


Your Voice

The free magazine for members of [rethink](#). £2.50 where purchased.

spring 2007

A close-up photograph of an hourglass with a metallic frame. Red sand is falling from the top bulb into the bottom bulb, creating a dynamic sense of time passing. The background is dark, making the hourglass and the falling sand stand out.

Time is running out

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Rethink is the operating name of the National Schizophrenia Fellowship.

Working together to help everyone affected by severe mental illness recover a better quality of life

Your Voice is published by:
Rethink
5th Floor Royal London House
22-25 Finsbury Square
London EC2A 1DX

Welcome Team: **0845 456 0455**
Advice Service: **020 8974 6814**
Email: **info@rethink.org**
Website: **www.rethink.org**

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Editor: **Ruth Bettie**
Deputy Editor: **Terry Hammond**
Production: **white halo design**

Recent highlights



The last three months have flown by in what has been an exciting period for Rethink. I have begun to enjoy the opportunity to get out and visit our services and other activities on the

ground and to meet staff, volunteers, Regional Reference Group members and other supporters. Over the coming months I hope to get round to many more.

A particular highlight has been the opportunity to share in the 10th anniversary of the Sahayak befriending and support service serving the South Asian community in Gravesend and Dartford. During a morning of celebrations, enlivened by demonstrations of traditional dancing and poetry, I was struck by some of the powerful testimony of the value of this service in a community where there can be a particular stigma in recognising a mental health problem and where rates of presentation to mainstream services are low. I was also struck by the enormous level of support for the service from within the communities it serves as evidenced by the large number of enthusiastic volunteers who work with the service.

Sahayak provides, as do a number of the other services I have seen, a really good example of where Rethink has been able to develop a valued local service which meets a very real need for a group of individuals who may not find it easy to obtain help from other quarters. (For more on Sahayak's anniversary celebrations, see page 13).

A second highlight has been the completion of work with Mind, Mental Health Media and the Institute of Psychiatry on our joint bid to the Big Lottery Fund for 'Moving People', a four year programme of work challenging stigma and discrimination. If successful, with additional funds from Comic Relief, this would be worth £20 million and would enable us to undertake a programme of activity comparable to the successful and ground breaking campaigns which have been carried out in New Zealand and Scotland.

Our proposed programme has a dual focus. As well as activities designed to challenge stigma and discrimination there is a theme around better inclusion of people with mental health problems through physical exercise. Again if successful, Rethink would lead a number of the activities including the delivery

of a national advertising and publicity campaign, building on the experience we have gained in both Norwich and more recently in Northern Ireland.

This is a tremendously exciting opportunity. As part of our bid we put together a short video based on the personal testimony of service users and family members. It is, as you can expect, enormously powerful in describing the impact of stigma on the lives of people experiencing mental health problems. Watching this, I have no doubt that when given the opportunity to be heard, this will be a message which will make a real impact on public attitudes. We are now in the period of waiting and expect a result in June. Whatever the outcome I am convinced that this is core business for Rethink and something we need to find whatever means we can to take forward.

A third highlight has been the success of the Mental Health Alliance in securing major amendments in the House of Lords to the Government's proposed mental health legislation. This has been a testimony to the effectiveness of our joint campaigning and to the support of many service users, carers and other supporters. I am really grateful for all the efforts which Rethink members have made in lobbying their MPs and campaigning in other ways. The key issue now is whether the Government will acknowledge the depth of feeling on this issue and accept some sensible changes to the proposed legislation. Unfortunately the signs so far is that this might not be the case and that they will try to reverse the Lords' amendments. By the time you read this, we will probably know the outcome. Whatever this is, Rethink will continue to campaign for the rights of service users and families in this area.

Finally at the end of my first three months I have completed a short management review which was agreed by the Board of Trustees together with the Business Plan and Budget for 2007/8. The Review includes the action required to put Rethink on a sound financial footing for the future. It also focuses on taking steps to promote better connections between services, campaigning and membership and to establish more of a clear common purpose across all parts of the organisation.

As I said at the outset it has been a busy and exciting three months for Rethink. If we are successful with the Big Lottery Bid the next three months could be even more exciting.

Paul Jenkins, Rethink's Chief Executive



Time is running out

Jane Harris reports

By the time you read this, the Mental Health Bill will be part way through its passage through the House of Commons. Time is running out to make it better, so please act now! The Bill will last for 25 years, we need to make it as good as we can.

What's happened so far?

This Bill actually started in the House of Lords, which is very rare, but was good news for our campaign. The House of Lords had very good, well-informed debates on the Bill and made six big improvements to it. They are:

- **Impaired decision making:** only people who are unable to make decisions about their treatment should be subject to compulsory treatment. This principle is written into the Scottish Act and would mean that people with mental health problems would be treated equally to people with physical health problems
- **Exclusions:** the Bill should specifically state that sexual orientation/identity, substance use, cultural/political/religious beliefs do not in themselves constitute mental illness. This is an important restriction on the new wider definition of mental illness.
- **Therapeutic benefit:** people should only be forced to have treatment if it benefits them. Taking away someone's liberty is a serious thing to do – why should someone have

their right to freedom restricted unless it's going to help them?

- **Renewal of detention:** A practitioner with medical training should be involved in renewing detention.
- **Age-appropriateness:** Children detained under the Act should be placed in age-appropriate accommodation, not simply admitted to ordinary adult wards
- **Compulsory community treatment:** Only people who have already been in hospital previously and deteriorated quickly when they returned home should be made subject to compulsory treatment in the community.

But MPs in the House of Commons could reject all these improvements and take us back to the terrible Bill we started off with. We need your help to make sure this does not happen.



What you can do

We want people up and down the country to go and meet their MP at their surgeries. Almost all MPs hold surgeries weekly in their constituencies to meet people they represent and hear their views. MPs really do listen, especially if a few people go together to talk about their views.

If you want to do this, please contact Rethink Campaigns, by telephoning 0845 456 0455, emailing campaigns@rethink.org or writing to Rethink Campaigns, 5th Floor, Royal London House, 22-25 Finsbury Square, London EC2A 1DX. We will give you the information and materials you need to help you.



Capacity and civil rights Alex Burner reports

One member recently wrote to us to express her concern that her son might not have been treated at a time when he was in crisis if his civil rights had been taken into account as he did not want to be treated at that time. This one member's concern raises a very important issue, which relates to capacity.

Rethink Campaigns
5th Floor
Royal London House
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London EC2A 1DX

0845 456 0455
campaigns@rethink.org

Why are we fighting for fulfilment of the civil rights of people who experience or have experienced mental illness, when often people are unable to exercise those rights due to an episode of illness? Is the ability to sit on a jury, for example, important when a carer's main concern is helping those they care for simply make it through the day?

I would have to say yes. Civil rights are important to the functioning of civil society. However this is not to suggest we would support the idea that everyone should sit on a jury or that everyone should always have the right to refuse treatment. A person's rights are mediated by their capacity. If a person has the capacity to sit on a jury, or vote, or do any

number of other things such as get a job or return to education then they should have the same access to these things as every other citizen.

The nature of mental illness is that it is often fluctuating, people will experience periods of 'wellness' and periods of 'illness', periods of capacity and impaired decision-making. But we must ensure people's rights are guaranteed so that everyone is able to participate in society during periods when they feel capable. Otherwise, people with severe mental illness will continue to be excluded from society.

If you have experienced mental illness it does not mean that you will never want to work, or participate in education or community activities, or vote, or appear on television – if that is your choice! *The Sun* recently drew attention to the history of one of the contestants of the reality television show *The Apprentice*, claiming that because she had been sectioned four years previously she should not be participating in the programme, as she was as 'vulnerable person'.

This is not to undermine the work Rethink does to ensure the provision of the basic entitlements of those who have experienced mental illness. Early intervention, access to the best possible treatments and care, training and support all remain integral to

the work Rethink continues

to undertake. What this project will enable us to stress is that the work does not stop there. We must work for the right to ensure that people can participate and achieve things when they are well and that they are provided with decent care when necessary.

Revealed MPs' attitudes to the Bill

In March, Rethink launched Revealed, a new survey about MPs' attitudes to mental health and the Bill. We found that:

- 77% of MPs think the Bill should be about service provision, though the Government disagrees
- The more experience MPs have of mental health services the more they opposed the Government's proposals, regardless of party
- Public safety issues relating to mental health are only an issue in 6% of constituencies
- 11% of MPs have themselves experienced mental health problems – "The highest percentage ever found"

Rethink will continue to work for a Bill which upholds the rights of people with severe mental illness and carers. Most people with severe mental illness pose no risk to the public. In the rare tragedies which have occurred, problems have occurred with services – the Bill should include a right to assessment to help solve these problems as the Scottish Mental Health Act has.

People detained simply because they have a mental health condition should have a right to legal representation, which suspected criminals who are detained already have.



The new Welcome Team

The launch of the new Rethink Welcome Team took place on Monday 2nd April. The new team will be based in Kingston and will take over the work previously undertaken by Front Door and Membership Records.

'This means that we can offer a rounded service to everyone who contacts Rethink and also an on-going relationship with our members by offering a keeping in touch facility when people contact us for the first time', said Martine Koch, Welcome Team manager.

The merging of two existing functions (the front facing phone/email work with the database/fulfilment function) will save Rethink around £40,000 a year as a result of cost efficiencies. Martine commented: 'This new team will allow us to take a more proactive approach to providing support to people affected by severe mental illness'.

If you have any questions about your membership or would like information about other areas of Rethink then please contact the Welcome Team on 0845 456 0455 or email info@rethink.org.

Rethink Rights project

This is a quick reminder of what the Rethink Rights Project is about.

What is the Rethink Rights project?

This project is aimed at creating a unifying agenda for the work Rethink undertakes based on informing and empowering service users and carers to exercise their rights, and protecting and furthering those rights. Rights-based campaigning has worked for other people with disabilities and we want it to work for mental health too!

We've all got rights under laws like the UK Human Rights Act 1998, and the European Charter of Fundamental Freedoms, but a lot of these are so called 'negative' rights. In other words, they give us basic protections.

But civil rights mean taking a bigger step forward. Civil rights means positive rights, that enable service users and carers to fulfil their aspirations. So instead of just focusing on basic entitlements such as home, work and security for those who cannot work, civil rights look at how people are able to function as citizens within modern society. This is about access to healthcare, social services and education. This project is about tackling discrimination and law that prevent people who experience or have experienced mental illness, and those who care for them, achieving their full potential, and ensuring that people are aware of the law that is already in place to protect them.

For more on this please see page 25.

Recent successes

Since the last edition of *Your Voice*, Rethink Campaigns has won some important victories for people receiving incapacity benefit.

We know that lots of service users have problems with the assessment test used to decide whether people should receive incapacity benefit. At the moment, it is much harder to get IB if you have a mental illness than if you have a physical condition, which is very unfair. Rethink has worked hard lobbying the Department for Work and Pensions and it now seems that, for the first time ever, physical and mental health conditions will be scored using the same system. This is a major victory.

We also got a change made in the Lords which says that there must be an annual independent report looking at the assessment test. Until now, the assessment has been done by a private company with no public scrutiny of it. This was the only non-Government amendment made on these proposals, again a major victory.

One carer helpfully wrote and told us about the problems his son was having, as he was evicted from his house due to anti-social behaviour caused by untreated mental illness. This helped us to ensure that very unfair proposals to cut housing benefit for people who have been evicted in this way have been postponed. This means Rethink has time to ensure that a proper pilot of these proposals takes place. If you've got a story of an experience you've had, do contact us and tell us. It really helps us to make people sit up and listen.

Finally, the Government proposed that charities like Rethink would be involved in providing employment services to people on benefits. Overall, we think that's a good idea – charities which understand mental illness are likely to provide people with a better service than general organisations like Jobcentre Plus. But the proposals also said that charities providing these services might have to decide to cut people's benefit. After lobbying by Rethink and others, the Government has now promised to change the plans so that this will not happen.

Treating persisting symptoms of psychosis

The work of the National Psychosis Unit is known throughout the world. Here Sukhi Shergill outlines some approaches it takes in dealing with persistent symptoms.



Psychotic illness commonly presents with symptoms such as hearing voices (hallucinations) and unusual beliefs (delusions) with associated changes in behaviour. Following a review of the background leading up to the presentation, most patients with psychosis will be treated with antipsychotic medication and, if the expertise is available, with cognitive psychotherapy. This approach will reduce the presenting symptoms in up to three quarters of the patients, although it will often not totally abolish

(negative symptoms), some impairment in attention and concentration (cognitive symptoms), and periods of low mood (affective symptoms). The effect of these residual symptoms is noticeable in the person 'not getting on with things' as they did prior to the illness, or 'not being themselves'. Thus, there is a considerable, less obvious, burden of illness which is still present once the medical treatment is in place, and this requires further input, usually in the form of occupational therapy and some continued psychotherapy.

Unfortunately, these changes are often accepted as being an inevitable part of the illness, both by the professionals involved in treatment and carers, leaving most people unable to return to work or to study. Sadly, there is considerable variation in the availability of, and the level of expertise within, aspects of these services. Because of the nature of a psychotic illness, the person experiencing the illness is rarely

residual symptoms, and that there need to be changes in funding strategies to allow these to be more easily accessible.

I work, along with my colleagues Professor Robin Murray and Dr Zerrin Atakan, at The National Psychosis Service, based at the Maudsley and Bethlem Royal Hospitals in London. This is one of the rare services specialising exclusively in the treatment of psychosis. I would like to describe the ethos of this service and to encourage wider use of such specialist resources. Patients are referred to our service because either the carers, or the clinicians in charge of the patient, would like a second opinion on whether any further clinical improvement is possible. Therefore, most of the patients that we are asked to see have a significant level of residual symptoms, usually a mixture of the common symptoms described above, despite having been treated with antipsychotic medication and perhaps having already had some form of psychotherapeutic intervention. Often, the patients, their carers and their referring clinicians do not anticipate much change, but would like to see if a specialised service can perhaps make a difference. Over the time that I have been working in the National Psychosis Service, the potential for change in people is one constant that never ceases to amaze me. Most of the patients referred to the service will demonstrate positive change; even for the few cases where there is little or no change, they benefit in having a thorough assessment and concrete proposals for aftercare; this is useful in securing the necessary resource: for example, accommodation suitable for their needs.



The Maudsley Hospital as it is today.

them. Up to a third of patients may only experience one episode of illness but, over time, the majority of patients will experience a relapse of their illness with further worsening of these symptoms. In addition to these reduced but still noticeable symptoms, both the patient and carers will often observe other less obvious effects of the illness, with decreased motivation

in a position to be assertive about requesting services, and it is most often left to carers to fight their corner. For those without assertive carers, in the current financial climate of cuts in mental health services, it can prove difficult to find adequate resources within the hard pressed services. I would argue that referral to specialist services can help in alleviating these

This leads on to the question, what are the ingredients of a specialised psychosis service? This question is even more relevant today, because some Primary Care Trusts do not appear to consider it worth spending extra resources on patients with chronic schizophrenia. They claim that treatment of psychosis is relatively routine, and the local psychiatry service is able to provide all these needs. However, often that is not the case in practice, where some of the local services are overstretched in their resources.

As one of our clinical psychology colleagues remarked to me recently, CBT (cognitive behavioural therapy) is not just CBT. In these complex cases, it will depend on how it is delivered – a wealth of data from psychotherapy research suggests that experience of the therapist, and particularly the quality of the relationship between the patient and therapist, contribute to effective therapy. The National Psychosis Unit is fortunate in having Dr Kathy Greenwood and Dr Emmanuelle Peters as the clinical psychologists on the unit and both are highly experienced in working with patients with psychosis. They are able to provide a flexible CBT based therapy which can be tailored to the abilities and wishes of the patient. Similarly, in accordance with the culture within the unit, our occupational therapists are very experienced and provide an intensive personalised occupational therapy programme, supplemented by the extensive facilities available within the large grounds of the Bethlem Royal Hospital. The width in the multidisciplinary approach is added to by the experienced social workers, crucial for discharge planning and placement issues; and pharmacists, including one of the pharmacist attached to the ward, David Taylor, who is one of the UK's foremost pharmacists with a special interest in drugs used for the treatment of psychosis. This has led to the unit having access to less widely used antipsychotic medication, which may not be available elsewhere.

Patients often arrive on the unit, after having been prescribed most antipsychotic drugs already; and in

line with NICE guidelines, have usually been treated with Clozapine, or been intolerant or unwilling to continue on it. The medical and nursing team will have an assessment period for detailed evaluation; this may even mean the patient being drug-free on rare occasions. This provides time to review the patient history in detail, complete or repeat any necessary investigations, including brain imaging, in order to re-evaluate the patient's difficulties and diagnosis and to put a treatment plan into operation. This phase necessitates often extensive contact with the carers and the referring clinical team.

patients, who will often be on the ward for a fairly lengthy time (4-6 months or even longer in some cases), and this culture serves to facilitate the implementation of the treatment plan. Where there are specific difficulties in implementing a plan, these are addressed in multidisciplinary meetings, and with carers, to get the widest possible range of views in order to formulate a solution.

In summary, most patients with the residual symptoms of psychosis can improve and effect some beneficial change. Specialised multidisciplinary services such as the National Psychosis Service are not only well

Most of the patients referred to the service will demonstrate positive change; even for the few cases where there is little or no change, they benefit in having a thorough assessment and concrete proposals for aftercare.

However, any treatment plan can only be as successful as the ability to implement it, and this is perhaps most relevant in the treatment of psychotic illness. On reflection, this is where the psychosis service may have an advantage; the culture of the unit is to treat psychotic illness in a holistic but pragmatic way. All the psychiatrists working in the service are actively engaged in research into psychotic illness, with a range of interests including links between cannabis and psychosis, genetic and lifestyle factors in psychosis and brain changes in psychosis; and have acquired considerable experience in the treatment of psychotic illness where the symptoms have not resolved (also called treatment refractory psychosis). The experience and research interest of the medical and nursing staff encourage flexible individually tailored treatment packages. The experience and ward culture also affect the

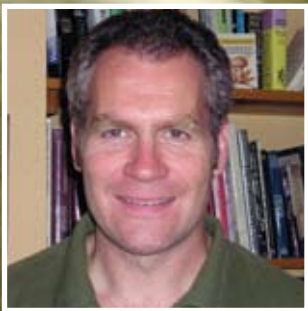
placed to help, but have a track record of doing so. We welcome referrals and enquiries to the unit; our contact is the Emma Isiakpere, the Clinical Nurse Leader, on 020 3228 4274/5.

Finally, I would like to express our sorrow at the recent death of Professor Rob Kerwin, who had worked on the service since its inception and was one of the first two psychiatrists to use Clozapine in the UK.

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- Weblink for national psychosis service within the South London and Maudsley Trust www.slam.nhs.uk/services/pages/detail.asp?id=766
- Weblink for the Institute of Psychiatry, the research Institute allied to the Hospital www.iop.kcl.ac.uk

Fast train approaching



Steve Walter was diagnosed with stress related illness, schizo affective and finally bipolar affective disorder. In this article Steve takes you through his personal journey

Breakdown. Nervous breakdown. Fragments. And in those fragments... something of the truth. I didn't see it coming until the third time around... bearing down on me. I'm more aware now, I watch for tell-tale signs, try to feel the ground ahead of me to predict and prevent that first slip into madness. As if it could happen at any moment.

I had my first breakdown in 1997 (when I was 37), and my second two years later in 1999. Up until then my life had been relatively uneventful, more or less ordinary. It had followed a familiar pattern: school, university, further qualifications, kept fairly fit, healthy, hobbies, cycling, drama, writing, got married had children, grandparents died. My life was normal. At least as normal as life ever is.

The first time, it built up slowly, over a few months. The year, 1997, didn't start very well for me. I discovered a cockroach in my cappuccino. I had to extract it from between my teeth! Ironical that I had been an Environmental Health Officer, like my friend who was drinking with me! There were relationship issues at home, and other contributory factors included the constant pressure to meet deadlines, lunch only being a hurried sandwich at the desk. On one occasion, I took what most would regard as a 'minor conflict' with a senior manager at work (over a stress research project no less!) as a major, personal insult and this blew the lid off everything for me.

It was May 1997, the day the IRA brought the country to a standstill with bomb hoaxes, just before the election. From then on life began to race wildly. I was on a high. My behaviour began to change. Gradually, more people realised that there was something wrong. At first, as far as I was concerned, I was having one of the best times of my life – I had so much creative energy. Ideas would come flooding in and I wanted to do everything, all at once. I was experiencing mania and later delusions as the ideas became further removed from reality, and towards the end profoundly disturbing.

This all took place over the space of six to eight weeks. During the last few days I really wasn't making sense. I met with my manager and his boss in a relaxed environment outside of work, and they diplomatically recommended (based on the erratic and unusual behaviour over preceding weeks) that I rest and see a doctor. By this time they had realised something was seriously wrong. Confused, at the doctors, I was recommended for psychiatric care and, on being admitted I broke down completely: I had experienced 'an acute psychotic episode'.

There were various further diagnoses: stress-related illness, schizo-affective disorder, and finally bipolar affective disorder (manic depression). However, the symptoms were mixed, unclear. I began to recover in hospital during my first week, with medication. Medication! *One Flew Over the Cuckoo's Nest* had put me off 'medication' for life!! I was in hospital for

Want to find out more?

a month, and off work for three months altogether. During that time even the first, brief visit by a very caring personnel officer, on neutral ground (a coffee shop near home, saving a trip into London), had me in tears for no reason. Everybody was very supportive: my employer, my manager and my work colleagues. I was the one worrying how people would take it, what I would say. How could I explain something that I didn't understand?

Importantly, the rehabilitation involved a gradual return to work. It was a well-managed process. For instance, after meeting with the personnel manager the first time, I met with both her and my line manager, again on neutral territory for coffee in an hotel. It helped just to talk about work and how to best phase me back in. With my consent, as well as obtaining general occupational health advice, my personnel manager would discuss my welfare with my consultant psychiatrist – not the detail of my illness, but the practical things to help ease me back into work. At every stage the options were also discussed and agreed with me. We talked about the job, likes, dislikes, strengths and weaknesses, but there was no pressure to change.

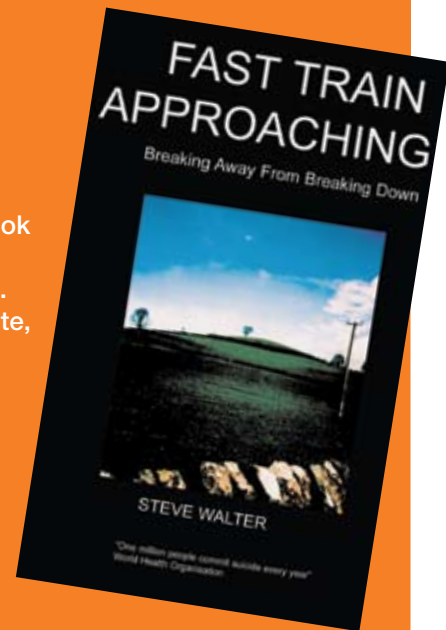
However, at our first, brief planning meeting while I was off work, in spite of the informal conversation in restful surroundings, I was still very tense and anxious. Although I was lucid intellectually, emotionally I felt very sensitive, vulnerable. After I had been off work for three months the rehabilitation involved being phased back in gently over a further three months: a few hours, a few days at a time to three and four days a week. Initially, I would arrive at work later and leave earlier. This would help counteract the sleepiness caused by the medication in the mornings and also help to avoid the usual pressures of rush hour.

First the return to work was just for me to visit, to be there to meet colleagues, to talk, to feel accepted. It was a case of just getting used to being back in the office again, with no expectation on me to answer calls, for example. At the start I was more closely supervised, and frequently and

For further insight into the nature and experience of Steve's illness see his book *Fast Train Approaching*, described as both shocking and disturbing in places. It's available through links on his website, www.makingconnectionsmatter.org, through the book's publishers, www.chipmunkpublishing.com, through www.mentalhealthshop.org or call 0845 456 0455.

Price £12.00, ISBN 09781 84747 091 1

If you have any comments on this article please email steve@makingconnectionsmatter.org



informally met with my manager and personnel manager. Gradually, still on medication and under the supervision of my consultant psychiatrist, the work increased until after two or three months I could cope with a more normal workload. The job was also redesigned in part to broaden the work to more closely match some of my concerns and interests. The whole process of a phased return to work helped to rebuild my confidence and to confirm my capability.

However, it seemed a long time to get back up to strength. I carried on taking Olanzapine for a year. The second breakdown, in May 1999, took everyone by surprise. It happened very quickly, beginning from the moment I woke up, away from home, on a day I was to be lecturing a small class on a course. Increasingly things seemed different, strange. I became afraid, out of all proportion to the usual pre-presentation nerves. I entered another frightening and deluded world. Two days later I was back in the same hospital. A few more days, more tablets and I was sane again. I was keen to return to work, to get back to normality as soon as possible. This time I was only out of work for a month.

The same consultative step by step approach was taken to phasing me back in. Underlying the pressures at work had been tensions in my home life. There were several sources of stress and there was much left

unresolved. It has taken me many months of therapy to realise what I had tried to ignore and I've yet to find all the answers. Even now, years later, I sometimes feel as if I'm still going through a form of rehabilitation. I have experienced what I would describe as minor blips, although two required a further week in hospital on each occasion.

In conclusion, there do need to be systems and procedures in place at work, to help to minimise the risk of pressures creating stress, and leading to ill health. Managers and employees have to know what precautions can help. Now, let me leave you with two further thoughts:

The Buddha was walking with his disciples through a park covered in autumn leaves. He stopped and picked up a leaf and held it out to his disciples and said 'this one leaf represents what I have told you. Look at all the other leaves. They are what I have left unsaid.'

Journey into Ladakh by Andrew Harvey.

Why choose life? Because when you think of it, the very fact that we exist at all, that we are conscious, that we live and breathe in this present moment of time and space in this world is nothing short of utterly amazing!

Steve Walter's book will be reviewed in the next edition of *Your Voice*.

Language and stigma

What can the language of stigma show us about underlying attitudes and beliefs of people about and towards the mentally ill? I think a proper educational strategy might usefully begin with language and labelling. Sarah Maitland in an open mind article has suggested we try and reclaim these terms.

Reclaiming does not simply mean that we use these terms publicly as Mad Pride try to do, but rather look to the origins and meanings of these terms in ways which might diffuse the stigma: 'in the context of jokes hysterical shows promise.'

Following this approach we find that some words contain some insight – having a screw loose means there is something in need of fixing while nuts is a slang word for your head. If as my CPN suggests, stress can cause psychoses, then being driven round the bend. And so on.

But there are a great number of terms which cannot be simply reclaimed. How do you try to explain the origins and meanings of dotty, potty, batty and loopy for example?

Put succinctly, although words seem to be at the root of much of the problem of stigma, they are in popular usage and unconsciously determine our perception of what these terms mean. So we are led to think of hospitals as a bedlam full of raving lunatics and, looking this up in the dictionary, we find it means a state of uproar and confusion so this does not enlighten us any further.

The problem with finding new terminology is that there are many other terms and perceptions which could confuse the issue. Calling madness mental health was originally meant to clarify this by signifying a medical condition, but hospitals soon became the 'loony bin' and 'nut house'. So while the terms lunatic and nutter are still in popular usage 'mental health' was bound to fail to enlighten us.

So some words which were originally technical terms became corrupted by common usage – take the similarity between psychotic (technical term) and psycho (popular misperception) and mania (technical term) and maniac (popular misperception).

Here I think the injunction implied to the lay man that such words are not what these terms actually mean because they are scientific categories is likely to fall on deaf ears – because people are still going to be unconsciously aware of other such labelling in society.

Maitland also suggests that our example above of the word mental is accessible and available however, Anstis in a previous Your Voice article, argued that this is the worst term in the long list of labels. Mental illnesses she argues are the result of chemical imbalances and are physical not mental. People may get the impression that, as she puts it, 'they are just like that' when instead the illnesses have medical causes.

Maitland too suggests a historical approach to some labels and states that she 'rather likes lunatic which is venerable and derives from lunar changes.' However looking to the Greek origins of the word schizophrenia, we find that it means split mind which conjures up the Jeckyll and Hyde image. We must then be careful which terms we try to reclaim and we may need to abandon some labels altogether – as was the case with the equally 'venerable' manic depression which became bipolar.

So while we may initially feel happy with calling our selves 'nutters', which seems as innocuous as Maitland's 'mental', until we read a headline about 'nutters on the loose' who commit serious crimes. 'Bonkers' too seems quite innocent but to me recalls headlines like 'Bonkers Bruno locked up.' And so on.

In the end the idea of simply turning such terms into a joke or badge is going to also require a proper educational strategy where use of terms like psycho can be fully and properly explained alongside less innocuous labels.

So where could such a strategy begin? This is where Maitland's reclaiming language comes into its own. The use of language reveals certain social attitudes. Hinshaw in *Stigma the Mark of Shame* (OUP 2007) argues the language examined in this article also reveals fear, fascination and ridicule:

"Purveyors of strange ideas are 'wacko' and facilities for those with mental illnesses are 'loony bins' or 'nuthouses'..."

Revealing fears that the affliction could befall the perceiver, morbid fascination with the illicit, mysterious and dangerous behaviour patterns underlying the terms and labels, and ridicule through the baseness of the terms utilised."

From here we can see many social attitudes betray prejudice i.e. that if we are ignorant of something we will judge it by our own standards. So I find it necessary to link Maitland and Hinshaw with the authority of William Hazlitt's maxim which famously states "prejudice is the child of ignorance."

We have a way of putting people into categories so we do not have to engage with them. The real trick is to overcome this mental barrier and the approaches outlined here should I think be usefully brought together with others to help achieve this.



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Ron Coleman comes to Bridgwater

A New Year's solution – a voyage through recovery

Around 130 people attended an all day event on 26th February 2007 as invited guests of Rethink's Burnham Windows and Bridgwater H.E.L.P. carers groups. The delegates comprised of over 100 carers and service users from all over the South West.

However, workers from the voluntary and statutory agencies also attended who (apart from some light-hearted heckling from Ron during the event) were welcomed warmly to the proceedings.

The event was the brainchild of Di Monaghan of Burnham Windows and Sonia Tucker of Bridgwater H.E.L.P. both of which are Rethink registered groups. It took some six months of planning which included raising the necessary funding for the speaker and the venues. Eileen Murphy, Rethink User Carer Involvement Manager South West, and her team provided the administration for the event. It had been decided that the venue could comfortably hold 130 people, but such was the interest and response to the invitation, we could have possibly hired the new Wembley Stadium and filled it! So sadly, for everyone who managed to attend, there were other disappointed people who we couldn't accommodate and therefore we will try to hold another similar event in the future.

Ron started the proceedings by asking the audience to define what recovery means generally and then apply the concepts of recovery to their own experiences. This was carried out in groups and generated a lot of discussion and gave an energy and framework for the rest of the day. It also set an understanding that, although Ron was describing his own journey, spontaneous input from the audience would be welcomed which would give a broader perspective of recovery.

The rugby club demonstrated their own version of recovery at lunchtime – the chef had called in sick so it was all hands to the pump in order to provide a soup and sandwich lunch – and the strawberry cheesecake for pudding was enjoyed by all.

In the afternoon, in his own inimitable and highly colourful style, Ron contested the arguments in place around good practice and used examples of his own and others' experiences to illustrate his challenges. It came as no surprise to us that Ron also works as a stand-up comedian – his comic dialogue and timing meant that we were able to laugh at events and situations which would normally be seen as taboo or too shocking to discuss. If ever there was an ambassador for busting stigma and ignorance in mental health, we were watching him. He ended the day by inviting questions and issues to be aired and encouraged the audience to help him to answer these.

The day ended with Ron leaving for the airport to continue with his international work that will take him to Australia, New Zealand and Palestine and left us with time to reflect upon his stimulating and challenging experiences of recovery.

We asked delegates to evaluate their experience of the event and overwhelmingly the event was found to be inspirational, powerful and full of hope. Delegates asked for more events and training which were service user and carer led and for more specific issues, for example self harm, personality disorders, substance misuse, self management and assertiveness.

All in all it was a terrific day and the overall response was – 'Let's have more of this type of event please!'

Rethink Sahayak celebrates a decade of success

Rethink Sahayak held a day of entertainment to mark its birthday. Paul Jenkins Chief Executive of Rethink, the Mayor of Gravesham and Councillor Harry Smith attended with Area Commander of North Kent Police Chief Superintendent Gary Beautridge.

The event at the Riverside Centre, Gravesend, on 28th March included dancing, music, a poetry reading and testimonies read from Services Users and Carers before the anniversary was officially marked with a cake-cutting ceremony and a balloon release.

The journey started in March 1997 as a small pilot project funded for one year only to provide a one to one befriending support service to the Asian community. It was set up in response to the growing need in the Gravesham and Dartford area, to provide support to individuals with mental health problems within the ethnic minority communities and their relatives during periods of mental distress and following hospitalisation and to promote mental health awareness within the ethnic minority communities. The service faced many challenges over the years to reach where it is today.

Sahayak means 'helpful' in hindi language and the service was named by the first trained volunteers in 1997, the service offered support in Asian languages.

In October 1999 Sahayak moved to a more accessible location in the heart of the Gravesend town centre. The service also expanded by developing the Asian out of hours mental health helpline for Kent and Bexley in 2001.

Sahayak further developed the service to also incorporate a Carers support service for Black and Minority Ethnic Communities in 2002. In 2004 the Asian helpline expanded to reach out to people in the Crawley, West Sussex area.



Cutting Sahayak's anniversary cake are (left to right): Gary Beautridge, Chief Superintendent Kent Police; Carol Gosal, Rethink ASM; Dev Sharma REC; Gurvinder Sandher REC and Paul Jenkins, Rethink CEO.

The highlight of Rethink Sahayak's work is the success of a community engagement research project *Oppressed Voices* which looked at understanding the effects of domestic violence on mental health for South Asian women in North West Kent (full report on www.rethink.org/oppressedvoices) we are pleased to say the recommendations of this research for an Asian counsellor has been supported by Kent Police Chief Superintendent Gary Beautridge and the CDRP – Crime Disorder Reduction Partnership locally.

Rethink Sahayak has received many awards over the 10 years both locally and nationally in recognition of the good practice model Sahayak provides to the Asian communities. This could not have been possible with the continuing commitment, dedication and passion of the staff, volunteers, service users and Carers and supporting Community Agencies and many partnership groups. Sahayak continues to grow from strength to strength even today and input to strategic development planning for shaping services to meet the needs of the Black and Minority Ethnic communities which has proven to be valuable at all levels.

Celebrating with Sahayak staff and volunteers are: The Mayor of Gravesham, Harry Smith; Gary Beautridge, Chief Superintendent; Carol Gosal; Dee Dhadwal and Paul Jenkins Rethink CEO.





Moving forward with the help of poetry

Ian Christie was inspired to write poetry following the discovery of his great great grandfather's accomplishments. Ian talks about his illness and how poetry has helped him on his journey of recovery

After several years working as a gardener for my local council, in 1985 I lost a cousin who was just 34 and this, combined with a change of job, led to my first bout of depression.

In 1988 my Grandma died, followed within 12 months by the death of my mother. My depression deepened and the bouts became more frequent until I was eventually sectioned under the Mental Health Act in 1992. As a result I spent several months in St Matthew's Psychiatric Hospital, Burntwood, near Walsall.

My health improved temporarily and I was able to return to work, until I was once again an in-patient at St Matthew's and then transferred to St Margaret's Hospital in Great Barr when St Matthew's closed. It was at this point that I was diagnosed as having BiPolar Disorder (Manic Depression).

There were endless different treatments, countless changes of

medication and numerous courses of ECT but after several months I was deemed well enough to move forward and left St Margaret's for rehabilitation at Archway House in Walsall.

After just six months I was on the move again to Lonsdale House, a Residential Home where I spent 14 months. At the same time I was attending Broadway North Day Centre and this helped me to cope with and manage my illness.

In 1997 my mental health improved and I was offered my own flat by a local housing association. I decorated the flat throughout and kept it clean, neat and tidy. I also started volunteer work with The British Trust For Conservation Volunteers where I learned many valuable skills, regained my motivation and potential for leadership. This period of stability lasted for seven years and was a key part of my recovery journey.

I now have a very active social life:

I visit Rethink's Schoolhouse Project in Brownhills a couple of days per week, I am an active member of my local Methodist Church and enjoy playing crown green and indoor bowls. I also enjoy gardening and am a keen amateur photographer.

My motivation for writing poetry came initially when I discovered the accomplishments of my great great grandfather while researching my family history. I think it is in some small way a desire to emulate his achievements. I had grandparents in Ross-on-Wye, a beautiful part of the country, and an uncle who was a farmer in Leicestershire, so the countryside scenes I saw on my many visits began to inspire me.

I started slowly at first but soon realised that expressing my feelings through my poems not only helped me but could benefit other people in similar circumstances. I write all my poems in rough before typing them up on my computer and I have now written over 500 poems!

My real ambition is to have my poems published in a book at some time in the future. In the meantime I will continue on my recovery journey using poetry as the 'vehicle' that carries me along, what can sometimes seem like 'a long and often bumpy road'.

God Bless, Ian Christie

Apology

Your Voice would like to apologise to Ian Christie for incorrectly crediting his poem 'Frustration' to another author in the Winter *Your Voice* edition. We apologise for this error. Ian was one of the runners up to this year's Pringle Poetry Award.

Meet your host... Des Lynam

Rethink are very excited to announce that the Rethink Challenge Quiz in October 2007 will be hosted by Des Lynam. The Quiz is primarily aimed at a corporate audience, with tickets at £100, to raise as much money as possible for Rethink.

It promises to be an exciting night and this year will take place on 17th October at the BAFTA headquarters in Piccadilly. The evening will be comprised of a sparkling celebrity

reception; a multimedia interactive quiz; a sumptuous meal and an action packed programme of entertainment, including an auction. Full details are yet to be confirmed, but if you have any ideas for sponsors, celebrity or corporate links, then please let us know asap.

For information contact the Rethink Fundraising Team on 020 854 9201 or events@rethink.org.

Digital switchover

TV in the UK is evolving. Starting in 2008 and ending in 2012, television services in the UK will go completely digital, region by region.

Just as with the change from black and white to colour forty years ago, this change will bring benefits to everyone who enjoys television. Turning off the analogue television signal and converting the whole broadcasting network to digital will mean for the first time, everyone will be able to access a range of free digital channels through their aerial.

During this change it's essential that no one is left behind and carers will have a vital role to play in helping people switch to digital. The digital switchover Help Scheme is designed to help those who have not already switched to digital TV. Alongside the general assistance on offer from Digital UK, the digital switchover Help Scheme has been created to provide practical help to convert one TV set each for approximately seven million people. Those eligible will be the over 75s, those with significant disabilities (in receipt of Disability Living Allowance or Attendance Allowance), those who are registered blind or partially sighted or those requiring assistance in the run-up to switchover in their region.

The estimated six million carers in Britain¹ will play an invaluable role in making sure that those eligible are able to claim the help on offer. There will be national and regional publicity about the scheme in the coming months and all eligible households will be contacted directly closer to the switchover date in their area.

The Help Scheme will provide the necessary equipment to convert one TV set, help with installation and provide follow-up support if needed. Help with installation will be provided by a registered digital installer from the scheme on request and by appointment only.

The scheme will be free to the



poorest eligible households, i.e. those on Income Support, Job Seeker's Allowance or Pension Credit, and other eligible households will be asked to make a contribution of £40.

For those individuals who are eligible for the Help Scheme, approximately £600m of funding has been ring-fenced by the government to ensure that it cannot be used for purposes other than digital switchover between 2008 and 2012. The funding will be provided by the BBC through licence fee revenues.

Research shows that take-up of digital TV among the over 75s, those that are disabled and those that are blind or partially sighted is often well below the national average even though it offers many benefits, including extra channels, more programmes with subtitles and audio description of programmes for those who are blind or partially sighted.

Approximately 40 per cent of people aged 75 and over have digital TV compared with 70 per cent of

the general population¹ and yet people aged 75 and over watch more television than any other age group – approximately four hours per day.

Disabled people are much more likely to have digital TV than people aged 75 and over, although they are less likely to have switched to digital than the population in general – approximately 58 per cent of people with a disability now have digital TV.²

Separately, Digital UK is working closely with local councils, charities, volunteer and community groups to 'help the helpers' and provide additional information and assistance for those unsure about how to make the switch.

Jane Ostler

Director of Help Scheme, Digital UK

¹ Communicating with the over 75s: desk research commissioned by the DCMS to support the digital switchover Help Scheme.

² Ofcom Media Literacy Audit, April 2006.

In the last edition Mary Napier raised the issue of whether too much responsibility is being expected of people with severe mental illness. Mary's article generated considerable debate and has certainly touched a nerve. The following are just some of the responses from readers.



Who should be responsible?

When is putting responsibility on to service users a cop-out for the lack of services and when is it cruel to push people into employment when they are clearly not ready for it? In these follow-up articles, *Your Voice* readers express their views.

Rodney Yates writes...

Mary Napier is spot-on in homing in on the local situation pertaining to mental health clients as current Government thinking starts to impact.

The pre-conceived notions emanating from Government circles about what can be expected of ourselves – as people with a life-long disability through mental health needs – that we suddenly pretend our limitations and lack of social opportunity away by going out to get ourselves a job are way off-beam, so much so as to be a con – or conjuring trick, when introduced into our context.

We have had community care with us for well over 20 years, and it has still not been delivered as a comprehensive service in all that time. The con is in introducing distractions, or smoke-screens to divert us from the likelihood that the Government no longer has any intention of delivering this provision. The failure to deliver on this commitment stems from

year-on-year cuts and low prioritising for mental health. As this currently impacts locally, continuing care clients are offered just one morning a week as part of a Community Care group, and this is funded by Social Services, whose budget for the forthcoming year has been halved (money going elsewhere?) We are now being told to pay for our own Community Care (Take Responsibility – Mary Napier).

The Hidden Agenda is that we are being shepherded into being tarred with the same brush as everyone who is not currently serving the Government's coffers and that soon we can be addressed as 'malingerers' along with all the other people who don't fit into the Government's Blue-print. The strong-arm tactics of ASBOs and CTOs can then be considered justified.

On another level, there is no way that DWP offers of Employment (like being invited to be an also-ran in a Competition they have dreamed up) opportunities should be a part of Day Care Service Planning – to mitigate lack of Community Care (?)

What is being mis-construed nationally is impacting locally as Healthcare implementation grapples with jargonistic gibberish like 'Well-being and Social Inclusion' as if it was a central tenet of some new Mantra to be purveyed by every local service.

Behind this are some fundamental deceptions.

1. That this is in the Gift of both Healthcare Trusts and Government to bestow, and 2. That it is in any way a duty of local Care Providers, that they should be charged with delivering such nonsense, when they have yet to deliver on satisfactory Community Care services in over 20 years!

Maybe this could be highlighted when we are clearer about how Cuts are impacting locally.

You find yourself smiling indulgently back at the mis-direction this has taken current policy, but in reality this is large-scale mis-management, and we are being patronised by them with something so drastically off the mark as to be lamentably damaging to us personally.

Pam Knight writes...

As a member of Rethink for about 15 years and with a mentally ill son I agree wholeheartedly with Mary Napier's article. This is being said again and again by the professionals, psychiatrists, social workers, nurses etc. Other members of our local carers' group in Scunthorpe are experiencing difficulties.

At the moment my son is in the Humbercare medium secure unit in Hull where he has been since last May. We had to fight to get him there as the local support services said he was 'faking mental illness' to get into the new Great Oaks mental health unit in Scunthorpe. His delusion was that God was telling him to strip naked to do penance for his past misdemeanours. This he did one icy Jan night outside his bed-sit and the police picked

him up. The local team said he was not ill and he was sent to prison for two months. It was only with me and my daughter writing letters to the magistrate's judge, the governor at Hull prison, that he had another assessment and was declared very mentally unwell. The social worker told him to 'be responsible for his actions!' The worst outcome is that now he is on the sex offenders register for seven years for standing naked in the middle of the night.

I fear that for the long-term mentally ill things are getting worse. On reading your article 'I'm a carer get me out of here' I can empathise fully especially the piece about social workers telling us to 'let go, let go'. If only we could in the secure knowledge that our family member was to be looked after and we could trust community care.

Jan Landon writes...

I read with interest the article entitled 'Who should be responsible?' (Winter 2006/7) in which Mary Napier questions the assertion that service users should always be made to take responsibility. I feel that before we can talk about responsibility we need to be clear about what the term means. There are different ways to take responsibility. Firstly the NHS Trusts are responsible for doing the job for which they are paid which is something to do with delivering mental health. It is their responsibility to ensure that they do this to the best of their ability. Secondly human beings benefit psychologically from being in control of their own lives and service users are no different. Therefore, it is clear that the more responsibility for his own life that a user can take the better for his psychological well-being. It follows that the services have a clear responsibility to understand the relationship between self governance and mental health.

It is therefore the professional's duty to encourage user responsibility. I argue that this duty of care can only be carried out via an understanding of a client's needs. I would agree with Mary Napier inasmuch as 'making' somebody take responsibility is an abdication of mental health professionals' responsibility of care because care is being denied

if the person is not ready to take responsibility – he or she might need help, support and a Care Plan. For example, somebody with agoraphobia might want to reach the stage when she can go out by herself but if she is 'made' to go out by herself she might become even more fearful – perhaps with traumatic results. So in such a case it is not the issue of responsibility that needs to be looked at but whether a person is ready to take responsibility. If he is forced to take responsibility too soon he will fail and feel even worse about himself. On the other hand if he is encouraged to take responsibility at the right time for him and succeeds he will feel good about himself. The art of the professional is in recognising when the person is ready to take responsibility. Surely that is only as the result of a time consuming caring process involving a supportive relationship between the professional and the service user. It must entail really listening to her and an ability to empathise – to put oneself in somebody else's shoes. Some people will be ready for responsibility but might need to be encouraged to take it (or even forced?); without empathy others might be made to take it before they are ready, perhaps with disastrous results.

So the question isn't who should take responsibility but how and when.

However, I think there is an even more fundamental meaning of

responsibility which goes to the very roots of our culture. As an existential counsellor (and an ex service user) I find the twin issues of freedom and responsibility are of special interest. NHS professionals are not magicians. They don't have the answer for many physical conditions let alone mental health problems. They encourage us to take responsibility for our diet and weight etc which encouragement, far from being an abdication, is an admission that they don't have all the medical answers to the human condition. There are some things that we can only do for ourselves. I see this as a huge step forward and feel it should be extended to mental health. Here it is not so much what we eat that matters but how we live. The services do not have all the answers and we should stop expecting them to be magicians. As a culture we do tend to feel that doctors can heal us and we have come to expect it as a right. My argument is that our physical and mental health might be more up to us than we can imagine; in other words lifestyle is important.

To sum up I am arguing that professionals have a responsibility to empathise with clients, that clients have a responsibility as human beings to take control of their lives whenever possible and that we all have a responsibility to be aware of how our individual lifestyle impinges on our mental health.

New in-patient advocacy service

Thursday 9th November 2006 saw the launch of the Rethink Mental Health Advocacy Service in Manchester.

The service will cover Manchester Royal Infirmary, North Manchester Hospital, Wythenshawe Hospital and Monet Lodge Independent Hospital and will be available to all in-patients with mental health problems aged 18 years and over (including older people). The service is targeted at people who are subject to detention under the Mental Health Act or who use the Mental Capacity Act 2005 within the city.

The Deputy Lord Mayor met senior Rethink staff, including Rethink's North West Regional Manager Grainne Currie, Service Manager, Advocacy Team, plus Joint Commissioner for Manchester Chris O'Gorman, Director of Operations for Manchester Health and Social Care Trust Margaret Worsley, Manager of the Pakistani Resource Centre (and Rethink's partner in service delivery) Yusuf Hussein, and EMF Director Rushi Munshi. Service users and carers from the Service Advisory Group also attended the launch event.

The staff team comprises a part time Area Service Manager, a full time Service Manager, part time Administrator and five



Grainne chats to Cllr Glynn Evans, Deputy Lord Mayor of Manchester, and Daniel Madge, Commissioner, Manchester Mental Health and Social Care Trust.

full time Advocates, one of whom will focus on the needs of people from Black and Minority Ethnic Groups and another on older people.

The service will be based in Central Manchester – Ethnic Minority Foundation House, 12 Charlotte Street, Manchester M1 4FL. The service is funded by Manchester Joint Commissioning Team for three years and will be accessible Monday to Friday, 9am to 5pm.



David Dodd retires

David Dodd, Regional Manager for the West Midlands, has retired from Rethink following his recent illness.

David is regarded with great respect and affection not only by his colleagues

across Rethink, but also by our members, service users and carers in the West Midlands and beyond.

David is most noted for his commitment and diligence to putting the values of Rethink right at the heart of all aspects of his work; his dogged determination in pursuing a better deal for all those affected by severe mental illness is renowned.

His reputation was built on the solid foundation of people's positive experience of either David's behind-the-scenes intervention or his direct help and support. David made an outstanding contribution to the success

of Rethink over the years, coming to us as an Area Services Manager in May 1992 from a National Health Service background. David became the Regional Manager for the West Midlands in 2004. His leadership of the West Midlands region over the years has led it to become one of the biggest and most successful regions within Rethink.

Ruth Sutherland, Director of Services, said: 'David will be sorely missed by the West Midlands Region and his many friends and colleagues right across Rethink. However, the impact he made on the region and all of the lives that he touched will be with us for a long time and for that we sincerely thank him and wish him and his family all the very best for the future.'

In his usual determined and pragmatic style, David is making a good recovery and many of his past and present Rethink friends joined him for his leaving do on 12th April.

Celebrations in Leek

The staff and project workers at Leek Social Enterprise were treated on Wednesday 14th February to a day of festivities and craft workshops!

The conservatory was adorned with paper lanterns, good wishes, pictures and even the odd dragon to mark the Chinese New Year (18th February



2007). The team had fun discovering which animal in the Chinese Zodiac represented the year of their birth. To everyone's surprise, Barry is a 'Tiger' (so is Juliette, but this didn't surprise anyone), and there will be no living with Stephen Rhead, Service Manager, since he discovered that he is a 'horse'! The team enjoyed festive Chinese nibbles and listened to traditional Chinese music.

We were also visited by talented local artist Anthony Hammond, who delivered a course in Willow Sculpture. After giving the group a talk on the art of working with willow, and a Health and Safety training session, Anthony

got the team to work on creating basic obelisks using traditional techniques.

The polytunnel became a hive of activity as the team attempted to get to grips with this fiddly new skill. Soon the place was full of unique willow planters, and we were left with many fresh ideas for craft activities to further enhance our Community Garden, which will be the venue for a number of events in the coming months including an 'Arts in the Park' weekend (linked to Leek Arts Festival). Well done to everyone who succeeded, and commiserations to our volunteer John who abandoned his creation when it began to resemble a bird's nest!

The celebrations were enjoyed by all, and rightly so as we have a lot to celebrate! We are delighted to have received a full 100% in our Quality and Practice Audit, which took place in January.

The auditors commented on our 'happy and confident' team, their active involvement in developing the project, and the hard work that has gone into landscaping the gardens. The audit was a very positive experience all round, and a great opportunity to share ideas and good practice. Everyone at the Project is extremely proud of our achievement.

A great big thank you to our Project Workers, who made the auditors feel welcome and valued!





National speakers attend Wigan event

Rethink members, users of our services, carers and staff came together for the first Members' Day in the North West on Friday 23rd March.

The programme for the day was designed to help people affected by severe mental illness, share information and support on practical issues including employment and benefits.

Speakers included Simon Francis of the Department for Work and Pensions and Carey Bamber from the Care Services Improvement Partnership who talked about direct payments. Sarah Gibson, Rethink Director of User and Carer Involvement, spoke about stigma and prejudice and the audience were shown a very moving DVD that graphically illustrated the reality of this issue for so many people.

Grainne Currie, Rethink's Regional Manager for the North West, said: 'People living with severe mental illness and their families tell us time and again that they desperately need information and support to understand illnesses like schizophrenia and depression.

'Often people find that the stigma that surrounds severe mental illness is worse than the illness itself. That stigma can unfairly affect all areas of their lives, and stop people getting back into work and being treated with the respect they deserve.

'This event will help our existing members in the North West as well as people new to Rethink to get practical advice and information on work and benefits. People will also find out more about what Rethink is doing to tackle mental health discrimination.'

Pictured top left:

Sameeia Luqman (Advocate Manchester); Grainne Currie, NW Regional Manager; Alister Rowe, Chair North West RRG; Elayne Woolley (Team Leader – Station Grove Supported Housing).

Minister drops in for tea

Minister of State for Reform, the then Lord Warner, dropped in for tea and a chat at the recently opened Rethink Crisis House during his visit to Leamington Spa, on Thursday 30th November 2006. Lord Warner enjoyed tea and cakes whilst having a chat with the Team about their achievements, and heard from service users about their thoughts on the service that they have received.

The service offers an alternative to hospital admission for mental health service users who experience a crisis during their recovery. It is known that caring for people in an environment which remains as close to their usual surroundings as possible aids recovery. The multidisciplinary team provides community based treatment, 24 hours a day, 7 days a week and aims to treat people who are experiencing mental health difficulties in an environment that feel more like their own home, causing minimum disruption to their lives.

Lord Warner praised the Team and said, "It has been a really interesting visit. Hearing directly from service users about their experiences helps me to keep in touch with what really matters."



Sandy Taylor, Chief Executive of Coventry and Warwickshire Partnership Trust said, "We are really pleased that Lord Warner was able to visit us to see what has been achieved and hope that he will find this beneficial in his work."

Diane, a service user who was treated by the team, said, "This service was incredible, I would not be here today if it had not

been for them. They gave me the treatment and support I needed and managed to make sure that I was able to stay with my family which was so important."

Local helpline award

Local group Rethink North Warwickshire Mental Health Helpline has been awarded an NEC internet-ready PC and a contribution towards one year's BT Total broadband access as part of the BT Community Connections award scheme. In addition Microsoft® office 2007 software is included as part of the winning package.

The scheme, now in its fourth year, has awarded more than 5,000 IT packages to thousands of community groups across the UK, benefiting over five million people, opening up a world of marketing, training, recruitment, fundraising, communications and networking possibilities to recipients.

The North Warwickshire Helpline was among thousands that entered the award scheme across the UK and impressed judges with their ideas on how a PC would benefit their group immediately and the wider community long term. The group plans to use the internet to reach the younger

population of Warwickshire, with a web page, email, text, and free phone helpline service offering information and signposting on a range of subjects which affect younger people not only on mental health issues but other issues that may affect or worry young vulnerable people.

Carol Lewis of North Warwickshire helpline said 'We are absolutely delighted with our BT Community Connections award. People without internet access will be able to get information off the net via our free phone service. Youngsters often find talking about their feelings difficult especially to friends or family and this award will give them the opportunity to remain anonymous and all information is confidential.'

Anyone who would like any further information please ring the helpline on 0808 800 0025 between 5pm and midnight; we are open seven days a week".

Carol Lewis
Helpline Co-ordinator



mental health shop

opening the door to information

Poppy Shakespeare – a novel by Clare Allan.

Poppy Shakespeare has been long listed for the Orange Prize for Fiction.

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Who is mad? Who is sane? Who decides?

Welcome to the Dorothy Fish, a hospital in North London. N has been a patient for thirteen years. Day after day she sits smoking in the common room and swapping medication. Like the other patients, N's ambition is never to be discharged. Then in walks Poppy Shakespeare in a short skirt and snakeskin heels. Poppy is certain she isn't mentally ill and desperate to return to her life outside and, though baffled, N agrees to help her. But in a world where everything's upside down, are they crazy enough to upset the system?

"Here is a serious novel which portrays the mentally ill with both raucous humour and with an empathy altogether lacking in sentimentality. The pitch of the narrative voice is perfect, and the characters, in all their bravado, pathos and absurdity, feel utterly true to life. It is a brave and original piece of work." – Patrick McGrath.

To order your copies, visit www.mentalhealthshop.org or call 0845 456 0455. Offer ends 31st July 2007. While supplies last.

Mental Health Shop founded by
Rethink and Mental Health Media

Mental Health Media 

rethink



Confidentiality By Mary Napier

Confidentiality, Data Protection Act, Human Rights, Information: words which are frequently used in Mental Health Services. Used in the right context they can be beneficial, but if used obstructively, they can be very damaging to the person or persons at the receiving end.

Practitioners need to understand the value and importance of sharing information with users and carers, and how to do it appropriately. All the research and evidence shows that failures in the delivery of care usually include, as a factor, the failure to communicate and share information.

I can see that there are difficulties for everybody: the practitioners may feel they could get the blame if they shared too much information, and users

and carers might feel they were being fobbed off, or just not listened to if they did not receive the information they asked for.

The key to providing a seamless care service is good communication. Getting this right will transform the service. I recently heard from a trust that one of the major complaints they received was all about carers being denied relevant information that could assist them in their role as a carer,

and other complaints have been of practitioners using the Data Protection Act in an obstructive way.

Luckily there are several of us who now realise that things must be changed. Peter Robinson and some of his colleagues from the Carers' Council Allies in Adult Mental Health, in association with the Carers Federation, has been in a group working with Nottinghamshire Healthcare NHS Trust to develop an Information Sharing Policy. Their involvement stemmed from their Confidentiality Conference in 2004. Their policy 'General Governance – Information Management and Confidentiality' was completed in February 2007 and you can see a draft of it on www.mhcarers.co.uk. We can learn so much from this policy. It outlines the basic types of information and issues around consent and confidentiality. It outlines expected trust practice and strategies for dealing with occasions when there isn't consent. It provides a checklist for practitioners to use regarding information sharing. Basically this policy is all about good practice, and of course a lot of it is about good CPA. For example Point 4.3.5 of the policy says "The issue of consent to information sharing should be discussed as part of the CPA process when care is being planned with the individual".

Point 4.4. of the document lists "When information can be Disclosed Without Consent". There is also a good section on Advanced Directives.

I conclude with a quote from David Kingdon's recent book *Tackling Mental Health Crisis*: 'Many carers can feel excluded when professionals use confidentiality to avoid speaking with them. Confidentiality means not sharing without permission; it does not mean neglecting to listen to the information and concerns expressed by others!'

International Women's Day

Kami Kooner writes...

Ealing Council asked their local Rethink Carers service to help with an international women's day exhibition in the town hall on Tuesday 20th March. Although it was a busy time for our service, we decided it would be a good idea to go along with a display of leaflets for the event.

Once there we set up a display and made contact with police community liaison and crime prevention officers. We worked alongside other mental health organisations in the area such as TASHA, CAPE and counselling organisations, Hammersmith and Ealing Adult education centre, the Children's information centre, and Ealing library. I gave out several of my new business cards that evening! It felt as if it were a very worthwhile event to go to even though it did not finish till 7.30pm and it had been a long day. I even managed to leave a couple of posters with the receptionist and I see today he has put one up in the entrance.

The NHS carers support worker was very interested to hear about the day and we gave some flyers to our colleague who is based in the local mental health resource centre to give to her carers. Partnership work and networking rules ok!

Kami Kooner (left)
with Denise Bradley.





Get fit, get active and get involved

Calling all runners and adventure seekers!

We have 15 guaranteed places for this September's Great North Run, and 10 places for October's Great South Run. So this is your chance to get fit and do something amazing to raise money for Rethink!

The BUPA Great North Run is the world's biggest half marathon: 50,000 people start in Newcastle and finish in South Shields and this year it could be you!

The BUPA Great South Run is equally as challenging, taking place in October. You will run over a fast 10-mile course providing varied scenery, historic landmarks and stunning views!

Or maybe you would prefer the Women's Hydro Active Challenge in September... you can walk this one, and it's a great way to get in shape for summer! Come on, join in!

But if running really isn't your forte then perhaps parachuting is? Or White Water Rafting? We're looking for hundreds of adventurous volunteers to take up the challenge and if you raise enough in sponsorship you will get to jump or go rafting with your friends for free!

This is your chance to really make a difference and it's easy to take part! The events team will be on hand to support you throughout and we'll send you lots of information, fundraising ideas, and trendy running vests/ t-shirts too! To get involved contact the events team today by emailing events@rethink.org or phone 0845 456 0455.

For more information about the events, or our range of Treks and Cycles in exotic destinations, go to www.rethink.org/get_involved/fundraise/challenge_events/. We look forward to hearing from you!



Summer raffle 2007!

We are running a nationwide Rethink raffle this summer. Great prizes... great fun... and a great way to make a positive difference to people with severe mental illness in your area!

If you would like to buy tickets please contact us 0845 456 0455 or email communityfundraising@rethink.org.

Your Shout

Rethink has been commissioned by the Electoral Commission to carry out an exciting new project called Rethink Politics, which is about the involvement of adults with experience of mental health problems in the democratic process. The project is supported by MDF - The BiPolar Organisation, Mind and the Mental Health Foundation. It's a national project that began in January 2007 and ends in December 2009.

The Your Shout enclosed in this instalment of *Your Voice* focuses on the views and opinions of service users on political and social issues that affect daily life.

We aim to collect **ONE THOUSAND RESPONSES** from service users via networks, groups and online members from various organisations by 8th June 2007.

We know thousands of people are affected by issues such as education, health, community facilities, benefits and employment opportunities but don't speak out because they think nothing will change. Now is the time for change, now is the time to speak out. Help us to support you and others in the mental health community take a stand.

We need your help – your views! Please help make a difference by getting involved and completing our brief questionnaire, or passing it on to someone else.

The questionnaire has been designed to be completed by service users only; however, we need carers and front line workers to help us pass the survey on so we can reach people with mental health problems across the country.

The questionnaire is available in paper copies and online. For paper copies, please contact the Rethink Welcome Team on 0845 456 0455 or you can complete the survey online by going to www.rethink.org/yourshout.



Terry Hammond retires as editor



Terry Hammond has been editor for six years and in that time he has helped to transform *Your Voice* in to a vibrant and popular magazine. Terry said 'It has been a privilege to edit *Your Voice* and I am so grateful to the many contributors who provided me with such a diverse range of material.

'I very much wish Ruth Bettie, the new editor, all the very best and I am sure *Your Voice* will go from strength to strength.' Terry Hammond told *Your Voice* that he very much hopes to continue his involvement with the magazine with the occasional article.

The jury's out: I'm guilty of having a mental illness

This article by the writer, Clare Allan first appeared in the *Guardian* earlier this year.

Like two million other viewers, I tuned in to *The Verdict* on BBC2 recently, curious to witness the goings-on behind the closed doors of a jury room in a major criminal trial – albeit a fictional one. Unlike most of my fellow viewers, however, I know that I will never be called to sit on such a jury. My mental health status rules me out. My judgment is invalid.

My friend Alec also watched the programme. In fact, we agreed on the verdict. But this was just a coincidence, for while Alec is a rational being who could be summoned for jury service tomorrow, my own considered opinion – at least in so far as the criminal justice system is concerned – has all the credibility of a casually tossed coin.

I might come to court as a victim of crime, or be called as a witness, but in both situations my mental health history will almost certainly be used to discredit my evidence. And I could, of course, stand in the dock myself, to be tried before a jury of my fellow citizens – ‘fellow’ except that, by definition, none will have shared my experience.

The Verdict did not make for reassuring viewing. Ironically, the deciding vote went to Jeffrey Archer, who changed his verdict to avoid the need for a retrial. Like me, Archer would be barred from jury service in a real trial situation. In his case this is because he has spent time in prison within the last 10 years. Unlike me, at the end of this time, the bar will be lifted and he may yet sit on a jury. I will not.

The criminal justice system website sets out the criteria for eligibility. ‘Jury service,’ it tells me, ‘is one of the most important civic duties that anyone can be asked to perform.’ It is also a duty that ‘all members of the public are expected to perform’. There follows a list of those presumably excluded from this category. The first criterion is age – you must be over 18 and under

70. The second concerns criminal convictions, and the third and final exclusion covers those with “mental disorders/mental health problems”.

There are four circumstances in which my mental health problems would disqualify me from service. If I am not sure whether these apply to me, I am advised to consult my doctor, or ‘to ask a family member, friend or neighbour to explain it to me’. I did try knocking on the flat upstairs, but, in my neighbour’s absence, I must do the best I can.

The circumstances appear to be these: if I am in hospital, if I am in guardianship under section 7 of the Mental Health Act, if a judge has decided I am not capable of managing my affairs, or – and here’s the clincher – if I ‘regularly visit a medical practitioner for treatment’.

I am not suggesting that patients be bussed direct from the wards to the Old Bailey. It seems reasonable that anyone in hospital for whatever reason be excused from jury service. But this is not the situation for me and thousands like me. I am, after all, deemed capable of working and of paying my taxes – taxes that pay for the judge and the lawyers and the sandwiches the jurors eat.

I see my psychiatrist maybe four times a year and visit my GP for prescriptions. I take medication daily and have come to accept that I probably always will. I don’t consider myself to be ill, but I do have a condition that needs regular treatment, in much the same way as a diabetic

needs insulin. Without my neighbour to clarify the matter, I can only assume that this bars me from jury service.

The issue is greater than this. The assumption that those with mental health problems have nothing of value to contribute needs to be challenged. When it comes to employment, the ‘mentally ill’ face more discrimination than any other section of society. Fewer than four in 10 employers would consider employing somebody with a history of mental health problems – a topic not even considered by the Equalities Review report, which lumps all disabled people together in a single category. If the government is committed to fighting stigma, then the jury system would seem a good place to start.

For more on this issue, please see page 4



Clare Allan's novel, *Poppy Shakespeare*, is published by Bloomsbury, RRP £7.99.

To order a copy please visit www.mentalhealthshop.org or call 0845 456 0455, alternatively go to www.guardian.co.uk/bookshop call 0870 836 0875.

Family work and psychosis



Rethink's Geoff Lindsay reviews a new book about working with the whole family.

An integrated approach to Family Work for Psychosis – a Manual for Family Workers is written by Rethink member, Gina Smith, a Consultant Nurse and two colleagues, Karl Gregory and Annie Higgs.

Family Work is using techniques from Cognitive Behavioural Therapy (CBT) and working with the whole family instead of only the service user. It is this that makes this book so vitally important to other Rethink members.

For many of the carers and service users I meet, CBT is hard to get, and then the carers are often not included. No wonder some say CBT stands for Can't Bloomin' Geddit. Yet Gina and her colleagues, all experienced practitioners, show how working with the whole family is very successful. In particular, there are testimonies; one service user says, 'The key word is "family", as I could not have beaten this on my own and my wife could not have continued to help me without the support and new direction provided by the family work'.

This is a book for professionals but could also be used by Rethink Carers' groups and Rethink services. It really is a joy to read so many 'how to do its'. This book is immensely practical. It moves the debate on from whether to work with carers to how to work with the whole family.

Each chapter can be read on its own but there is one I especially liked that can help Rethink services and groups. Chapter 10, How to promote Recovery through Family Work, is worth the price of this book on its own. It gives a 6 step problem solving method they can use, also laid out in Appendix 2. Few mental health services provide Family Work for Psychosis so it is crucial that carers, users and professionals can take parts of this book and apply them to their own situations. The authors themselves encourage mental health workers and carers to develop family interventions, so long as they have had some training and are receiving family work supervision.

This book is also a campaigning tool. Most readers will feel that they do not have the skills, confidence and support to implement family work in its fullest form. But you could buy this book as a present for your Care Coordinator, or even the Chief Exec of your Mental Health Trust!

The authors present family work in such a clear and understandable way that many carers and service users can make it work for them in their own lives. There are not many books that achieve that.

An integrated approach to Family Work for Psychosis – a Manual for Family Workers is available from all good booksellers or from the publishers, Jessica Kingsley, at www.jkp.com/catalogue/book.php/isbn/9781843103691

ISBN 978 1 84310 369

Relative stranger a life after death

Mary Loudon is an established author whose sister Catherine died of cancer in January 2001. Catherine also had a diagnosis of schizophrenia and had distanced herself from her family for some years prior to her death.

This is the story of a journey through grief that most of us will make similarly several times during the course of our lives, and is one of the most uplifting and affecting books I have ever read.

There is a piquancy running through Mary's experience afforded not only by her style of writing, but also by the context of her relationship with her elder sister. The sadness of the loss of her childhood relationship with Catherine to mental illness is movingly illustrated; and reflections on the invisible line between mental ill health and wellness are issues that, I think, many siblings will relate to.

Yet, Mary makes the journey through the final loss of her sister to cancer with great courage and common sense. She visits the people and places that her sister knew and, through this, finds solace and reunion with Catherine as an individual. The joy in Mary's life that her children and husband contribute is embraced, so that the reader is left with a moving account of awareness, acceptance and hope.

Reviewed by Ruth Bettie

Published by Canongate Books and available from all good bookshops, price £7.99, ISBN 1841958948.

Pen friend scheme

Your Voice is to pilot a pen friend scheme until autumn 2007. The scheme will be continued beyond that date if it is successful.

If you want to know more about the *Your Voice* pen friend scheme for Rethink Members, wish to advertise for a pen friend, or reply to a pen friend advert, please write a brief first letter to Ruth Bettie, Rethink Involvement, PO Box 13634, Polesworth, Near Tamworth B77 9ET.

On the back of the envelope please write 'Your Voice Pen Friend', your first name and your Rethink membership number (if you have one). Ruth will then send you a form to register on to the pen friend scheme.

Neither your last name nor your address will be published in *Your Voice*. Your details will be stored at the above office in accordance with the Data Protection Act.

I am a 34 year old woman with paranoid schizophrenia and depression since 1992. I would like to write to male pen friends between the ages of 30 and 45 who have any type of mental ill health with any type of interests who would like to share life's ups and downs.

I have been stable since 2001, but have more downs than ups. I have lots of interests, which include writing letters, going to the cinema, eating in or out, visiting the countryside etc.

Bhavini

Your Voice is sent quarterly to every Rethink member. Complimentary copies are also sent to every Regional Manager and Rethink service.

Ordering extra copies:

- *Your Voice* can be purchased at a cost of £2.50 each including postage from the Mental health Shop www.mentalhealthshop.org or call: 0845 456 0455.
- Members who have articles published can ask for two free additional copies of the relevant edition of *Your Voice*.
- Rethink members and staff can order up to ten copies for events and displays at a cost of £6.00 to cover postage
- Rethink members and staff can order up to twenty copies for events and displays at a cost of £11.00 to cover postage

Please call the Welcome Team on 0845 456 0455, and have your address and membership number, or service code, handy.

For enquiries about *Your Voice* distribution please contact the Editor, Ruth Bettie on 01827 896764 or email yourvoice@rethink.org.

Rethink Annual General Meeting Saturday 17th November 2007

Contact: Janine Woods

Tel: 0121 525 6105

Email: janine.woods@rethink.org

West Midlands Region Members' Day Monday 8th October 2007

Birmingham Council House
(postponed from 31st March)

Contact: Jennie Hodgetts

Tel: 0121 580 4365

Email: jennifer.hodgetts@rethink.org

Useful websites

www.ukselfhelp.info/links

(the self help section is very good)

www.healthcare-events.co.uk

(details of forthcoming conferences)

www.rethink.org

www.mentalhealthshop.org

www.rethink.org/jess

www.rethink.org/yourshout

keep us posted



**Deadline for copy
for the next edition:**

Friday 8th June 2007

Please send your letters,
comments and articles to:

Ruth Bettie, Editor

PO Box 13634

Polesworth

Near Tamworth B77 9ET

Tel: 01827 896 764

Email: yourvoice@rethink.org

and/or: Terry Hammond, Deputy Editor
terry@hammond2002.freeserve.co.uk

Please try to restrict your letters to 150 words.
A photo with articles is always welcome.
Your Voice reserves the right to edit letters.

What physical health problems are associated with mental illness?

Research carried out for the Disability Rights Commission in 2006 shows that people with severe mental illness are at higher risk of obesity, diabetes, stroke, coronary heart disease and respiratory problems, amongst others. The reasons for these higher risks are complex – possibly resulting from genetic factors, lifestyle and side effects from medications.

For information about the risks associated with specific medications, call the Maudsley Medication Helpline on 0203 228 2999 Monday to Friday 11am-5pm.

How can physical health be monitored?

If you have a mental illness, many GPs carry out a physical health check for you annually. These GPs now ask mental health patients if they wish to be added to their register (list) of people who need this annual check. This confidential register simply reminds the GP or nurse to contact you when a check is due. It is your decision whether you are on the register or not, and you are still entitled to a health check if you are not. A health check includes:

- Taking your blood pressure
- Taking your pulse
- Doing a urine or blood test
- Weighing you

These tests allow the GP or nurse to look for changes so that steps can be taken to deal with any potential problems. If you are having any problems with side effects, you can discuss them. You can also take this opportunity to ask for advice on smoking, alcohol or street drugs, diet, exercise, flu jabs etc.

How does diet/nutrition affect my physical and mental health?

The body and brain are made up of water, proteins, fats, minerals and carbohydrates. The food we eat must provide these nutrients so that the body and brain can develop properly and remain healthy. It is best to try to

get a wide range of nutrients through a balanced diet, rather than relying on specific supplements.

Proteins – Chemical messengers in the brain (neurotransmitters) carry information around the brain, including signals about mood. Proteins are formed mainly from amino acids. Most amino acids are produced by the body itself, but some are only available from protein foods ('essential amino acids'). The amino acids which are important for brain function can be found in eggs, lean meat, poultry, beans and pulses.

Fats – There are certain types of poly-unsaturated fats that are very important for flexible cell structure. These are 'essential fatty acids' (EFAs) that are only available from certain foods. Flexibility of cells is essential for the 'communication' of electrical and chemical signals which impact on mood and sleep.

There are two essential fatty acids in the brain: omega-3 and omega-6. These fats and the processes they go through are thought to contribute to brain health. The most common food source of fatty acids is oily fish (mackerel, sardines, trout, herring, salmon etc.). There are alternative sources including: leafy green vegetables, nuts, humus, oils (sunflower, olive, flaxseed, linseed), eggs, avocado).

Some people prefer to take fatty acid supplements. The Maudsley Prescribing Guidelines suggest that a daily dose of 2-3g of EPA may be worthwhile for schizophrenia when added to standard treatment (antipsychotics). Please discuss this with your psychiatrist.

Vitamins and Minerals – Certain vitamins and minerals have been found to play an important part in brain function. No mineral or vitamin can work without interacting with others, so we would advise trying to include them into your diet rather than buying supplements. Copper, zinc, magnesium

and Vitamin C appear to play important roles in creating brain neurotransmitters. All vitamins except Vitamin E have to come from food as the body cannot produce them.

What else do I need to know about food?

Carbohydrates that are digested slowly help keep mood stable: wholemeal/granary bread, oats, bran cereals, beans, lentils, potatoes, rice and pasta. These foods should form part of each meal along with protein and vegetables.

Sugary and refined foods, such as white bread, make blood sugar levels rise and fall very quickly, which can affect your mood stability. These are best avoided. Caffeine can also affect mood negatively.

High levels of saturated and hydrogenated fats will make you more vulnerable to obesity and heart disease. Foods containing these fats include meat pies, sausages, hard cheese, butter, pastry, cakes and biscuits.

Is there a link between gluten intolerance and schizophrenia?

Gluten is a protein found in wheat and some other cereal grains. A gastrointestinal disorder in which there is an autoimmune reaction to gluten is called coeliac disease. Research has shown that a history of coeliac disease makes the risk of developing schizophrenia 3 times higher. You should discuss symptoms with your GP and ask to be tested before making any changes to your diet.

Why do I need to exercise?

Exercise is an essential part of looking after your physical and mental health. The benefits to your physical health include lowering high blood pressure, burning fat and improving the body's ability to fight illness. Exercise also regulates blood sugar levels and can improve mood stability. 30 minutes, moderate activity per day is all you need to improve your fitness.