

NEWSLETTER

AUGUST 1998

From the NATIONAL COMMITTEE

I wish to put on record our gratitude to Barbara Vigar for her short term of office as Chair of APCMH. We are sorry that Barbara felt unable to continue in post, but, of course, respect her decision to step down. This clearly is a very difficult period for the organisation and as Barbara rightly pointed out in the March edition of this newsletter, APCMH does need to be structured with very clear aims and objectives. Perhaps one of our problems in recent years has been that we, at National Committee level, have considered so many initiatives and discussed so many new ideas that the whole process has seemed daunting so that we have failed to move forward.

An inability to attract core funding has meant that the whole burden of keeping a national charity going has fallen onto the shoulders of a very small number of people. This is a position which cannot be maintained long term. In my view we now have to put much of our effort into attracting funding for a Development/Training Officer.

In the meantime, perhaps we should be concentrating on the one thing which we know that we can do well - encourage churches and other local community groups to set up one-to-one Befriending schemes within their localities. There is a great deal of evidence that such schemes can play a significant part in keeping people well; many joint-finance committees of Health and Social Services will look favourably on well prepared local bids for the funding of these schemes and we do have an important and ready made network in the churches for the promotion of fr3sh initiatives.

Do you have any experience as a Trainer? Are you able to put together a bid for finance? Could you design or produce attractive, user-friendly information packs? Would you be prepared to address a group of potential volunteers in your area on the purpose and value of befriending? These are some of the ways in which the membership of the organisation - you and I - can help in the immediate future. Pam Freeman or David Walters, who is the acting Chair until the AGM will be pleased to hear from you if you are able to respond positively to any of the above, or if you have any other suggestions as to how we might move forward.

Mike Pritchard

ORGANISING TO CHANGE ATTITUDES

Sally Zinman, California Network of Mental Health Clients

There are many ways that clients of the mental health system have fought discrimination. But perhaps more effective in stigma busting than the actions taken is the process toward the actions of clients organising for their own civil and human rights. In their very civil rights struggle, they demonstrate strength and intelligence to others and empower themselves. They challenge the discriminating attitudes of others and rise above their own self-stigma.

**KEYNOTE ADDRESS BY PAUL BOATING MP
PARLIAMENTARY UNDER SECRETARY OF STATE FOR HEALTH**

Highlights of Paul Boateng's speech.

I am delighted that my Department has been able to work closely with Focus in organising this event. Such collaboration can only strengthen our ability to achieve our mutual aims to help mentally ill people. The Government has attached a high priority to the need to tackle the social exclusion of people by virtue of their unemployment, poor housing, poor access to services or poor health. This requires concerted action on a number of fronts.

Many factors contribute to the social exclusion of mentally ill people and I want to talk about some of those today. They include the failure of community care to deliver the necessary levels of care and support for many people who have moved away from institutionalised care; the stigmatisation of mental illness which can lead to a feeling of isolation and contributes to the high rate of suicide among mentally ill people; the high unemployment rates for people with mental illness; the poor access to services for mentally ill people who are homeless; the lack of attention paid by society as a whole to the civil rights of disabled people including people suffering from mental illness; and the insensitivity of services to the particular cultural needs of people from black and ethnic minority communities.

I hope to give a flavour of some of the initiatives which the Government has in hand to tackle these issues. We all have a responsibility to protect the most vulnerable members of our society and to provide them with opportunities to realise their potential. If we work together, I am sure that we can make real progress in combating social exclusion.

The voice of the user needs to be at the heart of what we do. The government is in the business of transforming our communities. Key risk groups need targeting. There needs to be a variety of approaches. Collaboration with the voluntary sector is essential.

NB I was very impressed with the government's strategies regarding mental health and hope that the plans come to fruition.

Pam Freeman

Employment Issues - Barriers to Employment

People with mental health problems frequently face stigma and discrimination when seeking employment. This results in them having the highest rates of unemployment amongst disabled people. Such high rates of unemployment play a substantial part in creating and sustaining social exclusion.

Income support captures people in a minefield of restrictions. To move in and out of work results in taking incredible risks with income insecurity.

The evidence indicates that barriers to employment are constructed by employers' attitudes and practices as well as the policies and practice of the range of health, welfare, social security and housing services used by mental health service users.

In order to dismantle these barriers in order to increase employment opportunities the whole situation needs to be looked at more creatively, stereotypes need challenging and a more flexible system created.

Professor Ann Davies - University of Birmingham.

" WELCOME TO NEW MEMBERS "

"Friends of Naseberry Court" were gathered in order to counteract the resistance among the people of Highams Park, to a unit re-providing a section of Claybury Hospital coming into their midst; the idea was first mentioned and approved at an ecumenical group, Lent 1997, which two of our parishioners attended; and later supported by Fr Michael at a Highams Park Council of Churches Meeting. We launched the idea that the local churches extend a hand of friendship to patients and staff of Naseberry Court, with a barbecue the last Saturday in August 1997 and this was well attended by church ministers of Highams Park, together with some of their members, and several members of our own church; all mingled happily with staff and patients and the afternoon was a great success. The ongoing working party is however comprised of members of three churches only; three members from Cavendish Road Baptist Church, one from Buxton Road URC Church and the following from our church. Pat Marshall, Noreen O'Connor, Terri Arend, Elizabeth Tutty, Fay Pedder and Sr Veronica.

Our activities have been as follows :-

- a) In view of the fact that patients were finding food not nearly so adequate as formerly in Claybury, we have been taking in cakes for tea on Sundays and one mid-week day.
- b) On Friday afternoons, as there is no occupational therapy that day and patients are very bored, we organise either the sharing of a skill or games such as Bingo or Beetle Drive.
- c) For the feasts of Christmas and Easter, we gave a present to each patient who was not allowed home.
- d) We hired a Country and Western Band to give entertainment on e Sunday afternoon before Christmas.
- e) As there is a good big garden area at the back of the Unit, but no seats there, we have provided some garden furniture.
- f) During the summer, we had some "at home" afternoons at the house of one of our parishioner "friends" to which we transported a few patients to have tea, fellowship and video - part religious, part entertainment. We hope to do the same this year as it is a real effort at CARE IN THE COMMUNITY for those who haven't families to go to, or are not yet allowed home. The same parishioner "friend" has transported Catholic patients to church on a few occasions. Unfortunately, we do not get many requests to go to church though three other parishioners have offered this service.

It is noteworthy, that for many of these activities we have gained help from other individuals and groups in the parish, notably, Legion of Mary and Hospital Conference of SVP and Jill Banks has shared her skill in flower arranging and dried flower decorations. We hope to see others coming forward to offer help of various kinds; for example, a Baptist member recently organised an informal Quiz evening which went down very well and we'd like other similar offers. Also entertainment, especially musical, would help to fill the hours of boredom which all patients complain of. The help of a few singers or choir would help Sr Veronica to provide an attractive Sunday service - so offers would be well appreciated.

E. A. Tully (Secretary)

" FOCUS " Conference on "Social Exclusion and Stigma"

I attended a day conference held by FOCUS on Social Exclusion and Stigma at Church House on Thursday, 2 April, 1998. Focus on Mental Health is a forum in which the groups working primarily at a national level is mental health work together towards common objectives, as follows :-

1. To help created a positive climate of opinion towards mental health and combat fear and anxiety attached to mental illness.
2. To stimulate communication and collaboration between groups in mental health.
3. To co-ordinate events involving member organisations which are beyond the organisational capacity of individual members of the group.
4. To organise and advise on concrete initiatives and activities such as WMHD aimed at promoting and improving the image of mental health.

I have written some notes of the day which will be of interest to members and friends.

Pam Freeman

MAKING HEADLINES, " THE ROLE OF MASS MEDIA CAMPAIGNS IN TACKLING STIGMA"

Lynne Friedli, Health Education Authority

The taboos surrounding mental health problems have a long history and many factors influence beliefs about mental distress. Press coverage, attitudes of employers and awareness of mental health issues in the services provided by local agencies, local authorities and health authorities, all contribute to public perceptions.

Challenging myths and stereotypes is an essential part of ensuring that people with mental health problems receive support, respect and high quality services. Stigma erodes confidence and self-esteem and makes it difficult for mental health service users to participate fully in decisions about treatment, care and services. It stops people from seeking help and excludes people with mental health problems from the workplace. Above all, it prevents us from recognising that anyone can experience mental health problems and that the mental health of individuals, families, organisations and communities concerns everyone and underpins the health and well being of society.

World Mental Health Day Campaign sets a framework for action. In 1995 there were 500 local organisers. In 1997 6,000 local organisers.

The Campaign aims to :

Raise local awareness,

Generate media coverage and

Develop resources to challenge stigma.

PARTICIPANT

"LOOK CLOSER - SEE ME"

What do you see nurses, what do you see?
Are you thinking when you are looking at me.
A crabbit old woman, not very wise,
Uncertain of habit, with far-away eyes,
Who dribbles her food, and makes no reply,
When you say in a loud voice - "I do wish you'd try"
Who seems not to notice the things that you do,
And forever is losing a stocking or shoe,
Who unresisting or not lets you do as you will,
With bathing and feeding the long day to fill.
Is that what you're thinking, is that what you see?

Then open your eyes nurse, you're not looking at me.
I'll tell you who I am as I sit here so still,
As I use at your bidding, as I eat at your will.
I'm a small child of ten, with father and mother,
Brothers and sisters who love one another,
A young girl of sixteen, with wings on her feet,
Dreaming that soon now, a lover she'll meet.
A bride soon at twenty, my heart gives a leap,
Remembering the vows, that I promised to keep:

At twenty-five now, I have young of my own,
Who need me to build a secure happy home.
A young woman of thirty, my young now grow fast,
Bound to each other, with ties that should last:
At forty my young ones, now grown will soon be gone,
But my man stays beside me, to see I don't mourn:
At fifty once more babies play round my knee,
Again we know children my loved one and me.

Dark days are upon me, my husband is dead,
I look to the future, I shudder with dread.
For my young are all busy, rearing young of their own,
And I think of the years and the love I have known.

I'm an old woman now, and nature is cruel,
'Tis her jest to make old age look like a fool.
The body it crumbles, grace and vigour depart,
There now is a stone, where once I had a heart.

But inside this old carcass, a young girl still dwells,
And now and again my battered heart swells,
I remember the joys, I remember the pain,
And I'm loving and living, life over again.
I think of the years, all too few - gone too fast,
And accept the stark fact, that nothing can last.
So open your eyes nurses, open and see,
Not a crabbit old woman, look closer - see ME.

(This poem was found in the hospital locker of an elderly lady after her death)

Contributed by Dr Gillian Craig

THE INSPIRATION OF MY LIFE

**Moira's Alzheimer's disease does not prevent
her beauty touching her husband David's life.**

Moira and myself are sitting in the garden of the Nursing Home. She has her eyes closed and her face upturned to the warm afternoon sun of late May. There is birdsong all around and in the distance the strident sounds of police sirens pierce the still air⁵. High above us and oblivious to her plight as she is to their passage, a procession of Transatlantic jets ply the air corridor that links Europe and America. Across the lawn can be heard the sound of laughter and carefree play coming from a nearby children's nursery. This then is the backdrop to her dementing world this Spring afternoon. I sit next to her watching, her reflexive movements and gestures are mere echos of a past that she no longer knows exists. I am musing on the fact that I can edit out and analyse the sounds and sensations of my surrounding world and thinking how for Moira it must all be just a confusing broth of sensory inputs which can neither be analysed nor understood.

My thoughts turn to the book on my lap, I am currently re-reading Oliver Sacks' "The Man Who Mistook His Wife For a Hat", I am constantly moved and affected by the humanity he displays for his patients. I warm to his ability to see through neurological disease to the essential being and to tap into the soul of a dementing person. However there are also observations of what must and can only be the sheer-terror of the nightmare world from which Moira and others like her can never awake. He speaks of one such person as ".....isolated in a single moment of being, with a moat or lacuna of forgetting all round him... He is a man without a past (or future), such in a constantly changing meaningless moment." These thoughts disturb me as I sit and watch Moira in the garden. Her eyes are still closed, her head is gently nodding as if in conversation with the ghosts of her private world. Her eyebrows raise, she smiles and makes quiet whispering sounds that are at the same time delightful yet indecipherable as spoken language, though clearly they are indicative of a prevailing mood. It is as if she is communing with spirits from another realm. In these her calmer moments, I draw great strength from her presence. It feels as if the great tide which is the vast ocean of the universe in which we exist and have our being, is washing over her and imbuing her with a spirituality that most of us only ever glimpse in rare moments of inspiration and heightened awareness. In this respect she is my teacher, my angel and spirit guide and the privilege of travelling with her down dark unlit pathways of the mind is the most life-changing thing which has ever happened to me. Sacks speaks of excesses and deficits in his world of the neurologically damaged. Certainly for Moira, there are deficits with all that she has lost, but in her moments of calm she belongs to a group of exalted beings whose altered states give them access to a communion with the Angels, whilst still breathing the air of our parochial existence here on Earth.

This magazine is about those on the margins of society. Moira is on the margins of consciousness at the edge of awareness, at the boundary of being and I wonder incessantly, how the World must look, smell and feel to her. Take just one of the senses, sight for example, and you realise how inextricably tied up it is with understanding. To see clearly you have to be able to understand, reason, interpret, edit and filter out the plethora of incoming stimuli.

Continued

" The Inspiration of My Life " Continued

We go to the cinema and sit in front of an enormous flat screen and have no difficulty whatsoever in accepting cinematic devices thrown at us. As the camera zooms in on a person's face, the image grows to fill the screen and we understand what is happening. How different this must look to the dementing mine, a veritable house of horrors, a waking nightmare to add to all the other incomprehensible images around them. Dementia has taken away Moira's ability to be self-referential, to be conscious of being conscious, to be alert to the space she occupies. She cannot place herself in the World any longer because the world she knew has fragmented in her brain. She has no yardstick to measure and compare herself with. She can no longer say that this is me and that is you. To Leonardo Da Vinci, man was the measure of all things. For Moira there is no context, no setting, she cannot even reflect on her existential moment existence. Yet despite all this - and this is where her story is for me so worthy of its telling in all its epic proportions - she still has a soul and her spirit is still intact. She can still, incredibly, show compassion and reach out with a gentle caring hand to a fellow sufferer. I look at her and her eyes are still full of energy of love and life.

As Oliver Sacks points out in his book, many patients with severe neurological damage can still get in touch with their spirit through Music and the Arts, apparently tapping into the primitive deep-seated brain centres that have not been compromised by disease which respond instinctively to such stimuli.

For myself watching Moira for over a decade of her young life - she was only forty-five when this first

struck - I have to constantly downgrade my expectations. If she is calm manages a smile and gives me a knowing look, then I am so incredibly delighted. As for her quality of life, she sleeps like a baby, enjoys her food, takes comfort from the warmth and safety of the home and, amazingly, she has a rich vein of droll non-verbal humour from which we both frequently roll about with uncontrollable mirth. Her looks are still those of a much younger woman and her hair still has all the lustre and beauty that it had when I first met her thirty-two years ago.

Most of all it is her spirituality, her dignity and her soul which shine through as an inspiration and a lesson to us all this side of the dementing divide that normally separates us from our loved ones. In this respect there is a very real sense in which she straddles the abyss and comes to us from afar; a wounded angel whose stoicism and energy embraces with equanimity the dreadful ravages of Alzheimer's Disease.

This is the mystery and wonder of Moira. My task, feels like a gift from her, to inform the world about her journey to a distant land. With her I can glimpse infinity and feel the richer for it. May God bless Moira and all who suffer with her. May Our Inspiration Raise Awareness of suffering and illness as a challenge which, at its highest, is life enhancing and part of the blueprint for our existence here on Earth.

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DATES FOR YOUR DIARY

APCMH ANNUAL GENERAL MEETING

is to be held on Saturday, 21 November
at

From 10.00am to 4.00pm

Venue : St John's Church, Waterloo

(more details next issue)

" Dancing in the Dark "

Annual Conference of the Guild of Health

To be held at High Leigh, Hoddesdon

September 14 - 18, 1998

Speakers include The Rev Roly Bain

Fee £110 members

£120 non-members

For brochure contact :

The Rev Antonia Lynn

Guild of Health, 26 Queen Anne Street, London W1 9LB

CLINICAL THEOLOGY ASSOCIATION

"FEELING and THINKING about EMOTION and CARE"

Passion, Affect and Mood are key words for this counselling Conference.

1ST - 4TH SEPTEMBER 1998

VILLIERS HALL

LEICESTER UNIVERSITY

Conference Events, Workshops and Small Groups

with **Ian Davidson** (Edinburgh), **Thomas Dixon** (Cambridge)

George Giarchi (Plymouth), **Stephen Pattison** (Open University)

David Runcorn (Bristol), and **Fraser Watts** (Cambridge).

Brochure from : CTA Office, St Mary's House, Church Westcote, Oxford OX7 6SF Tel 01993 830209

The Association for Pastoral Care in Mental Health

An association which supports those who are mentally ill and their families.

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The views expressed in the Newsletter are not necessarily those of the Association