

## **We take action - Overview**

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The workshop described three user involvement roles people could undertake at Macmillan, Activist, Advocate and Service Improvement Champion. This workshop concentrated on the first and last and gave examples of activities within each role. Then the facilitators listed current campaigns priorities and asked participants to suggest other possible topics for campaigning and policy work.

The workshops then looked at the skills needed for the activist and service improvement roles and asked participants if these were the right skills and if they could suggest any others.

Finally the workshop discussed the support and training Macmillan offers and what the next steps to get involved would be.

## **Key points**

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### **Service improvements and campaigns needed**

#### **Benefits**

- more benefits for carers who have to leave work to care as well as for patients
- better information about the “ benefits trap” e.g. for people who want to work part-time because of health issues or caring responsibilities
- Benefits – both improved information about currently available benefits and need for a more accessible responsive benefits system, specifically a better response to people being assessed re fitness to return to work in terms of sensitive and skilled assessors and the swift automatic triggering of the right benefits following assessment and being told straight after diagnosis what you’re entitled to

#### **Working through cancer**

- Publicising the discrimination faced re getting work once cancer diagnosis is known/disclosed - and that this is illegal
- Publicising the problems people have in keeping their job with late effects, need for follow up appointments etc in work time
- Providing more support for Trade Unions to address discrimination at work issues for people with/after a cancer diagnosis
- Publicising the fact that people affected by cancer are covered by the Disability Discrimination Act
- Not just returning to work but getting work once cancer diagnosis is known and keeping your job with late effects, need for follow up appointments etc in work

time – more help needed for employers to increase their confidence about employing someone with/after cancer

### **Carers**

- needs of the young carers of people with cancer

### **Healthcare**

- communication skills for health professionals, availability and high cost of complementary therapies
- value/benefits of trained patient advocates both in the community as well as in hospitals and hospices
- publicise the need for additional services post treatment
- value/benefits of preventative services e.g. lymphodema sleeves, which are relatively low costs but have high quality of life impact
- GP education – early diagnosis, importance of referring/willingness to refer for screening

### **Social care**

- Psychological/emotional support – combat taboo and stigma, highlight lack of resources and services
- Domiciliary care (practical and personal) free at point of use and funded by PCTs
- If fees continue to be charged for social care, campaigning for a fair system of means testing
- Influencing the outcomes of the current consultation on Green Paper on social care

### **Other**

- Macmillan taking test cases forward – or if that is not within our remit, promoting the impact of the outcomes of test cases
- Discussion of whether Macmillan should campaign with other organisations on issues of shared interest – mixed views – strength in numbers? Dilute our messages(s)?
- more innovative ways to disseminate outcomes of campaigns and information e.g. to people in residential care or sheltered housing

## **Skills, training, support needed for Activist and Service Improvement Champion Roles**

### **Skills**

- Telling your story without training can be a bit “hit and miss” and possibly upsetting
- Understanding your audience important – who they are, what they want, where they are at so you can get them to see your point of view
- Good chairing skills, clarity of vision
- Being able to signpost people to emotional support
- Also understanding how people might react emotionally to having cancer or being close to someone with cancer
- Listening skills vital – “after all, we have 2 ears and just 1 mouth”
- Leadership skills
- Skills in working with grassroots organisations
- Team work/collaboration
- Empathy
- Presentation skills
- Different ways to involve, consult and “hear” people – face to face, in writing, online, telephone
- Key messages important, being too passionate can lead to “tunnel vision”

### **Training**

- Cancer Support Certificate is excellent – but what next?
- Flexible access re where, how, when training delivered is vital
- With support , individuals can promote Macmillan’s training to other pabc

### **Other**

- Not just skills, it’s about confidence too – can be just as nerve-wracking to speak to MP as to present to a group
- Mixed views as to whether training is always beneficial – does it dilute the simple, direct, human response?

### **Future activity**

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In 2010 Macmillan will use the skills/training input to help colleagues in the Learning and Development team prepare people affected by cancer for these roles.