

Chapter 13: Living with kidney cancer

This chapter is part of a series of materials. For more information, and to access further materials, please visit www.KEYTRUDA.co.uk

For patients being treated with KEYTRUDA[®] (pembrolizumab) in combination with axitinib for advanced renal cell carcinoma

Your healthcare team should have provided you with materials to help you identify any side effects you may experience on your treatment. Ensure you read the Patient Safety Information Brochure and carry your Patient Alert Card with you at all times.

It is important to be aware of side effects. Telling your healthcare professional straight away as soon as you notice any symptoms may stop them from becoming more serious.

DO NOT ATTEMPT TO DIAGNOSE OR TREAT SIDE EFFECTS YOURSELF.

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at: <https://yellowcard.mhra.gov.uk/> or search for MHRA Yellow Card in the Google Play or Apple App Store. Adverse events should also be reported to Merck Sharp & Dohme Limited (tel: 01992 467272). By reporting side effects you can help provide more information on the safety of this medicine.



Living with kidney cancer

Kidney cancer can have a big impact on your life.

It can be stressful, both physically and emotionally, and it can affect your friends and family too.

Cancer, and the treatments you have for cancer, can change how you go about your everyday activities. You may feel weaker or more tired than usual and the side effects of medicines can also make you feel unwell.

Living with kidney cancer can have a big impact on your mental health.

It is normal to be worried about your work, your finances or your relationships. It is also normal to be anxious about your cancer and the future.

Living with kidney cancer

It is important to remember that you are not alone and there are people, healthcare professionals, and organisations that can help you get the support you need, throughout your treatment.

This chapter will provide support for living with kidney cancer, your KEYTRUDA and axitinib treatment, as well as organisations you can contact for extra support. These organisations can be found detailed in this chapter.



Living with kidney cancer

Fitting KEYTRUDA and axitinib into your daily life

After being prescribed with KEYTRUDA and axitinib, you may be able to carry on with many of your daily activities or you may need to make a few changes.

KEYTRUDA is given as an infusion once every 3 weeks, and it is important that you keep your infusion appointments.



Having infusions may mean you have to take time off work. The infusion itself lasts 30 minutes, but you may also need to consider travel time and waiting time at the infusion clinic. Talk to a nurse or doctor about arranging infusions at a time that could be more suitable for you.

Living with kidney cancer

Fitting KEYTRUDA and axitinib into your daily life

It is important that you do not miss your infusion appointment.

Tell your nurse or doctor if you are planning to go on holiday or spend a long time away from home (for example, staying with family in another city).

Axitinib (XNB) is a tablet taken by mouth **2 times a day, 12 hours apart**. You may find it useful to set up reminders or an alarm on your phone so that you remember to take it at the same times each day.



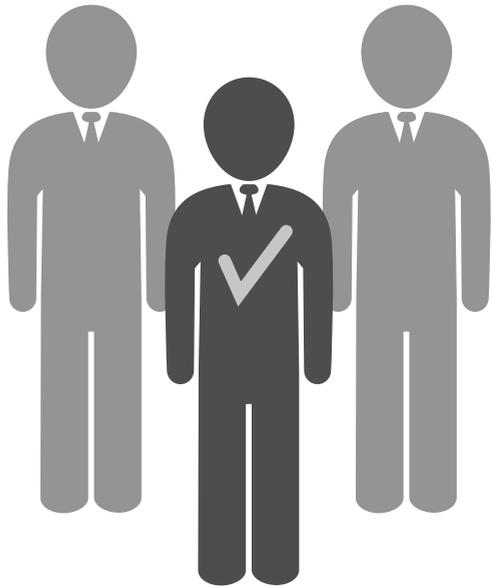
You could consider a tablet organiser which lets you put your axitinib tablets in small boxes labelled with the days of the week and time of day.

Always carry your Patient Alert Card with you, particularly if you are away from home. Your card has information about your treatment which can help healthcare professionals if you are feeling unwell.

Living with kidney cancer

Your employment rights with kidney cancer

- Regardless of whether you have symptoms or consider yourself disabled, UK law considers people with cancer to be disabled and therefore you are covered by the **Equality Act and Disability Discrimination act**
- This means that that your employer **must make reasonable adjustments** for your condition to help you continue your work. This includes changes to accommodate your infusions
- The law also forbids employers from making you redundant just because of a kidney cancer diagnosis
- You don't have to tell your employer you have kidney cancer but, if you do, you can also ask them keep this information confidential or agree on certain people that you will tell



Living with kidney cancer

Being active with kidney cancer

Kidney cancer can have a big impact on your everyday activities and your emotions. Following a healthy meal plan and being active can boost your energy levels and help you feel better emotionally. Your treatment with KEYTRUDA and axitinib may also have some side effects which can be helped by being active and eating well.

- A balanced meal plan can help you to **maintain strength** and fight off infections. For more information on a balanced diet, download **Chapter 7: Living with kidney cancer**



- For some people, treatment with KEYTRUDA and axitinib can lead to side effects such as feeling sick, diarrhoea or constipation. Eating certain foods may help to reduce some of these effects

- Your doctor may refer you to a dietitian who will provide you with advice about which foods to eat and which foods to avoid



- For more information on diet and exercise, download **Chapter 7: Living with kidney cancer**
- If you smoke, stopping is the healthiest decision you can make. For information on how to stop smoking, download **Chapter 9: Getting ready for your treatment with KEYTRUDA and axitinib**

Mental health support

Kidney cancer can affect many different areas of your life, beyond just the physical changes.

It is normal to feel upset, numb, frightened, confused, angry or resentful when living with cancer, and many patients experience times when they feel happy and times when they feel sad.

You may find it frustrating and difficult to find the right words to describe how you feel. Everyone reacts in their own way and it's important to remember that there is no 'right' way to feel. Help and support are available.



Talking to healthcare professionals:

- It's important to remember that professional support is available and it's there to help you. They have lots of experience supporting people who feel how you do
- Asking healthcare professionals questions can help you feel comfortable and increase your understanding of your treatment
- Healthcare professionals can also help you find the right emotional and practical support
- Your clinical nurse specialist is your main point of contact and is there to answer any of your questions. They will support you during your treatment and can provide specialist advice about your diagnosis and treatment

Living with kidney cancer



Talking to your friends and family:

- Cancer can place a lot of stress on your relationships with friends and family
- Help your friends and family by letting them know if you would like to talk about what's happening and how you feel
- It can often be hard to describe your feelings to your family, and many people with cancer worry about complaining too much. Take your time to explain your emotions, and let them know if your feelings are complicated

Living with kidney cancer



Talking to other people:

You might find it easier to talk to someone outside of your own family and friends. Hospices offer counselling, spiritual care and psychological support that you can access locally. Speak to your healthcare team to find out more information about your local hospice.

The following helplines are also available:

Cancer Research UK
www.cancerresearchuk.org

Helpline: 0808 800 4040
Mon-Fri 9am-5pm

Macmillan Cancer Support

www.macmillan.org.uk
Macmillan Support Line:
0808 808 00 00

Kidney Cancer UK
& Kidney Cancer Scotland
www.kcuk.org.uk

Patients' support Careline:
0800 002 9002
Mon-Fri 9am-4pm

Kidney Cancer Support Network
www.kcsn.org.uk

Helpline: 01209 890326
Email: team@kcsn.org.uk
Mon-Fri 10am-4pm



Cancer Research UK has online self-help strategies across a range of mental health issues related to kidney cancer that you can explore in your own time.

Visit **www.cancerresearchuk.org/about-cancer/coping/** emotionally to learn more.

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Living with kidney cancer

Dealing with money and kidney cancer

Living with kidney cancer may have an impact on your money and finances. You may have to reduce the numbers of hours you work or stop work altogether.



There are several organisations that offer financial advice and support. Please ask your nurse specialist for more information.

Organisations that provide advice on money issues (such as mortgage, pension, credit cards, and insurance):

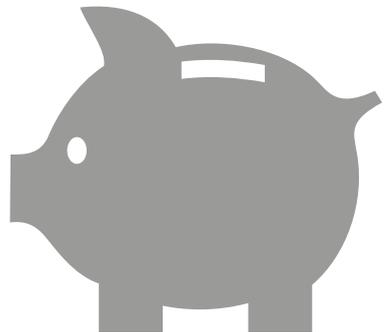
- Kidney Cancer UK
- Macmillan Cancer UK
- Turn2us

Charities and organisations that offer grants:

- Kidney Cancer UK
- Macmillan Cancer UK
- Turn2us

Organisations that offer benefits advice:

- Citizens advice
- The Money Charity
- National Debtline



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Living with kidney cancer

Thinking about your future

Throughout your treatment for kidney cancer, your doctor will arrange for you to have some tests to see if your treatment is working and how your cancer has responded. While everyone hopes for a good outcome, some people can find it useful and reassuring to plan ahead in case you receive some bad news.

Planning for end of life

While it is a difficult and often scary subject, planning for end of life can allow you to be in control of decisions and help provide reassurance to you and your family.



- It can be reassuring to talk about your finances and your will so you can understand how this will affect your family in the future
- Legal advisors can help you understand inheritance laws and make sure that your money goes where you would like it to

Living with kidney cancer

Choosing where to be at the end of life

Planning ahead for where you wish to spend your final days can help you know what to expect if your condition becomes worse. Talk to a healthcare professional in advance if you wish to be at home in your final days



- Being at **home** at the end of life allows you to be around your family and familiar places
- It is important that you and anyone involved in your care have as much support as possible



- **Hospices** offer a wide range of services to support you. These services include pain management, rehabilitation and complementary therapies as well as end of life support
- Hospices can be very different to hospitals. They can be quieter, have more flexible visiting times and provide care to suit you
- You may want to visit a few hospices to view the facilities and talk to the staff, and see which one feels best for you



- You may prefer to be looked after in a **residential care home** with qualified nurses
- Care homes can be government run, charity run or private. Talk to a healthcare professional about the most suitable option for you

Living with kidney cancer

Additional help

Decisions about end of life are often very complicated and filled with emotion. If you would like more detailed advice, the help is available at the following organisations:

**Kidney Cancer UK &
Kidney Cancer Scotland**
www.kcuk.org.uk

Patients' support Careline:
0800 002 9002

Cancer Research UK
www.cancerresearchuk.org

Helpline: 0808 800 4040
Mon-Fri 9am-5pm

Macmillan Cancer Support

www.macmillan.org.uk

Macmillan Support Line: 0808 808 00 00

Kidney Cancer Support Network

www.kcsn.org.uk

Helpline: 01209 890326.

Email: team@kcsn.org.uk



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References

Macmillan Cancer Support. Available at <https://www.macmillan.org.uk/> (Accessed September 2020)

Cancer Research UK. Available at <https://www.cancerresearchuk.org/> (Accessed September 2020)

Kidney Cancer UK. Available at <https://www.kcuk.org.uk/> (Accessed September 2020)

