

Patient self help support groups – need and value

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Krakow Presentation

- Patient reactions and needs
- The value of a support group
- Starting a support group
- Giving the patient a voice
- Summary

Patient reactions to Prostate Cancer

Some Emotional Reactions

- Fear
- Grief
- Uncertainty
- Anger
- Guilt
- Shame
- Isolation
- Confusion
- Depression

Patient reactions to Prostate Cancer

Other feelings

Alterations in one's sense of :

- Masculinity
- Identity
- Body image and sexuality

- Decrease in self esteem

Possibility of :

- Recurrence
- Death

Who can I turn to for help?

- Some family and friends are embarrassed to talk about cancer
- Partners also have their fears
- We may be keeping our concerns to ourselves to protect each other
- Some men want to be told what to do, but feel they are being asked to make decisions without sufficient knowledge – they are confused!

The value of a support group

- Patients bond – share common dilemma
- Allow expression & open discussion of negative issues (dilutes impact)
- Address concerns and fears of patients and carers
- Help patients take responsibility – lifestyle
- Patients become empowered - improves Doctor/Patient relationship
- Prolong survival time!

Starting a local Support Group

Key points to consider (1)

- Is there a local demand for a group?
 - How many people would use the group?
- How can you find out?
 - Ask your local hospital/medical professionals
- How do I promote the group?
 - Through the hospital/radio/newspapers/
display posters

Starting a local Support Group

Key points to consider (2)

- Should the group be patient led?
 - How will health professionals be involved?
- Who is the group for?
 - Patients and carers? All UK groups are for all.
- What are the aims and objectives of the group?
 - Make this a group decision

Running the group

- The secret of a successful support group is its members.
- The members are the group's greatest resource
 - collectively identify their needs
 - ensure that the group provides what members want.

Running the group - activities

- The group meetings
 - Informal meeting
 - Structured meeting with speakers
- Helpline
- Newsletter
- Information

Giving the patient a voice

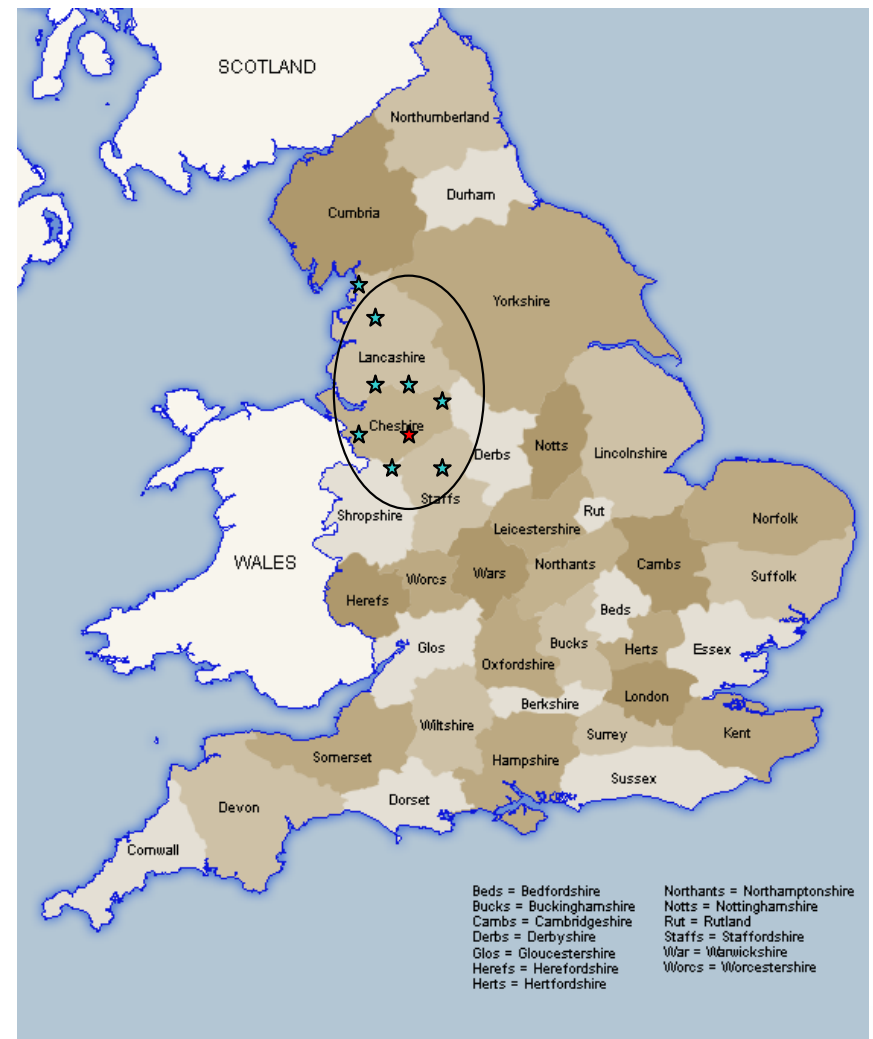
The 2nd purpose of the support group

To give a voice to all those affected by PCa.

Raise awareness

Represent the patient to

- Government
- Health professions
- The public



Giving the patient a voice

The voice of one support group is too weak

The objective - to bring all UK support groups together in a coalition to speak with one loud voice

The Prostate Cancer Support Federation has been formed

Currently - 38 groups

Aim - 100 groups and 10,000 patients by 2010



Summary

Learning that one has cancer is traumatic

It leads to all sorts of Emotional reactions

- Some are visible some are not

A support group can ease all of these problems

Collect together to make your voice strong