



TRANSCRIPT:

Follow-up after treatment (and recurrence)

In this video we're going to talk about:

- The different types of follow-up that you may be offered when your treatment has finished
- How to get help with ongoing physical and emotional issues once your treatment has finished
- And the symptoms to look out for which may mean that your womb cancer has grown back

[Types of follow-up you might be offered after treatment]

When your treatment has finished, your healthcare team may offer you face-to-face appointments, telephone or video appointments, or a mixture of both. If you're offered patient-initiated follow-up, or PIFU, this means you won't be offered any routine appointments, but you can ask for an appointment at any time if you're worried about something.

If you're not sure what type of follow-up has been recommended for you, ask your Clinical Nurse Specialist, or CNS, or your healthcare team to explain it to you. And, whichever type of follow-up you're offered, make sure you have the contact details of your CNS and healthcare team, in case you want to talk to them.

[Getting help and support after your treatment has finished]

When your treatment finishes, and you're no longer seeing your healthcare team, it's not uncommon to feel abandoned, vulnerable, and alone. You may, to family and friends, appear to be back to your usual self, but this may just be the start of your physical and emotional recovery, and it's important you seek help and support when you need it.

You may, for example, still be experiencing pain or discomfort from surgery, or a change in bowel or bladder habit, and it's important that you contact your CNS if these are not resolving, so that they can decide if you need to be seen.

And if you're struggling with low mood, fear of recurrence, or your mental health is affected in any way, you should contact your GP, or go to our website where you can find more information on where to get support.

We asked people who've been through womb cancer to tell us about their experience of follow-up, and what advice they'd give someone feeling lost and alone when their treatment finishes.

[Experiences of follow-up after treatment has finished]

I had a face-to-face appointment with the surgeon and the Clinical Nurse Specialist – or CNS - after my surgery. Because my cancer had been caught at an early stage, they put me onto patient-initiated follow-up, which meant that I had a further phone call with the CNS where she went through lots of different aspects of my recovery and signposted me to various different support.

The nurses give you a number and they say, if you've got any questions, call us. We'd rather hear from you and help you with what might be an issue, or might not be. We'd rather you call and talk it through than ignore it and be worried.

And I think, like a lot of people, I thought, you know, that's great, that's really lovely, and if it's really serious I'll call you, but I was reluctant to be a bother. And I felt like, no, that's a silly question, I'm not going to bother them. But the couple of times I have phoned, which haven't been about anything serious, physically serious shall we say, I've had such a lovely response, and on all of the occasions they've said, I'm glad you phoned.

I had face-to-face appointments following my treatment, about every three to four months for the first year. However, of course, if you have any issues in between, you can contact your Clinical Nurse Specialist. They are there to signpost you and to get hold of the appropriate people if you have any other questions.

The appointments are just to see how you are doing, if you have any side effects, if there's anything you are concerned about with any symptoms that you may have. The face-to-face appointments will usually consist of internal examination also. This is where the consultant can just have a look to make sure that everything looks fine and act on anything if there are any concerns.

[Emotional support: where to turn to if you're struggling]

I did feel quite low and lonely once my treatment stopped. I was on a bit of a roll when I was having my treatment but, once it finished, I was quite anxious about return of cancer symptoms, loss of libido, and fear about my lack of sex life and drive.

But I did speak to the specialist nurses, and they were brilliant. They sent me leaflets, samples, and offered me to come in for support. I didn't in the end, but I was really grateful for that, as it was something I couldn't talk to my husband or family about at the time, and I was really, really reassured by that.

Don't do it alone, you're not on your own. I'm quite used to being independent and coping with stuff but sometimes you need a different perspective. And the people at the cancer support centre at my hospital, and the people at Peaches, and the clinical staff at the hospital have been brilliant in helping me sort my head out.

I would say, if you're feeling a bit down, or you're feeling a bit lost, then get in touch with somebody. They're there, they say they're for you, and they are.

Find out what local cancer support groups are available in your area, and also look at what's available online. It's so easy nowadays to join an online support group and that can be really, really beneficial.

At the time I finished my treatment, I did feel very much on my own, and trying to sort out my bowel issues was a one-woman campaign. If you have got ongoing side effects from your treatment — I've had ongoing issues with my bowel — do speak to your GP or gynae oncology team about them, so they can refer you to the team best placed to help you.

Don't suffer in silence and don't give up on trying to get the help you need. I know personally it can be very hard to get the treatment you need, but I'm very glad I didn't give up and was able to get the treatment I needed in the end.

Peaches coffee mornings are a brilliant way of helping you realise that you are not on your own, and that there is someone who gets what you've been through, and what you're still going through.

[Fear of cancer coming back (recurrence)]

In the first few months particularly, there is a certain paranoia that any unexplained ache or other symptom could be your cancer coming back. Your body has let you down once, there's no reason why it won't do it again.

The fear of your cancer coming back never goes away but it does get better with time as you get your confidence back in your body. The main thing is to know what the red flag symptoms are of recurrence so you can just go back to your doctor straightaway and get it checked.

[Signs and symptoms of recurrence]

Womb cancer sometimes grows back after treatment, so it's important to be aware of the signs and symptoms that suggest this may have happened. The most common sign of recurrence is bleeding or spotting from the vagina. If you notice any vaginal bleeding, you should contact your healthcare team as soon as possible.

Although vaginal bleeding is the most common sign of recurrence, womb cancer can grow back anywhere in the body, so contact your CNS, healthcare team, or GP if you experience any new symptoms that persist after your treatment has finished. These may include: changes to bladder or bowel habit, tummy bloating or pain, feeling or being sick, or short of breath.

[Who to contact if you have symptoms of possible recurrence?]

Although you're bound to feel very worried about a possible recurrence, it's important to get checked out as soon as possible. Contact your CNS without delay if you have any symptoms of possible recurrence. Or, if you need urgent or emergency medical help, go straight to your nearest A&E.

[Where can I find further information and support?]

It can be difficult finding and accessing support for ongoing physical or mental health problems once your treatment has finished. To find out more about the different types of support available, you can go to our video titled, 'Accessing support and information'. You can also find a list of organisations on our website that provide helpful support and information.