Jo's cervical cancer trust

Full report

Cervical cancer stories: diagnosis, care, treatment and life beyond

38 experiences of cervical cancer

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version.1.0

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1 Executive Summary

Jo’s Cervical Cancer Trust provide information, emotional and practical support to women, and their families and friends who are affected by cervical cancer. We campaign for excellence in treatment, support and care and aim to raise awareness of the importance of prevention and early detection to the public, health professionals and key decision makers.

Every day in the UK, nine women are given the news that they have cervical cancer. As the only charity dedicated to women affected by cervical cancer, Jo’s Cervical Cancer Trust commissioned this landmark research, which brings together the experiences of 38 people. 35 women who have been diagnosed with cervical cancer in the last two years and the views of three partners have also been captured to gain a perspective of their experiences of supporting a loved one through diagnosis and beyond.

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

1.1 Key Findings

1.1.1 What women valued, and what they find difficult

- Family support is one of key factors for women and being able to rely on other family members is critical.
- Women hugely valued the medical professionals they came into contact with. Diagnosis and treatment were, in every case, more positive experiences when these women came into contact with informative and caring health professionals.

1.1.2 Key differences between care models and provision

- Some of the important factors included: choice of hospital; access to a second opinion; extent to which women feel involved in choices about their care and treatment; access to a Clinical Nurse Specialist (CNS).
- Very few women were given a written care plan or a holistic needs assessment although many said that they would have welcomed this.
- For many women, there was a mismatch between the care they received at the start of treatment and the follow-on care they experienced.
- There was a lack of emotional and psychological support for women.

1.1.3 Experience of cervical cancer treatment

- Impact on employment is a huge issue for many women – whether this is because of work being difficult to handle, or because of the amount of time they needed to take off.
- For many women, the impact on family life – either on their children or partner – is profound.
- The physical impacts are also dramatic for many women and undergoing treatment is for some an extremely challenging experience, with brachytherapy often being referred to as ‘hideous’.

1.1.4 Differences from pre-conceived expectations

- For many women there was a lack of material on what to expect during treatment.
- Information about side effects of treatment was lacking with many suffering unexpected side effects and finding this far more debilitating than they had expected.
- For most women, the level of care that they received in hospital was good and many had positive examples of specific members of staff who had helped and supported them.
- For some, however, the way that they were told about their diagnosis and then the way that consultants communicated with them was unhelpful and insensitive.

1.1.5 Where women felt their needs were not met

- Lack of emotional and psychological support, particularly during and after treatment, is one of the key areas of unmet need for many women.
- A lack of additional support services, such as holistic treatments, was reported. For many women, it is left entirely up to them to seek out their own support.
- Women are also not given the support they need in terms of dealing with the impact their illness and treatment may have on other aspects of their relationships, including on their sex life; personal and family relationships and on their children.

1.1.6 Potential support, information and policy related solutions

- Women want information at a time that suits them, and to suit their circumstances – women need to be able to define this for themselves and for there to be flexibility around what they receive and when. This is not happening.
- Provision of Personalised Care Plans and Holistic Needs Assessments needs to be looked at urgently.
- Provision of emotional and psychological support needs to be addressed.
- The financial impact on women and their family’s needs to be addressed, through provision of better information for women as well as employers.
- Support for women post-treatment should be looked to ensure that women do not feel abandoned.

2 Aims and objectives

1.1 Background

Each year in the UK, around 3,200 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, ten-year survival for cervical cancer ranks 8th highest overall (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 pre-cancerous 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.

The 2015 National Cancer Patient Experience Survey[2], which included the views of 71,186 cancer patients, found that 27% did not feel the possible side effects of treatment were fully explained at the time, 34% were not offered advice and support to deal with side effects and 46% were not told about side effects which could affect them in the future. Only 33% were given a care plan and 45% were not provided with information about potential financial help or benefits. Jo’s Cervical Cancer Trust wanted to understand the specific experiences of women affected by cervical cancer and commissioned Quality Health to help undertake this project.

1.2 Objectives

In carrying out the in-depth interviews with cancer patients, the core objectives were to:

- Identify what patients valued throughout their treatment journey, and what they found challenging.
- Identify any key differences between care models and provision.
- Truly understand the experience of cervical cancer treatment for patients and for their families.
- Illustrate clearly how this journey might differ from pre-conceived expectations, both before and during treatment, and how these expectations are managed throughout.
- Understand clearly where they felt their needs were not met, and identify where the most meaningful support can be given.
- Identify potential support, information and policy related solutions to improve the patient experience and quality of life, and that of their families.

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[1] Cancer Research UK: http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/survival#heading-Zero Accessed 07.09.16

[2] National Cancer Patient Experience Survey 2015 - National Data: https://www.gov.uk/government/statistics/national-cancer-patient-experience-survey-2015-national-data. Accessed 07.09.16

The information gathered from this project will be used to develop new services (e.g. services provided by the NHS and other health bodies, Jo's Cervical Cancer Trust and other leading cancer support organisations); improve services where needed; influence policy makers; and help to focus training and development of staff who work in cervical cancer treatment.

3 Methodology

3.1 Interview design and development

The template to be used during the interviews was developed and designed over a number of months during 2015 and 2016, following detailed discussion between Jo's Cervical Cancer Trust and Quality Health. A number of healthcare professionals were also involved including Gynaecological Clinical Nurse Specialists and Gynaecological Oncologists.

Once the interview script was agreed, it was tested on two volunteers who were willing to take part; and then discuss their thoughts on various aspects of the questionnaire design. This included comments on the questions and their wording; whether the answer options accurately reflected their experiences; whether there was anything missing; and on whether the interview was easy to follow. These test interviews were not included in the final data.

Further changes were then carried out and a final interview template was agreed.

3.2 Recruitment of participants

For this study women had to have been diagnosed with cervical cancer within the last two years, and needed to be willing to be interviewed about their experiences. Recruitment took place via online promotion on the charity's website, social media and online forum. In addition details of the study were sent to the charity's database of health care professionals so they could help recruit a range of participants.

We also asked the women who volunteered to be interviewed if they had a partner/spouse and if so, whether they would also agree to be interviewed. We were able to interview three partners/spouses. The aim was to find out more about how partners experience the care and treatment of their loved ones, and to identify further support which can be offered or provided to them.

3.3 Timescales and fieldwork

The interview template was agreed in January 2016 and interviews began that month. They took place between January and June 2016, with each interview taking between one-and-a-half and three hours to complete.

The interviews were carried out over the phone and detailed notes from every call were taken. Each interview followed an agreed format and covered experiences in chronological order, from pre-diagnosis through to treatment and care. The interviewers were all experienced at talking to people about potentially upsetting or difficult experiences and the interview template highlighted particular areas which were to be handled carefully. It was explained that all their responses would be confidential and anonymised. In the case of filmed interviews, real names were used and express consent was given from the women who took part. The vast majority of those who were interviewed were very happy to share their experiences in detail.

Following the interviews, each of the write-ups were reviewed and coded where possible to record not only the qualitative elements but also the quantitative. While this is a small sample of women, and therefore not statistically significant in terms of the qualitative data, we wanted to be able to show how this group of women compared to what we know about the make up of women who are being treated for cervical cancer. Similarly, we took care to ensure that we included women from all age groups, locations and ethnic backgrounds where possible.

The interviews were completed in mid-June 2016 and this report compiled as soon as possible after the close of fieldwork, in order that follow-on policy work can start swiftly.

The interviews which were filmed were written up in the same way as the phone interviews – and these interviews also followed the agreed format. Following this, they were edited into a series of short films, which will be published on the Jo's Cervical Cancer Trust website and on the charity's YouTube channel.

We are hugely grateful to all of those who took part in the interviews for their time and for telling their stories so candidly.

4 Results

Volunteers were recruited from across the United Kingdom including Inverness, Belfast, Manchester, Devon, London, Cornwall and Cardiff. Women we interviewed ranged in age from 24 to 78; and at diagnosis from stage 1a to stage 4a.

- 6% (2 women) were still undergoing treatment for cervical cancer at the time of the interview.
- 57% of women interviewed had children, 43% had no children.
- A total of 38% of all women interviewed had lost their fertility due to their treatment.
- 28 women were interviewed using the script over the telephone. Seven women were filmed during their interview – using the same script. A total of 35 women were interviewed.

4.1 Respondent characteristics

4.1.1 Age of participants alongside cancer stage at diagnosis

Stage/Age	Under 25	25-29	30-39	40-49	50-59	60+
1a	0	3	1	0	0	0
1b	1	7	7	6	4	0
2a	0	0	0	0	0	0
2b	0	0	2	2	0	0
3 or 4	0	0	0	0	0	2
Unknown	0	0	0	0	0	0

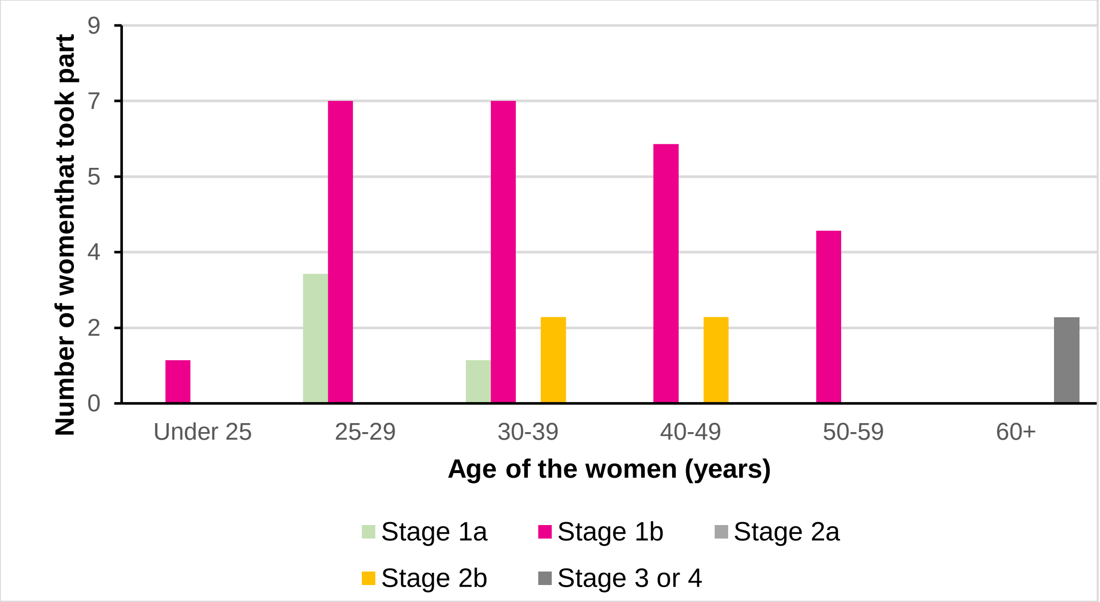

Figure 1. A breakdown of women that took part in the study

4.1.2 Ethnic origin

Ethnic background	**Number of women**
White English	27
White Scottish	4
White Welsh	1
Black Caribbean	1
Chinese	1
Northern Irish	1

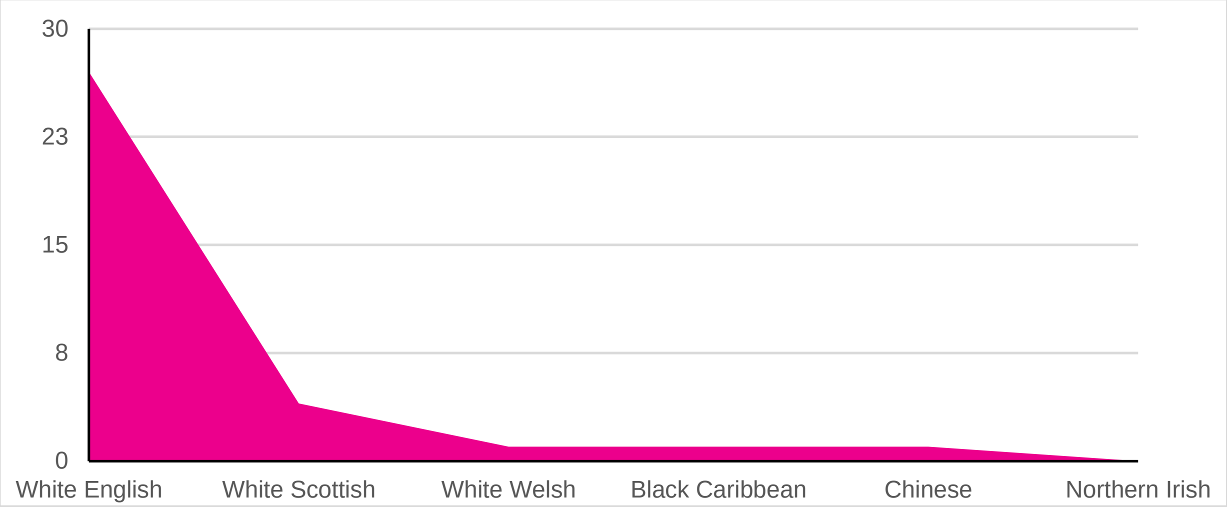

Figure 2. Ethnic origin of the women that took part

Age range	Number of women
Under 25	1
25-29	10
30-39	10
40-49	8
50-59	4
60+	2

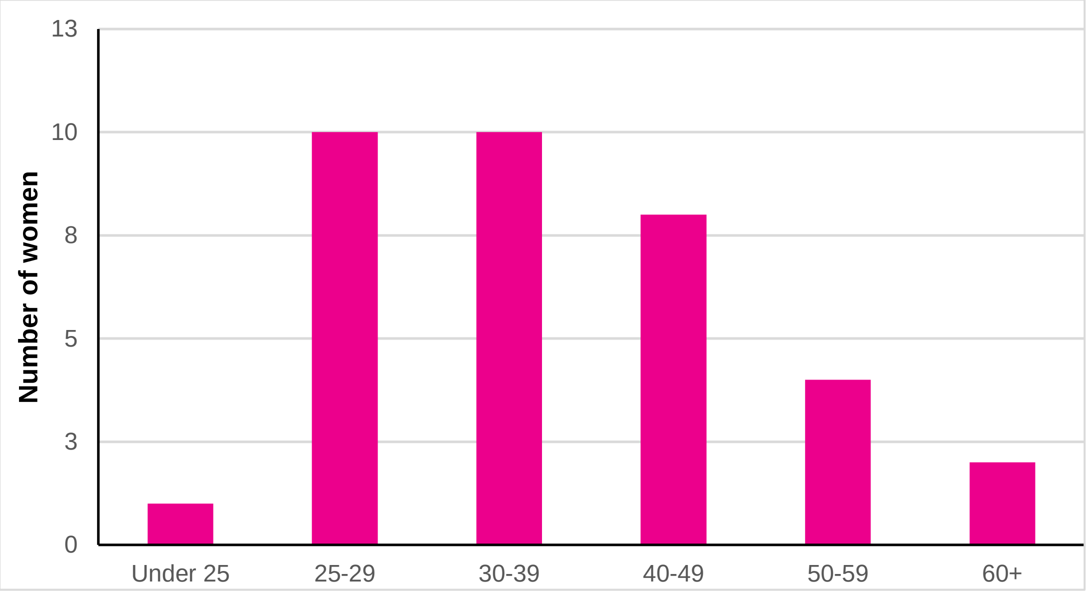

Figure 3. Age of women that took part

4.2 Pre-diagnosis

4.2.1 Route to diagnosis

Of the total number of women interviewed, well over half (57%) had their cervical cancer diagnosed through regular cervical screening, with 40% of women noticing symptoms and taking these to their GP, or similar, and just 3% having been treated for another condition when their cervical cancer was detected.

Many of the women interviewed had regularly attended routine screening and their cervical cancer was detected as a result of this being their first routine cervical screening, or they had made an appointment for a test after having been sent a reminder or being advised by their GP that their next screening was due. They had no suspicions of having cervical cancer.

> *"My cancer was picked up in a routine [cervical screening]. I always attended screenings and had never had any problems previously. I mentioned to the nurse that I had noticed an unusual discharge, which I was going to mention to my GP. I had a child the year before and thought it was something to do with this, which is what I told the nurse."*
>
> Stage 1a1, aged 36

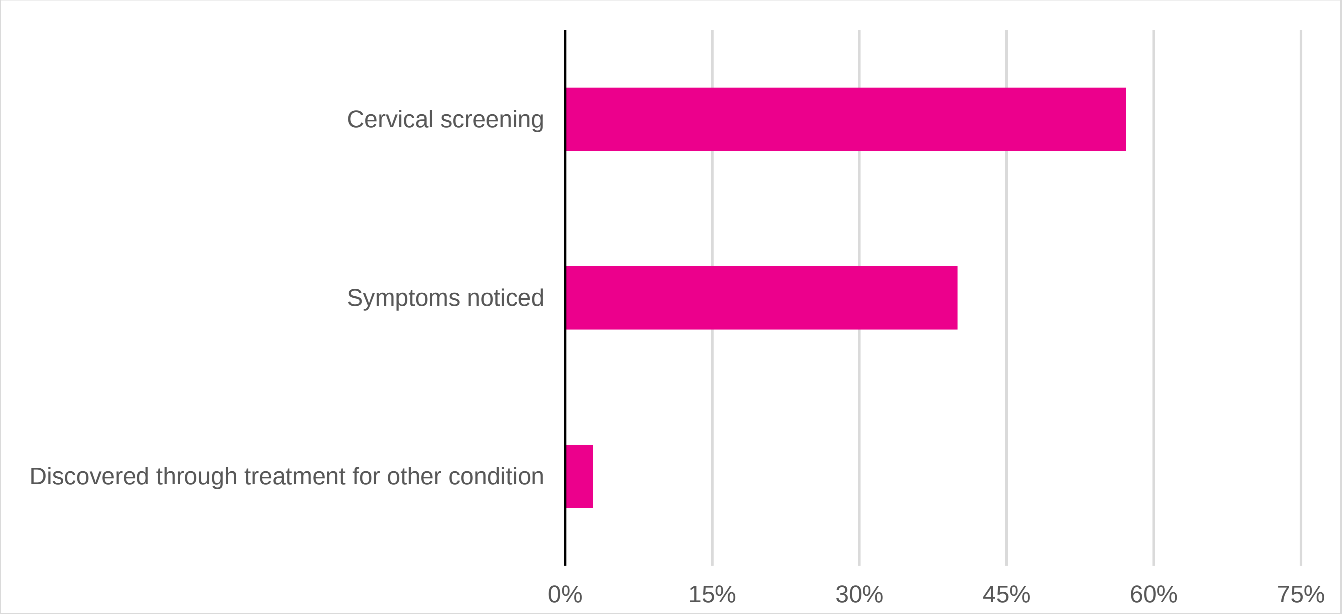

Figure 4. Route to diagnosis

For a smaller number of women, noticing potential symptoms of cervical cancer was more prominent., although these symptoms were not obviously recognisable as being symptomatic of having cervical cancer, and were more likely to be thought to be associated with sexual activity, menopause, contraception or another already present underlying condition.

> *"Just after I got pregnant with my 3rd child I started having bleeding. The midwife thought it was spotting. As the pregnancy continued it happened every day and then at 20 weeks the midwife referred me to the hospital. They thought it was a fibroid and just monitored me to get me to 34 weeks when I would have a C-section. I had my son at 34 weeks and I was transferred to another hospital and the specialist there said they could see instantly what it was and referred me straight to the hospital to be diagnosed."*
>
> Stage 2b, aged 33

Just one woman interviewed had no idea of cervical cancer being present, and, in fact had visited their GP for another reason altogether, when their cervical cancer was first suspected.

> *"I went to the doctor to have my coil removed in May 2013. During the procedure the doctor said she wasn't happy with what she was looking at and could see something on my cervix."*
>
> Stage 1b, aged 54

Due to the likelihood of symptoms being caused by other factors, some women had their diagnosis delayed.

> *"The nurse said there were 'abnormal cells are there but it shouldn't be anything to worry about, so I'll see you in six months. For me, that was out of sight out of mind."*
>
> *"They then sent me for a colposcopy, I had that and was told they didn't think there was anything untoward there, and to 'get on with it'. I then got a phone call a week later saying can you come in and see us. The gynaecologist said to me, I'm really sorry but there are cancerous cells, we're going to have to do a LLETZ."*
>
> Stage 1b1, aged 37

All women (100%) who had an abnormal cervical screening were referred for further investigation through having a colposcopy at hospital. Some of these women also had biopsies done at the same appointment.

> *"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. The nurse said she saw abnormal cells and could do a LLETZ procedure and they would see me again in 6 months."*
>
> Stage 1b1, aged 28

4.2.2 *Issues with screening*

Many of the women interviewed had had no previous issues with cervical screening and, in fact, it had been their first or they were very early in the screening cycle. Conversely, some women had had regular screening throughout their life, had had no issues with previous screenings and had now had cervical cancer detected in later life. Of these women, some were having their earlier results re-checked to identify if anything had been previously missed. Either as a result of error, or type of cancer, e.g. some adenocarcinomas are undetectable through screening. Whilst it is routine procedure to have previous screening audited, a small number of women found this disconcerting.

> *"I have never missed a smear test in my life – they're doing an audit of my smears at the moment to see if something hadn't been on one of my previous tests. Some of the girls I've been in touch with through Jo's Cervical Cancer Trust have also had their smear tests reviewed and they've found out irregularity – which they were never told about."*
>
> Stage 1b1, aged 59

> *"I had been with the surgery for 20 years and the doctor looked up my past screenings. She confirmed that I had never missed a smear test and that they had always come back clean and that I had never been recalled or had any procedures or anything."*
>
> Stage 1b, aged 54

The majority of women had no problem with attending screening. However, it was reported that the poor handling by medical staff of previous screenings had put some women off subsequent attendance at appointments. The inconvenience of screening time appointments also had been a barrier to attending, where it interfered with their normal patterns of work.

> *"I didn't really have any particular issues around screening, only the appointment times. They would always be offered at a time before I finished work, so these routine appointments weren't a priority for me. I would have found it far more useful to have been given the option of having an appointment outside the normal working hours."*
>
> Stage 1a, aged 28

Despite the majority of women attending regular screening, several of those that we spoke to had not attended straightaway and had not prioritised appointments, citing the everyday pressures of life getting in the way or underestimating the importance of attending on time.

> *"I always attended every three years, but this time I had left slightly longer because life got in the way. So it was probably four- and-a half years since my last one. But there were no issues with it."*
>
> Stage 1b1, aged 43

4.2.3 *Looking back after diagnosis*

Of the women we interviewed, almost two-thirds (63%) were not able to attribute any symptoms to having cervical cancer after they had been diagnosed.

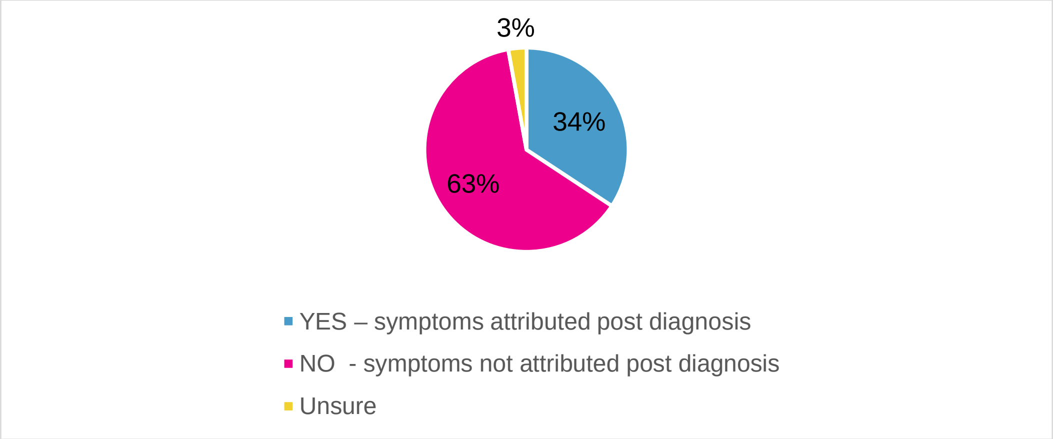

Figure 5. Looking back retrospectively after diagnosis

Although some women had noticed some symptoms, which presented mainly as abnormal discharge, post-coital bleeding and/or backache.

> *"Yes, I attributed my 'fake pregnancy' symptoms to cervical cancer. I joke that my friends had all been growing a baby, but I had been growing a tumour."*
>
> Stage 1b1, aged 29

For a smaller number of women (around a third), when looking back after diagnosis, it was quite obvious to them that the symptoms they had experienced before their cervical cancer being identified, could later be attributed to it. Conversely, many women had no idea at all and put what they had experienced down to other conditions or were not particularly alarmed by them, or attributed them to the general rigour of life.

> *"I only noticed the discharge, nothing really apart from that. I didn't display any other symptoms. I had backache, but I suffer with this anyway and I have a one-year- old."*
>
> Stage 1a1, aged 36

> *"I had nothing at all. I had the contraceptive implant so I had no bleeding. When I had that changed, there was a bit of spotting, but otherwise I was fit and well."*
>
> Stage 1b1, aged 30

4.3 Diagnosis

4.3.1 Being diagnosed

The majority of women that we spoke to suspected that they might have cancer before they attended their diagnosis meeting. This could have been as a result of the speed of their next appointment after initial consultation and exploratory treatment:

> *"I had a call from the hospital saying I didn't need to go to Leicester General, but that I needed to go to the Royal instead. I started to worry as the appointment was only a matter of days after the call."*
>
> Stage 2b, aged 45

Or, just to having a feeling that something was not right and turning to the Internet for answers before the appointment.

> *"I got results about two weeks later. It didn't tell me anything except that I needed to go to the hospital to discuss my results. And from what I'd read online I knew it was bad news if they don't tell you by letter. That was terrifying."*

Stage 1a1, aged 25

> *"There was a consultant and a nurse sat by the door. My gut instinct was that it would be bad news."*

Stage 1b1, aged 30

Some women did their own research before the appointment, including looking up the name of the doctor they were to see. Seeing that the doctor's specialism was oncology gave them the indication that cancer was present.

> *"I Googled the doctor's name I had the appointment with and by the time I got to the appointment I was a wreck."*

Stage 1a1, aged 36

> *"I got a letter saying 'severe dyskaryosis' – and that I had to have a colposcopy – and of course I went online first – I hit 'doctor GOOGLE'! – and found it was abnormal which could lead on to cancer."*

Stage 1b1, aged 59

Some women also first realised by chance, when they walked into the appointment and immediately saw a Macmillan nurse, or when they called a number provided and got through to the voicemail of the oncology department.

> *"I got a phone call from the hospital to say I had missed an appointment at the hospital, but I didn't know anything about it. I think it must have been a last-minute cancellation for someone else, but no one ever alerted me to it. So I had to wait another week. When I called to find out what was happening, there was no answer and my call went through to voicemail, with a message saying I had reached the oncology department."*

Stage 1b, aged 24

Others were alerted to the fact that they might have cancer by walking into a clinic and seeing posters about cancer, or being alerted by a nurse or other medical professional during investigation appointments.

> *"I turned up at my appointment at Leicester General and I did not know where I was going. I didn't know I was going to a cancer clinic. There were lots of posters on the walls about cancer and this got me really worked up. I suffer with anxiety anyway. It was all so vague after that phone call out of the blue."*

Stage 1a1, aged 36

Most women were told that they had cervical cancer by a consultant, face-to-face at a pre-arranged diagnosis meeting.

> *"My appointment was first thing in the morning. My husband went with me. I saw a different consultant; this was the one who had previously treated me for my stitches. My results weren't ready. I was told that the pathologist was still working on them. They told me to go and get cup of tea and come back in 30 minutes. My husband tried to reassure me by saying it had been the weekend and it was rushed that's why it wasn't ready.*
>
> *When I came back, there was a specialist nurse in the room and I knew that meant there was something bad. I was told that the results were bad and that I had cancer.*

> *I felt anxious as they couldn’t tell me what the treatment plan would be until I went to [another hospital]. I was very polite and thanked the consultant. Then I crumpled slightly and wondered how I was going to get back to the car. It wasn’t until I got back home, when I was sat next to my husband on the sofa, when I said, ‘I don’t want to die.’”*
>
> Stage 1b1, aged 32

Just two women interviewed were told in quite different circumstances and not by a consultant.

> *“Due to the last-minute nature of the appointment, there was no doctor present. I had called the hospital in the morning, as I was experiencing some bleeding. At that time, they realised that my test results were back and told me to come in anyway.*
>
> *The Macmillan nurse told me it was cancer. My partner was with me. It wasn’t as scary as it could have been. I was told by the Gynaecological Clinical Nurse Specialist (GCNS) that it was at a very early stage, so I was not too overwhelmed.”*
>
> Stage 1b1, aged 28

However, there were a small number of women who were told in less appropriate situations, which affected their emotional state at the time.

> *“I was coming round from the operation in the recovery room and was woozy and everything was hazy and the senior registrar who had done the procedure said ‘I didn’t like what I saw, I thought it might be cancer’. She started to talk and I don’t remember most of what she said. I was in a fair amount of pain, which might have been psychological. This was done on a Friday afternoon and she then went off duty. She hadn’t properly conveyed the information to the ward so they weren’t able to help me either. She did write a brief note that went to the ward with me and it said ‘query cancer’ – but nothing else so they couldn’t elaborate.”*
>
> Stage 1b1, aged 58

In one case, the woman concerned did not feel her cancer diagnosis was handled appropriately, especially as it was an auxiliary nurse who informed her that she had cancer.

> *“This was not at all straightforward. The appointment came round and I went to the hospital with my partner. We arrived and were sat in a room full of pregnant women. It was in the gynaecology suite. I was sitting there watching all these pregnant women, thinking, am I in the right place? The appointment really overran and ended up being two hours later than it should have been. By the time I got in there I was a bag of nerves.*
>
> *The consultant was very nice and told me that he would try and get me seen. He rang up to the gynaecology ward and asked if the sister was still there. She would be the one that would do a colposcopy. He also said he would arrange for an MRI scan and would see me in two weeks and that was the end of the appointment. Someone came in, who I think was an auxiliary nurse. She took me up to the ward. The sister was there and was able to do the colposcopy straightaway.*
>
> *The procedure really threw me, as I never had one of these done before and I wondered what on earth was going to happen. I was in one of those seats with my legs all spread out with people walking all around. The sister was looking at the camera and spotted something and said ‘there it is, there. That’s no bigger than a marble, that’s operative.’ I asked her what she meant and she told me I had cervical cancer. I couldn’t believe it as I thought I was only going for a check-up. She told me that it would be OK.*
>
> *I got changed and went back into the room and the sister was telling my partner that he should take me out for a nice meal and cheer me up. I hadn’t even processed what she had*

> *just told me! I was sitting there and I felt like I was drowning. I couldn't take all this information in. I remember walking back and getting in the car. I was speechless. I said to my partner, 'I don't believe she has just said that to me.'*
>
> Stage 1b, aged 54

Nearly all the consultants who attended the diagnosis meetings were reported to have a good 'bedside manner'; with most women interviewed talking in detail about how friendly they were, and how they explained everything clearly. This always resulted in a more positive experience for the women being diagnosed.

> *"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. He said they could see cancer cells floating about and they'd need to do further explorations to see how far they cancer had spread and what treatment I'd need."*
>
> Stage 1b1, aged 30

However, there were just one or two who were quite abrupt, clinical or straightforward in delivering the news of it being cervical cancer.

> *"The consultant was impersonal and delivered the news really badly. He was very negative and, in my opinion, far too matter of fact, giving me a very realistic view, which other consultants later disagreed with."*
>
> Stage 1b1, aged 29

> *"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 sign a consent form. It was pretty awful to be honest. I got the impression that the nurse (I guessed 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."*
>
> Stage 1b1, aged 43

For the majority of women, the consultant was supportive or they had a Clinical Nurse Specialist (CNS) present as support back up. The CNS was an excellent source of support for all women we spoke to.

> *"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."*
>
> Stage 1a1, aged 26

As is normal practice in these situations, the staging of women's cervical cancer was not usually confirmed at the first diagnosis meeting. Generally, an idea of staging would be given, but the patient would be advised that confirmation of this could not be made until further tests were carried out – usually involving an MRI and CT scan.

> *"He said I had cancerous cells stage 1b1. But until they did further tests they couldn't confirm the staging. He explained the various treatment options to me."*

Stage 1b1, aged 30

On the whole, for the majority of women we spoke to, their diagnosis meeting was quite short, meaning limited contact with the consultant. The majority of women felt they would have liked additional time to ask questions or find out more information.

> *"I felt I was only talking to the consultant for a few minutes. The nurse took us off to a separate room. I did get upset. The nurse went off to get appointment details for the MRI and CT."*

Stage 1b1, aged 30

However, in most cases, most women were given the opportunity to speak to a CNS after the appointment, or were given the contact details for them.

All the women we spoke to, described the diagnosis meeting as a challenging experience, at least to some degree. For women who had not suspected they had cancer, the meeting was described as 'overwhelming'. These women reported finding it challenging to take information in at their diagnosis meeting after hearing 'cancer' being mentioned; having someone with them therefore was beneficial.

However, some women, especially those who felt prepared for the news, found it less challenging and as so felt able to ask the necessary questions, or had already started to investigate what the next steps would be.

4.3.2 Accompanying person at diagnosis

The majority of women (75%) that we spoke to had someone accompany them to their diagnosis meeting. Of these women, 60% said that it was their husband or partner who came with them. This was considered to be a very important role.

> *"My husband came with me. He is very optimistic and didn't expect the worst. He balanced me out."*

Stage 1a1, aged 36

Just over a fifth of women interviewed (23%) attended the diagnosis meeting on their own. The reasons behind this were often that there was no expectation of bad news.

> *"I went to my diagnosis appointment on my own as I wasn't expecting it to be serious."*

Stage 1b1, aged 28

Or not being advised to bring someone with them to the appointment.

> *"I went on my own. They questioned why I hadn't brought anyone with me. They told me I had a few cancerous cells, but it didn't really go in. I was told I had to go and have a chest x-ray and realised that they were looking for metastases. My cancer had spread.*
>
> *I texted my husband who is an anaesthetist. He walked out of theatre and came to find me when he read I had cancerous cells."*

Stage 1b1, aged 30

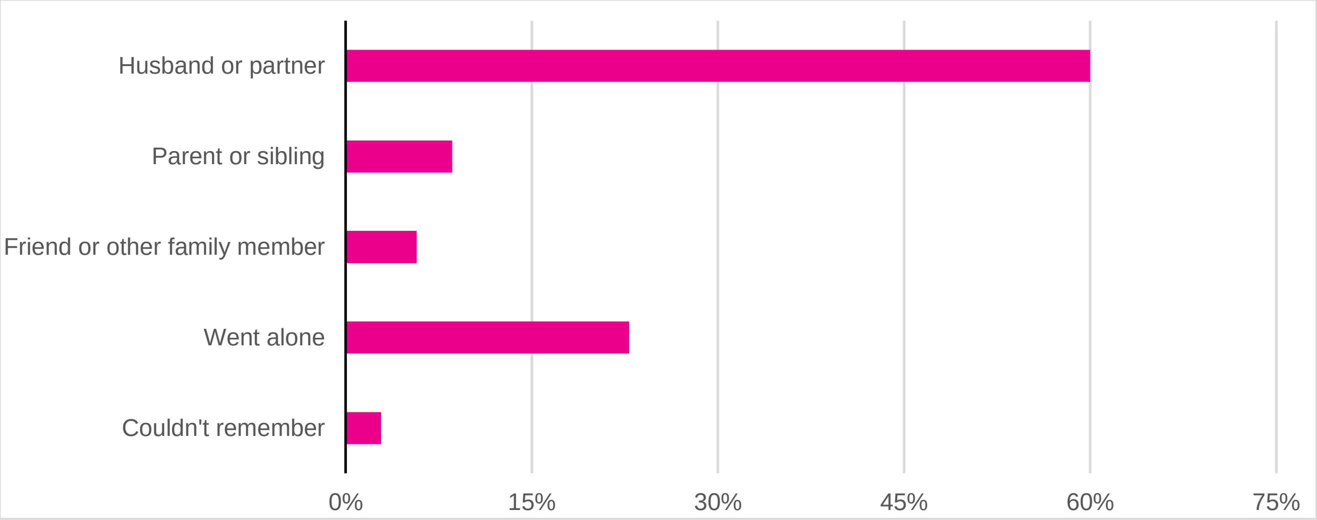

Figure 6. Accompanying person at diagnosis meeting

Many of the partners or family members that accompanied the women had some inclination of what was going to happen at the meeting, although some of these individuals would not have shared these thoughts with the patient.

> *"My husband came to the appointment with me. We both thought it was likely to be cancer, but we had not admitted it to each other."*
>
> Stage 1b1, aged 40
>
> *"My mum was with me. I was expecting the diagnosis; I knew deep down. She knew of my suspicions and came prepared with a few questions. She was trying to be strong for me."*
>
> Stage 1b1, aged 26

A small number of women interviewed reported that their partners were not expecting the news to be bad and were therefore very shocked at receiving a diagnosis of cervical cancer. It may be as a result of this that they also did not take in information, or understand medical terminology.

> *"My husband came with me. He didn't know what was going on really and didn't understand the medical terminology. He had prepared himself for the worst, though, as thought it would be bad news."*
>
> Stage 1b1, aged 29

Most partners who accompanied women to their appointments were very supportive, absorbing the relevant information that was unheard by the women themselves and asking relevant questions when necessary.

> *"My partner was very calm and sensible and very level-headed. He was good at listening to all the detail and he heard the things that I missed."*
>
> Stage 1b1, aged 28
>
> *"One of my old friends from university came with me to my diagnosis meeting. It was invaluable having her there as I didn't take anything in and she became my eyes and ears."*
>
> Stage 1b1, aged 43

“My partner came with me and I am glad that he did, as I was not listening to anything. After the appointment I had to ask him what had been said.”

Stage 1b, aged 54

“My husband was with me. I went into a daze and didn’t really hear anything. I really needed my husband to there to remember what was said – it’s so important to have someone there with you.”

Stage 1b1, aged 59

There were just one or two instances where partners or parents got very upset at the meeting and found the situation too overwhelming; sometimes more so than the women themselves.

“I tried to stay strong, but I broke down in tears. My husband did too. He cried for two days afterwards.”

Stage 1b1, aged 29

“My boyfriend took it worse than me. He had a nosebleed! The nurse had to tend to him.”

Stage 1b1, aged 30

4.3.3 Recalling the first meeting

All women interviewed reported that the diagnosis meeting was a difficult experience, at least to some extent, especially as they were first discovering that they have cancer. Of the women that we spoke to, a large majority (89%) said that they could remember what their consultant, or other medical professional, had said at their first diagnosis meeting.

‘He said “you’ve been a bit of a problem!’ ‘Through your biopsy we found something higher up your cervix’. I said: ‘are you trying to tell me I’ve got cervical cancer?’ And he said: ‘yes – why? Are you surprised?’

Stage 1b1, aged 59

“I remember only some of what was said. I missed the finer details, as it was all a bit overwhelming.”

Stage 1a1, aged 36

“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.”

Stage 1b1, aged 43

4.3.4 Involvement in treatment

Well under a third of women (29%) felt like they were involved in their treatment choices for cervical cancer.

“I was told that my cancer was at an early stage -1b1 – and as a result I would be able to have a cone biopsy. I was given the option of having a hysterectomy or trachelectomy. I was given a week to decide.”

Stage 1b1, aged 29

For many women, fertility was a serious issue for them, and in the forefront of their minds when treatment such as hysterectomy was mentioned.

> *"I had an MRI after my diagnosis appointment and went back after a week to be told it was stage 1b1. I felt quite involved. In Hull they wanted me to have a hysterectomy, but the consultant who had worked in Manchester, advised that a trachelectomy might be an option. They asked if I wanted to go to Manchester and have a trachelectomy instead. This is what I chose to do, as fertility was an issue for us. My partner was involved in this decision."*
>
> Stage 1b, aged 24
>
> *"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."*
>
> Stage 1b1, aged 28
>
> *"The consultant then came in the room and I told him that I wasn't happy about having a hysterectomy. I am young and getting married in five months and want a family. He said the 'gold standard' of treatment would be a hysterectomy and this would mean less of a chance of recurrence. But they would do a lesser treatment, if possible, and look at preserving fertility treatment in case."*
>
> Stage 1b1, aged 30

Some women reported that this was due to the type of cancer they had and the stage it was diagnosed. It was therefore felt to be the clinician's role to propose the treatment plan with limited or no options. All women reported finding this acceptable and were keen to get treatment started.

> *"The week after the MRI they talked about my options for treating it. They said I was stage 1B2 which meant I had to have a radical hysterectomy. That was a massive shock.*
>
> *They were kind of gentle but quite clinical and they said this was the only option. What did upset me was the medic in Doncaster had given me some false hope as he said a trachelectomy might have been viable but in Sheffield they said that had already been ruled out"*
>
> Stage 1b2, aged 25

As suggested, this was not a negative for women where this occurred. Women reported putting absolute trust in the medical professional treating them and felt reassured that they were being told what would happen to them in order to successfully treat their cancer.

> *"I wasn't told my staging at the first meeting. I was introduced to a GCNS who was really helpful and informative. She found out the staging was 1b1, as the doctor hadn't told me.*
>
> *I felt safe and secure that they had a confirmed plan in place. It made me feel confident that they knew what they were doing."*
>
> Stage 1b1, aged 26

Other women talked of feeling involved in the decision for treatment, but that the course of action was pre-determined.

> *"I was given written information and told my cancer was 1b1. Based on my situation and health status, I was advised it was best to have a radical hysterectomy. I felt involved in the decision, but I wasn't given an alternative."*

Stage 1b1, aged 49

However, there were some women who felt that they could have been more involved in the decision process, either at the time or retrospectively, and who felt that their lives were being taken into someone else's hands and were very much isolated by decisions being made about their treatment and care.

> *"I wasn't suitable for all the treatment options. There was a decision to be made between having a cone biopsy or a hysterectomy. I was already booked in for an MRI the following week.*
>
> *The results of my MRI and the LETTZ biopsy and my age were all put together and discussed at a multi-disciplinary meeting. I was not going to be part of this discussion, I was to be discussed. And await their outcome. I was kept informed, but I didn't feel involved."*

Stage 1b1, aged 28

Some women were made to feel as if they had no choice, and reported that the medical professionals were very blunt with them, making them feel as if they were not able to ask questions about their care, nor to be involved in making decisions.

> *"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'.*

Stage 1a1, aged 25

There were also women who feel that they were given false hope and were lead to believe that they would be suitable for less aggressive treatment options, only to subsequently find out that this would never have been the case for them.

> *"They were kind of gentle but quite clinical and they said this was the only option. What did upset me was the medic in Doncaster had given me some false hope as he said a trachelectomy might have been viable but in Sheffield they said that had already been ruled out."*

Stage 1b2, aged 25

4.3.5 Explanation on impacts of treatment

Almost two-thirds (63%) of women interviewed agreed that their consultant explained all that would be involved in their treatment for cervical cancer and how this would affect them at a later stage.

> *"It was all explained to me. The consultant went through everything and told me what would happen and what it would mean for the future."*

Stage 1b, aged 24

Many women agreed that their consultant told them exactly where their cancer was and what the possible course of action was regarding treatment, including drawing detailed diagrams to support their explanations.

> *"She talked me through what to expect from the operation and drew me a diagram of where they'd found the cancer, which was helpful. Seeing two tiny dots was reassuring as I'd imagined it had taken over my body."*
>
> Stage 1a1, aged 25

Women also confirmed that their consultant was good at explaining the implications of the treatment option they were likely to have and, where necessary, discussed the issues around fertility and future conception.

> *"I think they assumed it wasn't an issue for me about freezing my eggs as I had three children already. But three days before the chemo was due to happen I was given the choice to postpone and freeze some eggs but I decided not to delay the treatment. In the end I didn't have a hysterectomy."*
>
> Stage 2b. aged 33

> *"I don't know if it's the norm or not to have someone sit down with you and go over all your options prior to treatment or if it gets assumed it's fine unless you say something. I feel like I should've had an appointment with a specialist to go over everything and see if we wanted to freeze eggs etc. instead of me phoning up to discuss it and having two days to make the decision."*
>
> Stage 2b, aged 33

> *"That was the first time they'd brought up fertility. I spoke to my consultant in who explained what the op would entail and she talked about ovaries. My doctor explained that they could leave my ovaries which would stop early menopause and mean surrogacy was an option. So it wasn't the end of the world as I thought there were options for the future."*
>
> Stage 1b2, aged 25

Some women received a full explanation at their first meeting, whereas others only got a partial explanation, with their doctor explaining more fully at a subsequent appointment, once all the test results had come back and the treatment decided upon.

> *"They explained in brief. And gave me some information leaflets. They said they would explain fully when they knew what they were dealing with."*
>
> Stage 1b1, aged 30

This approach was appreciated by some, as they didn't feel they needed to worry about a potential course of treatment, and the associated side effects, if it was never going to happen to them.

> *"All the way through, things were discussed with me and explained and diagrams were drawn. I was made aware of all the side effects. However, I think it is not wise to give the full picture before surgery, as it might never happen."*
>
> Stage 1b1, aged 28

In some cases, the consultant gave a full explanation of the impact of treatment, but then either an alternative treatment was given, or with some women, more aggressive treatment was found to be needed and they felt disappointed and that they were not given an indication of this prior to the procedure.

> *"The surgeon drew pictures of the procedure and of a women's anatomy. But he didn't explain the lymphadenectomy to me or advise that there was a risk of lymphoedema. I thought a few lymph nodes would be removed and sent off to the lab and if they were cancerous I would have radiotherapy. I later found out that all my lymph nodes were removed and I have been left with lymphoedema."*
>
> Stage 1b1, aged 29

Sometimes women had the implications of treatment explained to them, but this was not done in a way that they enabled them to fully understand how the choice they were making might affect them in the future.

> *"The consultant said the MRI showed that I would have a radical trachelectomy or a radical hysterectomy. They gave me a choice as the first one gives you a chance of having more children. I knew the trachelectomy was a compromise in terms of the likely success so we had a lot of sleepless nights trying to choose.*
>
> *"I was pretty sure I wanted more kids. My partner said to get it all taken away as he thought it would be best. I was agonising over the decision so I rang the CNS and she said they hadn't explained it quite right, so I went to a different consultant who explained the chances of success were the same.*
>
> *"So I felt the first consultant was telling me to have a hysterectomy but the second one wasn't, so I ended up with a radical trachelectomy. I wanted to have more children and avoid hysterectomy.*
>
> *"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."*
>
> Stage 1b, aged 25

4.3.6 Information including support materials

The vast majority of women (83%) were given some kind of additional information at their diagnosis meeting, which was intended to support them. Some doctors went above and beyond and gave out personal contact details:

> *"At the very first meeting the doctor gave me her mobile number and told me about Jo's Cervical Cancer Trust and said it was a good website."*
>
> Stage 2b2, aged 25

Just a small number of women (9%) found that they had to gather their own information, through their own research.

> *"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."*
>
> Stage 1a1, aged 25

Of the women that were given information, it proved useful for them as it made them feel well-informed and more empowered to be involved in decisions about their treatment.

> *"They gave me a book with lots of bits in it. As soon as they gave it to me, I started looking at it. I remember the phrase in my head was 'knowledge is power'. I thought the more I knew, the easier it will 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."*
>
> Stage 2b, aged 46

4.3.6.1 Different types of information

The types of information provided differed in most cases. Some women were given a lot of information in the form of booklets and leaflets. This would generally cover cervical cancer, what it was, and the various treatments for it.

> *"They told me about Macmillan and Jo's Cervical Cancer Trust, and they gave me information about cervical cancer and what to expect at this hospital. This was an A4 piece of colour-photocopied paper that was folded. I still have this and still use it. I found the information useful, as it allowed me to go on the Jo's Cervical Cancer Trust website. The support and concise information I found was well organised."*
>
> Stage 1b1, aged 32

Some information also covered the various support organisations, such as the main cancer/ cervical cancer charities and details of local support groups.

> "*I was given information about Jo's Cervical Cancer Trust, Macmillan and Daisy. They also gave me details of a menopause support group, due to my age, and told me about lymphoedema."*
>
> *Stage 1b1, aged 49*

Depending on the type of treatment women were likely to receive, some also received additional information, such as information about specific side effects like lymphoedema and early menopause. Some women also received information on treatments such as radiotherapy, chemotherapy and brachytherapy.

> *"I was given Macmillan, leaflets: what would happen when you had radiotherapy, what the chemotherapy was about. It was all very overwhelming actually and it took me a long time to read them, but then I read them."*
>
> Stage 2b, aged 46

Some women did not look at the information they were given straightaway. Women reported feeling scared to see the word 'cancer' in black and white.

> *"I looked at the Macmillan booklet that evening and then threw it against the wall! It was seeing the word 'cancer' in black and white."*
>
> Stage 1b1, aged 30

Some gave the information to their partners to read as they felt too overwhelmed to take it in.

> *“When I got the materials it was too much information to read too far ahead so I’d just look at what was happening now. I couldn’t cope with thinking in detail about what would be happening in a few weeks or months’ time.”*
>
> Stage 2b, aged 33

> *“I didn’t look at them for a few days; I didn’t want to see it. My husband looked through them.”*
>
> Stage 1b1, aged 49

4.3.6.2 Jo’s Cervical Cancer Trust

Just under half of the women we spoke to (46%) were given information about Jo’s Cervical Cancer Trust. This was normally either verbally, or by being given a leaflet or card.

> *“I found the NHS and Macmillan info and found it quite clinical, whereas Jo’s [Cervical Cancer Trust] was more people’s stories which I liked reading. I found that gave me more of an idea of what was to come.”*
>
> Stage 1b2, aged 25

Some women did report that, despite finding the information helpful, they found the forum content sometimes a bit ‘off-putting’ as contributors would have far more serious problems than their own.

> *“Even with going on Jo’s [Cervical Cancer Trust website], I had to watch what I read as everyone has different experiences and problems. But it was good to see how other people felt.”*
>
> Stage 2b, aged 33

However, almost all women who were given information from Jo’s Cervical Cancer Trust found it to be useful; indeed, they found it more useful than the other cancer charities and the information provided by the NHS. This was especially true of the website forum, where they found support from other women either actively, through interacting in the various forums threads, or passively by gaining insight from what women had written about their experiences of cervical cancer.

> *“I was introduced to Jo’s Cervical Cancer Trust early on. I went on the website right away. I was on it quite a lot as it has real experiences and told more about the trachelectomy. I only used the Jo’s Trust website, as looking at the others caused confusion.”*
>
> Stage 1b, aged 26

Women said that the support from Jo’s Cervical Cancer Trust had been invaluable and had filled the gaps or complemented information from other sources.

> *“I think at the point of going for surgery I found that quite helpful. There was one girl in particular who was a similar age, had similar diagnosis and had similar treatment so we had private discussions and compared notes. It’s weird being friends with someone you’ve never met but it’s a very valuable friendship.”*
>
> Stage 1b1, aged 30

4.3.7 Role of the Clinical Nurse Specialist (CNS)

Almost three-quarters of women interviewed (73%) said that they had some, or a lot of contact with their Clinical Nurse Specialist (CNS), and that they valued this relationship.

> *"She was invaluable. Just the sort of person I needed to see. She was very grounded and quite blunt, which put things into perspective for me. She told me that I was not the worst case that she had seen that day."*
>
> Stage 1a1, aged 36

Just over a third of women (34%) said they had significant contact with their CNS and that this was a very important resource to be able to access.

> *"I had contact with three GCNS. They were really good and all accessible. It felt like they really put in the extra effort. If I called them and left a message, they always called me back, even if it was late in the day. It changed my view of Macmillan. They set up a special day for me through the Willow Trust, which involved a day out in London seeing a show and staying in a hotel. This is something that we had planned previously, but that I had to miss due to my diagnosis. Even though there were three CNSs, I built up a good relationship with them and could ask them anything."*
>
> Stage 1b1, aged 29

> *"They were brilliant. I had two, but built a relationship with one of them. I was told I could ask anything and as many times as I liked. They always called back before the end of the day.*
>
> *"There wasn't anything I couldn't raise with her. I wasn't nervous or embarrassed to ask. I felt a bit silly asking some questions, as I felt I should know the answer. For example, I asked how long I would need to wait until the hysterectomy and what would happen to the cancer in that time - would it grow? I could ask very practical questions. I felt comfortable with the CNS."*
>
> Stage 1b1, aged 49

For the women who said they only had some contact with their CNS, the reasons were that they only felt they needed to make contact at specific times during treatment, for example, before or after a procedure, or could source the information from elsewhere.

> *"Often my original nurse wouldn't be available, so I spoke to another in the team. I felt comfortable to contact them and they were helpful. I didn't feel I needed to ask much of them until after my operation."*
>
> Stage 1b1, aged 26

> *"I didn't make contact with the CNS until after surgery. I only contacted her three times. It wasn't that she wasn't approachable, it's because I worked at the hospital and could bypass the nurse."*
>
> Stage 1b1, aged 30

Only a handful of women said that they had had little or no contact. Of these women, a number of reasons for not engaging with the CNS were given:

Support was sought from forums:

> *"I did meet her, but I didn't have much interaction with her. Most of my support came from other women on forums. I was told that I could contact her, but she was not available as she covered three hospitals."*
>
> Stage 1b1, aged 32

Lack of consistency impacted on building relationships:

> *"There was no consistency. I saw a different doctor and nurse at each appointment. This meant I couldn't build a relationship with my Clinical Nurse Specialist. I no longer had the one I liked at my previous hospital. I mostly used Google to answer a lot of my questions, as I didn't feel comfortable asking lots of them."*
>
> Stage 1a, aged 28

Too emotional to seek support:

> *"I didn't ring my CNS at all. Mainly because whenever I felt I needed to I was too emotional to want to talk on the phone. I emailed her a couple of times and she got back to me. I'd have liked her to come back quicker but it took a couple of days each time. But I should have rung her for a quicker answer."*
>
> Stage 1a1, aged 25

Speed of treatment:

> *"I was given the number for a nurse. I could call any time and they'd get back to me if they weren't there. It was all quick after that. In less than a week I was back in hospital."*
>
> Stage 1b1, aged 40

4.3.8 Who was present at diagnosis?

For the majority of women, the normal practice reported was to have a consultant (either a Gynaecologist or Oncologist), and a CNS present at their diagnosis meeting. This was the case for the majority of women (77%) that we spoke to.

> *"The consultant and Clinical Nurse Specialist were at the first meeting. She was the first Macmillan nurse I had and she was really good. I was able to speak to her afterwards to clarify things, which I found was really helpful."*
>
> Stage 1b1, aged 40

The nurse was often a Macmillan trained nurse.

> *"I remember there was an Oncologist and a Macmillan nurse. I did not know why there was a Macmillan nurse in the room. I got a bad feeling as soon as I walked into the room. I had thought I was just coming in for some treatment. The people in the room were smiling but it was like a smile of pity."*
>
> Stage 1b1, aged 28

> *"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. I did not really warm to her, which was unfair because it wasn't her fault."*
>
> Stage 2b, aged 46

In a small number of cases, just the consultant was present, with a nurse being made available after the meeting, or at a subsequent appointment to answer questions and provide support.

> *"Just the consultant was present. The GCNS was not at the first meeting. She was introduced after the LLETZ."*
>
> Stage 1b1, aged 26

In one case, one of the women was told about her cervical cancer by a nurse, without the presence of a doctor at all.

> *"Due to the last-minute nature of the appointment, there was no doctor present. The GCNS gave me the news. I was OK with that; she was able to answer our questions."*
>
> Stage 1b1, aged 28

4.4 Treatment

4.4.1 Offer of an alternative place for treatment/seeking a second opinion

The overwhelming majority of women reported feeling safe in the hands of the medical professionals looking after their care and treatment, and felt no need to question their decisions.

> *"It was not dictated, I felt confident about being treated there. I considered going private, but decided not to, even though my husband thought this might be better."*
>
> Stage 1a1, aged 36

Only a small number of women (11%) said that they were given the option of going to an alternative hospital for treatment not offered at their local hospital.

> *"I was given the option of going to Brighton and London for different treatments. I saw the top gynaecologist in the country in London. This probably had a bearing on me deciding to go to London. I didn't seek a second opinion; I didn't feel I needed to. I trusted what my consultant was saying, but knew I could get a second opinion if I wanted to."*
>
> Stage 1b1, aged 29

However, this was not necessarily seen as a negative. Especially as their local hospital may be a leading provider in cervical cancer treatment.

> *"No, my hospital is a specialist in this area and a centre of excellence."*
>
> Stage 1a1, aged 36

Many women said that they did not know or had not realised that they were able to ask for a second opinion. And of those who did, they did not see this as being necessary, as they had trust in the medical professionals looking after their care and treatment.

> *"I didn't know I could ask for a second opinion at the time. After looking at the Internet, we found this out, but I didn't feel I needed it. I had a good doctor and I wanted to be treated by her. The quicker the better - to get it out of me. I was also later told about second opinions by our critical illness insurance."*
>
> Stage 1b1, aged 49

Also, women who did know they could seek a second opinion worried that this might slow down a process that they already felt anxious about.

> *“I knew I could seek a second opinion, but assumed that I was in the best place. I also thought that if I had sought a second opinion, it might prolong the process.”*
>
> Stage 1b1, aged 32

4.4.2 Personalised Care Plan (PCP)

Out of all the women interviewed, only two women remember being offered a PCP. However, it is important to note that the women interviewed did have a plan in place for their treatment, just that they didn’t remember it being referred to as a PCP.

Written care plan

Similarly, the majority of women were not offered a written care plan. Only 6% of women interviewed were given this.

4.4.3 Holistic Needs Assessment (HNA)

When answering this question, some women talked about the mental health issues they experienced during treatment – most commonly depression or anxiety. However, a small number of women reported that despite highlighting their issues to medical professionals they were not offered any additional support or therapy.

> *“I don’t think so, but can’t quite remember. I did mention my anxiety, but I’m not sure this was ever addressed.”*
>
> Stage 1a1, aged 36

Out of all the women interviewed, just 14% said that they were offered an HNA. Of the women that did receive this, some had to proactively seek this out.

> *“Yes… as part of the pre-op assessment. I was proactive in seeking this out, as I thought I needed this. I felt it was quite useful, but I did think the nurses would read it, so they would know my situation when I was on the ward. This was not the case. I had been on the waiting list for CBT, due to a previous car accident, but this was not taken into account or referenced at all. I was obviously made more anxious due to the cancer. This was not followed up, despite me asking about it.”*
>
> Stage 1b1, aged 32

And even then the results were not acted on or seen as very important.

> *“Yes, they collected this from me, but I did go through this at my pre-op assessment appointment. I didn’t find it that useful, though. I am a nurse and have to do these. They are really more useful for patients who have additional needs.”*
>
> Stage 1b1, aged 40

4.4.4 Life during treatment

Life during treatment for cervical cancer was clearly challenging for every woman we spoke to during this project. There were some areas which were more difficult than others, with every woman who underwent radiotherapy - and brachytherapy in particular - reporting it as a very difficult process to go through.

The earlier that cervical cancer was detected had a huge impact on the women we spoke to. An earlier diagnosis led to less invasive treatment options. Later or advanced cervical cancer required more radical treatment options, which resulted in much longer recovery periods.

4.4.4.1 Surgery including hysterectomy

A surgical treatment option was offered to the majority of women we interviewed.

Many women reported a number of issues and complications with their surgery. These included unexpected side effects, such as excessive pain or bleeding, extended recovery periods and being placed in wards which women felt were inappropriate for effective care and treatment.

> *"For me, nothing went smoothly. After the loop incisions I was told I would bleed for three days - I bled for five weeks. I was given antibiotics when I didn't have an infection. I felt like I was poorly handled. I tried to carry on as usual, but was in a lot of pain."*
>
> *"I had my surgery and stayed in hospital for two nights. My ward was next to the maternity ward and there was screaming all night. I thought that this was rather insensitive, given the circumstances. I was put next to women who had had troubled births or miscarriages or lost their babies. The nursing staff weren't very attentive, either. I was also next to patients undergoing chemotherapy who needed a lot of care. I felt ignored and a pest for using the buzzer. Visiting times were very strict and my husband was urged to go rather than stay and support me, as the nurses should be doing. I may have been treated differently as they knew I was a nurse."*
>
> Stage 1b1, aged 29

> *"After surgery I had a urinary tract infection, possibly from the catheter. I also had complications after surgery and was rushed back into hospital after being discharged. This time I was put next to two men that were dying, then moved next to a dementia patient. This was not a good experience for me and I was made to feel very isolated."*
>
> Stage 1b1, aged 29

Many women we interviewed talked about the importance of having a partner, friend or family member with them when they first attended hospital, in some cases, those that didn't have a partner, or were told their partner had to leave them, experienced increased anxiety.

> *"I went into hospital feeling very apprehensive. My husband went with me, but he had to leave me as I was put on an all-female ward. I was first on the list, so I went in quite quickly. I was anxious when I went into the anaesthetic room."*
>
> Stage 1a1, aged 36

> *"I was petrified before the surgery. I relied very much on my husband for what I should do before surgery. I was told that my husband couldn't go to the pre-op ward, as it was an all-female ward. I was in a state because of this. I was told that I could go to the waiting room instead, in order to be with him. So I sat in the waiting room for three hours. When they came to get me, I broke down. My husband had to walk with me right down to the door. I was then alone. I was beside myself."*
>
> Stage 1b1, aged 49

> *"I had to be at hospital at 7am. I went to the day case unit and was first on the list. I felt relieved about this, as I was really nervous. My boyfriend came with me. He was able to stay with me until right up until theatre."*
>
> Stage 1b1, aged 26

> *"My husband dropped me off on my own in the morning. He had to go and drop off our daughter at childcare. I had to wait in the day room for a bed. I kept being asked the same questions by different people. I asked for 'magic cream', as I have problems with my veins. I had to have an epidural type of injection and I didn't want this. I got into my gown and walked into the holding room before theatre. I was OK up to this point. Then the anaesthetist came in and it was then that I burst into tears, as the realisation of the situation came about."*
>
> Stage 1b1, aged 32

Those women who had a hysterectomy as part of their treatment for cervical cancer, reported a very challenging procedure and difficult recovery period.

> *"I was in recovery for a while due to having a rapid heart rate. I was very anxious. I was then put on to the ward. It was horrible. The ward was really hot and really overwhelming, especially for the first day or two. I have never been in hospital before. It was September, but it was too hot. There were no opening windows and no fans, due to risk of infection. I was drugged up to my eyeballs and it felt like I had been hit by a bus!"*
>
> Stage 1b1, aged 32
>
> *"My hysterectomy was nearly a six-hour operation. My anaesthetist was fantastic. My husband and my daughter were there when I came round. The consultant came round in the evening and said everything had gone well and to plan. That made things better."*
>
> Stage 1b1, aged 58
>
> *"I couldn't believe how much we obviously use our stomach muscles, I found this out after the operation. Even something as simple as coughing was incredibly painful. It was impossible to even get out of bed due to the pain and the number of wires and tubes attached."*
>
> Stage 1b1, aged 28

Following a hysterectomy, many women talked about the shock of coming round from the anaesthetic and realising the severity of the operation and the reality of how this had made them feel.

> *"The next thing I knew I woke up after the surgery. I was feeling really cold. The nurse gave me an electric blanket to warm me up. I was wheeled back to the ward past my husband and sons. I remember seeing their faces. I can't remember much else of that night. I was on morphine, but it was patient-controlled. The next day I was brought toast, but I couldn't eat it – I didn't feel hungry. My family visited me. I was being very practical and was trying to keep everyone in their routines. I didn't want to interrupt my son's university study, so asked that he only came back at the weekend."*
>
> Stage 1b1, aged 49
>
> *"I was in recovery for more time than I expected. I wanted the curtains closed around my bed, as I felt as if I was being stared at. But nurses were not keen. I didn't want to feel exposed to the whole ward. I knew that I would get emotional" about fertility and I didn't want everyone to see. I had panic attacks about this. The doctor came to see me and tried to reassure me that the nurses see this every day and this is the reason that they weren't that sensitive. But at least he listened. Some nurses were more sympathetic than others."*
>
> Stage 1b1, aged 32
>
> *"I was quite fuzzy after the operation. I asked for my family. No one gave me any information about the operation. I was told about pain control – this was morphine. My*

> *consultant saw me that evening and told me the operation was a success and everything looked normal.*
>
> *"The surgery had taken five hours. They were never sure how long it was going to be. My boyfriend was told to ring after midday. He kept ringing and ringing on the hour for news. The hospital then said they would ring him with any news. In the end they called my parents."*
>
> Stage 1b1, aged 26

There were two women who had surgery and reported that they felt pushed to become more active before they felt fully ready.

> *"The nurses forced me to get up out of bed and into the chair, as they said I needed to be up. I didn't like that. I was very tired and got back into bed for the rest of the day. I think I was on tramadol, which made me very moody and agitated."*
>
> Stage 1b1, aged 32

A number of women felt they had to wait for quite a while to get the attention of a nurse when they felt they needed help.

> *"The buzzer would always be left unanswered for a while, so I ended up getting up and going to get the nurses for the older patients. And I was supposed to be recovering!"*
>
> Stage 1b1, aged 32

A number of women talked about the importance of seeing their surgeon again after their procedure. For those that didn't get to speak to their surgeon again, the hospital experience was more negative.

> *"I didn't see my surgeon again after the operation, but I did see one that I had met on a previous occasion. And I did feel reassured. While on the ward I felt emotionally supported by the nurses, they checked on me regularly and especially after my partner left. The day after the operation, when I knew I was going home, I felt like I wasn't as much of a priority and all the focus was on discharging me."*
>
> Stage 1a, aged 28

4.4.4.2 Chemotherapy

Chemotherapy and radiotherapy are often concurrent treatment options, with brachytherapy often being included at the end of this treatment option. This was the case for most women interviewed as part of this project.

A large proportion of women interviewed (63%) had very successful surgical intervention and as such needed no further treatment.

> *"I received no other treatment. No chemotherapy or radiotherapy was needed."*
>
> Stage 1b1, aged 29

Chemotherapy was a challenging process to endure for almost all the women we interviewed who had received this treatment.

> *"I had a PIC line put in, as I had bad veins from surgery. It was painful, but useful. I had 25 lots of radiotherapy and five of chemotherapy. When I first had it, I thought I was walking into a normal ward, but it is quite shocking when you get there and are hooked up to a machine."*

Stage 1b, aged 36

> *"The chemo started mid November 2014 and all the dates were given to me well in advance. I had to see the department that runs chemotherapy, I was shown around. The same with the radiotherapy. I was given written information. I had appointments with the CNS – though I had different ones as my treatment is spread over two hospitals – Gloucester (appointments) and Cheltenham (treatment)."*

Stage 1b1, aged 58

> *"Because I was so young I got a lot of pity stares in the chemo room. I got on with some of the people there."*

Stage 1b, aged 36

This often manifested itself in increased anxiety, and in a small number of cases, panic.

> *"I started to panic and tried to get money together to plan my funeral."*

Stage 2b, aged 39

> *"I tried to keep upbeat and jokey. My friends said it was like I didn't have cancer. The chemo didn't really affect me physically, although I had some depression and anxiety."*

Stage 2b, aged 39

However, a number of women reported that the chemotherapy went very quickly, and seemed to be over in a much shorter time than first expected.

> *"In my head I thought I would be stuck having chemotherapy for ever more and it would affect my work, for me that was the hardest part. The chemotherapy ended up being only five weeks. I couldn't believe how quick it was."*

Stage 1b1, aged 28

A number of women remarked about how pleasant the medical professionals were they came into contact with during their chemotherapy.

> *"During chemo, everyone was extremely nice. They were wonderful. They did everything they could to make you feel comfortable."*

Stage 1b1, aged 58

Many women interviewed reported adverse reactions and side effects due to their chemotherapy.

> *"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."*

Stage 1b, aged 36

> *"I got really tired and had problems with my periods. I had excruciating pain from them. They had told me that they would stop, but I came on during radiotherapy."*

Stage 2b, aged 39

> *"I felt very scared, as every day brought another side effect. And I was told it would get worse as I had more treatment. I lost a lot of weight. I couldn't keep anything down. By my 18th session of radiotherapy, I was very low. I wanted to give up. It was brutal. I couldn't sleep, I was bleeding. I was in a very dark place. I wanted to give up. The radiotherapist asked what I needed and I was given cream and special foam and that helped. It was very lonely having cancer."*

Stage 1b, aged 36

"I got one infection when I was ill, but it hit me hard."

Stage 1b, aged 36

A number of women interviewed talked about the importance of having someone with them during chemotherapy, though others preferred to attend their sessions alone.

"I had friends come with me to the first couple of sessions, but afterwards I did it by myself. I just lay there and watched TV. For the brachytherapy I had someone come with me all times."

`

Stage 2b, aged 39

4.4.4.3 Radiotherapy including brachytherapy

Radiotherapy including brachytherapy was one of the most challenging treatment types discussed by the women who were interviewed.

"I asked my partner to look at what they had done to me and describe what it looked like. Before I left the ward to go and have radiotherapy, I had to eat and had to do this lying flat on my back. My partner had to feed me."

Stage 1b, aged 54

"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. I had to see my radiotherapists to get medication to help with this."

Stage 1b1, aged 33

"I went down for radiotherapy and was hooked up to a machine that looked like it might be used for charging a battery. The staff put clips on to the rods and then they disappeared out of the room, only speaking to you by microphone. They left me for 15 minutes with music playing. The oncologist then came in to take it all off. He walked in with a screwdriver in his hand! He was actually unscrewing the rods that were inside me, but I couldn't see any of this. None of this hurt, it was just very uncomfortable. They gave me gas and air."

Stage 1b, aged 54

"Then I had brachytherapy. My body was going through some major challenges. Because I had suffered so much with the radiotherapy, the brachytherapy was the last thing and then it was finished. I didn't feel as bad. I knew I had to do this last bit to have the best chance of surviving."

Stage 1b, aged 36

"I returned the next morning and went down the theatre. I was prepped for the procedure, which again was all new to me. Next thing, I was coming round. I had a catheter in me and all these rods sticking out. I couldn't close my legs. I was lying flat on the bed; I couldn't even have a pillow. Then I had to go back in a cat scanner, to make sure all the rods were in the right place. This revealed that they had gone through the neck of my womb. The

> *procedure had to be stopped and everything had to be taken out and they couldn't proceed. I had to return to the ward and be put on a drip."*
>
> Stage 1b, aged 54

Some women again reported issues around the wards they were placed on during their treatment. In particular, a small number of women highlighted that being placed on end-of-life wards was extremely challenging and negatively affected the way they were feeling.

> *"The brachytherapy happened on my daughter's birthday. I had to go to the cancer ward. I was in a ward with people who were at the end of their lives. They wanted me in there the night before, so that they could do the procedure first thing. I kind of understood what it involved. They were going to put me to sleep and then put these rods inside me, which would then be attached to electrodes that would deliver the radiation to my womb. I got to the ward and did not want to stay. I let them do the blood test and told them I was going home and would come back in the morning. I wasn't staying the night amongst all of those ill people, when I didn't feel ill myself. I just wanted to get out of there and run away and not be met with what might be my demise."*
>
> Stage 1b, aged 54

The location of the radiotherapy had a huge impact on a number of the women we interviewed, with some reporting a negative experience due to treatment rooms being located in the basement of the hospital.

> *"The hardest bit for me was having the radiotherapy. It was in a basement and I felt like it was a torture room. It was cold and eerie. The thing is with cervical cancer it's such a private part of your body. I found that hard. Pulling your knickers down in front of strangers etc. I know it's to save your life but I felt it could have been a nicer atmosphere."*
>
> Stage 1b2, aged 51

> *"I also had brachytherapy. I had four sessions over two days and that was scary. I walked into this room and they said sit on the bed and it was terrifying. They gave me an epidural and then put me to sleep. I didn't want to walk in. I would have liked to have gone in there asleep."*
>
> Stage 1b2, aged 51

A small number of women reported a more straightforward experience during treatment by radiotherapy and/or brachytherapy.

> *"It was all unknown to me and I was apprehensive. But it was all fine, at least for the first five weeks. I didn't have any problems when I was having the treatment, it was afterwards. The brachytherapy was also fine. It had been explained to me, and I knew what needed to happen."*
>
> Stage 4a, aged 71

Others reported more common side-effects.

> *"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 – diarrhoea, mastitis, urine infections. It started easing off after six months, but for that time I felt very ill and really rotten.*

> *"They gave me medication to help me through this. I was able to control it that way. I wasn't expecting it. I thought I was one of the lucky ones, as I felt fine through treatment, then it all hit me."*
>
> *Stage 4a, aged 71*

4.4.4.4 General views on life during treatment

Life during treatment was very clearly challenging for the women interviewed as part of this study. The reasons for this included significant and wide-ranging side effects (both of surgery and follow-up treatment); time needed to undertake treatment and recover; and the resulting change to the women's lives.

> *"I had been in and out of work taking time off when I needed to go to appointments. I took some holiday around the time of my diagnosis. I took a few days leave here and there, and work were quite supportive at that time. When I was waiting three weeks for my surgery, I had to go back to work full time. This was really difficult for me. I work in an office and I was told not to catch a cold before surgery. I was allowed to work from home, as I didn't have much holiday left and I didn't want to use my sick leave up, as would need it after surgery."*
>
> Stage 1b1, aged 28

> *"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."*
>
> Stage 1b1, aged 49

> *"I would say it took me at least four weeks to be able to get out the door and go to a shop for a small outing. Much longer before I felt closer to normal and less reliant on others."*
>
> Stage 1b1, aged 28

> *"It was a very surreal time, I spent a lot of time writing lists of things to be done. One of the first things I did was go through my filing system to make sure everything was in order in case the worse thing happened!"*
>
> Stage 1b1, aged 43

> *"I just tried to make things entertaining during treatment as it helped me to cope. I also kept myself busy, it was like being at work with a deadline. I made it into a project and kept myself really busy to make sure I was going to get better. I treated it like work and this helped me to cope."*
>
> Stage 1b1, aged 43

Some women reported becoming very practical and almost 'project managing' their cancer.

> *"I do remember phoning lawyers as I had to think about a will. I also had to manage my friends, I found it really hard working out how different people were going to respond."*
>
> Stage 1b1, aged 43

4.4.4.5 What helped during treatment

Many women found the medical staff they came into contact with during their treatment attentive and supportive. Women particularly valued it when their own surgeon or consultant visited them after their procedure. This reassured them and made them feel as though there was consistency in their care.

> *"Both of my surgeons came to see me the next day, which I valued. They were very casual about it. I liked that there was a round every morning, it felt like they cared and I liked that I*

> *could ask my doctor anything. The doctor came specifically to see me after his round to answer my questions. Some nurses were really friendly and caring. And all the support staff were really good."*
>
> Stage 1b1, aged 28

Some women also described staff who went out of their way to provide support to them during treatment. Women interviewed talked of how they felt emotional and vulnerable during treatment, especially when they didn't have friends or family around them. Coming into contact with a supportive medical professional was a huge benefit to these women.

> *"I liked that my oncologist rang my husband after the surgery to tell him personally how it went."*
>
> Stage 1b1, aged 49

The actions of some individual staff members made a real difference to some women's recovery and support in a particular area was seen as hugely impactful.

> *"There was a stand-in nurse from another hospital. She told me a really good way of getting out of bed. I remember thinking: "you don't know how much of an impact you've had on my day." Getting me out of bed pain free! That was really good."*
>
> Stage 1b1, aged 30

Support from external sources was also seen as being of great value to women. This was often the support offered by family and friends.

> *"I really valued the support that I had from my friends, and this has been the case all the way through. I valued them so much that I was afraid to leave them behind in London when I went to Leeds. My close friend would always drop everything to come to an appointment with me. This was one of the most amazing parts for me, she showed me so much support that it makes me very emotional even thinking about it."*
>
> Stage 1b1, aged 43

But also support that was provided by external organisations, such as cancer charities.

> *"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.*
>
> *"Having helplines available really helped me. It didn't really matter which one it was – whoever answered the phone quickly. It helped to speak to someone who was trained, and understood what I was going through. To be able to talk to someone who wasn't emotionally connected to what I was going through was really helpful."*
>
> Stage 1b1, aged 43

4.4.4.6 What was challenging during treatment?

Not all women were able to see their surgeon after their procedure and this was difficult for them, as they felt they had been abandoned, and that there was a lack of consistency. After having been through such a significant experience, women felt far more comfortable speaking to someone who they knew had a good knowledge of their history and who had been with them throughout the process.

> *"The negatives were that I only saw a registrar after my procedure, rather than my primary doctor. I was also quite emotional and had psychological issues due to being placed on a ward with other patients who were screaming and shouting."*

Stage 1b1, aged 29

> *"I was not made aware that my consultant was going on leave and I found that difficult. I saw another consultant, who worried me about incontinence. This was a teaching consultant, who was going in to lots of detail and worse-case scenarios, with two student doctors. The nurse who was present told me not to worry, but no one came back to discuss this or reassure me."*

Stage 1b1, aged 40

Not being able to get support from their partners was seen by many women as being a distinct negative.

> *"I felt apprehensive before my surgery and my husband wasn't allowed to stay with me."*

Stage 1a1, aged 36

Three of the women interviewed were placed on all-female wards before surgery, meaning their male partners would not be able to be with them to offer the support they needed. This had a very negative impact on some women, making them more nervous before a procedure. Some women were advised that they could go to a communal area, such as a waiting room, to be with their partners. However, this meant that they would have to sit for hours, in a gown, in a public area.

Staff being unavailable to provide adequate support while women were under their care was something that many women found very difficult. Four women in particular reported that staff often appeared rushed, and as such did not have enough time to properly attend to them. In addition, there were a small number of instances where women reported they had been made to feel as if they were a burden, just for calling out for help. One woman interviewed was being called on by other, mostly elderly, patients to provide help for them, as staff were unavailable.

> *"Staff were generally OK - some were quiet, harassed and rushed. This made me feel annoyed and was a bit scary. It puts you on edge, as I couldn't move very fast.*
>
> *"I was put in a room for a shower and then left there. The nurse said she would wait outside, but left me there for a few minutes, which felt like an eternity. It made me feel awkward and uncared for."*

Stage 1b1, aged 28

> *"My catheter exploded one day and the support staff made me feel bad about it. The staff focused on stripping the bed and this was clearly a hassle for them. I had to clean the pee off the floor with paper towels myself."*

Stage 1b1, aged 28

Almost a third of women (29%) felt there was a significant lack of support after their treatment had finished. Women reported an intense period from diagnosis through to treatment where there is a significant amount of focus given, but these women found this dropped off after they moved into the follow-up stage. Even after being given the 'all clear', women still reported having unmet emotional and physical needs.

> *"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….' "*

Stage 2b2, aged 25

> *"There was not enough information given about aftercare, though, and I didn't know what to expect about 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."*
>
> Stage 1a, aged 28

4.4.4.7 Additional support/services during treatment

Well under half of the women we spoke to (41%) were offered further support during their treatment for cervical cancer.

The types of further care provided included being referred to Maggie's centre, either at their treatment hospital or an alternative one.

Support was also offered, where appropriate, to lymphoedema services. Counselling was probably the most common form of additional support offered, although this was still for a small minority of women.

Many of these women sought their own support, or got this from their family or friends. It was beneficial, however, when their CNS went beyond their duties and provided more personalised care for the women.

> *"During my treatment, the Macmillan nurse always found time to come and see me and spend a great deal of time with me. I found the emotional support she offered me was amazing. If there was a day when I didn't want to talk to anyone, she reassured me that this was a valid response and I didn't need to feel bad if I wanted time to myself. Because she told me this was fine, I felt like a weight was lifted, as it removed the guilt I had been feeling."*
>
> Stage 1b1, aged 28

4.4.5 Complementary therapy

Just under a fifth of women (19%) were offered complementary therapy as part of their treatment for cervical cancer. Of the women that were offered this, all of them reported not taking it up as it was offered at their treatment hospital, which was too far to travel for them. All of these said that they would have taken up this type of therapy had it been offered to them locally.

> *"I did receive a booklet about the complementary therapies that were offered at the hospital, but as it was a three-hour drive to get to the hospital, it was just not practical for me to get there. I would have found it useful if someone had discussed this with me and looked at a possible alternative."*
>
> Stage 1a, aged 28

One woman was offered art therapy, which she took up, but did not continue.

> *"I was offered art therapy and went to the first session. But it really wasn't for me. One of the other patients was too overbearing. It was all too 'touchy feely' and everyone was a bit too in touch with their emotions!"*
>
> Stage 1b1, aged 29

4.4.6 Side effects

The vast majority of women experienced side effects as a result of their cervical cancer and its treatment. In fact, only one woman we spoke to said that she didn't experience any side effects as a result of her cervical cancer or treatment.

One of the most common side effects, and one which several women highlighted, was pain due to trapped wind after surgery. Much of the time this was an unexpected side effect, despite advice being given on various potential side effects which could arise after their procedure.

> *"The biggest thing for me was on day 3, I passed extremely painful trapped wind. As I had keyhole surgery, I was pumped full of gas. My body was in trauma. I really struggled with that. I had bad constipation."*
>
> Stage 1b1, aged 28

Another common side-effect was the presence of urinary tract infections after a catheter had been inserted for surgery, and then removed. Women did report that they were told about this in advance of treatment, but nonetheless still reported finding it distressing. Other urinary issues included urinary retention and bladder spasms.

> *"I had a problem with the removal of my catheter and had to go back in to hospital for two days. I had problems weeing. It has only recently gone back to normal. I went back to A&E a few days after and they did a bladder scan. I had two urine infections after surgery. I was prescribed antibiotics and then got pelvic fluid leakage. It was like wetting yourself. I had to wear a nappy and have a catheter. It was miserable!"*
>
> Stage 1b1, aged 28

Exhaustion and nausea were reported as being the main side effects for those women undergoing chemotherapy and radiotherapy treatment. Losing their sense of taste, or food tasting strange, together with bowel problems were also reported with this type of treatment.

> *"Side effects from chemotherapy were a horrible feeling of wanting to be sick all the time and everything tasted disgusting, it was very metallic.*
>
> *"The radiotherapy side effects come very gradually, it has been seven weeks since my last brachytherapy and I'm still getting the effects. The side effect that I got was dreadful diarrhoea. It was not so bad that I could not leave the house, but occasionally it was pretty bad."*
>
> Stage 2b, aged 46

Lymphoedema was also reported in a number of cases, especially around the groin and upper legs. Severe scarring after surgery and early menopause after hysterectomy were also highlighted.

As well as the physical side effects, several women reported significant emotional issues and experienced anxiety.

> *"I became very familiar with my own feelings of anxiety – particularly feeling like I had a hand round my throat; or feeling like someone was pressing on my chest."*
>
> Stage 2b2, aged 25

Most women did have potential side effects clearly explained to them prior to their treatment. However, side effects manifested themselves differently and some women experienced additional issues which had not been explained. In addition, many women also said that not all side effects were fully explained to them.

> *"I was told about urinary and bowel problems prior to surgery, but no one discussed the numbness I would experience. I really wish I'd known about the gas!"*
>
> Stage 1b1, aged 40

4.5 Impact and follow up

4.5.1 *Follow up appointments*

Follow-up appointments were clearly explained to just over three-quarters (77%) of women we spoke to. These women said they had been told about when their follow up meetings would take place and what would be involved when they attended.

> *"I was told I would see my consultant every two weeks after the surgery and this always happened without fail. My consultant also gave me a phone number to call so that I could see him in between these times if needed. He was excellent and was always available."*
>
> Stage 1b1, aged 28

However, some women were only given partial information, so, for example, they knew when the appointments were likely to be scheduled, but when they turned up they were unsure of what was going to happen.

> *"I was made aware of the frequency, but I wasn't entirely sure what was involved. The surgeon said he would examine me. My cervix and lymph nodes were taken out and tested and I was given the results in a three-week follow up meeting. Next meeting was in three months."*
>
> Stage 1b1, aged 28

One woman interviewed had her first follow-up appointment scheduled on a Saturday; she was seen by a locum doctor, rather than her own consultant, who did not know why she was there and what examination was to be carried out. This was an exceptional circumstance, although distressing for the woman involved.

> *"My first appointment was on a Saturday and I had locum doctor, who seemingly didn't know what the appointment was about. He asked me what I was there for and wanted to check my cervix, which would have been a bit difficult, as I no longer had one! I left that appointment feeling confused and worried and not knowing what was going on. My consultant later told me not to accept an appointment with a registrar again and only to see a consultant."*
>
> Stage 1b1, aged 29

For some women, the idea of the follow up appointment caused some anxiety, especially the first appointment or if they were receiving information about test results.

> *"I had a lot of questions but as I walked into hospital I couldn't speak as my anxiety was so high. I had asked the nurse what to expect and she said they might offer a vaginal exam and knew I didn't need one but I knew I didn't want one. At the meeting, which was really positive, the doctor told me the symptoms of recurrence and everything seems fine and I refused a vaginal exam. But now I'm panicking that I made the wrong decision."*
>
> Stage 1b1, aged 40

4.5.2 *Continuity of care during follow up*

Under half of women (43%) said that their level of care throughout treatment and follow-up remained consistent. They also agreed that this consistent care was generally of a good standard.

Those who said that their care had not been consistent indicated that the care seemingly dropped off during the follow-up stage and that they felt support and information was lacking.

However, almost a third of women interviewed (31%) were unsure if there had been any change in the level of their care throughout treatment and follow-up.

> *"It does feel like now I am past it, the after care is not as in-depth and intense. I felt really looked after up until the operation and then left to it and the care wanes. I can ring the CNS, but it feels like I would be bothering them and taking up time that could be used for others who still have cancer. They give the air of being contactable at all times, but in actuality this is not the case as everyone is too busy!"*
>
> Stage 1b1, aged 32

There were also some negative reports of lack of consistency when it came to medical staff. All women reported preferring to see the same medical staff throughout their treatment and follow-up, so when they felt that they had to explain themselves to a number of different professionals and retell their history they found this particularly challenging.

> *"I didn't feel as supported in the follow-up stage. I had to see a consultant and there were only nurse lead appointments available. Appointments were cancelled at short notice and this caused a problem with working, as I had to change shifts. This was very upsetting."*
>
> Stage 1b1, aged 30

> *"I was disappointed about going to a general clinic on a Thursday afternoon and saw a different doctor. I didn't know who I was going to see and it would be better to have consistency. I had to explain things over and again. I had to ask to see my own consultant."*
>
> Stage 2b, aged 45

> *"I expected that I would see the GCNS as well as the consultant at follow-ups, but she wasn't present."*
>
> Stage 1b1, aged 26

One woman in particular said that their care did not start off well, but once she was assigned a consultant, her care improved and remained consistent.

> *"The care didn't start well and there were a few blips along the way, but I am now seeing the same lady consultant who is much better."*
>
> Stage 1b1, aged 29

Only one woman interviewed said that she had experienced a consistently poor standard of care; with conflicting information and of a standard that is not satisfactory for her.

> *"For the last three years, through diagnosis to treatment, to the present day, throughout my process I have had very conflicting information and mixed 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."*
>
> Stage 1b, aged 54

4.5.3 Additional support not offered by the NHS

Just over a third (34%) of women felt the need to seek additional support from a service that was not provided by the NHS, such as complementary therapy. Of those who didn't seek any additional support, some women didn't think this was necessary; other women had explored the potential (but had not accessed it yet). This was especially true of services such as counselling and psychotherapy.

Of the women that did seek additional non-NHS services, the most popular were: counselling, massage, acupuncture and chiropractic services.

In addition to accessing face-to -ace support, most women interviewed talked of the importance of accessing the support provided by cancer charities. In particular, women talked of the added value of accessing online support, particularly through forums where they could share their story and access peer-support.

4.5.4 Children and the impact on relationships

Over half (57%) of women we spoke to had one or more children. Of those with children, well over half (55%) said their cervical cancer had a significant impact on their children and on their relationship with them. Many of the women who had younger children did not explain that they had cancer. Some told their younger children that they had to go into hospital, but others explained their absence in other ways. Many of the women with children reported wanting to protect their children from the truth about their cancer and preferred that they not be brought into hospital at visiting time.

> *"I told my daughter 'mummy has a sore tummy', so I couldn't pick her as much. I don't know what she was told about where mummy was. I didn't want her to come into hospital, due to emotional issues and being delicate. Plus, there was the germ risk."*
>
> Stage 1b1, aged 32

Although these younger children did not necessarily know exactly what was going on, they realised that something was different, either because they sensed it, their normal routine had been affected, or simply because their mothers could no longer pick them up or had the energy to play with them or take part in normal activities.

> *"My little girl would crawl into bed with me and bring her doctors' kit with her."*
>
> Stage 1b1, aged 40
>
> *"He has become frustrated at how tired I get and that I can't play with him for as long as he'd sometimes like."*
>
> Stage 1b1, aged 43

Children reacted in a number of ways, some regressing with sleep patterns, bed-wetting or other behavioural issues. Some children just became far more attached to their mothers and wanted to be around them much more.

> *"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 it with her dolls - mummy had a poorly tummy. She became quite clingy.*
>
> *'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?"*
>
> Stage 1a1, aged 36

For those with older children, the reactions were mixed. These children were far more likely to have been told what was going on and/or would have knowledge and an understanding of what their mother was going through.

> *"My youngest son was 15 at the time I was diagnosed. I had decided not to tell him about anything and keep him hidden from all of this. But he wanted to be a doctor and had a lot of medical knowledge and an interest in all things medical. He had actually been to a talk on brachytherapy and had read my medical paperwork, so he knew what was going on. This quite shocked me."*
>
> Stage 1b. aged 54

Some children simply wanted to know the likely prognosis and whether their mother was going to die. Some wanted more in-depth information and details of treatment. This was especially true for those women with older children.

> *"When I told my daughter I had cancer she burst into tears and asked two questions: Are you going to die? And, can I catch it?"*
>
> Stage 2b, aged 46

> *"He knew something was going on, but I never said it was cancer. I told him a little bit about what might happen. My son is very factual, inquisitive and knowledgeable."*
>
> Stage 1b1, aged 40

Naturally children were scared, and this was sometimes expressed by distancing themselves from their mothers not knowing how to handle or process the situation.

For one woman, her diagnosis had an especially strong impact on her relationship with her son:

> *"My eldest son took the news very badly and stopped talking to me and hasn't spoken to me in three years. If I go to visit my granddaughter, he will go in the other room. I thought at first he thought it was contagious. But I think that he just can't cope with it."*
>
> Stage 1b. aged 54

Mostly children were supportive of their mothers.

> *"He has been amazing and taken a lot of it in his stride, even having to go to a new pre-school in Leeds for a month and live with a different family. He showed a lot of interest in his medical kit and certainly wanted to help me get better."*
>
> Stage 1b1, aged 43

Some women talked about how their children did not want to talk to them about their cancer for fear of upsetting them, and instead chose to talk to an alternative family member.

> *"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."*
>
> Stage 1b1, aged 49

> *"He was quite interested, but very worried and would talk to his dad a lot."*
>
> Stage 1b1, aged 40

Some women talked positively about how their relationship with their children has changed through having cervical cancer, saying that it has allowed them to develop a better way of communicating with them.

> *"It feels like I am able to communicate with my daughter better now, as I can't just pick her up. Our relationship has changed for the better. I try to enjoy my relationship with her more now."*
>
> Stage 1b1, aged 32

Many women re-evaluated the relationship they have with their children as a result of having cervical cancer. It has made women feel that they need to spend more quality time with their children, having been through an experience which could have resulted in them no longer being around.

> *"I do tend to spoil her now and am far more protective of her."*
>
> Stage 1a1, aged 36

4.5.5 Impact on closest relationship

Many women interviewed talked of how having cervical cancer has brought them closer to their partners. Overwhelmingly, the partners, family and friends of the women interviewed have been very supportive.

> *"Having cancer has strengthened the relationships with my partner, my friends and my family. They have all been fantastic and it has brought us all closer. Challenge can be good for a relationship."*
>
> Stage 1a, aged 28

> *"I would say the majority of my close relationships have been enriched by this experience. In terms of my personal life, overall it's been remarkable how loved I felt and how much effort people made to care for me."*
>
> Stage 2b2, aged 25

A small number of women reported a feeling of isolation and becoming withdrawn.

> *"This is a lonely disease, and I felt very alone."*
>
> Stage 1b2, aged 51

This can then have a big impact on their partners and their wider family.

> *"My husband would say I withdrew and didn't talk about things, which was probably true. Conversation was usually triggered by my silence. He wanted to know how I was feeling and he wanted to talk about how he was feeling. When we did talk we had big talks."*
>
> Stage 1a1, aged 36

Despite this, many couples did find they were able to talk about their situation and eventually, with time, were able to work through their issues.

> *"Because my partner came to all my appointments with me, we were able to be quite open about it. We didn't want to hide anything from each other and I am able to tell him how I am feeling. We didn't need to seek any support with our relationship, we supported each other."*
>
> Stage 1a1, aged 26

We only spoke to one woman who had actually sought relationship counselling in order to support her and her partner through their experience, as she initially blamed him for her getting cancer.

> *"I thought my partner was responsible for my cancer at the beginning. I had to work through this and rationalise it. I wanted someone to blame and he was it. It affected us and we went to counselling. It helped us communicate."*
>
> Stage 1b aged 54

Many women talked of their partner as their main support mechanism throughout their treatment for cervical cancer. Women talked of partners who were there at every appointment, were close by during treatment and there to support them through recovery.

> *"My family and mum were very supportive and my partner was my rock. I think one of the things that got me through this the most was having such a strong partner, having a partner to depend on and to talk to, is really key to getting through the process."*
>
> Stage 1b, aged 26

But this can have an adverse effect on the partner themselves. It was reported that partners can find it hard to see someone so close go through so much, and feel powerless to do anything to change the situation.

> *"My husband is quite strong. Has been brilliant, but there have been a couple of times when he has wavered, as he feels overwhelmed. He knows he can't fix me and feels powerless."*
>
> Stage 1b1, aged 49

There was little comment about partners accessing any support for themselves, although many of the women felt that this would have been a good thing had it been on offer, as their partners struggled with their emotions.

Although many women felt that they could be open and talk to their partners, one that we spoke to did not like to do this at all, with either her partner or her family. She felt that she did not want to be the centre of attention and have the focus constantly on her.

> *"We don't discuss my cancer. Neither my partner nor I want to discuss it. I would rather talk to a professional about it, rather than my family or anyone else close. I don't want the focus to be on me. My family is the same."*
>
> Stage 1b, aged 24

There was just one woman whose relationship broke down completely as a result of her having cervical cancer and the emotional impact this had.

> *"The cancer initially made us stronger and we moved in together between the operation and it coming back.*
>
> *"When it came back the second time – our choices for the future were different. Things would be more difficult. When I started radiotherapy my ovaries stopped working and I started menopause. I didn't have a chance to freeze my eggs. I think the whole thing, for any couple, is super stressful and there is so much pressure on you both.*
>
> *"I felt so miserable all the time. I was in pain and didn't want anyone to touch me. We just grew apart. All I did was shout at him and all the pressure was on him to look after me. I felt guilty and he resented me. Once the treatment was over, we both agreed this was not making either of us happy."*
>
> Stage 1b2, aged 25

4.5.6 Intimate relationships

Almost two-thirds (63%) of women said that their intimate relationships were affected by them having cervical cancer.

Some women spoke of how intimacy was prohibited after a number of treatment procedures, but it was also far from the minds of many of the women we spoke to. As a gynaecological cancer, the majority of women with early stage cancer (not requiring chemotherapy, radiotherapy or brachytherapy) had had several investigations and surgeries to remove cancerous cells. This had a significant impact on their cervical/vaginal areas, making sex difficult, both emotionally and physically.

> *"We did speak about this. There was no sex after the LLETZ for four weeks, anyway. But we didn't have sex for six weeks. He didn't want to hurt me. We were a bit nervous about it and it is still a bit like that now."*
>
> Stage 1b1, aged 26

Women who had undergone chemotherapy, radiotherapy and brachytherapy felt sore, tired and nauseous and, as such, did not feel as if they were ready to have intercourse with their partner.

> *"It's the last thing I was thinking about. My husband doesn't want to put any pressure on me. Radiotherapy and chemo makes me sore and makes me feel rubbish. My CNS has given me dilators to use. The first couple of times we were a bit nervous and it was quite tender."*
>
> Stage 1b1, aged 49

Most partners were understanding and waited for the woman to feel ready before resuming intimate relationships, instead of rushing back into it. Although this did cause some upset for some couples, most were able to talk about it and addressed the situation together, working through this and gradually getting things back to normal.

> *"This was an issue for us. We did talk about it, plus there was a previous issue around sex that made this extra difficult to handle. But in time, and through talking it through, we were able to resolve things."*
>
> Stage 1b1, aged 40

However, once sexual relationships resumed, it was reported that this was not always straightforward and women did talk about experiencing some discomfort or pain, as well as suffering psychologically and feeling nervous about doing damage to themselves.

> *"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. Sex is more painful than it used to be. But it might be as we aren't doing it much. I feel pain in that area that I don't think I'd have noticed before. It's hard to switch off from that."*
>
> Stage 1a1, aged 25

However, for some couples the intimacy never returned and their relationship with their partners is now a platonic one. This was especially true for the older women that we spoke to, and those who had children that were grown up.

> *"It's changed our sex life and we don't really have sex any more. It's a fairly recent marriage. We got together 10 years ago and got married seven years ago. I'm eight years older than my husband. But he's not a young 50.*

> *"I'm not interested in my husband pleasuring me in other ways. It's put a huge colour on it for me. Because I see it as a sexually related cancer, as 98% are HPV related. I find it hard to disentangle that."*
>
> Stage 1b1, aged 58

Some of the women we spoke to talked about the perceived stigma attached to having cervical cancer; and that it is often associated with promiscuity – this caused anxiety for these women.

> *"The other thing is I wasn't promiscuous, but people think you get cervical cancer because you've had a lot of sexual partners. I felt tarnished and that wasn't true for me. I felt I lost ownership of down below and saw a counsellor who helped a lot. I told my oncologist about how I was feeling and that I was depressed about the dilators –I went to Ann Summers and bought a vibrator that was a bit more sexual."*
>
> Stage 1b2, aged 51

For one women, sex was only mildly affected by having cervical cancer and she reported that her sex life had improved.

> *"The last six to nine months have been better than before and our sex life has actually probably improved. I do feel comfortable talking about it with my husband and we talk openly. I had previously blamed him for not being able to have kids."*
>
> Stage 1b1, aged 29

Just two women that we spoke to became pregnant unexpectedly very soon after treatment and realised that sex was not as big of an issue as they first might have suspected.

> *"During treatment this was not on the table at all. Afterwards it was all a bit delicate. But now I am pregnant, so it was not that much of an issue!"*
>
> Stage 1a1, aged 36

4.5.7 Human papillomavirus (HPV)

Whilst HPV is responsible for 99.7% of cervical cancers, only a quarter (26%) of the women were aware that HPV may have caused their cervical cancer. Many of them found this out after they were diagnosed, either because their medical professional mentioned it at the time of diagnosis, or this was discovered through their own research after they were told they had cervical cancer.

There was an apparent lack of awareness about HPV and its connection to cervical cancer. Most women who did know about it, or who subsequently found out about it, were not particularly concerned about it, and were not worried about a risk of re-infection.

There were several women who were aware of the stigma attached to having HPV and it being assumed that there is a link to promiscuity.

> *"I didn't know I had HPV and no one really talked about it. My husband felt guilty that he had given it to me as I met him when I was 25 and he was initially worried about re-infection. But I blamed myself, as I had quite an active sex life."*
>
> Stage 1b1, aged 29

Some partners worried when they had more knowledge of HPV, but the majority had little or no awareness of it. They also were not concerned about the risk of re-infection and did not feel guilty that they may have been the source of the infection originally.

> *"I knew about HPV through working in schools and knew about the vaccines, but I didn't know I had it. My husband didn't know about it, but he knows more about it now. We are*

> *not affected by it. I thought everything was OK through screening, so I didn't feel a need to know about it. But I know more now. My husband doesn't feel guilty or anxious."*
>
> Stage 1b1, aged 49

4.5.8 Impact on other close relationships

Women's relationships with their families were mainly positive, with support provided by parents, siblings and the wider family. In some cases, where it was a young couple involved or where a partner did not feel comfortable to talk about the women's cervical cancer, a parent or sibling would fill the gap.

> *"My sister was very present and I discussed everything about how I felt with her. So I tended to talk to her about things as I didn't want to worry my husband and he didn't want to worry me. But I knew he was very concerned."*
>
> Stage 1b1, aged 58

Many parents of the women became very emotional when discovering their daughter had cervical cancer – with some parents, particularly mothers being present at the initial diagnosis meeting. This generated mixed emotion for some parents, especially those who had already experienced cancer in a close family member.

> *"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. My father had cancer too, bowel and liver. My younger sister was shielded from it as much as possible, as a result."*
>
> Stage 1b1, aged 29

Other women found telling their family too much of an emotional strain and only told them news when it was confirmed, just before procedures, or when something reassuring could be said, in order not to prolong the concern.

> *"My husband told my parents about my cancer, so it didn't get too emotional. I now feel a bit closer to my parents. I can talk more openly to them about issues now, as they normally don't like to talk about stuff. My mum describes my cancer as 'my situation'."*
>
> Stage 1b1, aged 30

> *"I didn't want to tell everyone at first, as my sister in law had just been diagnosed with breast cancer. I only told my mum and dad initially. My parents were very supportive, but did express their surprise about how long it took me to recover, saying it was a long time off work."*
>
> Stage 1b1, aged 40

> *"My mother-in-law was very 'matter of fact' about everything, too much so, and felt that I should just be getting on with things without making too much of a fuss."*
>
> Stage 1b1, aged 29

4.5.9 Impact on relationships with friends

Friends were again generally supportive, but cervical cancer did cause some adverse effects on friendships. In several cases, close friends did not know how to react to the news of cervical cancer being diagnosed and felt uncomfortable to be around the woman in question.

> *"One of my friends rejected me and didn't know how to treat me. My other friends were overwhelmingly helpful."*
>
> Stage 1b1, aged 29

Others could not come to terms with it at all.

> *"My best friend didn't handle it very well at all. She went into denial and didn't contact me. She didn't know what to do and pretended like it wasn't happening. People didn't know what to say."*
>
> Stage 1b1, aged 28

4.5.10 Impact on social life

Women interviewed talked of how finding out about having cervical cancer was a very daunting and emotional process. They became withdrawn and isolated themselves in their own worlds, not wanting to discuss their situation and not wanting to accept that they had cancer. This was the case for several of the women we interviewed. From diagnosis to treatment and recovery, many women decided to put their social activities on hold, with some hardly leaving the house at all.

> *"We didn't really do much throughout the whole journey. I was in a bit of a bubble. I saw only my partner and family. I didn't want to see anyone. I kind of withdrew until after treatment. I re-engaged with my friends afterwards. It was all a bit of a whirlwind."*
>
> Stage 1b1, aged 28

Women tended to find out who their closest friends were through their treatment for cervical cancer. Many women had friends that wanted to visit and did, thereby providing support. However, there were also friendships lost through people not wanting to accept the situation, or feeling awkward with the thought of the illness.

> *"With my relationships with friends – people don't know how to handle it – don't know what to say. I have a couple of friends that really turned up trumps – one didn't come to see me at all. One friend who was great at first, afterwards asked me if I really did have cancer! It was very weird. Some are great and others just turn away. It can bring people together – and others it pulls apart. My sister said to me – oh well you've had a good life – you're in your late 50s and you've done well. I told her I wasn't quite ready to throw in the towel yet!"*
>
> Stage 1b1, aged 59

Most of the women agreed that they went out less often and preferred to socialise with their partners and close family and friends at home rather than going out to events. Some women were conscious of their physical health, such as standing for long or getting easily exhausted, and how it would be affected by going out. Others were also worried about their appearance.

> *"Our planned social activities got cancelled - Christmas parties etc. I was worried about going to the pub and having to stand up. I am conscious about my compression tights and what I have to wear on nights out. I go for more meals with my husband now."*
>
> Stage 1b1, aged 30

In some cases, women's social lives were completely turned around as a result of having cervical cancer. Women talked of how the side effects and subsequent emotional drain was too overwhelming and described how they now live a very different life, preferring to stay at home for the majority of the time.

> *"I used to be the life and soul of the party. I've gone from being this outgoing and gregarious person that everyone wanted around to someone who never leaves the house.*

> *I've sat here in my front room watching daytime television for the last 18 months. At one point I thought I might be agoraphobic, because the furthest I went was the wheelie bin. There was a point that my phone would never stop with phone calls and messages, now I am lucky to hear from anybody but my family.*
>
> *"We haven't got a social life anymore. It's just me and him."*
>
> Stage 1b, aged 54

Social lives have improved for some women, with them valuing their lives more and finding they have more time to spend with friends and family. Having cervical cancer and time away from work and the normal everyday routine has made some women re-evaluate their priorities.

> *"From a friends' point of view, it has been great for me. Before my diagnosis I was really focused on work and on my son. I saw my friends quite rarely. 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."*
>
> Stage 1b1, aged 43

> *"You definitely feel the love from all your family and friends. It has brought everyone together. We spend more time with friends and family in the last year than we used to."*
>
> Stage 2b, aged 33

1.1.1. *Impact on employment*

Having cervical cancer has had an impact, at least to some extent, on all the women interviewed who are or were in employment at the time of their diagnosis. For some, their employment has had to change as a result of the treatment they have undergone. Some women have had to take early retirement as they are no longer able to do their job properly, and for some women their experience of cervical cancer has seriously affected the way in which they are able to perform at work.

> *"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. My GP and the occupational health consultant were very supportive of my early retirement and I had it at the highest tier."*
>
> Stage 1b1, aged 58

However, in the majority of cases, employers have been supportive of women undergoing treatment and have facilitated appropriate time off for necessary appointments, treatment and recovery.

Some women we spoke to, had a fixed period of sick leave entitlement at full pay. It was assumed by the women themselves that arranging sick leave would be straightforward with a cancer diagnosis, and it was for many, but for some women this proved to be an issue.

> *"I assumed it would be a straightforward to take time off work – it wasn't at all. I struggled with management. I was told that I had to take any medical appointments around my cancer as annual leave, rather than sick leave or them just being granted."*
>
> Stage 1a, aged 28

Most of the women interviewed took time off over their treatment. Depending on the treatment, this could range from a few weeks to several months and in some cases closer to half a year. Mainly, this was taken as sick leave, but some women found that they also needed to use their annual leave. Their return to work was sometimes dictated by their company's leave policy, meaning some women reported having to go back before they really felt ready to.

> *"My sick pay ran out when I was off at week 5, so for the last week I was on Statutory Sick Pay. I returned to work on reduced hours, and wasn't paid for the hours I didn't work. I worked 9-12, so the 12-5 part wouldn't be paid. This obviously lowered my income. At my work, for sick leave and pay, you are treated in the same way for cancer as everyone else is. For example, someone who has a cold gets the same entitlement as someone with cancer. This needs to be challenged!"*
>
> Stage 1b1, aged 28

For some, work was a distraction from their cancer. One woman reported working right up to the day before she had her procedure in order to try to keep life as normal as possible.

> *"I worked right up to the day before the operation. I wanted to work, and this caused more of a problem, as it affected my work record rather than just taking a long time off sick. I did manage to resolve this by getting sick notes from my GP."*
>
> Stage 1a, aged 28

The majority of women told their work colleagues about their cervical cancer. They reported how their colleagues were generally supportive, with many providing cover for women in their absence, without complaint. There were a few, however, where the woman's absence from work, despite having cancer, was not met so favourably. In addition, their suitability of their returning to work was also called into question.

> *"I had a close friend at work that questioned whether I should be in this job anymore or if I should look for another job. This was really unsettling and not very supportive."*
>
> Stage 1b1, aged 30

Some work colleagues were also friends, who the women saw socially. They visited the women, kept in contact with them and sent gifts and cards.

It was reported that some work colleagues, especially male colleagues, could often shy away from the issue and not speak about it at all.

In addition, there were a few negative comments made to some women; and reports of colleagues who had once been supportive friends, turning their backs on the women in question.

> *"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."*
>
> Stage 1a1, aged 36

> *"My direct manager, who is male, was a bit awkward around me. He was supportive, but he wasn't sure how to communicate. My line management was passed over to the team manager, who was female and more understanding. I was also quite complex to manage with my time off around illness, so a more senior manager was seen to be a better option for this. My male manager has since been re-instated."*
>
> Stage 1b1, aged 26

> *"I didn't want my cancer to be common knowledge, as I didn't want the pitying looks. I had spoken to my manager to convey this. But they somehow all knew, I think someone read my sick note, and it felt like they were all talking about me behind my back. I couldn't trust anyone. I then found out it had been brought up at a team meeting that I was not present at*

> *– I was discussed. All my colleagues worked in the caring profession, but none of them could care less about me. I worked in a team of 15 people and only two of them have kept in contact with me through this. These are people I socialised with."*
>
> Stage 1b, aged 54

> *"There were a few negative comments from my colleagues about not going to smear tests, but generally people were supportive."*
>
> Stage 1b1, aged 49

Work conditions needed to be amended for a number of women in order to accommodate the health status on returning to work after treatment. Women interviewed talked of changes at work including: a reduction in hours, a desk job rather than one where a lot of standing was involved, changing workload to more administrative tasks rather than emotive ones, more office-based work rather than travel to external meetings, working from home and in one case, a change of line manager, from male to female.

> *"My manager has been really good. She got rid of my workload at the start, as I knew that my cancer was going to have an impact on my work. I work with children who are dependent on me. I took quite positive steps to re-arrange my work so it didn't suffer."*
>
> Stage 1b1, aged 32

On returning to work, it was not possible for some to go back to their same jobs. Lymphoedema was stated as being one of the main reasons for this, meaning that the woman would not be able to stand for long periods, a requirement of their previous job.

> *"And then I couldn't go back to the same job due to me getting lymphoedema. I was previously a ward nurse, but I am now doing part-time nursing and a bit of teaching. I can't do long periods of sitting or standing, so I am limited and this has had an impact on me."*
>
> Stage 1b1, aged 29

Taking time off work was difficult for some of these women's partners. For the majority of women we spoke to, their partners had to take annual leave or work time off in lieu to be available to accompany them to appointments and treatment, or to be able to support them during recovery.

> *"My partner asked for five weeks compassionate leave, when I had the brachytherapy in Aberdeen and he was there for the whole time. His company have been very supportive. Unfortunately, he has to pay those extra weeks back so he is away for three months this time."*
>
> Stage 2b, aged 46

Just two or three women interviewed were able to take this time as paid compassionate leave, or their employers would allow them to alter their work patterns or colleagues would cover for them, in order to accommodate any time off.

4.5.11 Financial impact

Almost half of women interviewed (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.

There were some women who felt fortunate that they had taken out critical illness insurance, so the impact on their finances was very minimal. All of those women who had this type of insurance would recommend it to others as they reported it seriously reduced the burden when going through treatment.

Parking and travel costs had some impact, with costly parking fees at hospitals and continuous travel to and from appointments and treatment. This was especially the case for those women who underwent radiotherapy and chemotherapy and had to attend hospital on a daily basis. It was some hospitals' policy to provide free parking passes to cancer patients. However, this was not widely known and sometimes only found out too late when treatment had finished.

> *"Parking tickets were an issue. We didn't realise you could get a free pass for my appointments."*
>
> Stage 1b1, aged 29

There was a mix of women who were asked about free prescriptions. There was an almost equal split between those who knew about free prescriptions or not. Some women who found out later on were able to reclaim their money, but some never found out at all.

Despite prescription costs being covered, some of the women interviewed talked of the need to have support stockings for lymphoedema. In some cases, the quantity that were provided was not enough for woman to be able to get through the week, so additional ones needed to be purchased. These were reported to be very expensive items, costing in excess of £100.

> *"I have to have two pairs of support stockings per month. I get these on prescription, but I have bought more pairs, as two pairs are just not enough when you are working in them."*
>
> Stage 1b1, aged 30

Additional childcare and domestic help around the house were given as examples of additional costs to cover, but the overwhelming financial impact for women was the reduction in pay from not being able to work or reducing hours.

> *"I have dropped my hours at work by three hours already. I am less able to work night shifts - I would get paid more for this."*
>
> Stage 1b1, aged 30

> *"The biggest financial impact was being away from work as sick pay does not last long and is not at the same level as my salary."*
>
> Stage 1b1, aged 28

4.6 Life after a cancer diagnosis

4.6.1 Current health status

The majority of women we spoke to had completed their treatment and were given the 'all clear' for their cervical cancer. However, they reported now facing a number of years of follow-up appointments and repeated check-ups. Most of the women said they had recovered well and that they currently felt healthy, but only a few women described themselves as being 'cancer free' or a 'cancer survivor', as there was still some time to go before they would be able to confidently say this.

> *"I don't consider myself cancer free, as I haven't had a check-up due to my pregnancy. Not until five years have passed will I think that I am cancer free."*
>
> Stage 1a1, aged 26

Although for most women, treatment has removed the physical symptoms of cervical cancer, the emotional effects of these have remained.

> *"I feel quite healed, but also still feel quite emotional. I am cancer free, but at the same time, I don't quite know. I would have described myself as that before, when I possibly I already cancer."*
>
> Stage 1b1, aged 32

4.6.2 Follow-up treatment

Just 9% of women interviewed were still receiving follow up treatment for their cervical cancer, with the majority just attending routine follow up appointments.

Two of the women we spoke to were not yet receiving follow up appointments, as they became pregnant directly after their cancer treatment finished.

Of the women that were still receiving treatment, this was usually ongoing chemotherapy and radiotherapy, HRT or treatment for lymphoedema.

4.6.3 Current state of general health and wellbeing

Just under half (43%) of the women said that they had now changed their lifestyles as a result of having had cervical cancer, and said that they are now healthier after having received treatment for cervical cancer.

Women reported wanting to make additional changes to decrease the likelihood of their cancer returning, and made changes to diet and exercise in order to support this, even where they may not be a direct link to cancer.

> *"I do three hours of sport per week. My diet has changed. Aspartame has been completely cut out and I am now eating green vegetables and nuts and seeds instead of all those white products."*
>
> Stage 1b1, aged 29

However, having cancer and going through treatment made some women, who had previously been quite fit and healthy, go in the opposite direction and turn to food for comfort.

> *"It has deteriorated somewhat. It went the other way; I started comfort eating and drinking a bit more."*
>
> Stage 1b1, aged 40

And some women became disillusioned with being healthy and questioned whether this had any impact on getting cancer.

> *"I felt like I had a healthy lifestyle before my diagnosis. It was frustrating as I still found myself with cancer despite being healthy. I did make changes around the time of my diagnosis, drinking lots of juices and avoiding chocolate etc. However, the treatment I had made me more sedentary. I look forward to being more active again."*
>
> Stage 1a, aged 28

Some women reported not just focusing on diet and exercise, but on lifestyle and cutting down on the stress in their lives as a way to hopefully prevent cancer from recurring.

> *"I've changed my lifestyle completely since my diagnosis. I'm now living in a smaller city with a more relaxed feel.*
>
> *"I did a mindfulness course recommended by my counsellor. It's not for me but I can see the benefits and things from it have helped. If I'm starting to panic about appointments, it will help me calm down."*
>
> Stage 1b1, aged 30

4.6.4 Friendships/connections with other women

Generally, the majority of women reported that they felt they were now advocates for women having regular screening. Some of the women were proactive about this and used social media channels, their workplace and family and social networks to drive this message forward.

> *"I am now an advocate for regular screening. I take leaflets and posters around to GP practices. I told my friend horror stories to scare her so she would get screened. I have done some fundraising work for the Willow Foundation, in order to give something back."*
>
> Stage 1b1, aged 29

> *"I encourage other women to go for regular screening. I have done this with friends and colleagues already. I feel that I would get quite angry with people who don't bother with screening. A smear test is far more comfortable than the all the other interventions that will happen as a result of not having one and something being missed as a result."*
>
> Stage 1a1, aged 36

Although most women said that they do not feel outwardly jealous of other women, they did express feelings of self-pity and questioned why it had happened to them and not someone else. This was especially true of women who had not had particularly active sex lives and compared themselves to people who, in their mind, had been fairly promiscuous.

> *"I'm not jealous towards other women who haven't had cancer. But I do think that some women are more likely to have had cervical cancer, due to their lifestyle. I do feel upset when friends who are pregnant moan about it being unplanned."*
>
> Stage 1b1, aged 30

The loss of fertility as a result of cervical cancer was also a reason that engendered feelings of envy amongst some of the women interviewed. When family, friends or work colleagues announced that they were pregnant, some women described how this could emotionally affect them.

> *"The only time I have felt a bit jealous is around people announcing they are pregnant. At one point there were three people at work and my best friend, and my sister was trying to get pregnant. That was hard."*
>
> Stage 1b1, aged 30

This was true not only of women who had not started families, but also those who had completed their families, but felt as if their choice had been taken away from them.

> *"I struggled with the loss of fertility, even though my family was complete. The choice has been taken away from me. It feels OK, most of the time, but I can have a wobble now and then."*
>
> Stage 1b1, aged 40

4.6.5 Life now following treatment for cervical cancer

There was a general feeling shared by all women who were interviewed, that life should be more appreciated than it is. Women reported that only when you face the risk of dying do you fully appreciate what you have, and learn to value it.

Some quotes from the women themselves about their view of life after cervical cancer included:

> *"Live life to the full, you do not know what is round the corner. You have to do what you want to do and not waste time. You have to act and not just talk about it."*
>
> Stage 1b1, aged 29
>
> *"Life is too short to sweat the small stuff. There is good that has come out of cancer, in that I worry less about things that just don't matter and that I cannot change."*
>
> Stage 1a1, aged 36
>
> *"Having cancer does make you think differently and look at things differently. I still see myself in the mirror, but I am not the same person. Everything changed when I found out I had cancer."*
>
> Stage 1b1, aged 49
>
> *"Now I have in the back of my mind all the time, what the future is going to be like? Will the cancer come back? It is something I will have to try and cope with. I am young and I can't be thinking about it for the rest of my life."*
>
> Stage 1a1, aged 26
>
> *"I am very grateful for what I have. I couldn't have wished for a better family. Even though I do feel like I am missing out on having a child.*
>
> *"I have a diary that I write in every day. I write one thing I am grateful for. This helps when I am down."*
>
> Stage 1b1, aged 30
>
> *"I focus on what I do have. I have a healthy life and future. I have a good, loving supportive family. I wouldn't swap them for the world."*
>
> Stage 1b1, aged 30
>
> *"Live life to the full and live for now. Enjoy every moment."*
>
> Stage 2b, aged 45

5 Partners

In addition to speaking to women diagnosed with cervical cancer we also included three partners in this report. We wanted to learn more about the experience of a partner during the woman's journey through diagnosis and treatment for cervical cancer.

The three partners (all men) were interviewed and asked similar questions to that asked of the women themselves. This summary captures a general picture of their experience, giving insight into the emotional, practical and logistical side of providing support and represents responses from the partners themselves.

5.1 A partner’s view of diagnosis

> *“I wasn’t aware of what screening was for. I thought it was a normal procedure that girls have to go through. I had no idea.”*

> *“My girlfriend’s mum was with us and they were both quite emotional. I was pretty stoic; I was looking for all the information I could get. I needed to be strong for her and she was looking to me to be strong. I was heavily involved in the process.”*

Our partners felt that the presence of someone at a diagnosis meeting, and subsequent appointments, was important. As well as much needed emotional support, partners felt they were responsible for taking in information that the women affected could not, in what was is an overwhelming situation.

> *“I would say it is absolutely necessary to have someone there to remove the emotional side and be business like, if need be. It was also necessary to have me there as a support. So she could offload on me.”*

The partners we interviewed talked about the emotional feelings experienced being hidden below the surface for the sake of the women concerned, but that they were upset and fearful of their partner’s diagnosis and emotions often surfaced at a later stage.

> *“I was worried, but I felt quite confident that it wasn’t life threatening.”*

> *“I couldn’t sleep I was so worried, I didn’t know if when I was sleeping next to her, she was going to live for the next five years”*

> *“It was a difficult time. I remember getting very teary around friends when we went away. I did something very insignificant, like drop a drink, and proceeded to burst into tears.”*

While two of the men had some concept of the survival chances of their partner, one did not know whether their wife or girlfriend would be able to live through this disease.

The partners we spoke to felt very involved in their partner’s care. Procedures were explained to them as well as their partner.

Although the women were given support information, none of the partners we spoke to were given any. However, when asked, this is not something that they felt they needed or would have asked for or accepted had it been offered. Instead of professionals, the men had found that they turned to friends or family members if they wanted to talk about how they were feeling. There was a feeling that any support that was being offered should be directed to the woman who had cervical cancer, and not to the partner supporting her.

> “I talked to a very close friend about it, so that was my support system. I didn’t feel as if I needed to seek support from anyone else.”

> *“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. I got on with her. I think this is an invaluable role for women going through this.”*

5.2 A partner’s view of treatment

Life through treatment varied for the partners we spoke to. Some of the men took a very logical approach, recognising that there was a procedure that needed to be done and putting their emotions to one side.

> *"I was always very confident about the care that was being provided. I removed myself emotionally from it. I knew what had to be done and that it was going to be done. I am very logical person."*

One man felt the opposite effect and extremely worried and found the process to be very nerve-wracking and all-consuming. Although he tried to remain positive for his girlfriend on the face of it, he felt that he needed time to face his own feelings.

> *"We were living under a storm cloud at every moment. It was not fun at all. We weren't living together at the time. I was trying to be upbeat when I was around her, but I needed a break sometimes, just to mope around and feel how I wanted to feel."*

On the day of treatment, two of the three men accompanied their wife or girlfriend to hospital and were with them up to the procedure.

> *"I was able to stay with my partner right up to before the operation. We had to get up early and wait in the waiting area all morning. She wasn't put up on a ward. I went straight up to the theatre doors. Then I waited at the hospital while the operation took place."*
>
> *"The procedure went on for a lot longer than we thought. It seemed to last forever. After surgery, she was in recovery for so long that they did actually let me go through to her, as all the other patients had already left. She spent four hours in recovery. It was very stressful."*
>
> *"I was told the surgery had been extended. I went for some fresh air and was trying to pass the time. The surgeon called me when I was in the pub. I was so relieved. I went outside to cry. It doesn't look good a bloke crying in the middle of a pub. I literally ran to the hospital –* it was just around the corner."
>
> "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. We could ask questions. The consultant was also good and the nurses were also really good."

One man felt that he would better to keep to his routine and attended a training course in order to have something else to focus on, rather than his wife's surgery.

> *"It was difficult to concentrate on the course I was on. I told people what was going on. It was good to have something to focus on. It was good distraction. I was happy to do that and keep my mind off things. There were limited visiting times anyway, so I knew I couldn't be with her all of the time."*

5.3 A partner's view on the impact and follow up for cervical cancer

Generally, there was a positive perspective on the aftercare that was provided. However, one of the partners felt that the care was not satisfactory at all and that he noticed a definite decline after the procedure had taken place.

> *"The standard of care has been not at all good. There are issues with continuity in the gynae clinic. There are too many doctors involved. We saw different doctors each time we had an appointment. Each doctor didn't know what was going on or why we were there. There was problem with scheduling. The three-month checkup was late and done at six months."*

The side effects that the women experienced were generally lymphoedema, discharge and groin swelling, symptoms that the partners felt quite powerless to support them with.

> *"I am not going through personally, so I don't understand it terribly well. I feel a bit powerless, especially when she is at work."*

Employment was unaffected for the three men we spoke to, with their colleagues being generally supportive of their situation. None of the men stated that they were given compassionate leave or similar, although this was not always needed. For two of the men work was flexible and fitted around them. One man he was only able to take time out of his annual leave entitlement, his managers allowing him no compassionate leave. All the men stated that there was no significant negative financial impact on them.

All three men said that they felt that their relationship had been made stronger as a result of their partner having cervical cancer. Having been through such a significant situation and coming through the other side had brought them closer.

> *"It has brought us closer together as a couple. There have certainly been no negative effects. It has been tough at times. Not in an argument way, but there have been quite a few emotions."*

The men were less willing to speak about their emotions around their relationships than the women we interviewed were. They were also not particularly vocal when talking about their intimate relationships. However, the men spoke about feeling nervous around intimacy after their partner's surgery and not wanting to rush things and hurt or damage the women. They felt generally happy about discussing these issues with their partners.

> *"We refrained from doing anything for a while and when she had the tumour. I felt a bit nervous at first. It was a mutual thing, we talked about it. I wanted to give it six months' recovery time. I felt comfortable talking to her, but I did also tend to shut conversations down."*

6 Key themes identified as part of this report

6.1 Family

Jessica's story – 'being around my family has been the most help'

I received a letter in the post asking me to book a smear test. After I'd had it done, they said it was abnormal. This was only my second smear test so I sort of brushed it off. However, 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. The nurse said she saw abnormal cells and could do a LLETZ procedure and they would see me again in six months. I remember about two weeks after the appointment I kept getting missed call from a withheld number. Eventually I answered it and it was the practice nurse telling me they had found pre-cancerous cells. As they said 'pre-cancerous' I wasn't overly worried and was expecting another LLETZ procedure.

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.

I phoned all my family and they took it very well which really helped the situation.

After having some scans, they looked to see if it had spread and I was told I needed a radical hysterectomy. I had 11 days to prepare for the fact that I could not have a child again. I am so lucky to have two children so not being able to have more didn't worry me as much as it could have done.

After finding out your diagnosis, it is very strange getting back to normal life. It is strange having to look after your kids, cook meals and get ready for work. I was given my diagnosis on a Friday so I did get some time to myself and to process the information.

When we discussed the treatment plan for my radical hysterectomy, I was shocked to understand I couldn't do most of the things I normally do for 12 weeks. So before the surgery, I spent more time with the kids and went out for meals. All the normal things that I knew I'd miss.

When I went into hospital my father came with me which really helped. He stayed with me all day and didn't leave me. Coming round from the anaesthetic was reassuring as I saw all my family surrounding me.

I couldn't do anything that I had done before. I couldn't pick up my one-year-old and I found this really difficult.

Of most value to me was being around family and friends. I always had visitors and this made me happy. My family were excellent at looking after me and making sure I had enough food to eat.

I loved being around my kids because they didn't ask any questions! They knew I wasn't very well but they didn't ask questions; I liked spending time with them.

Throughout the whole process, I did not tell my children I had cancer. I did tell them that I had an operation which hurt my tummy and sometimes it hurts. My older child really tried to look after me when I was not well. I tried to protect his innocence so I did keep it secret from him.

I also didn't want my cancer to be discussed at school and with other parents, so I felt it easier to limit my discussions with my children.

My husband is keen to get back to work, but I know he is worried about leaving me alone and with the kids.

The relationship with my husband during this time has been good overall. However, it has been difficult at times. He of course never expected his 28-year old wife to have cancer. At the start he expected the worst and struggled to cope. But as time went on, he has been excellent – especially in managing the house and dealing with the children.

We have clashed occasionally but only because I have felt he doesn't understand how I am feeling at times. Talking through things and working through them together has really helped. It has made us develop a stronger relationship.

It can be difficult discussing certain things with my husband, especially if I felt it might make him think he wasn't good enough. However, I really found there was a snowball effect with arguments if I didn't talk through things.

My husband and my children have been my rock. I am also spending lots more time with the kids as you realise how precious your time with them is.

Family is an even bigger part of my life than before.

6.2 Fertility

Natalie's story – 'fertility was a big issue for me'

It was the beginning of 2014 when I got my letter for my first smear. I didn't go straightaway, I put it off for a little while. I'd never had any symptoms, so I didn't think I needed to worry. Then, I think it was within two weeks, I got a letter saying that they had found some abnormalities and that I needed to go to the hospital. I would need a colposcopy and potentially would also need to have a biopsy, so they could have a look and see what was there. That made me panic a little bit. They bombarded me with leaflets. That's when I got referred to Jo's [Cervical Cancer] Trust. I had a look online, which made me feel better about things.

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. Fertility was a big issue for me. I did have feelings of jealousy when I was first diagnosed. With having the miscarriage and then the cancer, I thought it wasn't fair that I was going to have problems having children.

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.

We discussed whether we would be able to have children. Although I had the LLETZ procedure, they had taken away quite a lot of tissue, so we were worried about being able to conceive. We asked about if we had more surgery what our chances would be. And what would be the chance of the cancer returning. I remember being told that they had caught the cancer really early and that I was lucky. They told me not to worry as they had caught it early.

I was worried about having children, and my fertility was really important to me, especially after previously having a miscarriage, but I got pregnant fairly soon after my surgery. I was filled with a mix of emotions of being ecstatic about my pregnancy, but also worried that I could not have all the checks that I needed post-surgery.

Cervical cancer meant that I had to have extra scans during my pregnancy and there was a higher risk of me having an early birth. I had problems with my labour and difficulty with dilating.

I spent my whole pregnancy worrying about how things would go, but it all went quite well apart from the labour. I also had some problems in my pregnancy due to scarring.

As I got pregnant not long after my procedures, I couldn't have the follow up appointments that I would have routinely had. It was three months after having my son until I could have my first smear and the wait for the test seemed to go really slowly. And then I received borderline results. As a young, new mother this was hard to cope with. I should be feeling excited, but am feeling quite worried.

I am worried, as I had previously been all clear before becoming pregnant. The next appointment is in July, six months after the smear, to see if the abnormalities have come back. I'm not sure what will happen if the margins are still borderline. It wasn't really explained to me what will happen next. I still have the contact details for the CNS, so I could get in contact with her.

All I hope for is to have a big family and to be cancer free.

6.3 Emotional support

Kate's story – 'I value my friendships far more than I ever did before'

I went for my smear test in August last year as normal. I received a text message shortly after that asking me to come in for a further test. I had no symptoms at all before I was diagnosed.

After my smear test, I was asked to attend an appointment at hospital. This concerned me so I did some ringing around to find out what the appointment was for. I was told the appointment was for a colposcopy at Guys. During the colposcopy, the nurse looked at me and said, 'I think I better call the consultant.' At this point I knew something might be wrong. The consultant said he wanted to take a biopsy to investigate further.

I sat down with the consultant who said, ‘there is something very abnormal here, we will need to investigate further and you will need an operation under general anesthetic.’ I was then taken into a room and given a cup of tea and asked to sign a form confirming the biopsy had been taken. I was quite frightened at this point; I could tell that something was quite badly wrong.

After nine days I hadn’t heard anything so I started making some calls. I was then told that biopsies take six to eight weeks. This confused me as I was told I would hear quite quickly. I then got a call telling me I had an appointment the following day and they told me it was in oncology.

I went for the meeting with my friend the following day at 9am. 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 sign a consent form. It was pretty awful to be honest. I got the impression that the 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.

The consultant did talk about my fertility – but very much in a ‘foregone conclusion’ type of way. He simply said, ‘well you’re 43 aren’t you so I assume your family is complete’. Then he moved on. He didn’t present me with any other options.

One of my old friends from university came with me to my diagnosis meeting. It was invaluable having her there as I didn’t take anything in and she became my eyes and ears.

I remember having to phone people and tell them which was really hard. I tried to come up with lots of different ideas to entertain myself while I was in hospital. One friend suggested knitting so I got knitting needles and wool to take into hospital. I kept myself as busy as possible and tried to stay very upbeat.

I just tried to make things entertaining during treatment as it helped me to cope. I also kept myself busy, it was like being at work with a deadline. I made it into a project and kept myself really busy to make sure I was going to get better. I treated it like work and this helped me to cope.

I do remember wanting to phone lawyers as I had to think about a will, but I couldn’t bring myself to do it. I also had to manage my friends, I found it really hard working out how different people were going to respond.

When I finally came round in my room properly I became very, very upset because I learned my bladder had been damaged during the operation. I remember I was thinking I had come to hospital to get better, but I ended up worse off especially as I now needed a catheter for two weeks. Having cancer didn’t seem real, but having a catheter felt very real to me which was horrific. I was in hospital for three days. I experienced some amazing things while in hospital including the way in which I felt looked after. I felt it very moving when someone brushed my hair or washed my face. It was also emotional when anyone came to visit or sent me messages, I remember I kept asking myself: ‘Should I be entertaining these people?’

When I left hospital I stayed with my sister who was amazing. My son stayed with my cousin so I didn’t see him in two weeks. My sister really did look after me. I didn’t realise I had to administer an injection every day to stop DVT. I struggled with that as I don’t like needles but my sister helped which was invaluable.

I really valued the support that I had from my friends, and this has been the case all the way through. I valued them so much that I was afraid to leave them behind in London when I went to Leeds. My close friend would always drop everything to come to an appointment with me, this was one of the most amazing parts for me, she showed me so much support.

As soon as I got the all clear my close friends were continually saying that they are delighted and telling me that I must be so happy and so relieved. I found this quite hard though, because for me the idea of my life going back to normal seems a long way off. Life will never go back to how it was before, it’s a case of finding the strength to build something new. I think many people don’t recognize this.

For me, I really just want my life to go back to normal and then I will start to feel better. But for my life to go back to normal seems a very long way off. I think many people don’t recognise this.

From a friends’ point of view, it has been great for me. Before my diagnosis I was really focused on work and on my son. I saw my friends quite rarely. Following my cervical cancer experience, I have been forced to lean and rely on my friends so much more, and I have also made amazing new friends. I have made a real effort to learn how to ask for help from my friends. As a result, the relationships I have with my them are much stronger.

I value my friendships far more than I ever did before and I put constant effort into maintaining my friendships. I also put more value and importance on family than I ever did before.

6.4 Lack of information on cervical cancer, diagnosis and treatment

Christine’s story – ‘I have had such conflicting information and mixed messages’

I went to the doctor to have my coil removed in May 2013. During the procedure the doctor said she wasn’t happy with what she was looking at and could see something on my cervix. She told me to wait while she looked something up on the computer. I remember lying there thinking I don’t know what she means, I only had my smear test eight months ago. Which is what the doctor then re-iterated, confirming my recent screening and told me not to worry about it. She told me that she thought it would be fine, but that she would arrange an appointment to see a specialist at the hospital. In the meantime, my coil was left in place until the specialists could see what they thought.

For the next two weeks I was absolutely terrified. I was on the Internet looking up stuff. The appointment came through and I went for the MRI scan. I thought again, I have never had a scan like this before. It was all very strange and I was in there for 35 minutes. With that over with, a couple of days later I had a letter saying I had to go for a cat scan in Rugby. I only lived ten minutes away from my local hospital, so was questioning why I now had to travel to Rugby. I later found out it was because they could offer me a scan earlier than my local hospital. I was petrified as I didn’t know what a cat scan was and I hadn’t been told that I needed one, so that confused me. But I went and had it done.

I went back for the results and I was petrified and I looked at the consultant who looked at me and said that he was sorry to have to tell me that I had cancer. I told him that I already knew this. He asked how and so I told him about what the nurse had said when I had my colposcopy. The consultant advised that she wasn’t supposed to have told me. He went on to explain that it was 4cm and gave me lots of information about the dimensions, which was all going over the top of my head.

I went for my next appointment with the surgeon. He pointed out that I was overweight and that I might want to go with a different treatment option, as due to the size of the tumour, there were other procedures that could be done. He said that they would give me something called cisplatin and I would have radiotherapy and chemotherapy. He told me that as he had such a long surgery waiting list, all of cancer patients, he wouldn’t be able to fit me in for another three months. All I could think of was that I didn’t want the cancer inside me. I thought that if the alternative option was going to be quicker, that is what I was going to do.

They arranged an appointment for me the following morning. I met with the oncologist. He was lovely. He told me the ins and outs of the procedures and that my cancer was curable. He told me that I might lose my hair, but that I wouldn't lose it all. He also told me that I would be having brachytherapy and six weeks of radiotherapy every day for 10 minutes. It was all going over the top of my head. I went with what he suggested, as he could start the treatment the following week and I just wanted it gone.

I was taken into a room with a Macmillan nurse and given lots of information about having a radical hysterectomy. It had already been decided in a multi-disciplinary meeting what treatment I was to have, so the nurse had all the relevant information. I didn't find about Jo's Trust from her, though, this was through my own research.

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.

To begin with I was probably on the phone to my GCNS too much. I thought they would be able to answer all of my questions. I often had to leave messages on a voicemail and they only got back to me sometimes. I think they were quite busy, but I lost confidence in them. Especially when one of them told me that I had to pull myself together and get on with things. I stopped phoning them. I used the Jo's Trust helpline instead and accessed a local support group. I also used the Cancer UK helpline, who were helpful. You could speak to a nurse there.

The Macmillan nurses made me feel like I was a hypochondriac. Once I phoned them as I was concerned about the amount of weight I was putting on. During chemotherapy I had lost all sense of taste and found it difficult to find anything to eat. But when I regained my taste I started to eat lots. I was told by them that it didn't matter in the grand scheme of things, so I carried on stuffing my face! I put on two-and-a-half stone. I went to see my oncologist who questioned why I had put on this weight. She told me that I would end up with diabetes or a heart attack with that much weight gain. I told her that the Macmillan nurse had said it didn't matter.

The chemo I went on to have was different to before. It took eight hours instead of two hours and there were three different lots of it. It made me quite ill. They give you this card, so if you feel ill, you can go to A&E and they have to see you within an hour. But I called the chemo suite and explained how I was feeling and that I couldn't breathe properly, with pains in my shoulder. They told me to take some co-codamol and to see my doctor. My situation deteriorated and my partner called an ambulance as he thought I was having a heart attack. It turned out I had blood clots on both lungs, for which I had to administer blood-thinning injections for six months.

By Christmas I had received a good partial result. I had a scan and my oncologist decided to give me three further rounds of chemo. The tumour had shrunk. Everything was looking positive. On Christmas day I woke and went to the toilet. I thought I had wet myself and turned on the light. I found that I was standing in a pool of my own blood. I was taken to A&E, my clothes had to be cut off me and they didn't know where the bleeding was coming from. It was a horrible experience. There was a lack of staff that day. I then saw my surgeon that had done my hysterectomy who told me this was the natural progression of the disease. A confusing time followed, as there was conflicting information from different doctors. They thought that some of the tumour could have fallen off and this is what had caused the haemorrhaging.

I went back for chemo and had two further rounds, a scan and then my last chemo session. After which I was told it had stabilised and that I needed to let my body rest, as it was not in a good place after all that treatment. This is when my work contacted me to say that they had paid me full pay

Through diagnosis to treatment, to the present day, throughout my process I have had very conflicting information and mixed 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.

I don’t know what to expect next. I am always waiting for results to tell me how long I have left. I

I don’t plan ahead now. I am no longer in charge. This disease has taken me over.

I am stuck in no man’s land with no answers.

7 Conclusions and recommendations

7.1 Conclusions

All of the women we spoke to had very different experiences depending on their own circumstances, diagnosis and prognosis.

7.1.1 What patients value throughout this journey, and what they find difficult

- Family support is one of key factors for women and being able to rely on other family members is critical – the need to support women’s families (particularly partners, but also other family members and children) should not be underestimated.
- Women hugely valued the medical professionals they came into contact with. Diagnosis and treatment were, in every case, a more positive experience when these women came into contact with informative and caring health professionals. This is particularly true for consultants and clinical nurse specialists.
- Throughout the journey, patients valued staff who were sensitive, honest and caring – for too many, there were examples of staff being uncaring or abrupt causing distress and worry.

7.1.2 Key differences between care models and provision

- There were some important differences between women’s experience of care – although it is hard to draw any conclusions about regional differences given the number of women who were interviewed.
- Some of the important factors included: choice of hospital; access to a second opinion; extent to which women feel involved in choices about their care and treatment; access to a clinical nurse specialist.
- Very few women were given a written care plan or a holistic needs assessment, although many said that they would have welcomed this.
- And for many women, there was a mismatch between the care they received at the start of treatment and the follow-on care they experienced once their initial treatment was over, with some saying they felt abandoned.
- There was a lack of emotional and psychological support for women with very few being offered this, while this remained a need for many.

7.1.3 The experience of cervical cancer treatment for patients and for their families

What is life like on a day to day basis when living with cervical cancer and going through treatment?

- Impact on work is a huge issue for many women – whether this is because of work being difficult to handle because of the amount of time they needed to take off, or because of the feeling that they have lost part of their identity.
- For many women, the impact on family life – either their children or partner – is profound and dealing with this while carrying on with some semblance of normality is very challenging.
- The physical impacts are also dramatic for many women and undergoing treatment is for some a brutal experience which results in long periods of isolation and sometimes loneliness.

7.1.4 Differences from pre-conceived expectations, both before and during treatment, and how these expectations are managed throughout

- For many of the women we spoke to, there was a lack of material on what to expect, and sometimes, when this was available, it was not provided at a time that they could process the information.
- Information about side effects of treatment was definitely lacking with many suffering unexpected side effects and finding this far more debilitating than they had expected.
- For most women the level of care that they received in hospital was good and many had very fine examples of specific members of staff who had helped and supported them.
- For some however, the nature that they were told about their diagnosis and then the way that consultants communicated with them were unhelpful and insensitive, and for some this was a particularly distressing part of the process.

7.1.5 Where women felt their needs were not met, and where the most meaningful support can be given

- Lack of emotional and psychological support is one of the key areas of unmet need for many women, with this aspect of their experience largely being ignored. This is particularly the case during treatment and the follow-up stage. Women interviewed talked in detail about a lack of support during follow-up in particular.
- Many women are left entirely on their own to seek out support and while for some people this is fine, for others this can lead to them not receiving the help that they need, leading to further feelings of isolation.
- Information about loss of fertility is something that many women feel is lacking and the way this is handled is sometimes insensitive and inadequate.
- Women are also not given the support they need in terms of dealing with the impact their illness and treatment may have on other aspects of their relationships, including on their sex life; personal and family relationships and on their children.

7.1.6 Potential support, information and policy related solutions to improve the patient experience and quality of life, and that of their families

- Women want information at a time that suits them and their circumstances – women need to be able to define this for themselves and for there to be flexibility around what they receive and when.

- Provision of Personalised Care Plans and Holistic Needs Assessments needs to be looked at urgently, as provision is patchy at best. This may be the way in which they are described to patients, but it is an area which should be investigated.
- Provision of emotional and psychological support needs to be addressed.
- The financial impact on women and their family's needs to be addressed, through provision of better information for women, as well as for employers.
- Support for women post-treatment should be looked to ensure that women do not feel abandoned.

7.2 Recommendations

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 or 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 understand 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 women addressed throughout treatment and after care, with signposting to appropriate services.
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 be suggested.

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 so patients do not feel rushed into decision making.
15. Signposting for support related to changes and loss of fertility should be given for all women affected

Impact and follow up

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 for further support for the family.
17. Clinical staff should follow The National Forum of Gynaecological Oncology Nurses (NFGON) guidelines on psychosexual issues after cervical cancer to ensure the impact of treatment on intimacy can be raised.
18. More work needs to be done to inform employers about the short-term and long-term impact cervical cancer may have on women in their workforce.
19. The financial impact of cervical cancer can be substantial. Extra support and advice in this area is urgently needed, alongside signposting to organisations such as Macmillan, who offer targeted financial support.
20. A collaborative project needs to be started to help design a care model to provide all of the above extra support that women with cervical cancer/partner and families require focusing on the long-term consequences of treatment.

8 Further help

8.1 Jo's Cervical Cancer Trust

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 crucial support and information on all aspects of cervical cancer.

Talk to us

Call our free Helpline on 0808 802 8000

Get shared support

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

Find information

Visit jostrust.org.uk to find out more about cervical cancer, treatment, being a partner of someone affected and moving forward after a diagnosis.

8.2 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.

8.3 Other sources of support

Jo’s Cervical Cancer Trust: jostrust.org.uk/support - 0808 802 8000

Macmillan Cancer Support: macmillan.org.uk - 0808 808 0000

Marie Curie: mariecurie.org.uk - 0800 090 2309

Pelvic Radiation Disease Association (PRDA): prda.org.uk - 01372 744338

The Lymphoedema Support Network: lymphoedema.org - 020 7351 4480

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