PETITION 1235 – PRESCRIPTION DRUG RECOGNITION AND SUPPORT BY STEVIE LEWIS SEPTEMBER 2018

1. OVERALL IMPRESSION OF LETTER DATED 27 JUNE 2018 FROM CABINET SECRETARY FOR HEALTH TO COMMITTEE (letter unpublished as at 18 Sept 2018)

I would like to thank the Committee members for their letter of 17 June 2018 to the Cabinet Secretary, which I felt acknowledged the problems experienced by people who provided evidence of how their lives have been adversely affected by prescription drugs. The response from the Cabinet Secretary, however, does not do that in any shape or form. Due to the fact that your letter refers specifically to the Substance Misuse Treatment Framework (I understand why; there is currently no other umbrella term under which prescribed drug dependence (PDD) and withdrawal falls) the response is entirely framed around the provision of services for people who have misused. I have concluded from reading it that the Cabinet Secretary has gained no understanding as to the subject and purpose of my petition, which is **to get recognition and support for patients who have followed their doctor's advice and have not misused**.

The prevailing attitude to PDD held at medical expert and government level is encapsulated in the Cabinet Secretary's response to the Chair's request for the Welsh government's view on whether antidepressants have the same potential for dependency and harm as other prescription drugs already recognised in this regard. He sidesteps the question by stating:

"The misuse of prescription-only and over the counter medicines causes serious health problems for some. Misuse can include situations where there may have been poor prescribing practices that may have led to dependency or other problems, as well as use for which the medication was not originally intended."

The beliefs underpinning this position are:

1. Antidepressants do not cause dependence and withdrawal
2. People who are harmed are "addicted" and become so due to their own misusing of the drug (eg: buying over the internet)
3. Rogue doctors contribute to this problem by prescribing off-label or inappropriately.

These opinions are insulting to both patients and doctors. In the next three weeks the All Party Parliamentary Group for Prescribed Drug Dependence (Westminster) will be publishing three reports which demonstrate that antidepressants do cause dependence and withdrawal, that doctors follow the guidelines and patients follow their doctor's advice. Please see section 3 "Forthcoming Reports" below.

2. COMMENTS ON SPECIFIC POINTS MADE IN THE LETTER

I had intended here to comment on specific paragraphs. However, as space is limited, I would rather use it to provide additional evidence to the Committee of the harms that antidepressants can do to patients. There is nothing in the letter which demonstrates that the forthcoming Substance Misuse Framework will deliver the needs of the people on whose behalf I am campaigning. Those needs involve firstly the **recognition** that antidepressants cause physical dependence and withdrawal; they should be targeted for reduction in prescribing and the guidelines should be re-written in support of that policy of reduction. Secondly, a **Wales-wide unified support service** is required to help those already harmed by PDD and those in the process of being harmed. Rising numbers of patients harmed are inevitable due to the high prescribing rates of antidepressants in Wales. In sections 3 and 4 I will provide additional evidence, including in section 4 a summary of a report written about the Personal Experiences submitted to the Welsh and Scottish petitions, of which I am a co-author.

3. FORTHCOMING REPORTS FROM THE APPG-PDD

Background

A letter by Profs Burn (RCP President) and Baldwin (Chair of its Psychopharmacology Committee) was published in The Times on 24 February[1], (responding to a letter by James Davies et al[2], which said *'the statement that coming off antidepressants has disabling withdrawal effects in many patients "which often last for many years" is incorrect. We know that in the vast majority of patients, any unpleasant symptoms experienced on discontinuing antidepressants have resolved within two weeks of stopping treatment*."

This was supported by a press campaign[3] declaring "The drugs do work – antidepressants are effective", and that "millions more should be prescribed them" These claims were made across the board in tabloids and broadsheets, insisting antidepressants are safe and effective.

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For those of us attempting to remove the blinkers surrounding evidence of dependence and withdrawal caused by antidepressants, this campaign is beyond misleading, it is frightening. It has prompted the writing of three reports, which will be published by the APPG-PDD next month. The purpose of the reports is to provide evidence to the PHE review of PDD. I am the co-author of one of them and have been given permission to share the meat of the report with the Committee in advance of publication.

Here is a short summary of two of the reports and, in section 4, a more detailed summary of the one I co-authored.

First report due for publication on 01 October 2018: **Davies, J., Read, J (2018) A Systematic Review into the Incidence, Severity and Duration of Antidepressant Withdrawal Effects: Are Guidelines Evidence-Based?**

"Methods
A systematic literature review was undertaken to ascertain the incidence, severity and duration of antidepressant withdrawal reactions. We identified 23 relevant studies, with diverse methodologies and sample sizes.

Results
Withdrawal incidence rates from 14 studies ranged from 27% to 86% with a weighted average of 56%. Four large studies of severity produced a weighted average of 46% of those experiencing antidepressant withdrawal effects endorsing the most extreme severity rating on offer. Seven of the ten very diverse studies providing data on duration contradict the UK and USA withdraw Guidelines in that they found that a significant proportion of people who experience withdrawal do so for more than two weeks, and that it is not uncommon for people to experience withdrawal for several months. The findings of the only four studies calculating mean duration were, for quite heterogeneous populations, 5 days, 10 days, 43 days and 79 weeks.

Conclusions
We recommend that U.K. and U.S.A. guidelines on antidepressant withdrawal be urgently updated as they are clearly at variance with the evidence on the incidence, severity and duration of antidepressant withdrawal, and are probably leading to the widespread misdiagnosing of withdrawal, the consequent lengthening of antidepressant use, much unnecessary antidepressant prescribing and higher rates of antidepressant prescriptions overall. We also recommend that prescribers fully inform patients about the possibility of withdrawal effects."

Second report due for publication 08 October 2018: **Antidepressant Withdrawal: a Survey of Patients' Experience by the All-Party Parliamentary Group for Prescribed Drug Dependence. Authors Davies J, Montague L.**

In Sep 2017 the All-Party Parliamentary Group for Prescribed Drug Dependence, in conjunction with researchers at the University of Roehampton, undertook one of the largest direct-to-consumer international surveys of its kind into withdrawal from psychiatric drugs (antidepressants, antipsychotics and benzodiazepines). There were approximately 1700 respondents, 319 of whom were antidepressant users living in the U.K. This report summarises both the quantitative and qualitative data on the U.K. antidepressant users (319) who reported their withdrawal experience.

I will quote some key points from the quantitative data:

- *66.5% of people taking only an antidepressant claimed not to have received any information from their doctors on the potential risks/side effects of the AD they were prescribed*
- *44% of people taking only an antidepressant were advised to reduce the dose over a few weeks or less, with 8.6% told to withdraw cold turkey.*
- *On a scale of 0-10 (10 being the most severe withdrawal) the mean average was 8.61.*
- *Nearly all who had accessed NHS Choice or NHS111 for withdrawal support found the service unhelpful or extremely unhelpful.*

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4. SUMMARY FOR WELSH PETITIONS COMMITTEE " THE PATIENT VOICE"

Third report due for publication on 08 October 2018: **All-Party Parliamentary Group: Prescribed Drug Dependence. Aug 2018 " The Patient Voice" An analysis of personal accounts of prescribed drug dependence and withdrawal submitted to petitions in Scotland and Wales.**

This report was researched and written by Dr Anne Guy, Marion Brown (Scottish Petitioner) and **Stevie Lewis (Welsh Petitioner),** with additional support from: Susan Reid, and Karen Espley; for response analysis, David Cope, and Catherine Maryon. This report has been made possible by all those who responded to the two petitions and the Petitions Clerks who published them.

The report collates and analyses 158 personal accounts of people impacted by prescribed drug dependence and withdrawal (specifically for antidepressants and benzodiazepines) that were submitted in response **to two petitions lodged with parliamentary Petitions Committees in Scotland[4] and Wales[5] in 2017/8.**

The report blends qualitative data in the form of verbatim quotes with quantitative data derived from a formal thematic analysis structured using a 'lean thinking' approach to process improvement. The analysis identifies eight systemic 'failure points' (**FPs**);

1. *Prescriptions were offered as an apparent first course of action*
2. *No-one said they were warned about possible side-effects or dependence and associated withdrawal effects so there was no possibility of informed consent*
3. *Treatment was sometimes continued despite drugs not helping and/or severe side effects*
4. *People experienced a lack of access to effective management / informed medical oversight of withdrawal process*
5. *Doctors did not recognise new symptoms as withdrawal and discounted patient experience*
6. *Locating the problem of new symptoms occurring at withdrawal with the individual, not the drug, leads to unnecessary action*
7. *There are no dedicated nationwide NHS services to access for help and*
8. *No effective avenues for patient feedback on their experience*

The aim of the report is a) to consider the question 'what went wrong?' in these peoples' interactions with a healthcare system intended to improve, not worsen, their wellbeing;
and b) to enable their collective voice to be heard as evidence in the consideration of the scale, harms and response needed for prescribed drug dependence in the UK.

The analysis of the submissions is represented in systems analysis Flow Chart Patient Journey Map A: 'Initial Prescription and Outcomes' and Patient Journey Map B: 'Withdrawal and Outcomes' with an additional page of 'Overall Impact' patient quotes (appended). All quotes can be referred back to the original full patient petition submission via the respective reference lettering/number given (W=Welsh).

The systems 'Failure Points' identified (see maps A and B appended) are **reflected in the NICE guidelines which are used UK-wide by GPs**:
FP1: GPs are encouraged to 'treat' symptoms of stress (anxiety, depression, insomnia etc.) – and medication is advised treatment even for mild to moderate depression (NICE GG90)[6]
FP2: The same guidance for GPs encourages them to:
Advise patients that antidepressants 'may take a while to become effective', 'keep on taking', 'may need to adjust dose and/or try another', 'are not addictive'
FP3: GPs are guided about 'relapse prevention' (NICE CG90) … ('keep on taking'…)
FP4: NICE Guidance for GPs about tapering and ending antidepressant treatment[7] is unrealistic for patients, too swift, and withdrawal effects attributed (by doctors) to 'relapse'.
FP5: Patients are not believed. Withdrawal symptoms (many of which are of a physical nature) are not recognised: instead the doctors are misdiagnosing as 'medically unexplained'.
FP6: Problem located with patient 'medically unexplained symptoms' (MUS) – and suggested that person's 'underlying condition' and/or unreasonable 'anxiety' is the problem.
FP7: There is no support – as withdrawal is not recognised
FP8: There is no way that patients can 'feed back' what is happening to them – and if they attempt to do so they are disbelieved and seen as 'difficult' patients.

Suggested preventative actions are identified including; increasing the availability of alternative responses to medication; educating the public about what psychoactive drugs actually do; amending and updating guidelines and training for doctors to enable truly informed consent, the provision of a service based on more current evidence about the prevalence, duration and symptomatology of withdrawal and how it is best managed.

To alleviate the suffering of those currently experiencing withdrawal the BMA's 2015 key policy recommendations[8] need to be implemented urgently; to create a national helpline for prescribed drug dependence and to create dedicated support services. (This was reiterated in the response to the committee from BMA Wales on 06 February 2018[9]). The suffering described in the petition responses requires systemic rather than individual solutions.

Ultimately this (APPG-PDD) report summarises the experience of only 158 people who submitted their accounts to these two petitions but who might be said to represent all those:

- who have not yet tried to come off their medications,
- do not realise there is an alternative narrative to the one they are hearing from their doctors,
- are too ill to tell their story or
- have not survived to tell it.

"I hope you make change, not only for the thousands of us that are suffering now, but for the hundreds of thousands that are currently on prescriptions, ignorant and unaware. This issue is as big as the current opioid crisis and the time for change has come" **(W4)**

Appended: 3 report pages - Patient Journey Map A; Map B; Overall Impact.

5. FURTHER ACTION

From the evidence submitted by the 7 Area Health Boards it is clear that there is not a unified health service across Wales. But from my research it seems that the Substance Misuse Framework is meant to be adopted countrywide. I would like to formally request that the Petitions Committee considers bringing together further experts to provide evidence on how we might formulate a Wales-wide Prescribed Drug Dependence Framework to implement the findings of these reports across the 7 AHBs. I recommend this group includes Dr David Healy, psychiatrist and expert on SSRIs and PDD, Bangor University; Professor John Read, author of "*A Systematic Review into the Incidence, Severity and Duration of Antidepressant Withdrawal Effects: Are Guidelines Evidence-Based?*" plus other published works about PDD; Ms June Lovell, manager of the NHS funded Prescribed Medication Counselling Service[10] in Mold (the only service of its kind in the UK); Ms Josie Smith, National Lead for Substance Misuse Also present should be people with lived experience of PDD – James Moore, Caldicot; Baylissa Frederick, Cardiff; Shane Cooke, Mostyn, all of whom wrote in with their stories to this petition; and Aled Jones, Cardiff, also with lived experience, who has set up PAST[11] (Prescription Awareness Support Team).

References

1.Letter to TIMES 24 February 2018 'Pills for depression' by Profs Burn and Baldwin
2.Letter to TIMES 23 February 2018 'Stigma and efficacy of taking antidepressants' by James Davies et al
3. https://www.theguardian.com/science/2018/feb/21/the-drugs-do-work-antidepressants-are-effective-study-shows
4. Scottish Petition PE01651: http://www.parliament.scot/GettingInvolved/Petitions/PE01651
5. Welsh Petition PE-05-784: http://www.senedd.assembly.wales/mgIssueHistoryHome.aspx?IId=19952
6. https://www.nice.org.uk/guidance/cg90/chapter/1-Guidance
7. https://cks.nice.org.uk/depression#!prescribinginfosub:31
8. https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/prescribed-drugs-dependence-and-withdrawal
9. http://www.senedd.assembly.wales/ieIssueDetails.aspx?IId=19952&PlanId=0&Opt=3#AI41808
10. http://www.nhsdirect.wales.nhs.uk/localservices/ViewLocalService.aspx?id=2556&s=Health
11. https://past.wales/

Patient Experiences of Prescribed Drug Dependence - Patient Journey Map A: Initial Prescription and Outcomes

Patient Lens

Medical Lens

Prescribed Drugs Lens

Patient Community Lens

FP1 "If I had been offered a talking therapy 17 yrs ago instead of mind numbing, habit-forming drugs that my life, career and health would be in a much better place than it now is" (V)

FP2"GPs and psychiatrists have never warned me of the side effects [of venlafaxine] or difficulties I might face in withdrawal. They have all however been very keen to increase dosage and discharge me" (AAAAAAAA)

FP2"My baby…had convulsions at 8 hrs after birth directly attributed to withdrawal from maternal Anafranil [antidepressant]. Psychiatrist unaware this could be a problem"(C)

FP3"Doctors didn't tell me about such severe side effects, not to mention about them persisting for years on" (OOOOO)

FP3 "Over time, the tablets have no effect and toxicity occurs, of which doctors do not warn a patient. Massive anxiety, depression, suicidal thoughts, anger outbursts, to name a few" (ZZZZZ)

FP3 When I started taking Venlafaxine around July I was suffering low mood and migraine pain. By October my mood was completely haywire. Big highs followed by big drops. I went to my local GP who increased the dose. My mood deteriorated rapidly and my mood which was already highly unstable became totally unstable and I was experiencing highs and deep lows within matter hours as opposed to over the week. I thought I was losing my mind." (PPPPPPPP)

Life Event

Illness	13%
Trauma	11%
Bereavement/other	5%
Work Stress	8%
Having a child	8%
Other	4%
Not said	51%

Initial Symptoms

Psychological	**68%**
Physiological	**14%**
Both	**2%**
Not Said	21%

Drug taken - did it help?

Yes	16%
No	**36%**
Not Said	48%

Were there side effects?

Yes	**67%**
Not said	33%

Consultation with doctor

GP / Dr Response*	
Given a prescription	**97%**
Offered talking therapy	**5%**
Lifestyle advice	**0.6%**

Warned re: side effects?

Yes	**82%**
No	1%
Not said	17%

Warned re: dependence & withdrawal effects?

Yes	**0%**
No	47%
Not said	53%

Consultation with doctor

Doctor response/s*	
Tried alternative drug	32%
Tried additional drug	35%
Adjusted dosage	28%
Didn't acknowledge side effects	**21%**

FP1 Lack of alternative interventions to drugs

FP2 No warning re: dependency & withdrawal effects = no informed consent

FP3 Drug treatment continued despite drugs not helping and /or severe side effects

Type of drug prescribed

Anti Depressants	67%
Benzos/Z drugs	24%
Antipsychotics	3%
Other	3%
Not said	3%

1st prescription	ADs	Benzo / Z drug
1960s	1%	3%
1970s	3%	11%
1980s	1%	5%
1990s	19%	16%
2000s	26%	**37%**
2010s	**37%**	21%
Not said	13%	8%

No. of side effects	
1-4	**37%**
5-10	**24%**
11+	**6%**
Not said	33%

Side effects included			
1	Agitation	6	Mania
2	Brain fog	7	Paranoia
3	Brain zaps	8	Psychosis
4	Burning sensation	9	Sexual function change
5	Insomnia / worsened	10	Suicidality

* Up to 3 answers recorded per petition responder

FP = Failure Point

Patient Experiences of Prescribed Drug Dependence – Patient Journey Map B: Withdrawal and Outcomes

Patient Lens

FP4 “Whilst on and trying to get off these meds (mainly SSRIs) I've experienced Incredible denial and confusion amongst GPs and psychiatrists. At the point where 4 different psychiatrists gave me 4 different diagnosis's and prescriptions in the same month this became very clear. You're essentially on your own on this journey, and no, your friends and family probably won't understand” (CCCCCC)

FP5 “...my psychiatrist wouldn't entertain the idea of protracted withdrawal. My psychiatrist kept saying my symptoms were somatic or medically unexplained” (YY)

FP 5 “The first time that I felt some sort of control over my condition was when we went for the second opinion – and everything that I said was BELIEVED. That...is vital to coping with dependence and, again, in withdrawal” (W10)

FP6 “the doctor started talking to me and acting like i was a junky he advised that I stop taking them immediately” (SSSS)

Withdrawal suggested by	
Patient	54%
Family	1%
GP	11%
Other person	5%

Withdrawal attempt

Result of attempt **82%** had new symptoms

Impact of combined effects is severe - 91%

Breakdown in relationship between Dr and Patient

Patient experience of Dr	
GP denied it was withdrawal	12%
GP helpful but inaccurate	15%
GP unhelpful and inaccurate	42%
GP denied, unhelpful or inaccurate total	**69%**

Patient seeks help elsewhere

Overall impacts on patient			
Loss of job:	47%	Loss of relationship	17%
Loss of home:	9%	Financial hardship:	35%
Loss of friends:	20%	Loss of hope:	27%
Profound loss of health and wellbeing:			82%
Average no of years impacted:			**15**

Medical Lens

Who oversees withdrawal?	
Self managed	35%
Own GP	23%
Not said	27%
Specialist	8%
N/A	6%
Other medic	1%

FP4 Lack of access to effective management of withdrawal

GP / Dr response

GP/Dr recognition of new symptoms as withdrawal	
Yes	12%
No	**47%**
Not said	35%

FP5 GP/Dr not recognising symptoms as withdrawal and not believing patient's experience

Actions taken*	
A&E visit	7%
Hospitalisation	15%
Original drug reinstated	16%
Polypharmacy	17%
Other diagnosis (incl MUS)	25%
Slower taper	22%

FP6 Locating the new symptoms with the person not the drug leads to unnecessary action

FP8 No effective feedback route for patients voice

FP7 No dedicated NHS support for PD withdrawal

FP4 “My prescriber came up with a month-long taper plan, which I followed to a tee. The mental and physical anguish that ensued is something I still can't put into words to this day, and was a thousand times worse than the anxiety I originally intended to treat. When I called my prescriber, she told me they had nothing to do with the Klonopin taper” (UUUU)

FP6 “I got no help from my doctors. Due to the extreme involuntary movements, my neurologists diagnosed me with a “functional movement disorder”, migraines, and chronic fatigue syndrome. I had none of these issues before taking and stopping the Venlafaxine” (GG)

Prescribed Drugs Lens

Number of symptoms by drug type	Not said	1-5	5-15	16-25	25+
ADs	18%	30%	34%	12%	7%
Benzos / Z drugs	13%	16%	42%	16%	13%

List of symptoms

1	Adrenal problems	9	Blood sugar disreg	17	Confusion	25	Dysphoria	33	Hairloss	41	Itching (severe)	49	Movement disorder	57	Restless legs	65	Swollen throat,tongue, hypersalivation
2	Agitated	10	Brain fog	18	Intrusive thoughts	26	Electric shocks	34	Headaches	42	Jaw clenching	50	Nightmares	58	Scalp pains	66	Sweating
3	Akathisia	11	Brain zaps	19	Crying spells	27	Eyesight problems	35	Hpa & hpg axis disregul	43	Joint pain	51	Numbed feelings	59	Seizures	67	Teeth feel spongy
4	Anaemia	12	Breathing problems	20	Crushed under own weight	28	Exploding head syndrome	36	Hot & cold flushes	44	Memory loss	52	Palpitations	60	Sensory over stimulation	68	Tinnitus
5	Anger (extreme)	13	Burning sensation	21	Depersonalisation	29	Fainting	37	Hunger (extreme)	45	Migraines	53	Panic attacks	61	Sexual function change	69	Tremor
6	Anhedonia	14	Chronic fatigue	22	Depression	30	Flu-like symptoms	38	Hypersensitivity to noise	46	Mood swings	54	Pins & needles	62	Stabbing pains all over	70	Urination - inc frequency
7	Anxiety	15	Compulsive behaviour	23	Distorted perceptions	31	Gut/digestive problems	39	Insomnia / worsened	47	Muscle spasms / pain	55	PTS response	63	Stomach cramps	71	Vertigo
8	Bloated	16	Concentration probs	24	Dizziness	32	Hallucinations	40	Invol muscle movements	48	Nausea / vomiting	56	Psychosis	64	Suicidality	72	Weight change

Patient Community Lens

* Up to 3 answers recorded per petition responder, 2 for helpful sources of information

FP7 “I have nobody I can discuss any of this with and I am really shocked that there is no support or information whatsoever available to people in my position” (W6)

Helpful sources of information*	
Websites	35%
Precription drug charity	8%
facebook groups	18%
NHS	1%

FP7 “The surviving antidepressants group has been an oasis for me” (BBBBB)

C: Overall impact on patients

"I was once a qualified primary schoolteacher… now I am suffering intolerable symptoms through Benzo Withdrawal Syndrome. I can't do anything with my 8yr-old. My partner goes out to work and leaves me bedridden with plates of food …" (CCCC)

"I was an avid gym-goer, dedicated to my fitness. I have never suffered physical illness in my life, prior to Citalopram. Now I have been so crippled with debilitating symptoms .." (DDDDD)

"As a consequence of all of this my wife's health has deteriorated rapidly over the years. She has gone from a normal functioning person, working and studying to being completely incapacitated. She has always taken care of her self through diet and exercise and does not drink or smoke, but yet a legally prescribed pill has left her this way" (AAAAAA)

"I was fully functioning working full time as accountant several staff under me, driving socialising dating - fully normal life. All taken away from me, driving included" (YYY)

"I don't believe I will ever again be the productive, happy, sociable person I used to be because of one 10 minute appointment where a GP decided it was appropriate to prescribe me SSRIs with no warning of possible side effects." (W6)

"Words cannot describe the utter hell , torment and terror that I have lived thru and continue to battle thru every single day and not one ounce of help, empathy or sympathy from any doctor" (YYYYYY)

Overall impacts on patient			
Loss of job:	47%	Loss of relationship	17%
Loss of home:	9%	Financial hardship:	35%
Loss of friends:	20%	Loss of hope:	27%
Profound loss of health and wellbeing:			82%
Average no of years impacted:			**15**

"Before I was put in this situation I was a 'normal' person doing things like most people are doing, have always supported myself, working full time. I have lost all savings, small investment and close to losing my home" (YYYYYYY)

"They took away my meds
They hung me out to dry
My world began to crumble
And all I did was cry
The paramedics came around
They rushed me to A & E
They said, carry on as normal
It's only anxiety
My body shook n shuddered
My mood was mean and low
I pushed away my loved ones
I wanted to die, just go" (VVVV)

"I am unable to work and housebound. Withdrawal is the single most gruelling and challenging experience of my life and I know that I am far from alone. I understand what is happening to me, many don't and are frightened by it" (W5)

"I continue to fight to get my life back , I could write a novel on the amount of suffering I have endured thanks to SSRI use. It has effected every part of my life , I can't work , I am not able to be active and even worse I can't get help because the prescribers are in the dark about the true harms of the drugs they prescribe" (XXXX)

"I regressed from an amateur international athlete to a very ill, depressed and withdrawn individual. At low points I considered suicide" (XXX)