

Not so simple.

The impact of cervical cell changes and treatment

220,000
women are
diagnosed with
cell changes
every year in
the UK

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Foreword

As Head of Support Services at Jo's, I see first hand the questions and anxieties that women and their loved ones come to us with. We directly support thousands each year through conversations on our Forum, calls to our Helpline and questions submitted to our Ask the Expert panel.

A large number are from those affected by cervical cancer. Another group are those looking for support or information about HPV vaccination and cervical screening. The third group is women for whom screening has identified cell changes (sometimes called abnormal cells) and who may need treatment.

Many women have very straightforward and positive experiences of colposcopy and treatment. It has a very high success rate and is an important step in preventing cervical cancer development. Yet through our services we see that anxiety among this group of women can be very pronounced, and the need for information and support is high. For this group the experience is not so simple.

Questions are wide ranging and include topics around every day practicalities such as "how soon after treatment can I swim?", confusion around terminology in the letters received, misconceptions around the human papillomavirus (HPV) and fears around symptoms post-treatment. There is a very real sense that many women do not feel prepared for what is happening to them. The side effects or experiences that some women report can also be far more severe than literature sometimes suggests.

There has been very little research into the experience of those diagnosed and treated for cell changes, and the questions and concerns we receive prompted us to look deeper to gain a better understanding of the issues and how we can improve the experience of those affected.

The extent of psychological impact was bleak. Worse still were the numbers dealing with side effects on their own, especially when services exist that could treat or lessen the impact on many.

We work closely with the colposcopy community and know that time is stretched. However, it should not be the case that some women are having such bad experiences. Falling between the gap of prevention and diagnosis of cervical cancer, women with cell changes are a group who need to be more visible.

This report is just the first step and we hope it will inspire further research to better understand some of the issues we have found.

Where possible in this report we avoid using the word 'abnormal', preferring 'cell changes'. After speaking with women affected, we want to recognise their preference for this term and help decrease the stigma around diagnosis.



Rebecca Shoosmith
Head of Support
Services, Jo's Cervical
Cancer Trust

Introduction

Of the five million women invited for cervical screening each year in the UK, around 220,000 will be told they have cell changes (abnormal cells). Many will be treated to prevent the potential development of cervical cancer.

The life-long impact of cervical cancer and treatment cannot be underestimated. Many women are living with consequences including changes to bowel and bladder function, pain, loss of income, loss of fertility and significant changes to sex and intimacy. Treating cell changes before they develop into cancer can prevent or reduce many of these impacts. Treatment is highly effective with about a **90%** success rate¹. However this preventative measure can have a lasting impact on some of those who receive it.

“The team that carried out the loop excision were so lovely and supportive and really looked after me... I was treated with dignity and able to feel at ease with the procedure to remove precancerous cells. I'm glad I had treatment but it was so stressful.”

Management and treatment of cell changes in the UK

Pathways for cell changes depend on the grade of abnormalities detected, past screening history and a woman's personal circumstances. Some treatments remove cells (large loop excision of the transformation zone (LLETZ) and cone biopsy), while others destroy them (laser therapy, cold coagulation and cryotherapy).

With current knowledge and tests, we can't be absolutely certain which cell changes will eventually develop into cervical cancer and which will not. Currently, treatment is recommended for CIN3 (high grade) and CGIN, and may be recommended for CIN2 (high grade). However, CIN1 (low grade) is likely to regress without treatment, so in this case most women are invited back for cervical screening in 12 months to review.

Finding the balance between conservative management and treatment is a challenge for colposcopists, particularly when CIN2 has been diagnosed. There is variation in the management of CIN2, with some colposcopists treating and others preferring to monitor women. A survey conducted by the British Society for Colposcopy and Cervical Pathology². found just over half of its members employ conservative management for some cases of CIN2 and **12.4%** for all cases. Selection criteria of who to treat – including age, HPV history and whether a patient smokes or has a compromised immune system – also varied between members.

Some treatments remove cells, while others destroy them

Risks and side effects of treatment

Treatment is only offered when a clinician deems it the right course of action and it is discussed with the patient. While all treatments are considered safe, as with any medical procedure, there are possible side effects that will vary depending on the individual, how much of the cervix is removed and how many treatments are given.

According to the NHS³

Common side effects of treatment include:

- mild pain, similar to period pain – this should pass in a few hours and can be relieved with paracetamol or ibuprofen
- light vaginal bleeding and brown, watery vaginal discharge – this may last up to 4 weeks

There's also a small risk of more serious complications, such as:

- an infection – this can cause heavy or persistent bleeding, smelly vaginal discharge and persistent tummy pain; see your GP if you have these symptoms
- a slightly increased risk of premature birth (before the 37th week of pregnancy) in future pregnancies – this is more likely if you need repeated treatments or a lot of tissue needs to be removed

As with all medical procedures, there are possible side effects

Limited formal research has been undertaken into the patient experience of being diagnosed with cell changes, especially potential long-term consequences. This research sets out to do that. It does not set out to criticise those working in colposcopy or the quality of treatment. Instead, it aims to provide greater insight into the experiences of those affected and identify where further support, information or research is needed.

We acknowledge that this research has limitations. The data collected is self-reported and some side effects might be causal of others or related to other factors in a woman's life. Furthermore, the respondents are a self-selected group and may not be representative of all those who have had a diagnosis and treatment for cell changes.

The intention of this report is not to create fear or doubt in the minds of those awaiting treatment. Treatment remains highly effective at preventing cervical cancer. However, every woman deserves the best possible care, and should feel fully informed and supported throughout their experience.

1,622
respondents

Methodology

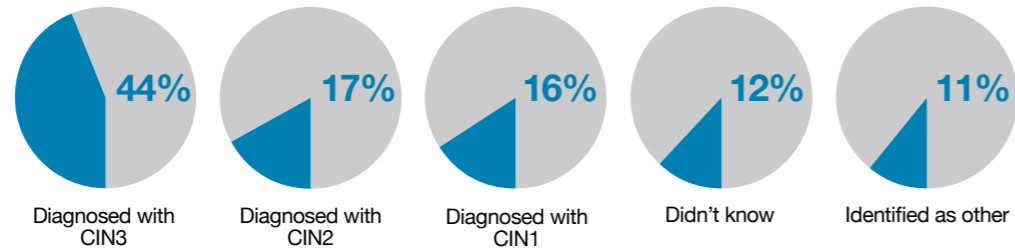
The research was conducted through an online survey open for three months from November 2018. 1,982 respondents completed the survey. Exclusions were made based on the research criteria, including those residing outside of the UK and those not having had cell changes, leaving a sample of 1,622.

Of these, 611 respondents were currently having treatment or were less than three months post-treatment, so were excluded from some questions. 289 subsequently had a cervical cancer diagnosis and were also excluded from some questions, as there was great potential for their symptoms to be impacted by their cancer treatment. The fact that such a high number had a cancer diagnosis is probably indicative of it being publicised through our channels.

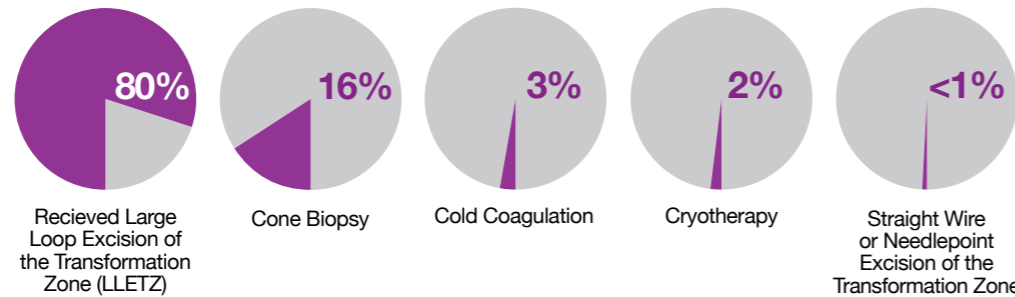
Eighty-nine per cent of respondents identified as being white British, **4%** as mixed or multiple ethnic groups and **6%** black, Asian or another ethnicity. Eighty-three per cent were living in England. Eighty-six per cent were non-smokers (**14%** of those had previously quit).

Fifty per cent were under 35 years old, **40%** between 35 and 49 years old, **9%** between 50 and 64 years old, and less than **1%** were over 65 years old. Sixty-eight per cent had been diagnosed under the age of 35, **14%** under 25 and **28%** between 35 and 49.

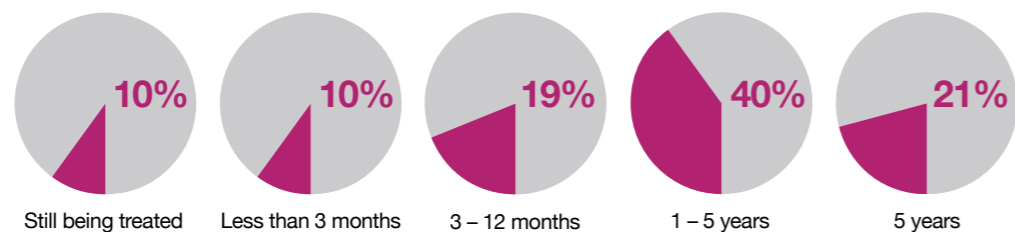
Diagnosis



Treatment received



Time since treatment



80%
received LLETZ
treatment

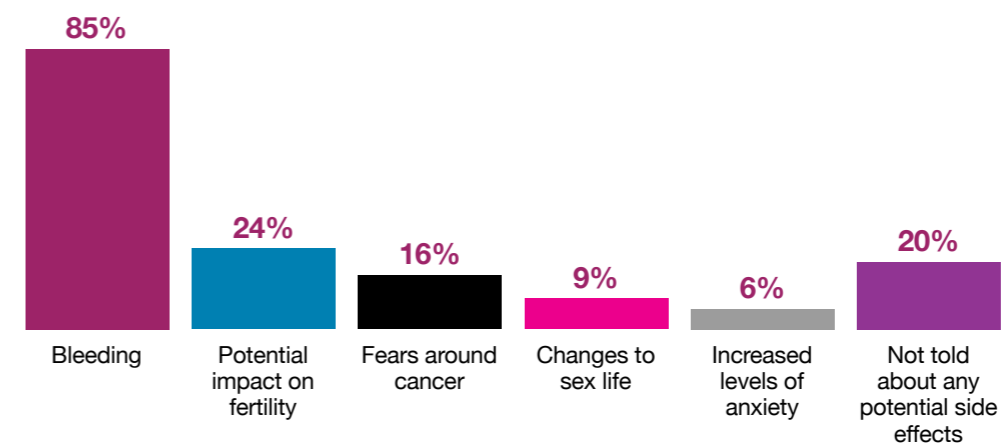
Key findings

Many women reported physical and psychological side effects due to their diagnosis and treatment. While most were short term and anticipated, some women experienced more profound side effects that continued for a significant period post-treatment.

Awareness of side effects

Being informed of potential side effects means women can be prepared to deal with any symptoms, and know how and when they should seek medical help. Worryingly **20%** said possible impacts were not explained to them, with varying numbers aware of specific impacts.

Percentage who had each impact explained to them



20%
said possible
impacts were
not explained
to them

“I would have appreciated more information at the time of diagnosis and also after treatment. The staff were wonderful with emotional support but there was little information given. I had to research it myself.”

Treatment options

Two thirds (**60%**) were not told about different treatment types prior to treatment and the number of women having treatments other than LLETZ was low, which raises questions around the availability and perception of other treatment methods in colposcopy. The amount of time given to appointments in colposcopy could be a limiting factor to discussions about treatment, side effects and choice. However this is again an important aspect of women potentially being able to make informed choices about their healthcare.

Some women reported not being aware that they were going to have treatment until after it had been carried out. Which was highly concerning:

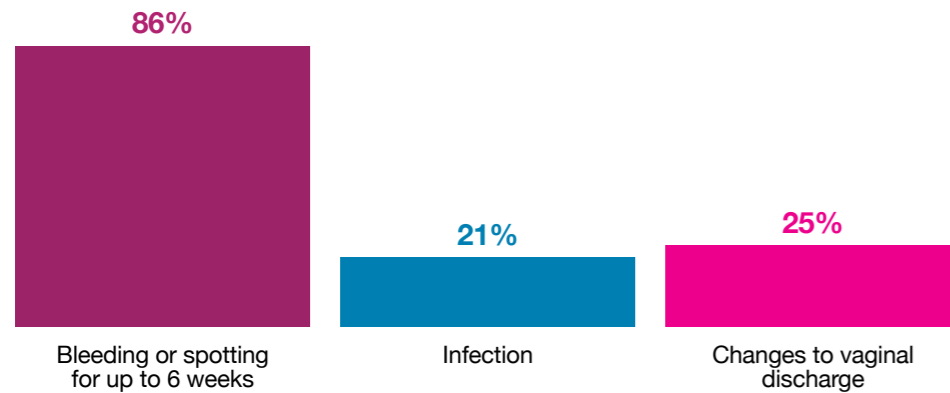
“I had a LLETZ but at no point beforehand was I told what it was or what & why it was happening. I was young, on my own and absolutely terrified and I wish I'd refused to have it at that point and insisted on making another appointment for another time.”

“I was given a sheet at the end of treatment. Which told me what I couldn’t do and what to watch out for. None of the above [known side effects] was discussed.”

Experience of common side effects

Unsurprisingly, high numbers experienced known and common side effects following treatment.

Percentage who experienced each side effect



Some women were underprepared for these side effects or experienced far more severe symptoms than they anticipated:

“Very heavy bleeding. I was going on holiday a week later and wanted to postpone doctor said no and that I would hardly bleed and could go swimming. Absolutely no chance it ruined my holiday and had cramps and very heavy bleeding.”

Most worryingly, high numbers reported feeling surprised or concerned when experiencing these symptoms, or being unaware of how long they would last:

“The following week I bled very heavily - blood poured out of me onto the floor when I got up in the night to use the toilet. Much heavier than any period I have ever experienced - it was alarming.”

Those who sought help usually went to a healthcare professional. Reasons for not seeking help included anticipating that side effects would clear up unassisted or feeling too embarrassed to do so.

These known and common side effects are mentioned in current literature given to women referred for colposcopy, so this lack of awareness indicates a reliance on women to have found, remembered and understood this information instead of discussion to ascertain this. Discussion should include when duration or severity may indicate the need for medical intervention and who the most relevant healthcare professional to visit is.

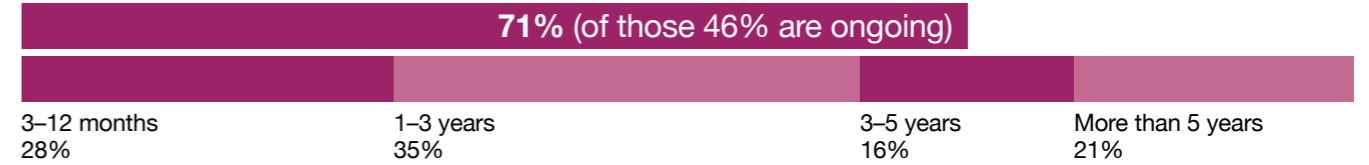
93%
of those who had an infection sought help
40%
of those with abnormal bleeding sought help
35%
of those with changes to discharge sought help

Emotional impact

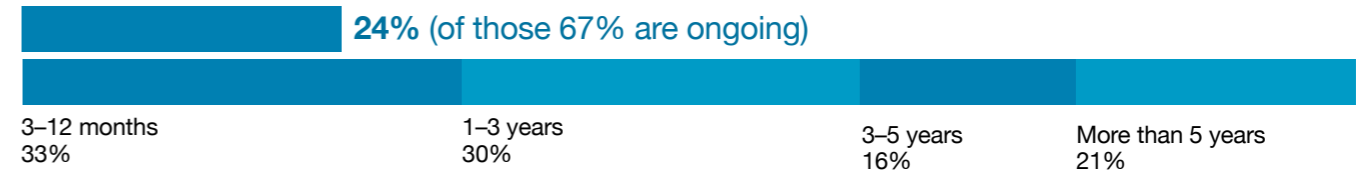
The psychological impact of diagnosis was profound, with high numbers affected by often long-lasting mental health problems or fears. An overwhelming number have not received any support to help them cope, with many feeling embarrassed or not wanting to bother anyone. Fear of cancer was especially prominent, remaining high even among those many years from diagnosis.

The psychological impact of diagnosis and duration since treatment where impact is ongoing

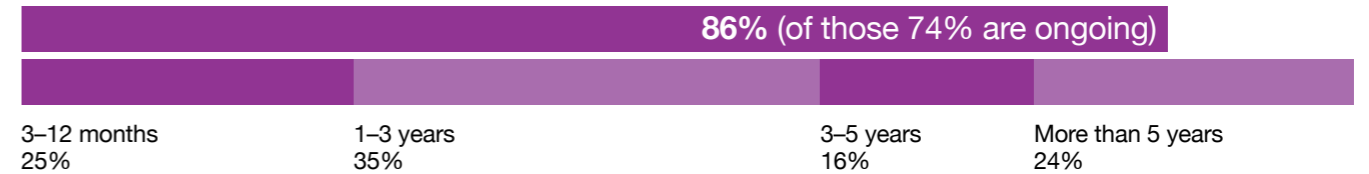
Anxiety



Depression



Fear of cancer



Onset was generally straight after treatment, but a significant number reported experiencing symptoms some time after, including a further 20% affected by anxiety within the first six months.

While impact lessened over time, extremely high numbers remain affected. Forty-two per cent of the full sample is currently living with anxiety, which they attribute to their diagnosis.

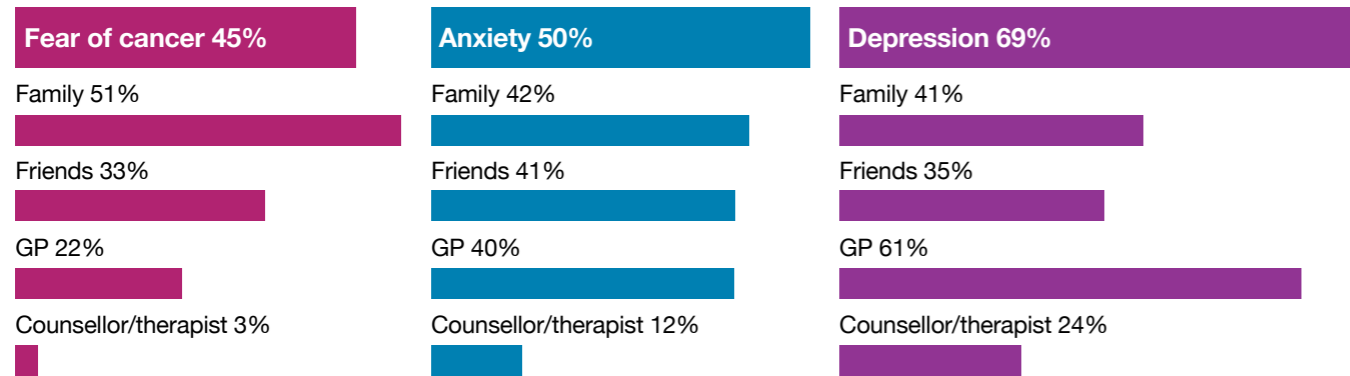
In the UK, one in four people will experience a mental health problem each year, meaning diagnosis may come at an already difficult time. Some women reported their diagnosis being triggering of existing health conditions:

“I’ve had episodes of depression for over 10 years but the diagnosis and treatment triggered the onset of a new episode. I felt ashamed and guilty about the HPV diagnosis and isolated myself as I didn’t want to tell anyone. I withdrew from my partner as I felt like he saw me differently.”

Only half of women affected by the psychological impacts told someone and of those who did, many chose friends and family instead of a health professional.

A further 20%
were affected by anxiety within the first 6 months

Percentage affected by each impact who sought help and from whom



Reasons for not seeking help included learning to live with it, feeling like they would be bothering people, finding it hard to ask for help or not finding their healthcare provider approachable.

“ had no idea emotional effects were common or normal and therefore did not seek the advice and support i perhaps should have done.”

An overwhelming **39%** of those with anxiety and over a quarter (**27%**) with depression did not go on to receive support, management or services.

Seven per cent of those with fears around cancer were told it would go away with time, **5%** were told that these fears were unrelated to their cell changes, **14%** were not told about available services and **3%** were told nothing could be done to help them.

A quarter (**24%**) experienced additional psychological impacts. This included feeling paranoid, embarrassment at having delayed cervical screening, loss of body confidence, fear for family members if a cancer diagnosis was received and anxiety over future cervical screening:

“I generally feel fine going to the appointment but then almost always start crying as soon as the speculum is inserted.”

“I previously suffered with depression and anxiety before the diagnosis, but this made me feel ashamed of myself, I looked at myself in a different way, I shut myself off and I continue to do so.”

Confusion and fear surrounding HPV was prominent. This was often highly negative and ongoing:

“I cry quite often when I think about the fact it’s an STI and that makes me feel quite dirty and that there would be social shame. I feel annoyed because someone has given it to me and now I’m having to deal with it and the on-going emotions. I’m scared for my next smears and the possible results. I’m anxious about every pain or discharge or bleed that I have which previously would have been nothing but now I’m worried about.”

“I’m anxious about every pain or discharge or bleed that I have.”

“I was given a number to ring but have never felt comfortable to do so.”

For some women, diagnosis can have a highly negative impact on their mental health and this needs to be urgently recognised. Women must be given time to raise concerns and be made aware of charities or services providing further support. This recognition should be in place from the first colposcopy appointment, as well as at subsequent colposcopy and GP appointments.

Sample takers should further take into account the impact diagnosis and any associated treatment can have on subsequent cervical screening, and provide opportunities for women to talk this through before the test.

“Anxious every time I see things like smear tests hate sex now or anything going near that area. Have not been back for a smear since the colposcopy.”

“Worry that it wasn’t all removed, worry when it was coming to my annual smear.”

Fears around fertility

Many women have fears about effects on their fertility, including miscarriage or being unable to conceive following diagnosis and treatment.

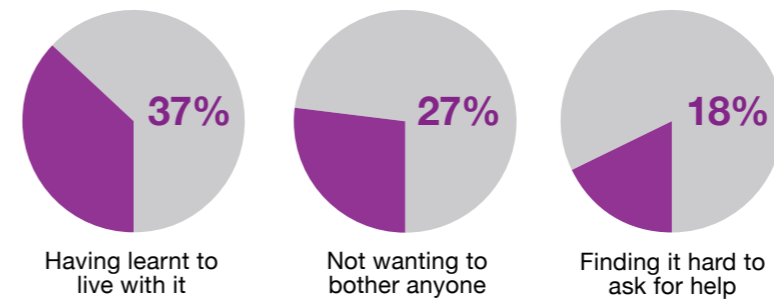
Some treatments can bring increased risk of miscarriage and premature birth (before 37 weeks) if more than 10mm of cervical tissue is removed or multiple treatments given⁴. However increased risk is very small (between **2-10%**) as most LLETZ and cone biopsy treatments remove less than 10mm⁵.

“I have never been pregnant, and just the idea of that choice being taken away from me just scares me terribly, with all my sisters and cousins having babies currently and recently I cannot get away from the thought that my latest smear may come back with abnormalities again and it mean another set back.”

“I was utterly convinced I would never have children.”

As most women having treatment are at no greater risk, many worries were disproportionate to risk. Ensuring women are fully informed about their individual treatment, for example the amount of cervix removed, and any risk or the absence of risk is important and could remove or reduce this additional worry or anxiety.

Reasons those affected did not speak about fertility concerns



“there was just a barrier... like what i was going through wasn’t enough to warrant needing support even know i really did.”

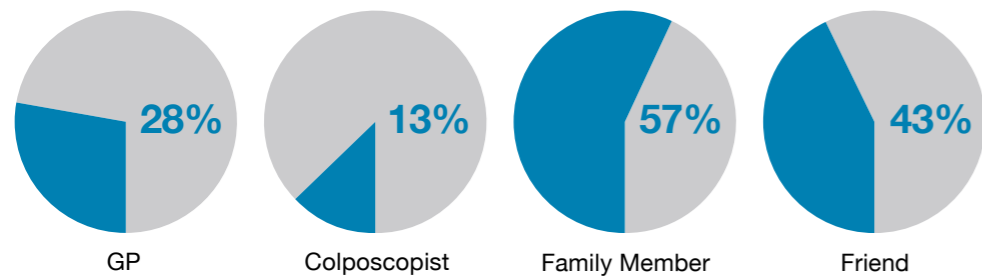
45% of respondents reported having had fears around their fertility

47% have not spoken about their fertility concerns

Only small numbers spoke to health professionals. Under half (41%) who spoke to someone received the support they needed, showing women are not seeking support from the right sources or being given information about where to access support.

While fears subside over time, 54% reported still being worried about their fertility.

Where those who sought help went



“I wasn’t given any info about the LLETZ and what it could mean. but then I got pregnant and the midwife said to me oh you’ve had a LLETZ, it’s likely you’ll have a miscarriage at 16 weeks onwards then.”

“With my 2 pregnancies since my treatment both babies came early. My cervix couldn’t hold them. This possibility was never explained to me before the treatment.”

“I felt that information about fertility in the aftercare leaflet was limited and I was concerned that the procedure would affect my ability to conceive or to carry a baby.”

For women who were told that their treatment may affect future pregnancies, fears were understandably heightened, demonstrating the additional need for support for higher risk pregnancies, as well as consistent information quantifying any risks:

“I was told I would have miscarriages, preterm labour or not be able to carry at all. I was told not to wait so I started trying and fell pregnant immediately. Was classed high risk. Had a very stressful pregnancy worrying about preterm labour and miscarriage and was sent for scans every 2-4 weeks. I ended up going 5 days overdue and had a healthy baby girl.”

“I had a miscarriage before my daughter and the idea of going through it again scares me so much – it made my pregnancy with my daughter fraught with anxiety.”

“After having my treatment and being told my cervix has been compromised and I’d likely need a stitch in pregnancy will only now add to that anxiety when we try for a second baby. I’m scared it will increase my chances of miscarriage – more so at a later stage in the pregnancy. I worry about it a lot and intend to speak to my GP when I fall pregnant.”

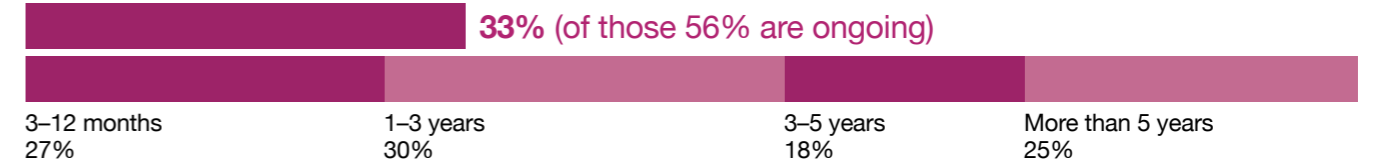
41%
of those who spoke to someone received the support they needed

Sex and relationships

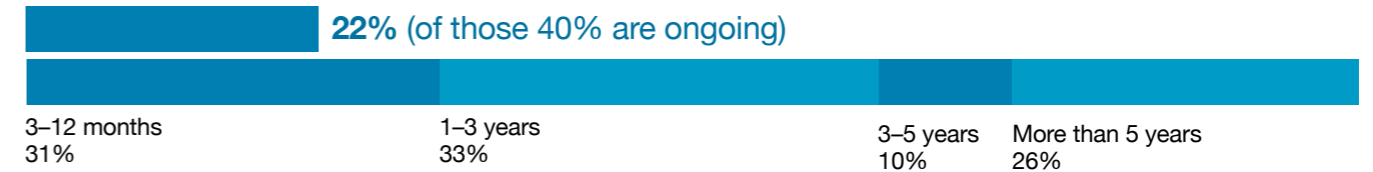
Issues related to sex and intimacy were prominent, with many women reporting negative changes to, or loss of, their sex life following treatment. Feeling less attractive or confident, fears about HPV transmission or feeling ‘dirty’ were recurring themes. The enduring nature of these issues, coupled with lack of support to treat or manage them, was especially concerning.

Percentage affected by each impact and duration since treatment where impact is ongoing

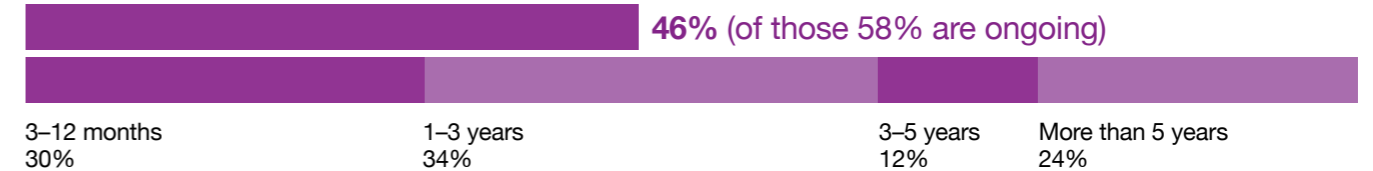
Pain during or after sex



Bleeding during or after sex



Psychological changes



“First time having sex – 4 weeks after treatment – was very painful and made me have a lot of pain after. It scared me. But weeks afterwards it was ok and now I do not think about it.”

Fear of pain, or remembering pain and symptoms was evident for many women:

“I was very tender and could not have sex for about 4 months at the very least. The first few times were not enjoyable as I was tender but also mentally it was terrible remembering the pain I went through during treatment and scared the sex would damage the area or I would get an infection even though I waited as long as I did.”

“I was constantly worried that I’d bleed after intercourse as it was an indication that something was wrong.”

“Mind would replay the worries I had prior to having LLETZ and being on the chair again.”

The psychological impact of diagnosis and treatment on sex and intimacy is significant. Women used words such as ‘dirty’, ‘ashamed’, ‘insecure’ and ‘fear’, which starkly demonstrates the profound impact it has among some.

Comments included feeling disassociated from the body as being sexual:

“I have had a complete change to my sex life since having the treatment. I used to enjoy sex and felt confident in my body... I felt like my body wasn't for pleasure, it was just anatomy and there for medical purposes. I felt uncomfortable when having sex, I was concerned I may have felt different internally, even though I know this isn't the case. I felt paranoid that it was going to hurt or that I was going to bleed. I would become emotional when my partner tried to touch me, I couldn't become aroused for a long while.”

Feelings about self, including body confidence:

“My lack of confidence in my body following my procedure. I didn't feel 'normal' for a long while.”

“I became depressed as I didn't feel normal, I didn't know anyone at the time with this as all my friends had had normal smears. It's also hard to explain it to your partner what's actually going on & that you feel kind of ashamed of your body. I lost all sexual desire & that I felt so unattractive.”

Feelings related to HPV and cervical cancer:

“I couldn't have sex for 6-8 weeks after LLETZ treatment and when I did, it was painful. This cleared up over time. Before diagnosis, I had experienced pain and aching during and after sex and now whenever that happens, I worry it could be related to the abnormalities returning. I felt contaminated by the HPV and didn't want to have sex. I was and still am in a long-term relationship.”

“My sex life was impacted in a negative way and it hasn't fully recovered. I'm insecure and I fear sex. I feel like I don't deserve to enjoy it because it is something that could cause disease. This depresses me and makes me sad about the quality of my love relationship.”

“I was convinced I would contract HPV through having sex with my husband and believed they could have missed some cells and I had cervical cancer. I became angry at my friends who were overdue their smear tests.”

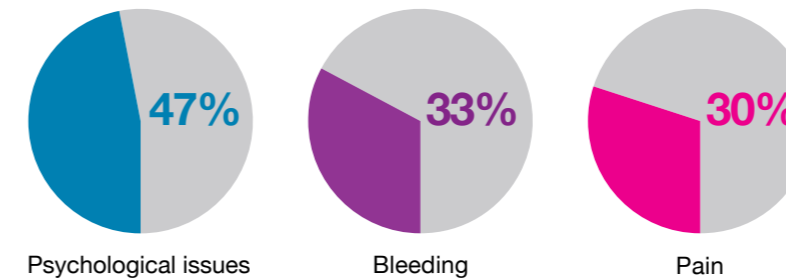
This is a further area where far greater recognition is needed. There is potentially an opportunity for literature or discussions in colposcopy to reference support needs which may exist post-treatment, as there are excellent treatments and services available:

“This is still ongoing now after 6 years, although my confidence has improved greatly following psychosexual therapy.”

“I was referred to psychosexual therapy after speaking to my GP and my practice nurse on a few occasions. This changed my life completely and helped me regain my confidence and begin to enjoy being intimate with my partner again although this has been a long process I don't think my sex life would have improved without it.”

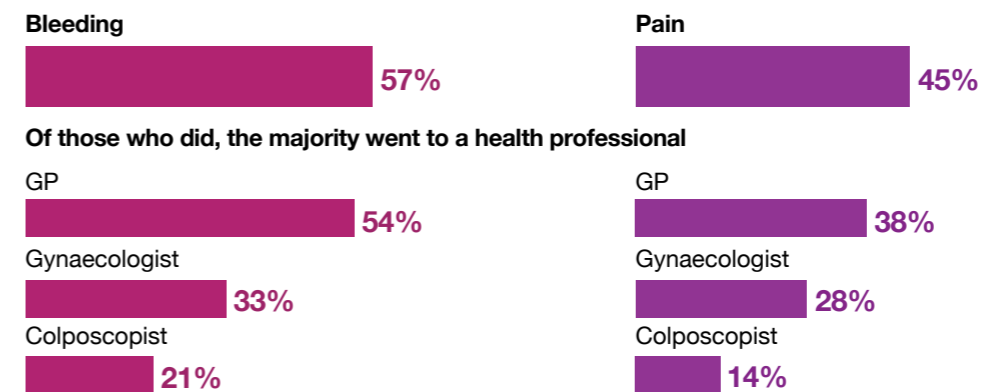
Sadly, too few women say they are getting the help they need, with high numbers feeling too embarrassed to discuss them.

Percentage affected by each side effect who felt too embarrassed to get help



Low numbers sought help for physical side effects, however, very few felt that the management, support or services they received met all of their needs.

Percentage who sought help and the source



For those affected by psychological changes, many which appear ongoing for a significant time post-treatment, only 28% have spoken to someone about these issues. Of those who have, the majority spoke to friends and family instead of a health professional. Only 8% got the help they needed demonstrating a significant unmet need.

Only 28% have spoken to someone about these side effects

Percentage who felt the help they received for physical impacts met all of their needs



“Obviously I was still upset about what I’d gone through as I didn’t expect it at all, so not only did I have that to think about, me and my boyfriend broke up in the progress of me going through this because in his words he “couldn’t cope”. So this just made the situation a whole lot worse.”

“I just don’t know how to articulate it. Suffice to say, at times I don’t know how my marriage is surviving.”

For some, relationships beyond their partner were impacted:

“My mum was worried for me and that has affected our relationship, she feared for my future more than [me] and it put a strain on her and guilt on me as a result of it all.”

Pain

The most reported pain was pelvic pain. Short term pelvic pain, lasting for a day or two, is an anticipated side effect⁷, after treatment such as LLETZ and cone biopsy. This research supported that, with over half (55%) of all women experiencing short term pelvic pain, generally starting immediately after treatment (79%).

“After treatment I had aches in my pelvic area, similar to period pains.”

However, it is concerning to see women were unaware they could experience this pain, and being surprised or concerned when they did.

“The healing was longer and harder than I expected... I would have found it helpful for the doctor to let me know I might have some quite bad lower stomach pains and to not expect to feel 100% for about a week so that I knew what to expect a bit more.”

“Unexpected pain. Wasn’t informed that I would have pelvic pain. Was treated for a cervical infection after the procedure. Still ongoing two months after.”

While pelvic pain reduced the further from treatment, high numbers were still affected far longer than the anticipated 1-2 days.

Percentage impacted by pelvic pain and duration since treatment where impact is ongoing



A potentially concerning finding is that 34% are still living with this pain which translates to around 17% overall of the women that took the survey.

29%
felt their treatment had affected their relationship

55%
experienced short term pelvic pain

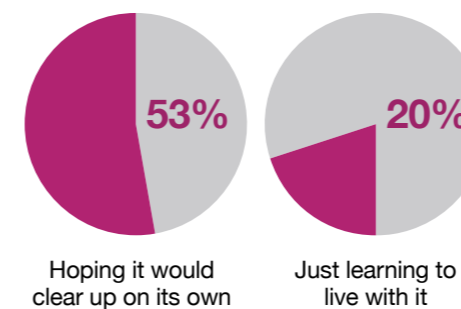
“I wasn’t informed that I would have pelvic pain”

Greater research is needed to understand if treatment, or certain circumstances, are causal of this ongoing pain and how prevalent it is in the treated population. Over half (55%) did not seek help for their pelvic pain. Furthermore, this research has highlighted a need for increased awareness or discussion around pelvic pain, so that women know what is normal and when to seek help if the type or duration of pain indicates the need for it.

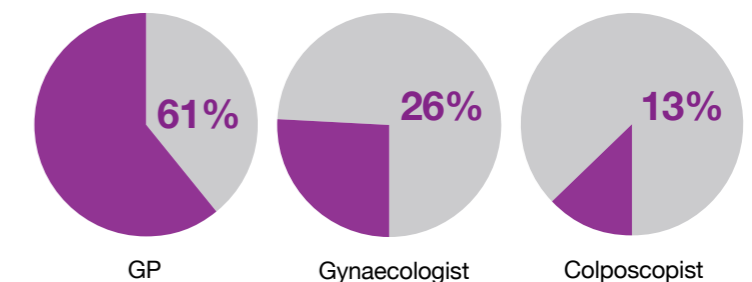
Over half 55%
did not seek help for their pelvic pain

“I still to this day have pelvic pain, but I brush it off thinking it is period cramps. I keep meaning to go back to the doctors but last time I told them they said it is normal.”

Reasons for not seeking help for pelvic pain



The majority of those who did report, spoke to a health professional



There may be a gap in understanding about pelvic pain and its causes, which could lead to needs not being met and referrals to gynaecologists or pain management clinics not being made or offered for those experiencing it ongoing.

“I had pain and aching for about 2 months after the LLETZ treatment, which I believe is normal. I still have pain and aching infrequently, sometimes triggered by sex but often without an identifiable cause. It’s not unmanageable pain though so OTC painkillers are usually sufficient to ease it.”

A small number of women (11%) reported other pain. This was generally immediately after or within the first two months of treatment (84%), and for 6% this pain is ongoing. Types of pain included back pain, leg pain and headaches. Just over half (55%) had spoken to someone about this pain, and for around 60% this was their GP. While the numbers are small, further research may be needed to explore this further, especially among those with back pain who were prominent in this group.

Only one fifth 21%
felt that all their needs were met
14%
were simply told that nothing could be done

Other issues

Additional consequences or impacts of treatment were rare, however further research may be needed to fully explore these areas.

A few women reported other physical impacts, these included changes in periods, loss of sensation in orgasm, dizziness and more painful cervical screening.

Some women (15%) reported changes to their day to day lives following treatment, such as their ability to work, with most (87%) occurring immediately after treatment. A third (38%) said this is an ongoing side effect.

Sadly, a few women reported highly negative experiences. This included feeling traumatised or receiving a diagnosis of PTSD. Whilst this is a very small group, their experiences should be further explored in the form of potential focus groups to establish any themes and areas where urgent attention is needed.

“I wish I never had it done and took the chance of my body healing itself as now I hate sex and will not have another smear.”

Positive impact

This research set out to better understand the experiences of women affected by the diagnosis and treatment of cervical cell changes. As such it is important to also highlight the positive experiences that were captured.

Many women mentioned using their experience as an opportunity to talk to friends about cervical screening or help address their concerns regarding treatment.

“After having two lots of treatment I got a letter back informing me the cells were not cancerous which is such a relief but it’s still in the back of my mind for next time. Overall though, I’m so glad I went for my smear as it was just a routine check and would urge other women to do the same. I have pushed my friends to go and get theirs done who either have never had one, or haven’t had one in a long time as they’re too embarrassed. I’m glad I have helped those people.”

“Everyone should go for their smear, I made all my friends do it and two other people had the same abnormalities as me so luckily they were checked in time.”

The majority of respondents (**78%**) felt that the experience was positive as it reduced their risk of cervical cancer.

“You are treated so well and compassionately during the procedure. I’m so glad I did it. The staff in the colposcopy department were lovely and made the experience easy.”

Just **4%** stated that they wished that they had not received treatment.

Given the range of physical and psychological side effects reported by respondents, this is extremely positive. It demonstrates understanding about the potential link between the detection of cell changes and cervical cancer among those treated.

Knowledge of Jo’s Cervical Cancer Trust

Most of the respondents (**85%**), including those who went on to receive a cervical cancer diagnosis, had heard about the charity before taking the survey. This reflects a limitation of the survey, as many who know us will have been looking for support, suggesting they may have had a certain type of experience.

The majority had found the charity online or through a campaign. **6%** were told by their colposcopist, rising to **11%** for those with a cancer diagnosis. Under **1%** were signposted by their GP.

53%
had used our
website
34%
had accessed
our online
Forum

Conclusion

A diagnosis of cell changes, subsequent colposcopy and potential treatment, can understandably be a worrying and confusing time. As with all medical procedures, treatment may have side effects and short term side effects are common. Treatment is extremely important in preventing cervical cancer, and this research has shown that the majority of treated women feel positive about that decision, demonstrating a general understanding of the importance of attending colposcopy and subsequent procedures.

Yet this research has also highlighted clear gaps in knowledge of known side effects, as well as women remaining affected for far longer than anticipated. It is also clear that many are not seeking or getting help to deal with these side effects or indeed know when, or from whom, to ask for help. Every woman referred to colposcopy is sent an information leaflet which briefly outlines known side effects and it is important that health professionals reinforce this information. Currently the onus appears to be on women alone to be able to read, remember and recall complicated information at a time when she may already be feeling concerned or worried.

One of the starkest findings is the ongoing psychological impact of treatment and even initial HPV diagnosis. It is evident that, whilst many women do view their diagnosis as straightforward, for some it can have a lasting impact. Feeling uninformed and not in control will only exacerbate these feelings, yet sadly far too many women reported feeling anxious, fearful and uncertain of what was happening to them.

The pronounced fear of cancer felt by high numbers of women, some many years from their treatment and despite the unlikelihood of diagnosis due to their treatment, indicates a clear need for greater provision of information at every stage of a patient’s care, along with more ongoing offer of support.

“Clinicians should not be so blasé about things they deal with on a day to day basis. For a lot of us, it comes as a shock and we fear the worst. Even now, many years after the initial abnormality, I have a fear of developing cervical cancer because of the HPV strain I have/have had (I still don’t understand that bit).”

Clarity and increased understanding is a clear theme throughout this report. It is important to consider this not only when directly supporting women, but when considering their treatment and management pathways too. It is evident that greater clarity regarding treatment for CIN2 is needed. While pathways for women with low grade (CIN1) and high grade (CIN3 and CGIN) cell changes are established, for women with CIN2 there is variation in whether treatment is offered. Given the impactful side effects this research highlights, a more conservative approach to managing these women may be favoured and we call on experts in this area to reach a consensus.

Screening and colposcopy services play a vital role in the prevention of cervical cancer which are estimated to prevent 5,000 cancers a year. Therefore it is important that women continue to have faith in those services. Health professionals, especially those working within gynaecology and colposcopy, have a responsibility to look at their own practice and identify if there are further ways they can provide support or clarity to the women they treat.

Recommendations

1

Further research should be undertaken to better understand, and improve, experience of diagnosis and management for cervical cell changes

This research is one of the largest into experiences of those diagnosed with cervical cell changes and we hope that the findings will be taken forward and built upon to improve understanding of the needs of women. As it is based on a self-selecting group, who are more likely to have had complications, further randomised research is needed with a wider group.

2

Standardisation of information about cell changes and potential side effects of treatment to ensure women are fully informed

There is currently some inconsistency in the information offered to women diagnosed with cell changes, with variation nationally, such as on the NHS website, and locally, where individual hospitals often develop their own materials. Standardised information will ensure that women are consistently informed about all aspects of potential side effects and their anticipated duration, as well as support services. While it is important to acknowledge this won't reduce the vital role of a health professional in confirming this information, it will help alleviate the many impacts discussed in this report and ensure informed choice regarding treatment. National public health agencies and the NHS in all four nations should take the lead on developing standardised materials, ensuring the full range of side effects are covered, with the support of patient organisations such as Jo's Cervical Cancer Trust.

3

Greater recognition of the impact of a cell changes diagnosis, and subsequent treatment, can have on women

While for many women diagnosis and treatment of cell changes will bring no significant consequences, this research has shown that for some women it can be an extremely difficult time, with some affected by a wide range of physical and psychological consequences. Far greater recognition is needed in colposcopy and general practice to ensure women are provided with, and signposted to, sources of support. This is not just the role of the colposcopist; instead GPs, gynaecologists and other health professionals should take opportunities to ask questions and ascertain if additional support is needed. Where services are not available, such as psychosexual, needs assessments should be undertaken and factored in to commissioning.

4

Greater consistency within the medical community over the treatment and management of women with cell changes

In addition to inconsistency in the information around cell changes and treatment given to women, for those with CIN2, there is additional inconsistency in when treatment is offered. The side effects of treatment can be pronounced for some women and it should not be the case that treatment pathways and care received varies based on where a woman is treated and by whom. The British Society for Colposcopy and Cervical Pathology must take the lead in reaching a consensus among its members around conservative management or treatment for CIN2 and the factors influencing decision to treat.

5

Increased HPV awareness and education

Misunderstanding and stigma surrounding HPV remains high. Every woman who is told they have the virus must be presented with the information they need in a clear and reassuring way, to ensure they fully understand what a diagnosis means. Consistency in how information is presented is essential to reduce the level of confusion and misinformation that exists. Health professionals must be equipped with the tools to discuss the virus with patients, starting at the first cervical screening appointment and extending throughout the treatment pathway, and proactively work to establish patient understanding.

6

All women with cell changes to be made aware of the services offered by Jo's Cervical Cancer Trust

As the UK's leading cervical cancer charity, Jo's Cervical Cancer Trust provides a wide range of additional information and support to thousands of women each year at every step regardless of diagnosis or treatment. Informing women of the charity and its services at first colposcopy appointment, with reminders at subsequent appointments or check-ups, will ensure women know where to go with any questions or concerns they have. Our services can alleviate some of the anxiety and fear which this report has uncovered and support those requiring additional treatment or medical intervention in order to make the right informed choices for them.

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“It was important as it reduced [my] risk of cancer, but I would like much more acknowledgment and support on potential negative effects of treatment.”

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