



How to set up a 'Fight Club' support group

A GUIDE FOR PROFESSIONALS, PATIENTS & CARERS

Patients and carers all need support to help cope with the effects of a bladder cancer diagnosis and treatment. The challenge is to meet their varied needs. Local support groups are part of the range of services that Fight Bladder Cancer supports throughout the UK.

The National Institute for Clinical Excellence's 2003 guidelines on supportive and palliative care emphasise the role of self-help and support groups, and state that patients, their families and carers need access to supportive care, which should be provided throughout the patient's pathway.

Support groups provide a forum for patients to access help and overcome some of the psychological trauma that accompanies a cancer diagnosis.

Currently there is a huge shortfall in the provision of bladder cancer support groups across the UK. But Fight Bladder Cancer has a current project to help create a local support group for every patient diagnosed with bladder cancer.

If you want to set up a local group, Fight Bladder Cancer will help you make it happen.



GETTING STARTED

The "professionally led" model

This is when a urology team decides that they want to set up a support group for bladder cancer patients linked with their hospital(s).

Usually this is when a urology Cancer Nurse Specialist (CNS) in a hospital takes the lead and works with Fight Bladder Cancer to scope and then establish the support group. FBC recently helped with the formation of the group in Brighton, which welcomed over 100 people to its first meeting. We provided bespoke designed posters and leaflets for the first series of meetings that we used to engage the patients and encourage them to join.

The CNS who helps to facilitate the groups should run it initially in a non-directive way, and always be available for advice and to answer any questions at group meetings. These are active groups where the patients support each other, share experiences and plan guest speakers, along with various fundraising activities. As the group matures, we find that the CNS can start to step back as the patients and carers take on a greater role.

To get a support group started, we advise that letters are sent to all patients known to the CNS over the past 2 or 3 years.

All participants wanting to join the support group should be informed of its aims and terms of reference – to provide a safe and supportive environment in which patients and carers can

gain support from each other, through openly sharing feelings and experiences.

Monthly meetings have been found to be successful as they aren't too great a commitment but are regular enough to keep the interest going. The meetings should last for no more than 2 hours and should have guest speakers to provide a focus on information whenever possible.

There are no real costs involved in setting up a group. The venue used can often be provided free of charge by the hospital. It is quite acceptable to charge a small entrance fee to help fund drinks, biscuits and other incidental expenses. We can provide you with awareness materials, posters and advertising of your event.

As well as talks and discussions on treatments, side effects and quality of life issues, we have found that groups also like to have talks on:

- diet and nutritional advice
- financial and benefits advice
- bladder cancer research
- awareness campaigns
- fundraising events



Men, people from ethnic minorities and patients from low socio-economic levels are under-represented in cancer support groups. Involving these patients and promoting equitable services poses a challenge for those planning and running the groups.

The “patient- and carer-led” model

This is when patients and carers themselves set up and run a self-help support group.

Many of the Fight Bladder Cancer groups have started after people who have made contact through our Confidential Forum realised that they live near to other members and decided to get together on a regular basis to support each other.

When professionals get involved in these groups they only play enabling roles, such as catalyst, consultant or trainer.



Support groups are fundamentally about human warmth, friendship and companionship with people who have had (or are having) the same experience as you. This helps to create a strong bond between people affected by bladder cancer and helps to ensure that these groups are sustainable.

The big difference with these patient-led groups is that they tend to start small and grow as word gets around of their existence. If you are setting one up, don't worry if only 3 people turn up at the beginning. Form the group and they will come!

To start with, many of these groups meet in a local pub or café for a chat and take it from there. As the groups grow you can start having more formal meetings if you want.

If (and when) you move to a more formal venue this can often be provided free of charge by the local hospital, or you could borrow the staff room at a local supermarket. Many national supermarket chains offer this facility to local community groups. Remember that it is quite acceptable to charge a small entrance fee to help fund drinks, biscuits and other incidental expenses.

At Fight Bladder Cancer we are always here to give advice and support to help your group find its feet and move it forward for you and your fellow patients and carers.



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CANCER

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ABOUT FIGHT BLADDER CANCER

Fight Bladder Cancer is a patient-led charity in the UK that exists to:

- **support anyone affected by bladder cancer**
- **raise awareness** of the disease in order to improve early diagnosis
- **campaign for and support research** into this disease
- **affect policy** at the highest level to bring about change

Fight Bladder Cancer has a worldwide reputation and is supported by top international healthcare professionals.

At Fight Bladder Cancer, we take great care to provide up-to-date, unbiased and accurate facts about bladder cancer.

We have a very supportive medical advice panel made up of some of the best professionals working with bladder cancer, and hope that our information will add to the medical advice you have had and help you to make decisions.

REMEMBER, YOU CAN CONTACT US AT ANY TIME FOR SUPPORT

or to engage with us in fighting bladder cancer

via our website at

fightbladdercancer.co.uk

via our online forum at

facebook.com/groups/bladdercanceruk/

by email at info@fightbladdercancer.co.uk

by phone on **01844 351621**

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