



We need to talk about living with kidney cancer

World Kidney Cancer Day | 15 June 2023

We need to talk with family, friends and other patients

A big question for many who receive a kidney cancer diagnosis is who, what and how much to tell other people. Kidney cancer is rare, so there's not always someone to ask. But experts agree that talking openly about your cancer and how it's affecting you, mentally as well as physically, is not only better for you, it's better for your family and friends. Patients and carers who also join support groups - where they can share information and get support from others going through exactly what they are - have described the experience as life-changing.

Telling those close to you

When deciding what to tell your family and friends it's tempting to think that saying you're OK and holding back about what's really happening and how you're feeling will stop your loved ones worrying. But that's rarely the case. It's more likely to make them worry more. Family and friends can see you're not OK, assume you must be hiding something and fear the worst. People close to you want to help you and be there for you. So be honest with them and let them support you, not just for your sake but for theirs. As one patient put it *"You will find that people love and care about you more than you ever thought"*.

"If my dad wouldn't tell me, I'd think that he doesn't trust me to be a source of support"



Claudia. Carer. Italy

“I strongly recommend to join a patient group”



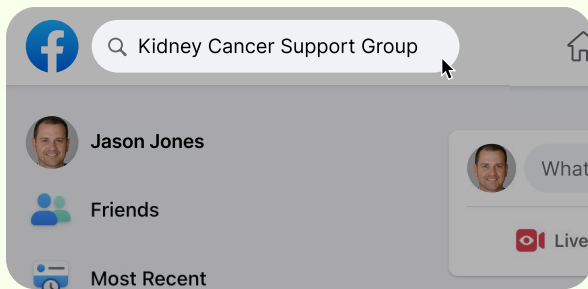
Hiro. Patient. Japan

Joining a patient support group

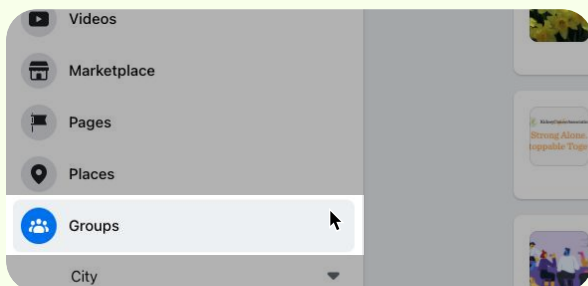
Most patients don't have anyone else living in their community living with kidney cancer, so joining a patient support group and connecting with others going through exactly what you are can be a great source of practical and emotional support. Some support groups are specific to cancer types and stages; others are more general and include people living with all cancers. Whatever type of support group you join it's an opportunity to share information, experiences, tips and to talk openly with others who truly understand what you're going through.

How to find a patient support group

Some support groups meet in person but most are online, many open to patients and carers from all over the world. Clinicians or friends may be able to recommend a group to you or you can search online. You can also find support groups on social media platforms such as Facebook and Twitter.



Search for groups in the top left of Facebook.



After searching, click the “Groups” tab on the left hand menu.

The World Kidney Cancer Day website has created an easy-to-follow guide to help you find groups that may be right for you together with advice to help you check they are credible and trustworthy [URL link]. The International Kidney Cancer Coalition (IKCC) website ikcc.org is also a great source of information and links to patient support organisations.

“It helps a lot because you see people who already had a surgery that you know is coming”



Ronald. Patient. Netherlands

“The Facebook community allows you to be more open than you would otherwise”



Joel. Patient. USA.

“It really does help to know that other people can go through this and come out the other side”



Lynne. Patient. UK

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