



World Bladder
Cancer Patient
COALITION



Guide **2**

Creating an
online community

Why an online community matters



An online support group offers far more than just a place to talk, it becomes a lifeline for people affected by bladder cancer. In a safe and welcoming space, members can share their personal experiences, ask questions they may not feel comfortable asking elsewhere, and receive comfort from others who truly understand what they are going through.

These groups can help reduce feelings of loneliness, offer practical tips for daily life, and provide encouragement during difficult moments. They can also connect people across towns, regions, and even countries, creating a sense of belonging beyond geographical boundaries.

For new patient groups, setting up an online community is one of the most cost-effective ways to bring your first members together, build trust, and start creating a supportive network that your group will grow for years to come.



Setting up your group

Creating an online support space is straightforward, but a little planning will make it far more effective and welcoming from the start. Here is how to do it step by step:

Choose your platform wisely Facebook is the most common choice because it is easy to use, has strong community features and is widely recognised. If Facebook is not popular or accessible in your country, consider alternatives like WhatsApp, WeChat, or a local social media platform. Think about your audience – what platform are they most likely to already be using?



Pick a clear, searchable name Include “bladder cancer” in the name and in a local language(s) so people searching online can find you. For example, “Bladder Cancer Support – [Country]” is simple, specific, and easy to remember.



Write a welcoming description Clearly explain who the group is for (patients, carers, family members, etc.) and what members can expect (peer support, information sharing, updates on events). A short, friendly introduction sets the tone and reassures potential members.



Set the right privacy level For patient support, a private group is best. This means people can find the group and request to join, but posts are only visible to members. This protects privacy while still making the group discoverable.



Create clear joining questions When people request to join, ask a couple of simple questions, such as their connection to bladder cancer and agreement to follow group rules. This helps keep the group safe and relevant.



Add strong branding Use your logo, a friendly cover image and consistent colours to make the group look professional and trustworthy. Images of people together, awareness month visuals, or symbolic elements like the bladder cancer ribbon can make the space feel inviting.



Post a welcome message Your first pinned post should greet new members, explain the group’s purpose, and outline the rules. This is your chance to set a positive tone and encourage participation from day one.



Moderating and growing your group

A well-moderated group feels safe, positive, and worth returning to. Good moderation does not just prevent problems, it also keeps members engaged and helps your community grow over time.

○ Recruit a trusted moderation team

At least one or two committed volunteers can share the responsibility of approving members, monitoring discussions, and keeping the group running smoothly. Choose people who understand your group's purpose and can communicate respectfully.

○ Screen new members carefully

Ask simple vetting questions when people request to join, such as their connection to bladder cancer and agreement to follow the rules. This helps ensure the group stays focused on its purpose and free from unwanted promotion.

○ Act quickly on spam or inappropriate content

A single spam post or offensive comment can damage trust. Removing such posts promptly shows members that you take their safety seriously.

○ Encourage regular conversation

Keep the group active by posting open-ended questions, sharing useful articles, and starting discussions about common challenges or uplifting moments. Regular activity helps members feel comfortable contributing themselves.

○ Celebrate milestones and successes

Highlight awareness events, treatment anniversaries, or community achievements. Recognising these moments helps strengthen bonds between members.

○ Share reliable, accessible information

Link to trustworthy resources on bladder cancer, treatment options, and patient support. This builds your reputation as a reliable source of information, which in turn attracts more members.

○ Be visible and approachable

Let members know who the moderators are, and encourage them to reach out privately if they have concerns. This fosters a sense of security and openness.

○ Listen and adapt

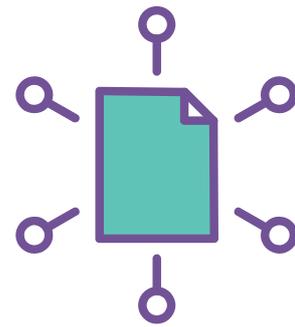
Pay attention to the topics and resources members respond to most. Over time, you can adjust your posts, events, and group features to better meet their needs.



Tip:

Healthy growth is better than rapid growth. Focus on creating a positive, engaged environment first, and new members will join naturally when they see the value your group offers.

Safety, privacy and rules



Trust is essential in a patient community.

- **Protect confidentiality:** Remind members not to share other people's stories outside the group.
- **Set clear rules:** No spam, respectful discussion, and no medical advice.
- **Be transparent:** Let members know how moderation works and how their data is handled.
- **Encourage kindness:** Foster a supportive tone in all interactions.



Case studies

Fight Bladder Cancer Support Forum

Fight Bladder Cancer UK started in 2010 with a small private Facebook group of just 40 members. Over time, it grew into a thriving community of almost 5,000 members from around the world, supported by a team of 10 volunteer moderators. Members use the space to share experiences, ask questions, and receive emotional support from people who understand what they are going through. The group's success comes from consistent moderation, a clear purpose, and active engagement that makes people feel safe and heard.



Melanie Costin, Director of Patient Engagement & Support at Fight Bladder Cancer UK

Join our private Facebook support forum.

Search 'Fight Bladder Cancer support'



"The strength of our community lies in the kindness and understanding of its members. We've built a space where people can be honest, ask anything, and know they will be met with respect and support."

To learn more, visit:
fightbladdercancer.co.uk



CANVES Bladder Cancer Support Group

When CANVES was created, one of their first steps was to connect patients online.

They launched a private Facebook group for people across Spain to share their journeys, exchange information, and find encouragement.

By partnering with doctors and patient advocates, they promoted the group to newly diagnosed patients, ensuring that support was available from the earliest stages.

This combination of medical endorsement and peer connection helped build trust and grow membership quickly.



Laurent Gemenick,
Co-founder of CANVES

“For many people, joining our group is the first time they meet others who truly understand what they’re going through. That shared understanding is the start of real connection and hope.”



Top tips for success:

- Post a welcome message for new members so they feel included right away.
- Use theme days (example: “Motivation Monday” or “Share Your Tip Friday”) to encourage posts.
- Share awareness month materials to start conversations and invite new members.
- Celebrate milestones, whether it is a member’s birthday, treatment anniversaries, or the group reaching a new size.



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www.worldbladdercancer.org