# Survey and Analysis of Adult Group-based Burns Support

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# Introduction

As the only charity working in the United Kingdom exclusively with adult burn survivors Dan's Fund for Burns is focused on providing and enhancing support for those in need as a direct result of their burn injuries. In June 2012 Dan's Fund commissioned this study with the aim of improving access to group-based support for burns survivors throughout the UK.

Few would argue against providing formal support to those with burn injuries. The latest National Burns Care Standards (2013) state that:

> "A support group should be available whereby patients, their families and/or carers have access to peer support from others who have experienced burn injuries. These groups should be subject to appropriate governance and employment checks (safeguarding and minimum skill set for group facilitators)."
>
> "All patients, their families and/or carers [should] have information and the opportunity to access an age appropriate burn support group."

Pete Saggers, London & South East Burn Network (LSEBN) Manager, in the Specialised Burn Project Bulletin July 2012 offers his opinion, that the emotional and psychological impact of a burn is just as important as the healing of physical wounds. He proposes that we need to focus more attention on the psycho-social wellbeing of patients.

Therefore it is clear that healthcare professionals within burns do see the value of self-help and support groups and encourage their existence. However, in practice a small number of burn services provide self-help and support groups meaning that groups are few and far between.

Published research examining the effectiveness of support or self-help groups following a burn or traumatic injury is virtually non-existent, suggesting that there is a lack of investigation into this topic. One study of a burns family support group established at the University of Michigan Hospital in the late 1970s, found that meetings were well attended and families began to form relationships with each other. One attendee was quoted as saying; "to find that one is not alone – that the carefully guarded secrets of being human are shared – is indeed a healing experience in and of itself" (McHugh, Dimitroff & Dinsmore Davis 1979). Support groups and peer counselling by burns survivors has been recognised as important by researchers and ideally burns services would have a network of burn survivors who are willing to talk to patients in hospital (Wiechman & Patterson 2004). Whilst research into the efficacy of support and self-help groups within the burns population is small there is evidence demonstrating that they are successful in other healthcare domains.

We know that levels of family and social support in the majority of the burns population is generally very low prior to injury. Professional help systems are designed to fill this gap (Humphreys & Rappaport 1994). Medvene, Volk & Meissen (1997) estimated that three to five percent of the adult population in the United States (four to six million people) participate in self-help groups at any one time. It is known that large numbers of people participate in self-help groups as a supplement to receiving help from professionals, as well as an alternative to professional care.

One definition of a self-help group is a:

“voluntary small structure for mutual aid in the accomplishment of a specific purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life disrupting problem, and bringing about desired social and/or personal change” (Solomon, 2004). Support groups are differentiated from self –help groups in that the former is a “professionally led group of people that share a common problem” (Humphreys & Rappaport 1994)

Humphreys, Mavis and Stoffelmayr (1991) studied self-help group involvement after substance abuse treatment (n=253). They discovered that those who attended self-help groups after professional treatment improved significantly more on medical, alcohol and drug problem measures than those who only went through professional treatment. Additionally Vachon, Lyall, Rodgers, Freedman-Letofsky & Freedman (1980) studied the adaptation to bereavement of 162 widows. Their results showed that those participants who were assigned a widow companion went through the bereavement process more quickly and adapted better to widowhood than those in the control group without a widow companion. This suggests that a peer assisted process can be therapeutic.

Lieberman and Bliwise (1985) evaluated the effects of a professionally led group versus a peer-led group. Participants were assigned to either one of these groups or a waiting list control group. Those in the professionally led group showed greater improvement than in the other groups on two psychotherapy outcome measures: self esteem and psychological symptoms. There are many more examples of how self-help and support groups can be successful, but these three examples illustrate that groups have demonstrated their value in providing therapy for individuals across a range of health conditions.

# Method

A series of research questions were posed:

1) Outside statutory burn care services provided by UK hospitals, what support is available to adult burn survivors?
2) Historically what group-based support for adults have UK burn services tried to provide? What might we learn from their successes and failures?
3) How do successful burns support groups work outside of the UK? What might we learn from them?
4) How do successful support groups operate in other (not burns) healthcare domains? What might we learn from them?
5) Who is currently asking for support, who do they ask and what do they want?
6) What other support programmes are available to adult burn survivors?
7) What are the individual opinions of a small sample of adult burn survivors regarding the value of burn support groups?

These research questions were explored using a variety of methods including; Internet research, telephone and face to face interviews, standardised questionnaires, SKYPE and electronic e-mail. Each will be outlined in more detail in its relevant section.

# Current UK Burns Support Provision

## Current UK provision

As of August 2012 there are nine organisations actively providing burns specific support for adults and a further two provide support to burns survivors as well as others. Information was gathered from Internet research, electronic mail, telephone and face to face interviews using a semi-structured questionnaire.

## Charities

There are two UK based charities specifically supporting burn survivors and their families: Dan's Fund for Burns focusing on adults and the Children's Burns Trust.

Dan's Fund for Burns - is a UK Registered Charity, founded in 2003 by Polly (Miller) Brooks. Polly looked in vain for support following her release from hospital after suffering severe burns as a result of the Bali bombings in 2002. She was subsequently responsible for inaugurating the first Support Group for Burn Survivors at Chelsea & Westminster Hospital.

Dan's Fund For Burns aims are to offer practical help to burn survivors in the UK and provide a wide range of support, including but not limited to; financial assistance for transportation back and forth to hospital, provision of television/telephone access, retraining for those wishing to re-enter the workforce, replacement of household items after house fire, equipment to hospitals where NHS funds are not available, camouflage makeup training for all burns units and travel for medical personnel to conferences. Dan's Fund for Burns also acts as a referral service for survivors seeking advice, help and support.

Changing Faces - is the leading UK charity for individuals with a visible difference. The charity organise workshops that cover a variety of topics for individuals and families whose lives are affected by conditions, marks or scars that alter their appearance. These are normally fully booked. They are facilitated by Changing Faces healthcare professionals. Burn injuries are probably the most common cause of visible difference of all workshop attendees.

The Katie Piper Foundation – is a UK charity aiming to make it easier to live with burns and scars. It operates an online chat forum and workshops. Forum posts are monitored by a volunteer who is not a professional or a burns survivor. Feedback suggests that users find the forum helpful. Workshops are facilitated by members of staff who in most cases do not have a healthcare background. The ultimate aim of the foundation is for the service to be user led. Workshops are centred on specific topics and often have a strong social element. The foundation is looking to develop a monthly programme in the near future.

McIndoe Burns Support Group – founded in 1983 at Queen Victoria Hospital in East Grinstead was originally a support group, it now operates exclusively as a charity. At the onset the group was facilitated by volunteers who were ex-healthcare professionals. They provided financial support as well as spending time in out-patient clinics talking with returning patients and families. When the volunteers stepped down from their roles four to five years ago the group was unable to find another willing survivor suitable to lead the group. Currently the McIndoe Support group is actually a committee of healthcare professionals whose aim is to provide financial support for both burns survivors and the burns ward at Queen Victoria Hospital. The group is self-sustaining through its own fund raising. At present they are unable to offer emotional support for burns survivors in a group environment but are considering the future options. Individual psychological input is offered through the psychotherapies team at Queen Victoria Burns Service.

## Burns Specific Support

Befriending Service for Burn Injured Patients and their Families –is a pilot project for burn injured patients and their families being run at the Broomfield Hospital in Chelmsford. It was developed following an unsuccessful attempt to run a support group. A befriending service was tried instead as it focuses on building relationships between burn survivors. Potential befrienders are nominated by psycho-social professionals or they can nominate themselves. They operate a multistage selection process:

1 – Telephone screen

2 – Criminal Records Bureau check

3 – Occupational Health Check

4- 15 hours of training including communication skills, difficult situations, boundaries, confidentiality, risk and safeguarding.

If candidates successfully pass all stages they enter a six month probation period with fortnightly supervision.

The project has now reached the matching process and as of writing has seven qualified befrienders. The main criteria for matching befrienders with befriendees are personal interests and personal preferences, rather than burn demographics. If the pilot project proves to be successful, the aim is to roll it out nationally, possibility in collaboration with a charity partner.

Burns Buddies – is a directory available to offer support to recent burns survivors at The Royal Victoria Infirmary Hospital in Newcastle. A healthcare professional is always present for the initial buddy meeting. No formal training is provided for the buddies and meetings often take place outside of the hospital setting. Burns Buddies can be for in-patients, out-patients, friends and family members of a burns survivor or staff members. Buddy relationships tends to last for one or two meetings, however if the buddy system was improved and had more resources, further interactions could take place. Buddies are matched on personality similarities and how they have coped with their injury.

Alongside Burns Buddies an annual social event is held for burns survivors, their friends and family. The Group assembles within the community and is an opportunity for people to meet and socialise with other burn survivors. It is facilitated by a healthcare professional but it is made very clear before the meeting that there will be no presentations or education. Neither service is formally promoted and has no internet presence at all as there is a fear that the service would not be able to meet the demand.

Burns Unit Group Support (B.U.G.S) – is an in-patient service run by volunteers at Salisbury Hospital. They visit the ward weekly to speak to patients and attend scar management clinics fortnightly. The service is available to burns survivors as well as their family and friends and aims to support and encourage people as they move out into the community as well as offering practical and professional help and advice.

Frenchay After Burns Club – is a three day residential camp for young people aged 16 to 25 with approximately 20 to 25 burns survivors attending each camp. There have been two camps thus far with a third confirmed to occur next year. The camps are funded by Dan's Fund for Burns. These events are facilitated by a mixture of healthcare professionals, volunteers and older burns survivors. Activities completed include ice skating, bowling and walking.

London Area Burns Adult Support Group – operates four times a year and is open to survivors, friends and family. The group is facilitated by Lisa Williams, Clinical Psychologist[1] at Chelsea and Westminster Burn Service and its structure varies across meetings. The group was originally set-up by Polly Miller. When she stepped down from the role the group was unable to find another survivor who wanted to take up the leadership of the group. Meetings are held at the Changing Faces offices in March, September and December, with a summer outing jointly held with the Chelsea and Westminster Burns Family Group. Average attendance is approximately ten people per meeting. The group is promoted on the Dan's Fund for Burns website, the Chelsea and Westminster Hospital website, can be found by Google search and regular e-mails and postal invitations are sent to the group database. The other LSEBN burns services also send information about the group to their patients. Ideally it would run once a month, but there is currently a lack of motivation from attendees, a lack of content material for each group and time pressures on staff.

Manchester Advisory Group - is held four times a year on the first Wednesday of every third month in the burns unit seminar room at Wythenshawe Hospital. The group is coordinated by the Burns Outreach Nurse – with support from the psychology team; between two and eight survivors attend each group. It is aimed at out-patients of the service, although some in-patients approaching discharge are invited to attend if appropriate. The structure of the group consists of short presentations from professionals, group discussion, and a buffet lunch. This location is not ideal but at present there are no funds available to hire a venue outside of the hospital.

Manchester Young Adult Burn Camp – is an annual four day residential camp in the Lake District for 16 - 25 year olds with approximately 11 - 16 young adults attending each year. The primary objective is to equip young burns survivors with the skills needed for young adulthood including: life skills; increasing independence; building confidence; improving social skills; engaging with a peer group who are encountering similar issues; and supporting the transition to the adult burns service. A supplementary post-camp event is held six months later giving a chance for attendees to reunite.

The camp is facilitated by healthcare and fire service professionals. In 2009 12 young people attended the camp. Evaluations have produced very positive results: qualitative data collected from attendees highlighted that one of the key benefits of attending is "the ability to share

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[1] Clinical Psychologist will hence be abbreviated to (CP)

experiences with a peer group who understands what is like to live with a burn injury.” Other data gathered indicated that staff felt the main benefit for them was “a deeper understanding on how to interact with young people who have a different perspective on life and increasing their own self esteem and self confidence.”

West of Scotland Regional Burns Support Group – is held within the burns unit at the Glasgow Royal Infirmary on the first Tuesday of every month during working hours. The group was originally facilitated by both the psychology team and a liaison nurse at the hospital. Now the group is solely run by the nurse. The psychology team prioritise offering one to one support. The group is for both in-patients and out-patients in addition to friends and family. The structure is very informal and content covers whatever members are interested in, including appearance concerns, coping with the injury, financial pressures and returning to work.

## Inactive/unable to reach burns groups

Burns Rehab and Voluntary Organisation (BRAVO) – started approximately 15 years ago at Whiston Hospital in Merseyside and was facilitated by healthcare professionals. The group ran one evening a month and was successful for many years. Anyone over the age of 16 who had suffered a burn injury as well as their friends and family could attend the group. The number of attendees started to drop but the group continued even with only one or two members. The location of the group was changed to a venue within the community but attendance still remained low. The team decided to send out a questionnaire to out- patients to try and understand why the group was dwindling. Whilst many people gave positive feedback and said they would be keen to become involved, attendance did not improve. Eventually the group ceased to function and has been on hold for the last two years. The group is still actively promoted as facilitators intend to revive the provision when and if they receive new interest from burns survivors.

Birmingham Adult Group – According to University Hospitals Birmingham NHS Foundation Trust website a support groups meets on the first Monday of every month except August and December, in the Plastics Seminar Room at Selly Oak Hospital. Four contact attempts have been made via e-mail and telephone without response.

Of the 14 organisations discussed thus far nine of them were easy to locate on the Internet using web searches. The other five were discovered through conversations with healthcare professionals. Information provided by services and organisations has sometimes been shown to be incorrect and out of date highlighting the difficulties individuals face when searching for support.

## Out of date information

Burns Survivors Association – is still being promoted by various services including the Burns Support Group Database. The website is unable to be accessed and e-mails are undeliverable; there is no other form of contact provided.

The Burns Support Group Database – is a website that lists all the adult and child burns provision across the world with details on how to contact them. Whilst much of the information is correct some details provided are invalid and out of date.

Broomfield Hospital – the promotion of the London Area Burns Adult Support group is one year out of date (see recommendations p.29).

**Summary**

**• Nine organisations were confirmed as currently providing burns specific support (three = burns support groups)**

**• All support groups are facilitated by healthcare professionals**

**• Most support is aimed at survivors, friends and family**

**• Obtaining current and accurate information about burns support is difficult**

# Unsuccessful Burns Support Efforts

This section explores a number of previous attempts by UK services to facilitate burns support programmes. At the time of writing, August 2012, most no longer exist. Telephone interviews with burns healthcare professionals have highlighted some theories for this.

Broomfield Hospital - Chelmsford

Cyryna Barritt, Counsellor, set-up a support group in August 2009 with six - seven burn survivors attending each month at first. Attendees formed a focus group and decided on key issues, such as location, (main hospital), time (Saturday) and agenda (informal). The group was promoted in clinics, on the rehabilitation ward and through charities. The group did not flourish and attendance dropped to two - three survivors each month, until eventually only one person attended. After a year of perseverance (July 2010) it was decided that the group was no longer viable.

Staff had been surprised by the group's choices of location and time. They felt that this was a significant factor in why the group had failed. Staff did write to attendees, but received little feedback regarding changing the meeting day and time. In addition, attendee feedback indicated that difficulty obtaining travel expenses was amongst the reasons why burn survivors did not attend. However, it had been explained to attendees that charitable funds were available to reimburse travel expenses.

The Broomfield team now encourage survivors to attend the London Area Burns Adult Support Group (see p.7).

Northern General Hospital – Sheffield

According to Adam Saradjian, (CP), there was a support group prior to his tenure but it ended due to lack of patient demand. The healthcare professional who facilitated the group is no longer employed by the service so no further details were available. There are currently no plans to set-up a support group.

### Nottingham University Hospital Trust

According to Laura Shepherd, (CP), and Mary Kennedy, Practice Involvement Nurse with the Midland Burns Care Network (MBCN) there was a self help group prior to Laura's tenure. It was facilitated by three - four survivors who were well known to burns staff. Meetings were held monthly at 7pm in the playroom close to the ward and lasted one - two hours.

New survivors did attend but their involvement decreased with time. Once the original facilitators of the group stepped down from their roles, it became apparent that other members were not prepared to take up the leadership and thus the meetings ceased. It is unclear why the group ended but, according to Laura, there is an idea that it was "generally unhelpful to other survivors" as a 'clique' had formed, meaning that new attendees felt uninvolved.

There have been thoughts of setting-up a new group and the service has applied for funding for an Assistant Psychologist to explore this as part of their role.

### Royal Victoria Infirmary Hospital – Newcastle

According to Susan Nicolson, Nurse Specialist, a support group did operate three - four times a year and was facilitated by healthcare professionals. Presentations and speakers were organised but the attendance of survivors started to dwindle. The facilitators stepped down from the role and thus it was decided that an independent person was needed to take on this role. This could have been a burns survivor, ex-healthcare professional or someone interested in setting up support groups; but they did not find an appropriate volunteer who wanted to take on the responsibility so the group ended. The original facilitator is no longer in employment with the service so no further detail could be obtained.

They did extensive research on support groups, the use of volunteers and various training materials. Whilst local burns professionals agreed that a support group would be helpful for some, the majority felt that burns survivors would find talking to others who had been through a similar experience more beneficial and thus the idea was not pursued.

The service currently provides support through Burns Buddies and an annual support group meeting event (see p.6).

### Salisbury District Hospital

B.U.G.S ran a support group in addition to its in-patient work (see p.7). Whilst the in-patient work continues the support group is no longer in existence due to a lack of interest from survivors. The only burns survivors who did regularly attend the group were those with severe mental health problems who were looking for support for their mental health issues.

As suggested in previous burn care reviews, Elaine Cockerham (CP) devised a Social Skills Training Group for burns survivors in accordance to recommendations set out by the National

Burns Care Review (2001). The group exists in theory but not in practise as currently there are no attendees and no interest from patients. It consists of weekly sessions and reached only a maximum attendance of three survivors when it was run. Large efforts were made to publicise and promote the group but it has not taken off. Elaine attributes this to survivors' reports that they had no appearance concerns or need for social skills training. There are no future plans to implement a support group, due to this lack of interest and time pressures on staff.

Whiston Hospital – Merseyside

A buddy list was employed consisting of three - four patient names. Its implementation appeared to help support newly burnt survivors but came to an end due to lack of interest from buddies. The aim is to get back in contact with these individuals and re-open the list as well as starting up BRAVO again (see p.8).

**Summary**

- **Support groups start off with some enthusiasm but dwindle due to a lack of patient interest**
- **Services often encounter a lack of enthusiasm from survivors when asked to take on the role of group leader/facilitator**
- **Difficult to obtain current information as groups are historical and healthcare professionals involved no longer work in the service**
- **It is unclear why groups are unsuccessful as attention is not always paid to understanding why people drop out or do not ever attend**

# International Burns Support Provision

Burns services were contacted in the USA & Canada, Ghana, South Africa, Australia, New Zealand and India using electronic mail and SKYPE. A total of 13 responses were received from the following individuals and organisations:

Africa
Ghana Burns Survivor Foundation operates six groups across Ghana. Local groups meet every two weeks, either within a hospital setting or in the community. The groups are facilitated by survivors and healthcare professionals. They are mainly for children and young adults but older adults can attend. Support is aimed at in-patients in addition to out-patients and the mission is to provide the tools that burn survivors need to cope with teasing, staring and rejection.

Australia & New Zealand
Five responses were received from Australia and New Zealand.

The Central Coast Burn Survivors Support Group (CCBSSG) in Australia meets monthly and provides survivors and their families an opportunity to meet. The group is facilitated by burns survivors and non burnt volunteers; there are currently no plans to expand the group.

SHARE (Sharing Hope Acceptance Resilience Experience), is a newly implemented peer support programme located in three different Australian hospitals. Peer support volunteers are all trained burn survivors. SHARE currently has eight trained volunteers who offer support to newly burnt in-patients. The aim is that the programme will become a permanent source of support. The facilitators also identified a supplementary need for a burns support group. They hope to form a co-operative of burn survivor groups around the country to mutually share resources and information. Support group meetings will be held monthly with inspirational guest speakers.

The Burns Support Group Charity Trust in New Zealand, visits families and patients whilst in hospital and is held every three months. Attendance is approximately 10 - 20 survivors per group. It is facilitated by healthcare professionals and is a chance for people to meet in a relaxed atmosphere.

The Waikato Burn Support Charitable Trust in New Zealand provided support for burns survivors and their caregivers. It operated for 20 years but has now stopped because of diminishing availability of volunteer support.

India

No responses were received from the two organisations identified and contacted. Much of the burns support appears to be targeted to women who have survived acid attacks.

South Africa

No responses were received from the two organisations contacted. Both provide groups and camps as well as an After Burns Trauma Support Programme. A range of activities is organised for youth members including amateur dramatics and choir sessions.

USA and Canada

Seven responses were received from across the USA. Many of the organisations that operate in North America use SOAR volunteers (see below). Five out of the seven groups are facilitated by burns survivors, with one charity claiming that this was “imperative” to the group. The additional two groups were coordinated by healthcare professionals. The number of attendees varies from 5 - 25 across the groups. The majority meet monthly, but some as frequently as fortnightly.

The Burns Recovered Support Group holds meetings in St Louis and Columbia. In St Louis in-patient support is provided three times a week. It is believed that this has greatly contributed to the growth of the monthly support groups as patients and families get to know of the group’s existence before they are discharged. Attendance is approximately 15 survivors a month. The Columbia group is much smaller and averages four - six attendees a month.

Victim 2 Victor is currently the only support group in North Carolina led by survivors for survivors. Multiple groups are held across the state, via SKYPE. Facilitators are not professional counsellors but promote the group as an opportunity for experiences to be shared.

Fire-fighters Burn Institute Regional Burns Centre in California was established in 1985 and facilitates burn camps and support groups, on-line support and a befriending service. The monthly support group is coordinated by a burns nurse. It is available to in and out-patients, friends and family. Survivors and their carers' are urged to attend at least one group prior to or immediately after discharge. The majority of sessions are peer lead and cover an agenda that attendees create. Occasionally specialists are invited to give presentations.

### The Phoenix Society and SOAR programme in the United States

The Phoenix Society for Burn Survivors is the leading US non-profit organisation "dedicated to empowering anyone affected by a burn injury through peer support, education, and encouragement." The aim is to support recovery, improve the quality of burn care and prevent burn injury. The society is committed to advancing recovery resources and to supporting a positive return to life.

The Survivors Offering Assistance in Recovery (SOAR) programme was introduced in 2001 and has helped to qualify and validate the peer support that had previously been provided on an informal basis. Six hospitals piloted the original the programme. After the pilot the programme was modified slightly and now SOAR volunteers are based in more than 48 hospitals across America

SOAR is an in-patient hospital based programme. It is not burns specific and includes all types of wounds and skin disorders that are treated at the burns centres. Their mission is to facilitate work between the burn service and volunteers providing peer support to patients its patients. SOAR volunteers are screened by two healthcare professionals, one of whom must have a mental health background. Volunteers need to be at least one year post injury, although most are several years post injury. They have many burns survivors interested in joining the programme; however a significant number of them are assessed as not yet ready. After screening volunteers receive training to provide key information and skills needed to provide appropriate forms of support

The programme was not originally designed for support or self -help groups however it was found that groups did begin to develop. The Phoenix Society hopes to expand further resources for those which do develop into groups. If survivors can be trained to facilitate healthy and productive groups, then the pressure on healthcare professionals may be reduced. However, mentoring of peer supporters is required to ensure their comfort and confidence in running a support group. The locations of groups vary; from within hospital settings to the community.

There is a certain level of professional involvement. Healthcare professionals are often coordinators of SOAR programmes and are available to discuss issues that peer supporters might face. There are also online peer groups that peer supporters can use.

It seems of particular interest that despite the success of the SOAR programme, it is not common for burns survivors to contact the Phoenix Society directly asking where they can find support. However, the society believe that support should be a standard part of care and should be offered to appropriate survivors and family members when they first enter the burns service and then repeatedly offered throughout their stay on the ward. The ability for the survivor or supporting family members to utilise the programme may vary depending on their stage of recovery.

**Summary**

- **Facilitators of groups are a mixture of healthcare professionals and volunteers - in most cases groups are led by burns survivors**
- **All groups are aimed at survivors, friends and family**
- **Phoenix Society has national volunteer programme for burns survivors**
- **Support groups have developed from their volunteer programme**
- **Phoenix Society does not regularly receive enquiries from burn survivors about where to find support**

## Support Groups in Other Healthcare Domains

These summaries are based on a sample of 20 support and self-help groups which cover a range of conditions such as mental health, visible differences and general health problems (for the full list of groups and their related problems please see Literature Review p.31). All but two of these groups run on a national scale with numbers of groups ranging from tens to thousands (Alcoholics Anonymous) across the UK. Information was obtained using Internet research and electronic mail.

### General format

The data gathered on the existence of self-help or support groups come from researching websites related to specific healthcare issues and their associated charity websites. Sections of websites are devoted to support groups. Searches can be made for local groups, contact details of facilitators and in some cases, dates and times of groups are provided. In the majority of cases the groups operate on a monthly basis outside of a hospital setting. The structure and content of groups varies from providing emotional support to promoting physical fitness.

Most commonly groups are facilitated by volunteers. In 16 of the sample groups, including the British Heart Foundation, Beat and the Stroke Association, volunteers can apply to charities to set up and facilitate their own self-help group. In the majority of cases these are individuals who are experiencing the related condition. Volunteers submit an application, are put in contact with other local volunteers and are provided with materials and in some cases given training. The support given to volunteers through this self start-up process varies across charities.

The following are common issues that charities focus upon when considering the set-up and maintenance of self-help and support groups:

### Facilitators

Many of the groups are promoted as not being solely user led; however, groups for facial disfigurement, alopecia, eczema, anxiety, HIV and alcoholism are solely user led. All the groups are facilitated by volunteers, including those with and without the condition who are interested in facilitating a support group or ex - healthcare professionals. Many of the charities suggest that a minimum of two volunteers are needed to start a group.

### Training and Supervision

In many cases if a group becomes affiliated to a charity, (see below), on-going contact and guidance can be provided. Very few of the charities mention formal supervision for group facilitators. A minority provide professional supervision and in some cases they promote peer supervision. The provision of training and supervision for volunteers varies across charities. Approximately one in four mention some formal training. Topics include health & safety, confidentiality and supporting others.

### Who are the groups for?

Groups provide support for both those with specific conditions/injuries and their friends and family. Some charities operate one group which is open to both to attend. Rethink, SHE and Beat have additional groups solely for carers.

### Promotion

All of the groups researched are promoted through their respective charity websites. Many offer the ability to ‘find your local group’ by postcode search. They often produce monthly newsletters, posters and leaflets for distribution in healthcare settings; in addition to adverts in local papers and announcements on the local radio. In much of the literature provided by the charities, sections are devoted to promotion and publicity.

### Affiliation and funding

For those charities which provide a self set-up option, there is the opportunity for the group to become affiliated with the organisation. In many circumstances affiliation makes the group eligible for funding by the charity, and/or a (fixed amount) start up grant to be used to get the group ‘off the ground.’ Affiliation to a given organisation can provide the group with training opportunities, insurance and materials to use at meetings. Affiliation can be granted through an application process and means that the group has to abide by a set of rules. If groups decide not to become affiliated then the charity holds no responsibility for the content or action of the group. In some cases groups are automatically affiliated with the charity and independent work is not an option. For those groups where self-set up is not an option, including Birthmark Support Group and Let’s Face It, affiliation and funding is not an issue. Volunteers are still used but group organisation and facilitation is managed by the charity.

### Literature

Information about and materials to enable the start-up and maintenance of self-help groups is provided by many of the charities to enable volunteers to start-up their own group. The level of detail in the literature varies hugely from a few sentences outlying possible guidelines to extensive downloadable information packs covering all aspects of running a successful group. Topics covered include finances, organisation, role assignment and content. Packs sometimes included prototypes for posters and information leaflets.

**Summary**

- **Charities allow volunteers to establish their own self-help groups**
- **Groups are sustained and funded by a charity linked to the health condition**
- **Groups are mainly for those with the condition but also their carers**
- **Groups are facilitated by volunteers**
- **Groups are predominantly user led**
- **Charity websites are the primary source of promotion for groups**

# Current UK Burns Healthcare Professionals Opinions

Telephone and face to face interviews were conducted with healthcare professionals across the UK to elicit their opinions on group-based support for adult burns survivors using a semi-structured questionnaire. The overwhelming theme of these opinions was that motivation to attend groups is extremely low in the majority of these patients. Healthcare professionals suggested a number of factors to explain this:

- The support/self-help group model does not fit the burns population
    - Burns professional interviewed at Stoke Mandeville Hospital, Nottingham University Hospital and Morriston Hospital believe that a mentoring programme would be more beneficial to the services
- Burn survivors may not be prepared to travel long distances to attend a group
    - Liz Pounds-Cornish (CP) felt that the geography of the burns population makes attendance difficult as burns survivors are widespread and attending groups often means a lot of travelling
    - The BRAVO group have found that the burns survivors who want to come are not willing or able to make the long journey
    - At the Glasgow Royal Infirmary, setting up an additional group was considered but a location could not be decided upon as interest from survivors was so widely spread across the catchment area
- Burn survivors are unaware that groups exist
    - Information on groups is hard to find and can be out of date
    - Rebecca Crawford (CP) felt that services need to promote support groups to patients early on in their burn injury. Burn survivors need to know what help is available and where to find it.

  - Susan Nicolson (Nurse Specialist) felt that materials promoting the support services need to be placed everywhere in the hospital where a burns survivor or their family might go, including the burns ward, ITU, HCU and A&E

- Burn survivors receiving one to one support from psychology services are less likely to attend a group

  - Elaine Cockerham (CP) felt that burn survivors have access to individual psychology, so do not feel the need to be part of a group
  - At Whiston Hospital in Merseyside the number of people attending the BRAVO group decreased when the ward received a psychology input
  - At the Glasgow Royal Infirmary interest in the West of Scotland Regional Burns Support Group decreased as some attendees were connected individually to the psychology team and felt uncomfortable by their presence at the group meetings

- Burn survivors are unsure on how they would benefit from attending a support group

  - Lisa Williams (CP) felt that groups need to be more focused and have specific goals that are clear from the onset
  - Existing groups including the London Area Adult Burns Support Group have found ascertaining common interests between survivors challenging, thus, making the selection of activities and topics for discussion difficult

- Burn survivors cannot commit too much time

  - At Wythenshawe Hospital and Salisbury District Hospital they feel that meeting too regularly can contribute to why groups are unsuccessful as burns survivors are not willing to invest the time

- Individuals do not identify themselves as a burns survivor

  - Liz Pounds-Cornish (CP) felt that the motivation of individuals to attend a burns specific support group may depend on whether they identify themselves as a burns survivor or not, and that how individuals indentify with their scar is important in determining group attendance

- Burn survivors do not always want to remain as ‘burn patients’ and be identified by their injury

  - Justina Page, burn survivor at the Amos House of Faith in the USA felt that survivors do not want to be reminded of their burn on a regular basis; they want to get on with their lives.
  - Liz Pounds-Cornish (CP) asked the question, “is <u>not</u> attending a burns support group actually a sign of success?”
  - Sally Norwood (CP) said that survivors may not wish to be kept in the patient role of being a passive recipient
  - One burn survivor contacted said that she does not attend a burns support group because she “just wants to forget about it and move on”

- Burns Survivors feel that their scar is not “big or bad enough.”

  - Ezinna Rospigliosi, co-ordinator at the Katie Piper Foundation, has found that people worry who else will be attending the workshops
  - Mary Kennedy (nurse with MBCN) felt that the attendance of groups needs to be normalised and an ethos promoting that the size or location of the burn is unimportant. Anyone whose burn is affecting their life is welcome to attend

**Summary**

**•The dominant view of current UK healthcare professionals is that motivation to attend support groups is low in the adult burns population generally. It is suggested that this lack of motivation stems from a number of issues including; people not wishing to identify themselves as a burns survivor, not wanting to remain a burns patient after discharge, and feeling 'unworthy' of attending a support group. It was also noted that there are often difficulties with group functionality, such as poor promotion, logistical issues and the potentially confounding presence of psychology services**

## Who is Asking for Support and What Do They Want?

Each healthcare professional and charity was asked who, how, when and what requests for support they receive in order to gage the level of demand across the UK. Many interviewees reported that they personally receive very few or no enquiries at all from burns survivors looking specifically for a support group to join.

According to Adam Saradjian (CP) at the Northern General Hospital in Sheffield not a single patient has expressed to him that a support or self-help group would be beneficial. This has influenced his belief that there is no need or motivation to attend a support or self help group within the patient population.

Liz Pounds-Cornish (CP) receives few enquiries from burns survivors looking for support in the Buckinghamshire area. When burn survivors do express an interest in finding support it is often regarding meeting someone who has experienced a similar burn to themselves, normally involving the location of the burn. She has also referred those interested to the London group.

At the Glasgow Royal Infirmary more support enquires are received from survivors who are some years post burn than from recently injured individuals.

At the Morriston Hospital in Swansea enquiries are more frequently made for one to one support although healthcare professionals can recall some burns survivors who they believed would have benefitted from the support of a self-help group.

Lisa Williams (CP) at the Chelsea and Westminster Hospital thinks that a small number of survivors are seeking support information from the Internet and in fact several have been willing to travel long distances to attend the London group. Lisa believes that because details of the London area support group are easily found on the Internet, she receives one or two enquiries per month from burn survivors who are not linked to her hospital. The enquiries are both looking for and offering support.

Dan’s Fund for Burns receives numerous enquiries from individuals (records not kept), asking about various types of assistance. In many instances enquiries come from burn survivors who were burned many years ago looking for support either by speaking to someone who has suffered similar burn injuries or participating in some sort of group, if one exists. Other enquiries come from concerned family members looking for support in how to help their injured loved one. The charity also receives many calls from healthcare professionals within the burns services on behalf of survivors or their families/carers. Although Dan’s Fund for Burns receives a minority of calls asking specifically about support groups, this is primarily due to ignorance of the existence of such group, thus Dan’s Fund for Burns acts as an information base.

From the 1st of January - 25th of October 2012, Changing Faces received 414 enquiries from adults asking for support; 239 of these enquiries were from new clients who had not contacted the charity before. Contact is most frequently made by telephone (123), then e-mail (94). Looking back at previous years, Changing Faces receive approximately 300 support enquiries from adults annually. These figures are not burns specific and are not necessarily concerning access to support and self-help groups.

From January to October 2012 the Katie Piper Foundation received 91 enquiries from burn survivors. All of these were made by e-mail, although occasionally individuals do contact the charity for support via their forum and Twitter. These enquiries have not been included as the individuals were directed to the charity’s official e-mail address. The most common enquiries (31) asked about volunteering with the charity, the second most common was asking for help and support (21). They received ten enquiries regarding their workshops and other activities. The Katie Piper Foundation received the greatest proportion of enquiries from people with scars from causes other than burn injuries, including mental health problems and sexual abuse. The number of enquiries can increase following a media appearance by Katie. They do not have a direct phone line as they feel they would be inundated with people hoping to speak to Katie personally. They are however reviewing this situation in order to make contacting the foundation more accessible.

Interestingly the number of support enquiries received by charities is considerably higher than those received by burns professionals. This might suggest that charities could play an important role in the maintenance and promotion of burns support and self-help groups.

## Summary

- **Majority of burns healthcare professionals do not regularly receive enquiries from individuals about where they can access support; with the exception of Lisa Williams who receives one to two enquiries a month via the internet**

- **Charities concerned with burns and other visible differences receive a considerably higher number of support enquiries (not support/self-help group specific)**

# Other Support Programmes in Comparison to Support Groups

Data gathered from telephone and face to face interviews exploring what support is available to burn survivors showed that outside of support groups various charities and burn services are operating mentoring and befriending programmes. Healthcare professionals were asked for their opinions on such programmes. Most used the terms befriending, peer and mentoring interchangeably, thus for the purpose of this section we will distinguish these as pair-based verses group-based programmes.

Professionals in Sheffield, Stoke Mandeville and Swansea felt that a pair-based scheme would be more appropriate than a support group for their service. In Swansea, it is felt that this would be something to get “excited about,” as long as careful attention was paid to the matching of pairs.

Liz Pounds-Cornish (CP) was unclear what a burns survivor would gain from a support or self-help group that they could not gain from a mentoring programme, therefore, believed the latter was preferable.

Henrietta Spalding, Head of Policy and Practice at Changing Faces, Adam Saradjian (CP) and Liz Pounds-Cornish (CP) believed that a mentoring programme would require a degree of professional involvement. All volunteers would need to receive appropriate training and supervision.  Links could be made to current successful pair-based programmes for this.

Suggestions have been made that burns services and charitable organisations work together sharing volunteers regionally. Below is a collection of thoughts and ideas from burns healthcare professionals on the positive and negative aspects of pair-based and group-based programmes:

**Pair-based**

Positive

- Opportunity to receive support from a fellow burns survivor who has been identified as sharing a similar experience
- One to one meetings allow for more variables, including time, location and frequency of meetings, to be in the burns survivors control and thus increasing the likelihood of attendance
- Elimination of potential “politics” of group attendance, or creation of cliques including concerns about who a group is for and who else might be attending
- Support is tailored to the individual. Pairs can work together to achieve personal goals and targets

Negative

- Programmes can screen out and exclude certain demographics, including burn survivors with mental health problems
- Smaller and more unique demographics may be neglected as the service is unable to find and match appropriate pairs
- Timetabling problems - interactions between pairs have to be scheduled around each individual’s on-going commitments
- The number of burn survivors who can be helped would depend on the availability of appropriate and willing volunteers, thus meaning large numbers might be required

**Group-based**

Positive

- Groups are an inclusive space in which anyone with a burn injury can attend, does not exclude survivors who have mental health problems or obtained their burn through self harm
- Receiving support is not dependent on finding appropriate matches
- Groups allow for practise of social skills. It is important that survivors can operate within a group dynamic
- Attendees can interact with multiple burns survivors and form a number of relationships
- Provides both professional and peer support
- The provision of support is not reliant on one individual
- Allows pairs to dip in and out of the group when the need arises and it is not a big commitment.

Negative

- A single group cannot fulfil the aims and objectives of all burns survivors within its catchment area
- Support is not tailored to meet each individuals needs
- Locations of groups are widespread meaning that survivors may not attend as they would have to travel far
- Aims, objectives and the type of support offered by groups can be unclear

- Attendees must contend with group dynamics and existing personalities within the group

The consensus from many healthcare professionals is that pair-based programmes have a definite place and benefit but offer a different form of support to group-based programmes. Therefore their presence should be offered alongside a group not in replacement of one.

**Summary**

- **Pair and group-based programmes offer varying forms of support**
- **Healthcare professionals see value in pair-based programmes; but feel they should be offered in addition to group support**
- **Professional involvement in pair-based programmes would be required**
- **Volunteers need to receive appropriate training and supervision**

# Feedback from Burns Survivors

Evidence would suggest that not all people favour self-help groups and a significant proportion of people who attend one or two meetings never return (Humphreys & Rappaport 1984). To aid our understanding of this, feedback from burns survivors has been elicited. Information was obtained from telephone and face to face interviews using a semi-structured questionnaire with individuals attending the London Area Burns Adult Support Group and with survivors completing their psycho-social screening follow-up at the Chelsea and Westminster Hospital Burns Service.

**Survivors who have attended a group**
Feedback from those who are currently attending a group reveals different ideas on who would be the best placed to facilitate them. Some feel that a peer led group would be beneficial; others would not attend if there was no professional input. Some people may be put off by the title ‘Support Group;’ the meetings may be more popular if they carried a different name. “Publicity of the groups is vital as support can be hard to find.”

When thinking about the structure of groups, some survivors would like them to be more frequent, perhaps once a month, so that they can maintain social relationships with other members. The social aspect of the group appears to be important; attendees felt that this should be the focal point of the gathering, rather than the discussion of medical issues and treatment. Topics of discussion could be decided by participants themselves. One individual explained that the most beneficial part of attending the group was being able to pass their experience on to someone else.

### Survivors who have never attended a group

Six out of the seven survivors contacted were not currently attending a group nor had ever researched support groups. The remaining individual researched “all sorts of things” when they left hospital, some of which related to burns support and self-help groups. Reasons for not attending a group included current health problems which limited ability to travel, the location of the group being too far away and most commonly, feeling as though extra support was not needed. Comments included the following:

“I just want to forget about it and move on”

“I am happy with the way things are going”

“I do not need any extra support”

“I have friends and family who are very supportive and who can offer the emotional support I may need.”

Survivors felt that they would possibly attend a group if the scar was on a visible part of their body, if they wanted to talk with someone about their injury, or to meet someone who was “worse off than them.”

Some were unsure what they would like to find in a burns support group because they had never given it much thought. Some felt that practical advice on the physical problems and issues following a burn would be beneficial and make attendance of the group more attractive. The use of the group for social events provoked a mixed reaction, whilst some thought it would be beneficial, others felt that it was not the most appropriate use of time.

It was commonly believed that the severity of a burn injury and how much it impacted on an individual’s life would be a determining factor of group attendance for other burns survivors. Having a chance to meet with and talk to people who had been through a similar experience were amongst the main reasons given as to why other survivors might wish to attend a burns support group. “The knowledge that you are not alone in what you are thinking and feeling would be very encouraging and motivating.” Some felt that they would be able to provide support to others if it was needed.

The one survivor contacted who had never looked into attending a burns support or self-help group, said they would never attend one under any circumstance and could not think of any reason why someone else would choose to.

### Summary

- **Divided opinion on who would be most appropriate group facilitator**
- **Name ‘support group’ can be off putting**
- **Being able to meet, talk and share experiences with fellow survivors is regarded as most beneficial**

**• Main reason survivors interviewed did not attend is because they did not feel they needed extra support**

**• Survivors would like groups to offer practical advice**

**• Divided opinion on the importance of offering social activities**

**• Small number of survivors felt they would be able to provide support to others**

## Future Directions

The information collected thus far highlights the difficulties faced by British burns professionals as well as their achievements in the provision of burns support. At first glance the evidence might suggest that attempts to provide burns support in the past have been unsuccessful due to a lack of interest and motivation from burn survivors. Presently, burns services do not receive frequent enquiries from survivors and family members about how they can access support. But this lack of interest expressed to burns professionals' contrasts with the high number of support enquiries directed to the charitable sector.

Healthcare professionals still consistently believe that peer-related support should be offered to burns survivors, with opinion varying on the most appropriate way to do this. There is consensus that whilst support should be available to burns survivors nationally, coordination of support would probably be more effective if carried out regionally. This is because different regions present their own unique needs and challenges including size of burns population, demographics, facilities and resources available.

One may question why support and self-help groups are successful in other health domains but not within the burns population. It could be argued that burns survivors are a special group in some respects in that they are likely to have higher levels of pre-existing issues including poor social support, other physical, emotional and psychological problems, in addition to their burn injury. This may result in there being a smaller number of highly motivated individuals who would feel motivated to or capable of becoming involved in offering support to others. Other health conditions may have more diverse demographics in that there are potentially a higher number of motivated and well resourced individuals who are willing and able to offer support.

If the demographic of the burns population is the main contributor to the lack of success of burns support and self-help groups in the UK, then we might ask why burn support provided by for example, SOAR, has been so successful in the USA? One argument might be that the American population holds a more positive view of and is more comfortable with giving and receiving help from peers or professionals. However, this is a cultural assumption which is not based on evidence and may not be supported by research. Alternatively Pam Peterson, SOAR Programme Director, argues that support should be offered as a standard of care and that many survivors want to help but do not know how. Could it be that having a support structure in place that burns survivors and carers are aware of from the onset of injury, into which they just 'fit,' without having to ask or search for support is a strong factor in the success of the SOAR programme? Patients and families are repeatedly offered support by volunteers from the start of their burn treatment journey, creating an environment where survivors have to ‘opt out’ of receiving support rather than having to ‘opt in’.

Furthermore Pam attributed the success of SOAR to their partnerships with burns services. Once burns professionals embraced the programme they started to identify and refer patients and families who could benefit from support. This would suggest that the backing and promotion of support and self-help groups on a multidisciplinary level is vital. The latter would be replicable within the UK if a pool of willing burns survivors could be recruited and trained to spend time on the wards speaking to current inpatients and their families.

This section will now outline five ideas about how burns support might be developed in the future as a result of these findings.

## Potential Role of Volunteers

Evidence from support and self-help groups in other health domains illustrates that the commission of volunteers is fundamental in the set up and maintenance of groups. According to Humphreys & Rappaport (1994), support does not have to be delivered by professionals to be helpful. Even well meaning professionals change the atmosphere and process of self-help groups. It has also been suggested that the relatively higher cost of professionals’ time may not always be justified, given the similarity in outcomes when working with volunteers.

The majority of charitable organisations in other health domains make use of individuals with a condition to facilitate their own support and self-help groups. The success of the SOAR programme highlights the effective use of burns survivors in providing burns support. The impression from many burns professionals is that burns survivors would benefit from peer support, although, it is recognised that finding willing, motivated and energetic survivors would be challenging. Groups that have previously tried to encourage survivors to facilitate the meetings themselves have been unsuccessful in generating motivation, e.g. Sheffield, Chelmsford and London.

This may seem quite a unique idea but in the absence of a large cohort of burns survivors willing to lead or facilitate support mechanisms and benefitting from the successful experience in other health conditions, it may be that the next best candidates to pioneer burns support are willing, motivated and energetic volunteers who are <u>not</u> burns survivors. There are a number of individuals, especially students and graduates, who may be very keen to become involved in burns support in order to gain experience in working within healthcare settings or with healthcare professionals.

## How might the use of volunteers work in the burns setting?

In most cases a charity takes responsibility for the recruitment and organisation of volunteers. Charity websites include sections on ‘How to Become a Volunteer.’ This section outlines the general tasks, roles and responsibilities. These responsibilities would include all areas of group promotion, such as designing posters and leaflets, contacting burn survivors, organising locations and activities. Thus, it is suggested that volunteers for burns support and self-help groups might be selected by a burns charity or organisation.

Criteria that volunteers must meet in order to apply would need to be established. This may include being a minimum number of years post injury, basic literacy, relevant experience or creditable references. The burns charity would be responsible for the selection of appropriate candidates, ideally a minimum of two volunteers per service. Names and contact details of successful volunteers would then be passed on to their local burns services. The timetable, specific roles and responsibilities of volunteers would be decided by individual burns services.

The logistics of a volunteer presence within a hospital setting requires further exploration. There are often limited resources available, including a lack of computer availability and desk space. The tasks involving confidential patient details would need to be carried out on site, but responsibilities around promotion of the group could be completed elsewhere.

Many healthcare domains operate a self start up support group programme (see p.14-15). This would not be appropriate for the provision of burns support as both healthcare professionals and burns survivors believe that there needs to be an element of professional involvement within the groups.

### Status Quo

Based on the findings, one option is not to change the current burns support provision.

Evidence indicates that burns services have attempted to facilitate groups previously, but have been unsuccessful due to lack of motivation and attendance from burn survivors. Healthcare professionals reported that they receive very few or no support enquiries from burn survivors. This might suggest that motivation from burns professionals to embark on the commission of support services may also be low, especially if they have been involved in pervious unsuccessful attempts.

Failures of some previous groups have been attributed to the presence of psychology input to burns services and the inappropriateness of the support group model for the burns population. Small changes to the current burns provision should be made (see recommendations p.29). One of the most difficult aspects in undertaking the study has been obtaining accurate and up to date information on what support is available and how to access it. Therefore, clearer and coordinated promotion of services is essential.

### Restructure/reboot Support Groups

Research from healthcare professionals has shown that having a structured group, with goals and aims is an important element in group success. The workshops provided by Changing Faces and The Katie Piper Foundation cover specific topics and have a clear focus. However, it is argued that the burns population is unlikely to share common interests, thus, devising a group that is helpful and relevant for all members would be a challenge.

Burns professionals have suggested that the presence of a psycho-social team in burn services can affect group attendance both positively and negatively. Furthermore, it is believed that it may be valuable to separate groups for survivors and carers as the concerns and issues faced by both are different. In terms of structure, workshops which have a social activity at their core e.g. cupcake making at the Katie Piper Foundation, have been very successful.

Responses obtained from burn survivors indicate a difference of opinion regarding the most appropriate group facilitator. On the one hand a benefit for survivor led groups is identified but on the other some individuals would not attend the group if there was no professional involvement. In addition burn survivors would benefit from more support on the practical elements of dealing with a burn injury.

In considering these factors a rolling programme could be devised to appeal to as many burn survivors as possible. Listed below is a suggested format of six meetings per year, meaning the group would take place every two months. Feedback from burns professionals and survivors is that monthly groups are too frequent (due to a lack of resources and motivation from attendees), however, every three months is too long as members find it hard to form relationships. The frequency and content of meetings could be flexible depending on the service and the demand.

Below is a bi-monthly rolling programme example

1 – A survivor led meeting, no input from professionals or a non burns survivor

- *An appropriate and willing survivor would only have to available once a year*

2 – A healthcare professional led meeting

- *Sessions with different healthcare professionals allow varying topics to be covered keeping interest high, this made include a medic, therapist or a member of the psycho-social team.*
- *Or an 'ask the expert' MDT panel question and answer style session*

3 – A social meeting– perhaps at Christmas or a summer outing

- *Can be led by a volunteer*
- *Allows for a change of setting, possibly outside*
- *Other organisations have demonstrated this to be successful*

4 - A survivor only meeting (friends and family cannot attend)

- *At the moment very few organisations provide a survivor only space, this is attributed to a lack of numbers*
- *Could be combined with option one*
- *Can be facilitated by a volunteer*
- *Friends and family could have their own separate meeting at the time but in a separate location*

5 & 6 – an activity based meeting

- *May include an exercise e.g. swimming, allowing individuals to expose their scars for perhaps the first time in a safe and controlled environment*

The particular types of meetings that are identified as popular could be held more frequently or in place of less popular meetings. The programme would be flexible and allow for a range of support to be covered without relying on the same individuals to provide it.

### Combine Pair-based and Group Programmes

Firstly each burn service could develop a directory of burn survivors who would like to offer support to others. Appropriate candidates could be referred by staff members, other organisations or self referral. Volunteers would visit the ward to speak with current in-patients around a topic of concern. Their presence would not only provide vital peer support but would be less intimidating than a visit from a member of the psycho-social team. As relationships develop between the pairs or when healthcare professionals deem appropriate, meetings can start to take place off the ward but within the hospital setting. A burns survivor could be paired with multiple in-patients and upon agreement directories would be shared regionally to increase the chances of making appropriate matches.

One concern raised by healthcare professionals is regarding the matching of burn survivors. The application criteria in place to become a volunteer can often exclude certain groups of people, for example those suffering from mental health problems. Ideally directories of burn survivors would strive to be all inclusive; however a basic level of screening would still need to be enforced. Interactions between pairings that are potentially more complex e.g. mental health, suicide, self harm, could be facilitated by a healthcare professional. The more general process of matching pairs could be done in a variety of ways and is an area that needs further research. Pairings could be matched on mutual interests, aetiology of the burn and common topics of concerns including fears around returning to work and appearance changes. Evaluations would be obtained after each meeting from the volunteer and in-patient, with the opportunity for any concerns raised by either party to be discussed.

Should the directories of burn survivors prove to be successful and should healthcare professionals have sufficient resources, a more formal mentoring programme could be implemented. This could be similar, or happen in conjunction with the Befriending Service at Broomfield Hospital (see p.6). The directory and/or mentoring programme would not be limited to in and out-patients of burn services but could include referrals from other charities providing burns support. Resources, mentors and mentees could be shared regionally to increase successful matching. The most appropriate form of support offered including face to face, telephone or e-mail contact would vary depending on the needs of each pair.

Some basic training should be provided but again this could be done regionally once potential mentors have been identified. Peer supervision amongst mentors would be heavily encouraged. One goal of the peer interactions would be to promote the burns support or self-help group. Mentors and mentees can accompany each other to meetings to offer additional support. The support group should be held regardless of attendance and would be heavily supported by volunteers (see above).

## Conclusion

In conclusion it appears that the majority of burns professionals see and understand the importance of providing group or pair-based support programmes to adult burns survivors.

- Burns professionals see the importance of after-burns support and expressed interest in being involved and working together with such groups
- The use of volunteers may enable services and charities to work together to provide better support mechanisms regionally and nationally
- Research is required to explore further what burn survivors would find most helpful

## Recommendations

- Bring together existing support groups, burn charities and pair-based programmes to find a way forward for more consistent, practical and accessible assistance to be provided to burn survivors
- Eliminate out-dated information and websites (see p.8-9)
- The Dan's Fund for Burns website could expand their promotion of available support services to include those discovered in this report (see appendix D p.39 for names and contact details of the current national picture as of 2012)
- Consider the creation of an adult burns support regional database available to all individuals, professionals and volunteers, involved in the provision of group or pair-based support
- Consider the practical possibility of providing textual and support materials including links to helpful and relevant articles, websites and self-help manuals to burn survivors. Appropriate materials and information could be obtained from speaking to burns professionals and other charities

# (9) Literature Review:

**Papers:**

Humphreys, K., Mavis, B. E., & Stoffelmayr, B.E. (1991). Factors predicting involvement in self help groups after substance abuse treatment: preliminary findings. *Journal of Consulting and Clinical Psychology, 59,* 591-593.

Humphreys, K., & Rappaport, J (1994). Researching self-help/mutual aid groups and organisations: Many roads, one journey. *Applied & Preventive Psychology, 3,* 217-231.

Lieberman, M. A., & Bliwise, N. G. (1985). Comparisons among peer and professionally directed groups for the elderly: *Implications for the development of self-help groups. International Journal of Group Psychotherapy, 39,* 155-175.

McHugh, L. M., Dimitroff, K., & Dinsmore Davis, N. (1979). Family support group in burn unit. *The American Journal of Nursing, 79, 12,* 2148 - 2150

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National Burn Care Standards (April 2013)

Solomon, P. (2004). Peer support/peer provided services underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal, 27, 4,* 392 – 401.

London and South East Specialised Burns Project Bulletin (July 2012).

Vachon, M. L. S., Lyall, W. A. L. Rodgers, J., Freedman-Letofsky, K., & Freedman, S. J J. (1980). A controlled study of self-help intervention for widows. *American Journal of Psychiatry, 137,* 1380-1384

Wiechman, S.A., & Patterson, D. R. (2004). Abc of burns: Psychosocial aspects of burn injuries. *British Medical Journal, 329, 7462,* 391-393.

**Websites:**
www.burnsupportgroupsdatabase.com

**UK Burns Provision:**
www.bugssalisbury.co.uk
www.changingfaces.org.uk
www.chelwest.nhs.uk/services/surgery/burns-service/burns-support-groups
www.fabclub.org.uk
www.katiepiperfoundation.org.uk
www.mcindoeburnssupport.org
www.uhsm.nhs.uk/patients/Patient%20Information/Flyer%20for%20Publicity%20MYABC.pdf
www.whistonbravo.com

**International Burns Provision:**

**Australia and New Zealand**
www.burns.org.nz
www.burnssupportfoundation.org.au
www.ccbssg.com
www.peterhughesburnfoundation.org.au

**India**
www.acidsurvivors.org/about.html

**North America**
www.aarbf.org/index.htm
www.azburn.org
www.brsg.org
www.burninstitute.org/bss/programs/adult.html
www.burnsupportnc.net/index.html
www.burnsurvivor.org
www.burnsurvivorsttw.org
www.flickerofhope.org
www.grossmanburncenter.com
www.healedwithscars.com/upcoming_events.html
www.hopkinsmedicine.org
www.nsffbts.ca
www.phoenix-society.org/programs/soar
www.tgh.org/sg.htm#q12
www.theamoshouseoffaith.org/about.htm
www.ucdmc.ucdavis.edu/burncenter/burn_resources.html
www.wncburnsurvivor.com/

**South Africa**
www.burnfoundation.org.za
www.nbasa.org.za/about-us

**Support Groups in Other Health Care Domains:**
www.alcoholics-anonymous.org.uk
www.alopeciaonline.org.uk
www.anxietyuk.org.uk
www.b-eat.co.uk – Eating disorders
www.bhf.org.uk – British Heart Foundation
www.birthmarksupportgroup.org.uk
www.blf.org.uk/Home - British Lung Foundation
www.chronicpainsupportgroup.co.uk
www.depressionalliance.org/how-we-can-help/self-help-groups.php
www.diabetes.org.uk
www.eczema.org/support-groups
www.lets-face-it.org.uk – Facial disfigurement
www.macmillan.org.uk/HowWeCanHelp/CancerSupportGroups/CancerSupportGroups.aspx
www.mssociety.org.uk/ms-support/support-groups - Multiple Sclerosis
www.oagb.org.uk/?page_id=71 – Over eating
www.pituitary.org.uk/component/option,com_groups/Itemid,141
www.rethink.org/how_we_can_help/our_support_groups/index.html - Mental illness

www.shetoshe.org/helping-each-other- - Aids & HIV
www.stroke.org.uk
www.theibsnetwork.org/selfhelp.asp - Irritable bowel syndrome

**Burns Professionals Interviewed:**

Adam Saradjian, Clinical Psychologist- Northern General Hospital

Caroline James, Paediatric Outreach Nurse – Frenchay Hospital

Cyryna Barritt, Counsellor - Befriending service at Broomfield Hospital.

Elaine Cockerham, Clinical Psychologist - Salisbury Hospital

Ezinna Rospigliosi, Foundation Co-ordinator - The Katie Piper Foundation

Henrietta Spalding, Head of Policy and Practice - Changing Faces

Julia Cadogan, Clinical Psychologist– Frenchay Hospital

Justina Page, burns survivor and founder of The Amos House of Faith in the USA

Laura Shepherd, Clinical Psychologist – Nottingham University Hospital

Lindsey Yates, Sister – Whiston Hospital

Lisa Williams, Clinical Psychologist – Chelsea and Westminster Hospital

Liz Pounds Cornish, Clinical Psychologist - Stoke Mandeville Hospital

Mary Kennedy, Practice Involvement Nurse – Midlands Burn Care Network

Nicola Heneghan, Specialist Matron - Queen Victoria Hospital

Pam Peterson, Programme Director - SOAR Programme in the USA

Patricia Bridgland, Psychological Therapist – Queen Victoria Hospital

Rebecca Crawford, Clinical Psychologist – Glasgow Royal Infirmary

Ron Evans, Mental Health CNS – Morriston Hospital

Susan Nicolson, Nurse Specialist – Royal Victoria Infirmary

# Appendices

## Appendix A: exemplar facilitator application form from Beat.

# SELF HELP & SUPPORT GROUPS APPLICATION FORM

**Thank you for your interest in volunteering for the Beat Network of Self Help & Support Groups.**

We currently wish to expand the **Beat Network** and welcome applications from potential Group Facilitators and Support Volunteers.

**Please note:** If you have personal experience of eating disorders, you must be out of treatment, recovered and not have displayed any symptoms of eating distress for a **minimum period of two years.**

Please complete this form as fully as possible and return to Louise Dunne, Network Development Officer, **Beat**, Wensum House,103 Prince of Wales Road, Norwich NR1 1DW

If you have any questions please email l.dunne@b-eat.co.uk or Tel. 01603 753338

Please state which role you are interested in:

Group Facilitator ☐

Support Volunteer ☐

Please state any particular area of interest as a Support Volunteer:

_______________________________________________

If you are applying to be a co-facilitator of an **existing Beat** group, please give details:

Group name:

_______________________________________________

Name(s) of co-facilitator(s):

_______________________________________________

## 1. Personal Details:

Name: _______________________________________________

Address for correspondence:

_______________________________________________

Telephone:

Home: _______________________

Mobile: _______________________

Work: _______________________

E-mail address:

_______________________________________________

## 2. Knowledge and experience:

Please outline your knowledge/experience of eating disorders:

_______________________________________________

Please give a brief outline of your reasons for wishing to become a **Beat** group facilitator:

_______________________________________________

Please outline your knowledge/experience of facilitating/being part of a group:

_______________________________________________

Please outline any relevant qualifications or training:

_______________________________________________

If you are applying to be a Support Volunteer, please outline any specific skills or experience relevant to these roles, e.g., finance/IT etc:

Please give any other information which you feel is relevant to your application:

Supporting people affected by eating disorders may raise certain issues for some volunteers. **Beat** group facilitators must look after themselves first and foremost. Information provided in this section will be kept strictly confidential.

What is your experience of eating disorders?

Personal ☐
Carer ☐
Professional ☐
Other ☐

**If you have Personal Experience of an Eating Disorder, please complete the questions on Page 4 otherwise please proceed to Page 5.**

**If you have personal experience of eating disorders, you must be out of treatment, recovered and not have displayed any symptoms of eating distress for a minimum period of two years.**

If you have personal experience of an eating disorder, for how long have you been recovered?

Please give details of recovery:

What kind of treatment/support did you receive?

How long since you last received treatment?

Please give details about why you feel you are well enough/suitable to support other people with an eating disorder?

## 4. References:

**Please note: your application is subject to satisfactory and appropriate references.**

Please provide details of 2 people whom we can contact for references.

**Referees cannot be relatives or partners**, and we do ask that one referee has known you in a professional capacity, e.g., employer, tutor, medical practitioner.

(Occasionally, medical practitioners may charge for providing a reference, please check if this is the case, as **Beat** are unable to cover this cost.)

They must have known you for at least 2 years and will be asked to confirm that you fulfil **Beat** criteria, and
they will also be asked to confirm that you are well enough to support others.

They should be people who can give an honest opinion of your suitability to volunteer for **Beat,** and somebody who you feel comfortable in asking.

Please note that we cannot accept references from your fellow group facilitators.

REFERENCE 1:
TITLE (e.g., MR/MRS):
NAME:

ADDRESS:
POSTCODE:
EMAIL:
CAPACITY KNOWN:
LENGTH OF TIME KNOWN

REFERENCE 2:
TITLE (e.g., MR/MRS):
NAME:
ADDRESS:
POSTCODE:
EMAIL:
CAPACITY KNOWN:
LENGTH OF TIME KNOWN:

Signature of applicant: ______________________________
Please print name: ______________________________
Date: ______________________________
How did you hear about **Beat** Self Help & Support groups?
______________________________

**IMPORTANT**: Please read the Data Protection Statement below

**Data Protection Statement**

We value your support and promise to respect your privacy. The data we gather and hold is managed in accordance with the Data Protection Act (1998). We will not disclose, or share personal information supplied by you. By giving your details you are agreeing for us to contact you about our work and other fundraising activities.

If you are not happy for us to do so please tick this box ☐

www.b-eat.co.uk Registered Charity Number: 801343

## Appendix B: exemplar of leaflet, provided by British Heart Foundation

### Speaking for themselves

“The group is developing all the time, which is great. I learn something new each week. When I had my by-pass operation, I thought it was the end of life as I knew it. I felt like people were telling me that I couldn't do this and I couldn't do that. Now I feel like I can, and I want to tell as many people as possible that they can too.”

*CRASH* – the Cardiac Rehab Awareness Support Haven – Cornwall

“I think it's great that patients who may be anxious about their future, following diagnosis, can see what other people in a similar position are now achieving – life after diagnosis!”

Darlington Coronary Support Group

“As soon as you walk into one of our meetings, all you can hear is laughter. We have all got the same problems – that's what brought us together in the first place – but we all have an incredibly positive outlook. It is such a happy group. That's what attracts people and keeps them coming back.”

*Upbeat*, West Suffolk Heart Support Group

The British Heart Foundation is the nation's heart charity, dedicated to saving lives every day through pioneering research, patient care and information to help people care for their own hearts. But we need your help, because without your generous donations of time and money, we simply can't carry on our vital work. If you would like to help us, please call our donation hotline on **0300 330 3322**, visit our website at **bhf.org.uk/donate**, or send your donation to us at the address below.

**HEART HELPLINE**

**For information and support on anything heart-related**

☎ **0300 330 3311** | **bhf.org.uk**

Phone lines open 9am to 6pm Monday to Friday

BEATING HEART DISEASE TOGETHER

**British Heart Foundation**
Greater London House
180 Hampstead Road
London NW1 7AW
Phone: 020 7554 0000
Fax: 020 7554 0100
Website: bhf.org.uk

# HEART SUPPORT GROUPS

## A helping hand for your heart

British Heart Foundation

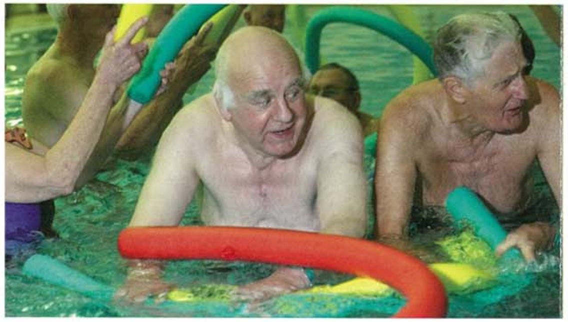
BEATING HEART DISEASE TOGETHER

## What is a Heart Support Group?

As well as the treatment and care they receive from health services, many heart patients – and their families – feel the need for further information and continuing support.

British Heart Foundation (BHF) affiliated Heart Support Groups do just that. They give people with heart disease the chance to support each other through their ongoing recovery and build the confidence they need to return to a good quality of life.

There are more than 300 Heart Support Groups affiliated to the BHF, bringing hope and a healthier lifestyle to thousands of patients and carers across England and Wales.



## So how can a Heart Support Group help you?

The groups are as varied as the people in them, and offer a range of benefits including:

- the chance to share experiences and gain emotional support
- opportunities for families and carers to learn about how others cope with living with heart disease
- options for exercise, eg, walking groups or swimming classes
- healthy lifestyle tips
- links to other services that are useful for heart patients, such as stopping smoking.

## And who are Heart Support Groups for?

They're for:

- people with any kind of heart condition
- partners, families and carers of someone with a heart condition.

## What else do Heart Support Groups do?

In addition to supporting each other, some groups play a vital role in their community through activities such as promoting heart health awareness in hospitals and schools and working with health care professionals.

## How can the BHF help you get involved?

It's easy – just email **hearthelponline@bhf.org.uk** or call our Heart HelpLine on **0300 330 3311** and we'll put you in touch with your nearest Heart Support Group.

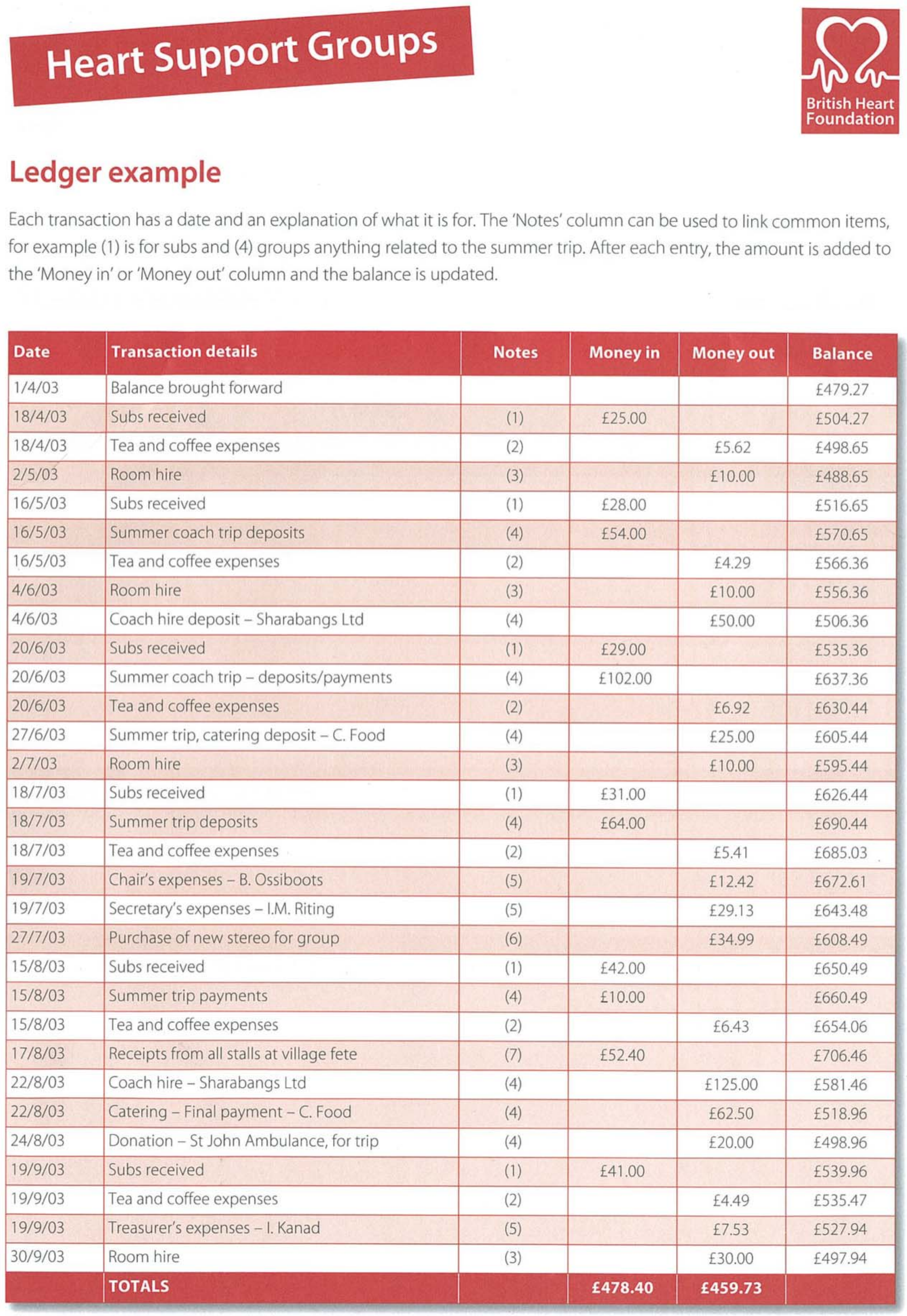
If you'd like to set up a local group to meet your particular needs or concerns, we can give you advice and resources to help get you started. And if you decide to affiliate to the BHF, you'll be eligible for many benefits, including free public liability insurance, a start-up grant and opportunities for networking and training. For more information please email **hearthelponline@bhf.org.uk** and to order a copy of the *Heart Support Groups toolkit – getting going and keeping going*, please go to **bhf.org.uk/publications**

**Join Heart Matters today**

Keep in touch with the BHF through Heart Matters. It's a **FREE** service that offers you a unique package of support and information on how to keep your heart healthy. As a member you'll benefit from regular issues of **heart health magazine**, a personalised **lifestyle check** available on the online members' area, and a dedicated **HelpLine** staffed by cardiac nurses and heart health advisers.

Sign up now to receive your welcome pack by calling 0300 330 3300 or visit bhf.org.uk/heartmatters

**Appendix C: exemplar of monthly ledger sheet, as provided by the British Heart Foundation.**



# Heart Support Groups

British Heart Foundation

## Ledger example

Each transaction has a date and an explanation of what it is for. The 'Notes' column can be used to link common items, for example (1) is for subs and (4) groups anything related to the summer trip. After each entry, the amount is added to the 'Money in' or 'Money out' column and the balance is updated.

| Date | Transaction details | Notes | Money in | Money out | Balance |
|---|---|---|---|---|---|
| 1/4/03 | Balance brought forward | | | | £479.27 |
| 18/4/03 | Subs received | (1) | £25.00 | | £504.27 |
| 18/4/03 | Tea and coffee expenses | (2) | | £5.62 | £498.65 |
| 2/5/03 | Room hire | (3) | | £10.00 | £488.65 |
| 16/5/03 | Subs received | (1) | £28.00 | | £516.65 |
| 16/5/03 | Summer coach trip deposits | (4) | £54.00 | | £570.65 |
| 16/5/03 | Tea and coffee expenses | (2) | | £4.29 | £566.36 |
| 4/6/03 | Room hire | (3) | | £10.00 | £556.36 |
| 4/6/03 | Coach hire deposit – Sharabangs Ltd | (4) | | £50.00 | £506.36 |
| 20/6/03 | Subs received | (1) | £29.00 | | £535.36 |
| 20/6/03 | Summer coach trip – deposits/payments | (4) | £102.00 | | £637.36 |
| 20/6/03 | Tea and coffee expenses | (2) | | £6.92 | £630.44 |
| 27/6/03 | Summer trip, catering deposit – C. Food | (4) | | £25.00 | £605.44 |
| 2/7/03 | Room hire | (3) | | £10.00 | £595.44 |
| 18/7/03 | Subs received | (1) | £31.00 | | £626.44 |
| 18/7/03 | Summer trip deposits | (4) | £64.00 | | £690.44 |
| 18/7/03 | Tea and coffee expenses | (2) | | £5.41 | £685.03 |
| 19/7/03 | Chair's expenses – B. Ossiboots | (5) | | £12.42 | £672.61 |
| 19/7/03 | Secretary's expenses – I.M. Riting | (5) | | £29.13 | £643.48 |
| 27/7/03 | Purchase of new stereo for group | (6) | | £34.99 | £608.49 |
| 15/8/03 | Subs received | (1) | £42.00 | | £650.49 |
| 15/8/03 | Summer trip payments | (4) | £10.00 | | £660.49 |
| 15/8/03 | Tea and coffee expenses | (2) | | £6.43 | £654.06 |
| 17/8/03 | Receipts from all stalls at village fete | (7) | £52.40 | | £706.46 |
| 22/8/03 | Coach hire – Sharabangs Ltd | (4) | | £125.00 | £581.46 |
| 22/8/03 | Catering – Final payment – C. Food | (4) | | £62.50 | £518.96 |
| 24/8/03 | Donation – St John Ambulance, for trip | (4) | | £20.00 | £498.96 |
| 19/9/03 | Subs received | (1) | £41.00 | | £539.96 |
| 19/9/03 | Tea and coffee expenses | (2) | | £4.49 | £535.47 |
| 19/9/03 | Treasurer's expenses – I. Kanad | (5) | | £7.53 | £527.94 |
| 30/9/03 | Room hire | (3) | | £30.00 | £497.94 |
| | **TOTALS** | | **£478.40** | **£459.73** | |

**Appendix D: contact details of current burns support provision:**

Befriending Service for Burn Injured Patients and their Families
Broomfield Hospital
No website available
Telephone number: 01245 516874
Befriending programme

Birmingham Adult Group
Selly Oak Hospital
www.uhb.nhs.uk/support-groups.htm
Telephone number: 0121 627 8779
Meetings are held on the first Monday of every month except August and December

*Burns Buddies
Royal Victoria Infirmary Hospital
No website available
Telephone number: 0191 282 5637
Buddy service and annual support group meeting

Burns Rehab and Voluntary Organisation (BRAVO)
Whiston Hospital
www.whistonbravo.com
Telephone number: 0151 430 1540

Burns Unit Group Support (B.U.G.S)
Salisbury District Hospital
www.bugssalisbury.co.uk
Telephone number: 01722 336262 ext 3139

Frenchay After Burns Club
www.fabclub.org.uk
07821 989845
3 day residential camp run 4 times a year for young people aged 16 to 25

London Area Burns Adult Support Group
Chelsea and Westminster Hospital
www.chelwest.nhs.uk/services/surgery/burns-service/burns-support-groups
Telephone number: 02033152504
Meetings are held 4 times a year at the Changing Faces offices

Manchester Advisory Group
Wythenshawe Hospital
No website available
Telephone number: 0161 291 6318
Meetings are held 4 times a year on the first Wednesday of every third month

Manchester Young Adult Burn Camp
www.uhsm.nhs.uk/patients/Patient%20Information/Flyer%20for%20Publicity%20MYABC.pdf

Telephone number: 0161 291 6319
Annual 4 day residential camp in the Lake District for 16 - 25 year olds

McIndoe Burns Support Group
Queen Victoria Hospital
www.mcindoeburnssupport.org
Telephone number: 01342 306617
No current support meetings

West of Scotland Regional Burns Support Group
Royal Glasgow Infirmary
No website available
Telephone number: 0141 211 4324
Meetings are held on the first Tuesday of every month during working hours

The Katie Piper Foundation
www.katiepiperfoundation.org.uk
No Telephone Number
info@katiepiperfoundation.org.uk

Changing Faces
www.changingfaces.org.uk
Telephone number: 0300 0120 275

*- permission needs to be gained before promotion.

## Appendix E: future considerations based on preferred support options.

Depending on whether Dan's Fund for Burns is interested in perusing either of the active suggestions (see p.26 -28) the following activities might be beneficial:

- Working with and learning from charities in other healthcare domains on their volunteer systems. Thinking in more detail about the types of training that would be needed and the finical repercussions of implementing volunteers
- Using data from the evaluation of the Befriending Service for Burn Injured Patients and their Families pilot at Broomfield Hospital to make advances in the implementation of peer support on a national scale
- Interviews/ focus groups with burn survivors, identifying reasons why they do not attend and what they would like to see provided in terms of burns support