

Mental Health Matters Newsletter

Spring 2010

Giving a voice to mental health service users in Canterbury and coastal locality

our Mental Health AGENDA: essentials for Recovery and care

‘The fundamental question for those concerned with high quality services for people with ... disabilities, is:

“*How can we use our resources to assist the people who rely on us to live better lives?*”

John O’Brien

In ‘What’s Worth Working for? Leadership for Better Quality Human Services’

Published by Responsive Systems Associates 1992 <http://thechp.syr.edu/rsapub.htm>

A) Care Plan Approach (CPA)

The new version of the Care Plan model should be brought to Kent. ~ With a care plan ready when the patient is released from hospital: Working to connect the individual with care and support in the community: a route to pathway of hope, support and recovery that embodies a belief in people’s own ability to manage, change and improve the quality of their lives: Working to support wellbeing and personalisation.

B) Increase use of alternatives to

medication, alone: not just resting on containment of the patient’s condition. This means best use of talking treatments, [e.g. CBT, increased access to psychological services, counselling etc] and creating opportunities for therapeutic activities [e.g. ‘Star Wards’] to aid recovery.

Working with the individual, using tools such as the CPA and the Recovery Star, -including consideration of physical health and social aspects, - to move away from ‘nothing can be done’ to ‘let’s see what we can do to change this.’

C) Maintain 24 hour Coverage for a Crisis

service to give access to support when it is needed, and ensure that service users & carers concerned are made aware of its availability. ~ *In mid-2009 this condition has not been met.*

D) Proper procedure when police detain people with mental health problems in custody. Full application of the recommendations of Lord Bradley’s Report.

E) Challenge stigma: Campaign to challenge *and change* public stigma & prejudice against people who suffer MH problems; ~to be service-user directed to ensure it is pertinent.

F) Protect and increase Funding for mental health services:

Funding for the Cinderella service must increase. To repair the deficit from MH missing out on increased funding invested in ‘Modernising’ the NHS since the millennium, MH should be freed from the ‘need’ to make 3.5% annual Efficiencies (budget Cuts).

LOOKING AT MENTAL HEALTH POLICY WITH OUR LOCAL M.P.



On 19th March 2010, Canterbury & District Mental Health Forum staff Mark Kilbey and Matthew Sands, together with East Kent Carers Support Group representatives Chris and Cheryl Ives, played host to local MP Julian Brazier in a meeting to discuss concerns about mental health policy.

With only a small part of current annual funding allocation for carers' breaks used for the intended purpose, Chris and Cheryl asked what could be done to get Carers the support they need. They also asked what would be done to ensure soldiers returning from Afghanistan, who could suffer Post Traumatic Stress, have their ongoing health needs met. Mr Brazier promised to take these issues to front-bench MPs, and said that, since his Party's Defence spokesman (Liam Fox) is a doctor, the latter issue is likely to be under his consideration.

In a wide-ranging discussion, looking at the Forum's Agenda, Mr Brazier said he had sympathy with the first two items; remedies for people in mental distress which go beyond containing their conditions with medication.

Julian Brazier spoke of his concern that having too many 'Targets' have meant health service staff are diverted to take too much time completing 'box ticking' tasks instead of doing the essential work of their profession.

Matthew Sands argued that any more imposed reductions in funding should not be called 'efficiencies', as such cuts would be likely to damage the quality of the service. Mr Brazier disagreed on this point, saying he is sure there is more waste that can be cut.

Candidates answers to questions on the Mental Health Agenda

Julian Brazier (Conservative)

didn't answer the questions sent with our Agenda to Canterbury Candidates but replied:~ Dear M. Sands,

Thank you for your email regarding mental health. I share your concerns on this matter. ...For far too long mental health services have been the Cinderella service of the NHS. We can no longer afford to neglect mental health services while the number of people suffering from mental illness continues to rise. We need to make sure that mental health services are an integral part of the NHS and that we end the stigma of people with mental health problems.

You may be aware that David Cameron recently spoke about the issue of Mental Health;

"Everybody knows somebody with a mental illness. There are as many people with mental illnesses in the UK as there are people living in London, Scotland and Wales put together. Despite this, there is still a cultural stigma attached to having one. As a result, far too many people don't seek treatment for their mental health issues, and a shocking number of people suffer discrimination or even violence because of them. This can't go on - the only mental health problem we should be prejudiced against is prejudice itself."

One in four people will suffer from some form of mental health problem in their lives and unfortunately the biggest barrier to seeking help and treatment is the stigma of having a mental health problem. We must also focus more on the preventative measures that will improve the nations' public health and reduce the number of people who will develop mental health problems. The Department of Health should be using its influence and its resources across Government to deliver positive improvements to people's standard of health. My Party will make the Health Secretary directly responsible for public health, while a new NHS Board takes over the day to day management of the NHS. There will be a separate public health budget, within the existing NHS budget, to address these problems, and this will be ring-fenced to prevent Primary Care Trusts from using this budget to make up for deficits in other areas.

My colleagues and I are committed to ensuring that mental health services in England meet the expectations and demands of the 21st century. Once again, thank you for taking the time to write to me.

Yours sincerely, Julian Brazier TD

Candidates answers to questions on the Mental Health policy Agenda were *not* received from. **Labour** or **UKIP** candidates; The **Greens** emailed that they “will be doing everything possible improve mental health facilities in the Canterbury District.” The Lib Dem answered:

Guy Voizey (Liberal Democrat)

Care Plan Approach (CPA)

A) ~ Is it right that a patient may be discharged from mental hospital without a care plan that fully connects the individual with needed care and support in the community?

No – One of the major problems with our current system is there is a gap between health care and social care. These should be brought together so that individuals are not lost by the ‘system’ once they are discharged.

Increase use of alternatives to medication, alone:

B) ~ What would your party do to ensure that more people with mental health problems can have access to talking treatments and therapeutic activities to aid recovery?

We would invest in psychological therapists to ensure that therapeutic activities are available and so people with mental health problems are not prescribed drugs unnecessarily.

Maintain 24 hour Coverage for a Crisis service

C) ~ If elected would it be your party’s policy to ensure a service giving 24 hour coverage for people with severe mental health problems in crisis?

~ No reply; Guy requested further information

Proper procedure when police detain people with mental health problems

D) A pilot scheme to find new ways to address m.h. problems for people in prison was cut during 2009/10 as Eastern & Coastal Kent NHS overspent its budget.

~ Kent is the county with the highest proportion of prisoners in its population, so was it the right choice for the NHS to cut this pilot scheme first –even though mental health services had not caused the overspend?

There are too many people with mental health problems in prison in the first place. The first task to ensure those people who should not be in prison have access to appropriate treatment. All prisoners should have the some right of access to mental health treatment as other people. We would want to invest more in mental health intensive care and forensic services so that the most appropriate treatment can be given to all.

Challenge stigma:

E) ~ What does your party propose to do to challenge the stigma and discrimination in society against people with mental health problems?

There are two main areas. Firstly, we would work to reduce the stigma associated with mental health problems by raising awareness of the issues.

Secondly, we would invest resource into ‘Job-Centre Plus’ and the NHS to try to reduce the numbers of people with mental health problems who are on incapacity benefit, but who are able to work. Too often a mental health diagnosis leads to a partial or total withdrawal of that person from society, making it harder for people to seek treatment in the first instance and reinforces the existing stigma.

... increase Funding for mental health services:

F) For decades, service-providing NHS Trusts have been obliged to find, in its annual budget, “cash releasing Efficiency savings”[CRES]. “Efficiencies” were defined as cuts which can be made while maintaining the quality and volume of services delivered. (e.g. KMPT must spend 3% less than the budget they are due to get each year)

1) ~ Do you believe much greater “Efficiencies” can be made (e.g. a further 5, 10 or 15% cuts each year to the health budget) without reducing quality or volume of service delivered?

Mental health in east Kent missed out on increased funding invested in NHS Modernisation since the millennium: In 2002 the anticipated extra annual funding was diverted to cover the Govt’s new 4 ‘Must Do’ targets for the health service, (chosen, it seems, not by doctors but by ‘Spin-doctors.’)

2) ~ To help remedy this deficit, the Forum proposes that mental health should be freed from the requirement to make 3% annual efficiencies. Do you support this proposal?

To answer both questions, the Labour government’s target based approach to the NHS has resulted in those activities which can be measured being prioritised. As a result, mental health services have suffered. There is scope for a more effective use of resources if the central, target-based approach is abolished – this will reduce the cost of the central bureaucracy and these resources can be diverted into treatment. In this context, the second question would, I hope, become unnecessary as resources would be more effectively allocated.

WHAT DO POLITICIANS WANT TO DO ABOUT THE MENTAL HEALTH AGENDA?

On the day the election was called, before the manifestos were published, the parties existing health policies were collected for examination

- **A) Care Plan Approach (CPA)**

Our Forum supporting promotion of wellbeing and Personalisation, is going 'with the grain' as far as Conservative and Liberal Democrat policy is concerned: **Lib Dem** policy says 'everyone should be entitled to a 'core package' of care.' & "individuals should be enabled to take control back over their own lives as far as possible.' With "Personal care budgets to be granted to those patients who are able to make informed choices." **Conservatives** would give patients with chronic illnesses or a long-term condition access to a single budget that combines their health and social care funding.

- **B) Increase use of alternatives to medication, alone:**

Liberal Democrat policy diagnoses a severe shortage of psychological therapists and family-oriented programmes which is compromising treatment and resulting in NICE guidelines on treatment not being met. As a result of this, drugs are often unnecessarily prescribed to individuals who need psychological treatment, as such therapy is not available.

Green Party Health Policy says: *sometimes conventional medical intervention escalates people's problems.* In response the Greens would procure the systematic review of evidence to establish the relative usefulness of various psychological therapies, such as Cognitive Behavioural Therapy, Imaging and relaxation with a view to the funding of techniques which are shown to be effective. But the **Labour** policy promises *When the Improving Access to Psychological Therapies policy is fully implemented, expert support will be available to 900,000 people with depression and anxiety.*

- **C) Maintain 24 hour Coverage for a Crisis service;**

Only **Conservative Party** health policy touched this concern, promising to *introduce a single number for every kind of urgent care to run in parallel with the emergency number 999.* And

to give people access to a doctor or nurse when the local family doctor's surgery isn't open.

- **D) Proper procedure when police detain people with mental health problems:**

On the mental health needs of people in the custody of the police and criminal justice system, only **Lib Dems** offer policy proposals "Many people suffering from mental health problems languish in prison without appropriate, effective treatment" To this the Lib Dem remedy is "extra capacity in mental health intensive care and forensic units to divert people in need of treatment away from prison and to assist those already in prison." And "the application of the mental health guarantee standard to mentally ill prisoners."

- **E) Challenge stigma:**

Labour states they are tackling stigma ... *through anti-discrimination law and by supporting anti-stigma campaigns, and we will work with other partners to combat ignorance and prejudice so that there is a greater public understanding of the issues and treatments."* While **the Greens** would legislate to protect those suffering mental distress from discrimination wherever it may occur. *It will further legislate to prevent the "demonization" of clients of the mental health services ... by the media.*

- **F) Protect and increase Funding for mental health services:**

Notably, in the Channel 4 "Ask the Chancellors" debate programme, the **Lib Dems'** Treasury spokesman Vince Cable proposed better funding for Mental Health. Their policy declares *Liberal Democrats are committed to ensuring that mental health services are resourced, organized and prioritized to make sure that no waiting time for treatment is longer than three months.*

○ In **UKIP's** health policy, though they quote a report that *numbers of those murdered by the mentally ill rose to 70 people a year in 2005 compared to 54 in 1997,* there are no specific policy proposals on mental health at all.



National Survivor User Network

News Update from South East region

www.nsun.org.uk



This Forum continues to act as the hub of activity for the work of the National Survivor User Network in the South East.

However, wider links are being forged which have proved to be of benefit to a range of those who use mental health services.

One such link has been a close working relationship with the **Bipolar Disorder Research Network** based at Cardiff University. This research is the largest ever into this mood disorder and to date 4,600 of those who have the diagnosis have taken part. Already some very interesting findings are being identified- genetic links via the blood samples taken for example. CaDmhf's Director, Mark Kilbey, attended the second 'Research Champions' day held at Cardiff University, in his role as NSUN's South East Regional Coordinator, to listen to **Professor Nick Craddock's** update on progress. Nick, (pictured above, with Mark), informed the Research Champions present that a target of 6,000 is now the figure of participants the researchers are looking for but the research team are delighted with the numbers from the South East Region who have taken part

to date. The research team will also be working with NSUN for mutual benefit in the future and it is hoped the network will be able to assist the researchers to hit the target of participants they seek. Please visit the website at www.bdrn.org for further information.

Another very interesting visit to Hampshire led to a meeting with James Gagliardini. He has been appointed as **Portsmouth**

City Council Service User Involvement Coordinator. This role has really raised the profile of engagement in the City. Whilst James recognises that he has some hard work ahead it can only be to the benefit of service users and groups he is in contact with that someone so dynamic is in this post. His enthusiasm for ensuring the current service user voice is being heard was apparent and NSUN wishes James well in his new post.

The network membership continues to grow and it is hoped that a complete redesign of the website, currently the subject of considerable investment both in time and financially, will only serve to speed up this process.

Please take the time to join NSUN as it is only with a strong membership that the true benefit of a National service user led network will be realised. Visit NSUN at www.nsun.org.uk for details of how to become a member.'

Woman's suicide allowed by doctors - Some mistake surely?

by Mark Kilbey

Last autumn the case of a woman's suicide made the news: as doctors knew that she had stated in an Advance Decision that she did not want to be saved if she attempted suicide, they did not intervene to save her. It is surely improper implementation of the law; an absurd blunder from a number of angles (notwithstanding it is illegal to aid someone in a suicide bid.)

The **Mental Capacity Act 2005** gave great authority to peoples instructions for what should happen when they become ill, if they write it down in an **Advanced Decision** while they have mental capacity.

Examining the **Mental Capacity Act 2005**, - **Clause 26 sub section (5)** states

“Nothing in an apparent advance decision stops a person—

(a) providing life-sustaining treatment.”

Perhaps the doctors were only familiar with **Clause 25 subsection 5** **“An advance decision is not applicable to life-sustaining treatment unless (a) the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk, and (b) the decision and statement comply with [specified requirements making it valid]”**

However by the legal **Golden Rule**, when a literal interpretation may lead to an irrational result that is unlikely to be the legislature's intention, the judge can depart from this meaning. **Advance Decisions** were given legal status with the intention that measure to be a positive life enhancing strength for patient and medical practitioner. So the overriding **Golden rule** would allow a judge to depart from a word's normal meaning in order to avoid an absurd result.

Knowing that the woman's “Advance Decision” said she opposed intervention doctors and medics then feared that their *duty* to save her would be assault, under this law. Why wasn't allegiance to the Hippocratic Oath so embedded in their souls so that they would save a life in spite of imagined courtroom consequences? Could one possibly expect that a

judge, following the custom of the **Golden Rule** is likely to have thrown out any Assault charge.

Under the **Suicide Act 1961, section 2** ‘aiding and abetting suicide’ is a criminal offence and this tragic case may lead to some important precedent. Have those caring for the woman ‘aided and abetted her suicide by not intervening medically when the means existed to do so? Does an attempted suicide imply loss of capacity? Interpretation of the law awaits further definition via case law that will invariably follow.

Are Advance Decisions a positive for service users? Yes!

We at the Canterbury Forum continue to urge service users to raise this issue with practitioners and where possible obtain and complete the form available as soon as possible.

The **MCA 2005** was a positive development and if properly implemented can be of great assistance to the service users and practitioners alike. It is doubtful that an act like this could have developed without the service user “movement” and therefore to get this point must be seen as a success.

Once it is established via a five point test, that then greater weight is given to their wishes with regard to their treatment- if these wishes were written down when that individual had capacity.

This is dependent on the following also being observed

MCA 2005 clause 25 subsection (6) (with P meaning the Advance Decision maker)

A decision or statement is valid if—

(a) it is in writing,

(b) it is signed by P or by another person in P's presence and by P's direction,

(c) the signature is made or acknowledged by P in the presence of a witness, and

(d) the witness signs it, or acknowledges his signature, in P's presence.

Guidelines indicate Advance Decisions can be verbal but the forum recommends a *written* Advance Directive, reviewed and updated regularly: Advance Decision forms in the approved format are available at forum office.

Further information can be found at www.kent.gov.uk.mentalcapacityact

Advanced Care Planning (ACP)

Different options for service users, useful information

At the core of current health and social care are efforts to promote patient-centred care, offer choice and the right to consent to or refuse treatment and care offered. This can be difficult to achieve when an individual has lost capacity– the ability to make one's own, informed decision. **Advance care planning (ACP)** may help in such scenarios.

It is described as a process of sensitive ongoing discussion between an individual and their care providers to enhance person centred care re choice and different options. These discussions should be undertaken as part of the care plan review process with the service user and reviewed regularly.

It is suggested that a mixture of **Advance Decisions to Refuse Treatment (ADRT) & Statements of Wishes & preferences** is the best approach.

The term **Advance Decision** has now superseded **Advance Directives** due to the introduction of the Mental Capacity Act 2005

(Concise Guidance good practice No 12 Advance Care Planning, National guidelines)

Advance Care planning should be seen as an ongoing process. It is the responsibility of professionals to highlight these options with service users.

Patients can demonstrate any of the following responses to discussions re ACP:

- The patient has not and does not wish to consider ACP.
- The patient does not wish to discuss specific aspects of future care, but may be willing to discuss other aspects.
- The patient would like to make a verbal statement about their wishes.
- The patient would like to document their wishes.
- The patient would like to review their wishes.

Advance decision

An advance refusal of treatment (ADRT) – see section 9.40 and 9.41 of the MCA Code of Practice:

- can only be made by a patient while they still have capacity, but only becomes active when they lose capacity
 - Only applies to a refusal of medical treatment
 - is invalid if any of the following apply:
 - The person withdrew the decision while they still had capacity to do so
 - after making the advance decision, the person made a Lasting Power of Attorney (LPA) giving an attorney authority to make treatment decisions that are the same as those covered by the advance decision
 - The person has done something that clearly goes against the advance decision which suggests that they have changed their mind.
 - is only applicable if it applies to the situation in question and in the current circumstances. An ADRT is not applicable if any of the following apply:
 - The proposed treatment is not the treatment specified in the advance decision.
 - The circumstances are different from those that may have been set out in the advance decision.
 - There are reasonable grounds for believing that there have been changes in circumstance, which would have affected the Decision if the person had known about them at the time they made the advance decision.
 - The ADRT must be in writing if it is for the refusal of life-sustaining treatment, but not for non-life threatening conditions; however, a signed and witnessed document will avoid confusion.
 - If an advance decision is not valid or applicable to current circumstances, the healthcare professionals must consider the ADRT as part of their assessment of the person's best interests if they have reasonable grounds to think it is a true expression of the person's wishes, and they must not assume that because an advance decision is either invalid or not applicable, they should always provide the specified treatment (including life-sustaining treatment) – they must base this decision on what is in the person's best interests.
- Personal Welfare Lasting Power of Attorney (LPA) – see section 7 of the MCA Code of Practice:**
- must be made while the patient has capacity, but an LPA can act only when the patient lacks capacity to make the required decision.
 - must act according to the principles of best interests
 - Only extends to life-sustaining treatment if that was expressly contained in the original application

- Only supersedes an advance decision if the LPA was appointed after the advance decisions and the conditions of the LPA cover the same treatment as in the ADRT.

N/B

Holders of LPA for Property and Affairs have no authority to make health and welfare decisions, but should be consulted as part of the ‘Best Interests’ determination.

Any professional making decisions on behalf of a person without capacity is required by law to have regard to the Mental Capacity Act

Statement of wishes and preferences

Through a process of ongoing discussion a Statement of wishes and preferences should document the following:

- a statement reflecting P’s aspirations and preferences
- a statement of general beliefs and aspects of life which P values
- a statement of types of medical treatment P would or would not want to receive

N/B Part of assessing best interests should include making reasonable efforts to find out what P’s wishes and preferences might be.

Professionals must take such statements into account, although they are not legally binding.

Tips for a successful ACP discussion.

- The individual needs to be ready for the discussion – it cannot be forced.
- Discussions usually need to take place on more than one occasion (over days, weeks, months) and should not be completed on a single visit in most circumstances.
- Discussions take time and effort and cannot be completed as a simple checklist exercise.
- Discussions should take place in comfortable, unhurried surroundings; time is a key factor.
- It is important that capacity is maximised by ensuring the treatment of any transient condition affecting communication and optimising sensory function (e.g. by obtaining the patient’s hearing aid).
- A step-by-step approach should be used.
- Discussions should be characterised by truthfulness; respect; time; compassion and empathy.
- A tool to introduce the concept and guide the discussion may help professionals to address ACP with people.
- Information should be given using words the person understands.

- Clarify any ambiguous terms used by your patient, for example: ‘could you explain what you mean by not wanting any heroics?’

Checking and reflecting in this way is a key part of effective communication.

- Individuals should be given sufficient information about their possible options and under what circumstances their plan would be activated. They need to understand what the consequences of their decision would be.
- The professional should look out for cues that the individual wishes to end the discussion.
- The professional should summarise and check understanding with the patient.
- The discussion should be documented if the patient so wishes.
- Not all people will be able to document their wishes, but may well be able to nominate their preferred decision maker and discuss their long-term values, as these come to mind more readily than anticipating abstract situations.
- Audio-visual recordings might be helpful in providing the individual a record of the discussion.
- Plan for a review.

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Resources

Mental Capacity Act 2005 Code of Practice:

www.publicguardian.gov.uk/docs/code-of-practice-041007.pdf

(Concise Guidance good practice No 12 Advance Care Planning, National guidelines) ~ Royal College of Physicians 2009

Office of Public Guardian:

www.publicguardian.gov.uk

- Dignity in Dying
www.dignityindying.org.uk/livingwills/
- Alzheimer’s Society living will
www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=143)
- www.goldstandardsframework.nhs.uk/advanced_care.php)

SIGNPOST KENT: Showing the way



JO WOOLETT, promoting the helpful Signpost Kent website

In Kent, voluntary sector organisation Signpost Kent is working with local authorities and PCTs, with funding from the Department of Health, to set up a brokerage framework to help people make choices about how they want to spend their personal budgets. They plan to use a co-production model, with local mental health service users helping to draw up a charter of good practice, quality standards and evaluation methods. Brokers could be freelance or employed by other organisations and will, Signpost hopes, come from a range of backgrounds and communities. Says Signpost director Jo Woolett: 'User groups and organisations may want to take on this role. We will expect brokers to demonstrate they can work within the charter of good practice before we register them, and service users will be able to access them from our register. We will also seek feedback from people at the end of the broker relationship about the service received.'

Canterbury and District Mental Health Forum is one of the local mental health user-led organisations working with Signpost Kent on the brokerage scheme. Says CADMHF director Mark Kilbey: 'Local authorities are struggling with how they are

going to deliver the personalisation agenda. Service user groups are ideal to do this kind of work. We have the trust of service users, we know all the statutory and voluntary sector services and groups in the area.'

But, he says, there has to be some kind of national accreditation and quality standards assurance system in place if service users are not to be exploited. 'There is a lot of opportunity for people to be ripped off,' he warns.

<http://www.signpostuk.org>



Box of Dreams will involve a major **art project** open to all, with an exhibition at Georges House Gallery Folkestone 1-13 October 2010.

Free starter packs are ready so send for yours now and get started.

If you are in a group and would like an introductory workshop please get in touch.

Lots of groups across the county have already got their packs including Herne Bay, Faversham and Canterbury Umbrellas, Chaucer House, Sevenoaks Mind, Canterbury College, Maidstone Mind, Porchlight Floating Support Group and numerous individuals.

Drama groups, film makers and creative writers are welcome to take part, using the Box of Dreams theme for inspiration. Contact Sandra Pearson M: 07870 320479 info@canterburymindthegap.com www.canterburymindthegap.com

The Patients Council;

**an exemplary collective advocacy service.
a 10 year review**

**Patients Councils are not new, of course:
Bedlam Hospital started a Patients Council in
1620.**

**~ It then took St Martin's Hospital, Canterbury,
379 years to catch up, and recognize the
untapped energy of patients' know-how!**

The Forum {now named *Canterbury & District mental health forum*} has now run St Martin's Hospital, Patients Council for 10 years in collaboration with the local mental health service trust (*KMPT*).

Matthew Sands, a Service-user / survivor employed by the Forum as Patients Council Worker since May 2000, provides this commentary on the founding and the work of the Patients Council.

Methodology

Without modesty I offer the independently run collective advocacy project, which I have custody of at St Martin's Hospital, Canterbury as a model of good practice:

- I go to each hospital ward regularly to offer in-patients a chance to meet and share comments on the service ~ and make proposals for improving hospital life for **all** patients. I also collect patients comments that may be posted in a secure suggestions box on the ward.
- The comments are recorded, - without ward staff present until –
- At the end, I seek the ward manager or senior nurse to join and respond to, what patients said on each raised topic. This response is recorded and included, in minutes, with patients comment.
- First names of patients involved are noted, and listed at the start of the minutes, but, in reporting concerns to staff, *and* in minutes, the one making the comments is not identified.
- The ward meeting minutes are reviewed in a monthly Joint Patients Council meeting, typically involving with the ward managers and the Modern Matron, and appropriate outcomes are sought. That joint meeting's minutes are circulated to all appropriate Trust managers.



It was intended here to be the means for collective (rather than individual) advocacy; considering issues that affect all patients. But, after many patients were dismayed at having their *individual* concerns [e.g. “*The medication I am given is wrong...*”] cast aside as Out-of-Order, the Agreement was modified to allow individual concerns to be recorded, but recognise that the Patients Council is not the intended means to resolve those.

How it began

East Kent service-user groups lobbied the public services for some time about the (then) lack of an Advocacy service locally for mental health service users. In reaction to this, Social Services prompted discussions linking Canterbury's user forum with St Martin's Hospital senior staff, and patients, about setting up means for patients to comment on and make improvements to the service; a Patients Council. ~ They agreed conditions for a 'pilot' project to run for four month from November 1999. At the close of this period a Partnership Agreement was negotiated between the responsible NHS Trust and the service-user Forum defining terms to continue regular hospital ward Patients Council meetings. The agreement was based on experience of the trial period, and informed by results of a questionnaire completed by the in-patients at the time.

In essence, under the Agreement (a) *the NHS Trust agrees to provide space for the ward Council Meetings and their follow-up 'Joint Patients Council' meetings; and to consider fairly the collected patients views and to act on clearly expressed patient requests, which are representative of patient opinion, or give clear reasons for not doing so.*

And (b) *the service-user forum agrees to hold regular Patients' Council meetings on adult wards at St Martin's Hospital; to produce*

minutes for meetings, and display these on ward notice boards it provided; working with Trust staff collaboratively to resolve issues raised.

Kent Social Services awarded the forum a slight increase to the Service Level Agreement funding, and with this fund, the forum employed me, from May 2000, as part-time 'Patients Council Worker' to undertake the Forum's side of that agreement.

The **UK Advocacy Network (UKAN)** argues that those who have experience of using the health services should run patient advocacy services. (This one is!)

UKAN identified three functional levels of independence needed:

Structural ~ Not constricted by funding or structure.

Operational ~ Not connected to Service Provider; not compelled to conform to expectation.

Intellectual ~ Client instructed (independence of mind)

Staff outlook

As it's the NHS staff who have the power to initiate, maintain or end changes, either in what is provided, or in their staff custom and practices on the wards, sincere co-operation of the staff is the key factor that determines if the Patients Council can get results. Happily, very few staff involved indicated that they cannot accept the idea that patients can be more than passive recipient of *Care* administered. On Amber House, which had the best 'take up' of any of the ward patients councils, one ward manager would respond with derisive scorn to his patients concerns coming from the Council: Payphone not working? *Patients can get mobile phones!*; No wall clocks on the ward? *Patients should buy their own watches!* - After this extended even to compliments on the treatment provided, patients stayed away from meetings. But, as another ward manager put it, for the patient, seeing that their view is considered and is evidently valued (by being in print) *can* help boost the patients self esteem.

Frequency issues

After the trial period, Patients Council meetings were offered *fortnightly*. In the first three years of the Patients Council the patients' "take up" of opportunities to meet fell from 60% at the start of 2000 to 32% in the latter half of 2002. ~ Longer-stay patients could feel they had no new comments to contribute after their first attendance. Patients had also indicated that

they found getting involved in a meeting every two weeks too much to take on. A change to offering meetings just once a month was proposed but after resistance from the Trust's PALS office staff, the Forum agreed to postpone the change until a twice-monthly schedule had been given a trial run: - If, in the first 4 months of 2003 Patients Council take up did not return to the overall average of 'take-up' - 47% - then (the forum decided) the frequency of PC visits would change to *monthly*. ~ This was exhaustively advertised to patients as "*Use It or Lose It*". Informed patients then made the choice: Take up fell to 22% in this 4 month period! Then, in the first year in which PC meetings were offered *monthly*, more meetings in total were held on the three treatment Wards than were taken up during the last year of offering meetings every 2 weeks.

The prime reason given by the few resisting the cut in visits was that having the Patients Council creates a good impression of the NHS Trust for reviewing agencies like the Quango called the Commission for Health Improvement. But, on one ward, two of the occasions when all Patients Council notices were removed from the notice boards were, [*by coincidence*], just prior to the statutory inspection by the external Mental Health Act Manager.

While reasserting Patients Council's operational independence, I am grateful for the positive support from many Health Trust staff: ~ To the ward managers and the nurses who each agree to come in at the close of ward PC meetings to give immediate consideration to concerns of patients there; to the Modern Matron, for the times they have represented the Trust at JPC meetings, ensuring that patients' issues were considered. chiefly, my grateful thanks to contributing patients who attended the meetings to comment on the service. They, - the experts on life in St Martin's Hospital, - are the key players in all this!

For those not up on the jargon

**MIND, the m.h. charity, defined "users" as: "people who have themselves used any services (such as inpatient, outpatient or primary care) because they experience or are thought by others to experience, emotional distress or 'mental illness.'"*

useful Telephone Numbers

WHEN IN DISTRESS

STOURCARE (For urgent help when
GP surgery is closed)
0844 800 1234

Mental Health Matters

HELPLINE 0800 1070160

(confidential and emotional support for service users and carers)

Available from 5 pm – 9 am next day on weekdays, with a 24 hour service at weekends and on Bank Holidays.

SAMARITANS 01227 457777

Community Mental Health Teams

(Duty Service):

Canterbury 01227 597111

Coastal 01227 594888

social services Out of Hours Service:

0845 762 6777

NHS direct:0845 4647

Asian Mental Health Helpline

freephone 0808 800 2073

Mon & Wed: 4.00 pm - 7.00 pm

Tues & Thurs: 12 noon-3.00 pm

YOUNG PEOPLE

HOPELineUK (Helping You to Prevent Young
Suicide): **08000 68 41 41**

Early Intervention Psychosis Service:

01303 222411.

8 am-8 pm Mon –Fri; (Also Self-referral)

Homeless Day Centre 01227 464904

SUPPORT

Canterbury and Coastal

Rethink Carers' Support Group

Tel: 01227 760707

Manic Depression Fellowship 08456 340540

Epilepsy Here: 01227 360207

(for support of those with epilepsy)

K&C Pharmacy Helpline:

01227 812115

Canterbury MDF Bipolar Self-Help Group:

Meets the second Tuesday of the month
at the Canterbury Umbrella,

St Peter's Place, Canterbury at 7.15 pm.

For further details ring: **08456 340543**

ADVICE & REPRESENTATION.

East Kent Advocacy Service

01843 224511

Citizens Advice Bureau

087101 264062

Kent County Council Helpline

–for needs assessment 24/7

08458 247100

ALCOHOL AND DRUG PROBLEMS

Alcohol Advice Centre 01227 454740

Alcoholics Anonymous 08457 697 555

Turning Point 01227 454374

Day Centres

The Mustard Seed 01227 451834

Canterbury Umbrella 01227 767660

Herne Bay Umbrella 01227 370200

Faversham Umbrella 01795 773038

Whitstable Umbrella 01227 274880

Residential

Porchlight 01227 760078

Canterbury Housing Advice Centre

01227 762605

Benefits

Income Support; (01843) 258000

Other benefits;(01227) 596700

Direct Payments Helpline: 01304 841987

Visit: www.kentdp.co.uk

For stress caused by the credit crunch.

○ **Call the NHS Stressline** Daily, 8am-10pm

Tel: 0300 123 2000 // Textphone: 0300 123 2810

Health advisors will listen, offer practical advice,

and put you in touch with other people who can

help such as debt, housing, employment advisors,

and counselling and talking therapy services.

St Martin's Hospital

Patient Advice and Liaison Service:

01227 812020

Spiritual and Religious Care:

01227 812021 or email

Peter.Richmond@kmpt.nhs.uk

Hearing Voices Group –for service users:

01227 597111

(Jill Knight at Laurel House).

CaD.

34 Military Rd, Canterbury, CT1 1LT.

~ Ring: 01227 788211