ovacome..
ovarian cancer

If your care needs increase

Deciding to end active treatment

Ovacome is a national charity providing support and information to anyone affected by ovarian cancer.

We run a free telephone and email support line and work to raise awareness and give a voice to all those affected by ovarian cancer.

This information is part of our *If your care needs increase* series. It gives information that can support decision making around ending active treatment for ovarian cancer when its benefits may be outweighed by side effects.

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Patient Information Forum

Deciding to end active treatment

You may have come to a time when your ovarian cancer is no longer responding to treatments that aim for no evidence of disease, or to reduce or control disease. Perhaps now treatment benefits are outweighed by the risks and side effects.

There may be other medicines and therapies that could reduce the cancer's impact on your health and your life, which could lead to fewer side effects, while keeping control of cancer symptoms.

You may by now have come to a crossroad. Further active treatment will not make a significant difference to how long you live. It is time to think about the best way forward for you and make decisions about your treatment into the future that will suit your individual needs and enhance your quality of life.

Choices and priorities

The choices can seem overwhelming, and it might be hard to let go of the hope that your illness can be cured. Family and friends may urge you to carry on with active treatments, such as surgeries, chemotherapy, maintenance therapies and drugs that could reduce the cancer, but the side effects reduce your enjoyment of life.

You may want to consider what is most important to you now. Where do you gain the most enjoyment and fulfilment in your life? It can help to take your decision step by step, putting your own needs first.

Talking with your clinical team

A first step can be to have a discussion with your oncologist to get realistic information about continuing active treatment. This may include whether it will work, the risks and benefits, side effects and the hospital appointments and admissions it may require.

You may want to ask:

- How is the cancer responding to my current treatment?
- What do you expect the outcome to be for me if I go on with active treatment?
- What do you think would happen to my health if I end active treatment?
- If I decide to stop, what symptoms and quality of life could I expect?
- If I stop, what treatment is available for symptoms I may experience?

Consider your current feelings. If you are feeling depressed, it could be important to address this before you make a decision about continuing treatment.

You might also consider asking for a second opinion about the likelihood of ongoing active treatment benefitting you. You could also see if there is a clinical trial testing new treatments that might help you.

You may decide to accept treatments that help you to stay as well as possible and as comfortable as you can be, rather than continuing with active treatment that aims to cure the cancer, but now causes side effects without giving any real benefit.

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Once you have heard and discussed all the options you will be closer to making a decision.

The decision you make will be the right one for you at this time. Your needs may change, and more treatments and therapies may become available so your choices can change over time.

It is important to remember that your choices will be respected by your healthcare team.

Making your decision

Moving from active to non-active treatments means deciding not to have further surgery, curative chemotherapy, or maintenance therapies such as PARP inhibitors and drugs such as letrozole.

It means looking at your life from a different perspective; accepting that you will live alongside ovarian cancer for the rest of your life however long that might be.

Your decision has to be the right one for you at this time. Your situation may change, or a new treatment may become available, which may mean thinking again – and your clinical team will respect this.

Non-active treatment aims to control and manage symptoms with as few side effects as possible. It is sometimes called palliative care. You can still have chemotherapy if it is needed to control symptoms. Radiotherapy is sometimes used for this too.

Other treatments at this stage may include using steroids to help your appetite and having blood transfusions if you are anaemic. These treatments aim to keep you well and able to enjoy your life for as long as possible.

Palliative care treatments can often be given at home so you won't have so much travelling to hospital appointments, which can be time consuming and exhausting. You may find you have more energy to spend being more independent and doing what you enjoy.

There is no right or wrong decision. You may find that the decision unfolds gradually over time, and you come to see that your needs are changing, or that active treatment is no longer effective for you. It is about your own view of your life and meeting your own needs.

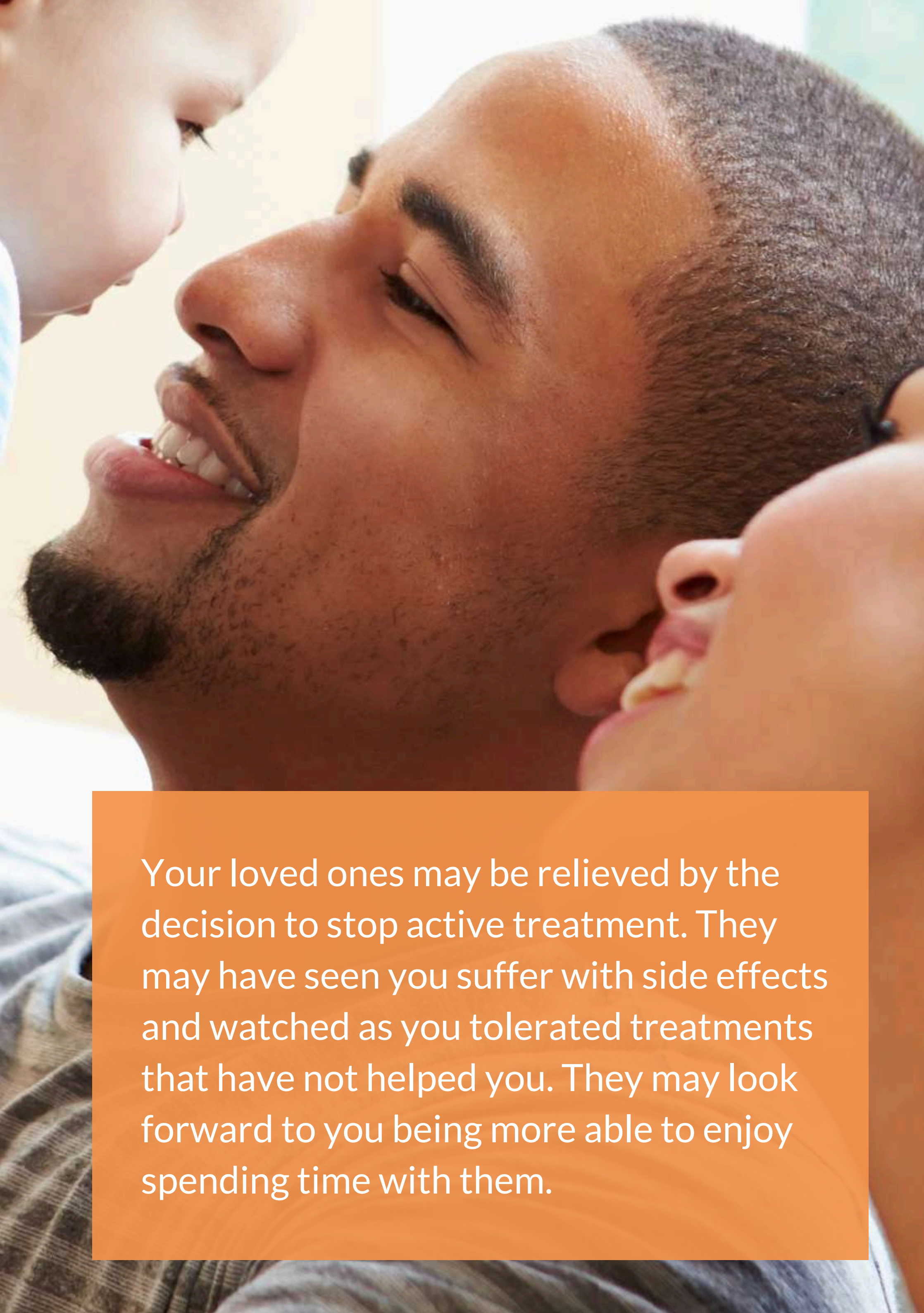
Family and friends

It may be best to talk to your family and friends when you start thinking about changing your treatment. This will give them time to get used to the situation. If your decision causes tensions then there is time to seek support from your clinical team, your clinical nurse specialist (CNS) or a counsellor.

Some of these services may be available for your family too, and you can seek support together or separately. However, you don't have to involve your family or friends in decision making if you don't want to.

Your loved ones may be relieved by the decision to stop active treatment. They may have seen you suffer with side effects and watched as you tolerated treatments that have not helped you. They may look forward to you being more able to enjoy spending time with them.

However, they may be shocked and upset that you are considering treatment for symptom control only.



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Your loved ones may want you to keep on with active treatment, even though it is not helpful to you. This could be because they are afraid for you and afraid of losing you.

They may view a decision to end active treatment as giving up; but it is a courageous decision that recognises the reality of your position, your preferences, and your feelings. They could be worried that you have lost hope. While your hope that your cancer can be cured has diminished, you may still hope to enjoy your life and to have time with your family and friends that is happy and meaningful.

They may have been in denial about the seriousness of your diagnosis. This could be the first time that they have had to think about the end of life, which happens to us all.

If your family needs support remember that hospices provide services for the whole family and can help them to come to terms with your situation.

Moving away from active treatment is likely to mean less time spent in hospitals and more time at home. Your palliative care team may treat you in your home and family members and friends could be involved in supporting and caring for you, if you wish. You may find this gives some relationships depth and intimacy or you may prefer to have professional carers.

You may find Ovacome's What services are there for me now? booklet useful. Go to ovacome.org.uk/what-services-booklet

It is important to remember that you are still in control and at the centre of your care and treatment. You have taken a step into another chapter of your life and asserted your needs. You are looking forward to care and comfort in the way that best suits you and that must be respected and supported.

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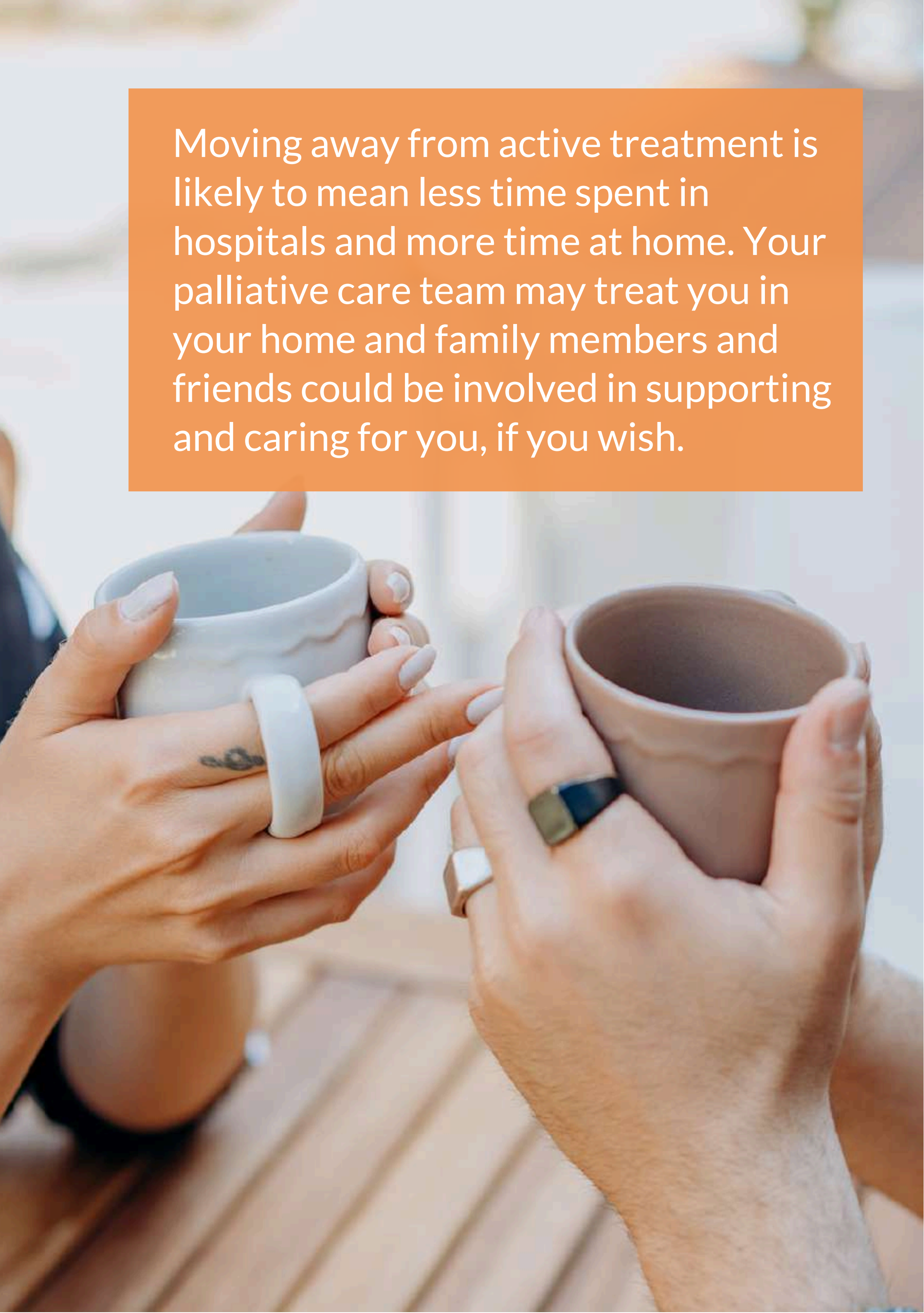

Further information

Ovacome support line 0800 008 7054 Monday-Friday 10am-5pm

Macmillan Cancer Support 0808 808 0000
www.macmillan.org.uk/cancer-information-and-support

Marie Curie Cancer Care 0800 090 2309
www.mariecurie.org.uk/information

www.england.nhs.UK/cancer/living

www.maggies.org/

This booklet is one in four in the series If your care needs increase.

We welcome your feedback on this booklet. Please email ovacome@ovacome.org.uk or call 0800 008 7054. If you would like to discuss anything about ovarian cancer, please phone our support line on 0800 008 7054 Monday to Friday between 10am and 5pm. You can also visit our website at www.ovacome.org.uk. This is one of a series of information booklets produced by Ovacome. You can see them here: ovacome.org.uk/information

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Disclaimer

Ovacome booklets provide information and support. We make every effort to ensure the accuracy and reliability of the information at the time of publication. The information we give is not a substitute for professional medical care. If you suspect you have cancer, you should consult your doctor as quickly as possible. Ovacome cannot accept any liability for any inaccuracy in linked sources.

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Ovacome is a charity. We receive no government funding and most of our funding is provided by our community of supporters. We want to continue providing free support and information to people when they need it most. If you can, then please help us by making a donation. You can **scan the QR code** to the right or visit **www.ovacome.org.uk/donate**

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