

# *Supporting Carers Better*

**Attend**   
Enhancing Health & Social Care. Locally.

Newsletter for the network of people supporting carers in mental health

**Issue 17** November 2008



## In this issue:

2 | **We're back!**

3 | **Politics and policy**

7 | **Around the network**

10 | **Training**

11 | **Publications**

12 | **The Back Page**



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## We're back!

Dear Friends,

Welcome to issue 17 of Supporting Carers Better, the newsletter of the network for people supporting carers in mental health, from support workers to nurses and everyone in between.

In April Attend took on the Supporting (Mental Health) Carers Better Network with the aim of integrating the network into Attend structures. My then one day per week is now three, which should hopefully be enough for a concerted work effort to achieve something akin to the earlier SCB days. I am keen to return to that same momentum and to again share the commitment of so many dedicated networkers!

This is a time of great potential for the SCB network, thanks to new legislation and initiatives. Our new relationship with

Attend has opened to the SCB network all of the resources at Attend's disposal, like the Mental Health Learning Network, Attend Academy training, and fundraising efforts, as well as the network of Attend member groups and volunteers. Together, we can combine efforts and achieve great results.

I want the new SCB Newsletters to summarise and explain relevant, topical items to inform carers in mental health; for instance, a compact explanation of existing policy and recent changes like the Mental Health Act, the New Deal for Carers, and new information on training, publications, research, and statistics. As always, feel free to contact me with any questions or comments.

Phil Partridge, Attend Carers Lead

## Join the network

Supporting Carers Better is a network for people supporting carers in mental health in order to share best practice, information, and support.

Membership to the Supporting Carers Better Network is free. Members will be included in our network of resources and support. If you know anybody who might be interested in joining, direct them to the new Supporting Carers Better website, [www.scbnetwork.org](http://www.scbnetwork.org), or forward their details to Phil at [phil.partridge@attend.org.uk](mailto:phil.partridge@attend.org.uk).

## Send us your email

Please ensure that we have your correct email details, so that you can receive correspondence from us. You'll not only get the Supporting Carers Better newsletter electronically, saving time, effort, money, and trees, but you'll receive email bulletins too, helping you stay connected with your network and keeping you updated with events and opportunities related to mental health and caring all around the UK.

Contact Phil Partridge with your email information at [phil.partridge@attend.org.uk](mailto:phil.partridge@attend.org.uk). Also be sure to check out our website at [www.scbnetwork.org](http://www.scbnetwork.org).

## Dates for your diary

- New CPA – October 2008
- Mental Health Act in force – October
- Personalisation begins – November
- International Stigma Conference – 4 January
- Carers' Rights Day – 2 December
- RCPsych/Meriden – 11 December

## SCB needs you

Our stories are from people in all roles, contexts and regions of the country, reflecting the make-up of the SCB network, what we do, and what we could do.

If you have an article, picture, conference flyer, information about a great service, policy or development, or something else you would like to see included in an upcoming edition of the Supporting Carers Better newsletter, please send it to us! Your contribution could help carers and their support get the information and help they need.

Email your stories to Phil Partridge. We need your help to make this newsletter great!

# New Deal for Carers



The Department of Health in 2006 published a white paper entitled 'Our Health, Our Care, Our Say', which included a commitment to a new programme of work: the New Deal.

This new programme includes several important endeavours that will change the available aid for carers in the UK. This includes a revision of the Prime Minister's

1999 National Carers Strategy, as well as the aim to set up a national carers' advice line, which is expected to be in place by April 2009, made possible by £2.8 million a year from the government to fund the service. The tendering process for this new service has begun, and the contract will be awarded this winter.

Other provisions of the New Deal include increased aid for emergencies (£25 million awarded through local authorities in England) as well as an Expert Carers Programme of training, now to be called 'Caring with Confidence'.

The revised New Deal strategy was published in June. In September and October, the Department of Health held nine regional events across England, called 'Supporting Carers: Everyone's Responsibility', to help create a common sense of purpose and foster collective responsibility, to ensure that carers have the services they need in their caring role whilst being enabled to have a life outside caring.

## The Government Standing Commission on Carers



The Government Standing Commission on Carers has several goals: to work with ministers to oversee the final stages of revision

of the Prime Minister's Strategy on Carers, to begin a programme of work on the long-term challenges which will impact carers, and to advise ministers on terms of reference for the second stage of the Standing Commission on Carers.

Dr. Philippa Russell, the Chair of the Standing Commission on Carers, says, "I feel very privileged to chair the Standing Commission on Carers. We have a major task ahead of us, but also a unique and probably once-in-a-lifetime opportunity to contribute to the national debate about the future shape of social care in this country. With major demographic changes, higher expectations of quality support amongst

carers and a strong focus on self-directed care and independent living, we need new solutions to old problems.

"I hope and believe that the Standing Commission has the potential to transform the future agenda for social care by putting carers at the heart of policy-making as equal partners in exploring new ways of maximising independence and developing high-quality and cost-effective services fit for the 21st century. It is a major challenge, but I believe we can achieve transformation if we work together."

### Contacting the Commission

If you would like to contact the Chair or any members of the Commission, or would like any further information about its work, please email [scoc@dh.gsi.gov.uk](mailto:scoc@dh.gsi.gov.uk).

## Rethink: ways to add your voice

### Rethink email

Challenge the discrimination faced by people affected by mental illness – it's easy! The campaigners for Rethink.org make a real difference by highlighting mental health issues to decision-makers across England and Northern Ireland.

Sign up to receive Rethink campaign emails and help make a difference by going to [www.rethink.org](http://www.rethink.org) and clicking on "Campaigning for Change" under the heading "How We Can Help", the clicking on the link that says "Sign up to Campaign by email!"

### Rethink politics

Rethink Politics is a three-year project funded by the Electoral Commission aiming to increase the political awareness and participation of people affected by mental illness. This year, service users and carers from across England and Northern Ireland have taken part in a training programme to become Rethink Politics Champions.

Following the training programme, Rethink Politics Champions are organising events in their local areas to help more people get involved in politics and engaging with local decision-makers.

### Rethink campaigning

Local campaigning is very important, as many decisions about health budgets and services are decided at a local level. Rethink encourages people to campaign on national issues at a local level, as local activism is an incredibly effective way of creating change. The local media is one of the most effective ways to change people's attitudes.

The Rethink Campaigns department is happy to offer help. On their website at [www.rethink.org/how\\_we\\_can\\_help/campaigning\\_for\\_change](http://www.rethink.org/how_we_can_help/campaigning_for_change), find a toolkit with information on how to campaign effectively, including who to target, how to plan a campaign, and pitfalls to avoid. So get campaigning locally! Together we can change the world. For more information, email [campaigns@rethink.org](mailto:campaigns@rethink.org) or call 0845 456 0455.

# National Carers Strategy explained

The new National Carers Strategy sets out a ten-year vision that, the report says, must be a shared responsibility between central and local government, the NHS, the third sector, families, and communities.

The principles behind the vision are that by 2018, “carers will be treated with dignity and respect as expert care partners; carers will have access to the services they need to support them in their caring role; carers will be able to have a life of their own; carers will not be forced into financial hardship by their caring role; carers will be supported to stay mentally and physically well; and children and young people will be protected from inappropriate caring roles,” says the Carers UK website.

Carers UK “believes this vision reflects what carers said they want to see. We feel that Government has finally got the message that caring is a critical issue and they have taken on the challenge caring poses to society. Delivering this vision would be genuine equality and recognition for carers, and it echoes our own call for a new ‘social contract’ which makes it clear what the state, employers, and others will provide and what individuals have to contribute.”

The National Carers Strategy seems to support this view. It states, “The long-term challenge is to create a new settlement between individuals, family, and the government... There needs to be an open and honest debate about the appropriate balance of responsibility between the family, the individual, and the government if England is to have a sustainable care and support system.”

The Strategy includes a set of commitments toward social care and health in general. It pledges an increase of £150 million in the amount of money available for breaks over the next two years, as well as more support from the NHS. The availability of breaks for carers is crucial for the carer to maintain his or her own health and wellbeing as well as remain in employment. The extra money for breaks will be allocated to Primary Care Trusts, who will work with local authorities to publish joint plans for the provision of breaks. In principle, this policy means that carers can access breaks more easily.

In the social services, the National Carers Strategy sets out the intention to

train professionals in local authorities for their day-to-day dealings with carers, “improving how agencies share relevant information and encourage close working between councils, the NHS, other statutory agencies, and the voluntary sector.” Increased co-operation will prevent carers from having to repeat details numerous times.

The Strategy also puts as a goal the development of relationships between local authorities and the third sector with carer-led organisations, making greater use of their expertise and providing carers with greater choice and control over services, including examination of how best to use the Carers Grant to benefit carers.

Plans for health services for carers are also laid out in the Strategy. It commits to a pilot programme of health checks for carers in a sample of Primary Care Trusts, as well as pilot training programmes for GPs to help them better understand carers’ needs. If these pilot programmes are successful, they may be rolled out nationally. The government is also considering prioritising funding for projects that offer emotional support for carers as well as physical, and developing pilot programmes that examine how the NHS can better support carers. Currently, health professionals often ignore the knowledge and expertise of carers; the new pilot programmes should help spread good practice.

The Strategy aims to improve employment support offered to carers by JobCentre Plus, increasing access to training and replacement care and ensuring that carers are offered appropriate support, to raise awareness about the right to request flexible working, and to review who qualifies for the flexible working request law.

Currently, a fifth of carers miss out on flexible working rights, including those who are not a close relation of the person they care for or who do not live with that person. The strategy promises to review the current regulations, possibly to extend the right to request flexible working, simplifying the issue for carers and employers as well as benefiting those who are currently excluded. The Carers UK Make Work Work campaign has fought hard for carers to have the right to request flexible working, yet many carers and employers are not aware of these new rights.



“He started it!”

The government’s campaign should do much to rectify this issue and spread awareness about carers’ working rights. Funding is provided for to ensure that carers have easy access to information about support services and their rights, as well as to ensure links to a future national carers’ helpline.

The National Carers Strategy also contains a £6 million package aimed at supporting young carers, recognising that support for young carers needs to be centred on the family and the person they care for, while also ensuring that young carers do not miss out on their education and other opportunities. Accurate data about carers is essential; the Strategy recognises this and commits to better, more detailed collection of data about carers’ lives and to a continuance of the question about caring in the National Census.

The single shortcoming of the new Strategy is its failure to commit to equalities legislation. Carers are often discriminated against in employment and other areas; however, the Strategy includes no plans to include carers in the forthcoming Single Equality Bill. Carers UK and other organisations, who have campaigned for many of the aspects of the new strategy, will continue to work to ensure that carers receive proper support and are not discriminated against. The new strategy is a huge achievement, and will hopefully be a major step toward supporting carers.

# Mental Health Amendment Act

The new Mental Health Act, an amendment to the Mental Health Act 1983, was implemented on 3 November 2008. The act makes a number of changes to the 1983 act, increasing patients' rights and safeguards against mistreatment.

The Act includes a single definition of 'mental disorder' and new criteria for detention – the 'appropriate medical treatment' test in place of the so-called 'treatability test'. It broadens the group of practitioners who can undertake functions previously performed by the Approved Social Worker and Responsible Medical Officer, and introduces Supervised Community Treatment for patients following a period of detention in hospital.

The amendments also give the patients the right to make an application to displace their Nearest Relative and enables the County Courts to displace a Nearest Relative. It reduces the amount of time required before a case has to be referred to the Mental Health Review Tribunal and introduces a single Tribunal for England.

Provision is also made for patients under age 18 who are admitted to hospital for a mental disorder, providing that they are accommodated in an environment suitable for their age, subject to their needs. The act introduces independent mental health advocacy for patients who are subject to the Act, and increases safeguards for patients given Electro-Convulsive Therapy.



The Mental Health Alliance

## Want more information?

The Care Services Improvement Partnership (CSIP) and the National Institute for Mental Health in England (NIMHE) website contains much more information about the recent legal changes, including an electronic copy of the revised Mental Health Act of 1983 Code of Practice, the Mental Health Amendment Act 2007 New Roles, with guidance for approving authorities and employers available for download, and the Reference Guide, which sets out the main provisions of the Act and the associated secondary legislation. Go to <http://mhact.csip.org.uk> for this and more about the law regarding mental health.

# New Care Programme Approach

The Department of Health has a new Care Programme Approach, implemented in October 2008. The new CPA emphasises shared understanding of problems and needs, involvement and engagement of service users, families and carers throughout the process.

Other aspects of the new Care Programme Approach put forth some important changes to policy. Families and carers are to be included in contingency and crisis planning, while service users and 'others involved in care' are included in risk assessment and management, including positive risk. Carers' own needs are to be addressed, and their assessments to be coordinated with those of the CPA. It addresses the fact that the service user may themselves be a carer, and includes entitlement to other services if the CPA is withdrawn.

The CPA is not to be used as an indicator of eligibility for other services, however. Access back into the Care Programme Approach following relapse is included.

The Department of Health has several publications dealing with the new Care Programme Approach, including a leaflet, a booklet, and Executive Summary and a DVD to be used with guidance.

For more information, visit [www.nimhe.csip.org.uk](http://www.nimhe.csip.org.uk) and click on 'Our Work', or go to the Department of Health website at [www.dh.gov.uk](http://www.dh.gov.uk).

# New Ministers for carers policy

Following the government reshuffle, a new set of Ministers now has responsibility for carers policy. Minister for Carers Ivan Lewis MP has left the Department of Health to join the Department for International Development.

He has been replaced by Phil Hope MP who was previously Minister for the Third Sector at the Cabinet Office. Hope will be a Minister of State, a more senior position than Ivan Lewis, who was Parliamentary Under-Secretary of State, the lowest rung on the ministerial ladder. The change should help raise the profile and clout of carers and

social care issues across the government. The Minister for Disabled People, who has responsibility for carers' benefits, will now be Jonathan Shaw MP, replacing Ann McGuire MP who has held the role since 2005.

Advocacy group Carers UK will be urging the new ministers to keep up momentum on carers' issues following the publication of the National Carers Strategy, as well as ensuring that they have a good understanding of outstanding issues. Carers UK will continue to work for reform of carers' benefits with the new ministers.

## Resources

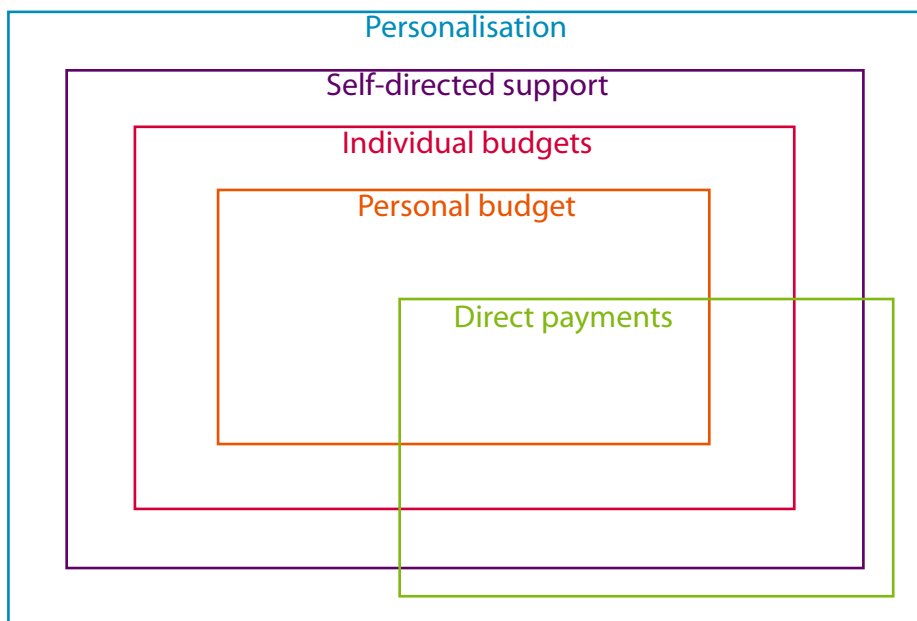
For more information about legislation, visit [www.dh.gov.uk](http://www.dh.gov.uk).

A great resource for policy and practice information related to caring in the UK is [www.carersuk.org](http://www.carersuk.org), an advocacy group dedicated to giving carers a voice in the government and increasing their support.

Also try [www.nimhe.csip.org.uk](http://www.nimhe.csip.org.uk), the website for the National Institute for Mental Health in England.

# Personalising social care

A shared vision and commitment to the transformation of social care



In December 2007, a *Ministerial concordat* entitled “Putting People First: Transforming Adult Social Care” set out a “shared vision and commitment to the transformation of social care.” It stated as its goal a new collaborative approach to adult social care, with shared aims and values between central and local government as well as the sector’s professional leadership, providers, and regulators. The publication states, “People who use social care services and their families will increasingly shape and commission their own services... The state and statutory agencies will have a different, not lesser, role, one that is more active and enabling and less controlling.”

## A whole system change

This new policy change is not small but radical and requires fundamental transformation of adult social care. The timetable is challenging: the government is expecting significant progress in delivering personal budgets by 2011.

“What it means is that everyone who receives social care support, regardless of their level of need, in any setting, whether from statutory service, the third and community or private sector, or by funding it themselves, will have choice and control over how that support is delivered,” says the Department of Health.

Personalisation is the process by which state-provided services can be adapted to

suit the person in need. This process will be achieved through self-directed support. In social care, this will mean that every person in need of care will have choice and control over the shape of their support, along with placing a greater emphasis on prevention and early intervention.

This change will require new means of managing government budgets. In this case, ‘individual budgets’ will be employed: a clear, up-front allocation of money that can combine several funding sources that can be used to design and purchase support from the public, private, and voluntary sectors. Individual budgets will be distributed with direct payments, cash payments given directly to the benefactor or carer, who can then acquire support, rather than having support delivered by the council.

## The central balance

Ideally, the new system will maximise choice and control, whilst effectively managing risk. The change is essential; the present system is based on matching a limited range of services to people’s assessed needs. Costs are rising and services are under increasing demographic pressures, causing many people to assess the current situation as being ‘in crisis’. The local authorities have responded to the new demands on the current system by looking to make efficiency savings, shifting large volumes of in-house

services to the private and voluntary sectors and through changing eligibility criteria to restrict access. The level of support offered through the local councils should be determined by need, with support offered to all citizens. In the future, support will be more available to all, increasing as care requirements rise, with spending more evenly spread across all levels of care requirements.

The change is from fitting people around services to fitting services around people, as well as being outcome-focused and supporting self-determination. New services will focus on prevention and early intervention, enablement and independence, and high-quality, personally tailored services, with individuals shaping and commissioning their own services.

## New ways of working

One person in the pilot program of the new personalised system said, “The assessment process was a bit like having a life coach, with questions being asked like, ‘What is important to you?’, ‘What is working and what isn’t?’, and ‘What needs to change?’” People in the personalisation programme have been able to put their money towards things like paying a registration fee for a charity trek in the mountains, having their bathroom redecorated, having a car fixed, or buying a dishwasher.

One person says, “I also bought a kite, a bike, and other clothing for outdoor activities. I’m on my bike around Skegness nearly every day... My paranoia and suspiciousness is considerably better. This is because I feel more confident which is mainly down to me being a lot fitter... Without individual budgets I would have probably just struggled on as I was doing last year. It has given me a kick start. I am feeling alive.”

Find the Care Service Improvement Partnership (CSIP) personalisation toolkit at [www.toolkit.personalisation.org.uk](http://www.toolkit.personalisation.org.uk), or the personalisation self-assessment tool at [self-assess.personalisation.org.uk](http://self-assess.personalisation.org.uk). The philosophy of personalisation is clear: it is a major shift in approach and a transfer of control. It is not about if the transformation happens, but about when and how.

# Opportunities for carers

## Respite: Carers Grant

In 1999, the government introduced the Carers Grant in recognition of the support carers need for breaks and services. The Grant is worth £224 million in total for 2008-2009, including £25 million that councils can use to provide emergency cover for carers in England. From 2008, the Grant will be paid to councils as part of the Area Based Grant.

This grant is part of an overall government initiative to support councils' needs for the flexibility and freedom to focus on their key targets. The Carers Grant is no longer ring fenced, although it does remain targeted.

Visit [www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Localauthoritiesocialservicesletters/DH\\_081123](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Localauthoritiesocialservicesletters/DH_081123) for the full details of the grant. More information about the grant, including guidance on grant distribution, can be found at the Department of Health's website at [www.dh.gov.uk](http://www.dh.gov.uk) under the 'publications' heading.

The Commission for Social Care Inspection ensures that carers' support is sustainable by monitoring the performance of the councils. To find out more about how they operate, visit [www.csci.org.uk](http://www.csci.org.uk).



## Counting carers

Carers of sick and disabled people have won their battle to keep a question on caring in the 2011 census. Treasury Minister Angela Eagle has confirmed that money has been made available for an extra page of questions that were under threat. A question on caring responsibilities was included for the first time ever in the 2001 Census and has led to unprecedented, reliable knowledge both locally and nationally about carers.

Imelda Redmond, Chief Executive of Carers UK, says, "We can't underestimate just how critical it is to have a question on caring in the census. Thanks to the information we gathered from the 2001 census we know that caring is an issue that affects millions of families across the UK. The census provides the best opportunity to get hard evidence on how we can support carers."

## Ecominds

Ecominds is a new open grant programme, run by Mind as an award partner of the Big Lottery Fund, that awards money to new and existing projects focusing on mental health and the environment over the next five years. The programme has £7.5 million to distribute to 125 different projects around England.

Ecominds aims to help people with direct experience of mental distress become involved in environmental projects that improve mental and physical health, as well as aiding their local communities. For more information and to sign up for updates about the funding opportunities, visit [www.mind.org.uk/ecominds](http://www.mind.org.uk/ecominds).

## Phil's 'Acid Test'

Finding whether or not a document is relevant to carers can be a daunting process, especially when there are other, more pressing matters to be dealt with. This quick 'acid test' can help determine whether legislation, guidance, reports, studies, procedures, training sessions, events, articles, or research is important for a carer.

First, look at the introduction and index, and check for clear, explicit, relevant inclusion of carers. Then use the search facility to scan the text itself, counting instances of 'carer', 'relative', and 'family', and check that it's not parents and children material. Look at any glossary or list of terms, checking for the same instances of words. Due to efforts from the carers' lobby, carers are included more often, though this is by no means universal or automatic, so we must continue to keep up the pressure!

## Use your network

The Supporting Carers Better network has the email addresses of people involved in mental health and caring nationwide, in a variety of situations and contexts. If you want to ask a question, consult on a development, do some research, find someone or find something that someone else may have already worked on, contact the SCB! If you want to publicise your event, consult on a development, or get to carers for lobbying purposes, contact us! We can send emails around to the entire SCB network, which are then forwarded on to other networks, exponentially increasing your potential to find what you need or send your message. This is your network; use it!

Contact us by email at [phil.partridge@attend.org.uk](mailto:phil.partridge@attend.org.uk), or by telephone at 0207 307 2875. Check out our website at [www.scbnetwork.org](http://www.scbnetwork.org).

## Useful websites for carers

Mental Health Care is an information and research news website developed by the Institute of Psychiatry, King's College, London, the South London and Maudsley NHS Foundation Trust and the mental health charity Rethink. The new website is aimed at the friends, relatives, and carers of anyone with a mental illness. Visit the website, or for more information, contact Sarah Gentleman, the Website Content Manager, through [www.mentalhealthcare.org.uk](http://www.mentalhealthcare.org.uk).

The London Health Observatory is an interesting source of information for London in particular, though the website contains some materials covering the whole country. Resources can be found at [www.lho.org.uk/searchresults.aspx?st=carers](http://www.lho.org.uk/searchresults.aspx?st=carers).

Also check the Mental Health and Well-Being Score Card at [www.lho.org.uk/DATAANDMETHODS/Local\\_Data/MentalHealthScoreCard.aspx](http://www.lho.org.uk/DATAANDMETHODS/Local_Data/MentalHealthScoreCard.aspx).

For enquiries, contact the LHO by phone at 020 7932 3961, or by email at [LHO.enquiries@lho.nhs.uk](mailto:LHO.enquiries@lho.nhs.uk).

# Campaigns and research

## National Carers Protest

A group of carers have come together to organise a national protest on 22 April 2009. This is a grassroots carer-led initiative, though Carers UK and other carers' organisations are supporting the group. What they need is for carers to get on board and help! Check out the online forum for discussion and planning at [carerspovertyprotestmyfreeforum.org/index.php](http://carerspovertyprotestmyfreeforum.org/index.php).

## The Fourth International Stigma Conference

You are cordially invited to participate in the Fourth International Stigma Conference to be held in London, 21-23 January 2009. The Conference is organised by the Institute of Psychiatry of King's College, London, and by the World Psychiatric Association Scientific Section on Stigma and Mental Illness. This international conference brings together service users, carers, practitioners and researchers interested in stigma and discrimination.

The meeting will focus on effective interventions to reduce stigma and discrimination in mental health and other areas. The conference provides a unique opportunity to engage with contemporary discourse and debate around stigma.

Care Services Improvement Partnership Midlands and the Mental Health Research Network Northeast have kindly offered to sponsor a few places including travel and accommodation costs for service users and carers residing in their regions. The sponsorship is on a first-come-first-served basis subject to verification of your residence. If you wish to take up these places, please complete the registration form on the conference website at <http://stigma.iop.kcl.ac.uk> and email it to [stigma@iop.kcl.ac.uk](mailto:stigma@iop.kcl.ac.uk), and indicate in the body of the email that you would like to apply for these places.

## A call for information

The Child and Adolescent Psychiatric Surveillance System (CAPSS), being set up in the Mental Health Research Network, is a system for recording rare childhood psychiatric conditions over the whole of the UK and Ireland. CAPSS enables doctors and researchers to find out how many children in the UK and the Republic of Ireland are affected by each particular condition.

Every month clinicians will be sent a report card containing a list of uncommon child and adolescent psychiatric conditions. When cases are reported, the CAPSS office informs the investigation team, who send the reporting doctor a short, confidential questionnaire for more information about the affected child. The new system will allow for more specific statistics about the prevalence of many childhood psychiatric disorders, allowing for better research into their causes and perhaps possible cures.

**time to change**  
let's end mental health discrimination

## Time to Change

The four-year anti-stigma programme Moving People have changed their name to 'Time to Change', a name suggested by Brian Gumbley as part of the Stigma Shout survey. He says, "I chose 'Time to Change' because of my experiences of the public perception of mental health. I myself have encountered instances of stigma that for lots of service users can ruin their chance of a quick recovery and return to employment of some kind. Stigma hurts. I hope we are approaching a Time for Change!"

The new website at [www.time-to-change.org.uk](http://www.time-to-change.org.uk) was launched in October.

Read more about the four-year campaign, Stigma Shout and the Cambridge Anti-Stigma Campaign launch at [www.rethink.org](http://www.rethink.org).

## Understand, prevent, cure

The Institute of Psychiatry's new research report for 2008-2009, which showcases some of the work taking place at the Institute, was recently published.

An online PDF file can be downloaded at [www.iop.kcl.ac.uk/virtual/?path=/research](http://www.iop.kcl.ac.uk/virtual/?path=/research). If you would like a hard copy, please email [deans.office@iop.kcl.ac.uk](mailto:deans.office@iop.kcl.ac.uk).

## Your stories

The Institute of Psychiatry of King's College, London, is always looking for stories of your experiences of caring for someone with a mental illness to include in the popular section of the Mental Health Care website. Visitors often say that reading about other people's stories has helped them through their own situation. A small compensation is offered for those accepted for publication.

Email [sarah.gentleman@iop.kcl.ac.uk](mailto:sarah.gentleman@iop.kcl.ac.uk) to submit a story, or read other people's stories online at [www.mentalhealthcare.org.uk](http://www.mentalhealthcare.org.uk).

## Mind Over Matter

*Mind Over Matter* is a series of research reports commissioned by Shift, looking at how the media covers mental health issues. The reports look at news coverage in 2005, analysing the way in which mental health is reported.

*Mind Over Matter 2* follows the first series by looking at news coverage from March and October 2006. The new report shows there is a long way to go in changing the media's perception of mental illness. The second report can be downloaded from Shift's website at [www.shift.org.uk](http://www.shift.org.uk), by simply clicking on the link under the 'news' section.

### Young Carers Initiative

The Children's Society National Young Carers Initiative is part of the Include Project, providing information, advice, and training to anyone who works with young carers and their families. The Initiative works with young carers projects and other organisations to develop high quality support and information for young carers, their families, and those who work to support them.

The Include project is carried out in consultation with young carers and their families, and receives funding from the Department of Children, Schools, and Families and the Department of Health. It is also funded by Hampshire County Council to deliver development work across Hampshire.

The Young Carers Initiative website, [www.youngcarer.com](http://www.youngcarer.com), is a valuable resource for young carers and their supporters, providing help and directing young carers toward support in their community. The website also features published resources, news, and bulletins that keep young carers and those who support them connected to each other through the Initiative.

### Voice for young people with depression

YouthHealthTalk is a national charity that produces the unique and award-winning website [www.youthhealthtalk.org](http://www.youthhealthtalk.org), which features the stories of young people talking about their real-life experiences with health, illness, and lifestyles.

YouthHealthTalk is looking for young people to help develop a new site about young people, low mood, and depression. They would like to hear from people ages 16-25 with experiences of depression or ongoing low mood who would be willing to share their experiences through an interview with an experienced researcher or by making a video or photo diary – the young

person will have the option of choosing whether a video, audio, or text version of the interview will be used on the website.

For more information about the project, contact the researcher, Ulla, at 01856 289 328, or by email at [ulla.raisanen@dphpc.ox.ac.uk](mailto:ulla.raisanen@dphpc.ox.ac.uk).

### Support for siblings of people with severe mental illness

Rethink, the national charity for people affected by severe mental illness, now has an online support network specifically for siblings of people with severe mental illness. Lucy Canning, Rethink volunteer and founder of Rethink Siblings, describes the effect on her family of her brother's schizophrenia, diagnosed 11 years ago following a psychotic episode. Ms. Canning talks about the lack of information and support specifically for siblings and the kinds of questions and worries siblings have that led her to work with Rethink to create Rethink siblings. Contact Rethink by phone on 0845 456 0455, or visit Rethink Siblings at [www.rethink.org/siblings](http://www.rethink.org/siblings).

Rethink is also a great resource for other carers and supporters. Visit their goldmine of information online for stories and tips about caring for people affected by severe mental illness.

### 90 naps a day

Narcolepsy affects 30,000 people in the UK and can be extremely disabling for them and their family. Accepting the condition can be a great difficulty or can be something to hide. For these reasons, narcolepsy parallels the experience of many people affected by severe mental illness.

The UK Narcolepsy Association (UKAN) is an association of people with narcolepsy, their relatives and others interested in improving the lot of those affected by the disorder. UKAN's registered objectives are the benefit, relief and aid of persons suffering from narcolepsy. Some

of its aims are to promote awareness of narcolepsy and provide authoritative information about it to narcoleptics, to the medical profession, and to the public. UKAN is also working to support the establishment of local self-help groups in which narcoleptics can exchange experience and provide mutual support, and pressing for the recognition of narcolepsy as a disability by the social services, encouraging research into the causes and treatment of narcolepsy.

For more information about the UKAN or its goals, call 0845 450 0394 or email [info@narcolepsy.org.uk](mailto:info@narcolepsy.org.uk).

### Risk: a personal view

Being plagued by illness, voices, prejudice, a confused mind, people and systems against you, vicious circles, and never-ending frustration must be maddening. Call this 'vulnerability' and a certain type of person wants to exploit you. Call it 'risk', and the issue becomes more immediate.

Considering the risk of a mentally ill person can be a far-reaching and indefinite process. The media sensationalises incidents of 'released madmen' attacking people randomly, while the government's emphasis is on public safety rather than improving practice. These stances simply reinforce the myth and stigma, to the detriment of public health. Carers seem to be considered last in risk assessment, though the slowly increasing practice of involving carers in patient risk assessments is an opportunity for workers to hear the carers' position of risk. Even though carers might know a mentally ill person well and can usually spot stress triggers, risk still exists, 24/7.

Formal, statutory pledges to identify, involve, and support carers are increasing. Take for example the new National Carers Strategy. We all look forward to the improvements such agendas can bring, and the day when proper inclusion of carers will be automatic and will no longer need regulation.

### Caring with Confidence

In January 2008 the Department of Health awarded the contract to develop an expert carers programme to a consortium of five organisations, the 'Caring with Confidence Consortium', led by the Expert Patients Programme CIC, with fellow members Carers UK, Crossroads, Partners UK, and The Princess Royal Trust for Carers.

Caring with Confidence is part of the New Deal for Carers, a package of support measures. The aim of Caring with Confidence is to provide 27,000 group session places during the period of the project.

The purpose of this project is to offer a range of learning opportunities to enable carers in England over the age of 18 to gain the knowledge, skills, and expertise that can make a positive difference to their life and that of the person they care for. One of the underlying principles of the Caring with Confidence project is that it will build on rather than replace current provision.

Organisations that can be providers of the Caring with Confidence training programme are currently being identified, and the programme should become available very soon.

As the lead administrative organisation for the Caring with Confidence Project, the Expert Patients Programme CIC has established a 'National Team' to lead and develop the project, provide the infrastructure that will enable the delivery of the service to carers, and provide support and funding to new and existing providers of training to carers delivering Caring with Confidence programmes. The National Team is based at the Expert Patients Programme's office in Leeds.

If any carers are interested, Caring with Confidence's administrator, Alex Welsh, will gladly store your details and send any relevant information when the time comes. Contact Alex by phone at 0113 385 4491, or by email at [alex.welsh@caringwithconfidence.net](mailto:alex.welsh@caringwithconfidence.net). Take advantage of this training opportunity once it becomes available!

#### Want to know more?

Visit [www.caringwithconfidence.net](http://www.caringwithconfidence.net) for programme information.

## Training for, about, and by carers



There are numerous different types, levels, intensities, aims, and availabilities of training around carers in mental health, and as of yet there isn't one unified, structured document that identifies and lists all of these different training opportunities to make them available to those who need them.

Training can be aimed at carers, either on how to cope or how to be better carers. For this purpose, there are many local initiatives by individuals, groups, workers, trusts, and Carers Centres. There is *Community Champions*, written by the Health and Social Care Advisory Service, a basic four-session cascade model of mental health carers training. There is the Caring with Confidence Programme, previously called the Expert Carers Programme. There is Rethink's Carers Education and Training Programme, and there is a single training programme for carers as advocates.

Many groups also offer training for workers, students, and professionals to learn about carers and what they do. This can be through universities as an integration of carers into pre-existing courses, through

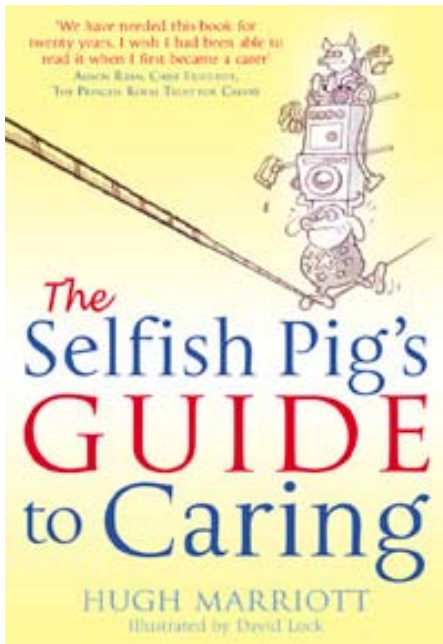
other institutes like the Royal Colleges of Nursing and Psychiatrists, or giving a "carers' perspective" in a more ad-hoc manner. There is also training for specific worker groups, like the STR Workers, CPA coordinators, and reception staff.

Much of this training is delivered by carers, so to empower them in these roles we need training for carers to get involved in representing their interests, helping develop practices, training, and services, and in training other carers, workers, students, professionals, and the public.

There are major issues and dilemmas here. It can be difficult to reach carers. There are costs associated with developing and providing training. Many times, training duplicates what has already been done; in a sense, much of training "re-invents the wheel".

These issues are what created the idea of the National Carer Curriculum, a structured, network-cooperative development of training for all roles. This concept is still in development, and we will continue to work on it.

# The Selfish Pig's Guide to Caring



The carer's job is often long, lonely, and hard, going unnoticed by the general public. Six million people in the UK provide unpaid care for disabled or elderly relatives or neighbours, yet there is limited support and formal training for the job. As a result, carers suffer frequent damage to physical and mental health.

It can be difficult to reach carers in their times of need, to provide the support and guidance that could help them cope with day to day life. But a new book, entitled *The Selfish Pig's Guide to Caring*, is here to help.

The book says, "Oddly, though carers by definition are anything but selfish pigs, they are liable to feelings of guilt, probably brought on by fatigue and isolation. So Hugh Marriott has written this book for them – and also for the rest of us who hadn't realised what went on behind closed doors. His aim was to bring into the open everything he wished he'd been told when he first became a carer. And he does.

"The book airs topics such as sex, thoughts of murder, coping with incontinence, and dealing with the responses of friends and officials who fail to understand. It's thought-provoking, informative, and brutally frank, but also funny and moving. This is a must-read for anyone involved with caring."

Alison Ryan, the Chief Executive of The Princess Royal Trust for Carers, says about the book, "We have needed this book for 20 years. I wish I had been able to read it when I first became a carer."

*The Selfish Pig's Guide to Caring* is available from Amazon.co.uk, or through the Mental Health Shop at [www.mentalhealthshop.org](http://www.mentalhealthshop.org). Also find it at your local bookseller, or through online bookstores.

## Interested in more publications for carers?

The publications listed in this newsletter and even more are available at Rethink's online Mental Health Shop at [www.mentalhealthshop.org](http://www.mentalhealthshop.org).

You'll find resources for mental health issues from caring to discrimination to laws and regulations.

For more information on Rethink and the Mental Health Shop or to order by phone, please call 0845 456 0455. To order products by email, contact [orders@mentalhealthshop.org](mailto:orders@mentalhealthshop.org). Direct questions to [queries@mentalhealthshop.org](mailto:queries@mentalhealthshop.org).

## Caring and Coping

Rethink has published a guide for people new to caring for someone with severe mental illness entitled *Caring and Coping*. The best-selling handbook for new informal carers offers strategies to deal with the practical day-to-day challenges raised by a diagnosis of severe mental illness.

The book is designed to provide a wide range of information in an easily accessible format. Sections include a summary of illnesses, disorders, and treatments, what to tell family and friends, carers' rights, a list of professional help and support available, coping in a crisis and understanding the jargon. The book also includes useful website links and addresses.

The reviews have been positive. The co-ordinator of a carer support group said, "We certainly never know half as much as is published here." A Mental

Health Policy Officer for the Social Services likewise endorsed the book, saying, "We feel this is an excellent pack and any new carer would have most of their questions answered." Carers have also found the book's contents useful. One such carer says, "A superb piece of work – well written, thoughtful, and above all, extremely meaningful for the particular audience it is meant to address."

Rethink is a leading national mental health charity, and works to help everyone affected by severe mental illness recover a better quality of life.

For your own copy of the book, contact Rethink or visit the Mental Health Shop at [www.mentalhealthshop.org](http://www.mentalhealthshop.org).

Contact Rethink at 0845 456 0455 or email [info@rethink.org](mailto:info@rethink.org).



# Guidance for carers

## Useful tips for dealing with difficult behaviour

'Defusion' is the means of reducing tension between you and a person you care for with verbal and non-verbal methods. It can be an important strategy in dealing with a mentally ill person in a tense situation. The tips listed here were developed from practice, and gathered from the resources at [www.rethink.org](http://www.rethink.org). The more you employ these strategies, the better at them you will become.

1. Don't invade their space. People like to have their own bit of territory, such as their own chair. Stay an arm's length away, and avoid being cornered or cornering the person. Always knock on their door.

2. Get to know the signs of rising tension. These could be rocking, stuttering, colouring of the face, pacing, or hand-wringing.

3. Keep neutral body postures. Keep your hands in sight, with no clenched fists, no hands on hips, no pointing, no leaning over the person, and make eye contact but don't stare. You are trying to make your own non-verbal communication non-threatening. They say that 90% of all communication is non-verbal, so it is of extreme importance. Smile!

4. Let everybody win. If you can defuse a situation, you have won. If your loved one has not lost face, has kept their pride, they have won, too.

5. Establish a warm environment. This can mean a lot of things, from literally turning a heater on, to sitting by it to talk things out, to being sensitive about colour schemes or the effect of the clothes you wear.

6. Be self-aware. If you are in a grotty mood, don't pretend you are feeling great or that it doesn't matter. Just being aware of your mood can help you make adjustments to how you deal with any given situation.

7. Walk, don't run. Apply this in lots of ways; for example, lower your voice, move slowly, and avoid sudden movements.

8. Count to ten. When first faced with a situation, start counting to ten. As you do this, check your mood, assess the situation, decide on a first course of action, confirm it to yourself, then do it. Your loved one will develop confidence in you to come up with safe solutions.

9. Use humour. A good one-liner can be worth all the other tips put together. Avoid negative humour like sarcasm, put-downs, and jumping to conclusions.

10. Empathise. This means saying, "I know how you feel." You can't always, but if you think you really do empathise, then use it.

11. Sympathise. This means saying, "I agree with you." Someone may well be right to show anger or distress. Develop this by talking about ways of doing something about it.

12. Once you get someone talking, let them let off steam. Ask open-ended questions like, "How did that make you feel?" rather than closed-ended ones like, "Did you do that?"

13. Use phrases along the lines of, "Lots of people feel that way when they are ill," or, "You are not alone in thinking like that," or, "That's not you, that's the illness."

14. Split up the people involved in an argument. This sounds obvious, but it's extremely important. Take one person off for a chat. If this is not possible, get them both talking to you and not so much at each other.

15. Sit out a threat. Never accept any kind of invitation to join in an argument or fight. This will be appreciated because you become safe. By setting a limit, you reassure. Threatened violence to a named individual is always to be taken seriously. Ask for any weapons or implements to be put down, not handed over.

16. Women are as good at defusing as men. There are more differences in individual ability within the sexes than there are between them. If your partner is dealing with the situation, you could just let yourself be seen. Be around to be called upon.

17. Accept that your life has changed, at least for as long as your carer or loved one is ill. If a problem develops, be prepared to stop everything, ignore a deadline or be late for something. It also means take breaks yourself, even when that also inconveniences someone. You all need respite breaks.

18. Be cautious about physical contact. Don't wake someone abruptly or aggressively, as this carries a high risk of an equal response. Don't touch the back of the neck or take a grip on the arm.

19. Some homes have places where tensions seem to come out. Think of some practical improvements like muting the colour scheme. Make some quiet space

where you can go for a chat or just to get away or play relaxing music.

20. Develop your own ways of defusing that suit your family, your personality, and the one who is ill. Apply the solution that fits. If that means getting a respite break because you are not getting enough sleep, apply for a carers' assessment and ask for what you believe you need.

21. Know how to call for help in an emergency. Have the means to do so handy, such as the number of the local crisis response team written down next to the phone or in the phone memory.

22. All of these are for the immediate situation. At the end of the day, don't accept the unacceptable. Zero tolerance of violence or aggression has to be the rule, so talk with your care team about how to deal with it.

23. If you have managed to defuse a tense situation, wait until a good time and then decide what to do about it. You could have a family conference to devise a plan you can all stick to.

For some carers, dealing with difficult behaviour is a fact of everyday life. You still need to plan for how you are going to cope in the long run. There will be times when you want to give up caring. A better strategy is to plan for your role and get a Carers' Assessment of your own needs.

### In next issue

#### Politics and policy

The new Care Programme Approach: some guidance

NHS Next Stage Review: Leading Local Change

Deprivation of Liberty Act

Carers Measures: National, Real, Effective, Visible?

#### Research

Mental Health Carers map of London

Statistics on Mental Health and Carers

#### Around the Network

Top level changes to CSIP/NIMHE