

Rethink Carers Lancashire

October 2018

lancscarersgroup@rethink.org

07534 369889 c/o Rethink Mental Illness, Paul's House, Tower Street, TA1 4BH

Upcoming meeting: Friday November 30th, 10.30 am to 3 pm

Brindle Village Hall, PR6 8NH

Doug Feery, Barrister, has once again been kind enough come and speak to us, this time on **negligence**, civil and **human rights claims**, including how they can be funded. Our group has benefited massively from Doug's expertise in Public Law, Equality Law and Human Rights Law and we look forward to another entertaining in-depth presentation. If you have questions for Doug relating to these aspects of mental health care, send them in beforehand. We will also have an equally expert presentation from **Dr. Sam Warner**, a freelance consultant clinical psychologist, trainer, therapist, and expert witness, and Research Fellow at Manchester Metropolitan University for over 15 years. Sam will talk to us about self-harm, and therapies for personality disorder. Some of us remember a previous visit from Sam and how she managed to make such a grim subject so lively and positive.

Please make sure you book early for this meeting as it will be very popular and open to others beside our immediate group members. Lunch will be either hotpot or butter pie, £5 to include all refreshments during the day (£1 for teas, coffees if you don't have lunch). Make sure you order your lunch at the same time as booking, deadline for food orders **Monday November 26**th. Remember that we can contribute to travel expenses/lunch for anyone coming a distance or hard up just at the moment.

Rethink Carers East Lancs meets on the second Wednesday of each month at Elmfield Hall, Gatty Park, Accrington, 6 – 8 pm. **Fylde Family Support Group** meets on the second Tuesday of every month at Empowerment Advocacy Base, 333 Bispham Rd, Fy2 OHH. in Blackpool, 7 -9 pm. Phone 07999 332804. <u>FyldeFamilySupportGroup@rethink.org</u> <u>www.Facebook.com/groups/FyldeFamilySupport</u> Every Wednesday Rethink Dog Walking Group. Find out information and get support in the fresh air, with or without a dog.10am-noon Stanley Park Blackpool Fy3 9HU.



You may remember the information (see our May newsletter) given by Charlotte Hammond, Mental Health Lead for Lancashire County Council, about the changes to how care is organised, with Care Act assessments for social care now being the direct responsibility of Social Services rather than the clinical practitioners. There has been some concern about who exactly will be carrying out these

assessments, and whether that will mean a reduction in help from support workers. We have received the following assurance from Charlotte: We are training Social Care Support Officers in all aspects of The Care Act, it will be the foundation of their work going forward in our new arrangements. As we have discussed at the meeting, the support workers have been involved in work that doesn't best fit their social care role, and which could be delivered by others, meaning we can create more capacity in the teams to ensure reviews are done, including sec 117 reviews, out of area reviews, carers assessments and supporting people to get on with their with person centred packages of care including direct payments, support agencies, employment support and carer support.

By ensuring the whole team is Care Act aware, we can ensure that the right practitioner is allocated the most appropriate case, including those with complex needs.

EVEN MORE HELP FOR CARERS FROM OUR GROUP Many of our members have recognised the value of having another person to support them in meetings with professionals. This can help the carer **understand** how mental health services are provided, **record** what has been said at meetings, **identify and clarify** issues and **get questions answered**, manage **confidentiality** problems, and ensure that mental health practitioners derive **optimal benefit** from the information the carer has to give

All this increases carer confidence and makes the relative-practitioner relationship as positive and productive as possible, so as to ensure the best care possible for the person experiencing mental illness.

We now have several group members, as well as the Group Coordinator, who have volunteered to provide this support. They have had training, and DBS checks (for safeguarding purposes). They have agreed basic principles and values, especially with regards to keeping everything confidential, respecting all the wishes of the person they are supporting, and not being judgemental in any way. Peer support by carers is a new concept for the mental health teams, but is now well accepted and appreciated in Lancashire.

We don't charge for this – the supporters give their time for free and receive expenses from group funds. If you think you could benefit from this kind of support, (e.g. if you're anxious about an up-coming meeting or unsure about how you should be involved in your loved-one's care) contact the Group Coordinator. We can provide a more information, discuss your options, or arrange an initial meeting with a group member who can really help.

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We now have copies of the Mental Health UK Information Guide which brings together four national UK charities • Hafal in Wales • MindWise in Northern Ireland • Rethink Mental Illness in England • Support in Mind Scotland Find out more at mentalhealth-uk.org. The guide is fairly general, covering 6 conditions and providing practical tips and signposting. It is, therefore, aimed at a broad audience of those affected by mental illness, carers or families.

This guide can help everyone get the information and support they need. It talks about the most common conditions, but there are many others. Some people will also experience more than one. You'll also find advice on: • Seeing your GP if you're worried about your mental health • What to do if someone you know is affected • How you can help yourself • Who to contact for more advice

You can find this guide at <u>http://rethink.informz.net/rethink/data/images/groups/Mental-Health-UK-Information-Guide.pdf</u> but we can send out hard copies to any individual or organisation - just let us know.

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THE WARM HOMES DISCOUNT SCHEME



Now is the time of year to contact electricity suppliers (either for yourself or the person you care for). If you're on certain benefits or a low income you could get £140 off your electricity bill for winter 2018 to 2019 under the Warm Home Discount Scheme. The money is not paid to you - it's a one-off discount on your electricity bill, between September and March. The discount will not affect your <u>Cold Weather Payment</u> or <u>Winter Fuel</u> <u>Payment</u>. Check with your supplier to see if you're eligible and how to apply. Check with your supplier as early as possible, as the number of discounts suppliers can give are limited.

Our recent meetings

At our meeting in August we welcomed **Usman Akram, Specialist Advanced Clinical Pharmacist** with Lancashire Care NHS Foundation Trust. This was probably the most interesting and informative meeting we've had, we could have kept Usman for the afternoon as well! But he has promised to come back soon with more updates and information.

Usman's role includes sitting in on patient reviews, looking at physical health, monitoring prescribing trends within the Trust, policing practices and assessing risk. The presence of a pharmacist within multi-disciplinary teams is a welcome new development, and now gives other team members, including consultant psychiatrists, access to this specialist advice, thereby preventing unilateral decisions. Usman attends 'Mood on track' bi-polar groups, and much of his role is to make symptoms of mental illness more manageable. There are also more pharmacists now working in GP surgeries. Usman directed us to some excellent sources of information on medications: http://www.patientinfo.clozaril.co.uk/ contains a variety of downloadable items to help both patients and their carers to find out more about clozapine and how it can help patients with Treatment Resistant Schizophrenia. Other sites are www.choiceandmedication.org and www.patient.co.uk. Usman explained that we can speak directly to the pharmacist for our area. If you don't know who that is, he is happy to receive enquiries from people outside his Central Lancashire area and will refer on to the appropriate person. His contact details are: 01772 401629 / 07950 870178 *: usman.akram@lancashirecare.nhs.uk +: Block C | West Strand House | Ashton on Ribble | Preston | Lancashire | PR1 8UY

Much of the discussion centred on Clozaril. Blood tests are done initially weekly for 18 weeks, then fortnightly for a year and after that monthly. There are two weeks' leeway, for instance if a patient is away on holiday, but if blood tests are more than two weeks overdue the prescribing of Clozaril is prohibited. If Clozaril is missed, after 48 hours there would be a need to retitrate, but not to go back to zero. After one week of missed medication, the start dose would be lower, and after two weeks there would be a need to re-titrate as a new patient. A 'red' result (indicating Clozaril-induced neutropenia, an immune-system condition that can lead to infections) from the blood test would not necessarily result in Clozaril being withdrawn, this would depend on the treatment history, and Usman assured us that very few patients actually have a red result. Plasma levels are checked to show whether the effect of Clozaril lies within the recommended therapeutic range, with a maximum dose being 900 mg; but the levels depend on individual patient response rather than the dose taken. Clozaril can cause hypersalivation.

We also learned that alcohol dehydrates the body, so is a big issue if people are taking lithium. Alcohol affects how much of the medication is metabolised by the liver or kidneys, so it's possible the levels of medication in someone's system could become toxic, and there is a double risk if there are heart issues. Patients should buy in to the idea that moderation is key, that drinking needs to be controlled and daily/binge/excessive drinking damages the liver. Medications aim to damp down the receptors in the brain, but alcohol does the opposite, as do smoking and caffeine, so that more of the medication is needed to achieve the same effect.

Side effects of medication should be discussed routinely at a patient's annual medication review. Weight gain doesn't occur in every patient, and may be more to do with increased urge to eat rather than caused directly by the medication. Low calcium is a common problem with schizophrenia. Schizophrenia has also been linked to brain shrinkage, but it isn't known whether this is the result of medication or the illness itself. There is a heart risk (arrhythmia / cardiac arrest) with all antipsychotic medications. But it's important to remember that any prescribing should weigh up the risks versus the benefit, and especially with psychiatric medication there is an element of trial and error, depending on individual patient response. It is difficult to assess the long-term effects of such medication because there isn't much evidence, but one important point is that people whose mental health can be stabilised have a better quality of life. The Trust bases its policies on current NICE clinical guidance and utilises guidance offered by the Maudsley Prescribing Guidelines and works to the British National Formulary maximums. Polypharmacy (prescribing of multiple medications sometimes for the same condition) is still a problem though less than previously, and more common with physical illnesses. Regular blood tests need to be done; if someone is transferred back to the GP, under a shared-care arrangement the blood tests should continue. LCFT has a summary sheet for all the blood tests which need to be done. Usman has provided a copy of this for any of our group members who would like to find out for themselves whether all the tests are being done. It is sometimes difficult to ensure that actions are carried out by GPs even when recommended by a Consultant. This document (SIDE EFFECT AND PHYSICAL HEALTH MONITORING FOR ADULTS, CHILDREN AND ADOLESCENTS PRESCRIBED ANTIPSYCHOTICS) gives a rundown of all the checks necessary (by GPs as well as the mental health services) in the monitoring of patients on anti-psychotic medication. Let us know if you'd like a copy

In September, **Sarah Murphy, Rethink's Associate Director for Advice, Information and Training**, came all the way from Birmingham to talk to us about this service. She outlined the statistics around the inquiries they receive, with the service able to answer only 7000 of the 20000 calls they receive, and how the Advice Service staff are selected and trained. The service has produced 118 factsheets so far (<u>www.rethink.org/resources</u>) which are reviewed every three years or if things change. **If you'd like to help with reviewing these, do let us know**. The most important thing we learnt was that the new money advice service (MentalHealthandMoneyAdvice.org) can take on individual cases, give an initial telephone appointment of an hour, and help individuals through their financial problems. They can't do face-to-face meetings, handle money, take on appointeeships or debt relief orders, but this is a unique and invaluable service that will help very many people.

On the same day, we had a talk from **Police Sergeant Andy McGinty, Lancashire Constabulary Mental Health and Dementia Coordinator**, who works in partnership with any agencies involved in support for people with mental health issues. He explained that police training in mental health is minimal, despite the high proportion of mental illness in what they deal with, but information is improving. On each of the 45 teams across the county there is one person who can be referred to for mental health information, digital access to information has improved, and they have access to a professional mental health helpline. He described the crisis units (now to be called support units) in Blackburn (6 places), Preston (4 places) and Blackpool (6 places) which patients can go to directly, by-passing A & E if there is no self-harm, but pointed out that, given the unprecedented level of A & E demand, these need to be much bigger. One of our members is involved in the on-going discussions about improving crisis care in Lancashire. Several group members asked about how much the police can do when someone goes missing – if a person is found but is over 18, and doesn't want the family to have information about their whereabouts, the police have to respect this.

Also in September, the East Lancs group welcomed Lancashire care's Mick Jenkins (lead for the Personality Disorder Managed Clinical Network) and Lisa Klesniks (Acute Therapy Service). They described some of the strategies they teach to enable people to shift their thinking, engage with therapy, and manage their emotions, and highlighted the importance of not being judgemental. People can be referred to a Mental Health Decision Unit, which provides six consecutive days of therapy. One group member whose daughter had attended such a course testified to the improvement it brought about, but commented that the lack of follow-up meant that some of the benefits had not been sustained.

Well worth a visit – the Community Greenhouses at Stubbylee near Bacup

An environment where all people of East Lancashire are given the opportunity to engage with a life transformative environment. Practical help, a helping hand and human connection enable them to find and develop their skills and grow personally. Support for the local community with a particular focus on rehabilitation for individuals who have physical or mental ill health or have long term unemployment issues. <u>https://thegreenhouses.org</u> Gardening, photography, art, woodwork, metalwork, building, courses, bikes refurbished and sold at good prices or given to people who couldn't otherwise get to Jobcentre interviews. The café serves food grown here by the volunteers, and is open Wednesday – Saturday 10.30 to 3, Sunday 11 – 3.

AN INSPIRING PROJECT IN BACUP



JOIN RETHINK MENTAL ILLNESS Membership of our local Lancashire group is free, but we'd like everyone to join the national organisation, as this gives Rethink more weight for its campaigning as well as access to your opinions and knowledge. In return you get the quarterly information-packed magazine, access to a special bit of the website, and free conferences (including in November our National Members Day which this year will be in Sheffield). Go to https://wethink.rethink.org/ or phone 0121 522 7007 If you prefer to do everything online, national membership costs only £6 a year. To receive the magazine and other information in the post, it's £27 a year, paid in 12 monthly instalments.

ONE COMMENT WE HEAR FREQUENTLY NOW IS THAT RETHINK IS THE BEST SOURCE OF MENTAL ILLNESS INFORMATION AND SUPPORT AVAILABLE TO CARERS IN LANCASHIRE. One way to show your appreciation of this is to join the national organisation.

Leading the way to a better quality of life for everyone affected by severe mental illness. For further information on Rethink Mental Illness Phone 0300 5000 927 Email info@rethink.org Visit www.rethink.org Please join us today www.rethink.org/join www.facebook.com/rethinkcharity www.twitter.com/rethink Registered in England Number 1227970. Registered Charity Number 271028. Registered Office 89 Albert Embankment, London, SE1 7TP. Rethink Mental Illness is the operating name of National Schizophrenia Fellowship, a company limited by guarantee. © Rethink Mental Illness 2014.