

Scottish Eating Disorder Interest Group Newsletter

September 2003

Attached to this issue of the newsletter is a conference application form for the next meeting (Thursday 30th Oct) which continues the theme for 2003 entitled "Self Expression through the Arts", based on Eating Disorders and Creative Therapies. The day will begin with coffee and registration 10 – 10.30am. Then, subject to change, Chris Achenbach has agreed to return, by popular demand, to conduct an experiential music therapy workshop in the morning, followed by the SEDIG business meeting and lunch 12.45 – 1.30pm. Professor John McLeod, University of Abertay, will present Narrative Therapy and Eating Disorders in the afternoon.

4pm close.

Please note that those who are due membership fees shall receive a separate reminder with their newsletter.

Many thanks,

Heather Marrison
Secretary

New Chair – Welcome!

Following previous announcements regarding her intention to resign, Chairperson, Maggie Gray, set delegates the task of nominating a new candidate during the March 2003 conference. After persuasion, Ian MacDonald, a carer and retired Psychologist, volunteered and was elected to take over from Maggie in 2004. SEDIG wishes to thank Ian and to welcome him onto the committee. Ian and Maggie will be chairing the October meeting together.

Donation to Chrissie Wright's Campaign

Members decided that SEDIG should donate £ 200 towards Chrissie Wright's campaign to raise funds in support of research into eating disorders. Chrissie has expressed her gratitude and has kindly written an article describing her fundraising cycle across Chile (page 4).

Awareness Week Update 2nd - 8th January 2003

Eating Disorders Awareness Week inspired a number of events across the country, many of which were attended and/or organised by SEDIG members, as reflected in the following reports.

Member, Hazel Cooper, reported on the Grampian teams Service Awareness Day held in Aberdeen. The day, aimed at GP's, with roughly 60 attending in the morning and 50 in the afternoon, included an introductory presentation on eating disorders from Dr Harry Millar, followed by three brief presentations on self-help from Gràinne Smith, Margaret Reid and Heather Marrison. Guests were also invited to try out Chris William's CBT CD ROM, experience therapy via tele-conferencing, browse through recommended literature and sample Grampian's new eating disorders website accessible on the intra-net.

Maggie also reported on the success of the Cullen Centre's open day, which attracted over 70 visitors and numerous enquiries from sufferers, carers and professionals alike.

EDA representative, Mark Reilly, informed SEDIG that Eating Disorders Awareness Week received national media coverage including airtime on Radio One.

NEEDS/SEDIG Petition

Gràinne Smith has thanked members for adding their names to the NEEDS/SEDIG petition calling for improvement in the provision of eating disorders services across Scotland. The petition has since been presented to the Public Petitions Committee (see “The Spirit of Jenny Geddes” article, below)

National Eating Disorders Group

Dr Chris Freeman informed SEDIG of plans to form a national society for professionals working within the area of eating disorders. The group, to be hosted by the EDA, will represent a multi-disciplinary forum for the exchange of ideas, offering meetings, training courses and communication with similar societies abroad. SEDIG intends to find out more.

New Eating Disorders Service

Glasgow’s Gartnavel Royal Hospital has recently become host to a new adolescent outpatient service. Launched earlier this year, the Parry-Jones Service, headed by Dr Jane Morris, aims to offer treatment and support for young people with severe eating disorders (report on page 3).

The Spirit of Jenny Geddes Returns to Edinburgh

On the bright and sunny morning of Tuesday 25th March 2003, three women met on the steps of the Waverley train station. A slight tension filled the air, but each had arrived with a purpose. One of the group, Grainne Smith had, for some time, been involved in putting together a petition, highlighting the lamentable lack of eating disorder services for individuals living in Scotland. The aim of the day was to present our petition to the Public Petitions Committee at the Scottish Parliament on behalf of SEDIG and NEEDS.

They began their short journey along the Royal Mile, heading towards George IV Bridge. The conversation was filled with humour and expectancy, but each member of the group carried within them the hope of being able to fulfil their role in the day. SEDIG Committee Member, Gràinne, headed the group representing NEEDS and the carer involvement. As a recovered sufferer, Heather Marrison, Secretary of SEDIG, was there representing individuals with eating disorders, and Dee Affleck SEDIG Member and Cullen Centre therapist, a late but willing recruit, represented health care professionals.

On arrival at the parliament building, the late, but willing member (Dee) found herself reflecting on historic matters, in an attempt to overcome feelings of ever increasing anxiety, triggered when the group discovered that they had centre stage. Indeed, not only were they centre stage, but their images were being projected on to television screens behind them as they put forward their case – a German Delegation occupying most of the public row behind. Faces, some familiar, some unfamiliar leapt out from the Petitions Committee Panel, Helen Eadie, Winnie Ewing to name but a few.

And so, in order to cope with this unexpected degree of attention, the late, but willing member (Dee), began to find other sources from which she could draw strength. Thoughts drifted to Robert Burns’ account of Jenny Geddes, a woman who had lived some 150 years before him. It would seem Burns had much admired Jenny as he named the horse, which had carried him on his tour of the borders, after her, describing the animal as stubborn but dependable.

By all accounts, it would appear that Jenny was an outspoken woman, campaigning for freedom of worship during the reign of Charles I. Not only did she throw a wooden stool, from her market stall, directly at Bishop Lindsey,

but also landed herself in more hot water during the reformation by setting light to the aforesaid market stall outside St Giles Cathedral. This final act of defiance was to result in Jenny being imprisoned in the tollbooth.

Thus, calling on Jenny's spirit, the team presented the petition. Gràinne provided the committee with an eloquent account of our mission, and Heather gave an equally eloquent account based on her own experience of living with, and overcoming, an eating disorder.

I don't know what happened to Jenny Geddes following her imprisonment in the tollbooth but, fortunately, the team escaped imprisonment, the petition was well received and we hope the voice of NEEDS and SEDIG was heard.

Dee Affleck

Launch of the Parry-Jones Service For Young People with Severe Eating Disorders

On Friday 28th March 2003, we launched the Parry-Jones service at the Winter Gardens in the Peoples' Palace Glasgow, with starry helium balloons, stalls and exhibitions, speeches and even the shedding of a few tears. The country was still preoccupied by war in Iraq, but people were thirsty for some good news, and we were featured on radio and TV six times that day, and appeared in the papers. When we were stopped in the street by folk asking 'didn't I see you on the telly?' I realised how publicly we have taken the responsibility to deliver something good, and what's more, we've hitched ourselves to a great name.

We held discussions with our patients before naming the service. They couldn't see themselves bragging that they were hanging out at 'the Adolescent Anorexia Clinic' but thought they could live with 'the Parry-Jones'. William Llewellyn Parry-Jones was Professor of Child & Adolescent Psychiatry in Glasgow until

his untimely death in 1997. He was passionate about teamwork; he helped young people from Lockerbie and Eastern Europe through traumas, and together with his wife Brenda, an archivist and historian, produced scholarly papers on the history of eating disorders. Brenda Parry-Jones was unable to travel up from Wales for the launch, but we look forward to inviting her up to see the fruits of a whole term's work, in our stylishly refurbished hut. At the Winter Gardens Dr Heather Gardiner spoke movingly of the Parry-Jones's energy and warmth. She quoted a teenage patient who told her 'the professor was a really cool guy'. Bill's secretary, our guest at the launch, was moved to tears.

Some other visitors at the launch included Pam from the Eating Disorders Association, a couple of wandering Goths (who signed up as EDA pen-friends), toddlers attracted by the balloons, old folk in wheelchairs, the next chairman of SEDIG and his wife, the Child-line lady, management, consultants from other services, and our own nurses hot from their shifts. Anne and her son-in-law spoke from the heart of their experience of losing a beloved wife and daughter to anorexia, and of the launch of their own carers' support group in Fife.

We admired our patients' art work and poems on the poster boards, alongside displays of the pilot study results, the specially designed workbook, and Lisa Ronald's review of research into evidence-based treatments for eating disorders. The day was far more than a publicity exercise: it was an opportunity to make links with many helpers and beneficiaries of the service and to feel the palpable goodwill and energy sustaining us and knitting us into the web of support for people with eating disorders and their families.

We are delighted to offer the first service of its kind in Scotland: a really joined-up

service, allowing teenagers with severe eating disorders a chance to receive intensive therapy on a day-patient or frequent out-patient basis without necessarily having to stay in hospital. If admission is unavoidable, it can be brief, and part of a seamless progression from maximum support through to greater independence and self-motivated care. Patients can also access the P-J programme from the in-patient unit, and use it to 'wean' themselves gradually back to being a part-time day-patient. We nurture links with community teams too, and with school guidance teachers, in order to facilitate and support patients' return to local care. Above all, we integrate relatives and carers into our service. This group of people suffer not only the strain of living with someone seriously ill, but often develop an assumed guilt, and sometimes a desperation that can prove to be counterproductive.

A few days after our launch we heard that the original financial arrangements had been frozen, because of serious deficits in the Trust. We resolved to make the best possible use of available resources to provide a high quality service. So far this has involved prioritising intensive treatments for a smaller number of patients, while offering consultation and training opportunities to a large number of professionals in the West of Scotland. We're particularly proud of progress in the Unit eating disorders programme, as a result of joint consultation, drawing up of guidelines, and a term's regular training days. We've been fortunate too in finding some creative ways to expand opportunities on a shoestring budget. One counsellor in a School Guidance Department saw the publicity surrounding our Launch and offered her services to P-J as a volunteer. She works with our Relatives' Groups and has given an acclaimed 'listening skills' workshop which we opened to all parents. We also cherish a research link with Dr Chris Williams, who pioneers computerized

self-help - a medium beloved of computer-literate adolescents. We are assured that finances will be restored after a year, so that if the Service survives, consolidation and even expansion may then be possible.

After a term's formal programme, and a host of less structured 'holiday' activities, detailed audit has shown us that patients and families have definitely benefited. Spontaneous comments and letters to us have been enormously encouraging, and criticisms have led to some modifications and developments in the design of the next block of groups. The first term's timetable included groups on motivation, self-esteem, assertiveness, body image, nutritional and medical education, a creative therapies group and a relatives' and carers' group, as well as our own staff supervision time. Supported mealtimes and snacks have become a crucial part of therapy too. Assertive outreach and crisis visits to patients in their homes have been particularly appreciated, and joint work with therapists in the community is developing creatively. We plan to repeat most of our programme for a new 'starter' group in the autumn, with the addition of a CBT skills morning for 'graduates' and older teenagers. We've learned too, that we need to pay enormous attention to the difficult transition of 18 year olds into adult services if our service is to be truly integrated. Things haven't been all roses, and the word 'shambles' has become prominent in my vocabulary, but I have heard a lot of laughter from the group room, and I can't forget the anonymous comment on a relative's questionnaire: 'Thank heaven for Parry-Jones!'

Jane Morris

Chile Sponsored Cycle In Aid Of Research into Eating Disorders (REID)

I returned from my second sponsored cycle in March, and have decided the experience was much like giving birth – at the time you feel you will never go

through such hell again, but then time heals and wow, you realise what an experience it was!

We left for Santiago fifty-five strong, and after eight days cycling, covering approximately 600kms across central Chile, we ended up in Peurta Varas, a small lakeside town. Our journey took us through monkey puzzle forests (a tree native to Chile), vast farmlands with herds of dairy cows, reminding us of home, and along scenic lakeside tourist areas. Our cycle was set against a stunning and continuous backdrop filled with snow-capped volcanoes frequently puffing out smoke from their tops, towering above the Andes to the height of 19,680 ft in places. These views kept us going over some of the longest inclines, known as “nippy little hills” by a few of our Argentinean guides! Although wonderful to look at, the volcanic lava, spat out over the years, was not so good to bike over. Our route was 90% off road and has been described as a “bone shaking, muscle thrashing experience”. In fact, the day we spent crossing, what could only be depicted as a lunar like landscape of solid lava intermittent with sandy stretches, was, for most of us, a day of horror – at least, it was certainly mine. After 11 hours on this particular road, I think I’d have slept on a bed of nails!

Despite various bandaged limbs (which, I suspect had more to do with the fact that our Argentinean doctor resembled Richard Gere, than with genuine injury), we all completed the course, including two sprightly OAP cyclists. Although the route had never been cycled before and was certainly tougher than expected, the wonderful camaraderie kept everyone going, and the weather was kind, with temperatures well into the 80’s.

Although we covered only a minute portion of this extraordinary and varied country, stretching from the Atacama Desert, the driest desert in the world, to Patagonia in the South, we were able to

witness a vast diversity of peoples. Here, Mauchape Indians (with very distinct features) and Swiss, German and Austrian settlers, all treated our strange band of cyclists with equal measures of friendliness and hospitality.

Purely to illustrate why I was determined to complete this challenge, I will confess that a slight hiccup occurred in my training, when a malignant tumour was found on my kidney. As a result, many people wrote off my chances of taking part in the cycle, but after swift treatment, the blessing of my consultant, and following subsequent meetings with the G.P. who was accompanying us, I left as planned. I’m aware that I’ve been very fortunate and in no way wish to belittle the horrors of cancer, however, I hardly need point out to members of SEDIG that, had I been diagnosed with anorexia, bulimia or some other eating disorder, I’d still be waiting to catch sight of a specialist let alone commencing treatment. This fact strengthened my resolve to continue raising the profile of these awful illnesses.

Lastly, I would like to take this opportunity to thank SEDIG members for their generosity in supporting me throughout my endeavours. The support I have received has meant a great deal to me and I’m pleased to report that I’ve reached £13,000, almost the same amount raised from my previous Vietnam venture, bringing my overall contribution to over £26,000. It sounds a lot to me however, all credit must go to everyone who has supported me and to Nina Jackson our organiser who, through her single-handed, meticulous planning has now handed over more than £352,000 to research into eating disorders (REID), a programme headed by Professor Janet Treasure.

Chrissie Wright

N.B. Personal reflections of the March 2003 conference will be included in the next edition!

Themes and Dates For 2004

Next year's theme centres on the physical consequences of eating disorders when combined with exercise.

Dates are as follows:

Thursday 11th March 2004

Thursday 7th October 2004

Also, please visit the SEDIG web site:

www.sedig.members.beeb.net

emailing any suggestions you may have regarding future themes and topics, ideas for workshops/presentations, or anything else you would like to see covered.

Conference application form overleaf.