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Draft version

**A GUIDE TO
STARTING A
PROSTATE CANCER
SELF HELP SUPPORT
GROUP**

JANUARY 2009.

Prostate Cancer Support
Providing confidential help, support and information
Patrons: Mr Patrick O' Reilly, MD, FRCS; Sir Stirling Moss
www.prostatecancersupport.org
Registered Charity No 1092102

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1. STARTING A SELF HELP PROSTATE CANCER SUPPORT GROUP

Prostate Cancer Support (PCS) has started, or helped to start, nine prostate Cancer Support Groups in recent times.

Some have been successful (judged by attendance) and some have been less so, but our experience has enabled us to recognise those actions that are more likely to achieve the former.

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 that 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.

Different groups operate in different ways - they have different styles - and occasionally a person finds that one group may not be for them while another is very appropriate. There is no right or wrong style; groups reflect the needs of the group's members.

We are often asked how to start a group. There is no fixed method, but there are some recommendations that we offer to those wishing to start a new group.

These are covered within this document prepared by PCS.

If you are considering starting a group, we hope that you will "follow through" and feel that you can call on assistance from PCS (Prostate Cancer Support) or from the PCSF (Prostate Cancer Support Federation).

Mike Lockett
Chair PCS

2. SOME KEY POINTS TO CONSIDER

There are a number of key points that those wishing to start a group will need to consider, or will find helpful before starting a new support group. These include the following

- What is the value of a group (section 3)
- Determine local demand (4.1 and 4.2)
- Define the aims of the group (4.1)
- Decide where, when and how often to meet (4.1. and 4.4)
- Decide how many people should form the committee (4.1. and 4.6)
- Prepare awareness material (4.2. and 4.3)
- Identify names and contacts for local Health Care Professionals (4.2)
- Introductions to local Health care Professionals (4.2)
- Location of meeting (4.4)
- Register of attendees (5.2.)
- How do we run a meeting (section 5 is dedicated to this)

These points and others are covered in this document and the numbers in brackets above indicate where reference is made to this point in the guide.

3. WHAT CAN SUPPORT GROUPS 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. Frequently we hear the comment that hearing the news was "traumatic".

As well as dealing with the effects of the condition and sometimes its treatments, people with prostate cancer often have to come to terms with many fears and myths about the disease.

Cancer patient 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.

3.1. WHY DO SUPPORT GROUPS HELP?

It is generally accepted that social support (perhaps within a family) is an important aid in dealing with stressful events. There is also strong evidence to suggest that a social structure, such as a patient support group, provides meaningful support, encouragement for the expression of emotions, and a buffering of patients from stress. It has the potential to impact positively on both adjustment to illness and, ultimately, the course of the disease. Many studies have shown positive effects of group therapy on such psychological variables as mood, adjustment and pain. A number of studies have suggested that quality of life and even survival time are improved through the positive uplift that many obtain through being a member of a support group.

The group experience offers to patients and carers a place to belong and to express feelings. It allows open discussion of negative issues - otherwise those issues percolate within the individual.

For some patients their cancer can divide them from friends and even family. But at a support group this is the common dilemma that creates an intense bonding among the members and a sense of acceptance. Being with others who have the same disease and who share similar experiences eases the anxiety of facing the illness on one's own and shows that disease-related feelings are normal.

Knowledge is important and apart from expert advice, which is sometimes available, members learn from each other by identifying new and more effective means of coping with the disease. Or simply realising that one can get on with one's life.

So groups provide an opportunity for both mutual and professional help and enable patients to become effective partners in their own medical treatment. The doctor-patient relationship is frequently improved and ultimately patients learn how to manage their disease.

The quote of one member is very telling; "but for the support of this group and the drive that I have developed, I would have been dead three times over!"

3.2. A WARM WELCOME

In a cancer support group you can expect a warm welcome, be introduced to other members, and have the opportunity to talk about yourself and your experience of cancer in a confidential environment.

You're not obliged or expected to talk about anything that you don't wish to discuss, and for some it takes a few visits before feeling comfortable enough to talk about personal matters. However, most people are surprised at how easy it is to talk openly about their cancer and express emotions to others who have similar experiences.

Each individual has their own way of coping, and their own way of getting back control and groups recognise that each person is his or her own best guide.

3.3. MEETINGS

The activities in groups can vary greatly.

As part of the meeting, there may be a talk from experts covering a wide variety of related aspects such as developments in treatment, clinical trials or diet. Sometimes a health professional may be available to talk to. Some groups produce a newsletter and have social activities. Some consist of just a few people who meet regularly and talk through their own experiences; others are much larger and may have premises or a drop-in centre.

Most groups are free, but some may charge for tea and biscuits or welcome donations.

Groups never express doom and gloom! Even though the people in the group have experience of cancer they will not have lost their sense of humour.

3.4. WHAT DO YOU WANT FROM THE GROUP?

Sometimes it's useful for members to think about their involvement as a two-way process: what do we want to get from the group, and what can we offer in return?

4. STEPS IN STARTING A SUPPORT GROUP

In an ideal world there would be a prostate cancer support group within easy reach of every patient and their carers, but sadly there are significant gaps in many locations. PCS is eager to see this situation change and we are keen to see that anyone interested in starting a new group receives all the support we can possibly give.

We are always pleased to discover people with the desire to take the first step towards a new group and we would be delighted to hear from you if you would like to find out more. You will not be under any obligation just by talking to us and you may even discover that it could be easier than you anticipated.

4.1. KEY QUESTIONS

At this stage you should perhaps consider the following questions. Some of these are for you personally, but many should be asked of other volunteers and attendees when the group is first formed. Whatever your views are the early meetings enable you to check the requirements of the attendees and to gain a consensus of opinion:

- Why do you feel there is a need for a group in your area?
- Is there sufficient concentration of prostate cancer patients in your area to warrant starting a group? (The local medical professionals can help to answer this question)
- Why do you want to set up a group?
- Do you know anyone else who could help you get a new group going?
- Do you have the support of your family & friends and how might your involvement in a group impact on them?

- What do you see the group offering?
- Should the group be patient led (this would be our recommendation)?
- If patient led, how will the health professionals be involved?
- Where and when will the group meet?
- How often should the group meet? (monthly is common)
- Would you want to develop social activities to bring people together?

If you view the overall responses to these questions to be positive, then go ahead. You will gain much satisfaction and friendship and will be providing a much appreciated service.

4.2. PROMOTING THE GROUP

The most important aspect to consider at the very beginning is how you are going to promote the group. This is the time to enlist the help and support of the local

medical professionals. Getting them "on board" increases your chances of success enormously.

Visit your local hospital urological department or prostate cancer department. You may already have contacts there if you have been receiving, or know someone who has been receiving treatment. It is possible that PCS may have some contacts in which case we would be happy to help. We would certainly be happy to visit with you to talk about other groups that meet and the benefits that they bring. In the past enlisting the help of some hospitals could be difficult, but this is rarely so these days, as the value of support groups are widely recognised.

The hospital can be instrumental in reaching the local PCa patient population. They know who the patients are and how to contact them. By law they cannot divulge this information to a third party, but there is nothing to prevent them from passing a letter, leaflet or poster to their patients. Two sample letters are enclosed, which were used by us in collaboration with the University hospital of North Staffs when we were looking to establish a group in the area. Sample (1) was handed or sent to patients of the department to gauge the interest level and determine the level of demand; letter (2) has been used from time to time since the group was established.

Many local medics (especially Specialist Urology Nurses) are keen to help and some are regular attendees at meetings. This can be a very powerful incentive for some people to attend as they can meet and chat to a professional in informal surroundings.

4.3. 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" on a story.
- Display posters - PCS has posters, leaflets and credit card sized awareness material and can supply these or you can design your own.
- Suitable locations include doctors' practices, chemist shops, gents' hairdressers, golf or bowling clubs.

4.4. ACCOMODATING THE GROUP

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 centre
- A Health Centre
- Libraries
- Clubrooms - golf, British Legion, etc.

There are many organisations that will provide a low cost (or even free) room for such a good cause. Some public houses and clubs will not charge for a room in the expectation that members will pay for some refreshment while at the meeting.

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.

4.5. HOW MANY CAN BE EXPECTED AT MEETINGS?

Although most established groups would have between twenty and forty regular attendees, the size of different groups will vary from a handful to fifty or sixty, with eighty or more being a possibility. Numbers may be small at first or even remain small. As long as the group is meeting the needs of its members it is serving its purpose.

As the network of prostate cancer support groups grows there is no reason why a small group cannot function as a part of a larger group elsewhere if this is deemed appropriate. The size should not be the measure of success; it is the benefit being offered that is important.

The first meeting can be the most nervous time for the organiser. You will wonder how many people are going to turn up, or if you will even get any attendees at all. On only one occasion have I experienced a first meeting when no one attended, and although that was very disappointing for the organiser, they stuck with it and that is now a thriving group. At the other extreme we know of a first meeting when over eighty people turned up. If you have enlisted the help of the hospital in promoting the group, it may be possible to get advance feedback from people who are going to attend. This will help you to determine how to conduct your meeting.

4.6. GET HELP

Do not try to run the group on your own. At an early stage, identify helpers who would be prepared to assist in the running of the group - you may even be able to

do this during the planning stage before the first meeting. Form a small committee and identify as many people as possible who are prepared to help with events and activities - awareness events, fund raising, etc.

5. HOW DO I RUN A SUPPORT GROUP MEETING?

There is no single right or wrong way to run a support group. In fact, they all tend to do things slightly differently, but there are a few points which need to be considered.

5.1. The first meeting

As this is the first occasion that the group will come together it is inevitable that there will be some uncertainty. But even if this uncertainty is reflected to the attendees it is not important. All present will recognise the situation and will value the efforts of those running the group.

It is remarkable how these first meetings just seem to progress without difficulty or tension and this frequently provides much needed encouragement for the future.

There tend to be two types of "first meeting".

1. An informal meeting to introduce each other and to understand the aims of the support group.
2. A more structured meeting with guest speakers to present to the attendees.

5.2. Informal meeting

Typically the person acting as the host (and perhaps other helpers) will welcome attendees and make them feel welcome - tea and coffee can be useful time fillers at this early stage as people will not arrive all at the same time.

When appropriate a brief introduction to the idea of a support group, its values, etc. can be given and it is probably a good idea to mention that personal information will and should be kept confidential. Some group leaders mention this before every meeting and have a confidential statement on display.

A valuable exercise is then to go round the room asking each person to introduce themselves (and don't forget the carers present). Give them an indication of what is expected; explain that this is by way of introduction (some people can give their life story and talk about their own situation at length) and say that the meeting can return to look at any specific situations that justify further consideration - and make sure that this is done. Set an example by starting with yourself and other helpers. If you wish, say a little about you personally but keep this brief.

The main aim is to tell the others about your medical situation:-

- when diagnosed
- a few statistics - people are often keen to compare PSA and Gleason scores
- perhaps options you were offered
- treatments to date

The aim of this is to show that you are all "members of the same club". You all have the same disease which creates a common bond between you and even at this early stage some attendees will experience a sense of acceptance and easing of anxiety.

Most groups have a register of members so that information can be sent to them about prostate cancer and about future meetings and events. Having a register of attendees may even be a safety requirement of the premises being used!

5.3. Structured meeting with speakers

If a large number of attendees are expected at this first meeting (or any meeting), which would make the informal meeting difficult to manage, it may be beneficial to organise a more formal meeting with speakers. This would include introductions about the group's purpose and style - how it is to be run - and may have a speaker known to many of the group - perhaps the local PCa consultant - to talk about the disease and to show his/her support.

Many groups move to this format after a while as they grow, but it is important to recognise that it can be very taxing to have to organise a speaker for every meeting (instead consider choosing a speaker for, say, one in three meetings). In any case there should always be provision for attendees to be able to talk to others about their situation. The value of a group is mutual support.

5.4. Regular meetings

The comments in 1 and 2 above are equally applicable to the ongoing regular meetings, but remember, the secret of a successful support group is its members. The people are the group's greatest resource and it is up to them collectively to identify their needs and ensure that the group provides what members want. Those members taking their turn to lead the group, the 'committee', are purely responsible for ensuring that activities are undertaken and that the group achieves its aims. As long as you can identify a core of people to form the initial working party you should be able to establish a framework on which the group can build as it develops.

Do not feel that the only way to run a large group is to have speakers. It is possible to divide the group into two or more smaller groups with a facilitator for each group. This can be done just by number of people or it can be done by some other criteria, for example those wishing to talk about a particular treatment like surgery or radiotherapy or what experiences people are having with hormone treatment. If this is done, try to allow some time for the whole group to come together before the end of the meeting and have a spokesperson for each group to very briefly cover any key points that emerged from their group.

5.5. OTHER CONSIDERATIONS

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.

At PCS we can assure you of our continued personal support to guide you through the development of the group's role and function. Do not hesitate to contact us with any questions or concerns you may have. We are always happy to visit groups, wherever they may be located.

TWO SAMPLE LETTERS



This is a communication from

Registered Charity No: 1092102

Dear Patient,

INFORMATION AND SUPPORT FOR PEOPLE WITH PROSTATE CANCER

You are probably aware of the fact that throughout the country there are various patient and self help support groups for many different forms of cancer. However there are very few support facilities for prostate cancer and in most areas none at all.

Our purpose in writing to you is to introduce you to PCS (The Prostate Cancer Support Association). PCS is a patient led support organisation. Our aim is to provide help, support and information to men, who have been diagnosed with Prostate Cancer, and also to their families and carers.

If you have recently been diagnosed as having prostate cancer, you will probably be experiencing the shock and fear that we all felt at diagnosis. We know how you feel, because we have been there. Whether you are newly diagnosed or have been managing your cancer for some time, our wish is to provide you with the knowledge and emotional and practical support to enable you to gain the maximum level of health and treatment that you would wish for yourself.

We are conscious of the fact that there is no local support group in Stoke-on-Trent and the surrounding areas. As we have good relationships with the medical profession and work together in many areas, we approached the University Hospital of North Staffordshire Urology Department to see if they felt there would be a need in your area. We are pleased to be able to say that it is also their view, that a local support group in the Stoke-on-Trent area would be beneficial to local prostate cancer patients and their carers.

As a result we are jointly writing to you to ask,

Would you like to learn more about a patient support group?

Would you be interested in attending a local support group?

Would you be willing to help establish a group?

If your answer is yes to any of the above would you please complete and return the attached document or contact one of the following,

PCS on 0161 474 8222 or the Helpline 0845 456 0678 (local call rate).

OR

Karen Smith, Urology Nurse Specialist, **telephone number or c/o Ward 120, City General Hospital, Newcastle Road, Stoke-on-Trent, ST4 6QG.**

Yours sincerely,

Mike Lockett
Chairman PCS

Karen Smith
Urology Nurse Specialist

N.B. We at PCS would like to thank the University Hospital of North Staffordshire Urology Department for helping us to reach current and previous patients of the hospital. At this point we should state that none of your information (neither medical, nor name and address) has been disclosed to us by the hospital. This communication has been sent, or handed, direct to you by the hospital and should you choose not to be interested in the above, we at PCS will have no knowledge of your identity.

Please complete and return to Prostate Cancer Support, Mansion House Chambers,
22 High Street, Stockport, SK1 1EG.

In the Stoke-on-Trent area,

Would you like to learn more about a patient support group? Yes/No

Would you be interested in attending a local support group? Yes/No

Would you be willing to help establish a group? Yes/No

Optional information:

Name and Address:

.....
.....
.....

Telephone number:

Email address:

The purpose of the above information is to enable us to contact you with further information regarding a local support group. We at PCS are geared to respond to you, but if you would prefer to return this document to the hospital please send it to Karen Smith, Urology Nurse Specialist, c/o Ward 120, City General Hospital, Newcastle Road, Stoke-on-Trent, ST4 6QG



This is a communication from

Registered Charity No: 1092102

Dear patient,

The purpose in presenting this letter to you is to inform you of the North Staffs Prostate Cancer Support Group, which has been established for patients and their families or carers.

If you have recently been diagnosed as having prostate cancer, you will probably be experiencing the shock and fear that most of us felt at diagnosis. We know how you feel, because we have been there.

You may also find yourself confused by this complex disease and the choices that face a man who is diagnosed with it - what treatment to have; indeed whether to be treated at all! Because there can be many choices this may make your initial task of coping with this disease more difficult.

Whether you have recently been diagnosed or have been living with prostate cancer for some time, the group offers patients and carers a place to belong and to express feelings.

- It allows members to learn from each other. How other patients arrived at their choices!
- It allows open discussion of issues - otherwise those issues percolate within the individual.
- It encourages patients to become effective partners with their medical staff in their own treatment.
- It provides an opportunity for both patient to patient, and professional help.
- This can improve your doctor-patient relationship and ultimately your ability to manage your disease.

A number of studies have suggested that quality of life and even survival time are improved through the positive uplift that many obtain through being a member of a support group.

From time to time, we have talks on a wide range of treatment (existing and new), research and diet.

The North Staffs Group meets at the Joiner Square Community Centre, Cornes Street (off Leek Road), Stoke-on-Trent, 6-8pm the third Wednesday of each month. There is ample parking should you travel by car.

Please feel free to just turn up; you will be given a warm welcome.

Yours sincerely,

Mike Lockett
Chairman, PCS

Karen Smith
Urology Nurse Specialist

USEFUL CONTACTS

PCS - Prostate Cancer Support
Mansion House Chambers
22 High Street
Stockport
SK1 1EG
Tel: 0161 474 8222
Helpline 0845 456 0678

Website: <http://www.prostatecancersupport.org>

Email : info@prostatecancersupport.org

PCS is an independent charity, but is a member of PCSF

PCSF - Prostate Cancer Support Federation
Mansion House Chambers
22 High Street
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SK1 1EG
Tel: 0161 474 8222

National Helpline 0845 601 0766

Website : <http://www.prostatecancerfederation.org.uk>

Honorary Secretary: Sandy Tyndale-Biscoe

Email : secretary@prostatecancerfederation.org.uk

Macmillan Cancer Support

Website : <http://www.macmillan.org.uk>

Telephone for publications or materials 0800 500 800
(Including running a support group)