



# March 2010

## Give us a Break

A few months ago, we talked about the Short Breaks programme that is available in Midlothian and EUF members thought it would be a good idea to have the same kind of scheme in Edinburgh.

In Midlothian, there is a fund managed by the Council that allows service users to get money towards a trip or a stay in a respite centre such as Cairdeas House in Edinburgh. It allows people who cannot afford a holiday to get away from home for a few days.

Service users in Midlothian have benefited from short breaks on their own or as a group and have also benefited from organising the trips.

The objective of the project is to support and promote recovery and allows service users and their carers to decide for themselves what kind of break they would benefit from.

EUF talked to John Armstrong, Joint Programme Manager for mental health, about the project and asked if it could be started in Edinburgh. He explained that at the moment there is no money available for a Short Breaks project. Resources would have to come from existing services stopping.

Although we do not know when funding would be available, we think it is important to look now at how we think the project could work, how to assess people who apply and how to make sure people get the most out of the project.

If money became available, we would then be ready to present our ideas and show the need for a Short Breaks scheme in Edinburgh.

Join us at the next EUF meeting and give us your views to help us present a proposal to the Council and give ourselves the best chance to benefit from short breaks in Edinburgh.

For more information, contact Laëtitia at CAPS on 0131 538 7177 or email [laetitia@capsadvocacy.org](mailto:laetitia@capsadvocacy.org).

### Our Next Meeting:

**Saturday 6 March 2010**

1.30pm - doors open

2.00 - 4.00pm - meeting

McDonald Road Library, Edinburgh

For more information contact CAPS  
on 0131 538 7177.

# Hot Topics

## ECT Network

The Scottish Electro-Convulsive Therapy Accreditation Network (SEAN) are setting up a Service User Reference Group in order to improve and develop the project.

Doctor Grace Fergusson (SEAN Clinical Lead) is looking for representatives from organisations such as EUF to be involved with this group.

It would be beneficial if the people involved had experience of ECT directly or indirectly and there should be a maximum of two individuals from each organisation.

The first meeting will be to establish the structure and aims of the group. Dr James Hendry, (Consultant Psychiatrist) one of the original founders of SEAN will chair this group. Travel expenses will be covered for individuals attending.

The first meeting will be on Wednesday 3 March from 10.30 to 12pm at the Information Services Division, Gyle Square, Edinburgh.

If you are interested in joining this group, please contact Laëtitia at CAPS as soon as possible on 0131 538 7177 or email [laetitia@capsadvocacy.org](mailto:laetitia@capsadvocacy.org).

## April Meeting

Please note that because of the Easter weekend falling on the first weekend of April, the EUF April meeting will take place on the second Saturday of the month (10 April 2010).

## Acute Care Review

In the last three years, there have been a lot of changes in acute psychiatric care in the whole of the Lothian. Midlothian and East Lothian beds have been moved to the Hermitage ward at the Royal Edinburgh Hospital. The Intensive Home Treatment Team (IHTT) has been introduced to look after people in the community.

Also a ward at the Royal Edinburgh Hospital closed, the number of beds was reduced and the model of care is being reviewed.

The review of the services in the hospital and the community is important to make sure that all the services work well together. With the development of the IHTT, people who are ill are more and more being looked after in the community and can therefore stay at home. To make sure the person is safe and can benefit from home treatment, all the psychiatry services have to work closely together.

At the moment there are four wards with 25 beds each and a mixture of people from different areas. The review will be looking at changing how the wards are organised and have five wards with less beds each.

One recommendation is to have a ward with only East Lothian and Midlothian people (at the moment there are also people from Edinburgh on that ward), two wards for South Edinburgh and two wards for North Edinburgh. The services could then more easily work with the different IHTT teams and Community Mental Health Teams.

## Newsletter Questionnaire

Another change for the wards would be the possibility of single sex wards. The review says that it could help to reduce bed numbers on the wards and help have more single rooms. Current UK standards specify wards should have single en-suite facilities but at the same time they should ensure safety, privacy and dignity for all patients. This means it would be necessary to develop specific wards that can be separated according to sex and level of need. Would you prefer single sex wards? Do you think single rooms are important?

The review is also looking at changing the areas covered by community mental health teams because the teams in the North and the South of Edinburgh don't have equal populations. At the moment there are five community mental health teams, three in the South and two in the North. The idea is to have instead one team for the North and one for the South and change the boundaries they cover to make it more equitable.

The way consultants work could also be aligned with the North and South division instead of being linked to the catchment areas of GPs. Again this is to try and maximise the time consultants have and help all services align with each other.

This review has been ongoing and fits in with the review of other services such as IHTT. It also fits with the re-provisioning of the Royal Edinburgh Hospital. As a new hospital will be designed, it is a good time to look at acute services in the hospital can be reorganised.

If you want to give your views on this review and if you want to read the full review papers, please contact Laëtitia at CAPS on 0131 538 7177 or email [laetitia@capsadvocacy.org](mailto:laetitia@capsadvocacy.org).

In October 2009 we sent out a questionnaire and asked people to tell us what they thought of the EUF newsletter.

Over fifty people filled in the questionnaire and gave their views. Most of these people were service users, but some staff and carers returned questionnaires as well.

Most people told us that they find the newsletter very useful and easy to understand. Some people wanted to receive the newsletter in a different format such as PDF by email, so we have made sure this happens.

A number of people who responded also told us that they find the newsletter a good way of keeping up to date with what is happening in mental health services locally. Only about half of the people who sent back the questionnaire said that they are actively involved in campaigning or going to meetings, so it useful to be kept up to date on what is happening in mental health services.

Some people suggested that it would be good to have more variety in the newsletter, such as colour. At the moment we are not able to print the newsletter in colour, but we would welcome suggestions about how to make the newsletter more interesting and relevant.

If you have any comments or suggestions about the EUF newsletter please contact us, as your feedback is important for us to give you the best information possible.

## Mental Health and the Internet

The Scottish Development Centre for Mental Health is doing a brief survey for people with close personal experience of mental ill health about how people with lived experience use the web in relation to mental health.

The survey results will be used to inform a conference on Mental Health and the Internet, and may also be used for media work around the event. No personal data will be recorded, so responses are entirely anonymous.

The survey should take 5-10 minutes to complete, and is available at:

[www.surveymonkey.com/s/mhandthenet](http://www.surveymonkey.com/s/mhandthenet)

## IMPROVING DETENTION

### WE NEED YOUR STORIES

We have enclosed with this newsletter a questionnaire about the experience of detention and the use of safeguards such as Advanced Statement and Named Persons.

EUf wants to campaign to improve the experience of detention. We need your stories and your views so that we can write a report and present it to NHS Lothian.

Please use our Freepost address to return it. If you need help filling it in or if you prefer to get it by email, please contact Laëtitia or Naomi at CAPS on 0131 538 7177 or email [laetitia@capsadvocacy.org](mailto:laetitia@capsadvocacy.org)

## Tender update

The City of Edinburgh Council has dropped the entire Care and Support Tendering process after a review of the process by an independent company.

The council has also agreed to meet with service users and representatives to discuss a fair rate for Direct Payments and negotiate with service providers to save money.

Jenny Dawe, the leader of the Council, also apologised for the upset and distress that has been caused by this process and committed to a proper consultation with service users about things which affect them.

If the Council decides to do something like this again, service users will be involved from the very beginning. Very soon the Council is going to meet with service users, service providers and advocacy organisations and groups to talk about Direct Payments.

EUf and CAPS will be asking service users to give their views as they want to make sure that mental health service users are represented properly in these meetings.

If you have applied for Direct Payments you now have time to consider whether this is the best option for you and if you want to go ahead with your application.

Please don't hesitate to contact us if you have any questions or if you would like more information. We have booklets from the Mental Health Foundation about Self Directed Support and Direct Payments which we can send out. To get one, contact Naomi at CAPS on 0131 538 7177 or email [naomi@capsadvocacy.org](mailto:naomi@capsadvocacy.org).

# At our last meeting.....

## Advocacy review

We had an update on the advocacy review. Keith reminded people that the City of Edinburgh Council is hoping to cut £100,000 from the money they give to advocacy projects. £25,000 has to be cut in this financial year (2009-10), and then a further £75,000 next year and £100,000 a year from then on.

A number of different models for advocacy services have been suggested by the Council. The advocacy organisations do not believe that some of these are going to result in better services.

NHS Lothian have also now got involved in the review as they provide money for some advocacy services.

A plan of how these savings can be made will go to the Council's Health, Social Care and Housing Committee in May.

Cuts of this kind are being made across a lot of Council funded services at the moment. Decisions are being made very quickly, too quickly for people to be meaningfully involved.

There have been 'consultations' with service users. It is important that the record of what has been said is checked with service user groups before they are interpreted and used to decide what will be the best way to provide services. EUF will write to repeat the points they felt were important.

We will keep you updated on what is happening next.

## Evaluation of the Crisis Centre

The evaluation report will be published at the end of March. Infusion, the organisation that has been doing this have had problems hearing from service users.

People who have used the centre, as well as people who have been turned away, have been reluctant to talk about their experiences. We need service users to give their views on the service so that it can be protected and improved.

If you would like to fill in a questionnaire or talk to us about your experience of the Crisis Centre, please contact Laëtitia at CAPS on 0131 538 7177 or email [laetitia@capsadvocacy.org](mailto:laetitia@capsadvocacy.org).

## Detention and Safeguards Group

A Detention and Safeguards group was created to look at people's experiences of detention and how it can be improved.

The group has met a few times already and has identified things that need to be improved such as the use of Advance Statements and Named Persons, the availability of advocacy in the evening and at weekends so that people can access an advocate at any time if they are detained. We also talked about the importance of training for all staff involved in detention such

as police officers or wardens in housing schemes.

The group thinks that it is important to be aware of policies in place and to look in a positive way at what is realistic so that we can produce a good report and present it to the NHS.

The group has written a questionnaire to get people's views. Getting people's experiences of detention is very important and a powerful way to show what needs to change.

We would like to use this questionnaire to write our report and give evidence of how people feel about detention at the moment. We also want to see why people don't use Advance Statements and Named Persons a lot so that we can make recommendations on how to improve the system.

For example some people don't know at all about it and others feel they need help to write it but don't know where to go to get this help.

Somebody felt that an advocate had not clearly explained to them what an Advance Statement was. The advocate had written an Advance Statement for the service user, word for word rather than sitting down with them and writing one that explained more clearly what the intentions of the service user were.

Someone said they thought WRAP can also be useful for writing down things that do help and things that don't.

A questionnaire is enclosed with this mailing and you can return it to our freepost address. If you need help filling it in or if you prefer to get it by email, please contact Laëticia or Naomi at CAPS on 0131 538 7177.

## Before it's a crisis...

Here is a short list of phone numbers you can contact for support when most services are closed. It is a good idea to have these numbers and others where you can find them when you need support or help. Services such as Breathing Space and the Samaritans offer a listening service. Social Work and the NHS are more appropriate if you need more than this.

### Breathing Space

0800 83 85 87 (6.00pm-2.00am)

### Samaritans

08457 90 90 90 (24 hours)

### NHS 24

08454 24 24 24 (24 hours)

### Emergency Social Work Service

0800 731 6969 (out of hours only)

### Crisis Centre

Free phone 0808 801 0414 (24 hours)

Text phone 0808 801 0415 (24 hours)

If you get support at home, you may have an 'on-call' number to contact staff. If you have contact with a Community Mental Health Team, they may also have a number for you to contact staff.

If you require individual advocacy you may contact:

**Advocard** 0131 554 5307

(Monday to Friday 9-5pm)

### Hospital Advocacy Service

0131 537 6004

# Community Happenings

## Documentary on Schizophrenia

Johanna Wagner is a film student at Edinburgh College of Art. She is currently working on a documentary on schizophrenia.

Her aim is to do a portrait of one or more people who have experience of schizophrenia. The focus will be on how they are coping now, their past experiences and the help they received.

The purpose of the film is to try to understand the experience of living with the disorder. She is therefore looking for people to interview who would like to share their story with her. It is both for research purposes (to hear different stories and accounts to build up a picture) and also for the purpose of finding characters to portray in my film.

Johanna is a documentary filmmaker and all her previous films have been on the subject of mental illness. One of her previous films on mental health, "The Inner Shape", was shown in the Mental Health and Arts Film Festival in Edinburgh in October last year.

She is interested in trying to make a small contribution to the debate on mental illness. She feels that these subjects need to be discussed openly and every opportunity should be taken to enlighten people on mental illness.

If you want to know more about the project, Johanna can send you more details about the film. If you would like to help out in any way, please email or call Johanna on 07506957641 or email [jojobawagner@hotmail.com](mailto:jojobawagner@hotmail.com).

## See me wall

'see me' has just launched its new Wall of Support. You can see it at: [www.seemescotland.org/badge](http://www.seemescotland.org/badge).

'see me' has asked people to think of practical ways that can be used to support friends, colleagues or family members experiencing mental illness. The message is that no one has to do anything special – just be there and be yourself. Be the friend you always were!

As part of this campaign, 'see me' is asking people to design a 'see me' badge and write a message of support. People can also add a photo of themselves if they want to.

## Recovering at the Back of the Bus

Michael Rowe, a specialist on recovery in the Yale Department of Psychiatry, will be in Edinburgh to talk about 'Recovering at the Back of the Bus: US Mental Health Care after Deinstitutionalization'.

The talk, organised by the University of Edinburgh's Public Policy Network, will take place at 4pm on 8 Monday March in seminar room 3, Chrystal Macmillan Building, George Square, Edinburgh. There's no charge for coming, but please book your place by mailing Craig at [ppn@ed.ac.uk](mailto:ppn@ed.ac.uk) or call 0131 650 4680.

The meeting will also be used to create a mental health interest group run by the Network.

---

## About Edinburgh Users Forum

The Edinburgh Users Forum (EUF) is an independent collective advocacy group. Our members are people who use, or have used mental health services. We were set up to give people who use mental health services a say in the services that are provided, and how services are run.

We have monthly meetings where we discuss issues and invite speakers along. We campaign on issues like services, benefits, housing, advocacy, crisis services and transport. If you would like any more information about EUF please contact us.

---

### Contact us

Write to:  
Edinburgh Users Forum  
c/o CAPS  
5 Cadzow Place, Edinburgh  
EH7 5SN

Phone: 0131 538 7177  
Fax: 0131 538 7215

Email:  
[info@edinburghusersforum.org](mailto:info@edinburghusersforum.org)  
Or visit our website:  
[www.edinburghusersforum.org](http://www.edinburghusersforum.org)

### EUF Meetings 2010

**Saturday 6 February**

**Saturday 6 March**

**Saturday 10 April**

(Second Saturday of April because of  
Easter Weekend)

**Saturday 1 May**

**Saturday 5 June**

### Monthly meetings

On the first Saturday of each month we meet at the McDonald Road Library, Edinburgh (on the corner of McDonald Road and Leith Walk). Come along from

**1.30pm** for a cuppa and a chat.

Meeting starts at **2.00pm**.