



CAUSE provides peer-led emotional and practical support to carers and families of people with mental illness.

Newsletter Theme

Earlier this year Carers UK's 'Our Care, Our Health, Our Say for Our Caring Future' report listed carers' priorities. Advance planning and emergency support during times of crisis were identified as immediate unmet needs and key priorities for carers. The report stated that 'good emergency support and planning would make carers feel valued ... and provide better services.' Previous research from the Charity also showed that emergency support and planning were sadly lacking, with devastating consequences for carers.

CAUSE agrees that planning, particularly within families to help prevent or deal with relapse, is of vital importance. The theme of this newsletter is therefore 'Planning Ahead - A Network Contract'. A number of articles contained in this newsletter particularly 'The Elephant In The Room' article, Book Reviews, and 'A Network Contract - Example' all look at this theme.

The Elephant In The Room

"During our family's years of caring for a family member with a mental illness, I became cynical about my husband ever making a recovery.

In the early years, I would have my hopes raised only to have them dashed by another crisis. I eventually learned not to get too excited by the 'in between periods'. I decided to expect nothing and I would then never be disappointed.

This approach served its purpose for me in that it helped me cope with a situation that I was powerless to resolve. I had no control over the events in my life, and it was a very scary place to be. It also helped my husband in a way too. It took the pressure off him and gave him a bit of space. I had no expectations so he didn't feel he had to perform, so to speak.

After this 'letting go' stage had become a way of life for a number of years, a miracle happened. My husband, very quietly found his own road to recovery, with no help from me I must add. It took a few years for me to even acknowledge this as I was afraid that if I mentioned 'it', 'it' might return as it had done many times before.

Eventually I had to admit that he was doing well and had not been admitted to hospital for a long time. I was still holding my breath for fear that something would go wrong and set him back.

I had read a few articles on Relapse Prevention and Advance Directive which both looked at making plans when things are going well for if, or when, things were not so good. I liked this idea and thought it made a lot of sense.

I didn't know how to bring the subject up. I was in a quandary. If my husband took it the wrong way it could set him back. I was afraid that if I mentioned relapse prevention he would think I had no faith in him or that I thought he was unwell again. It was a big worry. The possibility was there and it was real, we both knew it but couldn't talk about it, just like a great big elephant in the room that we both choose to pretend wasn't there.

I left a few articles about relapse prevention sitting about the house and waited. Eventually my husband brought the subject up and asked me if we could sort something out. It was a magic moment and only then did I feel that we have started on the right road to recovery. Our plan is very personal but simple and it is lovely to have that knowledge and understanding between us. It's just like an insurance policy - you need it, but you never want to use it."

Article provided by Mary, a CAUSE Carer

New Mental Health Board for NI

Health Minister Michael McGimpsey has announced the setting up of a new Mental Health and Learning Disability Board in Northern Ireland. This new Board, which includes **CAUSE** Chief Executive Marie Crossin, will be one of the driving forces in delivering the reforms proposed in the Bamford Review of Mental Health and Learning Disability.

Speaking after an Assembly debate, the Minister said: "The Board's role will be to challenge me and my Department and ensure that the most appropriate services are provided."



Pictured before the first meeting of the Mental Health and Learning Disability Board in Northern Ireland are Health Minister Michael McGimpsey (second from left) along with Board members including Marie Crossin (left).

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Meet the Board

Continuing our 'Meet the Board' series, in this edition we profile Maria McCaughey, **CAUSE** Board member and member of the Charity's Finance and Fundraising Committees.

Formerly employed in Relationship Management with Bank of Ireland Business Banking, Maria is currently enjoying a career break. She has worked in the local business community for the past 20 years, including almost 10 years in the Banking sector. She holds a Business degree, a Postgraduate Diploma in Business Strategy and is currently working towards a BSc Social Psychology at the University of Ulster. Maria is married and has 2 sons.



Maria McCaughey

Like all **CAUSE** Board members, Maria has experience of caring for a family member with a mental illness.

Maria said: *'It has been a pleasure to work with CAUSE over the past few years both as a volunteer on the Events Committee and briefly as a member of staff in 2003.*

I was delighted to be elected to the Board in April this year and hope to continue utilising my skills and experience, to help build capacity within CAUSE and further expand our support services.

I am particularly keen that we reach the many 'hidden carers' who don't necessarily relate to the term 'carer' but rather see themselves as 'a concerned parent, sibling, spouse, son, daughter or friend of someone with a serious mental illness'.

Assembly Motion

CAUSE patron, Carmel Hanna MLA, recently submitted the following motion to the NI Assembly:



Carmel Hanna

'That this Assembly calls upon the Minister of Health, Social Services and Public Safety to ensure that all carers, formal and informal, can access services and support to maintain their own health and well-being, and to recognise financially the vital role they play, and ensure uptake of all benefit entitlements'.

The motion was discussed during Private Members' Business and involved contributions from 17 other MLA's.

Speaking after the Assembly debate, Health Minister Michael McGimpsey vowed that carers will not be overlooked and their importance to society will be reflected in his priorities. He said:

"I share the view of Assembly members that not enough is currently being done to ensure that carers are aware of their statutory rights. All carers are individuals with their own needs, caring for people with a huge range of requirements and abilities in what can be very complex and emotionally charged relationships.

This is not a one solution fits all - carers deserve real choices based on their individual circumstances. I want to ensure that the contribution of carers is fully recognised. They are the unsung heroes and without their input the vulnerable people in our society who want to live independent lives will suffer."

Eastern H&SS Board Consultation

Where should acute inpatient units be located, and how many beds should there be?

A Commissioning Statement has been produced detailing the proposed future provision of Acute Psychiatric Inpatient Units and Beds in the **Eastern Health & Social Services Board area**. Influenced by a previous audit of admissions to inpatient beds in the area, the restructuring of local health services and the Bamford Review, the planned changes for acute inpatient care in the Eastern Board include the commissioning of 220 acute psychiatric inpatient beds (174 for adults, and 46 for those aged over 65) for its population.

In terms of mental health provision for older people, it is recommended by the Board that there should be separate accommodation, managerially aligned with other services for older people.

The Board is suggesting that the beds for adults could be accommodated in four new units at the Mater Hospital, Belfast City Hospital, Ulster Hospital and the new Downe Hospital, and that the beds for older people could be provided in separate facilities within the new units at the Mater and Ulster Hospitals, and in existing accommodation at the Lagan Valley Hospital.

A full copy of the statement is available from www.ehssb.n-i.nhs.uk. Please contact your local **CAUSE** Carer Advocate in the Eastern Board area at your earliest convenience if you would like to respond to the proposals.

The Search for Acute Care Solutions - A Local Initiative

Most people agree that there are times when people diagnosed with mental illness need refuge, somewhere away from their everyday lives. Twenty-four hour care for people in acute distress or crisis is something that will always be needed, but how it is provided needs to change.

Today acute inpatient care can still be perceived as the last resort when all else fails. People are admitted at their most distressed into a setting that would be hard for anyone to cope with under normal circumstances: a poor environment, with many other distressed people, sharing a dormitory with strangers, mixed wards, being watched, liberty removed, loss of autonomy, no information and boredom - a vicious circle can emerge.

Over the last 6 years, the Sainsbury Centre for Mental Health has been involved in a project called 'The Search

for Acute Solutions'. The project has been operating in England with some interesting outcomes including improved provision of treatment, advice and information, increased therapeutic activities, reductions in length of time spent in hospital, reductions in the amount of medication dispensed, reductions in 'observation' and in re-admission rates.

Sperrin Lakeland Trust (now the Southern Region of the Western Trust) is unique in Northern Ireland in implementing the Acute Care Forum model as a means of improving acute services. Carer and service user representation has informed all aspects of the work.

Outcomes achieved to date include new admissions criteria and a standardised referral form that will have a knock-on effect in producing further good outcomes, freeing up staff time for

therapeutic activities, including work with families. Other changes - for example in meals and menus, interior decor and the manner of dispensing of medication on the ward - are of immediate and important value. New acute ward information booklets and leaflets are also being developed.

Discussions are also ongoing in relation to the development of greatly increased activities of therapeutic value, to be included into everyday experience on the ward.

Discussions are also taking place about the planning of the acute wards in the new hospital to be built in Omagh. Forthcoming on the Acute Care Forum agenda is also the issue of carer participation, so watch this space! Further information on the Acute Care Forum is available from May McCann, the **CAUSE** Carer Advocate based in Omagh on 8225 8307.

Book Review

Below 'A Network Contract: A Tool For Safe Recovery' by Laila Gentzel (ISBN 91-631-9941-6) is reviewed by a carer, a mental health 'service user' and a health professional, each offering their own insights in to this useful book. The introduction to the book states that 'a clear and well thought-out contract lessens the suffering ... and increases the user's sense of security and chances of recovery'. Everyone who has read this book (available from the CAUSE office) agrees that it is a wonderful resource, so it is appropriate that the theme of this edition of the newsletter incorporates the book's title:

"A most inspiring book, in which the author succeeds in sharing her experiences, including details of her family, friends and professionals involved.



The book is brief and easily read, yet captures all the relevant detail. It emphasises the importance of knowledge and information for family and friends to enable them to act as supporting resources during relapse and also as an integral part of keeping well.

This book encourages the development of a shared understanding and negotiation between all the individuals involved. This enhances communication, trust, respect and the ultimate goal for the individual - to continue their journey of recovery and keeping well

This model promotes working with the family and social networks. It reflects the 'Thorn' philosophy in the case management and recovery based approach underpinned by the vulnerability-stress model. The emphasis is on trust and understanding with comprehensive communication between all individuals involved.

Laila highlights the difficulties around confidentiality and its impact on family and friends who care for the person and want to keep him / her safe and well. Often families are excluded due to confidentiality and this can leave them feeling powerless and frustrated. This model promotes the relationship between the family, individual and professionals, developing trust, openness and partnership working.

This is expressed in one of the stories in the book (by Torborg Klingselle). Language and terms around 'contract' may not be accepted by all individuals within their own personal experience, however it highlights the need for early signs and relapse prevention systems to be in place to enhance keeping well."

Susan Bowman
Community Psychiatric Nurse
(Thorn), Belfast HSC Trust

"This little book is worth reading if you are, like myself, someone struggling with mental health crises and determined to recover - i.e. take charge of your own life, and create a healthy and satisfying life for yourself. This is difficult, not just because of the episodes, but during crises. You have stressful interactions with friends whom you may cut yourself off from or drain, family (the same, only they may also take some legal responsibility for you), and the health services.

Special strengths of the network contract include:

- Network contracts were forged by Laila as a creative response during a crisis to cope with difficult issues, for example the pressure Laila was putting on friends and family.
- Everyone who cared about her was included in the contract, at her request. It was reviewed periodically, and she was in charge.
- The network contract works, despite initial hiccups. ALL who participate, especially Laila, but also those she cares about, find it useful.
- Finally, this tool works on a measurable level: Laila spends less time in crisis and in hospital, and gets on with living her normally interesting and happy life.

One tool cannot heal a life shattered by episodes of emotional crisis. But we can learn from Laila and this book, encouraging each person to be at the centre of their own recovery, to accept responsibility for their behaviour - both during and after an episode - and plan for a healthy future together with those they choose as supporters in this quest.

Finally, a word to other Experts by Experience (EBE - a term I prefer to service users) reading this book. Initially I found the language off-putting perhaps because it is a translation from Swedish, or perhaps because I find 'mental illness' and the medical model unhelpful. Many EBE's consider 'mental illness' part of a medical model whose dominance is unhelpful to recovery. However, each person's story and experience is unique; what is important to recognise is that each person is an expert in what is healing for them. So don't be put off - Laila Gentzel has a lot to say!"

Martha McClelland,
Mind Yourself, Derry

"In the care and recovery journey of our loved ones and indeed ourselves, there are many, many players - us included - sometimes not all playing on the same pitch, wearing the same kit nor shooting in the same direction, even though we should be!

Communication is one, if not the most important, factor for us, and the team that should be working with us. Laila Gentzel's book and approach will help our teams to come together - in it she recommends a common sense approach, which is helpful on so many levels.

It has at its core the fundamental philosophy that we are all purely and simply people, that we each play a vital part at varying times, and that we each need to understand each others roles for us to be an effective team for recovery.

The concept of a network, unique to the individual who is recovering, ensures that co-operation between all relevant agencies is regulated, with the long-term interests of the individual at the core.

The notion of a network contract is something that everyone can sign up to - Gentzel illustrates succinctly yet potently that levels of distress and periods of hospitalisation can be minimised with such a contract. She also points out the mistakes in her own journey, and the communication problems which ensued at the outset of her journey, and how these obstacles were overcome.

This is a must-read for anyone who is keen to improve co-operation and communication around, and with, their loved one and themselves.

It is also an inspiring example of how trust and faith in other people and themselves purely as people who have a role to play overcomes illness, builds collective resilience among the group and quickens our journey to and through recovery.

Structure is key to recovery. Without a strong structure the network and recovery journey may falter. With a structured network, the person is considered rather than the diagnosis, the illness is easier to manage and therefore recovery is more attainable."

Damien Kavanagh,
Carer and CAUSE Carer Advocate

A Network Contract - Example

As mentioned elsewhere in this newsletter, the theme of this newsletter is 'Planning Ahead - A Network Contract'. The **CAUSE** Carers Information Guide contains a sheet entitled the 'Authorisation For Release Of Confidential Information' - a simple version of a network contract.

The form, to be completed by the mental health 'service user', gives permission to health professionals to release information to a named person (a carer, friend, parent, sibling, workmate) about a number of factors including 'my condition and treatment', 'my medication and side effects', 'my care plan', 'therapy', 'discharge' and 'future appointments'.

The form also contains validation dates, and requires the signature of an independent witness, such as a solicitor, advocacy worker, or advice worker, working in an advisory capacity. This person should not be connected to caring or mental health services.

Copies of this 'Authorisation For Release Of Confidential Information' contract are available from **CAUSE** Head Office or in the appendix of the **CAUSE** Carers Information Guide.

Carers' Comments

Earlier in the year, **CAUSE** asked all our carers for their views. Enclosed below are 6 anonymised responses, outlining how valued the **CAUSE** service is to local carers:

*"I would like to say thank you to everyone at **CAUSE** for all the hard work you do to help us get through all the things that each day brings to us"*

*"I think **CAUSE** is doing a commendable job and is helping a lot of us cope and have hope for our loved ones eventually recovering"*

*"**CAUSE** has been a great benefit to me as a carer either for a chat, or learning something from a support group meeting, or just getting the opportunity to relax with other carers and friends"*

*"Being a member of **CAUSE** to me means never being alone. Having someone always there to listen, help and support me"*

*"**CAUSE** has been a lifeline and a turning point for me"*

*"Long may **CAUSE** continue its much-needed help and understanding for people like me who didn't know which way to turn to obtain help."*

Work in Progress

- The contact address for Arlene Wilson, **CAUSE** Carer Advocate for the Armagh & Dungannon area, is now c/o the Night Nursing Office, St Luke's Hospital, Loughgall Road, Armagh, BT61 7NQ - telephone 3752 2381. It is also now possible to contact Zoe Price, **CAUSE** Carer Advocate in the Northern Trust area, at the Advocacy Office, Holywell Hospital, 60 Steeple Road, Antrim, BT41 2RJ. Zoe also continues to offer a weekly Carers' Clinic at the hospital and is available on 07738 210628.
- A number of **CAUSE** staff are contributing to a DHSSPSNI booklet entitled 'Mental Health - Let's Talk' due for release within the near future.
- May McCann, **CAUSE** Carer Advocate based in Omagh, recently represented local carers at the Royal College of Psychiatrists' Annual 'Making our presence felt' Conference. May will also be attending a Health Promotion Conference focussing on the Western Trust's strategy for mental health, and attending a Nursing conference in Dublin looking at the psycho-social elements of mental health.
- Over the last few months, carers from North & West Belfast have benefited from a range of respite activities including trips to 'The Mikado' and 'A Night In November' at the Grand Opera House, as well as an Away Day at the Drumalis Retreat Centre outside Larne.

Thank You!

The following have been kind enough to recently donate towards **CAUSE**'s work with carers and families:

- Ardbarron Trust
- Tughan Trust
- Down Lisburn Community of Interest
- Regent House School

The following companies also supported September's **CAUSE** Golf Classic at Shandon Park Golf Club:

DHL Exel, Northbrook Technology, Belfast HSC Trust, McKeagney Pharmacy Practice, Lagan Holdings, Bank of Scotland (Ireland), Tughans, Successful Security, British Telecom, Drax UK, Dawson Whyte, BPS

As well as 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 **CAUSE** Head Office, and ask for a copy of the **CAUSE** networking form.

CAUSE also now receives in excess of £1,000 every year via monthly standing orders from supporters. Further details on how to donate to **CAUSE** by standing orders - or via a legacy (a will) - are available from the **CAUSE** Office.



The DHL Exel Team pictured receiving the Elsie MacPherson Perpetual Trophy from Sean Crummey (of BBCNI's 'Folks on the Hill')

And Finally....

The following extract from a recent speech by Prime Minister Gordon Brown perhaps offers hope that carers, and organisations supporting carers, will be given greater priority during Mr Brown's time in office:

"Nobody understands ..(carers' needs).. better than the organisations in the voluntary and community sector who support carers and the cared for, and advocate for them. I believe that the thinking that will be of best help for carers and those cared for will draw upon the ideas, the views and the values of ... carers themselves ... in future, working in partnership must mean not only listening and learning but involving and engaging carers themselves in the solutions we need".

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