



This edition of the newsletter is published to coincide with our conference 'Working With Families – Developing Caring Partnerships' being held in Stratford-Upon-Avon on 19–20 March. I have been really impressed this time around by the range of topics that people want to present on – it is heartening to see the different ways in which family work is being developed.

We have presentations on family work in a range of functional teams, several papers on issues relating to the needs of children and young carers, and a variety of presentations on different ways of offering support to carers. This time around, we also have new themes in our conference such as caring for older adults, and the needs of gay and lesbian carers. Another really positive development is that in keeping with the theme of the conference, several presentations are being delivered jointly by professionals and carers.

We have been fortunate in obtaining funds through the Care Services Improvement Partnership (CSIP) to support the attendance of carers and service users at the conference. It is so important to have this representation, and I am extremely grateful to the eight Regional Development Centre Directors who have all supported places. Thanks also to the Board of Birmingham and Solihull Mental Health Trust for approving Trust Charitable funds to enable carers and service users from Birmingham and Solihull to attend. Unfortunately, many professionals have been unable to obtain funding to attend the conference. I have been really struck by how tight NHS budgets in the UK are at the moment, and as always, training and development budgets are the first to be cut. I am particularly saddened that many of the trainers/supervisors who have been committed to the Meriden Programme for the past nine years have not been able to attend. We need to reflect on how to maintain the commitment, enthusiasm and new learning of committed and dedicated staff in the current climate.

In this newsletter, as usual, there are several interesting articles and reviews describing innovative work in

relation to developing services for families – plenty of food for thought. Two of the articles discuss carer support groups. Mandy Reed and Eric Davis describe how support groups can be developed in early intervention services, as well as other ways in which carers can be actively involved in services. This article again highlights the need for carers to have a forum where they can discuss their concerns. It also demonstrates very well that if carers are provided with the opportunity to come together, they can develop their own support systems once the formal group meetings finish. This has been my experience in running several support groups in the past. Paula Conneely writes about innovative training that has just taken place in Birmingham where groups of professionals and carers have been trained together to deliver support services to carers from Black and Minority Ethnic groups. It will be exciting to see how this rolls out over the coming year. In the same vein, Eve Thompson has done a detailed review of a book that has recently been translated into English on multi-family support groups and their benefits.

The article by Martin Atchison on issues for carers of those with personality disorders makes it clear that this is one of the groups of families that have been neglected to date in terms of services. Because people with personality disorders have sometimes been excluded from mental health services, the needs of their families have not always been recognised. This is an area that needs a lot more attention. Similarly, Lindsay Rigby highlights gaps in our knowledge in relation to how families perceive services they receive from home treatment teams.

There is plenty of food for thought in Peter McKenzie's article on recovery and hope, and how carers perceive these concepts. There is also an interesting review of Mueser and Gingerich's book for families dealing with schizophrenia. So hopefully, there is lots for everyone in this edition – as always, happy reading.

Exploring the Recovery Vision and its Relevance for Carer families

In this article I begin with the hypothesis that carers and families supporting someone with a mental illness have limited knowledge and exposure to the recovery vision. I would like to frame my contribution in terms of a preliminary set of critical explorations drawn from extensive discussions and the stories from carers, my clinical work as a family therapist and my position as a mental health Carer Academic in Victoria, Australia. I hope these explorations will provide an impetus and some points of entry into the recovery vision and its relevance for families living with mental illness.

The consumer advocate, Patricia Deegan, speaks about her vision of recovery using the metaphor of the sea rose which she describes growing out of the beach near her home. It seeks

"...a place to be rooted. A good soil to cling to and to be nurtured by. A home soil that could sustain it even in driving rains and tormenting winds... It teaches us that hope can grow in nurturing environments that allow one to become rooted and secure" (Deegan 1996: 1-2).

I believe that Deegan's vision resonates strongly with carers' aspirations and hopes in terms of family recovery. For many carers, this 'place to be rooted', 'a good soil to cling to and be nurtured by', 'a home soil that could sustain', is the environment that they work and struggle to recreate.

Family relationships and recovery

The challenge of understanding the issues for families living with mental illness adds a whole range of complexity to taken for granted ideas about families and relationships. In one study the author offers this observation:

The attachment and commitment to their relatives existing alongside the grief, anger and disappointment... seemed often to be something that simply could not be apprehended by mainstream models of contemporary kinship that emphasized the rational values of reciprocity, or obligation (Jones 2002: 155).

Another author suggests that:

Since it is family members whose emotional lives and fortunes

are most intimately entwined with those of the individual patient, family members are most vitally affected by that person's potential for recovery (Lefley 1997: 210).

Recovery's challenges and shared promise

Although recovery may represent a possible terrain of mutual benefit and shared vision of hope for both consumers and families, it is not entered into or is rarely considered in carer/family discourse in any direct or meaningful way. Its meanings and potential are therefore left unexplored in terms of family experience and carer role. In the sphere of clinical care and discourse, it is illness talk that represents the dominate paradigm, often at the expense of an opening to recovery talk. Finally, I propose that the recovery vision, although unnamed, is meaningful and relevant for the families' and carers' holding of hope and the shared promise it imagines and enables.

The Politics of Recovery

It has been widely acknowledged that recovery has been a vital aspect in the development of the consumer movement. It has encouraged a position which puts a priority on self-empowerment and 'self-rehabilitation' (Deegan, 1988). At the same time, in challenging the obstacles to the empowerment of consumers, this position can also critique families and mental health services as restricting the process of recovery. According to one researcher, 'Many consumers view their helper, whether treatment staff or families inadvertently reinforcing a message of weakness and need [or dependency]' (Campbell quoted in Lefley, 1997: 214). I think that this demonstrates that we need to better understand consumer-family relationships and according to Lefley 'the perceived role of families in facilitating or impeding the recovery momentum from the vantage points of the various parties' (1997: 210).

The individualised vision of recovery with its focus on personal empowerment and self-determination can also seem alienating of carers/families whose goals range from support to protection, as it promotes a position that could read, rightly or wrongly, of not including carers/families input-support or family recovery. The notion of agency implied in this conception of recovery also suggests a particularly western notion of the individual self as separate and independent. It could be argued that this construction of recovery seems to play down recognition of the individual as a social being who is significantly shaped by familial and kinship relations (see also Lefley, 1997: 218). I wonder

how recovery might be understood from an indigenous Australian or other minority cultural perspectives where – at least ideally – belonging, both communally and familially are aspired to.

On the other hand, consumers I have spoken to about recovery often acknowledge that carers play a vital role of support in their recovery. Yet there has been little attempt by the consumer and carer movements or the mental health service sector in Australia to articulate and educate about recovery in terms of carer/family experience and the role they could play.

Illness talk - Carers

The discourse around illness plays an important part for families living with mental illness as the struggle to understand what is happening often dominates their lives. From this perspective, illness talk for family carers facilitates the containment of uncertainty by naming and giving description and meaning to what seems unknowable, frightening and alien. It can provide a tenuous foothold to what is sometimes a very threatening and disturbing situation. Illness talk as a form of defence continually prepares the family for the worst by encouraging them not to raise their hopes too high, bracing them for the effects of trauma and loss that accompanies the next episode.

Paradoxically, illness talk can also contribute to a kind of blindness to the possibilities of recovery; often over-determining the carer role at the same time. The relationship between carers and their family member can become fixated or frozen in illness talk. Carers have often described to me their experience and constant fear of the illness and its ability to intrude, alienate and disconnect them from their family member. Even more significantly, the impact of illness continues to haunt the carer experience in times of wellness. According to one carer, 'it lurks in the bushes, so to speak, ready to stalk and strike at any time if we let down our guard'. This over-determining of illness talk imposes on the carer experience a psychology of vigilance and defence, which promotes a sense of avoidance or reluctance to talk about the possibility of recovery. Talk of moving towards recovery may also simulate fears of placing too much pressure on, or over-burdening, the family member. This may in turn trigger for families the possibility of relapse and a return of powerlessness.

Illness Talk - Clinical

If we acknowledge that clinical services are a powerful lens that shapes the way carers conceptualise and understand their family member and the illness that surrounds them, then the clinical context and discourse focusing on illness is an arena of considerable influence on the carer experience and role. Particularly at the earlier stages of the carer journey, illness talk is an important explanatory discourse that informs and supports the carer experience.

At other stages of the carer journey when developing a context for supporting recovery may be appropriate, access to the notion of recovery through contact with mental health clinical services is often limited. With the focus on triggers, symptoms and compliance issues, illness talk in this context may encourage carers and families to be in a constant state of alertness, both for the illness and its management. From a strictly clinical perspective, recovery may simply mean that the medication is working. According to David Castle of the Mental Health Research Institute, seeing the positive symptoms of psychosis as 'the gold standard for recovery, certainly in terms of pharmaceutical-sponsored medication trials' presents a problem.

'It is arguably the 'negative symptoms' and 'cognitive deficits' which are actually more disabling and arguably more important in terms of functional improvement' (Castle, 2003: 41). It could be also argued that in clinical contexts where carers find their lived experience and knowledge not significantly acknowledged, that even if recovery talk is introduced it could be couched in notions of the 'individual' and 'independence' which are often housed in the dictates of confidentiality. This can be read by carers as a sign of their further disempowerment in the process of support.

Psychosocial Rehabilitation

The notion of recovery seems more located in the culture and practices of psychiatric disability rehabilitation and support services. It is here also that the lived experience and day-to-day knowledge of carers/families resonates most strongly with the recovery values of this type of support. The recognition by consumers, carers and psychosocial rehabilitation support practice of the necessity to work with the often enduring and disabling impacts of negative symptoms, I argue, challenges the dominance of illness talk and crisis driven responses. This shared recognition opens the possibilities of collaborations that include carer families in the recovery vision and practices. But again, because of carers' limited engagement with and involvement in these type of services, the pooling of resources and mutual support for recovery is often left unexplored.

A Brief Ethnography of Carer Family Recovery

A few years ago I was invited to a carer support group meeting where I screened and facilitated a discussion of the 'F Word' video (produced by the Bouverie Centre).¹ The video portrays a number of consumers' sharing their perspectives about the involvement of families around their illness. The notion of recovery was introduced into our discussion when one of the carers spoke about how they were particularly struck when a consumer had said that his illness represented only 5% of him. This suggested to the carer that 95% was left to work towards recovery. This opened up our conversation as to what the notion of recovery may mean for carers and families.

¹ The 'F' Word in this context stands for 'Family'

One carer reported that for them, recovery means the 'holding of hope' on behalf of the family member, particularly at times when they are unwell. Contained in the 'holding of hope' was the wish by the carer that their family member will be able to be 'involved', 'contribute' and 'grow', even with the constraints of the illness. They also saw themselves becoming a reminder of this hope and the support of its enactment when the family member was well.

Another carer at the meeting spoke about how sometimes, carers find it hard to know when the family member is ready or 'able to cope and it is OK to pass the responsibility for the holding of hope back' to the family member. They suggested that it may be something that they and their family member need to learn how to do. Other carers argued that although some family members may be able to begin the enactment of recovery, which according to Lefley may entail 'acceptance of disability, taking responsibility, developing hope, or even effectively utilizing support' (Lefley, 1998: 216), for others this may be too overwhelming, particularly where there is a 'lack of insight'.

One carer believed that 'sometimes a lot of work may need to have happened for this to work'. Another carer then pointed out that an important way of understanding this for families is to recognise 'where you are on the journey of recovery... This may mean that a first step in the family's recovery is about coming to terms with your loss and grief (see Young, Bailey and Rycroft, 2004). In responding to this, another carer said that she identified with the idea that families caring for someone with a mental illness often experience significant trauma themselves (see Young, 2002). Here also, according to the carers, deep-seated fears and vulnerabilities can be continually awakened when you are intimately exposed to the family member's experiencing mental illness.

As the discussion continued, there were suggestions that further along on the journey there may be a need to accommodate the changes and challenges through the emergence and recognition of new forms of identity and relationship between family members. At yet another stage, it may mean the possibility of recognising recovery as a process that continually has to balance hope/expectations and capacity. I proposed to the group, that 'maybe the challenge for families and services, as Lefley acknowledges, is "to maintain a balance between over-expectation and under-expectation... to encourage progress without fostering failure"' (Lefley, 1997: 217).

As a response to the above proposition the group identified that another important element in terms of recovery is the process of negotiating a space of acceptance. According to one carer:

'The feeling I get when we talk about recovery is that it could be some way off. When my son struggles with the things we ask him to do or that he needs support with, you

come to realise that to keep trying to force him would only make things worse for him and us. We began to understand that nothing's going to change until he is ready for it. We still hold out hope, but we accept that it could be 12 months, two years or longer. Having accepted this, we've had to change our way of doing things and our expectations.

At the same time and in the spirit of family and relationship recovery, another carer suggested that if carers and their family members are able to attempt a process of 'taking up' and 'passing back' of hope, in one sense, this also can mean recognising the potential of 'recovery for the whole family'.

Conclusion

Reflecting on the issues as well as my contact and discussions with carers about family recovery has encouraged me to conclude with a number of questions:

- How can we develop the notion or vision of recovery to be more inclusive of carer families and other significant people in the person's life?
- How do we go about introducing/offering a vision of family recovery to the carer movement?
- Can we look to collaboration between consumers and carers to develop training for carers/families around recovery?
- What role should mental health services play?

In this article I have attempted to register some of the issues, challenges and hopes identified by carer families as a critical point of entry for further engagement, discussion and enquiry concerning the recovery vision and its relevance for carers and families living with mental illness.

Dr Peter McKenzie

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Birmingham Irish Research Project



From left to right: Birmingham's Lord Mayor, Councillor Mike Sharpe, Professor Paula McGee (University of Central England), Bridie Nugent (Irish Welfare and Information Centre), Conor McGinn (Federation of Irish Societies), Paula Conneely (Meriden Programme), Mervyn Morris (University of Central England), Dawn McCarrick (University of Central England), Melissa Roche (Immigration Counselling and Psychotherapy) and Frankie Doherty (Balsall Heath Health Centre, Birmingham).

Thursday 18 January 2007 saw the launch of the Birmingham "Irish Research Project", a study led by Professor Paula McGee at the University of Central England (UCE), Birmingham, UK. The study, which involves the UCE, the Federation of Irish Societies, the Irish Welfare and Information Centre, Immigration Counselling and Psychotherapy (ICAP) and Birmingham and Solihull Mental Health Trust is focusing on the mental health needs of first, second and third generation Irish in Birmingham and asks the question, "*What is appropriate and culturally competent primary care?*"

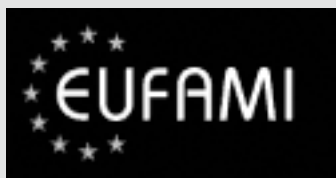
The launch, attended by the Mayor of Birmingham Councillor Mike Sharpe, was held at Birmingham Council House and was well attended with representation from all of the participating organisations including Paula Conneely, Clinical Specialist from the Meriden Programme. Paula leads on Black and Minority Ethnic issues in the Programme.

The study will gain information from a number of sources: through individual interviews with Irish service users, through focus groups of mental health practitioners, and through liaison with local service providers.

Further details regarding the project can be obtained by contacting Professor McGee at the address below, or by visiting the University website at www.ccmh.uce.ac.uk

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EUFAMI Congress 2007 "*Touching The Stars*" Mental Illness and Families Remission and Recovery Towards a Better Quality of Life

**The 4th EUFAMI Congress will be held in Torun, Poland from the 14th to 16th September 2007
It will be hosted by the EUFAMI member association Pol-Familia**

It is a Congress for family members, people with experience of mental illness and health and social care professionals. The congress will be designed for 300 to 400 people and the programme will provide up to date information, in particular relevant to family members.

The programme will be run over two days - Saturday and Sunday, 15th and 16th September. The days will be divided with talks and presentations taking place in the mornings and workshops in the afternoons.

The majority of the workshops planned will be repeated in order to allow delegates the opportunity of attending and participating in as many workshops as possible.

EUFAMI Office Contacts:

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admin.office@eufami.org**

For further information visit their website: www.eufami.org

Carers Psychoeducation Groups for a First Episode of Psychosis

Mandy Reed, Consultant Nurse/Senior Lecturer and
Eric Davis, Visiting Senior Research Fellow/Consultant Psychologist

The Gloucestershire Recovery in Psychosis (GRIP) Early Intervention Service was established in April 2003 with a remit to meet the requirements laid down in the Policy Implementation Guide (DoH, 2001) and the Early Psychosis Declaration (EPD)(WHO, 2004). A key area prioritised from the start was the principle of partnership working with carers by providing information and support. Local research prior to the setting up of the service (Davis, 2002) had highlighted that only 10% of those carers interviewed for the study had received a carers assessment, with the majority feeling excluded from their loved one's care and expressing a wish to receive more information about psychosis.

Carers' Assessments were routinely offered to all significant carers (who were mostly mothers) as part of the initial assessment process along with family interventions. These assessments confirmed the evidence from the literature (e.g. Addington & Burnett, 2004; Fadden, 1998) that carers not only were hungry for information about their child's difficulties and how they could help but also wished to meet other parents whose child has or was experiencing a first episode psychosis (FEP). Although Gloucestershire has a thriving carers' support service, the groups they ran were open to all carers and were often populated by people who had had a negative experience of mental health services and were living with relatives who had long term mental health issues. The team were also working closely with the Trust Carer Development Worker who was conscious of the lack of support she had received several years earlier when her son had developed an FEP and anxious to contribute towards the development of more effective and positive services. As a key aim of both the Early Intervention Service and the Early Psychosis Declaration (WHO, 2004) is to promote hope and optimism, running specific groups for GRIP parents was a logical conclusion.

Development of the course

All attendees on the courses were identified through their Carers' Assessment undertaken as part of the team assessment process and in line with the Trust Care Programme Approach (CPA) Policy (Gloucestershire Partnership Trust, 2003). All attendees to date have been parents of a young person with an FEP. The EPPIC model for family psychoeducation groups developed in the Melbourne Early Intervention Service (EPPIC, 1997) was used as the basis for designing the course with some adaptation for local needs. The Carer

Development Worker formed part of the small working group which met for planning meetings approximately monthly for a period of six months prior to the start of the first group in October 2004. The team had not been able to consider running a group before this time as funding restrictions had prevented the development of a full EIS. The programme was designed with a mixture of in-house and local experts to deliver the psycho-educational aspects of the course. The course each time has had a number of facilitators to provide continuity each week. This has been a minimum of three people with the aim of having at least two facilitators at each week's session.

It was initially decided to run the course for one and a half hours per session at the team base on a Monday evening and for an eight week period. An evening slot was chosen to target the parents who were in paid employment or who needed to find a sitter for younger children. The team base had good parking facilities and was well known to the majority of attendees. The length and timing was revised several weeks into the first course when it became obvious that not only was the content of each week's session crammed, but also that there was not sufficient time for networking and informal support to take place amongst the carers as they got to know each other. Therefore, the first group was extended by two weeks with subsequent groups having two hour sessions each week for a ten week period.

The provision of refreshments at the start and middle of each session also helped with networking. For the second and subsequent groups sandwiches have been provided as many carers did not have time to eat prior to attending the group. This was a popular move and was funded (as were other expenses such as babysitting costs if needed) by a small grant from the local Carers' Fund.

Content of the sessions

Handouts

At the start of each course, group members are provided with a folder to keep handouts and other information in. All presentations are provided along with a range of other leaflets and information found helpful by carers.

Week One

Introductions – each group member has time to introduce themselves and talk about their son or daughter and highlight what they hope to get out of the course. The facilitators also provide an overview of the content of each week's session.

Setting ground rules – as with all groups this provides the opportunity to set boundaries around confidentiality, timekeeping and respect for each other's views and opinions.

The Importance of Carers, Carers' Assessments and Care Plans – presentation and introduction from one of the facilitator/carers. For the first course this was led by the Carer Development Worker, and on subsequent courses by previous attendees of the course.

The final part of the session is spent summarising the session and facilitating a free floating discussion amongst the carers.

Week Two

Recap from week one – The start of this and every subsequent week begins with the facilitators reviewing the previous week and checking if group members have any queries. This is followed by a round where each person briefly talks about their week and raises issues they wish to talk about that week.

What is Psychosis? – presentation by team members/facilitators.

The work of the GRIP Team – presentation by team members/facilitators includes the key components of an EIS and describes case management.

Week Three

Recap from week two and how the week has gone for the group members.

Medication question and answer session – discussion with a pharmacist attached to the local mental health hospital.

The impact of drugs and alcohol – presentation and discussion with a Consultant Nurse for Dual Diagnosis.

Week Four

Recap from week three and how the week has gone for the group members.

CBT for Psychosis – presentation and discussion by team members/facilitators. This includes looking at coping strategies and early warning signs (EWS).

Homework setting – introduction following discussion of coping strategies to the idea of pleasant event scheduling which is fed back at each subsequent week.

Week Five

Recap from week four and how the week has gone for the group members.

Introduction to Family Interventions (FI) – presentation and discussion by team members/facilitators. Those group members already in receipt of FI encouraged to share their experiences with the rest of the group.

Recognising stress and setting boundaries – discussion led by a carer facilitator.

Homework setting – to reflect on the last discussion and/or build on pleasant event scheduling from previous week.

Week Six

Recap from week five and how the week has gone for the group members.

Problem Solving – presentation and discussion by team members/facilitators introducing Falloon's six step method for family work (Falloon, 1985).

Planning for future personal support – discussion led by carer facilitator.

Homework setting incorporating above discussion with encouragement to group members to schedule at least one pleasant event.

Week Seven

Recap from week six and how the week has gone for the group members.

Dealing with professionals – discussion led by carer facilitator encouraging the group to identify tips they have found helpful to share.

Hospital admission – presentation and discussion led by Ward Manager from the local inpatient unit.

Homework setting.

Week Eight

Recap from week seven and how the week has gone for the group members.

Money Management and the Benefits System – presentation and discussion led by carer facilitator.

Homework setting.

Week Nine

Recap from week eight and how the week has gone for the group members.

Family communication – presentation and discussion co-ordinated by carer and team facilitator.

Psychosis and the legal system – presentation and discussion about the Mental Health Act (1983) and Childrens Act (1989) led by Approved Social Worker (ASW) Team Manager.

Final Homework setting.

Week Ten

This session is held in a different venue wherever possible and is a social event with food and drinks provided.

Recap from week nine and how the week has gone for the group members.

Evaluation of the group and repeat of pre-course questionnaires (see below).

Planning for ongoing support networks – led by the group themselves.

Assessments and Evaluation

Pre- and post-assessments include the General Health Questionnaire (GHQ) (Goldberg & Hillier, 1983), the Experience of Caregiving Inventory (ECI) (Szmukler et al, 1996) and a locally derived assessment to determine what proportion of time a carer spends each week on caring as opposed to other activities such as work, recreation or household duties provided by the Carer Development Worker (Holland, 2004).

At the end of the course participants also complete a general evaluation of the taught and written course content, making recommendations for future groups and indicating what kind of ongoing support they would like and if they would be prepared to get involved in future groups or other types of training.

All participants demonstrated an improved sense of well being and increasing levels of hope and optimism for the future of not only their loved ones but also their own.

Post Course Activity

All attendees have found the group a positive experience with many of them continuing to meet up on an informal basis or keep in touch by email. A number have been involved with fundraising activities to increase the range of group activities provided by the GRIP Team, with a more recent development of an independent charitable trust to ensure protocol is followed. A number of carers have banded together and have formed an independent charity called GRIPPERS (email: andrewsabourin@ic24.net). Its aim is twofold: first, to help raise awareness of mental health issues; second, to provide funding for outward bound and social events to raise the confidence and self esteem of service users. Grants are also considered for carers eg for babysitting or respite arrangements.

Following the first group three carers supported by the Team Leader reviewed all the written information they had been given to pull together a specific Carers' Information Pack for the GRIP team. This is available to download from www.gripinitiative.org.uk Much of this was adapted for a UK audience by the Team Leader from the excellent resources produced by the British Columbia Schizophrenia Society (www.bcscs.org). Additional leaflets were added to the pack including the team's general information leaflet 'It's not just you' (www.gripinitiative.org.uk) and the checklists for carers and psychiatrists produced by the Royal College of Psychiatrists and the Princess Royal Trust for Carers (www.partnersincare.co.uk).

Carers are now routinely involved in all recruitment and selection for the GRIP Team and have had extensive input into formal and informal training programmes. As a result of this level of involvement, one member from the first group has since become a Carer Support Worker with Carers Gloucestershire and there are several others looking for similar roles.

Conclusion

Although running this kind of Carer group involves a considerable amount of time and commitment from team members, the benefits far outweigh the costs in terms of improved outlook and functioning of the group members determined by the post-course assessments. In addition, many other benefits have been found as demonstrated by the number of initiatives course members have become involved with and the following quote from the three carers involved in developing the Carers Pack:

"....six months later with our young people further down the route to recovery, we feel empowered to organise our own meetings on an ad hoc basis, both as a group but also as individuals as friendships have developed".

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The World Fellowship for Schizophrenia and Allied Disorders, the Schizophrenia Society of Canada and the Schizophrenia Society of Ontario present:

**The 2007 International Conference
'Lighting the Path: Hope in Action'**

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**For more information please visit
www.conference.world-schizophrenia.org**

Recovering Ordinary Lives: the Strategy for Occupational Therapy in Mental Health Services 2007-2017

Review by Paula Conneely, Occupational Therapist and Clinical Specialist, Meriden Programme

This strategy, published in December 2006, identifies clearly the unique contribution of occupational therapy (OT) within mental health services and provides direction for the development of the profession in this field. Three documents are available from the College of Occupational Therapists: "A vision for the next ten years", the "Literature review" and "Results from service user and carer focus groups", all of which are downloadable free from the College of Occupational Therapy (COT) at www.cot.org.uk.

A number of key themes arise within the report, which are then linked into the overall aims of the strategy. The "10 year plan" aims to:

- "Reassert the profession's belief that occupation is essential to health and wellbeing.
- Create a strategic vision for the future of OT services in mental health across the UK.
- Make recommendations for action to achieve the strategic vision." (COT, 2006)

As part of the development of the strategy, a number of focus groups were held within the UK involving Service Users, Black and Minority Ethnic Service Users, and Carers. After liaison with Debbie Green, Occupational Therapist and Programme Head at the Sainsbury Centre, the Meriden Programme was able to put the Research Team in touch with the West Midlands Carers in Partnership group. As

such, a number of Carers from the West Midlands area were able to contribute to the report by attending a focus group held in central Birmingham. A full report of their discussion forms a key chapter in the "Results from service user and carer focus groups" publication.

In summary, the attitude of those carers that participated in the focus group was positive. The flexible, holistic perspective of the Occupational Therapy profession was acknowledged and the skills-base and training of Therapists applauded. The role of occupation was acknowledged as a crucial aspect of recovery and social inclusion for the service user, and a call made for more Occupational Therapists to be available within the statutory and voluntary sectors. A number of comments and suggestions were put forward, including the recommendation that more Carers be routinely involved in the training of OTs at both pre- and post-registration level. Using Carers to help publicise and promote the role of OT was also suggested. More emphasis on mental health issues at a pre-registration level was also referred to in terms of both curricula and practice placements, with emphasis placed upon the development of specific skills in psychosocial interventions including Cognitive Behavioural Therapy (CBT) and Family Work.

For more details on Occupational Therapy as a profession or on the 10 year mental health strategy, contact: The College of Occupational Therapists, 106-114 Borough High Street, Southwark, London SE1 1LB. Tel: 020 7357 6480

Strengthening Service User and Carer Involvement: a Guide for Partnerships

"Strengthening service user and carer involvement: a guide for partnerships" recognises the central role of people in the design and development of the services they use. The discussion paper aims to assist organisations that are working in partnership to involve service users and carers effectively.

It provides a framework for thinking about types of involvement, describes key issues for organisations in approaching the subject and examines the options for involvement. Suggestions are made about questions to be addressed jointly and practical examples are provided to demonstrate what works in different situations. Case studies illustrating different approaches are included.

This ICN discussion paper forms part of the wider CSIP programme "Having a Voice". Having a Voice works to ensure that people who use services and their families have a strong voice in every part of the work that CSIP does with the Department of Health, local government, health trusts and community groups. More information on Having a Voice can be found in the document attached to this newsletter.

If you would like a hard copy of this publication, email: mbicn@dh.gsi.gov.uk

To download "Strengthening service user and carer involvement" visit: www.icn.csip.org.uk

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Email: mbicn@dh.gsi.gov.uk, telephone 0207 972 1330 or visit www.icn.csip.org.uk

Having a Voice

Care Services Improvement Partnership **CSIP**

What is Having a Voice?

Having a Voice is a new programme for the Care Services Improvement Partnership (CSIP). It started in May 2006.

It is working to make sure that people who use services and their families have a strong voice in every part of the work that CSIP does:

- With the Department of Health
- In all the National Programmes (there are 7)
- In all the Regional Development Centres (there are 8, covering all of England)
- In all the work we do in the Care Services Improvement Partnership
- In all the work that we do with other people and organisations (like social services, health Trusts, or community groups)

Why Having a Voice?

We know that listening to and working in partnership with people who use services and family carers is a good thing – it means that services are more likely to support people how they want!

The government is also clear that this is something that organisations and services need to do.

But... we also know this is not always enough. Sometimes services don't remember to include people. Sometimes just one person gets the job of making sure people who use services and family carers are listened to. Having a Voice is about making sure that everyone remembers to think in this way.

This means that if CSIP was a stick of rock, you could break it at any point and see the voice of people who use services and family carers running all the way through it.

This is why we have a stick of rock as the logo!

'Strengthening service user and carer involvement: a guide for Partnerships' gives some good ideas for how to make sure this happens.



What is Having a Voice doing?

Having a Voice is working with each Regional Development Centre and each National Programme to make sure that:

- They have clear ways of working in partnership with people who use services and family carers, and people know how they can be involved
- There is good support for people to help them have a strong voice and grow as leaders
- They have work programmes that help other organisations give people who use services and family carers a strong voice so they get the services and support they need
- We share and learn from the good work that is already happening in different CSIP programmes to help people who use services and family carers have a strong voice

Some examples of things that we are working on are:

1. **Individual Budgets Pilots and Self-Directed Support:** the Social Care programme in CSIP leads the work to support the Individual Budgets pilots. We are working with this team to make sure that people who use services and their families know about self directed support and can work in partnership with Local Authorities to make it happen
2. **National Framework for Risk:** the White Paper, Our Health, Our Care, Our Say promised a National Framework for Risk. This will help professionals and organisations that support people think about risk in a positive way – as part of everyday life. There is a small team working to develop this framework and we have helped them talk to some people who use services and their families about what the framework should include
3. **Making a Real Difference:** the National Institute for Mental Health in England (NIMHE) have done lots of good work over the past 18 months to look at how people who use mental health services and their families can have a stronger voice in the work of NIMHE. We are working with the Steering Group to look at how some of this learning can be shared across all of CSIP

The lead person for Having a Voice is Tricia Nicoll. Tricia is based at the Regional Development Centre in York. If you want more information about this, you can email Tricia: tricia.nicoll@csip.org.uk

Working with Carers and Families of People with a Personality Disorder

Martin Atchison reports on a study day held in Birmingham in December 2006

I welcomed delegates and highlighted that this was a joint learning event between the Meriden Programme and the Personality Disorder Service for Birmingham and Solihull Mental Health Trust. Over sixty people attended the day. Interest in organising this event has been led by clinical staff contacting the Meriden Programme asking for advice and support in working with families where there is a diagnosis of Personality Disorder (PD).

Traditionally, very little or no support has been offered to these families. This day was an opportunity to think about their needs and how we plan to meet them. When organising the event, it was fortunate that Nick Glover from the Personality Disorder Service had just delivered, in conjunction with Rethink, an 11-week course for carers and was looking at how to develop services for carers further. Duncan Henderson from CSIP was helpful in suggesting potential speakers in addition to the ideas that Nick proposed.

In the morning there was a range of presentations by different speakers:

— PRESENTATION —

What is Personality Disorder?

Dr Alberto Albeniz, Consultant Psychiatrist specialising in psychotherapy, Coventry PCT

Dr Albeniz began by asking 'What is Personality Disorder?' He then stated that he did not know. The two groups of experts (American and European) do not agree at an international level. If you ask different professionals they will disagree. This is because the diagnosis is a very difficult thing to describe. Some experts argue that PD is not a mental illness because there is nothing wrong with the brain. In depression and schizophrenia you can identify changes in the brain but this is not so with PD. He argued that PD is about our culture, the way we grow up in our family and relationships, which identify who we are, and our personality. Trauma can affect our personality. This could be physical, mental, and sexual or lack of appropriate contact and affection.

He then spoke about the things that stigmatise PD – newspaper headlines are not helpful and are generally very misleading in the way that violent crime is reported.

Politicians then talk about keeping the streets safe by ensuring that people with PD go into prison or hospital. This does not help people with a diagnosis of PD. Most people are not dangerous and do not create problems for others. He argued that we are 4 times more likely to be killed by our spouses or partners than we are by people with mental health problems.

He used metaphors and analogies to help think in a different way about PD. If a child is abused by a teacher or someone in authority, they learn at a very early age not to trust people in authority. They then become allergic to authority and as soon as they encounter authority, like someone with a food allergy they have an allergic reaction and do not respond well. This then often leads to difficulties. How do you overcome this allergy? How do you teach a child to ride a bike – you give support, encouragement and skills and then get them to practice until they become independent. If the child falls off their bike we offer support, comfort and get them back on as soon as possible. Do we do the same with people who have a diagnosis of PD?

He spoke about how the treatment of and recovery from PD could be analogous to learning a language. Why does the person want to learn the language? Does the person learn more effectively working individually or with others? In learning a language we will make many mistakes, but if we were criticised heavily for those mistakes this would make us much less likely to continue to learn. The attitudes and genuineness of those who teach the language play a very important part in the learning process too. He stated that if we think about the time it takes to learn a language fully it is a similar length of time for someone with PD to recover. There are many factors that play a part in this recovery and stressed highly the importance of staying positive and encouraging the person.

— PRESENTATION —

Carer Education and Support Group for Families with a Member With Personality Disorder

Nick Glover, Clinical Specialist (Personality Disorder Service), Birmingham and Solihull Mental Health Trust

Nick spoke about the background to a 12-week carers education and training programme that he had recently

delivered in Birmingham with Rethink. The rationale for the group was to support carers, which has been shown to have a positive impact on the person with PD. Ten carers took part, meeting weekly for 2¼ hours in a workshop style session. The kind of issues covered included the concept of PD, coping with symptoms, the carer's journey, PD treatments and services, problem solving and communication skills, coping in a crisis and 'looking after yourself'.

The issues that carers brought to the group were strong feelings of helplessness, despair, anger, grief and stigma. They reported the distress and the turbulence that was related to the role of caring for someone with PD and also the increase in family conflict. The carers' own mental health was affected and there was dissatisfaction with the lack of services for carers of people with PD. Some carers did express pride in caring for their loved one, and reported a deeper sense of relationships and improved family understanding.

The carers found it useful to be part of a group of people with whom they could share their experience. The information about PD helped to reduce the mystery around it and carers reported that the group was able to instil some hopefulness and decrease the sense of isolation. Carers were able to express their feelings of grief and loss in a compassionate and supportive environment. Carers also reported that they felt more able to cope at difficult times and felt more confident and assertive. They also said that the language used by professionals was helpful in that it was clear and jargon free.

Nick then went on to outline some research that indicates the benefits to people with PD by working with their families, including more empathic attitudes, more effective communication and reduced relapse rates. He then went on to discuss areas in which services could improve in relation to providing support for carers.

It was hoped that the group would be the first in a range of services developed for PD carers and Nick hoped that one of the outcomes from the day would be some support for similar groups in the future. More information about this group can be found in the September 2006 edition of the Meriden Programme's newsletter.

— PRESENTATION —

Supporting Carers of People With Personality Disorder in Oxford

Sara Clarke, Clinical Psychologist, Oxfordshire and Buckinghamshire Mental Health NHS Trust

This presentation described the 'Friends and Family Support Network' that has been running in Oxfordshire, a

service for carers delivered by the Complex Needs Service (CNS) and Rethink. This group developed after a 6-week programme for relatives of people who self-harm was delivered by the CNS following a request from Rethink. The success of this group led to the idea that a further group was needed, which would provide education and ongoing support to relatives and friends of people with complex needs (PD). It was hoped that a network across Oxfordshire and Buckinghamshire would be developed.

Staff from the CNS, a service user trainer from the Thames Valley Initiative (a 3 county wide network supporting people with PD), a carer support worker from Rethink and a student developed the group. It was an 8-week programme with a 2½-hour meeting every week. Each session was structured so that there was some educational content, e.g. definition of PD, the causes of PD, coping strategies, treatment options. There was also some time each week for a support group.

In addition to the structured group, an ongoing support group has been set up, which is open to anyone who attends the 8-week programme. The group has been successfully run twice and there are plans to hold another group in Oxfordshire, and the first group in Buckinghamshire, both planned for early 2007.

Feedback from members of the group was positive, with comments about how much it has changed the carer's life, about carers being able to develop understanding and see the part they play in their relative's life. Interestingly, the impact of the carers groups on their relative with PD was explored as part of the evaluation of the group. One service user said they hated the group because "he won't let me walk all over him anymore", indicating that relationships had been altered following the group. Another service user said that their relative "now really appreciates how hard it is for me to go to therapy every day", again highlighting how the group impacted on the level of understanding between family members.

The presentation also included a carer, Gill Haworth, describing how she has benefited from attending the group. She spoke about how she was able to deal with her experiences in a much more positive way. Kevin Emrys also gave his perspective on the group as a service user who is involved in the delivery of the training.

— PRESENTATION —

Personality Disorder Carers - 'In Our Own Experience'

Alison Williams, Carer

Alison was one of the carers involved in the group described by Nick Glover. She spoke in an honest, eloquent, engaging

and moving way about what it has been like for her to care for her daughter over the previous five years. Her daughter has a combination of anorexia and Borderline Personality Disorder and has been in contact with a range of mental health services. Alison recounted the impact on her family as her daughter became more withdrawn and was admitted to a private hospital in Birmingham. There was a lack of support for her, her husband or their two sons, and it is only now that she feels they are starting to come to terms with their experiences.

After a year in hospital her daughter was discharged to the care of Alison. She described how she developed a 'walking on eggshells' approach to life, which was extremely stressful. Through attending the carers support group she started to become more confident in being able to express her feelings to her daughter and to start to look after her own well being. She also stated that she was able to regain some perspective on her situation and to think things through rather than reacting straight away. She called for more of the groups that she attended to be made available so that carers can access help and support from each other as well as from professionals.

— WORKSHOP —

Carer Education and Support Group Nick Glover, Birmingham and Solihull Mental Health NHS Trust

During the afternoon session, Nick Glover (BSMHT Personality Disorder Service) facilitated a workshop that allowed participants to enter into an open debate regarding the issues within Personality Disorder Services from both a provider and carer/service user perspective. The session focused on two main areas of discussion, with the first being the need for development of political and organisational networks. The second related to the very real experiences of carers and families in terms of access to services and support.

When referring to the need for better, more effective networks, Nick reflected upon the American and Australian models where there are far more established organisations at a national level (i.e. the NEA-BPD in America). In the UK however, there are areas of good practice but no central network that draws them together. Nick spoke about the developing links between Birmingham services, Oxford services, the Henderson unit and CSIP (Care Services Improvement Partnership), and his hopes to expand this network further.

In terms of the issues facing carers, the workshop benefited from having a wide range of participants from diverse service areas/localities, including a number of carers from the West Midlands. Topics of discussion included the difficulties facing

those diagnosed with PD and the fact that the majority of the media's attention, and public funding, appears targeted at the most extreme end of the spectrum of PD (i.e. those individuals perceived as dangerous to others/society) with the vast majority of service users and families left with little support and resources. Families spoke of having to reach "breaking point" before they could access services and that psychological therapies, in particular, were in scant supply. Carers spoke of the relatively little money needed to develop services at a local level and the need to feel listened to and acknowledged. Different models of support were discussed and the services in Birmingham and Oxford commended. The development of a programme along the lines of Rethink's CESP model (Carer Education and Support) was also referred to as a potential way forward.

— WORKSHOP —

Using Dialectical Behavioural Therapy in Community Mental Health Teams Jane Cooke, North Warwickshire PCT

Jane's workshop informed the group about the above service that has been running in Nuneaton and Rugby. The service has been delivering individual therapy, a skills group and providing telephone consultation for people with Borderline Personality Disorder. There are 6 members of the team who work part time for the DBT service and part time in other clinical posts. Service users are referred to the service but remain in contact with the host team. Members of the team will have had some intensive training prior to joining the team.

The outcomes for the service have been positive. The service users reported increased confidence in dealing with crises, better self-understanding and a reduction in depression. Objectively, there was also a decreased use of inpatient beds and fewer acts of self-harm. The picture that developed was that DBT seemed to instil hope and empower people.

Jane reported that there would be the establishment of a North Warwickshire Personality Disorder Service, which would offer a more widespread training and advice network as well as a clinical service. In addition to this there would be the development of some support networks for carers.

Those attending the workshop were interested to hear about the service and felt that this kind of service would be very welcome in their own Trusts. However, as Jane pointed out, there have been a number of difficulties in developing and maintaining the service and it has taken a lot of commitment and persistence to get to this stage, but that the outcomes for the service are very positive.

— WORKSHOP —

Carer Involvement at Oxford's Complex Needs Service

Sarah Clarke, Gill Haworth and Kevin Emrys
Oxford Complex Needs Service

This session was facilitated by Sarah Clarke, Gill Haworth and Kevin Emrys and offered participants the opportunity to explore some of the issues associated with involving families and carers in the care of people with Personality Disorder, combining both professional and personal experiences from across the West Midlands with those from services in Oxford.

To begin, the focus of the session was on the importance of creating a supportive, safe space for both service users and carers. The benefits that might be gained by keeping service users' and carers' support groups separate were discussed and included service users and their carers having time and space away from each other, being able to share experiences with others facing a similar situation to themselves, working towards accepting personal responsibilities associated with their role and thinking about boundaries and taking personal responsibility towards setting and maintaining these. It was also noted that setting up more specialised support groups, for example, those for (adult) children of those diagnosed with Personality Disorder, may be particularly useful in allowing members to explore and come to terms with specific issues to the benefit of both themselves and their loved one.

The discussion then turned towards working with carers and families more directly. The importance of the professional's role in helping to provide carers with support and knowledge about their loved one's condition and taking the time to listen to carers' concerns (whilst maintaining confidentiality) was highlighted as a key issue in delivering effective services. With regard to specific, structured family work a debate started around the purpose of family sessions, the types of goals that might be set and some of the difficulties that might arise when trying to set up meetings with service users and their families. A view was expressed that the focus of family work might be on keeping the family unit together despite the fact that this might not necessarily be the best outcome for individual family members. This prompted much discussion about using structured family sessions to share information and build upon communication and problem-solving skills to enable family members to reach mutually desirable outcomes, which may or may not include family members seeking greater individual space and time away from the family unit. It was also noted that there might be specific issues associated with Personality Disorder that would make it very difficult for service users to engage with their families in structured meetings that would not necessarily occur when working with those experiencing other types of

mental health difficulties (eg. psychosis). However, there was much agreement that working closely and inclusively with service users and their carers and families should be a key aspect of providing effective Personality Disorder services.

Conclusion

The day was rounded off with a brief discussion about how to take the issue forward. The presentations highlighted that although services for carers of people with PD were starting to improve, there was still some way to go. There was some interest in the idea that the Meriden Programme develops a Special Interest Group to look at family work with a focus on PD. Certainly there was sufficient interest in attending the day to warrant holding another larger event around a similar theme. The organisers planned to meet with Duncan Henderson to look at ideas for developing networks and services.

The evaluation of the day was generally very positive. From the feedback it was evident that a substantial number of clinicians feel they have had little training in working with services users who have PD, and lack confidence in this area. There were several comments about how people felt motivated to start a group to support carers. It will be interesting to see how this area of work develops, both within the Meriden Programme and across the West Midlands.

For any enquiries relating to this article please contact:

Martin Atchison
Clinical Specialist – The Meriden Programme

COMING IN THE NEXT EDITION

- Report on newly developed training, for staff working with older adults by Martin Atchison
- Report on adaptation of Caring for Carers Programme for those working with alcohol and drug use
- Carers Group in South Staffordshire: An article by Esther Dawson and Suzanne Parsons
- Report on the Working with Families conference – March 2007

Family Work on Home Treatment / Crisis Resolution Teams

Lindsay Rigby

Teaching Fellow – University of Manchester,

Clinical Lead (Home Treatment Team) – Manchester Mental Health and Social Care NHS Trust

Ten years ago I became involved in the development of one of the initial home treatment teams developed in the UK. This was the first of the 'wave' of Crisis resolution/home treatment (CRHT) teams developed across the UK in response to the National Health Service Plan (DOH, 2000). The plan required the establishment of 335 home treatment teams across the country to provide an alternative to hospital admission for people who are acutely unwell as a result of mental illness. In order to realise this strategy the Mental Health Policy Implementation Guidelines (MHPIG) were published (DOH, 2001), proposing that home treatment or crisis resolution teams should provide a 24 hour service, 7 days a week for clients who are experiencing an acute phase of a longstanding mental illness. The guidelines also require that carers should be actively involved in the assessment of clients and the development of their care plans, alongside the provision of information, advice and practical assistance where necessary. A crisis is a situation in which an individual experiences overwhelming stress in response to a life event (Lindermann, 1944; Caplan, 1964). For someone vulnerable to stress, such situations can induce a psychotic episode involving distressing and disturbed behaviour which might be challenging and require intervention for both clients and their carers (Zubin and Spring, 1977; Rosen, 1997). Such behaviours include physical violence, verbal abuse, substance misuse, suspicion, paranoia and fluctuating moods (Steadman et al., 1998; Vaddadi, 2002). The pressures of caring for those in a crisis have been identified in a number of studies (Grad and Sainsbury, 1968; Heron, 1998; MacInnes, 2000; Wright et al., 2000).

Joy et al. (2006) conducted a systematic literature review to examine the components of care that seem to be beneficial in the management of a 'crisis'. The review analysed five studies of home treatment and found it is a viable form of service delivery for those with severe mental health needs. Burns et al. (2001) conducted an extensive systematic literature review of 91 studies to investigate the effectiveness of home treatment for mental health problems in terms of hospitalisation and cost effectiveness. Findings indicated that visiting patients at home regularly and taking responsibility for both the health and social care needs of clients could reduce the days that clients spend in hospital. As a clinician within such a CRHT team I became aware of the impact of carers and families of those who were offered home treatment in such circumstances. As a result, I chose to complete a systematic review of the existing evidence base in relation to the needs of those who provided a caring role for clients experiencing an

acute crisis of their existing mental health problem or for those who were experiencing a first episode of a psychotic illness and admitted to CRHT as a result.

The quality of the existing literature was reviewed by a critical analysis of the methodology to ascertain the legitimacy of inferences made from the evidence to date. In consideration of the effectiveness of home treatment, the burden, satisfaction levels and preferences of carers who receive home treatment with those who received in-patient care was compared.

Findings from the systematic review

A search of the literature base resulted in the acquisition of six randomised controlled trials selected for analysis (Pasamanick et al., 1964; Test and Stein, 1977; Fenton et al., 1979; Hoult et al., 1983; Muijen et al., 1992; Burns et al., 1993). These are referred to as 'primary studies' in order to differentiate them from three additional 'secondary studies' which applied comparative retrospective designs involving organisational analysis implementing both qualitative and quantitative data (Dean et al., 1993; Wasylenki et al., 1997), and an audit to evaluate the carers' preference of different service models (Fulford and Farhill, 2001). Only two secondary studies acknowledged the carer perspective as one of the primary objectives. The involvement of the total number of 577 carers within the studies varied considerably. Fenton et al. (1979) and Pasamanick et al. (1964) only accepted carers who were both available and agreeable to being actively involved in the care of the client. Burns et al. (1993) failed to define the role of carers or their involvement at all. The relationship of the client-carer dyad was also inconsistent and included family members (Pasamanick et al., 1964), 'anyone close to the relative' (Test and Stein, 1980), or paid carers and hostel staff (Wasylenki et al., 1997). Pasamanick et al. (1964) found 60% of clients were married to their carers compared to 20% in the study by Hoult et al. (1983), while Test and Stein (1980) found 43% of the carers were parents. The definitions applied to the term 'carer' were inconsistent in the studies. It is of interest that Dean et al. (1993) developed the home treatment team specifically in response to the identified needs of clients from Pakistan or the 'New Commonwealth' countries. Clients from these ethnic minority groups accounted for 47% of all participants all of which were in favour of the home treatment model compared to in-patient care.

All the reviewed studies offer consistency by offering 24 hour on-call support. The level of the support was however variable and includes telephone support (Pasamanick et al.,

1964), access to an emergency clinic (Muijen et al., 1992) and offers of home visits by nursing or medical staff when required by clients or their carers (Test and Stein, 1980; Fenton et al., 1979). Considerable heterogeneity exists in the interventions offered to carers. Despite carers' support being described as being a 'key focus' by Test and Stein (1980) only three studies (Fenton et al., 1977; Muijen et al., 1992; Wasylenki et al., 1997) provided adequate information in relation to the involvement of carers by professionals.

To measure the effectiveness of home treatment as an intervention, five studies have compared the levels of burden experienced by carers (Test and Stein, 1980; Hoult et al., 1984; Muijen et al., 1992; Dean et al., 1993; Burns et al., 1993). Burden is a complex issue, difficult to define and quantify. Many variables can affect the perception of burden by carers, and as such are difficult to control for yet might equally involve a change in lifestyle of a carer in response to a client becoming unwell, such as a wife leaving employment to care for her husband or a grandparent providing weekend respite for a family.

Pasamanick et al. (1964) anecdotally described 'some' clients within the intervention group as being admitted to in-patient units as a result of being unmanageable by carers who were reluctant to accept them home following an in-patient admission. Conversely, Muijen et al. (1992), in analysing the narratives of rhetorical accounts of carers, found them to be satisfied with their caring role within the home during the 'crisis' and welcomed clients home from in-patient care when admission had been necessary.

Two studies identified the satisfaction rates of carers as outcome measures of effectiveness (Hoult et al., 1983; Dean et al., 1992). Neither of the measures implemented had been validated or had proven reliability, although both studies found carers were more satisfied by home treatment. Hoult et al. (1983) found that satisfaction related to carers reporting increased coping strategies as a result of receiving an adequate service for those they cared for. The carers interviewed believed the out of hours support provided prevented an admission to in-patient services. Dean et al. (1992) found carers to be more satisfied with the increased face-to-face contact with professionals from the home treatment team in comparison to in-patient services.

Conclusions

Home treatment seems to be the preferred option for carers (Test and Stein, 1980; Muijen et al., 1992; Fulford and Farhill, 2001). This appears to be more evident for those carers who have previously experienced home treatment (Test and Stein, 1980; Fulford and Farhill, 2001) and for those caring for someone experiencing a psychotic episode for the first time (Hoult et al., 1983). Carers expressed increased levels of satisfaction with home treatment compared to in-patient care (Hoult et al., 1983). This was especially significant amongst Asian carers if the service considers the needs of this client group (Dean et al., 1993).

Of particular concern was the failure of studies to report quantitative measures relating to the detrimental effects of home treatment. Rhetorical accounts from carers are described within the texts of some studies indicating that home treatment was perceived as being 'invasive' (Burns et al., 1993). Other potential adverse effects could include an increased dependency by the client on the carers, increased risk of harm to carers or disengagement from those services perceived as being intrusive to family life or which might increase a sense of stigmatisation as a result of frequent visits by mental health professionals within the client's neighbourhood.

None of the studies discuss the increased risk placed upon carers who manage clients during an acute phase of their illness. If clients who are deemed to be at risk are residing with carers, professionals must have the ability to conduct timely and thorough risk assessment and management strategies. This is a source of concern as evidence suggests it is those 'intimates' such as spouses and mothers who care for clients who are at particular risk of serious violence in the context of schizophrenia (Estroff et al., 1998; Taylor, 2000; Reid, 2004). The incidence of verbal and physical abuse of those in a caring role by those with an acute episode of a serious mental illness is high, causing increased levels of emotional stress and adding to their sense of burden (Vaddadi et al., 2002).

Recommendations for Future Research

It is essential that suitable, reliable and validated outcome measures should be identified or developed so that they might be recommended in future research. The involvement of both users and carers in the development of such measures and the initiation of future research studies should be seen as a priority as research has shown that clinicians' views of effective services are different to users' and carers' opinions (Shepard et al., 1985; Strathdee et al., 1998). One such measure is the CUES (Carers and Users Expectations of Services), a reliable tool to establish the assessment of the needs of carers of people with a severe mental illness. (Lelliot et al., 2003).

The active ingredients developed for carers in home treatment teams need to be more clearly identified by the use of protocols and manualised interventions to ensure increased consistency in the composition, skills and experience of the multidisciplinary teams in order to standardise interventions offered. Specific 'carer groups' such as clients from ethnic minority groups, young carers or carers of those experiencing a first episode of psychosis or a co-existing diagnoses such as substance misuse, physical or learning disabilities might benefit from specific specialised support.

Home treatment teams must consider the engagement and involvement of carers as suggested within the National Service Framework for Mental Health (DOH, 1999). Carers have reported that it is not the content of

the service offered, it is the process by which they are delivered that is important to them (Arskey et al., 2002), suggesting the importance of engagement with carers, the presence of good communication skills by the team and the ability of professionals to increase face-to-face contact. Staff with previous experience of in-patient care or other community teams who are relocated to newly established home treatment teams may well need to develop new skills to assess and work effectively with carers of clients during a 'crisis' (DOH;2004, Crompton,2005).The studies reviewed fail to address the training needs of teams to implement interventions to support carers.

Further research

All the studies in this review used in-patient services as a comparative group, yet as home treatment teams have proliferated in recent years, researchers could compare different models of home treatment. Teams could then be compared for their effectiveness using different interventions or 'packages of care'. Teams where all team members have a global role to care for both clients and carers could be compared with teams that develop specific roles for individuals who have a role as being solely responsible for meeting carers' needs. Qualified staff could also be compared to support workers, as could statutory provision compared with non-statutory agencies.

The studies reviewed have identified numerous types of support for carers, including telephone help lines, home visits from various professionals, counselling, education, respite for carers, carer groups and information about benefits. Although there is some tentative evidence that home treatment might be of benefit and preferred by carers, there is a lack of clarity concerning the impact of specific interventions and the drawbacks of home treatment to carers. A balance of carer and clients needs must also be established as it is cannot be assumed that if the carers needs are met this will be of benefit to the client also. Policy makers and service providers concerned with the reduction of costs and redirection of clients from institutional to community care settings cannot at this stage assume that increased support for carers will lead to a reduction of in-patient admissions.

The needs of carers might vary considerably depending on the nature of the caring role. The nature of support required by paid hostel workers is likely to be different from the needs of parents or siblings of the client. The differing needs should be used to gain insight into different and variable experiences and perceptions of the caring role. It is clear from previous studies that despite the provision of substantial training, the delivery of family interventions within routine care remains problematic (Fadden, 1997; Smith and Vellman, 2002; Bailey et al., 2003; Brooker et al., 2003). Such difficulties can only be addressed by a commitment at management level whereby teams are actively encouraged to deliver a service to carers which is evidence based, supported by a supervision structure and monitored by auditing established standards.

Home treatment teams continue to be developed across the UK as an alternative to hospital admission, as the availability of in-patient beds is reduced (Owen and Sashidharan, 2000). The effectiveness of this method of service delivery has not been established from the carers' perspective. Carers as stakeholders are under-represented within the current research relating to the effectiveness of home treatment despite the contributions they make to the delivery of care.

For further information please contact Lindsay Rigby on lindsay.rigby@mhsc.nhs.uk

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Schizophrenia: through the maze and fighting back – a book for carers

by Georgina Wakefield with D C Lefevre

Georgina's youngest son developed schizophrenia at the age of 16 years. She has used her family's experience of dealing with mental health issues to write this book and hopes to provide a deeper understanding of what the whole family go through when a loved one has mental health issues.

The primary aim of the book is to provide carers with hope and with encouragement to ensure their rights as carers are met and they are able to obtain the highest standard of care for their family member. The book also aims to deepen the understanding of people working in mental health services.

Georgina describes how schizophrenia can take the family and friends on a rollercoaster ride. She has written this book with an interesting style in which she changes from one subject to another aiming to provide the reader with some insight into what life can be like for a mental health carer who is constantly having to change and adapt.

The book begins with a poem 'Schizophrenia Through the Maze' and then takes the reader on a journey exploring the many different issues facing carers and people with mental health problems. The book is

interspersed with poems to highlight the feelings and experiences of life as a carer and of life living with mental health problems. Through these detailed and personal experiences Georgina explores the many issues such as stigma and prejudice, the Department of Social Security, and practical guidelines for dealing with a crisis. In the chapter 'Some survivors and some carers' stories', she describes a 'typical' day for a mental health carer, which provides a great deal of insight for both the general public and people working in mental health. The description of her day will help people understand the constant balance between trying to meet her own needs and those of her son.

Through the exploration of her own experiences and stories of other carers Georgina offers advice, support and hope to carers and family members and provides many issues for professionals to consider in developing more effective working relationships with carers and more responsive services.

Schizophrenia: Through the maze and fighting back, a book for carers. Georgina Wakefield with D C Lefevre, published by Fivepin 2006.

ISBN 1 9038772 8 8

Georgina has written another book 'A Mothers Story' and her family took part in a documentary for BBC 2 about living with schizophrenia. Further information on her work can be obtained by visiting her website: www.georginawakefield.com

Reviewed by Chris Mansell
Meriden – West Midlands Family Programme

“Caring for Carers”; a Training Course for Black and Minority Ethnic (BME) Carers and Organisations

In the December issue of the Meriden newsletter, we reported on the work that is taking place in the West Midlands aimed at meeting the needs of carers from Black and Minority Ethnic groups. This report describes an innovative training programme that took place in January 2007.

“Caring for Carers” is a training programme for carers of people experiencing mental health difficulties, with a specific emphasis on the needs of Black and Minority Ethnic (BME) carers. The programme has been developed by the Meriden Family Work Programme (www.meridenfamilyprogramme.com) as a direct result of work undertaken by the BME Sub Group of Carers in Partnership. Its initial pilot project was delivered through the support of the West Midlands Care Services Improvement Partnership (CSIP), which provided funding for both the course delivery and venue.

The “Caring for Carers” programme is designed to bring together small teams of carer workers/carers to participate in an initial 3-day training event. During these 3 days, the teams are trained in the practical skills necessary to deliver an 11-week carer education package with specific reference to the experience of BME mental health service users, their families and communities. Learning objectives for the 3 days are for participants to:

- Develop a knowledge base for sharing information with carers, and for helping them to develop a range of coping strategies
- Demonstrate presentation skills required to share information with carers
- Demonstrate ability in planning, organising and delivery of courses, delivery of presentations and facilitation of group learning
- Have an understanding of the resources available to support the planning and delivery of courses
- Develop an overview of the programme to be delivered to carers

In using this cascade training method, the intention is that participants will go on to deliver locally tailored carer support and education packages that specifically meet the needs of their local communities. Delegates signed up to the training on the understanding that they would “roll out” a programme of carer education and support on completion

of the initial 3-days training. As such we expect that, as a result of this pilot, several “Caring for Carers” programmes will be running for BME carers across the West Midlands. Following the 3-day training, contact with the cohort will be maintained via a number of existing networks/groups, and a series of follow up events have been scheduled. An evaluation of this initial pilot has also been commissioned through CSIP West Midlands, data from which will allow for any changes/adjustments of the programme and support future roll-outs of the training in both the West Midlands and further afield.



Trainers and participants of the pilot BME Caring for Carers Course, which took place in Birmingham, January 2007

The first pilot of this programme ran in January 2007 at a central Birmingham venue. A total of seventeen delegates attended from a number of BME community organisations from across the West Midlands representing Asian, African Caribbean, Chinese and Irish communities. Representation was made by AXIS (Birmingham), ACCI (Wolverhampton), Coventry Mental Health Services, the Heart of Birmingham PCT, the Birmingham Chinese Community Centre and Sandwell Mental Health and Social Care NHS Trust.

Participants consisted of BME carers and professionals from both statutory and non-statutory sectors. The rationale behind this combination stemmed from the Programme’s previous experience of training carers in isolation, which highlighted a need for support and supervision at a local level. For subsequent “rolled out” carer education and support programmes to be implemented and mainstreamed, a level of collaboration between carers/service providers seemed advantageous.

A comprehensive training manual was designed by the Meriden Programme, which gives clear guidance and session plans for an 11-week “Caring for Carers” package. During the initial 3-day training course, participants were

introduced to this manual through a range of exercises, which aimed to develop teaching and communication skills, presentation and facilitation skills.

In terms of BME service user and carer involvement, both have been involved in the planning of this training through the work of the Meriden Transcultural Family Work Forum. The workbook, designed by Meriden, has been reviewed by BME service users, carers and BME clinicians/health workers who have been able to comment/add to its structure and content. In addition the 3-day training was co-delivered and facilitated by carer, Peter Woodhams.

Links with Delivering Race Equality Framework (DOH, 2005)

A BME specific Carer Education Programme provides a unique forum to address some of the issues faced by BME Carers and clearly fits with the current Delivering Race Equality framework (DOH, 2005). A comprehensive, community based programme would address some of the issues of access faced by members of BME communities, especially if on-going support programmes were to be delivered within existing community/voluntary organisation venues by trained, confident and appropriately supported carers. Indeed, the DRE refers specifically to services that offer,

“a more balanced range of effective therapies, such as peer support services and psychotherapeutic and counselling treatments...” (DOH, 2005, p.4)

and also those which facilitate a

“more active role for BME communities and BME service users... in the planning and provision of services” (DOH, 2005, p.4).



From left to right: Uma Sharma (Coventry Carers Centre), Melonie Phillips (Sandwell Carers Team), Riffat Bashir (AXIS) and Michelle Bhalroo (Heart of Birmingham PCT)



From left to right: Baljinder Bains (AXIS) and Baljinder Sandhu (Sandwell Carers Team)

In terms of engagement issues, “Caring for Carers” has made active attempts to both engage communities and develop partnerships. It also has direct links with the “more appropriate and responsive services” aspect of the DRE framework in terms of workforce development issues and in improving clinical services. We feel it is a unique and innovative approach to meeting the needs of BME carers, which clearly responds to the call for more information and support by BME carers, while demonstrating a new way of partnership working which ensures that local programmes are appropriate, accessible and meet local need.

Comments received from the “Caring for Carers” participants

“Excellent course and a great confidence booster”

“The information provided was top class and the information inside very relevant”

“I thought the presentations were excellent and covered the topics that I was interested in”

“Very, very useful indeed”

“Loved the course. I really feel very confident in using these skills I have learned - not only in the 11-week roll out, but in my home life”

“A personal thanks for putting together one of the first carers training courses specifically aimed at BME carers!”

For further information about the BME Caring for Carers programme, please contact Paula Conneely on paula.conneely@bsmht.nhs.uk or telephone the Meriden Programme on (0121) 678 2896.

Family and Multi-Family Work with Psychosis – a Guide for Professionals

Gerd-Ragna Bloch Thorsen, Trond Grønnestad, Anne Lise Øxnevad

This book is an account of a family group psycho-education service that has been running for ten years in Stavanger, Norway, in conjunction with an early detection and intervention project for people with schizophrenia. It is based on a model developed by William McFarlane, MD Director, Centre for Psychiatric Research, Maine Medical Centre, Portland Maine, USA. The clinicians who developed this service give a detailed description of a thorough belt-and-braces project to educate and support families.

The Stavanger service concentrates on the families of people with psychosis but the authors emphasise that the model can be applied to other disorders such as Anorexia and Dual Diagnosis. There is a chapter on drug abuse and psychosis by Christine Barrowclough, which describes in detail a method of working with families of people suffering from psychosis and substance misuse.

In the first chapter 'Introduction to Family Work' the concept of 'Expressed Emotion' is thoroughly explored. The stress/vulnerability model for serious mental illness and the part the family can play is also explained. It is made plain, however, that there should be no blame attached to carers who express critical comments or hostility to the patient, or become emotionally over-involved. The severe strain families experience is emphasised and the following excerpt encapsulates the refreshing and heartening attitude which underlines the Stavanger family work model.

'If we do not see the family's pain and its right to get support for itself, then it is not just the family that we let down but the patient as well. The family is often the patient's important resource. If it does not receive appropriate help then it may become overwhelmed in its task of supporting the patient. If we fail to help the family we deny the patient access to this important source of support.'

Chapter 2, **Methods**, describes how the Stavanger model operates and makes plain that considerable commitment is required from families participating in the service. The multi-family group will consist of four to six families plus two leaders, who will be experienced clinicians preferably from different disciplines. They will meet every second

week for two years. Each meeting will last for 90 minutes. This can seem daunting to relatives and patients and so an introductory meeting is held with each family where the group leaders can fully explain how the process will work and how they can benefit from the knowledge, advice and support they can gain from the group. Before this meeting the patient will have agreed to the family group being formed and that he/she will take part.

Before the multi-family groups begin at least three meetings will be held with each family. The first meetings are called 'crisis conversations' and give individual family members the opportunity to work through their own reaction to their relative's breakdown. The authors point out that the support and information the families receive from health services will determine how well they handle the initial crisis. They refer to the anger and frustration many relatives feel when trying to talk to hospital staff, and the sense of being rejected and ignored. If these feelings and events are not adequately worked through they may appear at a number of points in the multi-family group.

The next step is unusual and intriguing. The family is invited, with the group leaders, to draw up a family tree or Genogram. This helps the family to understand its internal relationships and provides insight into their significant life events. It is also an effective way of revealing any hereditary traits. House moves, planned abortions, miscarriages, a family member's problems with drugs or alcohol and other events which may have proved stressful, can be recorded and discussed and the quality of relationships examined. The genogram should cover two or more generations.

The third meeting is about early warning signs and is covered in depth. The patient attends and participates if well enough. He/she will also have separate meetings with a group leader. The aim is to establish positive relations and to see the leader as a sympathetic person who is there to help. Sometimes patients from the families taking part can come together for a joint meeting before the multi-family group starts. There may also be a get-together with refreshments, or a social activity such as a bowling evening which can give patients the opportunity of forming a common network inside and outside the family group.

After the introductory meetings have taken place a full day education seminar is arranged for all the families. The purpose of the seminar is to provide information about the

treatment and management of psychosis. The patients do not attend as it is felt that it may prove difficult for them to stay concentrated for a whole day at this stage in the treatment course. It has also been found that families need the freedom to express their own worries and anxieties. The group leaders conduct the seminar but may invite colleagues to present individual topics. The authors give an example of a seminar programme.

10.00 – 10.45

Presentation of the group leaders, the lecturers and the group members'

Distribution of the written material and a short discussion of the subjects on the agenda

Crisis Theories

11.00 – 11.45

Understanding Psychosis and Stress

Vulnerability Model

12.00 – 12.45

Different psychoses and different psychotic symptoms

12.45 – 13.45

Lunch

13.45 – 14.30

Warning signs of relapse

Intoxication and Psychosis

14.45 – 15.30

Treatment

The law concerning mental health services

Professional Secrecy

At the end of the group's first year, a second seminar concentrating on recovery will be held which both patients and families attend.

About two weeks after the educational seminar, the first meeting of the multi-family group will take place at a time convenient for the families. The patients will be part of the group. The group leader will explain that in this meeting family members will be able to share accounts of their lives, their hobbies and likes and dislikes. There will then be a follow-up meeting where they can talk about the illness and its impact.

Structure of Group Meetings

After the first two meetings, all meetings are structured as follows:

15 minutes	Informal chat
20 minutes	'Go round' (round table talk)
5 minutes	Selection of problem
45 minutes	Problem solving
5 minutes	Informal chat

In the fifteen minutes of informal chat, the course members will be encouraged to talk about general topics. Following this the 'go round' has two purposes. Each family member

can talk about current concerns about their mental health problem, and the group leaders will be able to use this information to decide which problem the groups should discuss. A group leader starts the round by referring to the previous week's problem solving discussion and asking the family whose problem was addressed how it went and if the solution worked. If the problem solving has proved ineffective, the reasons for this are addressed in a supportive manner so that the family does not feel blamed. During the 'go round' the leaders will listen for any warning signs of relapse.

In the round table discussion a lot of guilt, anger and anxiety may be expressed and it is emphasised that the leaders should show empathy and try to reformulate family problems in a positive way.

The group leaders will then take five minutes to choose a problem to discuss. They will talk aloud so that group members can hear what they are saying. Families whose problem has not been chosen this time will find taking part in the problem solving process useful since they may have or have had similar problems.

The problem solving method used by the group is very similar to the one practised within the Meriden Programme and is described as:

- 1) Mapping the problem
- 2) Suggesting solutions
- 3) Evaluation

The book lists three different categories of problem:

- Mismatch between the desired state and reality. For instance where the patient cannot handle a given task (e.g. to go to school or college)
- Problems in developing a task. For instance how to modify a goal in order to improve functioning (in order to gain knowledge)
- Speculations: for instance, brooding over possible difficulties that might occur (What if I don't tolerate the medication?)

The book concentrates on the mismatch category and the point is made that a problem should be chosen that presents a reasonable chance of success before the group goes on to tackle more difficult and complex situations. Each part of problem solving is then described in detail.

Many verbatim examples of actual conversation in the groups provide a vivid and effective illustration of how a group functions. Here is an example where the educational and yet empathic role of the group leader is clearly outlined.

Group Leader: 'How have things been going for the past two weeks, Peter?'

Peter: 'I am very tired in the mornings. Mum is constantly nagging and wants me to get up earlier.'

Group Leader: 'How long has it been since you were discharged from hospital?'

Peter: 'Four weeks. And I have increased the dosage of my medicine because of the voices. I need to sleep till 11.'

Peter's mum: 'I think it only fair that now he's out of hospital he should have breakfast with me.'

Group Leader: 'Do you remember the educational seminar, when we talked about an increased need for sleep, in relation to both the psychosis and medication? It's normal to need more sleep, but at the same time to have a good pattern of living; that is to go to bed as usual at night. I can understand parents wanting a speedy recovery and to return to the old routine, but it is important to be patient and to take one step at a time.'

Work with individual families can also occur during the two year period. Help to work out crisis intervention plans is offered and can be made by the patient together with his/her family and the group leader. Some families will also need help with communication skills which can be practised with the group leader using similar modules to those used within the Meriden Programme.

In Chapter 3 **Experiences**, there is a section focussing on differences between the single family group (SFG) and the multi-family group (MFG). The advantages of each model are compared and discussed. It appears that working with families in a similar situation in a MFG provides a secure framework of mutual support to tackle problems and change their situations. However some families require more time to devote to individual problems and in some cases, patients may find taking part in a large group intimidating or stressful and their resulting behaviour may disrupt the

group. As described above both types of approach can be used in the Stavenger model.

This book is described as a guide for professionals, and reviewing it as a carer, I am impressed by the authors' empathy with families and the vast amount of practical knowledge of the problems they face. My only reservation about the Stavenger model is the two year commitment required, particularly in the early stages after diagnosis. However, the importance that the model attaches to family involvement in recovery and the respect and confidence it shows in the ability of the family to rise to this challenge is both heartening and impressive. In Norway, the multi-family groups are well attended and there is a moving account by a carer as to the support and benefits they can bring. It would be interesting to see if carers would respond to attending a pilot group here, perhaps using a combination of Behavioural Family Therapy and the Carers Education and Support packages that are increasingly offered to families in this country.

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- Communication skills
- Problem solving skills
- Integrating different models of family work in early psychosis services
- Implementing family work in early psychosis services

For further information or to book a place please contact Sharon Hall on 0121 678 2896 or email sharonl.hall@bsmht.nhs.uk.

The Complete Family Guide to Schizophrenia

by Kim T. Mueser and Susan Gingerich

reviewed by Jeanette Partridge (North Warwickshire Carer)

There is no doubt that the authors of this book are highly qualified clinicians in the field of mental health. But, for me, the fact that Dr Mueser has had personal experience i.e. a family member with schizophrenia, is the best qualification he can possess. I do not think any one book can help a family cope with caring for their relative. However, the information it supplies and the strategies it recommends go a long way to equipping a family.

The reassurance throughout the book that carers are given should be well received. I cannot imagine any carer would sit down and read the whole book, as suggested, using the worksheets as part of the recovery process. Far more beneficial, I think, to absorb bite-sized chunks, possibly as part of a carer support programme, as recommended. This drip feeding approach has always been, in my experience, most effective. As the recovery process is such a unique process, different sections could be more relevant for different families.

The first five chapters give an overview of schizophrenia which is in adequate detail. I like the use of analogies e.g. schizophrenia is like playing tennis with too many balls coming over the net. This is family friendly language. There is a clear attempt to dispel myths from the past and give up-to-date research regarding topics like the complexity of diagnosis. It also gives families practical advice on these issues which is largely commonsense, whilst the sections on guiding families through mental health services, is particularly useful. The crucial role of families in relation to treatment and recovery is acknowledged and how the relationship between professionals and carers can be helpful or a hindrance.

The second part of the book reflects on special issues for families e.g. the concern of parents regarding the care

of their loved one, once they are no longer able to look after them. Again, coping strategies are given although the phrase 'easier said than done' comes to mind.

Part 3 tackles the subject of relapses. The importance of taking medication and the possible side effects are explored. This can be a problematic area for families. I cannot help feel that the suggestions are over-simplified. However the case histories could be usefully discussed at carer support groups.

The essence of Behavioural Family Therapy is covered in the following section of the book. A step-by-step approach is adopted to help families communicate in a more effective way and to attempt to solve problems.

Next, there is a section on coping with specific problems e.g. psychotic symptoms, depression, alcohol abuse and the delicate topic of lack of insight. It gives families realistic ways of evaluating their own situation and strives to provide an increased understanding. It details the help that families can offer coupled with professional treatment. It 'touches' on the importance of holding hope which, I think, deserves a much higher profile, although it is mentioned later in relation to stigma.

The final section is entitled 'Quality of Life' enabling a family to help develop and strengthen their relative's social skills and thereby improve their chances of having any form of social life. Following this, on the subject of education and employment, the greatest number of American references are made which readers outside the U.S. may not find particularly relevant. The last subject, independent living, addresses the difficulties faced by families in deciding what is best for their relative and careful planning for the future is emphasised.

In conclusion, this is a book worthy to be used as a source of reference, in particular, by groups of carers. At first glance, its substantial content may deter potential readers, but my advice would be "Try it". It is very likely you will find some items of interest.

The Complete Family Guide to Schizophrenia
The Guildford Press ISBN-10 1-59385-180-4 ISBN-13 978-1-59385-180-4
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