

**Long term consequences
of cervical cancer and
its treatment 2017**

Foreword

Today in the UK there are over 49,000 women who have had a cervical cancer diagnosis at some point in their life. Nine women are diagnosed every day and the good news is that survival is high, with around two thirds of women living for more than 10 years after diagnosis.

However for many, finishing treatment or even being given the 'all clear' is far from the end. There are many long term consequences of diagnosis and treatment which can have a significant and damaging impact on a woman's health and wellbeing, some of which can last a lifetime. Extending far beyond the physical and psychological, the impact on areas of life including relationships, finances and work, cannot be underestimated.

This is very likely the biggest ever data set of its type. It highlights that high numbers of women are affected by multiple, negative consequences of their treatment, and most worryingly large numbers are trying to cope with them without much needed support or intervention. Variations in the experiences of women across age, treatment type and length of time since diagnosis must be recognised to ensure each woman affected receives the personal touch when it comes to the information, care and support that they need. We must increase understanding and awareness of the long term consequences across healthcare and empower women to feel able to ask questions, ask for help and to feel confident their concerns will be recognised and addressed.

Cervical cancer is the most common cancer in women under 35, and so many affected will be starting or have young families, and have long lives ahead of them. It must be recognised that getting through cervical cancer is not the same as being 'well', and we must strive for improvements that will reduce the impact for those affected enabling them to have the utmost quality of life. The fact that people are living longer is to be celebrated, but we must renew our focus on ensuring they are not just living longer but living well.

I hope this report will inspire action across the NHS and the 'cancer community' to increase understanding about the long term consequences of cervical cancer and improve care for women affected.

John Baron MP

Chairman, All Party Parliamentary Group on Cancer



Photo: Paul Watson

Long term consequences of cervical cancer and its treatment

Contents

- 4 Introduction and executive summary
- 5 Key findings
- 5 Methodology
- 6 Participants
- 7 Findings
- 20 Conclusions
- 21 Recommendations

With thanks to Quality Health for their data collection expertise, and to the women who shared their experiences with us.

About Jo's Cervical Cancer Trust

Jo's Cervical Cancer Trust is the only UK charity dedicated to women affected by cervical cancer and cervical abnormalities. Our vision is a future where cervical cancer is a thing of the past.

For more information visit www.jostrust.org.uk

Introduction and executive summary

Over 3,200 women receive a life-changing cervical cancer diagnosis each year in the UK. It is the most common cancer in women under 35, however it affects women of all ages. With more women (63%) now surviving 10 or more years, survivorship is more important than ever.

At Jo's Cervical Cancer Trust we support thousands of women each year and are there from the point of diagnosis, throughout treatment and beyond. We have seen first hand the very different experiences of women affected by the disease and the impact of diagnosis and treatment cannot be underestimated. It reaches far beyond the immediate physical impact often permeating every area of life, affecting ability to carry out day to day activities, to start or complete a family and can significantly lower quality of life.

Some consequences are short term and will often occur during treatment, such as bowel or skin issues due to radiotherapy, pain following surgery or sickness during chemotherapy. While these can be extremely difficult for the women facing them, they will usually improve after treatment has finished.

Long term consequences of treatment (also known as late effects) can begin during or immediately after treatment or may only appear for the first time many months or years later as a delayed response to treatment.

These effects are likely to continue for many years or even the rest of a woman's life, they can be life-changing, distressing and complex. Due to the location of the cervix, organs including the bowel, bladder and vagina can be irreversibly affected, the consequence of which can be extremely embarrassing or difficult to talk about and may contribute to them not being addressed. Negative impact on sex life, fertility and emotional wellbeing are very common and many women also face significant changes to finances, work life and relationships. These can all be extreme in their presentation and devastating to women of all ages.

Through our previous research we know that the long term consequences of cervical cancer and its treatment are greatly underestimated, underreported and misunderstood, with many women suffering in silence without the support or treatment they need.

“In a way I feel it was best that I was not told all the possible problems initially because if I had known beforehand what the last four years were going to be like for me it is very possible I would have refused treatment.”

This report aims to better understand the profound impact of living beyond a cervical cancer diagnosis. Through identifying the challenges faced by women, in addition to gaps in provision of care and support delivered, we hope to facilitate change and drive improvements to ensure every woman affected by the disease is given the best opportunity to have a good quality of life and positive health outcomes after cervical cancer.

Key findings

- 1** Eighty-eight percent of women have experienced at least one, 63% at least three and 24% at least six physical long term consequences of their cervical cancer treatment
- 2** Women are suffering in silence with a clear disparity between those affected by long term consequences of their treatment and those who have spoken to a doctor. This is most pertinent for women who have had lymphoedema or experienced a negative impact on their sex life, fertility or bones
- 3** Only half of women who have experienced bowel and urinary problems had received treatment (41% and 54% respectively) and for those who have experienced negative changes in their sex life, just 10% had received treatment
- 4** Only 30% of women who received NHS management and support services said the services met all of their needs with 13% saying they met very few or none of their needs
- 5** Younger women are much less likely to seek support from a doctor than women over 55
- 6** Mental health issues are significantly more prominent among young women, however across all ages the emotional and psychological impact of cervical cancer is being neglected
- 7** The care and support received from GPs was ranked the lowest compared to that received from other sources, including family, friends and other health professionals
- 8** Impact on employment status is significant with 60% of those whose employment status had changed saying that this was a result of their diagnosis and treatment
- 9** Only 21% of the women who looked for information on the long term consequences of cervical cancer and treatment fully found what they needed.

Methodology

The project was carried out in three phases using the same question set.

Phase 1 Women identified as historical National Cancer Patient Experience Survey (CPES) participants (2010-2013) and who had agreed to be involved in future research, were contacted and invited to participate in the survey.

Phase 2 An online survey was publicised through various online and print channels throughout the period of both Phase 1 and Phase 3.

Phase 3 The same method as Phase 1, using 2015 CPES participants (due to changes in the timing of the CPES survey, there was no data collected in 2014).

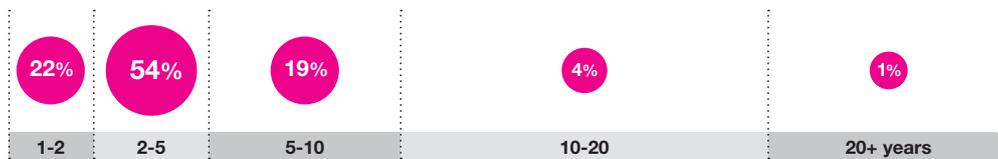
Participants

Long term consequences are defined as those that occur at least three to six months after treatment ending.

All three phases combined saw 828 completed questionnaires, however 140 women were excluded from the main report as they had been diagnosed within the previous year at the time of completing the survey. Their responses are summarised separately at the end of this report. This leaves 688 women who were diagnosed a year or more prior to completing the survey.

688
responses are
included in this
report

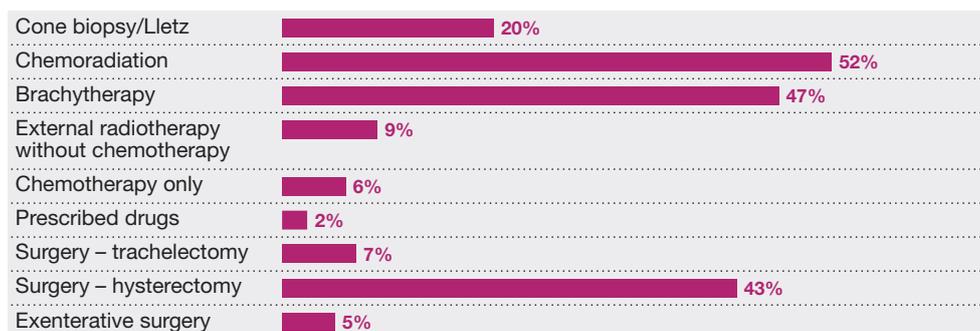
Years since diagnosis, percentage of participants



Seventy-two percent of the women surveyed were between the ages of 35 and 64 with 11% aged 25-34 and 17% over 65. Ninety-two percent identified as being white British, 5% white 'other' and 2% as black or another minority ethnic group. Most women (95%) were no longer receiving treatment, however 78% were still under the care of a cancer treatment team.

Treatment for cervical cancer depends on the stage and location of the cancer and can range from a biopsy to surgery to drug treatment including chemotherapy. Respondents were asked what treatment they had received for their cancer, and were able to choose as many as applied.

Types of treatment received



“ Sometimes it is difficult to know what to do. I have at times dreaded getting out of bed, there seems to be so many things: aches, pains. I can't keep going to the doctors. I think is the cancer back or is it my age.

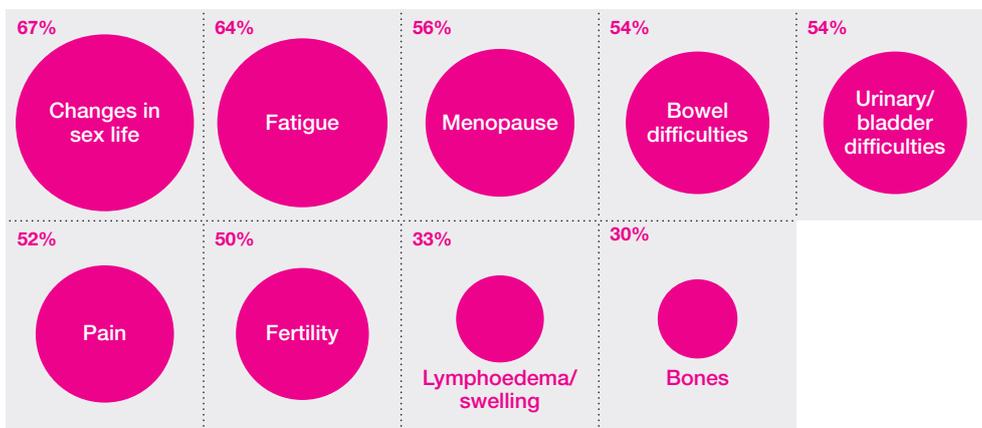
Findings

Women who have had a cervical cancer diagnosis are likely to have experienced, or still be affected by, several, often complex, long term consequences of their diagnosis and treatment.

Eighty-eight percent of women have been affected by at least one physical long term consequence. Co-morbidity is extremely common following cervical cancer with 63% experiencing three or more and as many as 24% experiencing six or more long term consequences of cervical cancer and its treatment.

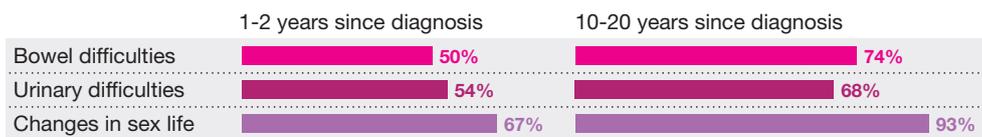
24%
have experienced six or more long term consequences of cervical cancer and its treatment

Percentage of women who experienced each long term consequence



Women who were further from their initial diagnosis were most likely to have had their ability to carry out day to day activities affected by all the long term consequences of treatment, demonstrating the longevity and life changing impact they can have.

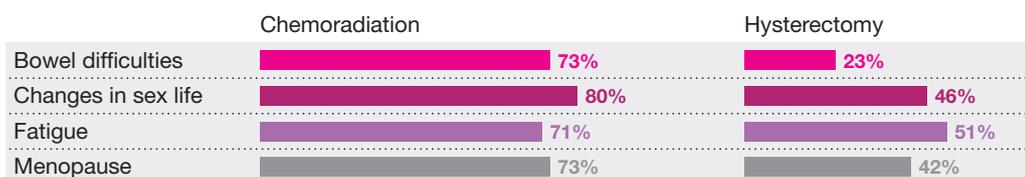
Women affected by long term consequences: years since diagnosis



74%
of women 10-20 years since diagnosis have experienced bowel difficulties

When comparing the experiences of the women treated by the two largest treatment groups, hysterectomy and chemoradiation (including brachytherapy), women treated with chemoradiation are far more likely to have been affected by long term consequences.

Women affected by long term consequences: chemoradiation vs hysterectomy



Do women feel able to tell their doctor about these effects?

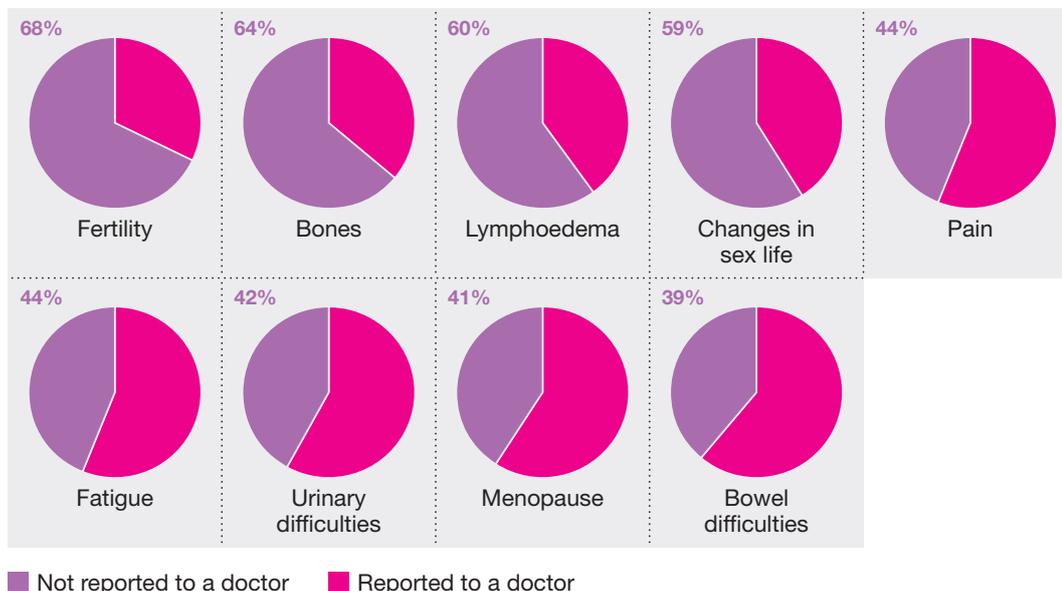
One of the most concerning findings is the number of women who have not sought medical advice about the difficulties they are experiencing. This means that thousands of women are currently suffering alone with the consequences of their treatment, including trying to cope with lymphoedema, pain, loss of fertility and negative changes to bowel or bladder function.

- Staggering numbers of women suffering from changes to their bowel function (39%) and urinary function (42%) had not told a doctor
- Almost two thirds (59%) who have experienced negative changes to, or a complete loss of, their sex life had not told a doctor
- Almost half (44%) affected by pain and/or fatigue had not talked to a doctor
- Only one third (32%) who have experienced reduced, or even lost, fertility had talked to a doctor
- Under two thirds (59%) of those affected by early menopause or related concerns had talked to a doctor.

42%

of women suffering from changes to urinary function have not told a doctor

Percentage of women who had not spoken to a doctor about each problem faced



“The aftercare [bowel damage] was very poor although many questions were asked by us to our GP and hospital staff, we were unable to get any answers or help with the problems. This seems once treatment is completed the follow up and help is very poor.

“Since having cervical cancer and a hysterectomy, I have suffered with anxiety and loss of libido. I have been to the doctor who has prescribed HRT – this is not helping and I’m worried my marriage will suffer.

Significant numbers of women at every age had not spoken with a doctor about the issues they were facing. Just 59% of women affected by menopause had spoken to a doctor, 56% of women affected by pain and just 61% of women with changes to their bowel function.

Among young women this was even more pronounced. Fifty-nine percent of those experiencing changes to their bowels, 78% of those experiencing bone problems and 75% of those with lymphoedema had not brought them to the attention of a doctor. This compares to much lower values of 30%, 51% and 56%, respectively, of 55-64 year olds.

Despite older women (age 55-64) being more likely to have sought medical advice, 36% affected by pain and 36% of women with urinary/bladder changes still had not.

Women who were furthest from diagnosis were more likely to have spoken to a doctor, however they were also more likely to have more complicated or pronounced side effects. Among women 1-2 years from diagnosis just 60% had spoken to a doctor about menopause, 33% about bone problems and 26% about impact on fertility. Among women diagnosed 10-20 years ago the number who had spoken to a doctor rises significantly to 81% about menopause, 47% about bone problems and 53% about impact on fertility.

Women treated with chemoradiation were far more likely to have spoken with a doctor than those who had surgery.

78%
of young women
with bone problems
have not told a
doctor

Percentage of women reporting problem to a doctor: hysterectomy vs chemoradiation

	Hysterectomy	Chemoradiation
Bowel difficulties	32%	76%
Urinary difficulties	43%	70%
Changes in sex life	23%	54%
Pain	45%	63%

Did you start experiencing these difficulties before, during or after treatment?

Some consequences of cervical cancer will begin prior to diagnosis and be unrelated to treatment, others will appear during treatment and others many months or years post treatment. A great many women will continue to be affected long term even for the rest of their life. Needs are complex as many women are sadly impacted by multiple symptoms and consequences of their treatment.

When difficulties were first experienced

	Before diagnosis	During treatment	Within one year after treatment	More than one year after treatment
Bowel difficulties	5%	57%	28%	10%
Urinary function	6%	43%	36%	15%
Changes in sex life	13%	39%	40%	8%
Lymphoedema/swelling	2%	14%	56%	28%
Pain	18%	31%	40%	11%
Bone problems	7%	16%	49%	28%
Fatigue	11%	54%	26%	9%
Fertility	5%	67%	25%	3%
Menopause	3%	41%	48%	8%

“ I dealt with the loss of fertility during treatment but now it’s the dealing with the menopause. It’s the not enjoying sex how it used to be and I am recently married. It’s the constant fear of the cancer returning.

Who did you receive management, support or services from for these effects?

Unsurprisingly, the majority of women who reported receiving support received it from a healthcare professional, whether a GP, oncologist, specialist nurse or specialist doctor. Some women reported receiving support from non-professional sources, such as family or friends.

It is of concern that over a third of women (37%) reported the support they received meeting only some or very few of their needs. Two percent said that none of their needs were met by the support provided.

Women more than 10 years from diagnosis were more likely to state that the management, support or services received met very few or none of their needs, compared to those closer to diagnosis (1-2 years since diagnosis, 10%; 10-20 years, 22%); and less likely to say that they met all of their needs (1-2 years, 30%; 10-20 years, 11%).

One hundred and thirty one women offered reasons for why they had not received management, support or services for these concerns. Twenty-three stated that they had learned to live with the concern, 19 women said they had accepted them as part of their illness and treatment, 14 women stated that they had addressed the concern on their own and nine acknowledged that they found it hard to ask for help.

37%
felt that the support received met only some or very few of their needs

For bowel, urinary/bladder and sex life difficulties specifically, did you receive treatment and was it effective?

Participants were asked specifically about changes to bowels, urinary/bladder function and their sex life. For the women who had received intervention for these consequences of their treatment, many reported that it had made an improvement.

Bowels

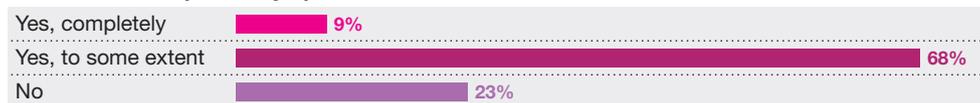
Experienced difficulties



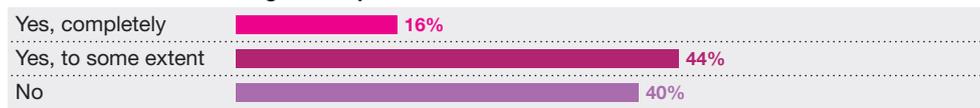
Received treatment



Treatment has improved symptoms/difficulties



Difficulties have had a negative impact on life



Urinary function

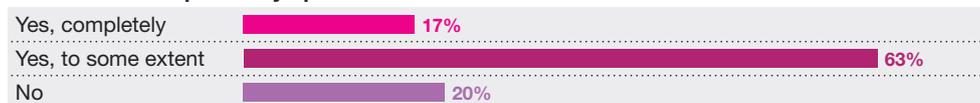
Experienced difficulties



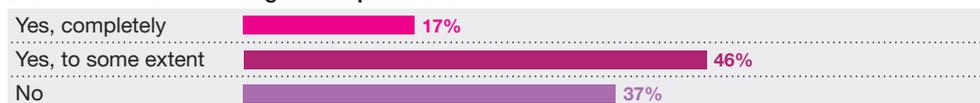
Received treatment



Treatment has improved symptoms/difficulties



Difficulties have had a negative impact on life



“ I listed that I have had bowel and bladder problems (muscle weakness). They are improving and I am optimistic that given time they will recover completely, so I have chosen not to seek out any help for these issues.

Sex life

Experienced changes



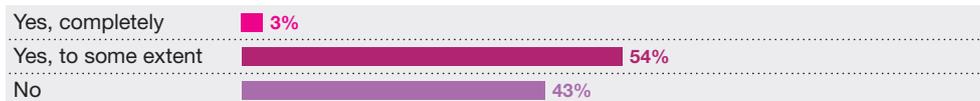
Changes have been positive or negative



If negative, receiving treatment



Treatment has improved sex life



“ Cancer treatment has affected my ability sexually, I feel very concerned about letting my husband down and feel a failure.

Irrespective of age, a large proportion of women highlighted that their sex life had been negatively affected following their diagnosis and treatment and for the vast majority (80-90% across all age groups) no treatment or support had been received. Sadly, negative changes to sex life were common across all the treatment groups, ranging from 86% of women in the trachelectomy treatment group to 100% of those who had experienced exenterative surgery.

Changes to bowels, sex life and urinary difficulties were more common in women diagnosed 10-20 years ago. These same women were least likely to have sought treatment for changes to their sex life, but more likely to have received treatment for bowel changes. Urinary difficulties and changes to bowels were more common in women over 55. This may indicate that older treatment methods carry greater consequences. However, it is important to note that the largest cohort in this study was those who had been treated 2-5 years ago, receiving modern treatment and still experiencing significant consequences of treatment.

It is unacceptable that so many women, many from a young age, are suffering for decades from the consequences of cervical cancer without accessing treatment that might improve their quality of life. It is essential that medical professionals are aware of the devastating and wide ranging consequences that women may be experiencing and ensure they create opportunities for women in their care to raise their concerns, providing prompts if necessary. The knowledge that consequences can appear many years following treatment will ensure more women get access to treatment and services which will significantly improve their quality of life. A commitment to investment in interventions and treatments is needed to ensure that there are services available for women and to promote research, improvements and adequate training in this relatively unexplored field.

86%
of women had not received treatment or support for changes to their sex life

In what other ways did your diagnosis and treatment affect you?

The need for treatment and support reaches far beyond the physical consequences of treatment, having significant and damaging impact on every aspect of life.

Percentage of women affected by further consequences of diagnosis and treatment



“ There is a constant worry at every ache and pain and the reluctance to even look for any kind of relationship.

A particularly concerning finding was the long term negative impact of a cervical cancer diagnosis on mental health. Irrespective of treatment received, over half of women stated that they had felt sad, down or depressed (57%). This ranged from 54% for those in the chemoradiation group to 67% of women in the exenterative surgery group.

Younger women (aged 25-34) and those diagnosed 10-20 years ago were most likely to be affected.

Seventy-nine per cent of women aged 25-34 said that they had felt blue, sad, down or depressed, compared to 57% overall and 72% said that they had felt anxious, compared to 57% overall. A larger proportion of young women also stated that they had experienced mood swings and had dates which make them think more about cancer and their experience. Fear of death or recurrence after a diagnosis is common however it is more pronounced in younger women with over half (55%) of 25-34 year olds having worried about dying, compared to 44% overall, and 89% having worried about cancer coming back compared to 78% overall.

For women 10-20 years on from their diagnosis, 69% said that they had felt blue, sad, down or depressed (compared to 57% overall) and 34% said that they suffered with depression (compared to 17% overall). The same group of women were also more likely than those diagnosed more recently to have experienced a loss of confidence and had their relationship affected by their diagnosis.

79%
of young women
feel sad, down or
depressed

“ Even though I have just reached 2 years in remission I feel that my main issues are now emotional... It's the constant fear of the cancer returning, it almost feels like you are just waiting for the cancer bomb to go off again.

When asked about impact on their work life, nearly half (47%) reported a change since being diagnosed. Worryingly, 60% of those women specifically correlated the change to a consequence of their cervical cancer treatment.

Impact on employment increased with age, being reported by 50% of those aged 25-34, 58% of those aged 35-44, 65% aged 45-54 and 82% aged 55-64.

Unsurprisingly, the more invasive the treatment, the more likely women were to say their employment status had been affected: 67% who had chemoradiation, 69% who had exenterative surgery and 43% who had hysterectomy or trachelectomy. Significant numbers (31%) who had a cone biopsy or LLETZ reported changes to their work status.

Changes to employment status may bring financial implications, but can also significantly impact mental health and for women who work, or worked pre diagnosis, returning to work may be an important part of rebuilding life post cancer. More research is needed to fully understand the issues faced by women regarding employment and returning to work following treatment for cervical cancer, to ensure they can retain a good quality of life.

“ Although I am now managing the problems I have been left with, I can no longer work full-time...I am now working part-time which has helped to some extent to balance my work/social life, but at the same time means we are struggling financially.

Have the long term physical and emotional impacts of your treatment for cervical cancer been fully addressed?

One of the most striking findings of this research is that the emotional impacts of diagnosis and treatment are being largely neglected. Thirty-four percent of women reported that their emotional needs had not been addressed at all and only 25% could say they had been completely addressed.

While women were more positive about the physical impacts being addressed, only 30% said they had been completely addressed with 20% saying they had not been addressed at all. This demonstrates a clear need for support and services to be offered to women affected by cervical cancer, the disparity in emotional and physical impacts may demonstrate a lack of awareness about the emotional consequences of cervical cancer and treatment which urgently needs to change.

Unmet needs were reported among women of all ages, however this was greater among younger women and women further from diagnosis. Only 7% of 25-34 year olds said that the long term emotional impacts of their treatment had been completely addressed and treated, rising to 46% for 65-84 year olds. For physical impacts, 27% of younger women compared to 19% of 45-64 year olds stated that these effects had not been addressed or treated at all.

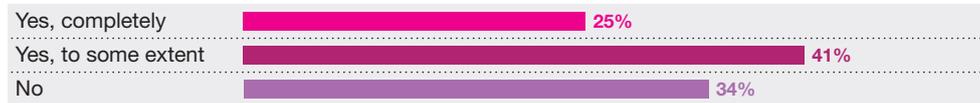
34%
reported that their
emotional needs had
not been addressed
at all

Extent to which physical and emotional impacts have been addressed

Physical



Emotional



For women who were diagnosed 10-20 years ago, only 10% said the long term physical impacts of their treatment had been completely addressed and treated, compared to 30% of women 1-2 years since diagnosis. They were far more likely to say they had not been addressed at all (1-2 years, 16%; 10-20 years, 48%). This is also reflected in responses for the emotional impact, with women furthest from diagnosis much more likely to state that the emotional impacts had not been addressed at all (1-2 years since diagnosis, 32%; 10-20 years since diagnosis, 52%).

“After I finished my treatment there was little support for my emotional needs. I think my emotional needs became greater several years after treatment, as the impact of the cancer on my life didn’t really hit me till then. I find friends and family have no understanding as the long term effects are not always visible or obvious.”

The more complicated the treatment women received, the less likely the physical impacts of their treatment had been fully addressed and treated. Women who had cone biopsy/letz were most likely to say ‘yes, completely’ (42%); compared to women undergoing chemoradiation (28%), and trachelectomy (21%). Women treated with a trachelectomy were most likely to say that the physical impacts of treatment had not been addressed or treated at all (29%); compared to chemoradiation (19%) and hysterectomy (18%).

“Most, if not all “treatment” is based on physical recovery “medical models”. No-one “treats” the psychological, mental health side which I find simply disgusting. No-one is interested; your body heals so you are fine. Cancer treatment needs to address both, or make both available as everyone is different.”

How do you rate the care and support you received before, during and after treatment?

Before and during treatment, women were relatively positive about the care they received. Two thirds (66%) were happy that the information they received about the risks of treatment and possible side effects met many or all of their needs. This was higher for older women (76%).

The majority of women were also satisfied with their treatment team, with 83% stating they met many or all of their needs during treatment.

“ From the time I was diagnosed with the cancer I have had the best care and treatment anybody could wish for from the oncology team right down to the carers, cleaners, everyone was and is remarkable. Nothing is too much trouble for them. They deserve stars and medals.

Women who were 10-20 years from diagnosis were less positive, with only 14% satisfied with the information they received and only 61% positive about the care they received from their treatment team.

While care before and during treatment was rated quite highly, it is apparent there are significant gaps in aftercare. Only 35% of women stated that their treatment team had met all of their needs, dropping to less than a quarter (23%) of 25-34 year olds. Just 14% of women diagnosed 10-20 years ago were fully satisfied with the aftercare received. This is extremely concerning as many women have complex and multiple needs following treatment which require ongoing care and follow up.

66%
were happy the information they received about the risks of treatment and possible side effects met many or all of their needs

“ I received no information on hormones and it's only through my own research that I understand my current symptoms are hormone related...Yes, the cancer is gone. Great but aftercare from oncology was non-existent, even in the private sector.

GPs were given the lowest score as just 63% rated the help and support received from their GP as good or excellent. This may be due to a lack of awareness or care pathways by GPs leading to longer time waiting to treatment or inappropriate referrals. GPs compared poorly to the help received from partners which 85% rated as good or excellent.

Women further from diagnosis were less likely to rate the support received from all sources as excellent: their partner (10-20 years since diagnosis 54%, compared to 69% overall), their oncologist (10-20 years 36%, compared to 58% overall), cancer nurse specialist (10-20 years 36%, compared to 50% overall), and their GP (10-20 years 24%, compared to 32% overall).

Did you receive sufficient information on the long term effects of cervical cancer before, during and after your treatment?

It is essential that women can readily access the information they need in the format they need it. Different behaviours were highlighted across age groups regarding the sources they went to for information, however regardless of age or source, the majority of women could not find what they needed. Just 21% of the women who looked for information on the long term effects of cervical cancer and its treatment said that they could find all the information they needed.

Percentage of women who looked for information



Percentage of women who found what they needed



Only **21%** said that they could find all the information they needed

Over half of women looked for information online (53%). This was more prominent among younger women (25-34 year olds, 63%; 65-74 year olds, 29%) and women further from diagnosis (10-20 years since diagnosis, 66%; overall, 53%). Other sources of information included their oncologist (17%) or cancer nurse specialist (12%).

Older women were less likely to look for information than younger women (24-35 year olds, 67% and 65-74 year olds, 43%). Women further from diagnosis were more likely to say that it took a lot of effort to get the information they needed (1-2 years, 11% compared to 24% of women 10-20 years from diagnosis), that they were concerned about the quality of information, that they felt frustrated during their search for the information, and that the information they found did not help them cope with long term effects.

“*Being diagnosed with cervical cancer at 28 completely shocked me, there wasn't much information around on my operation which was scary and there wasn't much I could do.*”

“*On reflection, after treatment and diagnosis, I feel that I was not given all the information about next steps and what ifs. Each stage was dealt with individually and I would have appreciated more of a complete overview.*”

How has your life changed following your experience of cervical cancer?

Amidst the reports of undisclosed and unmet needs, it was encouraging to see that many women felt more positive about their ability to address their own medical needs (46%), emotional needs (33%) and day to day needs (31%). Significant numbers felt more positive about their relationship with family (49%) and friends (42%) and almost half (46%) reported a more positive overall outlook.

Women were given a range of statements and asked to state which were true for them.

The positive statements that women agreed with the most were:

“ I feel that my experience with cancer has made me a better person. 32% of respondents

“ I feel that my experience with cancer has brought many positive things into my life. 31% of respondents

“ I feel I have made a complete recovery from my illness. 22% of respondents

The negative statements women agreed with the most were:

“ I feel that cancer is something I will never recover from. 28% of respondents

“ I feel that cancer has changed my life permanently so it will never be good again. 19% of respondents

“ I feel that having cancer has interfered with my achievement of the most important goals I have set for myself. 19% of respondents

Respondents who were diagnosed within a year of completing the survey

One hundred and forty women had been diagnosed within the previous 12 months. What is significant is that the experiences of the 140 women closely reflect those whose diagnosis was less recent, suggesting that many of the effects of cervical cancer start early on and, if not addressed, can continue to impact women for many years, potentially throughout the rest of their lives. Similar to women diagnosed over a year previously, recently diagnosed women were likely to have experienced difficulty with their ability to carry out their day to day activities because of changes in their sex life (74%), pain (64%), and fatigue (73%). They were also unlikely to have spoken to a doctor about these issues, for example just 64% experiencing pain and 60% experiencing fatigue.

Forty-one percent also highlighted that the emotional impact of treatment was not being addressed 'at all' and large numbers stated that their mental health was being impacted by a range of concerns. Most notably over half (51%) stated that they were preoccupied with concern about cancer, 54% that they were worried about dying from cancer, 86% were worried that cancer would come back and 67% said they were experiencing anxiety.

Many of the effects of cervical cancer start early on and, if not addressed, can continue to impact women for many years

“ Since I was told I had cervical cancer my life has changed. Although I had an operation to remove the cancer it still sticks in my head, is it back or is it going to come back... I’m hoping when my five years are up that I might be able to start fresh and look to the future with a positive attitude.’

Conclusions

This research demonstrates the complex, wide ranging and unmet needs of women affected by cervical cancer.

Regardless of age, time since diagnosis or treatment type, far higher numbers than anticipated reported suffering from life-changing consequences of their treatment.

These permeate every area of life ranging from emotional to financial to physical often having a significant and lifelong impact on quality of life. Women are suffering in silence with many simply 'putting up with it'. The lack of support and information reported is of huge concern, in particular the disparity between provision of support for physical needs and for emotional needs. Wide variations in the support experienced for women at different ages was uncovered.

It is essential that the right questions are being asked in primary and secondary care settings to ensure that women are getting the vital support that they require and are not being left to deal with the potentially devastating consequences of their treatment alone. The impact on emotional wellbeing must be addressed, in particular among young women where a large unmet need persists. There are many services that exist to treat or mitigate the consequences reported, including those offered through charities and the NHS, therefore it should not be the case that women do not receive access to them. Increased awareness about the far reaching, long term consequences of cervical cancer is essential to ensure women are receiving the treatment that they both need and deserve.

Urgent investment is required in training, care and referral to provide women with much needed services and care that will enable them to fully live their lives post treatment. The need for continued, joined up care is evident to ensure issues are identified and addressed as and when they arise. Oncologists must ensure they ask the right questions at follow up appointments after the one year point, there must be greater information provision to women about possible long term consequences of treatment and GPs need to have a greater understanding of the needs of patients living beyond a cervical cancer diagnosis. Appropriate and timely referrals are crucial.

Research is needed into appropriate care and treatments to improve health outcomes alongside workplace and return to work interventions to assist both employers and employees. There is more to be done to inform and empower women themselves to ensure they feel confident in their ability to self-manage their health and understand better how to get the help and support they need at the most appropriate time. This report should serve as the evidence required to make the necessary investment to do so.

It is not enough for women to be simply treated for cervical cancer and discharged. We must ensure women living with and beyond the disease have the best quality of life possible after diagnosis and do not just live, but live well.

*“ I have struggled every day since my diagnosis.
My life will never be the same.*

Recommendations

We need action to improve the lives of those affected by cervical cancer and want to see:

1 The management of the long term consequences of cancer should be recognised with a national tariff

Poor awareness of the long term consequences and late effects of cancer treatment, coupled with a lack of incentivisation for identifying and treating these problems, mean patients are being sub-optimally managed. Women presenting with problems are not being referred or diagnosed correctly, often being told there is nothing that can be done and being left to self-manage life changing symptoms without the right diagnosis.

NHS England and NHS Improvement must introduce a national tariff for the management of long term consequences of cancer. This would drive funding and research into this much neglected area leading to an increase in specialists and units equipped and experienced to deal with the wide range of complex issues that patients currently face. It would build a much needed evidence base and ensure healthcare professionals working within this field are recognised and rewarded for their work. Through the management of long term consequences being recognised as part of the normal post treatment care pathway, health outcomes and quality of life for women affected by cervical cancer, in addition to the thousands of patients across many other cancers, will be much improved.

2 Every person with cervical cancer, and the health professionals supporting them, should have access to a Cancer Recovery Package, including a Treatment Summary

Prior to receiving treatment women must be made aware by their treatment team of some of the more difficult or long term impacts that cervical cancer and its treatment can have on them, specifically bowel and bladder problems, issues surrounding sex and intimacy and fertility options. Women should be informed and feel empowered to ask for the treatment or support they need surrounding symptoms and challenge when they do not receive this. Furthermore, they should be asked the right questions in order to provide them with the opportunity to speak. This includes increasing access to psychological or psychosexual services and for patients to be put in contact with a fertility/adoption/fostering specialist if required.

Macmillan's Recovery Package is an example of a Recovery Package which aims to support professionals to deliver patient-centred care including helping to identify and address changing needs from diagnosis onwards. One aspect of this includes a Treatment Summary providing details of all treatment received and presented in an understandable way. It includes potential symptoms to look out for and contact details of key professionals. The patient can keep a record of it, share it with their GP and other professionals as needed. This encourages a seamless transition for the patient from secondary to primary care to ensure a more joined up approach to their long term care. If every patient and health professional is encouraged to use it to its full potential, it could significantly impact the quality of life for the patient.

3 Swift implementation of the new ‘quality of life metric’ to rarer cancers to measure, incentivise and highlight gaps in the provision of after care

Measurement of quality of life will provide a clear imperative for healthcare providers to support people to live well after treatment and highlight areas where improvements in cancer care are needed. It will begin to address underreported and unsupported effects, both physical and psychological. A metric is currently being piloted for several cancer types and we hope to see it applied to less common cancers as a matter of urgency. Appropriate measurement will drive improvements to ensure the needs of those living with and beyond all cancer types are addressed and better opportunities provided for personalised follow up care and early intervention.

4 Greater awareness amongst GPs of the long term consequences of cervical cancer and treatment

NHS England, the Royal College of General Practitioners and Jo’s Cervical Cancer Trust should work together to ensure that GPs and other clinicians are better aware of the late effects of cervical cancer and treatment, in particular underreported side effects and those that can appear many years post treatment.

Increased awareness is needed to ensure clinicians understand the barriers women face when asking for help or treatment, most specifically around bowel and bladder problems, impact on sex life, and fertility problems. Given the pivotal role GPs play in the care of women with cervical cancer, GPs should be given the training to address this with women in a sensitive way, asking relevant questions which will empower women to discuss their concerns, know that they are supported and enable them to be ‘treated’ in an appropriate manner.

5 Women with cervical cancer should be informed about Jo’s Cervical Cancer Trust at the point of diagnosis with a reminder at the 12 month clinic appointment

We believe that it is not just the role of the clinical nurse specialist, but that all healthcare professionals at all levels have a responsibility to inform patients about relevant or additional services available to them through external providers such as Jo’s Cervical Cancer Trust. Jo’s Cervical Cancer Trust is able to provide trustworthy, evidence based information and support to women and their loved ones no matter where they are in their experience living with or beyond cervical cancer. This includes services that allow women to gain mutual support and shared experiences through face to face events or online conversations.

Contact us:

Jo's Cervical Cancer Trust

📍 CAN Mezzanine
7-14 Great Dover Street
London SE1 4YE

T 020 3096 8100
W jostrust.org.uk
E info@jostrust.org.uk

🐦 @JoTrust
📘 Jo's Cervical Cancer Trust
📷 [joscervicalcancertrust](https://www.instagram.com/joscervicalcancertrust)

Call our helpline

0808 802 8000