

## Making decisions about treatments during cancer care

### Supporting informed choices

If you have been diagnosed with a cancer that is sensitive to hormones, such as an estrogen-receptor positive cancer, you may be offered cancer treatment involving direct manipulation of your hormones by medication or by surgery that will stop your body's production of estrogen, progesterone or testosterone. Discussing treatment options can feel overwhelming at that time and it can be difficult to take in information from your cancer care team about the pros and cons of different medications or possible surgeries. You may also find it hard to convey your own desires and concerns or feel that they're going to have any real influence on the medical plan being made.

This factsheet aims to support you in this process by providing information so you can ask the right questions, and weigh up decisions carefully, making sure you have taken into account your own experiences and wishes, your current quality of life, and your aims for the future.

### Cancers with hormone receptors

Not all cancers are linked to hormones, but when they are they are called 'hormone-sensitive' or 'hormone-dependent'; these types of cancers have receptors for a particular hormone. If you have an estrogen-receptor positive cancer it can lock onto the receptor and cause growth and spread of the cancer.

Hormone receptor positive cancers are found in the breast, ovary, uterus (womb) or endometrium (the womb lining). These cancers may be sensitive to the hormone estrogen and/or progesterone. In men, there is a type of prostate cancer that is sensitive to the hormone testosterone.

It's important for you to know whether your cancer is estrogen receptor positive or not as this will affect what treatments you are offered.

### Common treatment options for cancers with hormone receptors

If your type of cancer is identified as hormone receptor positive (usually known after a biopsy), there are a few types of possible treatments and these work in different ways.

Some medical treatments block the receptors on your cancer cells; this prevents the cancer from interacting with your hormones. Others stop your body from producing the hormone.

Surgery can be used to remove the part of your body which makes the hormone. For example, removing the ovaries (before menopause) takes away the main source of estrogen.

The potential impact of hormone withdrawal on how you will feel, and what your life might be like is worth bearing in mind when discussing these treatment options with your doctor.

### Effects of a surgical or induced menopause

If you were having periods before your cancer diagnosis, it's worth understanding more about the impact hormone withdrawal could have because of your treatment. When a medication is taken to block, or stop you producing the hormone, it's known as an 'induced menopause' and if your ovaries are removed it is termed a 'surgical menopause'. Either will usually lead to an abrupt lack of estrogen, progesterone and testosterone which can have a sudden and significant impact on your physical and mental health and influence your daily life,

including work, relationships, socialising and leisure time.

These changes may not be thoroughly discussed by your health professionals in the cancer clinic, so many people find they are not fully prepared for the range of symptoms that can occur. Hot flushes and night sweats are often the expected changes, but symptoms of the menopause are varied and involve many different systems in the body. You might have trouble sleeping, increasing headaches or migraine, joint pains and stiffness, fatigue, brain fog, anxiety, low mood, loss of confidence, urinary problems like leaks of urine or needing to go a lot, or urinary tract infections. You could have vaginal dryness and soreness, episodes of thrush, dry skin, hair loss or palpitations. You may get only a few, or experience a lot of these symptoms.

If you have begun hormone treatments, it's useful to know which symptoms could be related to hormone withdrawal, as many people put things down to general tiredness and consequences of the cancer and recovery process, rather than realising that what's happening is because of a lack of hormones.

## Your cancer doctor's focus

Your oncologist's focus is on the treatment that gives you the best chance of survival from the cancer. Because of this, they frequently tend to share just hard facts: the evidence, science, and standard treatment protocols to effect a cure. Their job is to communicate the best evidence to you in a way that you can fully understand and make it relevant to your personal situation.

Whatever cancer treatment is suggested should not, however, be at the expense of listening to your needs, appreciating your values, preferences and the impact of their recommendations on your current, and potential, quality of life. Your life and factors that may affect your wellbeing are just as important to include in decisions when deciding what treatment you should progress with.

## What's important to you?

One of your roles during this journey is to ensure you play an equal part in the decision-making process. This often means communicating to your oncologist what's important to you. Are they suggesting treatments that mean survival whatever the cost – even if it means living with associated symptoms or side effects – or is the quality of your daily life more important to you? Share what aspects of your physical and emotional health, and your daily activities and interests are a priority, and ask what effect the cancer treatment will have on these.

## Asking the right questions

It is essential that you, or those closest to you, are given the opportunity – and feel able – to ask your care team questions about proposed treatments or side effects if you've already been started on a hormonal treatment. You might find some of these questions helpful when talking to your doctors:

- What are all of the benefits and, especially, the downsides of treatments or trials that are recommended?
- How long has a treatment been used for, and how widely?
- What are the pure cancer survival rates for me, once the death rates from other causes have been removed?
- What will the consequences of the medication and resulting lack of hormones be on my day-to-day life and activities?
- Can I discuss the evidence of the pros and cons of HRT after my type of cancer, for my daily life and wellbeing, and their benefits such as improved bone health and reduction in the risk of heart disease?
- How would starting HRT influence my pure cancer survival rate?

Don't forget, if you aren't happy with the answers you receive, you can always ask for a further opinion from another specialist who treats patients with the problem you have. Asking these types of questions can help you (and your care team) see the whole picture, rather than having conversations that merely focus on the singular perspective of cancer survival.

## Making a decision

Having answers to these broader questions can be hugely beneficial, and help you feel you now have all the information to come to a decision that's right for you.

If you have already started hormonal treatments and are experiencing unpleasant side effects, be assured that you can always change your mind about that treatment and ask to re-visit a conversation about the pros and cons of continuing on it. Having that discussion may make it easier to come to an informed decision about what treatment options may be available and appropriate for you.

If you have had a full and frank discussion with your cancer care team, you may come to a decision that feels at odds with what the doctors are advising you to do to prolong life. This is often because some people with very significant symptoms decide that life without hormones is more unbearable than doing what is being recommended.

In that situation some people opt for hormone replacement therapy (HRT) to restore the estrogen and/or progesterone and testosterone that their body is missing. HRT usually relieves menopausal symptoms allowing people to feel a return of their old self and often be able to resume work, and social and leisure activities. An improvement in quality of life means that you will experience a more fulfilling life, despite a slightly increased risk of the cancer returning. HRT also has benefits; it reduces health risks that hormone manipulation increases the risk of, such as bone-thinning (osteoporosis), heart disease, type 2 diabetes and dementia.

Oncologists often advise against HRT due to the relatively limited evidence that this promotes cancer and reduces cancer survival. However, there is also some evidence that the contrary occurs – that HRT can improve cancer survival. Sometimes, having a second opinion may help if you are having difficulty in coming to a decision about what to do for the best. That opinion might be from another oncologist who has more rounded approach to your predicament, or a menopause specialist who can discuss the potential risks of cancer recurrence but also help supervise your treatment with HRT if that seems appropriate.

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