



TRANSCRIPT:

Accessing support and information

In this video we're going to talk about:

- Some of the problems that can affect people living with and beyond womb cancer
- And who to contact, or where to go, for further support and information

[Finding the right support]

Living with and beyond womb cancer can be scary and lonely for many, and it's not uncommon to experience ongoing problems with physical and mental health.

Finding and accessing support can be challenging, but getting the right support and access to reliable information can really help. Some of the problems that can affect people following womb cancer include:

- Low mood, anxiety, and depression
- Fear of recurrence
- Ongoing pain and discomfort
- Ongoing changes to bowel and bladder habits
- Menopause symptoms
- Loss of libido and impact on sex life
- Loss of pelvic floor muscle strength and incontinence, and
- Lymphoedema, which is a build-up of fluid in your legs or pelvic area that doesn't go away

Although you may feel like there's nothing that can be done about these problems, and you just have to put up with them, support is available, and we want to help you get the support that you deserve.

There's no one-size-fits-all approach when it comes to getting the support that will suit you most, but we asked what kind of support people who've been through womb cancer found most helpful, and what advice they would give about getting support.

[Where to find support: Your medical team and GP]

I've been well supported by the nursing staff, by the group of them that have been with me all of the way. It doesn't matter if you don't speak to the same person every time, because they all have a handle on what's going on, and they can all access your records, so they can talk to you. And if they don't know the answer, they will get back to you.

And I think, when you are on a journey to recovery, or living with womb cancer, you need to know that the people who are the experts are there for you. And I've never felt that I didn't have that kind of support there.

My GP did follow up my cancer and made a routine call, which I thought was brilliant, so I did have the opportunity to talk to my GP on the telephone regarding my fears and worries.

[Where to find support: A cancer support centre]

One day, I went along to the cancer support centre at the hospital and had such a lovely welcome. The people who were there showed me where all the tea and coffee was and asked me if I was new. And then somebody came out and asked, did I want to chat. And I found that really helpful, just to chat, informally, and just to see what was on offer.

The cancer support centre mentioned a meeting - a get together for people who had been affected by gynaecological cancers and suggested I might want to go along to that. And I did. I wasn't quite sure whether it would work, but I went along.

And, I did only go to one of them and I realised that wasn't quite the right meeting for me. It was helpful in small ways, but not really what I was looking for, which was fine.

My radiotherapy team suggested I went over to the cancer support centre, which was actually just near the hospital, and speak to somebody over there. And I did. We were in lockdown, so I used to go over after my radiotherapy, get a drink, and go and sit in their lovely gardens, just before I went back home to get on with normal life, and children, and family, etcetera.

Where to find support: Other trusted organisations

There are great resources out there that can help you with the after-effects of treatment. These include help and information, for you, if you have ongoing bowel and/or bladder issues post radiotherapy, and about how to deal with vaginal issues and that part of your body post treatment. Nobody should feel embarrassed about seeking help for that part of their body, and their sexual health.

I found a cancer charity that had loads of support with things like nutrition, exercise classes that you can join online, and mindfulness practises – relaxation practises.

www.peachestrust.org Email: admin@peachestrust.org
Registered Charity (England and Wales) no. 1190440

And also, for a confidence boost, I found a charity that provides lots of workshops for people who've been through cancer. They do skincare, make-up, nail care, and they also do hair care for people who lose hair during treatment.

Where to find support: Talking to others

I found a peer support group for people affected by womb cancer on a social media platform that's been really, really helpful. I think it just helps to ask questions of other people who've been through the same experience that you have. They've had the same surgery, and they really understand how you feel about it.

One of the best things I did was join a mindfulness course for people going through cancer. After the course finished, we set up our own messaging group, and we still meet regularly for a chat, and support one another.

I talked to friends who'd had hysterectomies, which was useful — how you deal with that, how you felt after. So, it wasn't just specifically to people who'd had cancer, it was also people who, that had had hysterectomies, and the same sort of hysterectomy as I'd had.

While I was having treatment, the best support I got was from my friends, and my employer, who made it very clear I should just focus on my treatment and recovery, which was great, as it meant I was very fortunate in not having to worry about my job. My friends were amazing.

[Where to find support: Peaches]

I signed up for a Peaches coffee morning, and that was exactly what I needed. It helped me to realise that those feelings of being, still not quite understanding what had happened to me, were quite common. Other people felt the same. And so, attending that meeting online once a month, I've found incredibly helpful, in allowing me to sort my head out.

You still have days when you think, oh wow, did that really happen? But it's been really helpful, and, I'm so glad that I found it, as I'd never heard of Peaches before.

I did get booklets, but I kind of refrained from reading too much into the booklets because I felt that I just wanted to ask questions, and tailor it to what I felt I needed to know. Peaches, I think, is brilliant because it's so individual to that particular cancer. I think to talk within a group of people who've experienced womb cancer is great. You can talk to people who've been through the same thing.

Peaches has been an absolute lifesaver — speaking to people that had also gone through the same as I had, and when you speak to them, they all feel the same.

It's great to get advice from your peers, and the people that have been through it, and ongoing physical problems that you may, or may not, have from your chemotherapy or your radiotherapy. I personally have had some ongoing physical problems, and emotional

problems, and it's just great to get advice from people that have heard about these things before.

The Peaches coffee morning, once a month, is just a place to go, a safe place, to talk to other people that have been through similar things as yourself, and you don't feel so alone.

[What advice would you give someone about getting support?]

I'm the one that's initiated the questions and asked, what if? What happens if this happens? And my healthcare team has always been incredibly reassuring, and I've been able just to ring in between appointments and say, I've had this, is this normal? Don't be frightened of doing that.

Don't be afraid to ask for support. I think it can be really difficult, but there's so much support out there, it's just a case of finding it. Ask your Clinical Nurse Specialist, or your GP, or other patients that are local to you, and find out what's available either locally or online.

The support was always there. It's a matter of reaching out for it. You might not realise that you need it.

Visit the Peaches website, sign up for one of the coffee mornings — it is completely a safe space — you can say as much or as little as you want, nobody will judge you. We all just want to help each other get through the trauma of having a womb cancer diagnosis and its treatment.

[Where can I find further information and support?]

We understand that living with and beyond womb cancer can be very challenging and cause a great deal of uncertainty, especially around knowing where to go to get support and reliable information.

We would always recommend contacting your CNS, healthcare team, or GP in the first instance if you have any concerns about your physical or emotional health. However, Peaches is here to provide you with that extra support and information, or to signpost you to trusted organisations who can help.

For further support and information, take a look at the other videos on our website or at our series of webinars. You can also find a list of organisations on our website that provide helpful support and information.