



As we prepare each edition of our newsletter, I am increasingly impressed with the range of articles which are submitted to us for publication. It is really heartening to see the amount of work that is happening in relation to family and carers issues in a diverse range of areas. This edition of the newsletter exemplifies that variety.

On the issue of cultural diversity, we have an article by Richard Bryant Jeffries who talks about working with a Muslim family and the issues that this gives rise to. Richard, a prolific writer, sets this in the context of his other publications. There is a review of an educational film from India which may be of interest to some groups both within India but also for other fields.

The Royal College of Psychiatrists (RCP) continues its commitment to carers, with the current President, Professor Sheila Hollins, identifying family issues among her presidential priorities. There is also the new RCP Education and Training Unit which offers the possibilities of joint working and continuing to promote the family agenda in this area. Following the very successful Partners in Care Campaign which we have reported on extensively in our newsletter, and the commitment of the Royal College of Psychiatrists to the involvement of carers and service users in the training of psychiatrists, I am delighted to see two articles by psychiatry tutors who are actually putting this into practice. Dr Mohammed Yusef Pervez and Dr Karolyn Hurren report on their experience of involving carers in the training of psychiatrists. Karolyn reports on the feedback from the course, and what is really impressive is the impact that people describe following a single session with either a carer or service user. Those attending the session report changes in practice and changes in the way they think about carers. This is a really hopeful message that being provided with the opportunity to listen to a carer's story can actually change what happens in clinical practice.

It is timely in relation to the changes in legislation in the UK that we have an article on Caring in Same Sex Partnerships by Roger Newman. Roger is a joint founder of the Lesbian and Gay Carers Network, and he describes the issues that can arise for gay couples when their caring

role is not recognised in services. Clinicians will need to increase their awareness around this whole area particularly as civil partnerships become more recognised.

There is an interesting article by Michelle Sherman who describes her writings around the area of parental health and the needs of children. Marie Crofts provides a review of this work which will be of interest to anyone dealing with children following trauma. We look forward to Michelle's forthcoming book on Children of Parents with Mental Health Problems.

Martin Atchison reports on a new initiative from The Meriden Programme in addressing the needs of carers of older adults. This development has been received very well and it is impressive from Martin's description of the learning event that was held in May to see the variety of groups with an interest in this area. The flexibility of the Behavioural Family Therapy approach is apparent as workers find imaginative ways of adapting it for those whose intellectual functioning is impaired. Gloria Higgins talks with a lovely mix of sensitivity and humour about the issues that arise in caring for someone with dementia. I'm sure readers will be touched as I was by the depth of love between her husband and herself that survived the inevitable changes in her husband's functioning and personality.

Apart from that, in this edition there are a range of notices about forthcoming events including the ISPS Conference and books that have been published by this group. There is further information on the Meriden Family Conference which we hope that many of our readers will be attending, and on other training events which we have forthcoming.

I hope that you will enjoy very much the range of articles in the newsletter and thanks again to all who have contributed items. If any of our readers have interesting topics they would like to present something on, please get in touch with us. As usual, happy reading: our next edition will be available in September.

**Dr Gráinne Fadden**

*Richard Bryant-Jeffries talks about one of his recent books, 'Responding to a Serious Mental Health Problem' which describes therapeutic work with a Muslim family. This will be of interest to our readers who offer family work in diverse contexts. A prolific writer, Richard describes some of his other works and emphasises the importance of the relationship in all of our therapeutic work.*

## Living Therapy – relationship at the heart of therapeutic process

I began my training in person-centred counselling and psychotherapy in the early 1990s, eager to learn and feeling as though a whole new world of human experience was opening up to me. Little did I imagine that within 10 years I would be writing my own counselling books addressing aspects of counselling and psychotherapy. It has been an interesting journey that still leaves me wondering what on earth my name is doing on the covers of books.

The *Living Therapy* series, in particular, has in so many ways broken new ground in presenting the psychotherapeutic process. I have wanted to enable readers to have what I call a 'therapeutic read'. Yet for many readers what has emerged has been a style described as more of 'a gripping novel' than a textbook. I am actually quite heartened by this, although I know that the style has also been experienced as quite a challenge for some readers and reviewers. I want readers to be affected, touched, challenged, emotionally engaged with the clients, the counsellors, and the process that I describe. These are not books to simply be read from the head, but to also be engaged with at a more visceral level.

Most of my books have formed part of the *Living Therapy* series (which will amount to 17 titles by the summer of 2006), addressing issues ranging from problem drinking, child sexual abuse, eating disorders, mental health, victims of warfare, gambling, death and dying, young people, drugs, work-related stress, disability and more. All the books comprise of fictitious dialogue between a counsellor and their client, and between the counsellor and their supervisor. Some of the books are devoted to a single therapeutic process involving just one client, other titles are in two parts, each part dealing with a different therapeutic process. Included are theoretical comment boxes, questions for reflection, all aimed to bring the reader in a way not only into the dialogue within the text, but also into a dialogue with themselves. How has what they have read affected them? How might they have responded differently? What would they take to supervision? What unresolved issues are they left feeling they need to address?

What has struck me increasingly during my time as a therapist and supervisor, and through researching and writing, is the fact that it is the relational experience of human beings that holds the key to much of the

psychological and emotional damage that occurs in life, and that, therefore, it is the relational experience in therapy (and it does not only have to be within a classical therapy setting) that is the key to healing, growth and the ability to become a more complete and authentically present human being.

Cooper has reviewed findings from a range of studies from researchers and theorists to argue that 'there is growing support for a relationship-orientated approach to therapeutic practice' (Cooper, 2004, p.452).

Writing these books was a journey for me as well. I have real emotion in the writing process. At times it has felt as though the clients have become real. They are real, to me, and I hope that authenticity is conveyed to readers. I feel a physiological reaction as I write a piece of the dialogue, as though it is in some way viscerally alive. It was therefore gratifying to read in the foreword for one of my titles<sup>1</sup> the comment that 'many of the passages in this fictional account gave me goose bumps reading them'.

People sometimes ask me what has been the hardest title to write? They have all offered challenges. Probably *Counselling Victims of Warfare* was the book I was aware of avoiding writing because of what it had to contain – traumatic experiences involving violent death, rape and facing life-threatening situations and events. Yet I knew it was a book that I had to write. It was humbling to address such extreme experiences, and although I was writing a fictional account, the knowledge that real people face these experiences on a daily basis was always very close to me.

This article has come about as a result of my publicising one of the books in particular, *Responding to a Serious Mental Health Problem* in which I address working with a Muslim mother, Fareeda, who is struggling to cope with her teenage son's mental health. She seeks counselling for support, and brings her faith to her counselling sessions. This in turn challenges the counsellor who works on it in her own supervision. In the second part of the book, her son, Ali, attends for counselling during which he experiences a psychotic episode within a therapy session. The application of 'Pre-therapy'<sup>2</sup> is demonstrated as a way of working with a client where there is minimal psychological contact. Configurations within self are also explored as a way of helping Ali make sense of what he experiences within himself.

Having clients from the Islamic tradition created an opportunity to convey something of the teachings of Islam, and in particular the way, in this instance, a mother might view her duty towards her family. I also include examples of Islamic prayer, leaving the counsellor (who is not an Islamic counsellor) to have to process her reactions and find her authenticity within this context

Until recently I worked in substance misuse in Central and North West London Mental Health NHS Trust, and now manage Equalities and Diversity for the same Trust. This has encouraged me to want to promote further the need for cultural and religious sensitivity and awareness amongst counsellors and all who work in helping relationships, whatever their profession. I come back to my comment earlier about relationship. I write from a person-centred perspective which holds the therapeutic relationship to be central to the therapeutic process. In fact, it goes further, for it argues that the relational process in therapy *is* the therapeutic process. Working within a multi-cultural setting or anywhere that involves difference requires the helping professional to be able to form effective relationships with their clients. They cannot have elements of their own natures that stand as barriers to relationship, to authentic communication, empathic sensitivity and the experience of a warm and unconditional feeling of positive regard towards their clients.

Negotiations are currently under way for 13 of my titles to be translated and published in China, something else that I certainly did not envision when I started counselling, or even writing. Later this year will see *A Little Book of Therapy* published, a small book written for those clients who don't make it through the door. It is a simple but direct book, presenting desperate statements expressing what people feel when they get stuck, when life grinds to a halt. It then provides affirming responses offering a fresh insight and direction. It is an experiment that I hope will assist people who choose not to seek help, or may perhaps help them to pick up the phone or do whatever it takes to find someone to talk to. It has been described as a book that 'constitutes a vote of confidence in the human spirit'<sup>3</sup>

When I heard about Meriden, the large geographical area it serves and the way in which the service cascades training to enable professionals to engage with families and their processes, I was moved to make contact, particularly as I know how important it is to work not just with individuals but also with family systems and processes. As a result, I am grateful to have had the opportunity to have shared something of my own work and learning in this short article for the Meriden newsletter.

I want to end by saying that in my view we need to use the word 'heart' more in therapy. Therapy involves working at a relational edge where sometimes silence and eye-contact can be the most powerful and profoundly therapeutic experience, where person-to-person contact

occurs that takes both client and therapist away from merely 'thinking about' an issue to a genuinely heartfelt sense of connection and mutual understanding. It is within and as a result of such moments of contact that the process of sustainable psychological change can occur. Certainly in my experience of working as a counsellor and supervisor, the moments of growth, the human moments that stand out, are those when there was a genuine person-to-person meeting that took us into the realm of the heart. It is here that I believe in the future, we will see crucially important developments in our understanding and practice of therapy.

**Richard Bryant-Jefferies**

**Titles by the author:**

*Counselling the Person*  
*Beyond the Alcohol Problem*  
*Time-Limited Therapy in Primary Care*  
*Counselling a Recovering Drug User*  
*Counselling for Progressive Disability*  
*Responding to a Serious Mental Health Problem*  
*Person-Centred Counselling Supervision: Personal and the Professional*  
*Counselling for Problem Gambling*  
*Counselling for Eating Disorders in Men*  
*Counselling for Eating Disorders in Women*  
*Counselling for Obesity*  
*Problem Drinking*  
*Counselling a Survivor of Child Sexual Abuse*  
*Counselling Young People*  
*Relationship Counselling – Sons and their Mothers*  
*Counselling Victims of Warfare*  
*Workplace Counselling in the NHS*  
*Counselling Young Binge Drinkers*  
*Counselling for Death and Dying*  
*Models of Care for Drug Service Provision*  
*A Little Book of Therapy*

He has also written a novel about childhood trauma and adult alcohol use and is currently seeking a publisher.

Books can be ordered direct from the author online at [www.bryant-jefferies.freemove.co.uk](http://www.bryant-jefferies.freemove.co.uk). Alternatively email [richard@bryant-jefferies.fsnet.co.uk](mailto:richard@bryant-jefferies.fsnet.co.uk) or phone 07930 163173.

Or from the publisher, Radcliffe Publishing: phone: 01235 528820 web: [www.radcliffe-oxford.com](http://www.radcliffe-oxford.com) email: [orders@radcliffemed.com](mailto:orders@radcliffemed.com)

**Reference:** Cooper, M (2004) Towards a relationally-orientated approach to therapy: empirical support and analysis. *British Journal of Guidance and Counselling*, 32, (4).

<sup>1</sup> Prof. Margaret Warner (Illinois School of Professional Psychology, Chicago Campus), in her Foreword to R Bryant-Jefferies (2003) *Counselling a Survivor of Child Sexual Abuse*.

<sup>2</sup> Prouty G, Ven Werde D, and Portner M (2002) *Pre-Therapy, Reaching contact-impaired clients*. PCCS Books, Ross-on-Wye.

<sup>3</sup> Brian Thorne, (Emeritus Professor of Counselling, University of East Anglia), in his Foreword to R Bryant-Jefferies (2006) *A Little Book of Therapy*. Pen Press Ltd., Brighton.

# Mazi Goshta (My Story...)

A review by Paula Conneely who leads on Transcultural issues with the Meriden Programme.

*“The sky is clear and transparent today... a sea of serene blue... I am feeling nice... I am reborn... to a life of new horizons... Can this happen?, Yes... believe this... this can happen... because it has happened...”*

Mazi Goshta (My Story) is a film written and directed by Vidyadhar Bapat and Jatin Wagle. It has been produced by the Jyotirgamaya Foundation, Maharashtra, India, and is in Marathi (the local language) with English subtitles. It dramatises the experiences of Akshay Chitrav, a young man faced with a diagnosis of Schizophrenia, and his family. The film introduces Akshay as a talented keyboard player about to take part in a local theatre production. Then, through the dramatisation of his memories and diary excerpts, takes the viewer through Akshay's journey – from his initial diagnosis through to the present date.

It would appear that the main aim of the film is to dispel some of the myths allied with Schizophrenia and the associated stigmas. Indeed the producers describe the motive of the film to “make all segments of society aware of new approaches to [the] cure of psychological disorders and also facilitate [the] process of destigmatisation”. The film is set in India and reflects



many of the issues related to hospital and community treatment within a cultural framework. Akshay's character is well played and believable, at times tortured by voices and persecutory beliefs associated with the CBI (Central Bureau of Investigation) and at other times deeply troubled by the social impact of his diagnosis and the effects on his family (including the financial burdens of his medical treatment).

The portrayal of Indian mental health provision is interesting. The overriding emphasis is on the medical model, which is particularly evident when the Doctor explains Akshay's

diagnosis to his parents. Throughout the film, numerous references to Schizophrenia as a “Biological condition, like Diabetes” are made, and emphasis placed on the provision of medication and Electro-Convulsive Therapy (ECT). From a Western perspective, the lack of attention to psychosocial aspects and interventions is striking.

When interviewed by the local Doctor, Akshay's parents report his experiencing symptoms for a number of months, with the film documenting an apparent first episode. However, the Doctor is quick to make the diagnosis of Schizophrenia and furnish the parents with a relatively grim prognosis! The general premise is that “cure” is a vague concept but, through medication, an improved quality of life can be obtained. When asking what they can do to help, Akshay's parents are advised to accept the disorder, assist in helping Akshay take his medication and to keep the Psychiatrist informed. However, emphasis is also placed on the family remaining connected and continuing to love Akshay. This message is reinforced when Akshay later meets a young man, also experiencing psychosis, who is mute as a result of his family disowning and “cursing” him.

On a more constructive note, it may be that some of the more complex dialogues within the film are lost in translation. Many of the scenes contain concepts that cannot be directly translated into the English language, and the impact of the film may be very different for those who can understand spoken Marathi. The film does, however, strongly highlight the discrimination faced by many users of services. It attempts to challenge the stigma associated with mental health problems in a direct and positive way. Although Akshay and his friends face challenges within their family lives, in employment and within the general community, the film generally takes a positive stance and shows that recovery is possible. Indeed, Akshay is able to return to his keyboard playing and at the end of the film successfully plays for an audience while his proud parents look on.

According to the Jyotirgamaya Foundation, the film has received an extremely positive response from both professional and public audiences in India, having been recently nominated and screened at the MAMI International Film Festival in Mumbai. The Foundation intends to organise further community screenings, followed by an interactive session with local Psychiatrists. It is hoped that the DVD can be used in this way.

Although perhaps the DVD is not directly of use in western mental health services in the way the makers suggest, it still makes very interesting watching and may promote discussion in terms of the contrast between mental health services in India and other locations. For further information regarding the Project or to obtain the DVD, contact Vidyadhar Bapat at [vidyadharbapat2002@yahoo.co.in](mailto:vidyadharbapat2002@yahoo.co.in)

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# I'm Not Alone – A Teen's Guide to Living with a Parent Who has a Mental Illness

Internationally, about one in four to five families has a loved one with a serious mental illness. Further, approximately half of these people have children. Many of these young people experience embarrassment, confusion, guilt, and fear. However, to date, children of parents with a mental illness have received little attention. British child and adolescent psychiatrist, Alan Cooklin, MD, once said:

*“Children with a parent with mental illness often fall through the professional cracks and are seen as nobody’s responsibility. Nothing is explained to them, and they often receive no help at all to deal with the effects of the parent’s illness. These children need to be seen and heard.”*

Michelle Sherman, Ph.D., and her mother and co-author, DeAnne Sherman (a teacher), have created Seeds of Hope Books ([www.seedsofhopebooks.com](http://www.seedsofhopebooks.com)) with the goal of seeing and hearing these children! The mission of Seeds of Hope Books is to empower families who are dealing with issues of mental illness or trauma by:

- Providing essential information
- Normalizing a variety of reactions
- Encouraging open communication
- Supporting healthy coping
- Offering comfort and hope.

## Effects of Mental Illness on the Family

When a family member has a mental illness, everyone in the family is affected. Everyday life in these families can be confusing and frightening. Nothing feels the same as it was before the onset of the illness. Many young people live with uncertainty, anger, shame, sadness, and fear. The children ask:

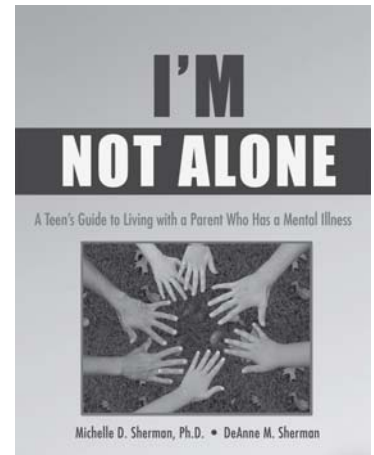
- *What is this all about?*
- *Why is it happening to me?*
- *How do I survive amid this confusion?*
- *What do I tell my friends?*
- *How can I make my parent better?*

Seeds of Hope Books™ provide much-needed hope for families. Our books strive to reassure the teenager and to stimulate helpful discussions. As the reader uses these books, he/she learns that:

- *I am not alone*
- *My parent can get better*
- *Helpful treatments are available for my parent and my family*
- *I can help my parent in specific ways*
- *I have people who want to support me*
- *I can make it through the tough times.*

Despite the pain involved in dealing with mental illness, going through difficulties can bring families closer. The

family unit can actually become stronger by facing the challenges together. Both parents and children may discover strengths, resilience and courage in themselves and in each other that never would have surfaced otherwise. Families can grow by communicating openly and supporting one another – so that they can navigate future difficulties more effectively. Further, given the heightened risk for these young people developing their own problems, our books can serve as prevention and early intervention for at-risk youth.



## New Resource for Teens

*I'm Not Alone: A Teen's Guide to Living with a Parent Who Has a Mental Illness* is a unique, three-part book that focuses on the teenager's experience of living with a parent who has a serious mental illness (depression, bipolar disorder, or schizophrenia). The reader learns about the causes of mental illness, common symptoms of each disorder, the role of mental health professionals, and treatment options. A variety of educational techniques are used throughout the text including stories, poems, inspirational quotes, and key lessons.

Part Two normalizes the teen's experience of a wide range of emotions and teaches effective coping tools. The reader then identifies his/her personal support system and weighs the pros and cons of sharing personal information with trustworthy friends. Throughout the book readers are encouraged to respond to questions, to consider hypothetical scenarios that may resonate with their experiences, and to reflect on their feelings via keeping a journal or diary. Part Three includes frequently asked questions, a glossary, and an extensive resource list. This practical, reassuring book connects with readers so they feel informed, in control, hopeful, and not alone.

Over 100 professionals (mental health staff, teachers, clergy, school counselors) reviewed *I'm Not Alone* and provided invaluable feedback. In addition to having professional reviews, we conducted focus groups with teenagers who said that:

- 14-year old female: “it’s easy to tell that you really care”
- 16-year old male: “it’s comfortable to understand – it didn’t feel like teaching AT you – it seemed genuine”
- 12-year old female: “I would be really happy (if I was

given this book). Since there are no other books like this, I could just pick it up and get some help when I feel insecure”

- 17-year old male: “very encouraging and uplifting and would make me feel better about my family”
- 13-year old female: “I would definitely use some of their suggestions on how to cope”
- 14-year old female: (If I were given this book, I’d wonder) “...is this the answer to all my questions?”

Our greatest authorities, however, in writing our book were families currently living with the situation. We had the good fortune to share our manuscript with several families and receive invaluable feedback from them:

- “I would have done anything to have had this for my kids – I give it an A+!” (a mother of 3 teenagers)
- “My children and I felt like we were the ‘walking wounded’ when my husband first got sick...I loved the workbook style of this book and found it very hopeful and respectful; it provides a lot of tools youth could use to cope...” (a mother of two teenagers).

In sum, *I’m Not Alone* is the first of its kind focusing on teenagers living with a parent with a mental illness. It

provides facts, practical tips, opportunities for reflection and journaling, reassurance and hope. It is useful for both youth and anyone working with teenagers, ranging from mental health professionals to clergy, teachers and pediatricians.

**Michelle D. Sherman, Ph.D.**  
**Oklahoma City, Oklahoma, United States of America**

Dr. Sherman and her mother have also written another book for teens, *Finding My Way: A Teen’s Guide to Living with a Parent Who Has Experienced Trauma*. *Finding My Way* is now available through their website [www.seedsofhopebooks.com](http://www.seedsofhopebooks.com). *I’m Not Alone* will be ready in late Summer 2006. Dr. Sherman can be reached at [authors@seedsofhopebooks.com](mailto:authors@seedsofhopebooks.com)

*Dr. Michelle Sherman is a licensed clinical psychologist and an expert on the effects of trauma and mental illness on the family. She is the Director of the Family Mental Health Program at the Oklahoma City Veterans Affairs Medical Center and the co-chair of the Family Studies Team of the South Central Mental Illness Research, Education and Clinical Center (MIRECC). She is also a clinical associate professor in the Department of Psychiatry and Behavioral Sciences at the University of Oklahoma Health Sciences Center.*

## FAMILY WORK IN EARLY PSYCHOSIS



**Venue: Uffculme Centre, Birmingham Dates: 25th – 29th September 2006**

A five day skills-based training course on working with families in early psychosis, covering the following topics:

- National Policy and Guidelines on family work in early psychosis
- Literature review on family work in early psychosis
- The response of families
- Issues relating to grief, loss and other emotional reactions in families
- Diagnostic uncertainty
- Confidentiality conflicts
- The needs of siblings and young people
- Communication skills
- Problem solving skills
- Integrating different models of family work in early psychosis services
- Implementing family work in early psychosis services.

**Cost:** £600 per participant including lunch, refreshments, course manual and all course materials

For further information please see our website [www.meridenfamilyprogramme.com](http://www.meridenfamilyprogramme.com)

This is the second course on Early Psychosis that we have held. The first course (March 2006) was extremely well received as evidenced by comments from participants:

- It was refreshing to use Behavioural Family Therapy in a creative and sensitive manner for first episode families
- Very relevant to the type of service we want to develop. Inspired me to ensure we put into practice what has been learned
- Very clear and appropriate, well illustrated with appropriate examples of how to use techniques, with time to practice
- Felt this was excellent for Early Intervention workers – felt that it balanced theory and practice very well
- Excellent balance of theory, practice and discussion.

# New Centre at the Royal College of Psychiatrists

*Lynne Christopher describes the Royal College of Psychiatrists' new Education and Training Centre. We look forward to having a close relationship between the Unit and the Meriden Programme.*

## The Royal College of Psychiatrists

The Royal College of Psychiatrists is the professional and educational body for psychiatrists in the United Kingdom and the Republic of Ireland. The College has been in existence since 1841. It received its Royal Charter in 1926 and in 1971 it received a Supplemental Charter to enable it to become 'The Royal College of Psychiatrists' as it is known today.

The Royal College of Psychiatrists promotes mental health care:

- Setting standards and promoting excellence in mental health care
- Improving understanding through research and education
- Leading, representing, training and supporting psychiatrists
- Working with patients, carers and their organisations.

Last year the College launched its new Education and Training Centre. It has already rapidly expanded and aspires to become an innovative 'Centre of Excellence'. Building on the College's strong professional reputation, its research profile and its existing provision of national events, it has introduced a new range of high quality learning opportunities for psychiatrists and other related health and social care professionals, service users and carers.

### Location

The new Centre has set up a main office base at Standon House in Aldgate, London E1, where the College has some training facilities, and has opened a Regional Development Office in Leeds. As it continues to grow, it will offer a wide range of events throughout the UK and Ireland.

### The Changing Health Care Agenda

In response to the changing health care agenda, the College's Education and Training Centre will not only focus on the needs of psychiatrists, but it will work with other professions to develop a wide range of specialist and cross specialist programmes. Its provision is being shaped to meet the future needs of all mental health and social care professionals, their



## The Royal College of Psychiatrists Education & Training Centre

Professional Development in Mental Health Care  
*Raising standards .....achieving excellence*

services and importantly, the needs of their patients, service users and carers. Also, by being part of the College's Research and Training Unit, it can focus its events on the most up to date issues and development areas which are influencing mental health today and in future years

### Client Focused

The Centre is priding itself on being entirely client-focused, proactive and flexible. It will constantly strive to keep the needs of its clients at the very heart of its curriculum development, and to offer a provision of excellent learning opportunities underpinned by high levels of customer service and event management. All training and development events are carefully planned and fully evaluated to ensure client satisfaction and continuous improvement.

### Expertise and Collaboration

The Education and Training Centre is drawing upon a range of expertise. It is collaborating with other organisations to ensure that its provision is enhanced by a breadth of knowledge and experience derived from other professionals who share the same values, aspirations and goals. By working in partnership with others, the Centre can build on best practice and harness the potential of the future. Examples of partners: the NHS, Social Services, Universities, Colleges and other educational providers within the private and voluntary sectors of health and social care. Additionally the Centre values and encourages the important contribution that patients, service users and carers can provide in helping raise standards by understanding and responding better to their needs.

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# Carers Involvement in Psychiatric Training – an experience

The Royal College of Psychiatrists and the Princess Royal Trust for Carers launched a national campaign “Partners in Care” in January 2004 to highlight the problems faced by carers of all ages of people with different mental health problems and learning disabilities. The campaign was designed to encourage true partnership between carers, patients and professionals. The Royal College of Psychiatrists committed to prepare a code of conduct for professionals on issues related to carers. The Royal College decided that from June 2005 it would become mandatory for psychiatric trainees to receive training directly from people who experience mental health problems and their carers, and this will be part of the accreditation visit to all training schemes by the Royal College of Psychiatrists and Postgraduate Medical Education and Training Board (PMETB).

Services users and carers may wish to become involved in the field of education. Taking on a positively valued role in education and training may contribute to a person’s self esteem and capacity to support others and enhance the process of recovery (Masters et al 2002). Walters et al (2003) have demonstrated that service users and carers who take on these training roles benefit, including the development of a more balanced doctor/patient relationship and better appreciation of professional perspectives. Service users and carers tend to value those services and practitioners willing to work in partnership with them and value their strength and knowledge about what works best in promoting or sustaining recovery. Tew et al, (2004) anticipate that carers’ involvement in training can confer benefits on all involved and will lead to the development of practitioners capable of delivering improved and more relevant outcomes for carers and service users.

As a practitioner, I have always been very passionate and committed to work in partnership with carers and service users and this has been an integral part of my clinical practice. As a Clinical Tutor responsible for the training of trainees in my hospital, I proactively approached carers and started the process of involving carers in the training of trainees. This is an exercise to share my experience of carers involvement in the training process of psychiatrists and can be best described as a journey which started with informal discussions with a carers’ group and then went through different stages. These sessions were well received by the trainees and were appreciated by carers and valued and rated very highly.

We delivered two sessions and in each session a carer shared their personal experience with the trainees and senior medical staff which was well received by all.

- The first carer was a father of a young man who suffers from serious mental illness and is receiving treatment from mental health services. He is in recovery stage and is receiving rehabilitation from community services. Our carer shared his experiences by telling the story of his son’s illness as he saw and observed it as a father. He described how he saw his son withdrawing from society and social interaction very slowly which at the time was un-noticeable, but looking back now was significant. He described how he saw his son passing through different stages of the illness but was not aware of it at the time. The trainees showed an empathic understanding and the interactions were positive for both. The carer felt that this was a positive and empowering experience.
- The second carer was a mother of a male patient who is in remission from his illness and living in the community with appropriate support. She chose to tell us of her interactions with services during the years, describing her positive and at times unpleasant experiences. This was an emotionally charged session but there was no anger or bitterness expressed. The meeting was smooth and interactive; listeners were attentive and sensitive in their responses. This was an example that people can draw our attention to the weaknesses and deficits in services which can be modified without additional resources. This was an excellent way of giving developmental feedback without generating a feeling of hostility or negativity.

Delivery of training can still feel daunting to potential presenters but it can also feel immensely rewarding if it goes well, as a chance to be heard and an opportunity to influence in a real way the attitudes and professional practice of practitioners.

## Planning

It is very important that the whole process is carefully planned and followed through.

- Explore and identify the carers’ organisations in your area – usually they are more than willing to participate
- Identify the willing participants and it is important to treat carers as equal contributors. They are experts by experience and can contribute in a very positive way.
- Meet and discuss with the carers the aims of their involvement in psychiatric training and emphasise that this is not an opportunity for protesting or raising personal negative experiences, rather a time to give a group perspective and not individualise it. This is an opportunity to focus on what would be helpful and making suggestions for improvement in behaviours or services.

## Format of presentation

Delivery of training can be anxiety provoking for the carers. They may not be familiar with doing this or comfortable and they may need support and reassurance. Carers should feel able to express their feelings and experiences openly including elements of service, service provision and their contact with professionals. It is important to discuss with the carers their needs in relation to their presentation. They may need help with preparation. Some may not be familiar with the computer equipment and may need IT support. It is important to discuss with them the duration of the session and the format. Different carers may want to do it differently.

- Questions and answers session
- Two way conversation
- Story telling.

## Preparing the audience

It is a new experience for trainees to understand that they are at the receiving end and in a way it is role reversal but this is a significant learning and sharing opportunity and can be powerful and engaging while listening to direct personal experience of emotional and practical problems carers face in their day-to-day life. The following may be stressed to the audience prior to the actual session.

- Mutual respect
- Need for sensitivity
- Need for thoughtful questioning following the sessions.

## Logistics

For the majority of the carers, being a part of training will be a new experience. The impact of providing care along with the distress of being stigmatised may lead to lack of confidence. It is important that they are properly prepared and supported during the process. This may be a novel and first experience for some carers.

**VENUE:** Discuss with carers the venue for the meeting and explain about the lay out. It may enhance their confidence if they are able to visit the venue before the presentation and familiarise themselves with the surroundings. Provide them with adequate information about parking facilities and discuss and facilitate transport needs

**WELFARE:** Someone should be identified as a KEY person to liaise with the carers who will be responsible for their welfare during this process, meet and greet them at their arrival. Make sure that their expenses are paid promptly

## The session itself

You need to be aware that these presenters and sessions are different compared to our normal teaching sessions. There is a need to be more sensitive to the needs of the

carers who are participating as trainers because they are not professional trainers but rather Experts by Experience. The sharing of personal emotional experience can not only be painful but also anxiety provoking. This needs a good Chairperson who is able to control the audience and support the carer during the process. Following are a few useful things to keep in mind.

- Introduce the presenter and explain the process, duration and format of the presentation
- Check frequently with the presenter during the session
- Manage and control the Question and Answer sessions
- Express your thanks at the end of the presentation.

## Debriefing

It is important that arrangements are in place to meet the carers following the completion/delivery of training to discuss any issues which may arise during the training process. There may be a need for some support if difficult issues have been raised. Express your thanks and write to them acknowledging their participation in the training process.

Involving carers and service users in the training process is a new initiative and is evolving. This is a learning opportunity for us who are responsible for training and will lead to more responsive and proactive clinicians. There is a greater need to discuss ways of improving shared training delivery and this can be best achieved by regular evaluation of this process.

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## Royal College of Psychiatrists – Presidential Priorities 2005-2006

It is really positive to see that the current President of the Royal College of Psychiatrists, Professor Sheila Hollins, is committed to continuing to work with service users and carers, and to the implementation of the work that was begun in relation to this area by the previous president, Dr Mike Shooter. Sheila has identified among her priorities the following:

‘To work in partnership with users, carers and other disciplines with a commitment to improving mental health services especially for the most vulnerable’

### ACTION

- Continue to work with the users and carers committee
- Implement the recommendations of the Partners in Care campaign
- Work with the Mental Health Alliance
- Invite a focus group of carers who are psychiatrists to meet the President and Deputy Registrar on a regular basis
- Involve users and carers throughout any College campaign.

### Book review: **Living with a parent with PTSD (a teen’s guide)**

This book is a really useful resource for young people and their families where a parent is experiencing post traumatic stress disorder (PTSD). It describes symptoms in terms of behaviour and how they would manifest in the parent. It gives clear rationales for these behaviours and examples of what parents might have experienced.

It is easy to read and young people could select relevant chapters without reading the whole book, and there are frequent references in each chapter to issues or concerns discussed elsewhere in the book. There are useful suggestions and advice on coping with behaviours and feelings and the language appeals to young people.

As Post Traumatic Stress Disorder is a condition that many professionals lack understanding of, this is an extremely helpful guide to enhance clinical knowledge. In addition, professionals working with these families may feel more confident in helping both the sufferer and their children living with the difficulties outlined in the book.

Having read the book, a young person would feel much more empowered and have a greater understanding of why certain things were happening in their family. It gives them an opportunity to reflect on their own feelings and develop a plan to cope with their situation whilst ensuring they acknowledged the experience and subsequent reactions associated with this from their parent’s perspective.

In summary, this is an exceptional book, which should be recommended to any young person who finds themselves in this situation. A really informative read.

Marie Crofts.

## Rethink/National Institute of Mental Health (NIMHE)

National Early Intervention Programme  
The 3rd UK National Early Intervention in Psychosis Conference,

Tuesday 3<sup>rd</sup> October 2006 at the  
International Convention Centre, Birmingham

This one day event features national and international speakers, a range of workshops and the chance to talk to UK and International EI ‘experts’ unplugged.

### Seminar and Workshop Topics include:

- Delivering Early Intervention in Rural Communities
- Working with Siblings
- Working with Black and Minority Ethnic Groups
- Raising Awareness in Schools
- Tackling Stigma.

The Conference will also present the latest research, international good practice and learn from the experiences of UK EI practitioners, service users and carers, closing with a service poster display showcasing the work in the UK.

**Registration Fees: From £162** (Early Bird before 31:6:06) **£200** (Standard). See [www.iepa.org.au](http://www.iepa.org.au) for **registration and free IEPA Membership. For informal enquiries contact Marcia Thorpe** [earlyintervention@rethink.org](mailto:earlyintervention@rethink.org)

rethink



International Early  
Psychosis Association

NHS

National Institute for  
Mental Health in England



# Impact on Trainees of Involving Users and Carers in Teaching

The Royal College of Psychiatrists together with the Princess Royal Trust for Carers have recently concluded a campaign highlighting the needs of carers and promoting working in partnership to enable better care for people who need to use mental health services. As part of that campaign they held a series of workshops for members of the Royal College of Psychiatrists who have

Table 1: Feedback on Carer's Session

Amount you agree	Not at all	A bit	A lot	A great deal
1. I found the session interesting	0	1	10	6
2. I learnt new/unexpected things	0	4	9	4
3. I have a better understanding of a carers' perspective	0	2	10	5
4. The session was well organised	0	0	9	8
5. My practice will change as a result of this session	*16 replies 0	2	12	2
6. Write down one or more key points you have learnt from session	<ul style="list-style-type: none"> <li>• Enlightening to hear carer's perspective</li> <li>• Listen, empower patients and carers</li> <li>• Importance of treating the issue more broadly</li> <li>• Involve and listen and try to understand carers' role</li> <li>• Carers' stress / emotions / distress</li> <li>• How we inadvertently become callous and condescending</li> <li>• Educating the carers</li> <li>• Sounds like we do a bad job</li> <li>• Importance of hospitalisation on carers.</li> </ul>			
7. Will you change your practice? If so, how?	<ul style="list-style-type: none"> <li>• Yes, I will try and actively involve carers and patients and find out about support groups</li> <li>• Try and have regular meetings with carers to get these perspectives</li> <li>• I will think more about an individual's perspectives rather than being judgemental</li> <li>• Make carers' perspectives and needs routine to my psychiatric evaluation, documentation and follow-up</li> <li>• The importance of working together with carers</li> <li>• Try to find more time to explore carers perspective</li> <li>• Need to co-operate and co-ordinate with our colleagues</li> <li>• Be more collaborative in treatment approach</li> <li>• Listen to patients and carers more</li> <li>• Trying to explain in a simple way avoiding scientific jargon</li> <li>• Increased awareness of issues</li> <li>• Desperation of people who need hospitalisation.</li> </ul>			
8. Would you like another session on carers' issues? If so, what topics would be of interest/value?	<ul style="list-style-type: none"> <li>• Yes, how to set up forums</li> <li>• How to access services, particularly from GP point of view</li> <li>• Listening to another carer's point of view</li> <li>• Their experiences and expectations</li> <li>• More carers, experiences / suggestions</li> <li>• How carers help their relatives / friends, what they do to understand them.</li> </ul>			
9. How could this session have been improved?	<ul style="list-style-type: none"> <li>• Good</li> <li>• It was great, very lucid</li> <li>• Please do not assume audience have no experience of mental illness / caring for mentally ill relatives in their private lives.</li> </ul>			
10. What grade of experience do you have?	4 consultants, 1SpR, 9 SHOs, 1 clinical attaché, 2 undeclared			

Table 2: Feedback on Service User's Session

Amount you agree	Not at all	A bit	A lot	A great deal
1. I found the session interesting	0	3	10	6
2. I learnt new/unexpected things	0	7	9	3
3. I have a better understanding of a carers' perspective	1	3	12	3
4. The session was well organised	0	3	11	5
5. My practice will change as a result of this session	1	9	8	1
6. Write down one or more key points you have learnt from session	<ul style="list-style-type: none"> <li>• How much service users are asked their opinion on services</li> <li>• The importance of good communication, user involvement and trying to fit yourself into the patient's position</li> <li>• Users' likes and dislikes e.g. large meetings</li> <li>• Try to listen and consider users' views and perspectives more</li> <li>• A good overall orientation</li> <li>• Importance of listening / giving time to giving information</li> <li>• Relationship of issue of stigma and paternalism</li> <li>• Users can be motivated to realise their potential</li> <li>• Service users' perspectives, needs and expectations</li> <li>• The impact of hospital stays on patients, what patients expect from us</li> <li>• User focus groups</li> <li>• That people are employed as service user reps (did not know they existed).</li> </ul>			
7. Will you change your practice? If so, how?	<ul style="list-style-type: none"> <li>• Re-iterated the importance of listening to service users</li> <li>• To be more aware and vigilant about providing information and listening</li> <li>• Yes, I will, to adjust to users likes</li> <li>• Communicating in a better way and help service users make an informed choice</li> <li>• Yes, I will find out if patients are aware of how they can get involved in user groups</li> <li>• Definitely, now have a better perspective on users views and points where I need to improve on</li> <li>• To be more receptive to users' and carers' views</li> <li>• How to give more time to these issues during consultations</li> <li>• Try a collaborative approach</li> <li>• Be more open and ask for criticism of my practice</li> <li>• I'll try</li> <li>• Like to attend user group meetings</li> <li>• If time allows me to.</li> </ul>			
8. Would you like another session on users' issues? If so, what topics would be of interest/value?	<ul style="list-style-type: none"> <li>• To hear a service user explain how they found their experience of services, e.g. Being admitted</li> <li>• Techniques to resolve complaints, changing attitudes on ward</li> <li>• Experience of stigma e.g. for people with personality disorders</li> <li>• What qualities patients value most in their doctors</li> <li>• Yes, their personal stories and experience</li> <li>• Local information, practically how to get involved</li> <li>• Yes, stigma</li> <li>• No</li> <li>• Not necessary at present, would value focus groups being set up in North Durham in-patient units</li> <li>• Definitely, more about regional groups</li> <li>• Service users and Mental Health Act (present and new).</li> </ul>			

9. How could this session have been improved?	<ul style="list-style-type: none"> <li>• It is very informative and I'd be grateful for two way discussion</li> <li>• More detailed presentation</li> <li>• More time</li> <li>• More direction about where we were going</li> <li>• Specific patient views on medical staff, what was helpful, what wasn't</li> <li>• More case examples of more variety.</li> </ul>
10. Are you a consultant/ SpR/ SHO/ staff grade/ clinical attachment/ medical student/ other?	5 consultants, 12 SHOs, 2 clinical attaches.

responsibility for training the current generation of trainees, stating that they would expect to find evidence that training programmes were involving users and carers in local training programmes (Fadden et al, 2005). This does raise a series of challenges for tutors who have the task of arranging programmes and ensuring the training is delivered. Sometimes these barriers can seem enormous but I would encourage others “to get started and have a go” as the impact on trainees is worth the effort.

### Local training programme

Our programme covers the trainees working in the north of County Durham who have time set aside on a Friday morning. The programme has developed to include the elements expected by the college and includes case conferences, an evidence-based journal club, deliberate self harm supervision, audit presentations and occasional visiting speakers. Practically, it is easier to give some time from the programme over to involving users and carers in training than trying to find time from somewhere else. The local Education committee decided, that as a trial we would devote a session each for a carer and a service user in each six month block. As the organiser of the programme, I had been to one of the college workshops and had started to build relationships with users and carers who were interested in this area and wished to get involved, so I already had in mind likely people who would come along. The carer and user I approached were both keen to be involved. We had some discussion about the size of audience and any support they would like from either me or anyone else.

### Carer's session

This was the mother of someone with a diagnosis of bipolar disorder and she gave a very moving account of her experience as a mother, the development of her understanding of her daughter's illness, her experience of how professionals behaved, and the stigma felt by her. Initially the family all tried to avoid the illness and wished to keep it secret in the family. Her presentation lasted about forty minutes with time for feedback and discussion. She struck the right balance between saying what experiences had been good as well as ones that had been very unhelpful, avoiding identifying any specific individual. She was concerned afterwards in case she may have been too explicit, but my feeling was that these sessions should not be too comfortable for the audience – otherwise the purpose would be missed. There was a

mixed audience of consultant psychiatrists and trainees, 17 in total.

### Service User's session

The service user session was led by a person employed by the trust as a user representative with a background in training who gave an overview of the roles that users might have within health care organisations rather than a personal description of his experience as a recipient of care. Again we had met to discuss what he could include (the time was limited to 1 hour in total to fit in with the postgraduate education programme). Nineteen people attended the session.

### Comment

The impact of these short presentations is striking. If even a few people start to think about their own behaviour and what changes they need to make then the effort has been worthwhile! The feedback also has identified learning needs of the medical staff group that we can try and address in further sessions.

### Useful resource

Fadden, G., Shooter, M. and Holsgrove, G (2005) Involving carers and service users in the training of psychiatrists. *Psychiatr. Bull.*, 29, 270-4.

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## SIBLINGS WEBSITE

Readers may be interested in a new website for brothers and sisters of people with special needs.

Sibs is for people who grow up with a brother or sister with special needs, disability, or chronic illness. There are at least two million of these siblings in the UK. They need support and information at different stages of their lives.

The website states as its purpose: ‘To make a positive difference to the lives of siblings – to make growing up with someone with special needs a bit easier.’

**www.sibs.org.uk**

# Caring in Same Sex Partnerships

When my partner was diagnosed with pre-senile dementia in 1992, the consultant told me to leave him in their hands and go away! There was no recognition of what 22 years of living together might mean, and no attempt to understand any of the raw feelings involved. When he was subsequently moved from the hospital ward to a residential home, without any reference to me, I knew then how few rights we had as gay men and lesbian women, and how little service providers knew about our situation. With unique foresight, the Alzheimer's Society subsequently did not take many years after that to own this issue and form a Lesbian and Gay Carers Network; it committed funding for phone lines and printed display materials to show their intention that our unique needs were to be met.

We soon realised that it was one thing to set up an organisation controlled from the centre of the Society but another thing to ensure ownership of the cause at area and branch levels. Indeed it is only in the last year that we have begun to see a significant change in response to Lesbian and Gay issues from these levels. Branches have started to phone our lines, with volunteers saying 'I am dealing with someone in the early stages of dementia and I think they may be 'gay'. What should I be doing to enable them to receive the best service from me?' Similarly we have begun to receive invitations to speak at conferences and training sessions, asking us to outline the distinctive needs of Gay, Lesbian, Bisexual and Transgender people who are carers of people with dementia. The recent formation of an Inclusion Unit within the Society with the Network as a key participant has reinforced the feeling that our needs are clearly as important as the other groups at the centre of the Society's work.

We also realised that professionals and service providers needed to have their Equal Opportunities principles refined in the light of having to come to grips with real gay people who might now be more open about their sexuality. They might wish to be treated with dignity and empathy because they were gay, and not treated secretly, as if their orientation was something to be swept under the carpet. When one of the callers to our helpline told us that he had been given our number by the consultant dealing with his gay partner, then we knew that 'we were on our way' and that other calls from similar destinations would be likely. However we also get calls from men and women whose experiences with professionals and service providers are much less satisfactory.

A GP told one of our clients that he could not be expected to care for his relative since he was gay, and therefore was assumed to have multiple sexual partners (and this was clearly not the case!).

Yet we also realised that it was wrong to assume that all older gay people had the same feelings when in need. Our successful bid for funding from 'Comic Relief' was based on the statistic that with 700,000 people suffering from dementia, and with probably at least 5% of the adult population being lesbian or gay, then 35,000 gay people were likely to have dementia; but we did not and do not know where the majority of those people are. Dealing with gay carers is in some ways, the easy part. Dealing with gay sufferers, who have not 'come out', is much less straight forward. In consequence we are starting,

what may be a long process, of trying to determine how we can produce a service which will be happily taken up by single gay people, who are alone, and suffering from dementia, and not necessarily 'out of the closet' or wanting to be so.

Possibly we are also 'suffering' from the attitudes of those who rejoice in the changes taking place in our society and who assume that the issues of gay rights and the needs of gay people are yesterday's issues. With Equal Opportunities legislation, civil rights partnership and the brave public acknowledgement of their sexual orientation by well known national figures, there is the assumption that all is well and that people no longer need to care whether someone is gay or not. Sadly this is not the case. We still get calls from men and women who are isolated in their communities and are almost terrified of being known to be gay. Without support groups available to them as gay people, we still hear the relief over the phone as the caller knows that at last, he or she, is talking to someone who is 'family' and who is gay too. It is worth remembering that older people bring into the present, memories of far less happy times when they were entrapped and almost hunted down because of their sexuality, and therefore are less willing to acknowledge their sexuality.

Demographic changes in our society will mean that in the next few years, with a progressively ageing population, there will be more gay people over 60 than those under 26. Older gays will probably have the confidence to begin to make greater demands to have their needs met, and the gay community will have to take this change on board. It will also mean more, and not less, gay people will be suffering from dementia, and the implications for service providers and for the Alzheimer's Society and the Carers Network, are therefore potentially huge. Significantly in recent weeks, Age Concern has published a resource pack for professionals entitled 'The whole of me... - Meeting the needs of older lesbians, gay men and bisexuals living in care homes and extra care housing'. Also significantly our web site hosted within the Alzheimer's Society web site ([www.alzheimers.org.uk](http://www.alzheimers.org.uk)) is receiving an increasing number of hits.

Our aim is for the Lesbian and Gay Carers Network to be ultimately abolished because the system for those caring for people with dementia and for sufferers themselves is so good that a separate group will no longer be necessary. We are a long way from that happening and, in the meantime, we will continue to make our service available to all who contact us.

The resource pack is available from Age Concern England, Astral House, 1268 London Road, London SW16 4ET [www.ageconcern.co.uk/openingdoors](http://www.ageconcern.co.uk/openingdoors). The Lesbian and Gay Carers Network Inclusion Pack is available from Alzheimers Society, Gordon House, 10 Greencoat Place, London SW1P 1PH. Email [www.alzheimers.org.uk/gaycarers](mailto:www.alzheimers.org.uk/gaycarers)

**Roger Newman**  
**Lesbian and Gay Carers Network**

(Roger Newman is a joint founder of the Lesbian and Gay Carers Network and can be contacted through the Alzheimer's Society National Helpline on 0845 300 0336 or on 01843 220932,) email [roger-newman@lineone.net](mailto:roger-newman@lineone.net)

# ISPS UK

These are a few lines to tell you about ISPS UK. ISPS stands for the International Society for the Psychological Treatments of the Schizophrenias and Other Psychoses. There are ISPS networks in many countries around the world. ISPS UK has around 300 members drawn from all the mental health professions (clinical psychologists probably have the strongest showing) as well as service users and carers.

We have three core aims.

- (1) To promote greater knowledge of the different psychological approaches to psychosis and psychotic experiences, and their better integration with each other and with pharmaceutical approaches. The psychological approaches include psychodynamic, cognitive-behavioural, arts-based, family and holistic approaches.
- (2) To draw together and support individuals who are interested in the psychological understanding and treatment of the psychoses, and who want to develop psychological approaches in their own places of work.
- (3) To provide a forum where professionals, service users and carers can share their ideas, hopes and struggles, and can examine their differences in constructive dialogue and debate.

One of the main things we do is organize conferences exploring areas of psychological significance, which don't get much of a hearing elsewhere. In the last six months we have organized day conferences on 'Culture and Psychosis' and on 'Psychosis and Spirituality', and later this year we are putting on a conference in London on 'Working with Emotion in Psychosis'

(November 1<sup>st</sup>) and in Newcastle on 'Making In-patient Wards Therapeutic' (December 1<sup>st</sup>). These will be followed next year by a workshop on the effectiveness of arts therapies for psychosis, and our biennial two-day residential conference in the lovely city of Bath at the end of March.

As Chair of ISPS UK, I know that each of these conferences is a labour of love by a few of our members who feel passionately that they want to generate greater awareness and understanding of an aspect of their work they care deeply about. The conferences are also a way that ISPS can gain enough income to keep going and do the other things we do, as we don't get government grants or seek drug company sponsorship. These include publishing a regular Newsletter, running a lively email information and discussion group for members, and supporting local groups and special interest sections. One of these is a Carers Section, co-hosted by Dan Pearson, Grainne Fadden and Jen Kilyon. ISPS is also developing a book series, for which Brian Martindale is series editor. *Models of Madness*, the first in the series, has been a great success, selling 2000 copies in its first two years. The first British title in the series, *Experiences of Mental Health In-patient Care: Narratives from Service Users, Carers and Professionals*, is due to be launched at the conference next March.

If this has whetted your appetite to find out more you can go to our website (which is still being developed) at [www.isps.org/uk](http://www.isps.org/uk), or contact our admin assistant Marianne Taylor at [Marianne@ispsadmin.co.uk](mailto:Marianne@ispsadmin.co.uk). Membership costs £30 a year (£10 for people on low income).

**David Kennard**  
Chair, ISPS UK

## 2007 ISPS UK RESIDENTIAL CONFERENCE

Psychosis: Experiencing • Understanding • Recovering

University of Bath 26-27 March 2007

Keynote Speakers: Johan Cullberg (*Sweden*) Courtenay Harding (*USA*)  
Peter Chadwick (*UK*) Douglas Gill (*UK*) Glynn Harrison (*UK*)

The aim of the conference is to draw together three processes that are central to contemporary approaches to psychosis.

- respecting and exploring **the experience of psychosis**, through verbal and non-verbal forms of self-expression
- integrating different attempts to **understand the causes** of psychosis as a truly bio-psycho-social phenomenon
- developing the skills, attitudes and values that hold **hope of recovery** from symptoms and disabilities for all.

The conference will be relevant to all mental health professionals interested in psychological approaches to psychosis: psychiatrists, nurses, psychologists, arts therapists, occupational therapists, social workers, family workers, as well as service users, carers, service managers and commissioners.

To register your interest for further information contact Annabel Thomas, ISPS UK Conference Organizer, PO Box 707, Gerrards Cross, Bucks. SL9 0XS; Tel/Fax: 01494 580101 email: [isps@athomas99.freemove.co.uk](mailto:isps@athomas99.freemove.co.uk). Check out our website at [www.isps.org/uk](http://www.isps.org/uk).

# Family Working in Older Adults Services

I am very pleased to be writing about this learning event in this edition of the newsletter, and very pleased generally that the event actually took place! Our original venue had a power cut 2 days before the event was due to take place, and we didn't find out about this until the day before. Given the uncertainty about whether the venue would be functional or not in time, it was fortunate that we were able to find a different venue and managed to contact everyone to inform them of the new venue. My thanks are given to Marie Murphy and the team for their efforts in ensuring that the event went ahead.

I chaired the day and started by giving some background to the 'Older Adults' focus of the day, given that organisations linked with the Meriden Programme had started to request that there be some developments within older adults services around family working. A special interest group had met 3 times and there was an open invitation for all those present to attend further meetings.

The first speaker was Carol Courtney, Admiral Nurse Manager, Birmingham and Solihull Mental Health Trust. She spoke about the history of the Admiral Nursing Service, which started twelve years ago and there are fifteen teams totalling around fifty Admiral Nurses across the country. They are all qualified nurses with extensive experience of working with people with dementia. Their core business is to support carers of people with dementia. This is done in a variety of ways including practical advice, emotional support, development of coping skills, Cognitive Behaviour Therapy and so on. Part of the role is also to promote best practice within services, which is carried out through a mixture of teaching other agencies and acting in a consultancy capacity. Carol had recently completed the Behavioural Family Therapy (BFT) course and was hoping to incorporate it into her working practice.

Maria Parkes then presented on the Dementia Support Worker role within the Alzheimer's Society. The range, flexibility and the collaborative nature of the role were highlighted. Maria described a couple of case studies to highlight the nature of her role. One case study showed how, in order to offer emotional support to a carer, Maria liaised with a social worker and an interpreter. In order to provide a cohesive package of care, she also worked with carers in order to help them appreciate the experiences of the person with dementia. Maria has recently completed BFT training and was looking to work with colleagues from other agencies in order to deliver family work.

Carol Bannister, Consultant Psychiatrist, and Dave Mushrow, Community Mental Health Team Manager, from Oxford and Buckinghamshire Mental Health NHS Trust, presented on Systemic Family Working in an Older

People's Service. They outlined how the service developed through the building of skills within an interested group of clinicians and how the family sessions are delivered, with some of the team observing the process and giving feedback during sessions. The team outlined some of the issues they have dealt with. For example, when someone in a family becomes unwell, there are changes in roles that impact on different family members in different ways and can lead to difficulties for that family. The model of therapy works to bring families together to share expectations and view difficulties as something that all the family need to be involved in rather than focus on a particular individual.

Gloria Higgins then spoke movingly and humorously of her experience of caring for her partner, who was suffering from dementia, over a number of years. Many in the audience reported that they had found this presentation informative, enlightening and that it would inspire them to focus more on carers when they returned to work. Gloria has written this up as an article in this newsletter.

Sarah Cottingham, Clinical Specialist Practitioner, Carer Support, Sandwell, who had worked with Gloria Higgins over a number of years, then spoke about her role in supporting carers of older people with mental health problems. She only works with carers who are at risk of developing, or have developed mental health problems themselves. She is an Occupational Therapist, so having a professional background and a role in supporting carers enables her to provide support from a valuable viewpoint. Sarah spoke about some of the issues that she has supported people with, and how a wide range of emotional, familial and social factors impact on how a person copes with the role of caring. She then talked through the process of how she supports a carer, about the importance of accepting a situation they don't necessarily have to like, about exploring expectations, guilt, and developing understanding of the illness. The main part of her role was to provide emotional support, as well as the physical and practical concerns that a carer may have. Sarah also read out some poetry, and referenced this quote, "It is in the shelter of each other that the people live". This underlined the importance of the human contact that people need in order to deal with their own situations.

Following lunch, Verity Mitchell, Senior Lecturer, Staffordshire University, spoke about the recent service development guide *Everybody's Business – Integrated Mental Health Services for Older Adults*. This guide is clear about psychological therapies being part of the mainstream within older adults' services, as it has been widely acknowledged that older people have had poor access to these therapies in the past. Verity also outlined some other developments, for example the Social Psychological

Experience and Relationship Centred Care. All of the above link well with and support the implementation of BFT within older adults settings and Verity said there is a move within services to start using more psychological based approaches. Verity then went on to outline how the BFT model could be adapted to apply to families where someone had dementia. She found that breaking down components of the model had been useful, for example, using a single card for each step of the problem solving process rather than present families with the whole process on one sheet of paper. Also, simplifying some of the language used had been an important factor in applying the model. She generally advised people to 'give it a go' with the general principles of the model being applicable to working with older adults.

The dates for the forthcoming special interest groups for older adults were circulated and it is hoped that the ideas and interest generated on the day would help to develop family work in this area.

In the afternoon, a number of workshops were held – these are summarised below.

### **Training Needs in the West Midlands, UK – Martin Atchison**

This workshop was designed to obtain views about what training around family working and carer support would be required across the Midlands. Some awareness raising around carers issues for staff working in older adults services was suggested as a way of developing services which would be positive towards carers and families. A specific BFT course adapted for use in older adults services would also be useful, as well as a training day specifically to look at adapting the model for those staff who have already completed the BFT training.

### **Specialist Carer Workers – Sarah Cottingham**

Sarah used the workshop to talk in more detail about the kind of support she offers to carers. This led on to discussion around how other areas could set up or evolve services for carers, and how these might link in with or become part of existing services. There was also discussion about how some professionals misunderstand carers or don't fully appreciate the difficulties that a carer faces. Services often seem to be focussed towards the service user. However, it was also raised that often professionals can become frustrated with not having enough time to work with carers – there is a willingness to work with carers but not always the time to do so.

### **The Admiral Nursing Service – Terry Downes and Carol Courtney**

Following Carol's introduction to the Admiral Nursing service earlier in the day, the workshop began with a quick overview of the sorts of issues that developing and setting up a service like this might highlight. It became clear that the initial stages of setting up the service in Birmingham had involved a lot of inter-organisational working. Carol

was clear that the Admiral service was very much an adjunctive service with the focus being on identifying how Admiral nurses can add to what Community Mental Health Teams already provide. Similarities between the roles of Admiral nurses and community psychiatric nurses in terms of providing effective preventative mental health care were mentioned. The group then went on to think about the value of Admiral being a nurse led service. Attributes associated with nurses included security, trust, relevant skills-base, credibility, a caring and receptive attitude and time to deliver this type of service. It was thought that, of the professional groups that might be involved in providing care to people affected by dementia, nurses (with mental health training and experience) were particularly well placed to meet the needs of both service users and their carers.

However, as talk turned to the future of the service, it was noted that it is increasingly likely that there will be a shift towards multidisciplinary team working including a range of professionals. Whilst the benefits of nursing experience and the skills of trained mental health professionals in the team were considered invaluable, as the service offered far more than 'just a cuppa and a chat', the inclusion of carers' support workers to work alongside the Admiral service was also highlighted as a way to further develop the scope of the service.

### **Behavioural Family Work with Older People – Verity Mitchell and Alison Hay**

Both Verity and Alison have been working in clinical practice with older people using the model. An introduction to Behavioural Family Work set the scene to allow workshop participants to use Problem Solving. In small groups they first discussed a recent situation in their own lives and how they had dealt with it – themes were summarised. The stages of Problem Solving were explained and each group used prompt cards adapted by the facilitators to follow the stages in applying Problem Solving to their original situation. Participants noted the relevance of having a shared understanding of how they were to reach their desired goals. They then reviewed the themes identified earlier in the workshop and found that issues such as misunderstandings between people might have been avoided if they had used this framework. This experiential session enabled participants to briefly 'try out' using an element of the model.

### **The Systemic Family Therapy Team, Oxford**

In this workshop, the Oxford Family Therapy Team gave participants a flavour of their model of working through the use of a case scenario, role played by members of the team. The role-play centred on the systemic assessment of a family where the client (mother) experienced symptoms of frontal lobe dementia and depression. The Team explained how at referral, the team would meet to hypothesise what the main issues may be for the service user and family. They then gave a taste of the initial meeting, which would usually be of 45 minutes duration and held

within a clinic setting. This initial assessment was role played by the Team, demonstrating how they used a “Reflecting Team” of clinicians who would watch the session behind a screen or 2-way mirror. Following the meeting, the Reflecting Team would be asked to comment upon their observations, while the family looked on and listened. The family members were then asked to comment themselves. The Team then explained how further sessions would continue, and that on average families would be seen 3-4 times at intervals of 4-6 weekly.

This workshop gave a brief overview of this model of working which was clearly very different to the Behavioural Family Therapy model commonly used within the West Midlands. The session was interesting and allowed the participants to discuss differences between the two models, but also some of the parallel concepts.

The themes arising for the family were familiar (the role-play being based on a real family engaged by the Oxford team), with both the Team and the “family” reflecting upon the impact of the illness, changes of role and altered relationships. The sharing of information (psychoeducation) also arose as an issue, which reinforced that although models of intervention may differ, the needs of families often share a common ground.

**The Care Services Improvement Partnership guidance paper ‘Caring for someone with a mental health problem who is 65 or over’ is now available  
email [contact@nimhe.wmids.nhs.uk](mailto:contact@nimhe.wmids.nhs.uk)**

**Martin Atchison  
Clinical Specialist, The Meriden Programme**

## My Experiences as a Carer – Gloria Higgins

My husband suffered for about fifteen years with Alzheimer’s disease and vascular dementia. For all of that time, apart from when he needed to be admitted to hospital, I was privileged to be able to look after him at home until he died peacefully a few months ago. In his earlier years he had served in the Second World War and was a veteran of Dunkirk; he had spent most of the war serving in the Middle-East working in military intelligence. After the war he became a teacher, and was a gifted linguist. He was an exponent of ‘Bel Canto’ singing, possessed an exceptional voice and perhaps more importantly than any of these things, he was a very kind man full of integrity. Unfortunately these traits became less evident as the disease progressed and people only saw an old, difficult man to whom they could not relate.

I have divided his illness into three main stages. The first stage, which lasted several years, was when only I was aware that he had a problem. I could see he was changing and I thought I recognised what the illness was. As far as I knew there was no treatment available for dementia, so there did not seem any point in telling him what I thought was wrong. He appeared totally unaware that anything was happening to him. The first sign I noticed was when he had an hallucination. This was followed by loss of memory and episodes of aggression and agitation, together with loss of physical powers. It was at this time that we got married as I was afraid of the difficulties that would arise dealing with the medical profession if I had no legal status. We had already been together for thirteen years and eventually had twenty four wonderful years together.

I felt very lonely not being able to share the problem with him or anyone else. I did not know where I could go for confidential advice. It felt like a betrayal of my husband’s trust to voice my concerns to other people. It would have been useful if I had known where to go for anonymous help. Eventually I did go the Alzheimer’s Society and they were very supportive.

The second stage of the illness began when he himself felt something was wrong with him and we booked an appointment to see his G.P. This led on to a hospital referral and eventually to a diagnosis. Confirmation of his illness was devastating to us both, and we tried desperately to find something positive to hang on to. The ‘A.D. 2000’ drugs trial came to our rescue, when he was offered the chance to take part in the research programme. This at best meant there was a possibility of treatment or at least the chance to further research that may help others in the future. We had a glimmer of hope to hold on to.

A need for support was vital for me, and the Alzheimer’s Society was my main source of easily accessible information, mainly through telephone calls and the internet. My husband did not want to know what was in store for him and preferred to believe it was a problem he would deal with at some point in the future when he thought he had become ill enough to need help. I think the aspect of the diagnosis that upset him most was the fear of loss of status and that people would no longer have respect for him.

Everyone is an individual with his or her own personality and my husband certainly knew who he was and what it was that he believed in. Throughout his illness he strove constantly not to allow anyone to take his identity away from him: this often led to conflict with the professional organisations with which he became involved. Constant supervision was required, which he very much resented, and social services allowed me two hours a week so that I could leave the house to go shopping. The Alzheimer’s Society also gave me three hours a week to have a little time for myself. I did find it difficult at first to accept the restriction of not being able to leave the house any time I wanted to, but I soon settled to the new routine and it became the accepted norm. The constant tiredness from lack of sleep and the extra work of helping him with the tasks he could no longer manage all had an effect on me and sometimes I did find it difficult to manage to stay

calm and cheerful. At these times a sense of humour kept me going – one morning I found a pair of his slippers in the bedroom full of urine. I said to him that I would need to buy some new ones as his had got wet and I threw away his nice old leather ones and bought a soft washable pair. A few nights later I awoke to the sound of him shouting and swearing. When I asked what was the matter he replied, ‘These new slippers you got for me, they leak!’ Laughter was a wonderful release of tension.

More understanding from the public and professional agencies of the difficulties we faced would have made life a bit easier for us. Strangers told me “I should not allow him out on his own” when he strayed out of the house while I was hanging washing out to dry, but it is very difficult to keep someone a prisoner in his own home, and the professionals could perhaps have tried harder to see that what we needed was information and practical advice to solve difficulties. We did not want a takeover, we wanted to stay in charge of our own lives.

The third stage of my husband’s illness was marked by his admission into hospital with a urinary tract infection. It was in some ways easier than the previous stage, as he was no longer able to walk and move around, and in other ways the most difficult as I was watching the person I loved slowly disintegrate. At times he was able to have insight into what was happening to him, and this in some ways made the situation even more difficult for me as I understood the fears and frustrations he must have been feeling. When he was admitted to the hospital, the doctors warned me he may not survive and we discussed if he should or should not be resuscitated. He was so poorly I thought it would not be kind to prolong his suffering and the doctors agreed that resuscitation was not in his best interest. There were very many occasions over the coming weeks, months and indeed years ahead when, despite all the dire predictions, he somehow always managed to recover, though each episode left him a little weaker than before.

After six months in hospital and having recovered from a prostatectomy operation he was ready to be discharged. The advice I was given was that he would best be placed in a nursing home. I was vehemently against this and insisted that I wanted him to come home so that I could take care of him. It took several weeks to put in place a care package suitable for his considerable needs, but finally the day came when I was able to bring him home. I had a need to look after him. I realised I could not do it without support but I wanted to be the one to wash and dress him and take care of all his needs – to me that was what marriage and love were all about.

Two carers from social services homecare team came three times a day and after a few weeks another agency provided two night sittings a week, as he was at his most active at night. I am extremely grateful for the help we received but it took a lot of getting used to. To supplement his night care I needed to purchase some night sits myself each week. The result was that some weeks we could have twenty or thirty different people coming in to our home.

This constant change of faces was particularly hard for my husband to cope with; he would start to get used to a carer and suddenly there would be another change. This lack of continuity resulted in him showing aggressive and agitated behaviour. Some carers he responded to well, whilst others he found more difficult to get along with. I found myself in a ‘piggy in the middle’ situation, which caused me to be constantly worrying about who would be coming to help at the next visit. I did not want to see my husband distressed by a carer he could not relate to and neither did I want the carer to be upset by one of his aggressive outbursts. The support of the community psychiatric nurse was invaluable as she supported my stance that sedation was not the best answer to resolving the problem. What we needed was continuity of carers.

In an effort to get the right care for my husband I applied for N.H.S. funding, and it was granted without any problem. It was plain his care needs justified specialised nursing care. Hurray! I thought my problems were over, but my jubilation was short lived. Social services decided that, as they were no longer responsible for his care, they would set a date to withdraw. The N.H.S., though they accepted responsibility for his care, were not in a position to provide it – though they *were* able to provide the funding. We were at an impasse. Social services could only provide social care, as they were not regulated to provide nursing care. The N.H.S. could only provide the finance, as they were unable to find a source of nursing care. The result was that we were left without the care that had been previously provided by social services homecare team. I tried every avenue I knew to highlight our situation but nothing seemed able to change it. I managed as best I could with the help of friends and neighbours until the N.H.S. were able, over many months, to eventually find carers. It took about a year for a full care package to be put in place and was complete just a few weeks before he died. I felt let down by the two principal services responsible for caring for my husband. It was a time when my energies should have been focused on his needs as he was slowly slipping away from me. Instead, I was constantly distracted by the worry of how I was going to find someone to help me hoist him out of bed and give him care. Common sense seemed to have deserted the situation.

Even though I experienced many difficulties I have no regrets about the decision I made to keep my husband at home throughout his illness. I found it a positive experience, and a privilege to care for him. I met some lovely people along the way, and many remain friends with me now. I am thankful for the good friends who supported me and tried to help in any way they could. Perhaps the most compelling reason why I have no regrets is due to my knowing that the care I gave to my husband was very much appreciated by him. One day he said to me “I have told Gloria (me) about us.” “Oh yes,” I said, “What did you tell her?” He said, “That we have fallen in love.” “What did Gloria say to that?” I asked next. He then replied, “She was very pleased for us”. I couldn’t help thinking that Gloria was a very understanding woman. It was nice to know that if he met me all over again he would still choose me.



# Working with Families – Developing Caring Partnerships

19-20 MARCH 2007

Holiday Inn (formerly Stratford Moathouse) Stratford-upon-Avon, UK

## Speakers

Prof. Christine Barrowclough, *University of Manchester*  
 Prof. Paul Bebbington, *University College London*  
 Prof. Saul Becker, *University of Birmingham, UK*  
 Prof. Max Birchwood, *University of Birmingham*  
 Mr Frank Burbach, *Somerset Partnership NHS & Social Care Trust*  
 Dr. Alan Cooklin, *Camden and Islington and University College London*  
 Dr. Gráinne Fadden, *Meriden and University of Birmingham*  
 Professor Ian Falloon, *Italy*  
 Mrs Diane Froggatt, *World Fellowship for Schizophrenia and Allied Disorders*  
 Professor Sheila Hollins, *President, Royal College of Psychiatrists*  
 Prof. Dale Johnson, *President, World Fellowship for Schizophrenia and Allied Disorders*  
 Prof. Elizabeth Kuipers, *Institute of Psychiatry, London*  
 Mr. Mike Kelly, *Dorset, UK*

Prof. Julian Leff, *Institute of Psychiatry, Royal Free and University College Medical School, UK*  
 Dr. Bill McFarlane, *Maine, USA*  
 Mr Roger Newman, *Lesbian and Gay Carers Network, Alzheimer's Society, Kent, UK*  
 Dr Vanessa Pinfold, *Head of Research and Policy, Rethink, UK*  
 Mr. Cliff Prior, *CBE, Rethink, UK*  
 Ms Sharon Scott Mulder, *The Manitoba First-Episode Psychosis Family Support Group, Canada*  
 Prof. Antony Sheehan, *Department of Health, UK*  
 Dr. David Shiers, *NIMHE/Rethink, UK*  
 Dr. Mike Shooter, *CBE, Past-President, Royal College of Psychiatrists, UK*  
 Dr. Jo Smith, *NIMHE/Rethink, UK*  
 Dr. Adrian Sutton, *Manchester, UK*  
 Mrs Brenda Wentzell, *Prevention and Early Intervention Programme for Psychosis, Canada*  
 Mr Peter Woodhams, *Carers in Partnership, UK*

## Themes

- Recovery for individuals and families
- Family work in early psychosis
- Trans-cultural family work
- Family involvement in the training of professionals
- Multi-family groups
- Family work in in-patient settings
- Issues of caring in same sex partnerships
- Mobilising community resources to develop services for families
- Helping families where both substance misuse and psychosis are present
- Parental mental ill-health and the needs of children
- Confidentiality issues in working with families
- How government policy can inform practice in relation to families
- The interplay between caring in our personal and professional lives
- Training of staff to deliver family work
- Educational resources and materials
- Family work with older adults
- The organisational context
- Performance management of the delivery of family work

We are delighted with the interest already shown in our conference with enquiries from several countries. A reminder to people that rooms in the hotel get booked up very quickly and last time many people were disappointed at having to stay off-site. Book early for the 2007 conference to avoid disappointment.

For further details please check our website on [www.meridenfamilyprogramme.com](http://www.meridenfamilyprogramme.com). To register for the conference please contact: Conference Line, 5 Leopold Road, Wimbledon, London, SW19 7BB  
 Tel: 0208 944 5050 Fax: 0208 944 0866 Email: [meridenconference@conferenceline.co.uk](mailto:meridenconference@conferenceline.co.uk)