

Special Interest Group: Community Based Support  
Notes from meeting 17<sup>th</sup> March 2010



SIG meeting attendees

Anne Demick	Ileostomy Association
Carol Johnston	Oxford John Radcliffe Hospital
Carole Summer	Southampton Ostomy Support Group
Carolyn Stammers	Ileostomy Association
David Morris	Wessex Urology Support Group
Don Haines	Urostomy Association
Jo Pragnell	Oxford John Radcliffe Hospital
Kirsta Rizzo	Hollister Ltd
Mandy Rimmer Gray	Lister Hospital
Margaret Giles	Lister Hospital Support Group
Mary Morris	Wessex Urology Support Group
Michael Slater	Wessex Stoma Support Group
Neil Basil	Ostomy Lifestyle
Reena Patel	Convatec
Robert Azevedo-Gilbert	Inside Out Support Group
Shirley Stabler	Ostomy Lifestyle
Sjarlot Verhoof	Convatec
Sue Hatton	Colostomy Association

## Discussion Questions

### **Benefits of community based support**

#### *What advantages do community based support or information events bring to people affected by stoma surgery?*

- Access to medical professionals, stoma care nurses (SCNs) in particular, which may be a comfort to people
- Meeting other patients allows people to share information in an empathic, accessible and social environment and may bring about a sense of 'belonging' and develop befriending
- Geographically specific events mean they can be tailored to fit around local needs and facilities
- These types of events may be a facility for partners/family too
- Conversely they might provide a 'different space' away from partners/family
- Continuation of hospital support
- Access to an alternative 'learning' environment
- Information/open days allow people to get support and remain anonymous
- A huge diversity of events is possible
- Often there is more time available for discussion of issues

#### *What disadvantages are there?*

- Potential lack of privacy or anonymity may put people off
- The timing and location of events may be unsuitable for some people
- It can be difficult to define 'local' and coverage is inconsistent
- Events might not cater for specific individual needs so people may have a negative experience.
- There is no standard process for promotion of events and communication between agencies is inconsistent
- Too many sources of support lead to an overall dilution
- Over-exposure to other people's stories may mean people don't get an opportunity to focus on their own needs
- Some members of the group may give unskilled or inappropriate counselling
- A lack of funding can limit the quality of events which may lead to fewer people attending and those who do having a worse experience
- Currently not enough diversity of events

#### *How can we measure these impacts?*

- Attendance of events and uptake of membership etc are obvious indicators of interest
- Face-to-face feedback, paper surveys and over the phone interviews, either at the event or later on
- National database of patients with statistical information e.g. quality of life
- Getting exhibitors and companies etc involved in the feedback process may be useful to get input from different perspectives
- More regular contact with suppliers & exhibitors

## **Awareness of community based support**

### ***How can we ensure individuals are made aware of community based support initiatives?***

- A broad spectrum of coverage is ideal to ensure many different audiences are reached and different stages of the patient journey are taken into consideration
- SCNs are key figures here and can make patients aware of the support available by including info in discharge packs and promotion in clinic areas
- Other medical professionals (e.g. GPs, consultants, practice/community nurses and pharmacists) also have a role to play
- Patients and local groups themselves should be encouraged to take some responsibility for awareness of what is going on
- Local press/media can be used to reach new audiences
- Libraries, GP surgeries, pharmacies and other public spaces may be utilised to promote local events
- The internet is an increasingly widespread medium of communication and may be used in diverse ways
- National organisations can signpost to local level
- Cross-promotion of events (between companies and organisations etc) can maximise on mailings and reach new audiences
- Celebrities may be able to help raise the profile of the cause

### ***What is preventing them from knowing about community based support?***

- Key point of contact (i.e. medical professional) not providing information
- Lack of communication between all the agencies involved
- Patients will get different information at different points along their journey

## **Attendance of community based support**

### ***How can we encourage individuals to attend community based support initiatives?***

- Remember the 4 'Fs' – Fun, free, food and friendship
- Making information about what is on offer easily accessible to all
- There needs to be clarity in the advertising of events so people know exactly what to expect
- Having diversity of events will ensure different needs are met
- Moving the venue around, in terms of both time and location to allow for varying lifestyles
- Encouragement from medical professionals
- Putting on quality events will not only attract first-time attendees but encourage people to return to future events
- Ensuring venues are accessible

### ***What are they looking for?***

- Improved quality of life
- Peer support
- Increased confidence to help them adapt to 'normal' life
- Getting specific needs met
- 4 'Fs' (fun, free, food and friendship)

### ***Why don't they attend?***

- If there is a charge for events this may become a barrier if people feel unable to afford it
- If the event is free it may not be valued in the same way and people may not feel it is worth attending
- Some people simply do not feel they need this form of support
- A lack of definition about what is on offer at the event may mean people misunderstand it and not see any benefits
- People have different needs at different points on their journey as a patient
- The timing of events may mean lifestyle factors prevent certain people attending
- Embarrassment may also be a factor

## **Organising community based support**

### ***How can we encourage individuals to help deliver community based support initiatives?***

- Co-operation between groups can help share the workload and maximise the benefits
- Making it easy for people by making resources available and roles easy to manage is important
- Responsibility should be shared around
- Being focused on outcomes and results can help people see the value of what they are doing
- Element of giving something back
- Organisers should be alert to people's potential to contribute to group and ease people in with gentle tasks to start with
- Making people feel valued and saying thank you is paramount

## **Inclusive community based support**

### ***What groups of people will benefit the most from community based support initiatives?***

- The 'lone' person
- Those new to the locality
- Groups that are already marginalised (ethnic minorities, those with learning difficulties, very elderly or young people, etc)
- Partners and family members
- Those who are not already in a network
- Parents of young patients
- Those missing out on certain communication channels (e.g. internet)

### ***Who misses out?***

- People without transport to travel to meetings
- People whose lifestyles don't fit around the timings of meetings (e.g. those who work when the meetings are held, elderly people who would be put off by late night/evening meetings)
- Socially disadvantaged and marginalised groups

### ***What groups are in the greatest need?***

- Those who are not a member of a group already
- Those who are not linked up to a hospital/nurse and develop a problem/issue

### ***Where are they currently accessing this support, if at all?***

- GP surgery? Although most acknowledge this is not the optimum place for specialist advice

**All acknowledged that it is important to welcome all attendees to groups/meetings/events!**

## **Outcomes of community based support**

### ***What are the potential outcomes of delivering community based support successfully?***

- Patients feel more empowered, confident, and independent
- Reduced strain on the NHS (clinic time, product wastage etc)
- Patients helping each other to help themselves
- Better relationships between hospitals, patient organisations, and industry ensure full range of support
- Identification of specific areas of need:
  - Improved products & services
  - Better patient care as a whole
- Reduce postcode lottery

## **Outputs for community based support**

### *What activities will be needed to deliver these outcomes?*

- More activities where they are lacking
- More consolidation of events where there are many different activities in one area
- Regional larger events
- Educational sessions
- Workshops
- Choices
- Social elements – fun, food etc
- Something different e.g. fashion shows
- Leisure activities
- Raising awareness of the cause
- Collaborative working – consolidated events including
  - Companies e.g. bags, accessories, clothing
  - Medical professionals
  - Local & national organisations
  - Disease related organisations e.g. Macmillan, NACC, Beating Bowel Cancer
  - The general public
- Invitations mailed to patients
- Proactive referrals from hospitals, companies and charities
- National database of stoma patients
- Less competition, more cooperation
- Opportunity for public exposure or public events e.g. World Ostomy Day
- Being involved with other organisations events e.g. IBD & cancer events

## **Inputs for community based support**

### *What do organisers need to deliver these outcomes?*

- Enthusiastic people
- Funding
- Suitable venues e.g. accessible
- Attendees to take part in these activities
- Publicity – broad range, word of mouth
- Ideas & planning
- Industry support
- Cooperation with industry & hospital
- National coordination & linking with others
- Support from wider networks e.g. PIPS, BHTA, WCET

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**Initial next steps/ideas for consideration**

- Distribute meeting notes to attendees and other group participants
- Encourage more participants in SIG, especially:
  - Nurses
  - Local branches of national groups i.e. IA & UA
  - Industry
  - Anyone considering establishing these types of support initiatives
- Comprehensive list of groups & events, made accessible to beneficiaries
- Identify any resources, funding etc that may be available
- A 'how to' guide providing the basics of setting up a support group, event, or other community based support initiative
- Booklet to promote community based support initiatives to Stoma Care Nurses
- Presentation of findings at WCET
- Formal method of consolidation or collaboration regarding patient contact, invitations etc

**Neil Basil at Ostomy Lifestyle will distribute notes and coordinate any responses to facilitate any of the actions suggested.**

**If feedback shows that this Special Interest Group will be useful in enabling more people to benefit from community based support initiatives in their area, we will schedule a follow up meeting to facilitate this.**

**Any questions please contact Neil on 0118 324 0069.**