



SEDIG News

Spring 2007

Please send to all interested in Scottish Eating Disorders news..

ISSUE 4

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'Delivering for Mental Health' – eating disorders representation?

Following the publication in Dec 06 of Scottish Executive 'Delivering for Mental Health', the new Mental Health Delivery and Services Unit is being established under Alex McMahon, assisted by Philip Harley and a team of policy and professional advisors, taking the lead in implementing the report, monitoring progress and taking responsibility for child and adolescent mental health as well as the State Hospital.

'Work has already started on many of the commitments and support elements within the plan,' writes Alex McMahon. Part of this work is the development of peer support workers, an example of expert patients – trained staff who have had direct experience of mental illnesses themselves and are part of the care team; the first peer support workers will be employed in 3 Board areas in 2008.

To help introduce this important new concept and take forward the commitment, each NHS Board area is invited to send up to 6 people from a variety of backgrounds including users and carers to the first-ever 'Peer Support Worker Conference' in Edinburgh on 8th February 07.

With ED representation lacking in the past at planning conferences and organisational level, it is important that individual professionals and volunteers try to ensure that the needs of people with eating disorders in future are recognised by Health authorities. *How many representatives from your area will be there on 8th February to highlight their views and concerns known about Scottish ED services and resources?*

Contact Helen.Sandilands@scotland.gsi.gov.uk for more information.

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Scottish ED Training plans under way...

Following the success of the recent Aberdeen November conference 'Eating Disorders for Non-Specialists', with delegates enthusiastic about making this an annual event, Drs Harry Millar and Jane Morris have initiated discussions about Scottish training in eating disorderslook forward to hearing more information on 22nd October at SEDIG.

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Working Together towards more effective 24 hour care

'To call anorexia nervosa an eating disorder is like calling cancer a cough.' Professor Arthur Crisp 2000

Professionals and families working together...surely not?! Using scripted

"Families are the cause, not the solution – Minuchin said so."

"No-one will tell me what to do – how do I know what to do?"

"We haven't got a family therapist so we can't work with families."

"The stress of this is affecting our marriage, our whole family – we all need help."

"They might complain to the press – best avoid them."

"Families are terrible things – I know, I have one myself."

Full article by Dr Jane Morris and Gráinne Smith is attached, or view on www.sedig.members.beeb.net

monologue - involving a wincingly recognisable caricature of an angry parent, plus brave volunteer 'carers' waiting with hope to meet an unknown professional - and group discussion, reasons for the frequent lack of constructive communication were explored at the SEDIG October 06 meeting as well as the benefits of such co-operation.

With some members wearing 2 hats – former sufferer/current professional, for instance – and a mix of professionals, carers and former sufferers, discussion was open and wide-ranging. Morning discussions featured a few large groups, each containing only professionals or only families, encouraging free expression of difficulties of working with the 'other' side – airing grievances and frustrations, stating some fundamental beliefs, riding our hobbyhorses and identifying particular flashpoints and bugbears. After lunch, to allow as much variety of attitude and opinion as possible as well as the traditional SEDIG opportunity for 'networking', groups were smaller and more mixed.

Key issues included –

Separation/individuation – yes, but when is the appropriate time and to whom should you entrust your sick and misguided child?

Expectations and need for exchange of information

Issues of confidentiality – a patient's right to confidentiality...and their right to lie?

High levels of emotion – and how to help carers cope

Motivation issues- how can carers help?

Abuse concerns – what is abuse? Is it what anorexia feels is abusive, or what a healthy person would consider abusive?

During the day, through discussion and brainstorming the following questions were explored -

What problems arise most often between professionals and families?

Why would professionals not want to work with families?

Why don't patients want their therapists and families to work closely together?

So why DO most families ask to work more closely with professionals?

Why do some professionals want to work with patients' families?

What do families need to provide effective 24 hour best care (often over years)?

- and afterwards the presenters collaborated to present a practical document outlining the answers delegates suggested, plus some useful reading and ideas, including...

Areas affected in family life by anorexia nervosa/binge purge type

What, for families, are the most difficult aspects of living with anorexia and/or bulimia?

What information can professionals give home carers without breaking confidentiality? And how?

Helpful 'openers' for professionals working with families.

What information do professionals need?

Carer Power

References and resources

The full article written by Dr Jane Morris and Gráinne Smith is attached with this SEDIG News, and can also be downloaded from SEDIG website at www.sedig.members.beeb.net

New Era for SEDIG –

Discussion of committee proposals on SEDIG subscription fees will be discussed on 22nd March, when members will have the opportunity to give their views.

‘Email – Blessing or Bugbear?’ will also be under discussion... members are asked to bring along any ideas to lighten the load.

**See Editor’s notes below.*

Since Scottish Eating Disorders Interest Group was started in 1993, it has operated on a shoestring and much goodwill. While the goodwill continues, it is becoming increasingly difficult to stretch the shoestring far enough....

Since publication in 2005 of SE Health Committee recommendations on services for people affected by eating disorders, followed very recently by detailed QIS Guidelines, SEDIG members have been aware of much increased public awareness of eating disorders and associated problems for families as well as individuals directly affected.

In November 06, SEDIG committee discussed how best to support developments needed to meet all the recommendations in QIS (as well as NICE Guidelines and the AED International Patient/Carer Charter). To allow SEDIG to play a full part in developing the training programmes necessary to meet these new challenges, the committee recognize that it is no longer possible to offer members resources through current SEDIG finance arrangements.

It is therefore proposed that SEDIG subscription fees should be increased to a more realistic level, in line with those of other similar professional organizations. Discussion of these proposals will take place during the SEDIG conference on October 22nd 07, when members will be invited to give their views.

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News from near and far –

Mark Reilly of beat (formerly EDA) talks about the organisation’s recent change of name and image...

‘I’m writing this hoping that SEDIG members will be have already heard or read about the new organisational name and the campaign starting during February’s Eating Disorders Week - “Making a change”. We’ve not only changed our name but were also hoping for a broad change in the way that the media, the government and in the way the general public view eating disorders.

The key message is actively promoting the fact that with the right help and support, eating disorders can be beaten - a bold statement with a very positive message which embraces and promotes recovery in a world where the media often focus on the negatives, pro-anorexic websites amongst others.

Our new name **beat** is a manifesto, a call to action and a message of hope. Nobody should have to hide their eating disorder because of the stigma and shame they feel. Eating disorders are not about magazine headlines, they are not a fad or fashion accessory. With the help of individuals, SEDIG and other organizations, journalists and broadcasters will be challenged to present the truth about eating disorders. Eating disorders will be beaten when they are no longer sensationalised or trivialised. People need to have confidence in the healthcare system, and get the help and treatment they need.

beat recognises the great work already being done in Scotland. **beat** needs to campaign to improve services throughout the country and engage with government, supporting research and developing the professional skills of teachers, doctors, nurses and youth workers. Eating disorders will be beaten when the most effective treatments are available to everyone who needs them, wherever they live with knowledgeable professionals

No-one in Scotland should struggle with an eating disorder alone or in silence.'

Ideas for a ***Scottish Eating Disorders Carers Day***, possibly autumn 07, are under discussion, to offer information, practical workshops, sharing and support. Planning is in early stages - possibilities for venues and funding are being actively explored. Offers of active help welcome...please contact SEDIG News editor with your ideas for action....

confident and properly resourced to carry out their work. We want to change the way people think about eating disorders.

With the support of SEDIG members I feel that our changes could be an early step in changing the way that the greater public look at eating disorders. We should improve upon the help and treatment on offer to Scottish people. The petition to the Scottish government is a great example of how personal stories and positive action can affect decision making at governmental level. **beat** wants to be a part of supporting this work and making it commonplace.

It takes determination, courage and persistence to beat an eating disorder. **beat's** staff and volunteers are ready for the challenge.

We already have an army of supporters in Scotland who are well placed to help -

- Our SEDIG colleagues who support positive change and work to make things better
- The professionals in the NHS and private sectors who support the work of our organisation (and particularly the work of the self help network), committed to helping sufferers and their carers.
- The contacts we have made in the media who are helping raise public understanding and who report issues sensitively.
- And finally close to my own heart - **beat's** own self help network volunteers, who selflessly share their knowledge and experiences through groups, telephone, postal and e-mail support in Scotland. We need more of these committed people who are "experts by experience".

No-one in Scotland should struggle with an eating disorder alone or in silence. Together, we are beating eating disorders. I feel confident that **beat** and its message can help us all bring some positive change to Scotland – that eating disorders can be beaten.

Au revoir... Mark Reilly has been EDA (now **beat**) representative to SEDIG for several years – thank you Mark for your personal contributions at meetings, you'll be missed!

..and welcome in October to Emma Healey who will take over as **beat's** new representative in Scotland.

AED Patient/Carer Charter – service audit and evaluation tool

Susan Ringwood of beat (formerly EDA) reports –

'EDA has been approached by a leading eating disorders service in London to conduct an audit of their provision from a patient and carer perspective. They will be using the AED Patient/Carer Charter as a framework for this audit, and hope to produce a model that can be used by other services across the UK'

And from Ulrike Schmidt, Maudsley –

'Tatjana Koch, a medic from Chile, working on MSc in Mental Health at

'To allow SEDIG to play a full part in developing the training programmes necessary to meet these new challenges, it is recognised that SEDIG subscription fees will have to reach more realistic levels.'

Email – blessing or bugbear?

Without email, and websites, the AED international consultation and Patient/Carer Charter would not have been possible. And the work of many organisations including SEDIG, EDA and beat would be much more limited.

London 's Maudsley Hospital, is carrying out qualitative analysis of data from the huge Academy for Eating Disorders' email survey into services for eating disorders worldwide which yielded thousands of responses and led to the development of the AED International Patient/Carer Charter. Ms Koch will be supported by senior qualitative researcher Joanna Murray.'

Editor's notes – Email, blessing or blight?

Try to be brief -
email's the thief
of time.

Recently email was under discussion by SEDIG committee members....Long long ago – 10 years - when I gave up my job, email was not part of my life; mobile phones were brick size. Now, email and mobile phones raise expectations, make constant demands, need constant decisions often fitted into a hectic working day.

Blessing?

Without email, SEDIG communication would be limited to phone and snail-mail letters; AED professional/patient/carers survey could not have been conducted worldwide, nor developed into an international charter by a small taskforce working in countries thousands of miles apart, nor been translated into many languages, signed and adopted by so many... Without email, few groups/organisations today would be able to operate effectively.

For those living at a distance, contact with other members of a group can ease feelings of isolation. Ideas may be shared and discussed; it's possible to check with others before taking action; arrangements may be easily confirmed.

There is however, as so often with good ideas, a price....

Bugbear?

Meetings may be cancelled at short notice. A large number of bankers, having left homes all across Scotland very early to reach a 9 a.m. start, gathered in a grand hotel on a Monday for several days' trainingonly to find that the main speaker and trainer had emailed the organiser's secretary on the preceding Friday to inform that his wife had been taken very ill and he therefore couldn't deliver the course. The secretary had taken that Friday on holiday; and no-one checked her emails.

Different approaches, styles and expectations can cause problems. Writing styles vary with individuals. A texting style? – 'gr8, c u at 5 in SPO, bring f with u'. Or a fuller letter style, exploring ideas and seeking suggestions? Headings and endings? 'Dear' and finishing 'All the best' or a variation – or not?

For some, text style seems brusque/rude; lack of headings/endings also. For some, a letter style may greatly irritate – explanations, questions, take extra time to read, may not seem relevant at that moment.

And decisions - to send to an individual or the whole group, reply to an individual or all in group, to respond at all? - or not?

Comments, articles and ideas for SEDIG News welcome!

SEDIG conference dates for your diary – see website

Assumptions that because message sent it's been received - overenthusiastic internet anti-virus guards sometimes delete legit items, especially attachments; deliveries may be delayed for various reasons; people may be ill, on holiday, may have left early.

Lack of editing, differing vocabulary and language styles can easily lead to unfortunate misunderstandings.

Growing volume of e-mail in a techno world e.g. message re car lights left on in the car park outside someone's office.

Very different personal time constraints, needs and priorities...

Differing personal needs for information etc

Feelings of exclusion/isolation/uncertainty especially when no dept, no big organisation; no immediate colleagues; distance, travel and finance constraints; few opportunities for face-to-face discussions – (this is the situation of some professionals/most volunteers).

Feelings of much frustration all round!

What might help?

Brainstorming/Discussion? = Agreed-practice guideline within an organisation, especially useful for newcomers or inexperienced members.

In the meantime, as often as possible, perhaps adopt the newly-minted motto at the beginning of this item? (I too have been guilty of asking questions, exploring ideas, seeking confirmations, using too many words...)

Coming events

'Eating Disorders 2007 – a three day practical conference and exhibition'

– Imperial College, London 29 - 31 March 07

Tel 01722 716007

Email – ED2007@markallengroup.com

Late news item – Michelle Conway, postgraduate student at Edinburgh University and SEDIG member is undertaking a Ph D into the value of psychotherapy in the recovery process in anorexia. Michelle has discussed her research plans with Dr Jane Morris, and hopes that SEDIG members may be able to help recruit participants to take part. For more information about this interesting and valuable research, please contact Michelle on 07729132190, or at michelle.conway@fshc.co.uk

	
	