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So much is happening. The whirr around NDIS is alarming – lots of buzz, many predictions but little substance reaching us. We read of news of funding cuts to agencies in preparation for the NDIS, but roll-out is a long process – what is to happen to the needy in the meantime? Is funding currently used to benefit our Loved Ones to be used to fund yet another forum predicting how things **might** happen beyond 2017?

Committee and I have spent (?wasted) many hours listening to tedious predictions. I'm going to avoid discussing the NDIS in newsletters until there is factual material. In the meantime, I think it essential that everyone reads the NDIS website (<http://www.ndis.gov.au/>) weekly as important material just flies past on it.

**NDIS HOUSING SHOWCASE - TUESDAY 31 MAY**

Despite my above comment, the Housing Showcase may be very useful as it relates to a specific topic of interest to many of us.

Perhaps if this reaches you too late to attend you'll reconsider and ask us to send you emails rather than costly, work intensive snail mail.

**JUNE MEETING – 7.30 pm Tuesday June 14**

**Betty Day Centre - 67 Argyle St, St Kilda**

**PACER - VICTORIA POLICE AND ALFRED HEALTH WORKING TOGETHER**

**SPEAKERS: A/S Sgt Kev Treacy, Angela Gallagher**

**PACER stands for Police, Ambulance and Clinical Early Response - a joint crisis response unit in which trained police officers and mental health clinicians work together in health crises in the community**

**I doubt there's anyone in our group who has not either utilized after-hours help, or wondered what to do when things went awry out of hours.**

**These issues – and their answers – will be discussed at this meeting, at which consumers and carers alike will receive practical advice.**

**Major Forum: Free and open all individuals experiencing psychosocial disability, their families and carers, especially if they live in Stonninton, Port Phillip, Glen Eira, Bayside or Kingston.**

**EMPLOYMENT AND VOCATIONAL PATHWAYS**

**4 pm to 7 pm Tuesday June 7, 2016**

**Kingston City Hall 985 Nepean Highway Moorabbin**

**Easily accessed via Morabbin Station or buses 823, 824, 825, see Melways map 77 D5**

**Small group discussions, informed staff providing useful information, tasty food provided.**

**Please book by 3 June:**

**Trybooking: [www.trybooking.com/186062](http://www.trybooking.com/186062)**

**The form is being run by Inner South/Bayside Mental Health Network. Contact Lindy Alcorn for information: 9076 6204**

**CONGRATULATIONS AND CHANGE OF NAME**

In my view a very welcome name change.

When I first came into this arena, the concept of 'mental illness' was rarely questioned, so 'Mental Illness Fellowship' made sense. Later, the change of name to MI Fellowship seemed sensible.

I strongly welcome the name change to 'Wellways'. Those of us following progress in this field; those of us who met the inspirational Flick Grey last meeting; or heard Prof John Reade last AGM or John Watkins; or read about issues that affect our Loved Ones ...know that Recovery is a realistic concept; that the term psychosocial disability is a far better description in most cases than 'mental illness'.

Personally I congratulate Wellways for this name change. It emphasises the possibility of recovery rather than a lifetime of being medicated into subservience.

<http://www.mifellowship.org/news>

## 18<sup>th</sup> ANNUAL BRUCE WOODCOCK LECTURE

“It’s community participation that turns recovery into a reality.”

This idea of inclusion, and the need for a more human rights-based approach to mental health, was at the heart of the keynote speech delivered to a packed audience at the 18th Annual Bruce Woodcock Memorial Lecture by Dr Mark Salzer professor and Chair of the Department of Rehabilitation Sciences at Temple University in Philadelphia and his colleague Rick Baron.

Dr Salzer and Mr Baron have been working with MI Fellowship (now known as Wellways) on a publication that challenges approaches to mental health that focus on illness and impairment. The publication, 'Well Together – a blueprint for community inclusion', looks at the role of community, strongly arguing that community inclusion is a human rights issue and that urgent change is needed across the mental health and broader disability sector.

The theme of inclusion in the community being a basic human right and the need to ensure that inclusion happened was continued next day at:

### TOWARDS RECOVERY CONFERENCE

Sue Johnson and I shared a two day ticket to this conference run by VicServ conference.

Some issues raised which we need to keep in mind when dealing with stigma, discrimination and frank abuse.

### UN Convention on the Rights of Persons with Disabilities

#### Article 19: Living independently and being included in the community

Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to

- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

**It was highlighted throughout the conference that meeting these criteria and facilitating inclusion in the community is crucial to the process of recovery.**

**It is up to each one of us to work towards this goal.**

### PUBLIC ADVOCATE’S AWARD 2016

We congratulate Liz Crowther, President, Kim Koop, CEO of VicServ and their extraordinary Team for the above conference and for winning the 2016 Public Advocate’s Award from the Office of the Public Advocate.

### NEWS FROM TANDEM <http://tandemcarers.org.au/>

Tandem is the peak Victorian body for families and carers of individuals with psychosocial disability. It is well worth joining and attending their meetings.

Julien McDonald, who headed Tandem tirelessly for many years retired this month. Her shoes will be hard to fill!!

We thank her for her work on our behalf and wish her all the very best in her new role as ‘retiree and grandmother’.

#### **DINING GROUP : MILANO’S BISTRO TAVERN**

**12.30 pm Sunday 10<sup>th</sup> July 2016**

**4 The Esplanade Brighton**

**<https://www.milanos.com.au/dining>**

**Menu on website, senior menu included**

**Dining Group events have been highly successful family events. Diners have included family groups with three generations, aged from 10 years to... , so bring the family, especially as this is a lunchtime event, rather than a dinner as previously.**

**We constantly seek suitable, well located modestly priced venues serving delicious food. Meal account is generally shared.**

**Drinks are paid individually.**

**Committee would greatly appreciate suggestions, so if you could suggest a venue, please let me know: [judi.burstyner@gmail.com](mailto:judi.burstyner@gmail.com) or [isfaf@alfred.org.au](mailto:isfaf@alfred.org.au) or call 0425 723 746.**

## VIOLENCE, GENES AND MEDICATION

Some projects which members have alerted me to recently follow. As I have not read the original papers, please do not hold me responsible, but I pass them on, as members have asked me to, for your general consideration.

<http://www.irishexaminer.com/ireland/psych-drug-link-to-violent-episodes-analysed-400571.html>

The article mentioned deals with a specific medication, but many other medications also have side effects which include violence, altered behaviour, such as suicidality. This is a chilling reminder that sometimes our Loved One's behaviours are a direct result of their meds and not of their 'diagnosis' or of their 'own inner motivation'.

Genetic variations affect how different people react to medications in general and in certain cases this accounts for lack of response or unexpected response to medication. In some cases, the genetic variants can be tested for and identified at moderate cost – and certainly less cost than continuing with meds that are not working.

The above research, published recently in the **Journal of Forensic and Legal Medicine**, was carried out by a medical specialist, a forensic psychiatrist and a pharmacogeneticist.

Similar material regarding the variation due to genetic differences in response to lithium was broadcast on the ABC:

<http://www.abc.net.au/news/2016-01-22/bipolar-treatment-revolution-lithium/7108158>

Just as there are many research projects looking at how genes influence individuals' responses to medication, there are many other projects investigating genes which may be related to the degree of vulnerability or susceptibility to developing schizophrenia (and/or other psychosocial disabilities)..

Though it is widely believed that a person cannot inherit a psychosocial disability in the way that one can inherit blue eyes, or blond hair or other simple, inherited trait, it is also widely believed that a person's genes can make them more likely to suffer from a psychosocial disability. This is unlikely to be due to a single 'mental illness gene,' but possibly due to a group of genes and their interaction with environmental factors such as (psychological) trauma, or possibly virus or other environmental factor.

It is therefore recognized that schizophrenia is 'brought on' through a combination of environmental, genetic and psychological factors, but an exact cause of schizophrenia remains unknown.

A team of international researchers at Queensland Brain Institute claim to have uncovered a piece of the puzzle. Tarjinder Singh, the lead author of the paper from the Wellcome Trust Sanger Institute in Britain, said they had completed the largest analysis of individuals to date.

"After looking at the genomes of over 16,000 people, we were able to implicate single letters in one gene that contribute to significant risk of giving you schizophrenia," Mr Singh said.

"So we're estimating close to 35 times the risk."

This is an estimate, not to be understood as a simple 'cause', especially because the variation "is rarely seen in a general population ever and even in people with schizophrenia, it's only seen in one every [1,000]."

Nevertheless, as Professor John McGrath, from the Queensland Brain Institute at the University of Queensland, said: "We've known for a long time now that genetic factors can increase a lot of mental disorders, like depression and anxiety, and also schizophrenia," but also that: "we know that cannabis use increases the risk, childhood trauma, prenatal infection and prenatal nutritional work also increases the risk factors. Some of these things are modifiable, but the genetic factors are always there and we're trying to join the dots to explain why some people go on to get the illness.

Now just because you have a gene or a variant of [that gene], doesn't mean you will definitely get the disorder, it increases the risk. And this new finding has given us a big new clue to track down what may underlie some types of schizophrenia."

The study from the Wellcome Trust Sanger Institute has been published in the journal Nature Neuroscience.

### **Psychosis Symptoms associated with**

#### **3 Distinct Biotypes**

<http://www.psychiatrictimes.com/schizophrenia/biomarkers-delineate-3-distinct-psychosis-biotypes?GUID=&XGUID=&rememberme=1&ts=09032016>

In other words, by contrast to diagnoses of diseases such as diabetes in which biological measures correspond to symptoms – such as sugar levels corresponding to symptoms of diabetes - psychiatric 'diagnoses' are made on the basis of symptoms, not on biological measures.

This study found three different types of underlying 'biotypes' for the one single psychiatric diagnosis of 'psychosis'. These biotypes did not correspond to psychiatric diagnoses - ie, each 'biotype' included patients with schizophrenia, schizoaffective disorder, and psychotic bipolar disorder. Hence 'diagnosis' may not be an accurate term, but may merely describe symptoms

resulting from a variety of underlying causes, some (or all) of which may require different management. See more at:

<http://www.psychiatrytimes.com/schizophrenia/biomarkers-delineate-3-distinct-psychosis-biotypes?GUID=&XGUID=&rememberme=1&ts=09032016#sthash.INQ3CRqR.dpuf>

Clementz BA, Sweeney JA, Hamm JP, et al. Identification of distinct psychosis biotypes using brain-based biomarkers. Am J Psychiatry. 2015 Dec 7. appiajp201514091200.

## EATING DISORDERS VICTORIA

runs a variety of useful groups in a variety of locations. Most, but not all, meetings are held at 7 pm to 8.30 pm. For example:

### Family and Friends Support Groups

Wed 1 June – Abbotsford

Tues 14 June – Ringwood

Mon 27 June – Camberwell and Geelong

Wed 6 July – Mornington....and many more

**Recovery Support Groups** are held at similar times and venues on different days.

If you would like some help with respect to an Eating Disorder either for yourself or someone else, have a look at the website of Eating Disorders Vic.

[http://www.eatingdisorders.org.au/events/family-friends-support-groups?utm\\_medium=email&utm\\_campaign=Newsletter%204516&utm\\_content=Newsletter%204516+CID\\_f8fc9bcfee2f69afe7490bafd3ade136&utm\\_source=Email%20marketing%20software&utm\\_term=Family%20%20Friends%20Support%20Groups](http://www.eatingdisorders.org.au/events/family-friends-support-groups?utm_medium=email&utm_campaign=Newsletter%204516&utm_content=Newsletter%204516+CID_f8fc9bcfee2f69afe7490bafd3ade136&utm_source=Email%20marketing%20software&utm_term=Family%20%20Friends%20Support%20Groups)

### ARE YOU A CARER AGED OVER 50 YEARS?

Researchers at the Institute for Health and Ageing are exploring the physical activity and mental wellbeing of older carers. Participants complete a 15-minute questionnaire and enter a draw to win a \$100 Coles gift card.

Call 0411 098 286 for paper copy or complete the questionnaire online at [www.tinyurl.com/carersurvey](http://www.tinyurl.com/carersurvey)

**The opportunities I have come across for interesting courses are so many that I can't include them all. The following are merely a few:**

### City of Port Phillip

<http://www.portphillip.vic.gov.au/lifelong-learning.htm>

### Centre for Adult Education

<http://www.cae.edu.au/>

### Centre for Culture, Ethnicity & Health Literacy

<http://www.ceh.org.au/what-is-health-literacy>

Health literacy is essential for maintaining good health and improving the quality of life. Conversely there is extensive evidence linking low health literacy to poor health outcomes.

### Victorian Council of Social Service

<http://vcoss.org.au/>

## IN CONCLUSION, DON'T FORGET TO DIARIZE

### TUESDAY 12 JULY

when we will be privileged to have as our speaker, Victoria's representative on the Australian 10 Year Mental Health Plan: **De Backman-Hoyle** | Independent Mental Health Advocate, Speaker & Educator

Coordinator for Victoria - Private Mental Health Consumer Carer Network (Australia)

National Suicide Prevention Australia Lived Experience Leadership Group

Centre of Research Excellence in Suicide Prevention Lived Experience Expert Group

Co-chair - ERG Australian Mentally Healthy Workplace Alliance

beyondblue Ambassador - BlueVoices representative

Former Deputy Chair - VMHCN now Tandem

Former Co-chair - NMHCCN

### And our AGM: TUESDAY 9 AUGUST.

Please do not hesitate to call me if you need transport to any meeting or have suggestions for the group.

I look forward to hearing from you and catching up at meetings,

Warm Regards, Judi Burstyn M: 0425 723 746.