



**GAMIAN-Europe**

Do what you can, with that what you have, wherever you are

# **Mental Health and Treatment**

## **The Patient Perspective**

*Interest Group on Mental Health,  
Well-being and Brain Disorders*

**Pannel response by Paul Arteel,  
Executive Director of GAMIAN-Europe**

European Parliament, 2 June 2015

# MY PERSONAL EXPERIENCE

- First manic episode in 1999 at 28 years of age
- Severe depression in 2000 (duration: 9 months)
- Hospitalisation  
& Wrong diagnosis and treatment with anti-psychotic medication
- Relapse into second depression in 2001
- Hospitalisation  
& Treatment with anti-depressants -> switch into mania
- ! Finally correct diagnosis in 2001 & treatment with Lithium !
- Treatment with **medication, psychotherapy, psycho-education**
- Contact with Ups & Downs, **selfhelp organisation** for people coping with bipolar disorder and chronic depression in Belgium (Flanders)
- Return to work life in 2004 after retraining from Art Historian to Management Assistant in 2003(loss of job due to illness)
- Episode free since 2001 & Full recovery

# TREATMENT NEEDS

- Quicker diagnosis is key
  - > for most patients with bipolar disorder it can take 8 to 10 years to receive the correct diagnosis
  - > in my case it only took 3 years (1999 - 2001) ...
- Quicker prognosis of treatment success (positive response) with certain medications
  - > Trial and Error to find the correct medication
  - > Long periods of taking medication with no effect at all !
- **Psychoeducation & psychotherapy & self-help groups (peer support) = essential parts of the treatment**
  - > Patient = expert in his own condition = expert by experience
  - > The more the patient knows about his symptoms and his treatment, the more he is in control of his own recovery process
    - > **DIALOGUE between patient & doctor**

# TREATMENT NEEDS

- Side effects of medication
  - > most prominent reason for patients to stop taking their medication
  - > patients should be taken seriously when complaining of side effects
- Insufficient symptom reduction and relapse prevention in medication treatment
  - > GAMIAN survey on Mental Health and Work (2013) showed that:
    - \* patients felt that due to poor symptom reduction they could not go back to work
    - \* patients were afraid to relapse and therefore could not go back to work
- Enough availability of existing and new medications
  - > often patients only find the correct medications that work for them after years of searching in trial & error with their doctor
  - > more different medications give more treatment options to some patients that have a hard time finding the correct medication that works for them (personalized medicine)

# TREATMENT NEEDS FOR MENTAL HEALTH

## Holistic treatment view

- > see the treatment as a tool to improve the life of the patient as a whole
- > recovery = to lead a meaningful life again on all levels (physical health, personal and family life, relationships, work, role in the society, etc.)
- > **treatment = chair with 4 legs**: to stay stable all 4 legs need to be strong !



1. Medication
2. Psychotherapy
3. Psycho-education
4. Self-help groups

# FOCUS ON RECOVERY

- **Recovery oriented treatment approach :**

- > recovery of the patient is the true objective of any successful treatment plan, only symptom reduction is not enough.

- > **recovery = to be able to lead a full and meaningful life**, including being able to take up all one's social roles again and to work again !

- > medication and treatment should enable the person living as well as possible with the illness

- > focus on the **possibilities** of the patient and not on the limitations!

- > focus on **empowerment of the patient**, on the recovery , the positive aspects of the life story of the patient: engaging with and becoming active in self-help groups and patient organisations as a means of support to reach recovery !

# THE STRENGTH OF SELF HELP GROUPS

- > self-help groups offer simple and low cost peer support
- > self-help groups offer a kind of psycho-education that will help patients to understand their own symptoms better and communicate about them in a proactive way with their doctors
- > the volunteers active in the self-help groups or patient groups are positive and hopeful examples for other patients
- > self-help groups motivate patients to follow through with their treatment and keep on taking their medication
- > self-help groups = advocacy for patient rights
- > self help groups = contact points for professionals and researchers
- > self-help groups = pool of experts by experience -> testimonials for the general public, schools, anti-stigma campaigns etc.

# HOW TO INVOLVE PATIENTS

-> self-help groups and patient groups can offer a contact point for researchers

-> self-help groups can help to bring together patients in focus groups with researchers: start a dialogue between research and patients

-> surveys, questionnaires on what patients expect from new treatments , what they think of side effects (which are acceptable, which not), what they think of the effectiveness of new medications or other treatments (new brain stimulation techniques), of the use of apps or other internet tools etc.

! professionals should not underestimate the expertise and knowledge present in patient groups !

Just ask us what we think and you might be surprised at what we understand and know

-> **we should be sharing our knowledge in a DIALOGUE !**