

Setting up a Support Group

Introduction

Support groups can benefit patients, families and carers by providing emotional support, friendship and relief from isolation. They offer the chance to share information and experiences with those in a similar situation. The value to those who attend the meetings is very personal and it is true that a small number of people will attend only a few times. People are individuals and the personal make up of some people is that they are very private and are not able to change this aspect of their nature. Others find the negative aspects of this disease to be overwhelming and cannot balance this against the positive aspects of meeting others who are coping with the same condition.

Fortunately the vast majority of support group members benefit greatly and attend regularly for year after year. They gain from both the help that they receive and the help that they give to others.

Prostate Cancer may be restricted to the male, but it also affects his partner and his other loved ones as well. For this reason we believe that men with prostate cancer and their carers should all be welcome at support groups and believe that they can all gain immeasurable help.

Before you start - fact finding

To help get your group started you should find out about local services in your area. Ask what is already available and needed from -

- Patients at your local hospital
- GPs, CNSs and managers of health centres
- Ready established support groups for other cancers
- Macmillan drop-in centres or voluntary health groups
- Citizens advice bureau

Your local Library should be able to supply phone numbers for the above.

Further points to consider

- Determine local demand and ask why are you forming a group?
- Where, when and how often will you meet?
- How much time can you spare and what will it cost?
- What are your aims for the group?
- Decide how many people should form a committee?
- Identify local health care professionals who may be willing to help?

What can you offer

A diagnosis of Prostate Cancer is a catastrophic event in any man's life. It is typically unexpected and a terrible shock. Initially, no matter how well adjusted he may be, he may feel ill-equipped to cope with it. Upon hearing the diagnosis, many patients, and those who care for them, feel helpless, confused and overwhelmed, fearing the worst. As well as dealing with the effects of the

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condition and sometimes its treatments, people with prostate cancer often have to come to terms with many fears and myths about the disease. Cancer self-help support groups assist people through such difficulties and can turn a negative experience into a positive one. They can help people regain a sense of control over their lives and give them the chance to talk to others who understand.

Making a start

Decide on a venue. Groups meet in a variety of locations. Almost any room that can accommodate the numbers and provide some confidentiality can be suitable, although access for people with disabilities is important. Examples of meeting places include:

- Hospital meeting or presentation rooms. Some hospitals will provide rooms free of charge. Others charge quite high fees. Some people prefer to get away from the clinical environment, but there can be benefits from having links with the hospital.
- Private room in a public house.
- A church hall
- A community or health centre
- Clubrooms – golf, British Legion, etc.

It is quite common for the early meetings to be held somewhere appropriate, like a hospital, but to move to another location after a few meetings when the group is more established.

General points to consider before meeting

- Elect a leader
- Start slowly eg. monthly or bi-monthly. Be flexible about times and venue.
- Share tasks and get to know each other, utilise member's skills.
- Share your experiences, support others during treatment, welcome newcomers.

Other Considerations

- Think about whether your aims are to raise awareness or to raise funds. There is a big difference. Most groups look to raise awareness locally but need a certain amount of income to be able to advertise or arrange to have a presence at local shows or shopping centres.
- Consider a simple constitution to help frame your meetings and establish what your group's aims are. See Appendix A for an example taken from the Charity Commissioners.
- Don't rush into a web site presence until you have a modicum of support and a core of members – there is nothing worse than advertising a web site that has nothing on it or where there is no-one willing to update it.

Advertising the group

There are lots of ways that the group can be brought to the attention of the general public. They include the following:

- Use local media – a local radio station or a local newspaper. Both like to demonstrate that they support the local community and will repeat announcements about the groups presence, although some (especially newspapers) like an "angle" or article on a story.
 - Display material – posters, leaflets and credit card sized awareness material are ideal if you can design your own or ask the Prostate Cancer Support Federation for examples.
 - Suitable locations include doctors' practices, chemist shops, gents' hairdressers, golf or bowling clubs, libraries.
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Everyone is Different

Not everyone who would benefit from a prostate cancer support group will be able to or want to attend. People suffering from prostate cancer disease can experience overwhelming fatigue at certain times, as well as other debilitating symptoms. Sometimes they might feel relatively well and at other times they will have neither the energy nor enthusiasm to be involved with the group. The nature of some forms of prostate cancer disease means that some members may 'dip in and out' of the group depending on their need for support at any given time. This need not be a problem or deter patients from serving on the 'committee'. However, it is sensible to identify other members who would be willing to step in for them if and when required. Above all, consider how the group will appear to potential new members coming along for the first time. How will you overcome the feelings of anxiety, shyness or embarrassment which some people may have? How will you ensure that new people feel really welcomed and comfortable in the group from the outset? If they don't leave feeling this way you will probably never see them again. Finally, forget any perceived stereotypical view of 'support groups'. Your group can be anything you want it to be. The more appealing it is to a cross-section of people and age groups the better.

Good Luck!

Tackle Prostate Cancer hopes that this information has been of help to you and we wish you every success with setting up your group.

If you need help at any time with your group or would like a copy of our larger 'guide to setting-up', then email Roger Wotton on roger.wotton@tackleprostate.org

As a member group of Tackle you could take advantage of a grant of up to £500 towards running costs, raising awareness or providing support for members. Download an application form at:

http://www.tackleprostate.org/uploads/files/Grant_Application_Form.pdf

APPENDIX A - SAMPLE CONSTITUTION

SMALL CHARITY CONSTITUTION

Suitable for small charities with an annual income under £5,000 that do not own a building or employ people and do not intend to register with the Charity Commission.

1 **NAME**

The charity's name is _____

2 **THE PURPOSES OF THE CHARITY ARE:-**

1. To promote and protect the physical and mental well-being of prostate cancer sufferers in the Aylesbury Vale area, through support, education and advice.
2. To raise awareness of the general public in all matters relating to prostate cancer.

3 **TRUSTEES**

The charity shall be managed by a committee of trustees who are appointed at the Annual General Meeting (AGM) of the charity.

4 **CARRYING OUT THE PURPOSES**

In order to carry out the charitable purposes, the trustees have the power to:

- (1) Raise funds, receive grants and donations
- (2) Apply funds to carry out the work of the charity
- (3) Co-operate with and support other charities with similar purposes
- (4) Undertake any activities that are lawful and necessary to achieve the purposes

5 **MEMBERSHIP**

The charity shall have a membership. People who support the work of the charity and are aged 18 or over can apply to the trustees to become a member. Once accepted by the trustees, membership lasts for 3 years and may be renewed. The trustees will keep an up-to-date membership list. The trustees may remove a person's membership if they believe it is in the best interests of the charity. The member has the right to be heard by the trustees before the decision is made and can be accompanied by a friend.

6 **ANNUAL GENERAL MEETING - AGM**

- (1) The AGM must be held every year, with 14 days notice given to all members advising them of the agenda. Minutes must be kept of the AGM.
- (2) There must be at least 10 members present at the AGM.
- (3) Every member has one vote.
- (4) The trustees shall present the annual report and accounts.
- (5) Any member may stand for election as a trustee.
- (6) Members shall elect between 3 and 10 trustees to serve for the next year. They will retire at the next AGM but may stand for re-election.

7 **TRUSTEE MEETINGS**

- (1) Trustees must hold at least 3 meetings each year. At their first meeting after the AGM they will elect a chair, treasurer and secretary. Trustees may act by majority decision.
- (2) At least 3 trustees must be present at the meeting to be able to take decisions. Minutes shall be kept for every meeting.
- (3) If trustees have a conflict of interest they must declare it and leave the meeting while this matter is being discussed or decided.

