

PATIENTS COUNCIL NEWSLETTER

March 2017

NEWS, VIEWS AND COMMENT FROM THE ROYAL EDINBURGH HOSPITAL

Patients Council Meeting – 30 January 2017 Guest speaker: Daniel Johnson, MSP

Daniel, our local MSP, favours increased funding and a more holistic approach to mental health, starting with mental health counsellors in every school and better training for teachers. Mental health deserves parity with physical health but treatment might be about finding ways to cope, such as self-help techniques, rather than having a fixed diagnosis. Daniel supports a focus on primary care, getting people the right help as early as possible, but spending has been cut in real terms in the last ten years. Society needs to reach a better understanding of how mental health works and support people to be treated at home. Open Dialogue, from Finland, addresses mental health in the societal setting but it needs political will to implement it. People can feel rejected by society when they leave hospital. Health and Social Care integration and local government need to be properly funded. The cabinet secretary should adopt mental health as a priority.

Local people see the Royal Edinburgh Hospital as part of the local community and welcome the long overdue redevelopment despite concerns about parking and the impact of future developments at the Astley Ainslie site.

We expressed concerns about the efficacy of psychiatry, the side effects of medication, losing control of your finances and changes the Scottish Government might make to benefits. Long-term hospital admission renders people homeless then they can get stuck in hospital due to the lack of suitable accommodation in the community.

Force and compulsion should be banned, consent to treatment should be mandatory – the system will work better if people are engaging with it rather than complying to avoid the threat of something worse happening to them. They should choose the treatment that works best for them.

We prefer the bio-psycho-social model to the medical model which gets funding from pharmaceutical companies. People can be forced to take medications which can cause physical damage. Could the government encourage health boards to fund more talking therapies? Nurses do now try to work with patients instead of doing things to them but talking therapies tend to be time-limited and expensive.

Medical students and GP's, often the first point of contact, need more training in mental health. Their workload can be overwhelming so primary care must be reorganised - for example, easier referral to mental health services. There should be a mental health specialist (not necessarily a doctor) in every GP practice. Social media should be used to inform people about available services such as the Mental Health Assessment Service.

Stories of Changing Lives Three

The Stories project is underway! I know some of you are already writing your stories, and I can't wait to read them. If you've spent time on a rehab ward, or had a longer stay on another ward, you're invited to contribute your story about your experiences with mental health too. You can write, draw, tell, paint, take photos, and/or be part of the Stories film.

Join us for a workshop (or two or three!) to get inspired – come along to try it out with no pressure to put anything in the book.

- **Creative writing:** Friday 31st March, The Library at the REH, 2-3pm
- **Storytelling:** Friday 7th April, The Library at the REH, 2-3pm
- Film and photo taster session: 11th April, The Hive at the REH, 10am-1pm
- **Poetry:** Friday 14th April, The Library at the REH, 2-3pm
- **Creative writing:** Thursday 20th April, Eric Liddell Centre, 6.30-8pm

You can email, call or pop into the office for more info, and support with getting your story on paper if you need it. You can also tell your story and we'll transcribe it for you.

If you're raring to go – go for it! We can include up to 1500 words and/or up to 4 photos or pictures per person. Just let us know what you're planning!

katherine.mcmahon@rehpatientscouncil.org.uk

Shirley Gowers

Shirley started to volunteer with the Patients Council in 2007 and remained an active member until ill health prevented her from participating for the last couple of years. Shirley stayed in touch with us though and we were very sorry to hear that she passed away in her sleep on 30th January, with her lovely little dog, Cassie, by her side. We were able to pay our last respects to Shirley at the very moving service of thanksgiving for her life which was held at St Mary's Cathedral, Palmerston Place, on 9th February

Group Advocacy

In the rehab wards we introduced our new Stories worker, Katherine, to the groups and were fascinated to learn how many people had written stories, poems and even had whole film scripts stored in their bottom drawers. We hope lots of these lovers of the written and spoken word will work with Katherine to help produce our third edition of Stories of Changing Lives; we also discussed the sorts of things that thwart creativity and how to overcome these obstacles. People who prefer photography, film-making or social history will also have a chance to contribute their lived experience to the project - contact Katherine for details.

At the Firrhill house out in Oxgangs, it was great to hear from a resident who may be the first to move on from this new joint NHS/Carr Gomm/Penumbra type of community rehab. The indications are that each of the four new localities in Edinburgh might develop similar types of service, so we are glad that the new model seems to be working for patients. In the other Rehab wards, members of groups talked about the type of social issues that had caused community placements to break down in the past: often people had been exploited by others or had got into difficulties with drug use. We discussed how the new model of rehab could address these types of problems. Many group members feel that they've been in hospital too long and we debated the idea of a right to a community life and how to realise this.

In the acute wards, smoking remains a problem, both for non-smokers and those trying to quit, but also for those smokers who have not chosen to be in hospital nor wish to give up smoking. The idea of reintroducing smoking rooms is still raised at many meetings; the current direction of travel in policy seems to be moving firmly in the opposite direction.

Another common complaint in the acute wards was of delayed discharge due to a lack of suitable accommodation in the community. The hospital management are fully aware of this problem and now have dedicated staff coordinating between the hospital and community in the hope that people can move on as soon as possible.

In CAMHS, young people came up with some innovative ideas about how patients could personalise their bedrooms during their stay. They wondered if new technology and new types of display panels could allow patients to change the colour of their walls or project soothing images. It highlighted the importance of the environment on how therapeutic or not people find their hospital stay. It's too late to incorporate these ideas into the new hospital building, but we're hoping that when patients move in over early summer they see a big improvement in the therapeutic environment. The Patients Council will certainly be around to listen to the patient experience and feed this back to the people who need to hear it.

Have a look at our website

www.rehpatientscouncil.org.uk

Lots of information about the Patients Council and links to other interesting items

www.facebook.com/rehpatientscouncil/

twitter.com/rehpatients

The Royal Edinburgh Hospital Patients' Council

The Patients Council is an independent collective advocacy project for people who use or have used the services of the hospital. We provide a forum for common issues about mental health treatment and care and represent patients' interests in order to improve services. We hold general meetings every two months. To get involved with mental health issues from the service-user's viewpoint, contact our staff.

Telephone: 0131 537 6462 Email: info@rehpatientscouncil.org.uk

Write: The Patients' Council, Royal Edinburgh Hospital, Morningside Terrace, EH10 5HF

Our Management Committee

Albert Nicolson, Martin McAlpine, Stephen Muirhead, Stephen Polockus, Alison Robertson, Patricia Whalley

> Co-opted member: Cathy Robertson

PATIENTS COUNCIL MEETINGS 2017 2 – 3.30pm

30 January

27 March

29 May

24 July

25 September

27 November: Annual General Meeting 1.30 – 3pm followed by buffet

History of the Patients Council

A few of our members have written a history of the Royal Edinburgh Hospital Patients Council highlighting some of our activities since 2000. Please contact us for a copy.

To receive the newsletter direct, by post or e-mail, please complete and return this section. *I would prefer to receive the Newsletter by post* \Box *email* \Box *(tick as appropriate)* Name _____

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The Royal Edinburgh Hospital Patients Council is a registered charity Scottish Charity No SC021800 Our offices are between Outpatients and Mental Health Tribunal in the ADC www.rehpatientscouncil.org.uk



Post code_

All patients, former patients, staff and visitors are warmly invited to attend

PATIENTS COUNCIL MEETING

from 2.00-3.30pm on

Monday 27 March 2017 in **The Hive**

Our guest speaker will be

Shulah Allan

Vice Chair of NHS Lothian and member of Edinburgh Integrated Joint Board (Health and Social Care Partnership)