Enhancing the Mental Health Carers' Contribution to Healing

Mary Seacole Leadership Award 2010

Enhancing the mental health carers’ contribution to healing

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**Glossary**

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<tr>
<td>BME</td>
<td>Black Minority Ethnic</td>
</tr>
<tr>
<td>Carer</td>
<td>Normally a family member or friend supporting the service user and if required helping with everyday living.</td>
</tr>
<tr>
<td>CETP</td>
<td>Carer Education and Training Programme</td>
</tr>
<tr>
<td>CPN</td>
<td>Community Psychiatric Nurse</td>
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<tr>
<td>DH</td>
<td>Department of Health</td>
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<tr>
<td>EPP</td>
<td>Expert Patient Programme</td>
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<tr>
<td>HM Govt</td>
<td>Her Majesty’s Government</td>
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<tr>
<td>IGT</td>
<td>Information Governance Team</td>
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<tr>
<td>LTC</td>
<td>Long Term Condition</td>
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<td>MH</td>
<td>Mental Health</td>
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<td>MIND</td>
<td>Mental Health charity</td>
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<td>MSA</td>
<td>Mary Seacole Award</td>
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<td>NHS</td>
<td>National Health Service</td>
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<td>NICE</td>
<td>National Institute for Health and Clinical Excellence</td>
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<td>RCN</td>
<td>Royal College of Nursing</td>
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<td>SLaM</td>
<td>South London &amp; Maudsley NHS Foundation Trust</td>
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<tr>
<td>SNAP</td>
<td>Survey software solution offered by SNAP Surveys</td>
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<tr>
<td>SU</td>
<td>Service User</td>
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<tr>
<td>SUITE</td>
<td>Service User Involvement in Training and Education</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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Enhancing the Mental Health Carers’ Contribution to Healing

Project Summary
A literature review, mental health carers’ comments about their lived experience and personal insights highlighted the gap in provision for carers’ needs. The needs of mental health carers are regularly overlooked and largely omitted. Mental illness is a devastating and usually a long term condition for the service user and can be doubly so for the carers as they feel helpless and impotent to help. Carers are an essential arm of the healing role to the service user within the home environment, and instrumental in enhancing the ‘healing environment’ of the service user. Good practice directives from the Department of Health (DH 2010c) and National Institute for Health and Clinical Excellence (NICE 2009) emphasize the involvement and inclusion of carers. However, practice has been tentative to take up these benchmarks. This project addresses the service gap identified by developing peer support for carers.

In the genesis of the project it was evident that there were two distinct phases to it: phase 1 being the education inputs for carers and phase 2 being the preparation of carers to become peer supporters for new carers. Phase 1 offered eight workshops, plus one celebratory session of two hours duration to ten carers from November 2010 to June 2011. The two key elements of these workshops were support and education. Phase 2 is designed to continue the educational inputs by focusing on the preparation of peer supporters.

Phase 1 workshops content was negotiated with the carers. The group was run as a closed group to nurture peer supporting and constructive group dynamics. Expert guest facilitators provided valuable information and perspectives to the carers. As lead facilitator, I retained contact with carers and ensured continuity and addressed individual needs. A Community Psychiatric Nurse (CPN) assisted me with supporting the participating carers. Academic and clinical supervision was availed throughout the project. The project was executed ethically, the Trust information governance guidance was adhered to, and remained carer focused.

It was repeatedly observed that the carers were selfless in their care of their loved ones and had to be reminded that their needs were equally important. In addition, carers were made aware that by looking after themselves they modelled ‘well-being’ behaviours to the service users. Peer support within the group evolved with some coaching and prompting from me. One of the mutual support strategies encouraged was giving the carer-participants space and opportunity to share personal experiences of ‘how they dealt’ with specific concerns. The group learnt from each other and those insights had added value because they were acquired from peers with ‘lived carer experience’. The comments in the written evaluations were consistently appreciative and affirming of the workshop inputs. Project outcomes included

• carers becoming more proactive in their caring role (e.g. challenging treatment plans) and
• carers asserting their confidence and skills as carers (i.e. becoming committee members for a carers’ strategy group)

Phase 2 of this project consists of identifying interested carers who wish to become peer supporters and developing a programme to drive this forward.

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1. INTRODUCTION

This Mary Seacole Leadership Award (Appendix 1) report provides the background and the narrative of the carer workshops that were facilitated from November 2010 to June 2011. This project is a direct response to a gap in the service provision and is in tandem with the national drive to address the needs of carers (see 1.1) and also linked to the South London & Maudsley NHS Foundation Trust’s carer strategy and work stream. This is a unique two-phase project designed around carers and their needs.

Phase 1 relates to eight workshops of two hour duration each offered monthly to a closed group of carers. Although each workshop was integer in itself, each enhanced continuity and a logical follow through to aid understanding and development of group members. The focus of the workshops was both educational and supportive with an overarching intention of establishing a baseline for preparing the carers to become peer supporters.

Phase 2 will further the development of the carers to enable them to become peer supporters. It is acknowledged that the process of preparing individuals for a specific task i.e. becoming peer supporters cannot be rushed (Repper & Carter 2010, pg 11-12)

Scoping of the background to the carers’ workshops is provided to ease understanding. This report relates specifically to Phase 1 of the project: it details the project proposal, its evolution, project methodology, key findings and some early outcomes. The last section offers a discussion of the findings together with the proposed next steps.

1.1 Definitions

Mental illness can affect one in four of us in our lifetimes and there is still misunderstanding, stigma and discrimination associated with it as highlighted in the Attitudes to Mental Illness Report (DH Research Report 2010a, pg 8-9). Mental illness can present as emotional distress and interference of daily functioning as with depression and anxiety to more serious conditions of psychosis with its associated disordered thinking and distorted perception of reality (McManus S, Meltzer H et al 2009, pg 11 & 89). The World Health Organisation in its international classification of mental and behavioural

Although this is not a psychoanalytical group, it was decided to have it as a closed group so that the carers could form group relationships. A group as defined by Garland (2010, pg 2), is ‘individuals coming together to collaborate on a common purpose’.

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disorders also identifies other conditions like dementia manifested by memory impairment and decline in ability in learning new information and bi-polar disorders with its episodes of mania and depression (WHO 1992, pg 25 and pg 91-93). There are many permutations of mental illness as an individual can have dual diagnosis (e.g. addiction and schizophrenia) and people with long term physical illnesses can become depressed.

Mental illness is usually a long term chronic condition and the journey to recovery can be slow, include remissions and relapses, requiring both the individual and the family to develop many lifelong strategies. A mental health carer (carer) is normally a family member or friend supporting the service user and if required helping with everyday living in an unpaid capacity. A service user (for this project) is someone who accesses in-patient or community mental health services. All the carers in this report had relatives with serious mental illnesses as described above.

1.2 Mental Health Carers

The strategy for mental health, No Health without Mental Health (HM Govt 2011) advocates the placing of the service user at the centre of their care. The value of peer support for service users with ‘lived mental illness’ experience is gaining momentum (Repper and Carter 2010, pg 2) as it is accepted that service users themselves are best placed to dictate their care. In contrast the notion of peer support for carers has yet to gain momentum.

There are 1 million carers of people with mental illness and many are poorly served by statutory and voluntary services with 74% saying that they were at breaking point (Carers UK 2008). For these carers, the carer-role is both complex and multi-faceted. In reality the carer role is one that is bestowed (by professionals) and accepted (by the carer) at a tacit level. Although it is likely to be a long term and often a lifelong commitment, carers and particularly carers from the black minority groups (BME) have little or no preparation for it and lack professional support as carers (Keating & Robertson 2004; Sandhu 2008). An additional factor that confounds many carers is the lack of shared information from staff and services due to concerns of confidentiality. Sometimes due to their mental illness or perhaps because of perceived shame or pride, some service users may not want their carer involved in their care. Staff who are duty bound to exercise their ‘duty of care’ to their service users may expunge the carer from any further communications and considerations (DH 2006).

The carer experience is lonely and alienating as there is a lack of support facilities and the fear of being ostracised in the community due to its association to madness (Rethink 2003; DH 2010b, pg 12). This is more so
with the BME groups whose poor experience and stigmatization of mental illness is well documented (Trivedi 2004; Bhui & Sashidharan 2003). The fear of ‘madness’ can be internalised by BME communities further adding to the burdens of dealing with diagnosis, disabling symptoms and a complex health care system. Furthermore, BME carers have a worse experience due to cultural barriers, poor carer health and social exclusion (Carers UK 2011, pg 2-3). Carers are also in the bewildering predicament of trying to discern how much is the ‘person’ and what can be legitimately regarded as due to the illness.

There is evidence indicating that working with carers can improve the relationship with the health care professionals and aid service user recovery (Slade 2009; Maphosa & Kuipers 2004). The National Institute for Health and Clinical Excellence (NICE) guidelines for schizophrenia (NICE 2009, pg 14) recommend “working in partnership with carers”. A hitherto undeveloped area of educational innovation in mental health, both in the local area and nationally is an adapted “Expert Patient model” (DH 2001a) designed for families and carers. One initiative to note is the carer education and training programme (CETP) offered by the mental health charity, Rethink (Rethink 2011). As there is a cost attached to this service, its uptake is limited. There is sparse research on buddying / peer support in mental health (with service users and carers) though the value of collaborating with service users and carers is emerging (Tew et al 2004; Leiba 2010).

Since the advent of care in the community (Hoult 1988) more service users are living with families and in the community thus putting the onus onto families to care for the clients. Families most anxious about the relatives are those for whom it is a new experience, have limited resources and cannot take time off to care (Heru & Drury 2007). In psychiatry, families, (and particularly families expressing high expressed emotions), after decades of being regarded as dysfunctional and contributing to the service user’s condition and relapse of psychotic behaviours (Vaughan & Leff 1985) are now acknowledged as a strength and an asset (Marsh & Lefley et al 1996). For example, Marsh & Lefley et al (1996) identified four guiding principles for psychiatrists: (see diagram 1).
More recently, Heru & Drury (2007, pg 33) found that the behaviours of the families maybe a direct reaction to their relative’s illness. It is understandable that when a loved one becomes mentally ill and fragments as an individual that family members may become protective and over zealous about the relative’s well being.

An approach of care widely practised in psychiatry, is the ‘recovery’ oriented practice (DH 2001b; Watkins 2007) which includes three principle tenets:

a) There is always hope for every service user regardless of the severity of their illness and only the individual can take that road to recovery.
b) Staff can only aid and assist them on the way.
c) The part families play in the recovery is immense and their contributions and support should be actively utilised.

1.3 Peer Support

Repper & Carter’s (2010) comprehensive literature review of peer support for service users’ was triggered by their interest to employ peer support workers and their desire to identify best practice. They acknowledge that peer support for service users is becoming well established nationally and internationally. Their key recommendation is ensuring that the strategies and policies are in place before employing peer supporters. It is the ‘lived mental illness experience’ that makes the peer supporter unique and enhances their role as a worker. While it is accepted that peer support relationships can evolve naturally, the role of peer supporters provided by the health sector is engineered specifically to meet needs of the service user.

Peer support is mutual empathetic support offered by people with similar experiences invoking a wellness model that draws on the strengths of self help (Basset, Faulkner et al 2010, pg 8-9). There are many similarities as well...
as essential differences for peer support with carers. For example, like service user peer supporters, carer peer supporters are also basing their expertise on their ‘lived carer experience’ (Kolb 1984). It should not be assumed that all carers (including those who have vast experience as carers) can or may wish to develop into peer supporters. It is important to offer carer-peer supporters targeted training and supervision and not expect them to support other carers without an infrastructure to underpin the process. The preparatory programme would ensure that both the carers and carer-peer supporters have clarity about the scope of their roles and the boundaries to which they are working. Furthermore, there should be on-going support e.g. quarterly group meetings with a co-ordinator to assist with addressing ongoing needs. This is an evolving arena where the literature is not readily available about the best ways to proceed.

2. BACKGROUND TO PROJECT DEVELOPMENT

The espoused theory in psychiatry / mental health (MH) service provision is that care provision is a tripartite partnership between the service provider, service user and carer (DH 1999). Similarly, Triangle of Care (The Princess Royal Trust and The Mental Health Development Unit, 2010) advocates the need for better local strategic involvement of carers and families in the care planning and treatment of people with mental illness in acute in-patient and home treatment services. Essence of Care (DH 2010c) provides practice benchmarks to embed the carer involvement.

An examination of the tripartite partnership reveals that two of the three strands of the partnership are easily discernable, i.e. the existence of direct links between (a) the service user and statutory MH services, and (b) the service user and carer. However, the third strand, that of a direct link between the statutory MH services and the carer, particularly in the acute services is virtually absent. Similarly, if one examines the education and training strategies of a provider Trust, it is evident that it is required to exercise its employer duties by ensuring that their staff are adequately prepared for the roles s/he is appointed to and continue to receive the necessary in-service training and education whilst in employment. Many staff offer service user education sessions / programmes on individual or group basis to raise awareness of their conditions etc. Until very recently, it was very rare to witness services geared towards carers with certain exceptions (see section 2.1). Thus the reality is many MH services are responsive to service user needs but they have yet to embrace the needs of carers.

Literature (also see section 1.2) indicates that the majority of carers are lay people who are unpaid and could be classified as ‘older adults’, therefore are also likely to have their own unmet health needs. In essence carers are an invisible and silent army underpinning front line service MH provision. Any
calculation of the carer contribution to the long term care and support of relatives with enduring MH illness would need sophisticated statistical modelling to take account of a plethora of key factors such as lost income from premature retirement, smaller pension entitlements, etc.

Both literature and practice confirm the existence of a gap in service provision in supporting carers. In addition, the NICE (2009, pg 14) recommendation of “working in partnership with carers” has not materialised apropos service development in this field. These insights enthused me to want to address the gap in my own workplace by focussing on a single key question:

“How can carers be prepared and supported for the role so that the healing environment is enhanced for the benefit of the service user?”

Thus began the process of identifying existing literature pertaining to supporting carers in the health sector. There is ample evidence that other models and initiatives exist to support individuals with long term conditions (LTCs) as well as other acute illnesses such as cancers. For example, the Expert Patient Programme {EPP}, (a DH 2001a initiative) for people with LTC and adapted programmes for parents of children with LTCs are acknowledged as being beneficial (see Wilson 2007; Wilson & Mayor 2006). In contrast in MH the EPP provision for service users and carers has been limited. In the MH sector, many services for children and young people incorporate family therapy into the care programme – thus extending carer support to entire families.

Perusal of these initiatives led me to conclude that my role as lead educator in equality and diversity could facilitate the development of an eclectic model to provide carer-centred educational inputs. The five guiding principles I adopted for this development were:

a) I would draw on my current practitioner-educator knowledge

b) It would be carer centred, therefore inputs would be agreed with carers

c) It was imperative that carers were not cast into role as co-service users or victim blamed for their relatives’ condition.

d) Be pragmatic in delivery by using the services of Trust employees and expertise where possible

e) Be low cost on resources so as not to require recurring funding at a time of cutbacks
Furthermore, the model had to be one that could be adapted easily to address the various sub-specialisms within the Trust, and in time for others to emulate if they so wished.

In 2009, under the leadership of the Director of Nursing, South London & Maudsley NHS Foundation Trust began work on the Carers’ strategy endorsing a commitment to work in partnership with carers. There were two early outcomes of this strategy – the first was the inception of a Trust wide annual ‘listening’ and responding to carers’ views event. There is a cultural expectation that senior staff will attend and hear the concerns and views of carers with the intention that carer voices will be used to change and develop practice. The second outcome was the initiation (in September 2010) of quarterly ‘empowering family and carers events’ hosted by the Service User involvement in Training and Education team (SUITE). I am actively involved in both initiatives - as a member of the Trust carers’ steering committee and the carers’ peer support lead with SUITE.

Personal insights and observations that carers benefit from education and support led to the Mary Seacole Award (MSA) project proposal, which serendipitously coincided, with the Trust’s family and carer initiative. The partnership with the SUITE team was facilitated and agreed by the Education and Training head of department. The advantages included a group to collaborate with from the onset of the project and a gateway to all the carer initiatives in the Trust e.g. a Trust wide carer committee, a Southwark carers’ group and a Southwark peer support group. The latter had started a major three year project on peer support for service users. There were parallels with the peer support project with service users that would be beneficial and could be adapted for the peer support carers’ group.

Another distinct benefit of the ‘empowering family and carer’ events was that they complemented some of the MSA project draft objectives (see Appendix 2). I ensured that the Mary Seacole project remained a discrete entity and was not subsumed by a different agenda. The empowering family and carer events included thematic presentations and a number of ‘drop-in surgeries’ facilitated by specialist staff giving advice and information as well as answering individual questions. (See Appendix 3 for details of the surgeries). Taster sessions of the carers’ workshops were also offered at these events. (See section 4.1).

2.1 Service Needs

The MSA project endorsed the Trust’s core value of ‘Everything we do is to improve the experience of people using our services and to promote mental health and well being for all’. Carers provide the greatest single resource in terms of caring for their loved one. However, there is the possibility that
without adequate support and help the (free-of-cost to the NHS) carer system can break down with dire consequences for the service user and service provider costs. Under legislation (Carers Recognition and Services Act 1995), carers are entitled to carers’ assessments so that appropriate services can be alerted to their (carer) needs. It is recognised that the social background of carers has an impact on their needs as well as their ability to engage with the care providers. For example, a family with better knowledge of the system or having greater financial security is able to navigate their way through the system more easily in order to access or procure more relevant resources for their loved one.

The Trust’s carers’ handbook (South London & Maudsley NHS Foundation Trust 2010) boldly states that all teams should offer carers written information about their service and the conditions treated. Although certain services e.g. older adults’ and some of the specialists’ services run support groups for carers and families, these initiatives are not always available across the Trust. It is of paramount importance, therefore that carers are informed of support and information available outside of a specific service.

2.2 Project Proposal

I proposed a model drawing on the principles of a peer support/ budying framework that is both supportive and educational is developed and implemented to prepare new (lay) carers, as early as possible, for what is essentially a critical supportive and partner role with health professionals. Pragmatically, it seeks to:

a) Enhance their understanding of their carer role;

b) Facilitate the ways of working with health professionals currently and in the future and

c) Empower them for their advocacy role.
3. PROJECT AIM and OBJECTIVES

3.1 Aim

The key aim of this project is to: support and develop carers as informed partners and peer supporters to enhance their contribution to healing by offering them a series of specially designed skills workshops and support them in their carer role. Healing in this context refers to ‘an enabling and supportive response to an individual’s distress’.

3.2 The Objectives of this Project were:

Short term (Phase 1 of the MSA project: from inception to June 2011)

1. To empower and enable carers to play a strategic pivotal role for the service user, through developing a thorough understanding of clinical care pathways and recommended treatment interventions

2. To demystify health professional roles so that enabling working relationships between staff and carers are fostered

3. To manage carer expectations and promote greater transparency about the service inputs and care plans

Medium term (the beginning of Phase 2 of the MSA project: six months post Phase 1)

Develop a model/approach of carer mentoring / carer peer support

Long term (the core of Phase 2 of the MSA project: twelve months post Phase 1)

1. To develop a forum for peer support to develop enablement of families & carers through a (buddying) system which is carer led

2. To use the experience of this project to refine and roll out a similar programme in other directorates of the Trust

3. To begin to assist the development of other staff members to deliver similar workshops in their own directorates

4. To reduce the potential of carer burnout through support and a peer support model for new carers

5. To involve carers in the delivery of similar programmes

6. Develop teaching and learning resources that can be adapted for use in the different directorates
3.3. Ethical Considerations and Approval

Bearing in mind that any work undertaken with service users and their carers warrants ethical consideration and approval, advice was sought from the Trust research nurse and the Mary Seacole project supervisors prior to discussing it with the Trust information governance team (IGT). The IGT advised that although the project did not require full ethics approval because it did not directly affect service users it had to meet the Trust information governance requirements. The application to the IGT received chair’s approval (due to time constraints) subject to five recommendations:

1) Obtain written consent from carers before collecting data
2) Provide information to carers so that they make informed decisions
3) Maintain anonymity of the carers
4) All information to be password protected on Trust network
5) All files on the carers and their details to be kept in a locked cabinet

These recommendations were incorporated into the project.

4. METHOD

4.1 Recruiting Carers to the Project Workshops

The main focus at the commencement of the project was recruiting the participants. The partnership with SUITE provided the opportunity to offer taster sessions for the carers attending the family and carer events (see section 2). Post session, carers were invited to indicate their expression of interest in the MSA project workshops by providing their contact details. Table 1 details the content of the twenty minute taster sessions (with 6-8 carers):

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<td>Introduction / Ground rules</td>
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<td>Discussion on well being / Managing stress</td>
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<td>Support on offer</td>
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<td></td>
<td>Summary</td>
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<tr>
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<td>End / Invitation to sign up</td>
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2 IGT meetings are held quarterly. It processed my application under its powers for ‘Chair’s approval’ thus ensuring that the project was not delayed.

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My experience of participating in these taster sessions affirmed that carers were keener on gaining information, and developing skills and strategies rather than sitting in a group hearing other carers’ narratives. Though there is value in hearing carer stories; (e.g. they are not alone; empathy from other carers) they were more focussed on acquiring knowledge and help for their loved ones. It is possible that these carers were at a particular stage in their caring that they wanted this sort of assistance rather than listening to each other’s experiences.

Participants for the project were recruited from these taster sessions and also from the Trust wide publicity flyers.

4.2 Publicising the Workshops

Prior to commencing the project key stakeholders were identified and contacted with the aim of canvassing support and assistance with cascading the information to interested parties. For example, presentations were made to a number of carer steering groups within the Trust: a brief summary was included in the Trust newsletter and the Trust Equality & Human Rights group informed.

The workshops were publicised in the carers’ induction sessions, via a variety of carer networks i.e. carer newsletters and carer groups and also Trust newsletter and Trust staff. As I had a specific interest in recruiting carers from the acute services I made a point of targeting those services. The Cares of Life service (a BME service within the Trust) assisted by distributing the flyers (see Appendix 4). It was expected that carers would self-refer for participation.

The flyer included the details of the dates of first two workshops (as I planned to run the sessions as a closed group after that), venue, purpose of workshops and contact details for queries or further information. The advantages of working together in a closed group are that carers have an opportunity to:

a) adhere to ground rules and listen and learn from each other. Equality between the carers is nurtured allowing space for carers to contribute

b) define the boundaries and expectations from staff and each other

c) benefit from other people’s experiences and knowledge, discovering that they are not alone
d) offer a different perspective and opportunities to challenge and ask questions. This helps the carers to rehearse strategies when dealing with health professionals and their loved one

e) enable the carers to take risks in a safe environment

f) give carers time to reflect and talk about themselves as opposed to talking about their loved ones

The response to the flyers was less than anticipated; therefore flyer distribution was extended to all the carer groups within the Trust. About half of the group recruited were the carers I had met at the September family and carer induction session. This is a valuable insight that will be taken into account when recruiting carers for the next set of workshops. Carers who had expressed an interest in the workshops were contacted (e-mails and or telephone) to ascertain their continued interest and confirm the start date. It transpired that a number of them had deleted my e-mails because they did not recognise the sender and would have been lost to the project had I not telephoned them.

4.3 Group Participants

The number of participants per group was envisaged to be 12-15 members which is a good group number (Proctor 2000) without being too large to overwhelm individual group members or so small that the carers feel too spotlighted. Entry to the workshop-programme was geared to sessions 1 or 2 to ensure consistency and continuity and promote the likelihood of the group participants getting to know each other (Garland 2010, pg 3) and becoming peer supporters to each other.

Organisational administrative activities e.g. booking the rooms and negotiating with the administrative staff about welcoming the carers were initiated. Laminated posters of the flyers helped signpost the room. The recruited carers received confirmation letters with travelling directions and maps. As per the Trust’s training department protocol, reminders were sent and followed up with phone calls.

I had quite in depth (telephone) conversations with a few of the carers who were very interested in what was being offered and how it would help them. These informal conversations enabled me to gain information about their circumstances and noted the key issues raised. I was also able to point some carers in the right direction for them to access or seek help. These conversations confirmed to me that some carers were unaware of the
services available or how to navigate the systems and were oblivious of their entitlements. Moreover, the informal data generated informed the content of the workshops.

A total of fifteen carers were recruited. However, three of them withdrew prior to the first workshop due to changes in their personal circumstances e.g. escalation of carer responsibilities, a sudden bereavement and childcare concerns. These three carers were provided with a copy of the Trust’s Carer Handbook and information about the family and carer quarterly events. Two other carers only attended the first workshop and withdrew because of childcare commitments leaving a core group of ten carers. All subsequent information in this report about the carers refers to this core group. All subsequent information in this report about the carers refers to this core group. Tables 2, 3 and 4 display participant ethnicity, gender and age. The diverse ethnicity of the participants reflects the Trust in-patient profile. The gender of the carers (i.e. predominately women) corresponded to patterns noted in other studies e.g. Victor (2009); Carers UK (2008). Similarly, the age of the carers (Table 4) highlighted that 40% were over 56 years old as in the other mentioned studies.
Table 2: Ethnicity of workshop participants

Total number of carers: 10

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indian</td>
<td>35%</td>
</tr>
<tr>
<td>Any other Asian background</td>
<td>25%</td>
</tr>
<tr>
<td>Caribbean</td>
<td>20%</td>
</tr>
<tr>
<td>Any other mixed background</td>
<td>15%</td>
</tr>
<tr>
<td>White British</td>
<td>10%</td>
</tr>
<tr>
<td>White Irish</td>
<td>5%</td>
</tr>
<tr>
<td>Any other White background</td>
<td>0%</td>
</tr>
</tbody>
</table>

Table 3: Gender of the workshop participants

Total number of carers: 10 : 6 female: 4 male

Table 4: Age of workshop participants

Total number of carers: 10

<table>
<thead>
<tr>
<th>Age of carers</th>
<th>Number of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;65</td>
<td>1</td>
</tr>
<tr>
<td>56-65</td>
<td>2</td>
</tr>
<tr>
<td>46-55</td>
<td>2</td>
</tr>
<tr>
<td>36-45</td>
<td>3</td>
</tr>
</tbody>
</table>

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4.4 Preparatory Work and Hospitality

The workshop room was prepared in advance of each session to ensure a prompt start. In the course of delivering the first workshop it became evident that the first floor room was not disability compliant, therefore the remaining workshops were relocated to a ground floor room. As access to the new venue was through a security coded door, it required additional support to accommodate latecomers. The carers’ workshop flyer posted on the room door provided carers with the assurance that the workshop was happening.

Carers were provided with refreshments including biscuits and fruit as they arrived. Carers were each given a bookmark with all the workshop dates. Photographing any part of the workshops was intentionally avoided to protect the anonymity of the carers. For the same reason care is taken in this report to anonymise carers by not using their given first names or revealing too many personal details as they are a small group and could be identified. An exception is made with one carer who requested that his short summary is included in this report (Appendix 5).

Other major milestones of the project included refining the workshop timetable and confirming the expert speakers. The timeline was monitored as a standard component of project supervision.

4.5 Staffing of Workshops

The core staff facilitating each of the workshops included myself as lead facilitator and a community psychiatric nurse (CPN) whose brief was to provide me with peer support and act as my personal assistant (see 5.1). Guest expert speakers were invited to six of the eight workshops.

5. WORKSHOPS

5.1 Structure and Content of Workshops

Eight workshops were facilitated starting in November 2010 and finishing in June 2011. These workshops (each of 2 hours duration) were designed to include:

a) Topics of strategic use for the carers (see Appendix 2 for draft programme). It was intended that the topics would be dovetailed to accommodate carer needs and requests.

b) Expert speakers to present and discuss with the carers specified / negotiated issues.

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The basic structure of the workshop included introductions and ground rules and then a short presentation followed by time for the carers to ask questions and share information. The last part of the session was for the carers to think about how they can use/apply session content with their loved ones. Carers could also use this opportunity to discuss their own experiences or ask specific questions. In practice, the two parts of the workshops merged with carers asking questions and relating it to their situation as the workshop progressed. Where pertinent, examples of carer generated issues have been included. For example,

**Carer example 1**

When we were discussing power, the guest facilitator referred to personal power. Immediately one of the carers mentioned her situation. Her husband had a mental illness and cardiac difficulties; his physician had prescribed medication for the cardiac problem without consulting the psychiatrist or the family. The carer was becoming utterly despondent about the situation as she felt impotent in challenging the doctor. The opportunity of raising and discussing the matter during the workshop empowered and emboldened her such that she felt ready to talk to the physician. She relayed to us at the next group meeting that she managed the discussion with the physician well and had a positive outcome.

The carers were not curbed or controlled when they asked questions or told their stories or started conversations with the facilitators as it worked very well. However, firm time keeping was essential as the sessions were limited to two hours with little flexibility beyond the planned ‘end-time’. Each workshop ended with an evaluation which the carers all completed without any reservations.

Participants were reimbursed reasonable travel costs. Many did not take up the offer either because they had freedom passes or already had travel tickets that could be used. One of the carers had to take two buses to attend the workshop and usually arrived rather breathless at the venue. It was suggested that if she was running late she could take a taxi to the group.

Five to six carers per workshop was the normal attendance. At the beginning of workshop 1 the carers completed the pre workshop questionnaire (Appendix 6) and at the end of workshop 8 they completed the post workshop questionnaire (Appendix 7). In June 2011 there was a recall workshop when we spent some time reflecting on our work and ended with a celebratory lunch. The celebratory lunch fulfilled two functions, a thank you to the carers and a symbolic ending to our work together.
In the first workshop the carers were asked about the type of issues that they wanted addressed in the workshops. Their wish list was central to editing the content of the subsequent workshops. This ensured that the carers were involved and gave them shared-ownership of the workshops. Giving the carers control facilitates collaboration and also models a way of working with professionals. It was also useful to be candid about what could be delivered and how this would affect them. Aspects of carer requests that overlapped with the family and carer events were omitted from the programme.

At the start of every workshop, carers were reminded about the ground rules. As there was a different expert facilitator for each workshop, the introductions component was repeated, with everyone saying their name and who they were caring for and their relationship to the loved one. Everyone including facilitators also wore a name label so that individuals could be referred to by name.

5.2 Workshop Management

The carers were informed about the Mary Seacole Award and the project at the outset. The Community Psychiatric Nurse (CPN) was introduced and her role was clarified as support for me as lead facilitator. It was agreed by the Education and Training Head of Department and project supervisors that it was important and best practice to have a second person in the group as a contingency arrangement in the event of any emergencies.

Initially it was envisaged that different colleagues would be available at the workshops. Instead I was very fortunate to have a CPN colleague who negotiated with her manager that she could attend all the workshops, thus becoming an integral member of the group. To begin with, her role was that of my personal assistant i.e. she helped with welcoming carers and hospitality, waited for the late comers and accompanied them to the room.

Prior to the first workshop, we had agreed that the CPN would sit a little outside the group; the rationale being that she was there to support me and I could call upon her services as required. Ten minutes into the first workshop the CPN was asked to join the group because the physical separation and observer role ascribed to her felt contrived and wasteful of her expertise. In hindsight it became clear that these tacit insights were derived from my reflection-in-action (Johns 2004); recognising these anomalies and permitting her inclusion necessitated a change in role to that of a participant-observer thus involving her fully in her professional capacity as a MH registrant.

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Table 5 provides an outline of the themed timetable and a brief summary of the content.

**Table 5. Timetable of workshops with brief summary of content**

<table>
<thead>
<tr>
<th>Workshop Topic/Theme</th>
<th>Facilitator</th>
<th>Summary of content</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Introduction</td>
<td>Esther Craddock</td>
<td>Welcome &amp; introduction. Confidentiality, support &amp; information pack Needs &amp; Expectations of carers</td>
</tr>
<tr>
<td>2. Identity</td>
<td>Service user consultant</td>
<td>Exploration of personal identity. Impact of mental illness, issues of stigma &amp; discrimination. Also looked at the need of a group name which was suggested by one of the carers after the session as we ran out of time</td>
</tr>
<tr>
<td>3. Boundaries</td>
<td>Cares of Life service lead</td>
<td>The need for boundaries and skills practice of saying 'no'; coping strategies</td>
</tr>
<tr>
<td>4. Recovery care approach</td>
<td>Learning &amp; Development Advisor</td>
<td>What it means for the service user and how carers can play their part</td>
</tr>
<tr>
<td>5. Conversation with a psychiatrist</td>
<td>Consultant Psychiatrist</td>
<td>Asked carers what they wanted him to talk about and allowed them to ask questions. Gave two clear messages that carers are the experts in knowing their relatives/loved ones and psychiatrists are human</td>
</tr>
<tr>
<td>6. Carer perspective</td>
<td>Carer</td>
<td>Gave a personal perspective and highlighted coping strategies. Addressed particularly forward planning i.e. what is going to happen when the carer is not there anymore?</td>
</tr>
<tr>
<td>7. Power</td>
<td>Service user consultant</td>
<td>Addressed the dynamics of power and how carers can claim aspects of power for themselves and use it constructively</td>
</tr>
<tr>
<td>8. Peer Support</td>
<td>Peer Support Lead</td>
<td>What it means and how it can work</td>
</tr>
<tr>
<td>End &amp; celebration</td>
<td>Esther Craddock</td>
<td>Reviewed our journey together and considered next steps</td>
</tr>
</tbody>
</table>

(5 weeks later)
The group did not stop for a formal break but replenished drinks when a natural break occurred in the sessions. After the first workshop the group actually stayed back to chat and talk to each other. Unfortunately as we finished at 5pm and as the training centre closed soon after we could not as a group linger too long after sessions. If I was busy attending to carers who had specific questions for me, the CPN assisted with undertaking other administrative tasks such as clearing up and collecting the workshop register and evaluations. At the end of each workshop the CPN and I undertook a brief evaluation to decide what had to be followed up particularly regarding specific information or any action points. For example, one carer wanted some specific information on a condition and any other support or information available in one of the Trust boroughs. The CPN brought in some leaflets from MIND and some borough specific literature. We agreed verbally on action points and followed up any outstanding issues by e-mail.

Confidentiality was an issue that needed clarification and exploration. It was discussed in detail in the first workshop using the Royal College of Psychiatrists’ guidance. During workshop 8 the issue of confidentiality re-emerged: this time the discussion was that perhaps participants could adopt pseudonyms in preference to using their own names. A number of the group members rather liked the idea. This is another consideration for future workshops.

The carer was the central focus of the workshops yet the carers needed to be reminded that these workshops were for them and it was their health and well being that was paramount. For example, when it seemed that the loved one was not making any progress or perhaps has had a relapse (two of the relatives were hospitalized) during the period of the workshops or when feelings were reaching a low ebb, the carers needed group reassurance (perhaps a virtual permission) that they should allow health professionals to take over the care of their relatives.

It was a hard lesson for the carers as they felt that they were responsible for the welfare of their loved one.

### Carer example 2

One of the female carers said that initially she did not think she had any needs. She felt her carer role was an extension of her natural spousal role in looking after her husband. The subsequent group discussion helped her identify that she was exhausted, had a poor sleeping pattern and was constantly worried. She had to be reminded that she needed a break sometimes so that she could re-charge her batteries in order to continue functioning.

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6. KEY FINDINGS

Data analyses point to six broad themes (see Table 6) and are presented as thus, to protect the confidentiality and anonymity of the carers. The data available is based on my reflections, clinical supervisions and 2 sets of pre and post workshop questionnaires. The questionnaires were analysed using survey software called SNAP\textsuperscript{3}.

Due to word limitations only some of the emergent themes are presented. These findings from phase one of the project will signpost and influence phase two and future workshops.

In the workshops I focused on their individual responses to what was happening to them and allowed the group to join in and comment. In this way the carers were able to share responses and receive affirmations e.g. ‘you are doing your best’. I was always made aware of their commitment to the relative. Carers were looking for ways to help their relative. It was apparent to me that some of them had evolved coping strategies from taking up running, practising yoga to helping others i.e. being an expert carer. These activities helped retain their identity and also role modelled to their loved one about keeping healthy.

Carers can become over involved and over protective of their relatives so it is essential that they learn to separate themselves from their adult relatives. The maintaining of boundaries was a hard learnt lesson. The temptation of letting the mental illness take over their lives was all evident. There was a need to build in carer resilience. Almost all carers indicated that they had to become introspective and find strength/support from within themselves. For those with strong spiritual beliefs, faith was cited as ‘helping them cope’. Sometimes in the discussions there was sadness expressed – see Carer example 3.

\textbf{Carer example 3:}

‘I had one year of my retirement before I had to start my caring role’. The discussion highlighted that this carer had missed out a status passage of being retired and all that the process of retirement entailed in terms of transitions, activities he may have taken up etc. He had not had much time to enjoy his retirement before being propelled into full time unpaid employment as a carer.

\textsuperscript{3}Survey software solutions offered by SNAP surveys used by clinical governance team.

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Another carer said that she did not expect gratitude or appreciation from her loved one and that helped her cope with her relative’s illness and behaviour. Hers was a particular difficult role as she felt her relative was alienated from her and blamed her for his illness and poor state of health.

Relationships with health care staff were explored. The group reflected that staff are cautious about their relationship with carers. The staff focus is on the service user and there is hesitancy in engaging with carers in case it jeopardises the staff-service user therapeutic alliance. Concerns of confidentiality are always cited as a stumbling block (see section 1.2). It is possible too that there is lack of time due to clinical demands on staff time. For staff to undertake work with carers it is likely that they will have to restructure their ways of working to free up time in order to progress this. Additionally, they would also need a targeted programme of inputs and invest time to develop their relationships with carers.
<table>
<thead>
<tr>
<th>Themes</th>
<th>Carer feelings, experience, thoughts</th>
<th>Group reflections</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not being listened to by health care professionals</td>
<td>Confusion that condition was not diagnosed or identified. Staff perceiving the behaviour of the loved one as deviant rather than symptoms of mental illness so delay in receiving treatment and care</td>
<td>Carers acknowledge their feelings and experience. They are the experts</td>
</tr>
<tr>
<td>Emotions</td>
<td>A recurring theme, sadness at loss and guilt e.g. ‘I live in a lovely home but my son doesn’t’</td>
<td>Emotions are normal and part of the process. Important to find allies who will listen –this points to need for peer support</td>
</tr>
<tr>
<td></td>
<td>Why me? Why my family?</td>
<td>To counter emotional responses there is need for appropriate relevant Information and health promotional literature</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Develop a personal resource file of what is there for the carer and service user</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Do not blame self</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Update carers on current literature re causes of mental illness</td>
</tr>
<tr>
<td>Things not going well—recognising deterioration/ crisis points</td>
<td>Hospitalization, exacerbation of illness</td>
<td>Carers knowing own limitations.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Letting go, Allowing professionals to take over. Support and looking at how carer is looking after self</td>
</tr>
<tr>
<td>Stigma and discrimination</td>
<td>Labelling of condition, how society saw the relative and the carer</td>
<td>Accepting and modelling behaviour to relative. Some carers found that the use of terms (e.g. psychological distress or even neurological dysfunction) helpful in managing how other people referred to them</td>
</tr>
<tr>
<td>Culture</td>
<td>Family orientation, have to look after relative, cultural norms</td>
<td>These cultural norms were affirmed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The model of showing that you care</td>
</tr>
<tr>
<td>Values and beliefs</td>
<td>Carers spoke of their faith in seeing them through the rough patches</td>
<td>Helped carers to see how they are aided in their caring role by their faith</td>
</tr>
</tbody>
</table>
In the first few workshops (particularly workshop 2 on identity) the discussion helped carers to recognise that they are more than ‘mere carers’ i.e. they actually maintained multiple roles. The carers remarked that professionals seem to only see them as carers and forget that individuals have other roles and responsibilities extending outside the home and family.

The part culture played on the carer role was frequently remarked on. In all cultures there are numerous variants of what is perceived as traditional carer dyads, i.e. those involving spousal dyads (usually wife caring for husband), parent- (adult) child dyads, and occasionally sibling dyads. The group discussed that even when it is culturally expected it does not have to become a duty. Alongside the carer role the normal carer-kin (service user) relationship needs to be maintained and nurtured e.g. expressing affection. Within the group some non-traditional carer roles were noted e.g. a son looking after his mother and a husband caring for his wife.

In other workshops the group explored communication strategies with a focus on avoiding arguments as it creates tension and gets them locked in an adversarial position. During a discussion on ‘recovery’ (workshop 4) it was acknowledged that it was better to shift the person along and allow s/he to find the change that they want. It was more important to show empathy rather than provide a solution (Slade 2009).

The impact on the family is huge and many spoke of the consequences for other members of the family. Stigma and fear manifested themselves within the family and many of the carers became protective of the service user. One mother remarked that her daughter moved out of the family home and had very little to do with her sibling (with mental illness). A number of them shared how the relationships with the wider family were affected by the mental illness. The group discussed such changes with compassion and tried to reflect on different perspectives (see Carer example 4)

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**Carer example 4**

In response to the carer who had remarked that her daughter had moved out of the family home and had very little to do with her sibling (with mental illness), other carers suggested that ‘Perhaps it was too painful for the sister to see her brother so ill’. The discussion facilitated a shift from ‘rejecting her sibling’ to ‘a coping mechanism to deal with her brother’s mental illness’

A number of carers had devised alternative ways of talking about their loved ones to other people e.g. they found that by avoiding mentioning ‘mental illness’ they received more favourable responses from others.
Carers need time to discuss their issues. Much as they had concerns about their relatives there is a great compulsion to share and talk about their journey. Sometimes the same narratives were recounted. This is an indication that there are unmet needs and feelings of not being heard for carers.

In workshop 6, the facilitator raised a sensitive yet important issue of after-care by asking the carers if they,

a) “had prepared wills,

b) had considered who was going to take over once they died or had to give up the role, and

c) had considered advance directives?”

Although these were difficult discussions the issues needed addressing. The group agreed that these discussions required the inclusion and involvement of the service user so that plans could be made. Carer examples 5 and 6 demonstrate the difference in the thinking and approach of 2 carers.

**Carer example 5**

One of the male carers stated that he had agreed and initiated a plan of action which in time would mean that his son could step into the carer role for his mother. Their first steps towards this goal were to gradually coach his son in monitoring the mother’s medication. This approach incorporated two strategies: that of a structured preparation for the eventuality of after-care and some low level ongoing support.

**Carer example 6**

The focussed discussion about the necessity and importance of planning after-care provided another carer the opportunity to verbalise her fears. She spoke (perhaps for the first time) about being fearful of the aftermath of her death. Her fear was solely about leaving her son because it raised the question of who would look after him.

7. DISCUSSION

A recall workshop was designed as a means of celebrating the conclusion of Phase 1 of the project. Participant –carers, facilitators and contributing guest experts were in attendance. One of the facilitators said she was so pleased to see the carers chatting together and laughing. She felt that it was cathartic and symbolic of what they had achieved in the group. Carers openly
acknowledged learning from each other and were very appreciative of the space and time created and offered to them. These ten carers were experienced in their carer-role; many of them had been functioning as such for 5 years or more, yet they still valued being together and listening to each other. From the carers’ point of view the project was a success; their evaluative scoring was consistently excellent. During the course of the workshops, it was noted that the carers responded to the facilitators very warmly e.g., after workshop 6 several of the female carers hugged the facilitator – a carer herself. The hugging was a clear demonstration of their connection with each other, empathy and a shared lived experience as carers.

For example: In the process of evaluating Phase 1, a number of outcomes were identified: five examples are cited below:

<table>
<thead>
<tr>
<th>Outcome 1: A carer’s personal empowerment</th>
</tr>
</thead>
<tbody>
<tr>
<td>The growth in confidence following a specific topic group discussion had enabled at least one carer to address a matter with her husband’s physician. This was a marked change from the individual feeling marginalised by the physician to taking action.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome 2: Carers using skills in assessing excellence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two of the carers acknowledged their confidence and skills as expert carers and identified that they had skills to serve on the Trust committee for nursing awards. Their role will be to assess the suitability of the nominations for the awards.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome 3: Forging partnerships within organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>The purposive inclusion of the CPN and guest-expert-facilitators in the delivery of the workshops has been invaluable in demonstrating the value of partnership working within the same service.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome 4: Remaining practice and carer focussed</th>
</tr>
</thead>
<tbody>
<tr>
<td>The process of a dual system of clinical supervision ensured that the project remained embedded in practice and carer focussed.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome 5: Becoming a champion for carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>There has been a marked shift in my professional interest and engagement in the carer agenda. I have become a champion for carers and can advocate for them in my training and educative role. My continuing involvement with the family and carers’ events together.</td>
</tr>
</tbody>
</table>
7.1 Project Governance incorporating Post Workshop Supervision

In addition to the regular supervision received from the two MSA project supervisors, three other aspects of either direct or remote supervision were incorporated. These were:

- Formal clinical supervision
- Informal clinical supervision
- Information Governance team requirements. See Table 7 for details

Table 7. Project governance

<table>
<thead>
<tr>
<th>Strands of Project Governance</th>
<th>Who with</th>
<th>Focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Project supervision</td>
<td>MSA supervisors</td>
<td>Academic and professional issues associated with executing the project.</td>
</tr>
<tr>
<td>Formal clinical supervision</td>
<td>Clinical supervisor</td>
<td>Foci were negotiated &amp; linked to the happenings of the preceding workshop. (See 7.2)</td>
</tr>
<tr>
<td>Informal clinical supervision</td>
<td>Community psychiatric nurse</td>
<td>Assisted with identifying issues that I wished to address at professorial supervision; action points to address for subsequent workshops; areas that needed specific follow up and any amendments to the content or briefings to next guest facilitator.</td>
</tr>
<tr>
<td>Trust Information Governance</td>
<td>Pre and post project with Information Governance Team (IGT)</td>
<td>Compliancy with Trust policy. Meeting the five conditions imposed. Lodging final report with IGT.</td>
</tr>
</tbody>
</table>

7.2 Formal Clinical Supervision

Prior to proceeding to the delivery stage of this project the academic supervisors identified that it was essential for me to receive clinical supervision as I was working with potentially vulnerable individuals. This was subsequently negotiated with an emeritus professor in mental health and learning disability who had a special interest regarding partnership work with service users and carers. Professorial supervision was via face to face
meetings at regular intervals and telephone supervision after each group. Clinical supervision foci were negotiated: in essence these were linked to the happenings of the preceding workshop. These opportunities were useful in allowing me to discuss issues that I wished to explore further or wished to identify strategies when dealing with specific concerns. In the course of these confidential discussions, care was taken to ensure that participant anonymity was not breached. Regular and timely supervisions were instrumental in identifying patterns of emergent themes from group sessions. An added bonus was the identification of salient issues such as service users’ sexuality which I had not previously considered.

An example of an emergent theme was group engagement of the carers particularly addressing the needs of the reticent carer. I had been using open questions by asking carers e.g. “what is happening?”; “What do you think will be helpful?” – yet did not always manage to improve the level of engagement. Supervision assisted me to consider carers’ behaviours as an indicator of what was happening at home. It enabled me to understand and accept that some of the carers were able to articulate their emotions and note what was happening while others were quieter and had to be drawn out more.

During supervision I also explored the best way of managing the key question posed by carer “Am I doing this right?” Clearly, it would be unethical to reassure individuals with platitudes as each family is different and there are no magic formula answers to their question “Am I doing this right?” By reflecting on the workshop discussion, it became evident that the question itself was multifaceted, being dependent on the role or concern the questioner posed the question about. It could be responded to as a parent / spouse / sibling / carer / etc. The workshop discussion stance was that of the carer ‘showing s/he carer’. The majority of the group had concurred that ‘doing the right thing’ was about the carer being constant, outwardly affectionate and show that they care. This tenet did not sit comfortably for those carers for whom overt demonstrations of affection were not the cultural or family norm. The group quickly formulated an alternative suggestion: that of spending time with the individual in ways that were not associated with hospital e.g. accompanying to appointments but going for walks together, sharing a meal and just chatting. A simplistic change in focus from ‘ill-health duets’ to activities of daily living that people can engage in at a tacit level without having to construct them as ‘therapeutic inputs’.

The report has been read by the clinical supervisor who has been able to authenticate its reflective aspects.
8. EVALUATION

Reviewing the initial proposal of the project there are definite positive outcomes for the group in terms of enhancing their carer role, working in partnership with health care professionals and empowering their advocacy role (see sections 6 and 7). The evaluations from each of the workshops were consistently ‘excellent’ but the pre and post questionnaires did not identify significant shifts of thinking and change for the carers. It is possible that this outcome is associated with:

a) the group being substantively experienced as carers

b) the questionnaire design being too simplistic and therefore did not capture the changes in situ

c) the timing of the post-questionnaire at the end of workshop 8 provided a limited time for its completion thereby affecting the responses. It is possible that a delayed period of 3 months may have been more appropriate

However, the carers valued and gained from the workshops and identified very positive outcomes for themselves (see Appendix 8 for more detail).

8.1 Dissemination and Celebration

To date the initial project findings have been disseminated within the Trust and other opportunities are being explored.

8.1.1 Dissemination within the Trust:

- The Trust celebrated excellence in nursing with the Daisy Award in June 2011. I had the opportunity of presenting the Mary Seacole project as part of the programme on the day.

- On 17 June 2011 I presented my work at a Listening Event (see introduction) organised by the Trust for carers and staff as part of the broader activities that the Trust is engaged in. The project innovation was very well received and made all the more special to have three of the carers from the workshops present at the event.

- The success of this project has ensured my continuing involvement at the Family and Carers’ events hosted by the Service User involvement in Training and Education team.
• The project is regularly discussed as an innovative practice development in the course of training delivery and at employee induction sessions.

8.1.2 Planned Dissemination:

A number of strands are being explored concurrently and or being negotiated. These include:

• Follow up article in the Trust’s electronic and published newsletter
• A paper aimed at mental health practitioners is being prepared for publication
• Participate jointly (with fellow awardees) at a symposium at the RCN Research Conference 2012
• Presentations to the various carers’ groups in the Trust & The Equality & Human Rights Group
• This report will be shared with the Trust Carers’ Steering Group and the facilitators and participant carers

9. NEXT STEPS

There is much scope for partnership working within the Trust and in the four boroughs to further develop or initiate carer-focused services. For example, SUITE is exploring a project to offer carers training programmes on similar lines as this project. Thus, there is potential for learning from this project to inform newer initiatives. Having successfully completed Phase 1 of the two phase MSA project I shall be concentrating on:

a) The training of peer carer supporters for Phase 2 of the project
b) Repeating Phase 1 with another group of carers

On completion of Phase 2 a ‘whole project’ evaluation can be undertaken to inform the preparation of standardised education materials for both phases of the project. These materials can be made available to other interested carers groups.
10. CONCLUSION

Phase 1 of this project is the starter component of a much larger project. Both the literature and carers experience (gleaned in the course of this work) indicate that there is an acute need to provide support, skills, education and information and coping strategies to the silent army of carers. This report offers an account of one pragmatic eclectic approach developed and implemented to address the gap identified. A tailored approach offering carers time to be part of a group and access to information that hitherto they had not been in receipt of was evaluated by the ten participants as a success. The group came together over eight months, got to know each others’ histories and challenges faced and were supportive of each other. The carer examples capture some of the positive project outcomes. Initiatives designed to provide both support and education to carers require vision, leadership and an investment of resources. While it is acknowledged that the findings from this group were specific to them, participant evaluations and facilitator insights indicate that the participants benefited from the inputs as well as the reciprocity of their peers.

For the peer support model of carer development to be taken forward requires a robust infrastructure and careful preparation. As an educationalist, I acknowledge that the best ways to facilitate carer preparation for their complex role is far more obscure because carers are individuals at varying stages of their caring journey and have different needs and expectations. Furthermore, any programmes offered are likely to need modification to suit the carers’ preferred learning styles, expressed needs and individual resources.
11. References


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Hoult J (1988) Community care of the acutely mentally ill *British Journal of Psychiatry* Vol 149 (2) pg 137-144


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Rethink (2003) **Who Cares?** (carers’ survey) Rethink, Surrey


Slade M (2009) **100 ways to Aid Recovery** Rethink. London


The Princess Royal Trust for Carers and The National Mental Health Development Unit (2010) **The Triangle of Care** The Princess Royal Trust for Carers and The Acute Care Declaration Consortium


Mary Seacole Leadership Awards 2010
for Nurses, Midwives and Health Visitors

Funded by the Department of Health and NHS Employers and awarded in association with Royal College of Midwives, Royal College of Nursing, Unison, Unite CPHVA

The Department of Health and NHS Employers are funding these annual awards for nurses, midwives and health visitors in England to honour Mary Seacole’s name and acknowledge her achievements.

Awards Available

The Mary Seacole Leadership Awards are worth up to £12,500 each and emphasise Mary Seacole’s pioneering role in leadership by providing the opportunity to:

- enhance personal effectiveness, leadership style, communication skills and the ability to influence
- select and concentrate on a specific health care project
- gain confidence in leading a project which has the potential to achieve a high national profile
- develop research and project management skills
- promote change and manage the transition from operational to strategic management

The award scheme also provides Mary Seacole Development Awards of up to £6,250 each to enable nurses, midwives and health visitors to make positive and lasting contributions that promote high quality patient/client-focused care.
APPENDIX 2: Draft programme of workshops constructed at project outline stage.
The comments column provides a summary of subsequent amendments made to ensure that duplication was avoided.

<table>
<thead>
<tr>
<th>Topic (each workshop is of 2 hours duration)</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working with carers as experts (part 1)</td>
<td>Integral to all sessions</td>
</tr>
<tr>
<td>Inclusion in assessments &amp; the Care Programme Approach (CPA)</td>
<td>Addressed in workshop 4</td>
</tr>
<tr>
<td>Carers in being involved in discharge planning</td>
<td>Addressed in workshop 6</td>
</tr>
</tbody>
</table>

**Service**
- The use of more traditional treatments
- Mental health promotion
- Evidence and research (What works? / What doesn’t
- Managing the system
- Negotiating, when you feel you are not being heard
- Being an expert in your “child, sibling etc, exerting the power of your knowledge” (part 2)
- Stigma, grieving and acceptance of ill health, as well as moving on to celebrating difference

Addressed in workshops 2, 4, 5, 6, 7
Also information leaflets relating to specific conditions & relevant websites were given

**Carer specific**
- Impact on individual/family
- Carers’ well being
- Support networks
- Partnership system
- Buddying
- Looking after self
- Keeping healthy- physical/ stress/ depression and ill health in carers

Addressed in all workshops but specifically in 6 & 8

**Condition**
- Mental illness – signs and symptoms
- Mental health awareness
- Clinical care pathways

These were covered in the Family & Carer events that started in September 2010. These were planned but omitted as the carers could access the information in the family and carers’ events.
Leaflets and relevant websites were also given.

**System**
- How to get help
- Sources of help
- Confidentiality

**Practical help**
- Support
- Form filling for benefits and entitlements
- Ways of negotiating with the health professionals
**APPENDIX 3**

**Empowering family and carer induction event**

Quarterly events with a key theme presentation and taster carer session facilitated by MSA awardee

<table>
<thead>
<tr>
<th>Who ran the Surgery?</th>
<th>Content</th>
<th>How did they do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dept for Work &amp; Pensions</td>
<td>Advice and guidance about benefits, disability allowance &amp; pensions</td>
<td>Answer questions, give leaflets and help to complete forms</td>
</tr>
<tr>
<td>Patient information</td>
<td>Leaflets from within the Trust and also from external agencies like MIND on specific mental health conditions but also many health promotion literature e.g. health eating; managing stress</td>
<td>Answer questions, give leaflets.</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>Advice on efficacy, dosage, storage, side effects and any other drug information</td>
<td>Sheet information on specific medicines. Answer questions</td>
</tr>
</tbody>
</table>
| Southwark Vocational service (At each borough we had different well being teams or the Voluntary Sector addressing similar services) | Mission to help *people who want work, now or in the future*  
Help with CVs, job applications and advice education & training | Advice for carers to take to their loved ones relating to employment paid and voluntary |
| Welfare Dept | Advocacy and advice on benefit entitlement and welfare rights | Information leaflets, help with making claims for relatives and carers |

**Carer taster session (20 minutes) with a small group of 6-8 carers. After ground rules and introductions, the group addressed coping strategies and carer well being.**

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Esther Craddock_Mary Seacole Leadership Award 2010
# Enhancing the Mental Health Carers’ Contribution to Healing

**Who can attend**: anyone living with or caring for a relative (parent, partner or sibling) with mental illness

**Workshop Dates**: 25 Nov; 9 Dec; other dates will be given on attendance of workshop 1

## Peer Support Workshops

- We know that mental illness symptoms have a tremendous impact on carers.
- We know that carers learn and benefit from talking and being with other carers.
- We know that by supporting and helping carers we can improve the care of your loved one.

## Workshop Information:

- You are invited to attend a 2 hour workshop held every month over 8 months (total of 8 workshops). You can help to design the content of some of the workshops.
- You will be an involved participant – learning and practising skills.
- You can find out about support for yourself using the peer support model.
- You will be part of an educational programme.

## Facilitator:

**Esther Craddock**  
(Education and Training Advisor)

## Venue

**Southwark Training Centre**  
Maudsley Hosp  
Denmark Hill

For further information please contact:  
esther.craddock@slam.nhs.uk  
020 3228 5320
APPENDIX 5

A statement made by carer participant who gave consent for his name to be used.

A summary of a carer’s life by A Aumjaud.

First and foremost we are not alone. There are millions of us across the globe with different tasks to fulfil and to cater for. Don’t be ashamed to open up your feelings to others. Be honest to yourself, enthusiastic and bold. Look after yourself so you will give your maximum to the person you look after and that will enhance the quality of life emotionally, physically, socially, spiritually, psychologically.

Having a caring attitude is a great asset because it makes your task and role easier and very rewarding. Don’t ring-fence yourself – seek help from the carer group. Access the facilities that exist in the local borough – GP, professionals who are quite willing to help, assist and will give the right support depending on your individual needs.

These are my experiences I have encountered and am delighted to share with you all. Never forget the Creator at anytime. You are not alone. God bless you and have mercy on us.
Dear Carer

Thank you very much for taking the time to complete this questionnaire. We want to use your responses and evaluation to improve the services that we provide for carers and families. The questionnaire is completed at two points; today at the start of Workshop 1 and at the end of Workshop 8.

Your answers will be treated in confidence. When the results are presented in a summary report no individual or their responses will be identified.

If you have any queries please speak to Esther Craddock. She will be available on the day and will be happy to help you.

Thank you for attending the workshop.

Pre-questionnaire
Carers’ Workshop 1

Please complete the survey for your most current experience of the workshop.

Please tick the score which best matches your personal view about your role as a carer and your recent experience as a carer. Read each question carefully but give your immediate response.

5 = very confident – definitely yes
4 = confident
3 = think I know but not always sure
2 = need more information – not much
1 = not confident – not at all
1. How well do you understand your relative’s / loved one’s mental illness?

5------------4--------3----------2--------------1
Very confident not confident

Your comments:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

2. How much do you understand about the care (provided by the health care worker/ service) of your relative / loved one?

5------------4--------3----------2--------------1
Very confident not confident

Your comments:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

3. How confident do you feel about speaking to a care professional on behalf of your relative/ loved one?

5------------4--------3----------2--------------1
Very confident not confident

Your comments:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

4. How confident do you feel that you can help your relative/loved one to make an informed choice /decision about changes in their care?

5 ------------4--------3----------2--------------1
Very confident not confident
5. Do you feel listened to by the staff caring for your relative / loved one?

5 ------------4------------3-----------2------------1
Definitely                                                       Not at all

Your comments:
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
8. How confident do you feel about supporting another carer if you are given support and training?

5-------------4-------------3-------------2--------------1
Very confident                         not confident

Your comments:

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

9. If you will be willing to talk and support another carer, what help or support will you need?

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

Thank you for your time and participation
Dear Carer

Thank you very much for taking the time to complete this questionnaire. We want to use your responses and evaluation to improve the services that we provide for carers and families. The questionnaire is completed at two points: at the start of Workshop 1 and today at the end of Workshop 8.

Your answers will be treated in confidence. When the results are presented in a summary report no individual or their responses will be identified.

If you have any queries please speak to Esther Craddock. She will be available on the day and will be happy to help you.

Thank you for attending the workshop.

Post-questionnaire
Carers’ Workshop 8

Please complete the survey for your most current experience of the workshop.

Please tick the score which best matches your personal view about your role as a carer and your recent experience as a carer. Read each question carefully but give your immediate response.

5 = very confident – definitely yes
4 = confident
3 = think I know but not always sure
2 = need more information – not much
1 = not confident – not at all
1. How well do you understand your relative’s / loved one’s mental illness?

5-----------------4-------------3-------------2--------------1
Very confident                                      not confident

Your comments:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

2. How much do you understand about the care (provided by the health care worker/ service) of your relative / loved one?

5-----------------4-------------3-------------2--------------1
Very confident                                      not confident

Your comments:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

3. How confident do you feel about speaking to a care professional on behalf of your relative/ loved one?

5-----------------4-------------3-------------2--------------1
Very confident                                      not confident

Your comments:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

4. How confident do you feel that you can help your relative/loved one to make an informed choice /decision about changes in their care?

5-----------------4-------------3-------------2--------------1
Very confident                                      not confident
5. Do you feel listened to by the staff caring for your relative / loved one?

5 ------------4------------3-----------2------------1
Definitely Not at all

Your comments:
_________________________________________________
_________________________________________________
_________________________________________________

6. Do you feel involved in the care of your relative / loved one?

5 ------------4------------3-----------2------------1
Definitely Not at all

Your comments:
_________________________________________________
_________________________________________________
_________________________________________________

These questions are about helping another carer in a similar position to you and provided that you are given support and training.

7. How confident do you feel about talking to another carer about mental illness?

5 ------------4------------3-----------2------------1
Very confident not confident

Your comments:
_________________________________________________
_________________________________________________
_________________________________________________

Esther Craddock_Mary Seacole Leadership Award 2010
8. How confident do you feel about supporting another carer if you are given support and training?

5-------------4-------------3-------------2--------------1
Very confident                                    not confident

Your comments:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

9. If you will be willing to talk and support another carer, what help or support will you need?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Thank you for your time and participation
Data and Analyses of Workshop Evaluations and Pre and Post Workshop Questionnaires

Workshop Evaluations by Carers

All carers who attended the workshops completed the forms. Total number of carers = 10. The attendance per workshop ranged from 5-7 carers.

a) The written evaluation forms were completed immediately after each workshop. The key issues asked were:
   1. Meeting expectations?
   2. Facilitator knowledge?
   3. Comprehension?
   4. What was useful? What would you take away?
   5. What can be improved?

b) The Likert type score was 1 = inadequate to 5 = excellent.

The overall scoring for “How well did the session meet individual expectations?” was consistently high, scoring 4 and 5 on the Likert scale. Some of the comments from “What would you take away?” and “What could be improved?” are tabulated below:

<table>
<thead>
<tr>
<th>What would you take away?</th>
<th>What could be improved?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge /handouts</td>
<td>More time for the sessions – this comment was frequently repeated</td>
</tr>
<tr>
<td>Greater understanding of (here carers listed the specific subject e.g. confidentiality)</td>
<td>More carers (in group)</td>
</tr>
<tr>
<td>Useful tips, e.g. ways of maintaining boundaries</td>
<td>Too early to comment</td>
</tr>
<tr>
<td>Where to find information/learning about services/resources</td>
<td>Nothing</td>
</tr>
<tr>
<td>Feel more positive /feel better</td>
<td>Another session with psychiatrist</td>
</tr>
<tr>
<td>Feel more confident</td>
<td>More similar sessions</td>
</tr>
<tr>
<td>Not to blame self</td>
<td>Not sure</td>
</tr>
</tbody>
</table>

Pre and post Questionnaires (see Appendices 5 & 6)

All 10 carers completed the written pre questionnaires and 9 carers completed the post questionnaires. The scoring system was Likert style score with 1 = not confident to 5 = very confident.

There are no significant differences in the scoring of the questionnaires of the majority of the items included. The exceptions are Questions 1 & 8 which show a positive shift (tabulated below). As noted previously this group of carers can be described as experienced: of the ten carers, five have been in the carer role for more than 5 years and at least 2 of them for more than a decade.
<table>
<thead>
<tr>
<th>Question</th>
<th>Pre-workshop</th>
<th>Post workshop</th>
</tr>
</thead>
<tbody>
<tr>
<td>How well do you understand your relative's mental illness</td>
<td>1 carer scored it as “very confident” = 5</td>
<td>3 carers scored “very confident” = score 5</td>
</tr>
<tr>
<td></td>
<td>5 scored 4</td>
<td>2 scored 4</td>
</tr>
<tr>
<td></td>
<td>3 scored 3</td>
<td>3 scored 3</td>
</tr>
<tr>
<td></td>
<td>1 scored 2</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How confident do you feel about supporting another carer if you are</td>
<td>3 carers scored it as “very confident” = 5</td>
<td>5 scored it “very confident” = score 5</td>
</tr>
<tr>
<td>given support and training</td>
<td>5 scored 4</td>
<td>2 scored 4</td>
</tr>
<tr>
<td></td>
<td>1 scored 2</td>
<td>1 scored 1</td>
</tr>
<tr>
<td></td>
<td>1 scored 1</td>
<td></td>
</tr>
</tbody>
</table>