

C.A.U.S.E. for Mental Health newsletter

Autumn 2006 Edition



C.A.U.S.E. for Mental Health provide peer-led emotional and practical support to carers and families of people with mental illness.

Carer Contact Analysis

C.A.U.S.E. provided a record 3,938 carer contacts in the 2005/06 financial year. Such contact - with a local carer/family through the 'Relative Reach' programme - shows an increase in demand of 57% for **C.A.U.S.E.** services compared to the previous financial year.

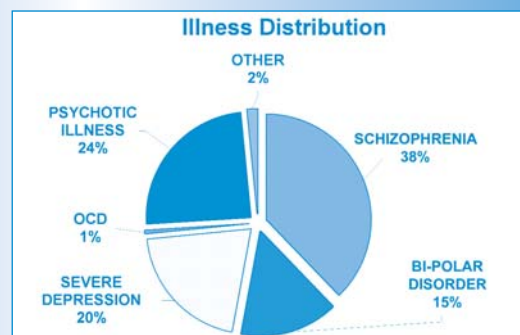
The statistics show that 53% of carer contact was provided via the telephone, with 15% via the network of support groups and 13% during carer training events.

38% of contact was from local people caring for a family member or friend with schizophrenia, followed by psychotic illness (24%), severe depression 20% and 15% with bi-polar disorder (manic depression).

The vast majority (85%) of contact from carers was from

females, with 71% of those 'cared for' being male, usually a son (44%) or husband (19%). 26% of carers contacting **C.A.U.S.E.** wanted a 'listening ear', with 22% seeking 'information'.

Carer contacts for the current financial year show a continuation in demand for **C.A.U.S.E.** services displaying a 38.5% increase compared to the equivalent period last year.



More Cash for Mental Health Care is Urged

The Bamford Review of Mental Health and Learning Disability (NI) has claimed that more cash needs to be spent on Northern Ireland's mental health and learning disability services. The Review also states that a new approach to mental health problems among children and adolescents is needed.

The report, 'A Vision of a Comprehensive Child and Adolescent Mental Health (CAMH) Service' argues that it makes sense to spend more on mental health disorders in children, to avoid the danger of storing up problems for the future.

Moira Davren, convenor of the Review's Expert Working Committee on CAMH services, says the balance is wrong:

"We all know that adult mental health problems are common in Northern Ireland, but the fact is that many of these difficulties could be prevented or lessened by investing more in children's mental health services," she said. Until recently only 5% of the mental health budget went to CAMH Services, even though people under 18 years of age make up over 25% of Northern Ireland's population.

Ms Davren continued:

"Mental health problems often appear at school. Effective partnerships between schools and local healthcare providers would help to identify problems at an early stage. As a result, children with mental health problems would benefit from an holistic approach involving schools, parents and carers, health professionals and the children themselves."

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C.A.U.S.E. Contact Details:

C.A.U.S.E. for Mental Health
1st Floor, Glendinning House
6 Murray Street
Belfast
BT1 6DN
Tel: 028 9023 8284
Fax: 028 9024 3838
E-mail: info@cause.org.uk
Website: www.cause.org.uk



Meet the Board

Continuing our profiles of **C.A.U.S.E.** Board members, in this edition we hear from Helen Kirkpatrick:

Otherwise known as the 'ballerina of the balance sheet' - referring to her profession as a chartered accountant, and a spell as the resident accountant on a radio programme about business - Helen joined the Board in April 2006.

Helen feels privileged to have been nominated as a director, and aims to act to the best of her ability to continue and develop the **C.A.U.S.E.** organisation.

"C.A.U.S.E. is a magnificent charity and unique in terms of representing carers of people with severe mental illness. Not only is this work at the policy level as a key player in influencing the changes in mental health legislation, but also at the very practical level through the Carer Advocate team".

Like all Board members, Helen is a carer and some years ago, she experienced that feeling of hopelessness, of there being no one to turn to and only meeting barriers to information. The development of **C.A.U.S.E.** means that there is someone to turn to.

Helen is also a member of the Carers' Reference Group of the Bamford Review of Mental Health & Learning Disability. Chaired by **C.A.U.S.E.** Chief Executive, Marie Crossin, Helen feels that **C.A.U.S.E.** and Marie have provided the leadership to the carers' input to the Review. Helen added *"the significance of this is that the status of carers in mental health legislation will be elevated"*.

Helen holds a number of non-executive director posts. She contributes her commercial skills to the management of **C.A.U.S.E.** In return, **C.A.U.S.E.** has given Helen *"lessons in being compassionate, a notable strength of the organisation"*.

Stress Management Activities

With funding from the Dunmurry Locality Partnership Board Brenda McFall, **C.A.U.S.E.** Carer Advocate for Lisburn area, recently provided a number of stress management activities for carers in the area. Enclosed below is a selection of carers' comments:

"I appreciate very much the support I receive from C.A.U.S.E, which in turn impacts on my whole family and in particular on my daughter who uses mental health services. Thank you."

"Excellent – I rarely get out and it was great!"

"Had a great night, was good to see the carers relaxing and having a good time. Very much appreciated"

Details on any stress management activities in your area are available by contacting your local **C.A.U.S.E.** Carer Advocate.

Crisis Accommodation in EHSSB

The Eastern Health and Social Services Board's plans for the development of mental health services for those aged 18 to 64 was completed in 2004. The Board called for the development of a greater range of services to support people with mental health needs at times when they become acutely unwell. The new services would offer service users, and their carers, an alternative to hospital admission, if that was what they wanted and it was safe to do so.

Over the past few years, 'Crisis Response and Home Treatment' teams have been set up and, although it is early days, there is evidence that these teams are helping many people, who previously would have been admitted to hospital, to remain at home with intensive support from mental health professionals.

There are plans to provide additional crisis accommodation that could be used by people who are unwell when it is not possible, or desirable, for them to remain at home but when hospital admission is not necessary. Working with the EHSSB Mental Health Users and Carers Forum, the Board has asked Trusts to prepare plans for two 'crisis houses' - one in Belfast and one in County Down.

The crisis houses will be domestic in character and in quiet, peaceful locations that are conducive to recovery. Each house will provide for 4 to 6 service users.

To allow for the service to meet local needs, the Board has asked that they should fit in with the existing range of services for people experiencing mental health crises, and that proposals from the Trusts;

- are drawn up with the active involvement of the EHSSB Mental Health Users and Carers Forum;
- are drawn up following consultation with General Practitioners;
- state how user and carers will be actively involved in the management of the service;
- describe the way care will be provided;
- explain how the crisis house will integrate with other mental health services; and
- include consideration of the service being provided by the voluntary sector.

The Board hopes that decisions to proceed can be taken before the end of 2006.

Peter Gibson, Deputy Director of Social Services, Eastern H&SSB

Beyond Caring



The North West is the location for a new and innovative project which aims to test ways of overcoming barriers faced by carers and disabled people in accessing training and sustainable employment. Its focus is on the barriers faced by people living in rural areas and it is being rolled out throughout Tyrone and Fermanagh.

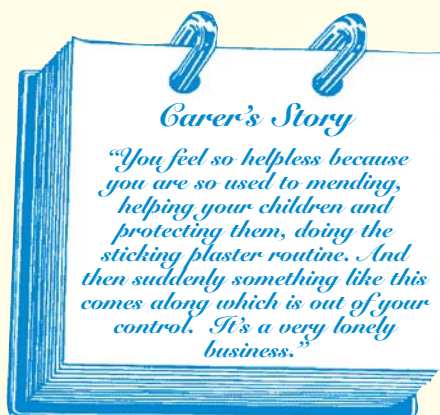
The aim of the project is to recruit 400 participants to pilot programmes and support them in preparing for employment, identifying the barriers they face along their journey to employment and testing how best to overcome these barriers. Participants will be closely mentored and supported throughout their progression. There is no cost for people participating in the project and in addition the project will contribute towards travel expenses and dependant care expenses.

Those participating in the project will be assisted in identifying their interests and aspirations and prepare an individual action plan to guide them in reaching their goals. This may involve personal development courses, recreational courses, vocational training and work experience.

To date the project has reached its target numbers for disabled people, but has been less successful in recruiting carers. Recruitment is on-going. It is interesting to think about why not enough carers are coming forward to fill places. Some have suggested as relevant the age at which people become carers, and the employment focus of the project may be a serious problem. Many carers say that beyond caring, an important need is respite.

The project is managed by Fermanagh College on behalf of the Beyond Caring Development Partnership. Further information can be obtained from Beyond Caring Project Officers in East Tyrone, Fermanagh or Omagh College.

May McCann, **C.A.U.S.E.** Carer Advocate, Sperrin Lakeland area





Direct Payments

Sarah Price, **C.A.U.S.E.** Carer Advocate for the North Down & Ards area, details her understanding of Direct Payments:

Direct Payments were updated in 2002 to include direct payments to carers. A Direct Payment is money given to carers to enable them to buy in necessary services (e.g. home based respite) to help them continue in their caring role. These payments are instead of receiving services directly from the local Trust and are designed to give more choice in how, who from and when the services are provided. It is possible to receive some services from the Trust and others from direct payments. Ideally it should allow for greater flexibility in organising the help needed.

According to government figures, in June 2005 only 283 people in Northern Ireland had taken up Direct Payments. Direct Payments can only be accessed by first having a Carers Assessment. It is best to discuss Direct Payments at this stage.

Direct Payments means recruiting and management of care staff, taxation and accounting. Receipts and records must be kept, and the Trust will carry out a formal review process to ensure needs are being met and monies spent appropriately.

There is support available to anyone considering Direct Payments. The Inland Revenue will offer advice on tax issues. Carers NI and The Centre for Independent living in Belfast can help with how to deal with Direct Payments. Trust staff are also receiving training and information.

A micro board can be set up to manage the Direct Payment on your behalf. This is a legally constituted body of family and/or friends.

The Belfast Centre for Independent Living's website www.cilbelfast.org provides further information on Direct Payments, as does the DHSSPS website www.dhsspsni.gov.uk

Work in Progress

Over the last few months, **C.A.U.S.E.** staff have been continuing to work hard representing and supporting carers. The following are some of the initiatives which staff have been involved in, or will be involved in, within the near future:

World Mental Health Day - A whole week of events took place in the Down Lisburn Trust area during the week of World Mental Health Day on 10th October including a special event specifically aimed at carers featuring inspirational speaker, Marie Kee.

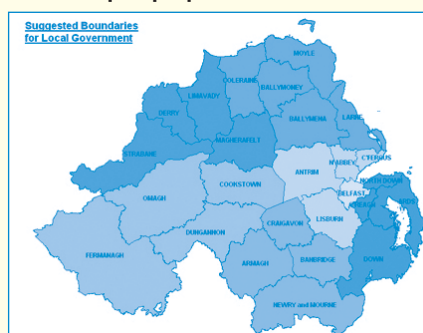
Translation of 'You and Yours' - With funding from the Community Foundation NI, **C.A.U.S.E.** is currently organising the translation of a version of the 'You and Yours' Carers Handbook into Chinese/Mandarin. The project involves working in partnership with a number of agencies including the South & East Belfast Trust's Ethnic Minorities Development Officer and the Chinese Welfare Association.

Bamford Review of Mental Health & Learning Disability - **C.A.U.S.E.** Chief Executive Marie Crossin continues to lobby for local carers' rights. With other members of the Carers Reference Group of the Review, Marie recently met a number of local politicians at Stormont to highlight the work of the Review. Marie has also met the DHSSPS Permanent Secretary and Department Board, as well as the Health Minister to raise carers' concerns about mental health services.

The Royal College of Psychiatrists held a public speaking competition on mental health issues for pupils at local senior schools. The **C.A.U.S.E.** Carer Advocate for North Down & Ards - Sarah Price - made a presentation on **C.A.U.S.E.** at each of the heats and the final, whilst **C.A.U.S.E.** Chief Executive Marie Crossin was one of the judges.

Changes To Local Government - As mentioned in previous editions, the biggest shake up in Northern Ireland's local government history is currently underway. The Department of Health's 7 proposed local government areas have now been announced, as have the Chairs of each of the 5 health trusts which will replace the 18 existing health trust areas.

Map of proposed boundaries



Family Holiday Association (FHA)

The Family Holiday Association offers a self catering holiday at a holiday centre, together with funding for food and travel, at an off-peak period of the year.

For FHA purposes, 'family' means parent(s)/carer(s) and a child or children, one of whom must be over the age of 3 and under the age of 18. The FHA funds holidays for the family unit going on holiday together. It does not fund individuals, children holidaying on their own or couples without children.

The family must not have had a family holiday more recently than 4 years prior to the application, unless there are exceptional circumstances. The family must be on a low income or in receipt of state benefits, and must be referred by the welfare agent, e.g. health visitor, as in real need of a break.

Completed application forms should be submitted to FHA in early November of each year, and funds are allocated on a first come first served basis and are normally committed by Christmas. Further information from the Association on 020 7436 3304 or www.fhaonline.org.uk

Rethink Anti-stigma and Discrimination Campaign

Rethink Northern Ireland are planning an anti-stigma and discrimination campaign in the early part of 2007. The campaign will involve 'an extensive campaign in all media', and special events including a week-long festival at the Queens Film Theatre, Belfast and performances from the HeARTH theatre company.

The campaign aims to achieve positive shifts in public awareness of mental health and discrimination, as well as positive shifts in public attitudes.

C.A.U.S.E. hopes to also contribute to the campaign. Further information is available from Rethink on 028 9040 2323, www.rethink.org

Carer's Story

"As a wife, mother and carer, life has been turned upside down, not only for me but for our two children. They have lived with their Daddy's illness and have had to cope with the long spells of 'hell', but we all love him very much and hope some day there will be a new medicine to bring him back to us."



Book Review

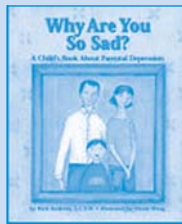
The following is a selection of books currently available to buy or loan from the **C.A.U.S.E.** 'library':

'The Complete Guide to Psychiatric Drugs'. A layman's guide to anti-depressants, tranquillisers and other prescription drugs, Ron Lacey. ISBN 0 09 181367 0

'Climbing Out of Depression'. A practical guide for sufferers, Sue Atkinson. ISBN 0745922481

'Living with Schizophrenia', An Holistic Approach to Understanding, Preventing and Recovering for Negative Symptoms', John Watkins. ISBN 085572272X

Brenda McFall **C.A.U.S.E.** Carer Advocate for the Lisburn area reviews **'Why Are You So Sad?, A Child's Book About Parental Depression'** by Beth Andrews:



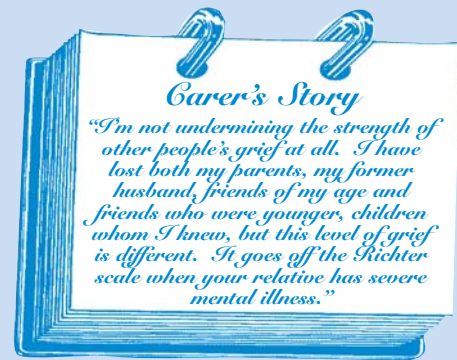
This is a lovely little book written for 5 to 8 year olds, to explain a parent's depressive illness. The focus is on feelings, with lots of space for the child to express themselves through drawing. Although it talks about depression and the effects on a parent, it could be used to explain any mental illness in any relative, as from a child's point of view the behaviour of the person who is ill will be similar.

Children aren't caught up in all the medical definitions and jargon that we as adults have to come to terms with. They just see someone they love and care about behaving in a different way. Getting answers to questions they can't always ask will reassure the child and allay some of their fears.

Dealing with a difficult problem by using language a child will understand, this book gives a very simple clear message. As quoted by one young girl, whose father is ill, after reading the book, she said "It's not

my fault, I can't fix it, I can't catch it and it's not to stop me having a good time."

Beautifully illustrated, this book will appeal to children and will help adults explain the family situation, and encourage discussion between adult and child on this hard-to-broach subject. With notes and guidance for adults on how to use the book, it will prove most helpful to many families. ISBN 1557988870



Stephen Fry: my long battle with manic depression

The BBC2 documentary, The Secret Life of a Manic Depressive, hosted by Stephen Fry detailed his experiences, those of others in the public eye and members of the public who have battled the condition. Through the programme, Stephen hoped to help break the taboos surrounding mental health. Below he recalls some of his experiences after being diagnosed as 'bipolar':

"I'd never heard the word before, but for the first time, at the age of 37, I had a diagnosis that explains the massive highs and miserable lows I've lived with all my life. There's no doubt that I do have extremes of mood that are greater than

just about anybody else I know. My mind was full of questions. Am I now mad? How have I got this illness, could it have been prevented, can I be cured of it? Since then, I have discovered just how serious it is to have bipolarity, or manic depression as it's also called.

Fry re-examined his life in the light of his diagnosis, in the programme discussing the first time he tried to kill himself at 17. He also speaks to others in the public eye who have battled the condition, including the comedian Tony Slattery and the Hollywood actors Richard Dreyfuss and Carrie Fisher.



Comedian Jo Brand - a former nurse at the Maudsley Hospital, London - also contributed to the programme stating:

"A lot of the time it's the families you feel sorry for, because they are the ones that have to cope with all the fall-out and the damage - both emotional and physical - that their relative does"

Raising Funds for Carers

Almost 150 supporters of **C.A.U.S.E.** gathered at the Europa Hotel, Belfast in May for the **C.A.U.S.E.** Mid-Summer's 'Ball' to raise money for the Charity's vital work. Guests bought tickets for the event featuring a champagne reception, 5-course meal with wine, Auction and the musical talents of 'The Jukes'. Compered by Mike Nesbitt, guests included the Charity's Patron, Professor Monica McWilliams, members of the local business community, carers and a number of Health and Social Services Trust staff.

Almost £10,000 was raised by the event, and the same venue has now been booked for a May Ball on Saturday 19th May 2007.



C.A.U.S.E. Chief Executive Marie Crossin, comper Mike Nesbitt and **C.A.U.S.E.** Founder and Chair Dr Carole Castles
(Photograph courtesy of Ulster Tatler)

Thank You!

Over the last few months, the following have been kind enough to donate towards **C.A.U.S.E.'s** work with carers and families:

Ardbarron Trust Limited
Four Acre Trust
Regent House School, Newtownards
Antrim & Ballymena LH&SCG
British Telecom
Nortel Employees' Charity Fund
InBev Ireland
Lagan Holdings

As well as established regular supporters of our work, we appreciate the generosity of these supporters. If you or a local company, school, individual or group would be interested in making a donation towards the work of the Charity, please contact Peter at the **C.A.U.S.E.** Office.

C.A.U.S.E. is supported by
the D.H.S.S.P.S.



Department of
**Health, Social Services
and Public Safety**

As many of the articles in this newsletter are from external sources, the contents of this newsletter are not necessarily the opinions of **C.A.U.S.E.**

And Finally....

'Our greatest glory is not in never falling but in rising every time we fall.'

- Confucius