



# PATIENTS COUNCIL NEWSLETTER

March 2018

NEWS, VIEWS AND COMMENT FROM THE ROYAL EDINBURGH HOSPITAL

## Patients Council Meeting – 29 January 2018

Our new Chair, Martin McAlpine, introduced our guest speaker, Professor Alison McCallum, in her capacity as NHS Lothian's Caldicott Guardian, whose role ensures that patients' identifiable information is treated with dignity and respect. If patient consent is required, it must be given freely and can be withdrawn at any time. She ensures that rights are respected, needs are assessed, the correct treatment and care is given effectively and adequate information is provided. She receives 500 applications a year to use patient data for research and sometimes comes into conflict with the Scottish Government by insisting that information is anonymised and patient consent is given. Patient Information must be transferred and stored safely and securely and can only be used with patient consent.

The process of transferring patient information from paper to electronic systems is not yet complete – it has to be done carefully, ensuring it's complete and well-organised. Clinical staff need access to enough information to enable them to treat the patient well, and it must be available when needed.

Mental Health Tribunal papers should be sent to patients in lockable, tamper-proof bags.

If you have an Advance Statement, there should be an alert on TRAK to state this. Patients' Emergency Care Summaries should be available to the ambulance service. TRAK has lots of screens and tabs, and runs checks to make sure that staff are not accessing information inappropriately – indeed, some staff have been sacked for doing this.

Psychologists need to have a summary, agreed with the patient, of what information to share with other clinical staff on TRAK. Every patient should have a Key Information Summary, compiled with their GP. We discussed concerns about diagnostic overshadowing and cited examples of people being treated less favourably in A & E when clinical staff learned about their mental health conditions. We also raised security concerns about sharing information with social care staff who are severely stretched due to budget cuts.

We heard about new developments at Outlook, Redhall Walled Garden and the hospital gym.

## I love to wait for you

I love to wait for you  
the way it concentrates my mind  
on the fact that you are not here for me  
I listen for the footsteps of the approaching therapists  
I glance up, register their faces,  
watch as the waiting room empties  
and I'm left alone with my thoughts

So I wait  
I immerse myself in the lifestyle magazines  
the photos a self-protective fold between the world and me  
but I've read them all now, when I was waiting  
The wait takes the problems of my world which fill my days  
with a bleak weariness  
the pain and desolate despair, the hopelessness  
press my shoulders down  
I slouch wearily in my chair, bury myself  
While I wait

Have I told you how I feel when I wait?  
Small details overwhelm  
with each passing minute my insignificance intensifies  
someone else is more important, more needy than me  
For here I am  
abandoned, uncared for  
not worthy of attention  
old patterns of neglect – abuse you call it – play out again  
this time at your hands

You come, try to catch my eye, but I turn away  
give your shoes the dull glare of a defiant child  
I trudge up the corridor,  
take my surly resentment into the therapy room  
until the day comes when I tell you of my anger  
the great gaping hole that sucks all the light,  
all the matter, all that mattered  
into it  
because you did not care

Our next appointment comes and you are on time  
I notch up a small victory against you  
Less withdrawn now I tell you more of how the waiting  
makes me feel  
Of how tiny and unimportant I am, far beneath notice  
The torment of having your own insignificance marked out  
I think you've heard me but then in the last seconds of our  
session  
you tell me you'll be late next week,  
you have a client before me  
obviously more needy  
I drop my eyes, swallow a retort,  
and feel that familiar sense of unworthiness sweep over  
me  
I know now that I cannot rely on other people  
They only disappoint in the end

**Hazel Christie**

## **Group Advocacy**

One of the most commonly raised issues on the wards since the beginning of the year has been the old favourite topic of 'activities'. Patients spoke positively about their increased access to art and music therapy – several times people showed us art-work, gave the groups poems to read, or played us music they had made, something we're keen to encourage. We want groups to be accessible to everybody and if people want to express their views in ways other than just attending a meeting in the traditional way, then we're all ears. People also spoke about how beneficial they find being able to do physical exercise and how much they valued access to the gym as well as the exercise equipment available on some wards. Some people wondered if a running group could be started, many people seem to find this form of exercise very therapeutic.

That other old chestnut issue - smoking – was also brought up in groups often. Patients had noticed the variations in the way the policy is implemented in different wards and groups discussed whether or not this was justifiable. Many patients felt that allowing smoking in courtyards/gardens meant that people were less likely to smoke within the wards. Nevertheless, we learned that a further change to the smoking policy will come into force in August, when the rule about no smoking within 15 metres of hospital buildings will be enforced. This would put an end to smoking in courtyards.

The other issue that arose frequently was around the use of force, restraint and seclusion. Patients spoke about their experiences of compulsion and of feeling that their safety, privacy and dignity had been affected. At times, they often found it difficult to balance the use of force with their wish to be treated kindly and compassionately. There was a widespread feeling that at times, wards operated according to a punishment model and that there exists a power dynamic between patients and staff and that in any such situation there is a danger that "power corrupts". On the flip side, other patients spoke about how they had been "saved" many times by being detained. We also heard from people who had spent time in the hospital's High Dependency Units: this can be a very difficult experience for patients. We also heard that using this type of seclusion for hopefully short periods of time can actually reduce the use of restraints. It seems like there are no easy answers in mental health care.

**Have a look at our website**

**[www.rehpatientscouncil.org.uk](http://www.rehpatientscouncil.org.uk)**

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

**[www.facebook.com/rehpatientscouncil/](http://www.facebook.com/rehpatientscouncil/)**

**[twitter.com/rehpatients](https://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](mailto:info@rehpatientscouncil.org.uk)

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

**Our Management Committee**

Martin McAlpine, Stephen Muirhead,  
Alison Robertson, Patricia Whalley,  
Safini Bibi

*Co-opted members:*  
Cathy Robertson, Isla Jack

**PATIENTS COUNCIL  
MEETINGS 2018  
2 – 3.30pm, The Hive**

**29 January**

**19 March**

**28 May**

**23 July**

**24 September**

**26 November:  
Annual General  
Meeting  
1.30 – 3pm  
with refreshments**

**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.

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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](http://www.rehpatientscouncil.org.uk)

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

# **PATIENTS COUNCIL MEETING**

from 2.00-3.30pm on

**Monday 19 March  
in The Hive**

**We will be joined by**

**Prof. Alex McMahon  
NHS Lothian's  
Director of Nursing,  
Midwifery and Allied  
Health Professionals**