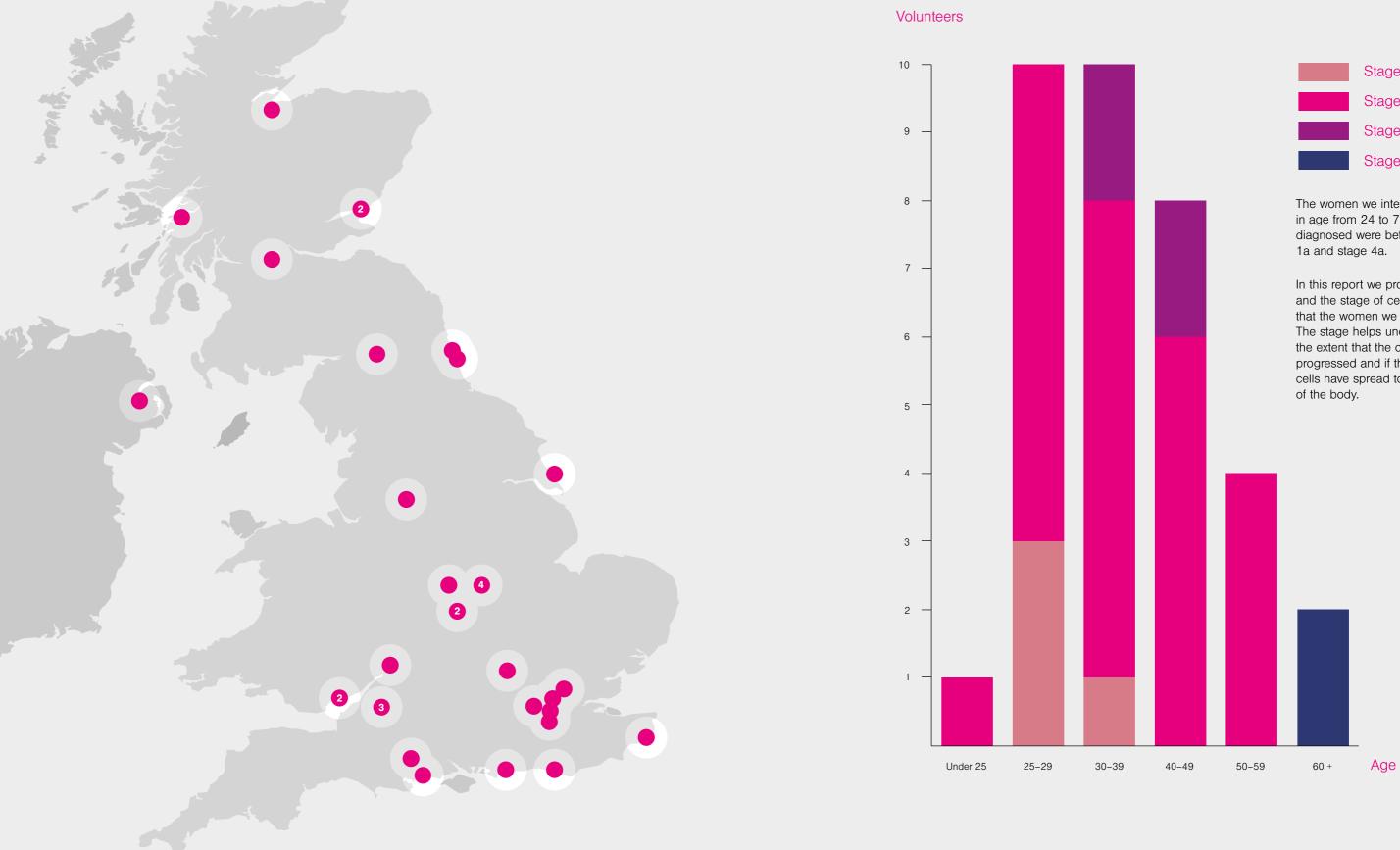
In early 2016, we developed an interview template with significant input from women who had been affected by cervical cancer, as well as healthcare professionals. It was essential that the interviews covered every aspect of diagnosis and treatment for cervical cancer, to life beyond. The template ensured that a consistent approach was taken whilst allowing flexibility according to the individual and their circumstances.

Recruitment took place over six months and 35 volunteers came forward who were willing to share their stories, all of whom had been diagnosed with cervical cancer during the last two years. Seven of these volunteers were filmed and 28 were interviewed over the phone.

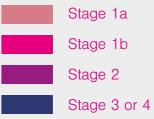


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Age & stage of volunteers







The women we interviewed ranged in age from 24 to 78; and when diagnosed were between stage

In this report we provide the age and the stage of cervical cancer that the women we spoke to had. The stage helps understand the extent that the cancer has progressed and if the cancer cells have spread to other parts



In the UK women are invited for cervical screening every three years from 25-49 and every five years from 50-64. Screening detects changes to the cells of the cervix, which if not treated may develop in to cancer. However, it can also detect cancerous cells if they are present. Screening often results in an earlier stage diagnosis meaning less invasive treatment and better health outcomes for women.

Over half (57%) the women in this research were diagnosed following regular cervical screening, while 40% of women noticed symptoms and presented at their GP.



I had a couple of days where *I* had a small amount of bleeding. The blood was very fresh and it didn't seem right. So I went to my *GP* to get it checked out. *My GP* did a swab and a lot of blood came out. But she thought it was just an infection and was very calm about it. But she gave me a two-week referral just in case.

Age 25 Stage 1b *I* was 24 so not yet able to have a smear but *I* kept bleeding every time I had sex and my friend was a midwife and she prompted me to go to the doctor.

Age 28 Stage 1b1

I got a letter in the post asking me to go for a colposcopy. It was a bit daunting, as I didn't know what it was so I looked it up online. I wasn't overly worried.



At their diagnosis meeting, of those we spoke to:

- 77% had a Clinical Nurse Specialist (CNS) and consultant present
- 17% met just with a consultant
- 3% had only a CNS present
- 65% brought a family member with them
- 38% noticed a CNS in the room prior to diagnosis

Age 26 Stage 1a1

> Age 43 Stage 1b1

The diagnosis appointment was really hard, as it was exactly a year after we had had a miscarriage. This was a lot to go through and it felt like this was something else to go through and it was a lot to take in all in one go. It was very overwhelming, but the consultant was very good. He drew diagrams to explain what surgery they had already done and what they were going to have to do. And he explained where the cancer was situated and all about the different abnormalities.

There was a consultant and nurse in the room. The first thing the consultant said was, 'yes, I am sorry you do have cancer'. He then very quickly went on to show me the operation they would do and a list of things that could potentially go wrong; he then asked me to sign a consent form. It was pretty awful to be honest. I got the impression that the nurse, I quessed she was a Macmillan nurse, was there to pick up the pieces after the consultant had spoken to me. It was very technical, it felt as though he wanted to get the operation done as quickly as possible.



Almost all said that while the diagnosis meeting was difficult, the consultants they saw were sensitive at the time of diagnosis. Many mentioned factors which could make diagnosis slightly easier and potentially less traumatic, including: who is present at the time; the manner in which a diagnosis is given; how partners or family members are treated during diagnosis; and what happens immediately afterwards.

Age 30 Stage 1b1 The consultant was great. He introduced himself and ran through where I'd come to so far. He drew diagrams of what cancer looked like and what mine looked like from the colposcopy.

Most of the women said the diagnosis was an overwhelming experience but 89% said that they could remember what their consultant, or other medical professional, had said at the meeting.

Age 43 Stage 1b1 I remember mainly what I wasn't told. I wanted to know about chemotherapy and radiotherapy. Would I even need them? No one told me this. I remember being told to set up an appointment for an MRI scan and CT scan. I did struggle to retain this information after the shock of what I had been told. Thankfully, my friend took it all on board.

Age 30 Stage 1b1 They made me an appointment with a consultant that afternoon, three hours later. I didn't feel happy about waiting on my own. They suggested that I call my husband or call a friend or colleague from downstairs, I work at the same hospital. I was sat in the waiting room, near the early pregnancy clinic waiting to hear if I would ever be able to have children. The initial diagnosis meeting is the first opportunity for clinical staff to provide information and support materials. Some women felt bombarded with too much information, others were happier to take information away with them. The role of a partner, friend or family member was critical here, with some saying that they were unable to absorb everything initially, and the person accompanying them was able to do this for them.

Age 46 Stage 2b

They gave me a book with lots of bits in it. As soon as they gave it to me, I started looking at it straight away. I remember the phrase in my head was 'knowledge is power'. I thought the more I knew the easier it would be to cope with. I read them over and over again and I made a decision in my head that as I looked through all the things that go wrong/side effects, I'm not going to have that and I made a conscious decision that's what was going to happen, and it worked.

Age 25 Stage 1a1

Age 28 Stage 1b1

Age 54 Stage 1b protect me from the fear of it I guess.

I didn't read it straight away as I wanted to call people first. I read all the information when I got home later to help me know what to expect on this journey.

I was taken into a room with a Macmillan nurse and given lots of information about having a radical hysterectomy. I didn't read any of it; I was too distraught. I gave it all to my partner and told him he had to read it. I couldn't take any of it in.

Most of the information I got was from my own research. I didn't get much from appointments which I think is because they were trying to protect me from the fear of it I guess.

Jessica Age 28 Stage 1b1

When I went into the hospital to see the consultant I saw a Macmillan nurse and didn't understand why I needed her. The feeling in the room was *'morbid'*. *Eventually the* consultant said 'you do have cancer and it's a rare form so we need to start treatment urgently'. That was when I was diagnosed.

The role of the Clinical Nurse Specialist

Clinical Nurse Specialists (CNS) are an invaluable part of the cancer journey. They will often be present during the initial diagnosis as they will be a crucial point of contact postdiagnosis and throughout treatment. 74% said contact with their CNS was important. However, there were some women who found the initial presence of the CNS, prior to receiving their diagnosis, alarming and upsetting. Spotting a CNS in particular provided a cue that something wasn't right.



We eventually convinced ourselves that it would be OK, so I went to the appointment on my own. I went in and noticed that the nurse came in with a box of tissues - not a good sign. So I expected bad news.

Age 39 Stage 2b There was a Macmillan nurse that met me in the waiting room. This confirmed to me that it was cancer. They had the results and said it was cervical cancer.

Age 54 Stage 1b

When I walked into the room initially, I knew there had to be something wrong, as there was a nurse sat in the room. I remember thinking to myself, what is she doing here? She had a Macmillan badge on. After the appointment with the consultant, I was taken into another room and this nurse sat down with me. She explained about what would happen next. That I would receive an appointment to see a surgeon, to discuss my course of treatment. She said it had been discussed that a radical hysterectomy would be the best option. She gave me a lot of leaflets about this procedure and how it affects you. I just sat there. The appointment must have been about 45 minutes, but it felt like forever. Afterwards I thanked her and walked away. I just felt absolutely devastated.



When I was diagnosed with stage 1 at the second meeting, there was a nurse. I knew there was something up because she was sitting there too. She had Macmillan on her badge and I thought that is a dead giveaway. Initially I was quite annoyed that she was there because it meant that I had cancer.

Three-quarters of the women we spoke to said that an ongoing relationship with their CNS was important to them, however almost half (47%) would have liked to have had more contact with theirs. Often this was linked to CNSs being busy and rushed or overworked. Nearly a quarter had little or no contact with a CNS.

Age 32 Stage 1b2

Age 28 Stage 1b1

Age 25 Stage 1a1 I think I would have benefited from ringing her for reassurance but I didn't want to bother or annoy her.

A partner's view:

My partner joined the online support group that the CNS ran and was in a lot of contact with her. She also went to one of the support group meetings with her mum. I also spoke to her on the phone a few times. Got on with her. I think this is an invaluable role for women going through this.

I did meet her, but I didn't have much interaction with her. Most of my support came from other women on forums. I felt the CNS was more helpful before staging than after. I was told that I could contact her, but she was not available as she covered three hospitals.

I built up a good relationship with my CNS and I am still in touch with her now. I felt like I could ask her anything I wanted, but I didn't necessarily understand everything.



Treatment options for cervical cancer include: surgical, drug based (chemotherapy) and radiotherapy including brachytherapy. The earlier the cancer is detected, the less invasive the treatment. Later or advanced stage cervical cancer required more radical treatment options which can result in much longer recovery periods and greater possibility of side effects.

All of the women were asked about their treatment, the options they were given, if any, whether they sought a second opinion and whether they felt fully informed about the impact of the treatment.

6% (two women) were still undergoing treatment at the time of the interview.

Two thirds (59%) had a surgical procedure, 26% combined chemo-radiotherapy, and 15% of women had both surgical and chemo-radiotherapy.

As a result of treatment:

- 15% reported being diagnosed with lymphoedema
- 26% experienced early menopause.
- **38%** lost their fertility.

Almost all the women reported feeling 'safe in the hands' of the medical professionals looking after their care and treatment. This was often given as the reason for not seeking a second opinion on their treatment options.



It felt very much as if the plan was already in place – but this wasn't necessarily a negative. I did feel like I could ask questions along the way, though I didn't feel like they were particularly involving me. This wasn't really an issue for me though, as they were the professionals and knew what they were doing.



I didn't have any choices – at least I wasn't given any. I wasn't told I could have a second opinion. It didn't occur to me, it wasn't mentioned and I didn't have any doubts really about what I was told. Once I saw the second consultant he was so brilliant. I was told I had one of the best men in the field.

The consequences of treatment on fertility were particularly evident especially when evaluating treatment options.

Age 25 Stage 1b

I didn't get answers on fertility but don't know if they didn't know or didn't want to scare me. They didn't tell me they could have removed my eggs. They said it wouldn't affect my fertility but might affect my ability to carry children as they were taking away a big chunk of my cervix. That felt ok to me. What I wanted to know was how likely that was to happen. I still don't really know what my risks are.



As I hadn't yet had children, they chose to do a radical trachelectomy. They were sensitive to the fact that we didn't have children and they avoided a hysterectomy. My partner was involved in that decision.

Age 25 Stage 1a1

One of my biggest concerns throughout all of this was how my fertility would be affected. I asked her then about this – how would it affect my ability to have children and her response was 'you can't have children if you're dead'.





Two-thirds (63%) said that they did not need further treatment following the surgical intervention they received. However, the long term effects of treatment were something that many of the women were now dealing with. For example isolation, sickness, fear and tiredness were also reported.

Each woman had a different experience of treatment with the impact often influencing physical, emotional and practical aspects of their lives. For some the frequency and intensity of the treatment resulted in significant changes to their day to day routine. For others their family or work life were where they felt the most disruption or pressure.

Age 33 Stage 1b1 The radiotherapy wasn't painful. I had all the help I needed from my CNS. I asked my husband to leave me to it, although he did come with me for chemo appointments. It was sad to see all the other patients there, especially the older ones. It made me put my own treatment into perspective. The side effects all kicked in at once in the second week. I was so tired; I just didn't want to do anything. All the plans I had made in my heads to do things alongside my treatment went out of my head. The chemo wasn't too bad, but it was painful. The radiotherapy gave me the worst side effects.

Age 36 Stage 1b

The first session of chemotherapy wasn't too bad. Then I went off to have radiotherapy. I started to have bad reaction to the treatment, I had nausea and went into the menopause.

Age 71

Towards the end of the treatment I became very tired and my hair thinned. I suppose it was everything leaving the body. Then I started to get lots of side effects. I seemed to get everything going including diarrhoea, cystitis. Stage 1b1

Age 49

I felt bewildered and withdrew from life a bit, but this was changeable. People were visiting and flowers and cards were being sent, but I didn't want this as it meant I was poorly.

Robyn Age 46 Stage 2b The oncologist made it quite clear 'this is what we're going to do'...it wasn't until the treatment was all finished that I realised that I could have had a choice, that I could have said no. Care and support

Only half (43%) said that their level of care throughout treatment and follow up remained consistent. Almost a third (29%) felt there was a lack of psychological support after their treatment had finished.

Age 25 Stage 2b2 There was no support after you get the all clear. There is no emotional support. I see on the forums a lot that people think they should be happy as they have got rid of cancer but that's not how it feels. There are still physical problems, there could still be recurrence, I'm better but.



There was not enough information given about aftercare though and I didn't know what to expect about with my own recovery. I wasn't sure about wound care, and what was normal and what was not. More information in this area would have made my recovery easier.

During treatment, women value the support provided by external organisations, such as cancer charities.

Age 39 Stage 2b The Macmillan nurse spoke to me afterwards and gave me a load of leaflets. The Royal Marsden was mooted at the time. The process of what would happen was explained to me. It was all quite factual, which is what I needed at the time.

A partner's view:

It was really nice to be able to speak to and see one of the surgeons afterwards. He was very visible on the ward and was very approachable.

If I was talking to a partner at the beginning of this process, I would say that's it's all going to be alright. Stage 1b1 Age 43 I did value the support offered by certain organisations. In particular I accessed support through Jo's Cervical Cancer Trust, but also accessed support through my company's health support system.



Katherine Age 33 Stage 1b1

I know it was the right decision to make to have the treatment. Not necessarily the decision I wanted, and that was why it was more painful. We agreed that we've got to make the decision that is right rather than the decision we wanted.



The impact of diagnosis and treatment

While each woman had a different experience depending on their personal circumstances, treatment and stage of cancer at diagnosis, some common themes came out of the interviews. These included loss of fertility; the impact on relationships including sex and intimacy; changes to employment and finances; and the impact on families and children.



Impact on fertility

Some cervical cancer treatments result in changes to fertility while others cause complete loss of fertility as the ovaries may need to be removed and / or chemoradiotherapy can cause early menopause.

For many, having to make decisions about their fertility before they have even considered having children is very traumatic and for others, telling family or their partner that their fertility has been affected is very difficult, especially when there are other factors to take into account, such as an increased risk of miscarriage.

Age 49 Stage 1a1

They said it wouldn't affect my fertility but might affect my ability to carry children as they were taking away a big chunk of my cervix. That felt ok to me. What I wanted to know was how likely that was to happen. I still don't really know what my risks are.



I love kids. I have two girls and would have loved to have a boy. I was pretty sure I wanted more kids. My partner said to get it all taken away as he thought it would be best. In the end he was supportive but it was a very tough decision.



They talked about fertility. They said radiotherapy would kill my ovaries. I knew I wouldn't be able to have kids. I didn't have them already and I didn't want them at the time. I just needed to beat this. You have to make snap decisions. Maybe I should have thought about it more at the time, but I didn't prioritise this.

A partner's view:

It matters more to A than me about fertility. I was not as worried about that. I felt fully involved, but it was not an issue to me. All the issues were about my wife.



Impact on employment and finances

All the women interviewed who are or were in employment at the time of their diagnosis reported an impact on their working life. This included financial situation; practical issues such as taking time off and telling colleagues; coping with changes in their employment status and concerns about going back to work following treatment.

Age 58 Stage 1b1

Age 43 Stage 1b1 The biggest problem has been not so much the physical toll, it's the cognitive. My memory is awful. I couldn't have done the job at the level I was before.

I had to be honest telling them how tired I get and that I lack energy. I am going into work for a few hours a week now which is great, but I am having to learn how to manage my time and not take too much on. This is really hard for me as I liked to be in control of things. I would like to be back in work and working longer hours. I still can't find the energy to work any more than three half days a week. I feel very tired after each trip to the office and it takes me time to recover.



Impact on children

Over half (57%) of the women had one or more children and of those women, over half (55%) said their diagnosis had a significant impact on their children.

Children reacted in a number of ways, some regressing with sleep patterns, bedwetting or other behavioural issues. Some children just became far more attached to their mothers.



Age 49 Stage 1b1

Age 40 Stage 1b1

Age 58 Stage 1b1 I couldn't pick my daughter up for several months. I couldn't take her to her swimming classes for a while due to my bleeding. She got upset with this and gave up her swimming lessons. She played it out with her dolls.

Our sons are OK. My eldest son is at university, so is somewhat removed from the situation, he doesn't see it all. But he knows what is going on. My younger son is still at home and he asked lots of questions. He couldn't come to terms with it for three days. As I was upset, he didn't want me to be and felt if he was upset, I also would be. I also didn't feel comfortable talking about women's problems to my teenage son.

My son's behaviour has deteriorated in the last six months. And his sleep has worsened. For my little girl it is more about: when is mummy coming back, when will your tummy stop being sore, when can I sit on you again?

I wanted to minimise my fears and concerns for them. I want to protect them as a mother. Over the years, we've known a number of people, close relations, who've died from cancer – my brother died from a brain tumour and three close friends of mine too. So I wanted to reassure them that I was going to be ok and this wasn't going to be a death sentence.

Age 36 Stage 1a1

There wasn't much impact. I told close work colleagues and my managers. I worked from home a lot after I was diagnosed. I worked right up to my treatment – I needed to work. My colleagues have been very supportive. My male colleagues didn't know how to react around me. They were quite tentative. I didn't know who knew and who didn't, and who had been told while I was off work.

In the majority of cases, employers were supportive of women undergoing treatment and facilitated appropriate time off for necessary appointments, treatment and recovery.



I'm not back at work yet. I can take six months' sick leave at full pay. I am feeling nervous about going back. I worry about the physical demands of my job and if I will have enough stamina. There's also the emotional side of it. I have not been away from work this long since I started working. Having cancer has knocked my confidence.

Almost half (45%) reported that having cervical cancer had at least some financial impact on their lives, with 11% saying that it had significantly affected their financial circumstances.



If I had stayed off work for longer than eight weeks, it would have had an impact on my sick leave and pay. I had only worked there for less than a year, so I only got two months of full pay.

A partner's view:

I had to take annual leave from work. I took about two or three weeks. They gave me one days' compassionate leave. It was not very generous.



All of the women reported relationships changing following diagnosis and treatment, sometimes improving and sometimes being negatively affected and even breaking down.

Age 43 Stage 1b1 Following my cervical cancer experience, I have been forced to lean and rely on my friends so much more. I have made a real effort to ask for help from my friends. As a result, the relationships I have with my friends are much stronger.



One of my friends rejected me and didn't know how to treat me. My other friends were overwhelmingly helpful. My mother got very emotional and didn't know how to deal with it. She lost her parents to cancer. This changed the dynamics of the family.

Two thirds said their intimate relationships were affected.

Age 54 Stage 1b As our relationship was being affected we sought out our own counselling and we paid to go to Relate. We did that over a six-week period and it was really helpful. I couldn't talk to my partner about how I was feeling, I just couldn't express it. This helped me to do this.

Age 28 Stage 1a This [sexual relationship] was more of a worry for me than it was for my partner. We didn't get any medical information about this. It felt uncomfortable to ask about this, although I did manage a couple of questions. I underestimated the time it would take to get back to normal. It's massively affected our sex life. We had a healthy sex life before and since this happened we've had sex maybe three times. The first time I burst into tears as it was impossible not to think about it. It's a mixture of me getting emotional and him worrying that he's going to hurt me. We talk about it with each other.

Stage 1a1

Age 25



I have had very conflicting messages. This has remained consistent. From curable to incurable, at the moment I still don't know my actual prognosis. This makes me feel like I am stuck in time – I don't know how long I have left.



Route to diagnosis

- 1 Further investment in symptom awareness campaigns to ensure earlier diagnosis.
- 2 Increased investment in targeted campaigns encouraging women to attend cervical screening (smear tests) when invited.
- 3 Employers to raise awareness of cervical cancer in the workplace and increase accessibility to cervical screening by allowing female employees the time to attend screening if they cannot get an appointment out of work hours.
- Diagnosis 4 Invitation to the diagnosis appointment should always offer the choice of having someone with them during the appointment.
 - 5 Consider how those present at the diagnosis meeting, for example those badged as cancer nurses, can be introduced more gently or sensitively to the process and consider removing cues which could alert women to the diagnosis before they have been told e.g. tissues.
 - 6 Share the results of this report and work with health care professionals who would be present at diagnosis to improve the experience for women. All women signposted to the support Jo's Cervical Cancer Trust can offer at point of diagnosis.

Care and treatment

7 Effective information provision is critical for patients and their families. Practitioners need to ensure that women are given the information they need, at the level they require and when they require it.

- 8 The role of partners, family and friends is crucial at times when difficult information is being given. It should always be suggested that woman are accompanied to appointments.
- 9 Each patient should be introduced to their CNS as soon as possible and care should be taken to ensure the patient understands the support a CNS can offer and how and when they can contact their CNS during and after treatment, especially if CNS contact is patient led.
- 10 Psychological and emotional needs of patients addressed throughout treatment and after care, with signposting to appropriate services.

- be suggested.

- so patients do not feel rushed into decision making.
- given for all women affected.

for further support for the family.

Impact and

follow up

- ensure the impact of treatment on intimacy can be raised.
- financial support.

11 Consider the potential impact on a patient if their partners/family members/ friends are not allowed to wait with them or if a ward stay is needed, visit them on the ward. Use of new media such as Skype or FaceTime could

12 The potential long term and short term, physical and psychological side effects should be presented when discussing each treatment option to facilitate shared decision making and ensure informed choice.

13 Complementary therapy should be discussed as an option to help support psychological and physical recovery alongside conventional treatment pathways, for example acupuncture, reflexology or mediation.

14 Ensure time for significant discussion about treatment options is provided

15 Signposting for support related to changes and loss of fertility should be

16 Specific support should be offered for women who have children. This should include how to talk to children, how to deal with their questions and signposting

17 Clinical staff should follow The National Forum of Gynaecological Oncology Nurses (NFGON) guidelines on psychosexual issues after cervical cancer to

18 More work needs to be done to inform employers about the short and long-term impact cervical cancer may have on women in their workforce.

19 Sufficient support and advice about the financial impact of cancer to be provided alongside signposting to organisations who offer specialised

20 A collaborative project needs to be started to help design a care model to provide all of the above extra support that patients, and their family and friends, require focusing on the long-term consequences of treatment.

Support for women and their families

As the UK's only charity dedicated to women and their families affected by cervical cancer and cervical abnormalities, Jo's Cervical Cancer Trust provides a wide range of support and information.

Talk to us

Get support

Join our online forum: jostrust.org.uk/forum.

Find information

Visit our website: jostrust.org.uk.

Help us be there for more women facing a diagnosis

Text JOTR01 £5 to 70070 to donate £5 and help us ensure that women affected by cervical cancer don't face a diagnosis alone.

Emma Age 26 Stage 1b

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My advice for anyone going through cervical cancer treatments is to talk to someone, don't do it alone. If you don't want to talk to your partner or family go onto Jo's Cervical Cancer Trust, there are loads of other women in your position. You will instantly feel so much better, as there will be someone who has been through it and done it, or someone who is just at the same stage as you. Even if you don't want to talk to someone face to face just that online chat or on the phone is really important.

Call our free Helpline on 0808 802 8000.



Contact us:

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