

National Prostate Cancer Conference

Local Support, National Action

William Davis
The MS Society

The MS Society

The biggest organisation in the UK representing people with MS:

- 43,000 members (30,000 with MS)
- 340 branches
- 18 regional committees

Our branches focus on

- Working to improve health and social services across the region
- Supporting branches and organising training for volunteers
- Holding information days and other events for people affected by MS

Our regions focus on

- Providing information and support to individuals
- Raising funds
- Raising the profile of MS and the Society locally

The challenge of consistency..

We needed to:

- meet the needs of everyone affected by MS, no matter where they were
- reach out to wider public
- attract new volunteers
- be taken seriously by professionals
- practice what we preach

Preparing the ground

- 3 year programme of 21 non-compulsory Core Branch Activities
- Staff-run workshops to discuss with and persuade branch committees members in all regions
- Involvement of volunteers on working group

The Essentials

- 8 essential activities with 28 simple standards
- Sent out self-assessment forms and offered help
- Quick-fix sheets and individualised response
- Focus help on branches with problems achieving standards

Reasons for success

- Support of volunteers at AGM
- Positive arguments – not “management-speak”
- Simple achievable standards focusing on minimums rather than good practice
- Trusting approach self-assessment backed up by audit
- Additional Support Programme to target weak branches

The impact of the project

- Consistency of services to people affected by MS
- “Weak” branches have been identified and helped
- Branches are attracting new members and new volunteers
- Increased credibility with professionals

Campaigning

- Campaigning activity is led by the National Centre and regions
- Branches are mostly not geared up for campaigning but have information on issues and access to members
- Each region has a Health and Social Services sub-committee

Lessons to be learned

- If you want groups to be involved in campaigning, do it from the start
- Make sure there is a focus to campaigning – and people focusing on it
- pick 1 or 2 issues that speak to everyone
- Don't depend on groups but make sure you have means of involving individuals
- Think about a campaign network of e-mail alerts

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Norman Best

Scottish Association of
Prostate Cancer Support Groups

The Scottish Scene

Origin

- Lorne Wallace
- Norm Oman

- Initial funding
 - Bank of Scotland
 - Tullis Russell



13th March 1999 delegates from 7 meetings
agreed to form an Association

- Constitution
- Recognised as Scottish Charity 9th July 1999

Original meetings agreed to form 7 Area Groups

- Autonomous
- Operate under single charity approval
- Constitution not to differ significantly to Association constitution

Development

- Now 9 Area Groups – one lost – decided to become a Social Group
- 2 new groups planned
- 2 groups require Association help



All groups financially independent

With own accounts – reviewed – forwarded to
Association Treasurer – consolidated into
single audited account

- Association meets 5 times a year
- Association tasks allocated to groups with particular expertise
- Website (www.prostatescot.co.uk), three Newsletters per annum mailed via groups to all members
- Group handbook offers suggestions on setting up and running groups

Does it work?


The best measure is against constitution aims and objectives

- To promote :
 - (a) awareness of prostate cancer and its treatment
 - (b) improved detection and treatment of prostate cancer in Scotland

- For 5 years at awareness days, meetings, shows, doctors' surgeries, hospitals and libraries, thousands of leaflets relating to Benign Prostatic Hyperplasia (BPH) and Prostate Cancer have been distributed.
- At group meetings consultants, nursing staff and associated professions give talks on current practices and developments.




To represent, assist, advise and correlate the work of the support groups.



Association meetings provide a forum for representatives to discuss matters of common concern and encourage adoption of “best practice”.



To seek and generate appropriate funding for prostate cancer support in Scotland.


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- Support group meetings schedule time for discussion among members, partners and carers, usually over a cup of tea or coffee.
 - Regular telephone contact is maintained with members.

Problems

- Succession in groups and the Association
- Once in office general health improves
- Recruitment is difficult – patient confidentiality prevents hospitals and doctors notifying groups of new patients.
- Some consultants and GPs do advise patients of support groups. We hope the number will increase.

In summary

- Members and the Scottish general public increased knowledge of BPH and Prostate Cancer symptoms and treatments.
- Our organisation together with GPs, consultants, nurses and associated staff have contributed to this.

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- Fairer distribution of funds to obtain improved diagnosis and treatment of prostate cancer, with reduction of side effects.
 - Represented on NHS Scotland committees, Managed Clinical Networks, Scotland Against Cancer, Scottish Cancer Coalition and others.



Experience in abundance –

how to tap it?