

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

Winter 2005/6 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.

C.A.U.S.E. Bids Farewell to Elsie

After many years as Chairperson of the **C.A.U.S.E.** Board, Elsie MacPherson has stepped down from the position. Awarded an MBE in the 1990's for services to mental health, Elsie has served as **C.A.U.S.E.** Chairperson during our rapid expansion over the last couple of years.

Elsie - still practising yoga in her 80's - has now moved to Stockport, Greater Manchester to be near her daughter and will be sorely missed by her many friends at **C.A.U.S.E.** Speaking at a special farewell dinner, Dr Carole Castles - who replaces Elsie as Chairperson - said: "I have been privileged to know Elsie for over twenty years since I first became involved in the world of mental health. She was one of the founder members of **C.A.U.S.E.** ten years ago and we have benefited from her knowledge and experience ever since. She is extremely knowledgeable about a great number of things and this, together with a keen sense of humour, makes her great company to be with. She has been there for me over the years when I have needed her and, although I am happy that she is going to live near her family in England, I will miss her greatly."



Elsie at the special farewell dinner to commemorate her retirement

New Carer Advocate for Antrim & Ballymena areas

The families of people who suffer from mental illness in the Antrim & Ballymena areas now have a new source of help and information with the appointment of Zoe Price as part-time **C.A.U.S.E.** Carer Advocate for the area.

Appointed at the end of August 2005 Zoe, a native of Newcastle-Upon-Tyne, has personal experience of the problems facing families as she herself has been personally involved in caring since 1999. Zoe's position has been made possible by funding from the East Antrim and Antrim & Ballymena Local Health & Social Care Groups. Zoe can be contacted c/o **C.A.U.S.E.** Head Office on 028 9023 8284, or on her mobile - 07738 210628.



Zoe Price

Meet the Board

The current **C.A.U.S.E.** Board - elected at The AGM in April - consists of 7 people, all of whom are current or former carers. Forthcoming editions of the **C.A.U.S.E.** newsletter will feature inputs from Board members. In this edition we hear from the Board's Secretary, Maureen McParland:

"Since my son was diagnosed with a serious mental illness eight years ago, I have volunteered for a number of roles within **C.A.U.S.E.** Initially I was solely involved as a member of a local **C.A.U.S.E.** support group and still attend monthly meetings. However, watching someone I love experience a serious mental illness also motivated me to volunteer to help other local carers in my position, and lessen the hopelessness and isolation experienced by new carers.

For the last couple of years I have therefore been involved in the **C.A.U.S.E.** Management Board, most recently as Secretary. Being a member of the Board has opened many doors for me to air my opinions and experiences, and help others.

Contributing to the Board helps me become more knowledgeable and also ultimately helps others with similar experiences. The social interaction which takes place among carers - whether they be Board members or members of a Support Group - is very uplifting and I would recommend anyone to get involved in the work of **C.A.U.S.E.** helping to make a difference to the lives of local people"

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Carers and 'Confidentiality'

Many carers have had the experience, when asking for information about their relative's treatment, of being blocked with the word 'confidentiality'. This can be frustrating and make us feel excluded. More than that, lack of information can be dangerous when, for example, a carer is not informed when their relative is discharged from hospital or when medication has been changed. So how do we deal with the 'brick wall' that confidentiality appears to be at times? What can we reasonably expect to be told about our relative's care and treatment?

The Royal College of Psychiatrists has produced a booklet on this topic as part of their "Partners in Care" project. In the paper Dr Mike Shooter, of the Royal College, is quoted as saying "Good practice is built on partnerships – not only between doctor and patient, but between patient and carer and between carer and doctor."

The booklet addresses some interesting questions including:

- Why is it important that appropriate information is shared with carers?
- What are the particular problems in information-sharing in mental health?
- How can these barriers be overcome?

Increasingly, mental health teams are trying to involve carers and families. Ideally the issue of confidentiality should be discussed with the patient at a time when s/he is not acutely ill. An 'advanced directive' can be used, that is, a plan for what a person would like to happen in the event of them becoming ill.

Training for professionals is important as is training for carers. We need to have the confidence to ask the right questions at the right time, and to realise that information-giving is a gradual and continuous process. Sometimes it is up to us to keep the professionals on the right track.

Patients, professionals and carers should be helped to distinguish between sensitive and personal issues which are to remain confidential, and more general information about the illness and its management which should be shared. The primary carer should always be given sufficient information to enable them to provide effective care.

The last word should go to a carer who is quoted in the Royal College leaflet;

"I need to know what you are trying to achieve for my son and how you are planning to do it. I need to understand the treatment that he is receiving so that I can play my part in his recovery programme. What I do not need to know are the personal details of what takes place between him and the professionals concerned."

The booklet can be obtained by phoning The Royal College of Psychiatrists' London office on 020 7235 2351 exts127/131 or on www.partnersincare.co.uk, or contacting **C.A.U.S.E.**

Review by Linda Hutchinson, C.A.U.S.E. Carer Advocate, The Shannon Clinic regional secure unit.

NI Review of Mental Health and Learning Disability – Carers' Involvement

May McCann, currently temporary **C.A.U.S.E.** Carer Advocate for the Sperrin Lakeland area, comments below on the progress of the Review and its importance to local carers:

"Among public authorities there is an increasing awareness of the importance of consulting and involving those who use, and are affected by public services, as a means of providing more appropriate and effective services. Within the area of mental health this entails seeking the views of, and developing relationships with, what are currently referred to as 'service users' and 'carers'.

In the early stages of the Review, when the Carer's Reference Group was set up, it was not considered as a permanent, on-going part of the Review. Neither it nor the Service User's Reference Group were included among the list of Expert Groups dealing with the various sub-divisions into which mental health and learning disability has been divided. However the commitment of these groups and the gradually recognized value of their input have meant that they have played a much greater role than initially anticipated.

For the past two years the Carer's Reference Group, made up of carers from all over Northern Ireland, have met at least monthly. Unlike the other 'professional' working groups in the Review, the Carers Group - chaired by **C.A.U.S.E.** Chief Officer, Marie Crossin - works through and responds to every document produced by all of other Review groups.

Most of the working groups have now requested that a carer work with their group on a regular basis. This means that some of the Carers Reference Group also sit on other groups. I, for example, sit on the Human Rights and Equality Sub-group of the Social Justice and Citizenship Group.

The input of carers has made a significant impact, and brought about many differences to the content of the Review. The process of the work has been as important as the changes in content as new relationships have been formed among carers, between carers and service users, and with health care professionals. Participation of carers has been shown to be valuable and effective, and structures are being put in place to ensure the duration of such relationships are on-going. The first of the Review reports - 'A Strategic Framework for Adult Mental Health Services' - has now been completed and is in the public domain for consultation. I sincerely hope that this report – and other Review reports – will help the carers of today, tomorrow and the future." Further information on the Review is available on www.rmhdni.gov.uk

Carers Get a Break

Carers have benefited greatly from a number of recent Respite Weekends at the Derrynoid Centre near Draperstown with the following a selection of carers' comments after the most recent weekend:

"I couldn't believe the treatment we had from start to finish - a lovely group of people. Would really enjoy meeting up again. Staff and accommodation 100%"

"Served as a necessary requisite to understanding ourselves and our bodies. Weekends like these make our journey through life more helpful and bearable"

Further information on carer respite is available by contacting your local Carer Advocate.



Carers attending a recent respite weekend couldn't believe their eyes when they saw an elephant at the side of the road (proof, if it was needed, that the carers needed a break!). The elephant turned out to be part of a circus in the area, so the carers continued on to their destination at Derrynoid!

Carer Discounts

Many carers got in touch about the Cinema Exhibitors' Association Card - entitling the cardholder to one free ticket for a person accompanying them to the cinema - featured in the previous edition of the **C.A.U.S.E.** newsletter.

Lisburn City Council's 'Buddy Card Scheme' also entitles friends and family members of people with a physical and/or mental disability to free admission to a number of Council facilities, including the Island Arts Centre and Lisburn Leisureplex. The 'Buddy Card' is issued to the person with the disability so different carers can accompany a card holder when using the appropriate facilities. Further information is available from Lisburn City Council on 028 9250 9250, or Brenda McFall from **C.A.U.S.E.** on 07966 809427.

The Grand Opera House in Belfast also provides a free seat for carers. Anyone who needs a carer to accompany them to the theatre is entitled to one free seat along with their normally purchased ticket. This service is available through the Grand Opera House Ticket Shop Manager, Ross Hickey on 028 9024 1919.

Mental Health – A Carer’s Perspective

Rosamund Smyth, **C.A.U.S.E.** Carer Advocate for the Armagh and Dungannon area, recently wrote an article to the press in her area. The following are excerpts from the article:

“If you have tried to support someone you love through the pain of a mental illness, you will understand the many difficulties faced by other carers in a similar situation. When a person first suspects that someone they love might be struggling with the onset of mental illness, it is difficult to know how to tell them of your concerns or even the most effective way to help them. Being understanding and prepared to listen sympathetically is very important, but they may be withdrawn, defensive or become upset at any suggestion that they should talk to their GP or other health professional. This is usually when the role of carer begins.

Those just setting out on the road of caring for someone with a mental illness, soon find themselves confronted by a number of dilemmas. One of the carer’s first dilemmas

is deciding whether or not to seek help on someone else’s behalf, and if so, when. The responsibility of this action is daunting because it can involve issues such as breaking confidences and may ultimately put at risk the person’s job, lifestyle, income, social and family life.

It is very tempting for a carer, especially one placed in this situation for the first time, to keep waiting and hoping that, given time, the illness will go away and everything will return to normal. Often it is only when a carer can no longer cope, or a person’s life is at risk, that the family GP is involved. However, evidence shows that the earlier a mental health problem is addressed, the less the impact it usually has on that person’s life.

Mental illness is very distressing for both the person who is unwell and their carer. If someone is admitted to hospital the carer is often thankful that the responsibility is being taken off them by trained staff.

However, the mental health system is complex and communication with ward staff, social workers, and psychiatrists can throw up more questions than answers at a time when carers are hoping for support and reassurance about their relatives’ recovery.

Caring for someone with a mental illness requires patience, understanding, love and if possible, a good sense of humour. It is also important to learn as much as possible about your relatives’ illness and the different types of treatment and therapies available. Carers and those who have to live with the experience of an illness will soon realise they are far from being on their own if they contact a local support group”.

Further information on **C.A.U.S.E.** support groups and the work of **C.A.U.S.E.** in the Armagh and Dungannon area is available by phoning Rosamund on 07730 623867 or by writing to her c/o the Beacon Centre, 17 Abbey Street, Armagh, BT61 7DY.

Special Relaxation CD

Sarah Price - **C.A.U.S.E.** Carer Advocate for North Down and Ards - has helped compile a special relaxation CD for use by both carers and service users in partnership with a number of other community agencies in the area including Action Mental Health, Ulster Community & Hospitals Trust, Praxis and Rethink.

The CD, which was launched on World Mental Health Day, features UTV’s Lynda Bryans and Mike Nesbitt and includes a range of breathing, relaxation and muscular relaxation techniques. Special thanks to Bob Price from Zirkus Creative for his help compiling the CD.



Pictured at the recording of the CD are Bette McMullan (Ulster Community & Hospitals Trust), Lynda Bryans and Sarah Price.

Anti-Depressants 'Not For Young'

A recent report from The National Institute for Health and Clinical Excellence (NICE) stated that medication should not be readily dished out to children and young people with depression, and that drugs should only be considered in moderate or severe cases. NICE said young people should first be offered a course of psychological therapy lasting for at least three months. Campaigners say this is not happening as therapists are in short supply. There is also concern that too many young people are being medicated without any access to psychological therapy. The NICE guidance stressed drugs should only be offered in tandem with, and not instead of, therapy.

Anti-depressants known as SSRI’s have already been barred from use in young people in the UK over concerns of a heightened risk of suicide. NICE also warned that many young people with depression are not being diagnosed - putting them at increased risk of self-harm and suicide. The report also said that healthcare professionals in primary care, schools and other relevant community settings should be trained to detect symptoms of depression, and to assess children and young people who may be at risk.

Andrew Dillon, NICE Chief Executive, said: *"It is important that children and young people taking anti-depressants do not stop taking them abruptly, but we would advise people to talk to their GP at their next regular review about whether a psychological treatment may be a more effective treatment option."*

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:

- **C.A.U.S.E.** is now working in partnership with the Craigavon and Banbridge HSS Trust to provide support for carers in the area. A **C.A.U.S.E.** Support Group has started meeting in The Trasna Centre, Connolly Place in Lurgan from 7.30 p.m. on the first Wednesday of every month. A local ‘PREP’ course for carers is also taking place during the autumn and winter months.
- A number of **C.A.U.S.E.** staff recently attended a Conference on ‘Risk’ at Knockbracken Healthcare Park organised by the South & East Belfast HSST. **C.A.U.S.E.** Chief Officer Marie Crossin gave an address to delegates addressing the carer and family perspective.

- For the last couple of years, **C.A.U.S.E.** staff have been pivotal to a number of local events to commemorate World Mental Health Day in October. In 2005 initiatives contributed to by **C.A.U.S.E.** staff included a special Information Day in the Atrium at the Mater Hospital, and a Health Fair in Bangor. The Down Lisburn Trust also organised a week of events including a talk on ‘Tough Issues’ (how to approach your child about drugs, alcohol etc) and a number of suicide talks and dramas.
- Angela, the **C.A.U.S.E.** Carer Advocate for North & West Belfast, recently attended a Conference in Belfast Castle entitled ‘Providing for People with Personality Disorders’. The Conference was chaired by Dr Maria O’Kane, Consultant Psychiatrist at the North & West Belfast Day Hospital. With little current provision for local people with personality disorders, Angela was encouraged that positive moves are being made towards the development of a much-needed service.

C.A.U.S.E. Golf Classic

More than £5,000 to provide comfort and support to local people caring for a loved one with a mental illness was raised from the inaugural **C.A.U.S.E.** Golf Classic at Lisburn Golf Club. Stephen Watson from BBC NI and Paul Loughran (best known for his role as 'Butch Dingle' in Emmerdale) helped launch the event with everyone who attended the tournament having an enjoyable day despite torrential rain and a sodden course.



Elsie MacPherson presents the perpetual trophy in her honour to winning captan Nigel Beggs from The Diamond Group. Also included is Paul Loughran.

Book Review

Jean Johnston's book **'To Walk on Eggshells'**, talks about her experiences caring for her daughter, Suzy:

"I'll never forget the moment when Suzy told me she was to go into a psychiatric unit. I have never felt such a total and utter failure in my entire life. To see our daughter tormented with psychotic and delusional thoughts – without trust and consumed by a fear of everyone, including her own family – was the most harrowing time of all. What could I do? Nothing really – just be there. I'd spend most of the day at the hospital, leaving home in the morning, back in the evening in time for supper.

Slowly the right medications were found and imperceptibly she began to improve. It would take a long time for her to move forward and totally recover but at last we were on our way. It is funny what utter desperation will have you do. One night, as I drove the road home, I was having a chat with God (as you do). I promised I would never have my hair highlighted again if he would only get Suzy better and never let her get that ill again. I've kept my promise – she is well and I am grey. Mums – we'll try anything".

'To Walk on Eggshells', Jean Johnston, ISBN: 0 954809211

'How Do I Get Help?' booklet

Carers NI has produced a new booklet entitled *'How Do I Get Help?'*. The booklet gives carers information about how to get the help they need to continue in their caring role. The booklet is arranged into 4 clear sections:

- Explaining how the person you care for can get a community care assessment, and how you can get a carer's assessment
- Giving practical advice to help you, and the person you care for, prepare for

your meeting with the person who will carry out the assessments

- Explaining what happens after your assessments
- Explaining what you can do if you don't agree with a decision made by your Health and Social Services Trust.

Some **C.A.U.S.E.** carers may already have a copy of the booklet which is available from the **C.A.U.S.E.** Head Office or from Carers NI on 028 9043 9843.

Day Of Yoga For Good 'C.A.U.S.E'

Local yoga enthusiasts recently gathered at the David Lloyd Centre in Dundonald for a special day in aid of **C.A.U.S.E.** The event also celebrated the long service of the Chairwoman of the Yoga Fellowship of NI and **C.A.U.S.E.** member, Moira Harper. Experienced 'yogis', 'yoginis' and 'beginners' attended a range of morning and afternoon workshops raising £400. Maggie Crawford from the Yoga Fellowship of Northern Ireland said, "everyone who attended the event had a great time. To raise much-needed funds for a local Charity at the same time was a great boost to the event and we are delighted to do so".

Anne Cunningham (centre back row) from C.A.U.S.E. with representatives from Yoga Fellowship of NI



Carers Urged to 'Catch The Vaccine, Not The Flu'

For the first time, the annual DHSSPS flu vaccination programme includes carers as an 'at-risk' group. The *'Catch The Vaccine, Not The Flu'* advertising campaign is calling on people who normally receive the flu vaccination to take advantage of the free vaccine on offer and protect themselves from a bout of influenza this winter.

Dr Lorraine Doherty, Senior Medical Officer at the DHSSPS, said: "This year for the first time people who are carers are included in the programme and are entitled to be immunised free of charge. I would urge all carers to make an appointment with their GP with a view to getting the flu vaccine."

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:

- Rayne Foundation
- Craigavon and Banbridge HSS Trust
- William A. Cadbury Charitable Trust
- St Colm's High School, Belfast
- Rotary Club of Bangor
- NEXT plc
- The Ardbarron Trust Limited
- Stuart Elliott (donation of football signed by NI v England squad)
- John Moores Foundation
- Sacred Heart Grammar School, Newry
- D'Oyly Carte Charitable Trust

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

And Finally....

Rosamund Smyth, **C.A.U.S.E.** Carer Advocate for the Armagh and Dungannon area, recently heard a song called 'Heroes' on the radio by The Isaacs, and thought that the lyrics were appropriate for carers. The chorus of the song is as follows:

*"He's a hero and she's a hero
It doesn't matter that nobody knows their name
They keep on giving to make life worth living
Might go unnoticed, but they're heroes just the same"*

C.A.U.S.E. is supported by
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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.**