

**Shame, trauma and self-harm:
when self-harm is a sane response
to an insane world**

**Merinda Epstein
Our Consumer Place**





ourconsumerplace.com.au

RESOURCE CENTRE FOR MENTAL HEALTH CONSUMER DEVELOPED INITIATIVES (CDI)

- Our Consumer Place is a resource centre run entirely by people diagnosed with "mental illness" (we choose to call ourselves "consumers").
- We provide information, training, support and advice to consumer-developed groups and projects.
- We also support what we call "consumer perspective" recognising that the lived experience of "mental illness" provides a crucial source of insight that is of value and must be respected.
- We believe that we are part of an important cultural shift, towards valuing and respecting the lived experience of "mental illness."
- We are recognised internationally
- We are the only consumer organisation in Australia that has a special area of interest in self harm and Borderline Personality Disorder

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QUOTE FROM A YOUNG HOMELESS WOMAN
CIRCA 1993. FROM "IN A NUTSHELL"

Attacking Self Harm?

- Why do we want to attack something that's the outer expression of souls that have been attacked enough already?
- **Reframing:**
 - Attacking shame
 - Attacking trauma
 - Attacking social dislocation, despair, alienation, unsafe places, unsafe people

Three Different Faces of Self Harm

The self harm that others can see

The self harm that no one else knows about

The self harm that is endemic

The self harm that others see

Cutting, burning, amputating, stabbing, slicing, overdoses of prescribed drugs, cocktails of prescribed and illicit drugs

This is what people generally mean when they talk about self harm

Much social & medical prejudice against people who self harm in these sorts of ways

All ages all stages all cultures all life situations

Different from 'suicide' attempts. Consciousness studies outline the different thinking people have

After my introduction the remainder of this talk will be focussed on this very overt demonstration of self harm

The Self harm that no one else knows about

Very hard to keep self harm secret and yet many do. Most of us get severe 'anxiety' experiences because we are terrified we'll 'get caught'. Subterfuge is for the brash and the confident and most of us are neither. Often the pattern of self harming feels out of our control. However we still can't tell anyone because of the shame (you're not supposed to want to be in hospital for example) or because we are protecting others close to us.

Examples of hidden self harm: over use of prescribed medication but never to the point of overdose; 'accidental' burning and/or falls; infecting wounds, scratching skin into an infected mess...

These forms of self harm are dangerous both psychologically and physically and we are on our own. It does not attract the overt prejudice that is experienced by people who 'live' in casualty departments but secret self hate is pretty bad.

Can go on for twenty plus years of living a lie before anyone else finds out and by then it's a way of living with terrible ongoing consequences.

If psychiatry or other medical professionals catch us we are likely to cop the totally unhelpful labels of somatoform disorders, factitious disorders and/or a whole raft of personality disorders. There is as much good reason not to be 'caught' as there are psychological reasons not to live a lie.

The self harm that is endemic

Most people in this auditorium sometimes behave in ways that are harmful.

There are socially acceptable ways to self harm and socially unacceptable ways to self harm. This does not make one subset 'good' and the other subset 'bad'.

The socially sanctioned ways that people self harm or potentially self harm include high risk sports, high risk adventuring, going for records by defying the elements, smoking, eating foods that aren't good for you, racing motorcars and motorbikes, prostitution, unprotected sex, ... and so on.

Who are we as a mental health community to make moral judgements about other people who self harm in these ways.

Sometimes we even make heroes out of people where there is a paper thin line between hero and 'self-harmer' (sic).

My focus is...

- **My friends and me – not (never - ever) ‘the other’ – ‘the objectified other’;**
- Chronic self-harming over relatively long periods of time;
- **The ignored and judged nobodies;**
- The irritating unexplainable (on the surface and to the service);
- **Those who just won’t take responsibility for their lives;**
- ‘Ugly personality disorders’, ‘the borderlines’, ‘somatoform disorder’, so called ‘factitious disorder’ as well as other ‘mental illnesses’.
- **Those of us who look like we have NO excuse for over-utilisation of services meant for others.**

NATIONAL INSTITUTE OF CLINICAL EXCELLENCE (NICE Reports)

England: Two major reports into the medical system's capacity to deal with people who self harm

- 2004: Self Harm- *The short term physical and psychological management and secondary prevention of self-harm in primary and secondary care*
- 2011: Self-harm: *longer term management*

Both reports were comprehensive and compelling but also stirred up a hornets' nest of resentment and controversy by some clinicians across the board who felt unfairly accused.

NICE GUIDELINES -2004 & 2011

The care people who harm themselves can expect to receive from healthcare professionals in hospital and out of hospital

The information people who have self harmed can expect to receive

What they can expect from treatment

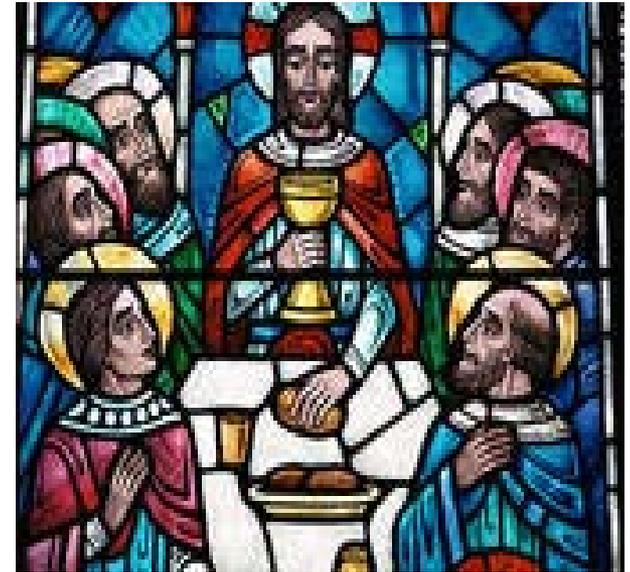
What kinds of services best help people who harm themselves

NICE Report (2004)

- The report was comprehensive and should be of interest to consumers and clinicians in Australia as well as England. For now I have pulled out two events related to the 2004 NICE report that caught my 'consumer-lensed' eye.
- 'The creation of 'The Haven'; and
- The letter from Dr Rachel James

The Haven – a pilot program that seems to have put down roots

- A number of pilot projects were funded after the 2004 NICE Report.
- Mixed success but one stands out:
'The Haven' – The Haven, the brainchild of Heather Castillo is a stand out. One of the activities for people who self-harm is the opportunity to participate in studio creating and selling stained glass products. Wow! Is that brilliant or is that brilliant!
- <http://www.thehavenproject.org.uk/Team.html>
- <http://www.guardian.co.uk/society/2004/dec/15/mentalhealth.comment>
- <http://www.thehavenproject.org.uk/Research.html>



Cut it out please



Accident & Emergency Departments featured in 2004 NICE Report. The report – claimed that A&E Clinicians were in need of education about self harm



“A&E clinicians need further training to enable them to treat people who self harm with the respect and dignity they deserved.”



Infuriated at the implied and stated criticism A&E clinician, Rachael James (pseudonym), wrote the scathing letter to the Guardian



It was what happened next that was so startling. A tumultuous landslide of doctors wrote in to support Dr. James

Dr Rachel James A&E Clinician's Letter to the Guardian Tuesday 3rd August 2004

Cut it out, please

"If people must self-harm, they shouldn't turn up at A&E afterwards demanding to be patched up", argues Rachel James



- “Any A&E doctor could tell you that in psychiatry, crisis management means rolling up at 10am the next morning, latte in hand, when the blood and vomit have been cleared away and the patient is no longer drunk and abusive.”
- “A&E is an emergency service!”
- “It seems that we are suffering from an Oprah-fication of our culture: this will be the century of the victim. Proper argument is rarely heard about important, and therefore emotive, issues because it is drowned out by the howls of victims. "I'm upset and therefore I'm right," seems to be the winning argument. When people who see themselves as victims complain about the National Health Service, their premise is never challenged.”
- “Almost without exception, we clinical staff are doing our best in the most challenging of circumstances - and we are not sorry.”

More from Rachael James...

- It is hard not to get frustrated: people who self-harm do have a choice, although it may not seem like it at the time. They should not do it, or they could do it and stay at home to deal with the consequences. Just please don't lacerate yourself, come to hospital and then complain about it.
- One imagines that people who repeatedly set fire to their own houses would get short shrift, no matter what their mental state.
- Self-harmers who attend hospitals habitually are unable to take responsibility for their own lives and actions. And it might be that being so patient and non-judgemental we are fostering that destructive cycle.

Responses to Dr. James from Doctors

- More than 50 responses from Drs. on doctors' discussion board **doctors.net.uk**
- Most agreed with Dr James
- <http://www.psychminded.co.uk>

- “I think she [Rachael James] speaks for many of us who have spent years dealing with these people and, from a psychiatric point of view, getting metaphorically pissed upon by those serial offenders who are not mentally ill”
- Consultant Psychiatrist: Dr David Bramble

- **"In my humble opinion, unless there is a robust clinical reason for not doing so, they should be encouraged to apologise for and, perhaps even, pay towards the costs of their wilfully immature behaviour."**
 - Consultant Psychiatrist

- **Most self harming patients "will merely be displacing more needy but less dramatic patients . . . [The NICE Guidelines just increase] . . . "the influence of the nanny state, while totally ignoring a fundamental breakdown in the fabric of society . . . These days, when something goes amiss, it is always the services which have "failed" the individual. The individual is never considered to have "failed" society.**

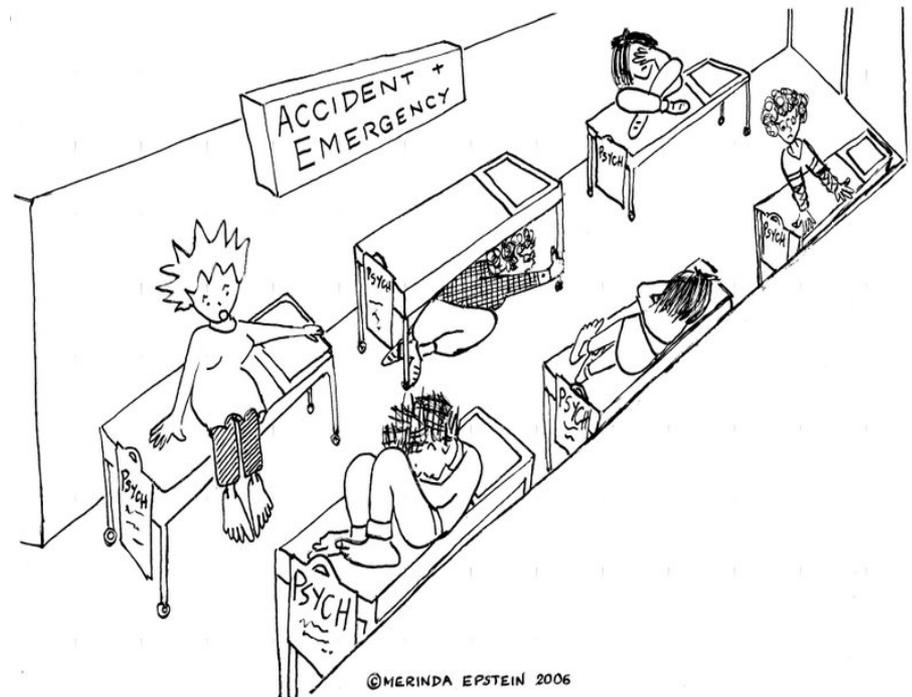
- Consultant Psychiatrist Dr Robert Davies

“Psychiatrists rebuke colleagues over remarks on self harming patients” - Dr Adam James

- There were some dissenting voices
- Interestingly they seemed to be younger doctors
- A senior house officer, Dr Carolyn Nahman, wrote:
"I don't approve of antagonizing/being rude/unhelpful to self-harmers - it doesn't help them or the staff dealing with them."
- A staff grade psychiatrist, Dr Silke-Yvonne Habel, added:
"It's not the patient who is chaotic, but the service. If the service isn't chaotic, then the patient doesn't need to seek attention by creating more chaos. You need to offer separate services and dedicate time."
- http://thestressoflife.com/psychiatrists_rebuke_colleagues_.htm

The compelling reasons why A&E clinicians do need education

- The two **'good'** comments above still use language and make assumptions that are deeply problematic to consumers. The use of language such as 'attention-seeking', 'making chaos' and calling people 'self-harmers' is all a problem.
- The education that we need to be provided to A&E clinicians must be consumer-led; BUT the fracas following the Rachael James letter identifies the need for astute sensitivity to deter other groups of clinicians from reacting defensively. Many excellent pedagogues in the consumer arena will be an invaluable asset.
- A&E is an area of high priority for reform for consumers who self harm



Good story from a consumer— unfortunately in the minority

- *“ One of the sisters in A&E has stood for an hour stitching me up . . . they’ve never turned around once and said, “you’re a pain in the arse for keeping coming in. Why do you do it?”*”

2007 literature review for SPECTRUM –The State-wide Personality Disorder Service

- Read 376 articles about self harm and about Borderline Personality Disorder;
- Some of the literature was ‘grey’ literature. We desperately need to challenge the status of this informal, local, grounded material. It provides a different perspective on what is and what is not knowledge.
- Much of it was also from the professional literature
- Much was about self-harm beyond the Borderline tag

- "A new kind of stigma has arisen in services. It applies to legitimacy. The mark of infamy is no longer that of being mad but rather that of not being mad".

- Anne Olsen & Merinda Epstein in Mental Health in Australia: Collaborative Community Practice (2007) Graham Meadows, Bruce Singh and Margaret Grigg (eds) p. 17

What people who self-harm said they thought clinicians thought of them (2007)

As told by patients/consumers

1. Wilful – we do it all on purpose;
2. Disruptive;
3. Attention Seeking;
4. Cries for help;
5. Difficult;
6. Manipulative;
7. Weird way to get our needs met;
8. Not even a proper suicide attempt;
9. Dependent;
10. Demanding and difficult;
11. Time wasting;
12. There to create chaos;
13. Need punishment;
14. If they come wanting sympathy they won't get it;
15. Can put our dressing on themselves;
16. We did it, we do the time – wait till last;
17. We never feeling anything – its just behaviour;

Research 2007 –literature review – what clinicians actually did think of them!

1. These people are attention seekers;
2. These people are narcissistic;
3. These people deliberately want to traumatise clinicians;
4. These people are always pushing the boundaries;
5. This behaviour is totally unacceptable;
6. This is simply a behavioural issue;
7. These people make choices;
8. These people play victim and get away with it;
9. It is always everyone else's fault except the person who self mutilates;

A&E clinician's comments cont.

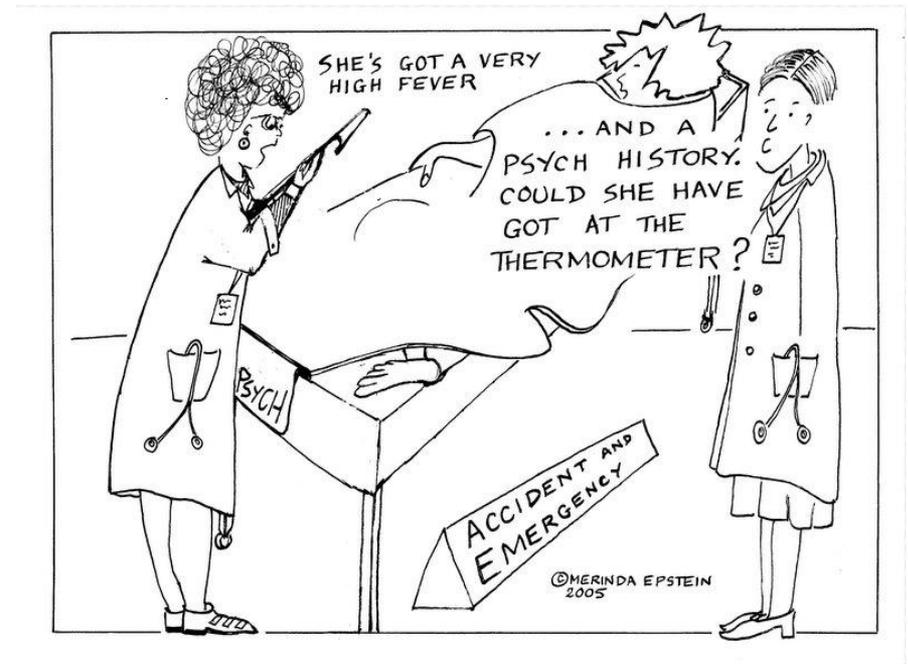
10. These people use up clinician's precious time that should go to more deserving patients;
11. We need to control their behaviour by making them sign contracts collaboratively;
12. These people get psychological gains from causing chaos;
13. We need to control the behaviour by setting limits;
14. These acts are deliberate and controllable;
15. I'm afraid I lack sympathy;
16. We are not resourced to deal with this;
17. This is not a medical issue;
18. Need to apologise to us and other patients for wasting everyone's time.

Reasons clinicians in A&E gave for people self harming

1. **They've got problems and they're trying to fix them but they're not medical;**
2. They're addicted to the A&E Department, self harm is addictive;
3. **They crave attention and unfortunately we can't give it to them;**
4. They self harm to stay in control. It's a power trip for some;
5. **They like the chaos and energy in an A&E department;**
6. It's sad. I don't know why they keep coming back but they seem to be doing something they need to do.
7. **They're just habitual trouble makers and enjoy the fuss they can make.**
8. They want to be mothered;
9. **They lack self-control and hurting themselves physically is just a habit**
10. Its all about manipulation of everyone around them;
11. **They are impulsive;**
12. They get some sort of high from causing chaos;
13. **They haven't got basic social skills;**
14. They are just difficult and demanding people who put their demands in such a way that they can't be ignored.

84 explanations why people self-harm

- A&E clinicians seem to be stuck on such a few ways of understanding self-harm (narcissism, creating chaos, wilfulness, attention seeking etc.)
- In my review of the literature I found 84 reasons people gave for self-harming.
- I have included the whole list here (including a few double ups which helps us understand some of the more common themes)
- It is not necessary to read them all
- It is necessary to appreciate the huge gap in knowledge between the perspective of A&E clinicians and the perspective of those of us who self harm.
- Once again there are issues for all of us to understand about the seriousness and suffering people experience and the secondary harm from a system which reckons punishing us for our wilful behaviour isn't such a bad idea.



Explanations by people who self harm

1. I self harm **to test that I am still alive;**
2. it's sort of to get someone to see how much I'm hurting;
3. **I give my body up as a sacrifice;**
4. it gives me the ultimate control over my body;
5. **to let him know he can't treat me like that;**
6. to purge myself;
7. **it's a distraction from the pain;**
8. to deal with emotions women are not supposed to have;
9. **to deal with emotions that I don't think I can survive;**
10. I had become dependent on it;

Explanations by people who self harm

11. to let my Mother know she should have protected me;
12. so I wouldn't suicide;
13. diminishes emotional intensity;
14. it helps me deal with highly stressful and painful experiences;
15. as a means of coping with life;
16. managing anger, fury or rage: better me than someone else;
17. it's a way of getting people to notice that I'm alive;
18. I use self harm sometimes when I can't find any words;
19. self harm is my coded message to those who can't hear me;
20. I know now that I re-enact the abuse;

Explanations by people who self harm

- 20. it had become an auto-response to stress;
- 21. self harm helps me to avoid and escape pain;
- 22. it is my code to myself;
- 23. because I was terrified I would hurt someone else;
- 24. self hatred;
- 25. it stops me being invisible;
- 26. because I hadn't been abused so I had no right to feel so bad;
- 27. because I wasn't who I wanted to be;
- 28. because I'd let my family down;
- 29. it gives me a high. Isn't that a terrible thing to admit?

Explanations by people who self harm

- 40. to relieve tension;
- 41. profound shame and guilt;
- 42. hyper-alertness to danger – hurt yourself first – before they hurt you;
- 43. to dumb down and deaden my feelings;
- 44. I was so ashamed;
- 45. to realize I'm alive;
- 46. it's my ethics: I would never harm anyone else;
- 47. when I desperately need to feel real hurt;
- 48. Guilt;
- 49. to know my body belongs to me;

Explanations by people who self harm

- 50. to stop me dissociating;
- 51. communicate internal pain;
- 52. because I mustn't ever look sexy;
- 53. because I am not allowed to speak;
- 54. when I need to see blood;
- 55. because it seemed to work for other women on the ward;
- 56. because I couldn't feel anything when I had sex;
- 57. when I hate myself;
- 58. so I could keep being part of the group;
- 59. because I didn't know who I was;
- 60. because I wanted him to love me;

Explanations by people who self harm

61. when I'm scared my thoughts are perverted or the thoughts themselves can hurt people;
62. when I had the impression I was not being taken seriously;
63. when I need to feel really human;
64. transferring pain to a place I can handle it;
65. because sometimes inside no one can handle it but I know the body can;
66. not to die but to live;
67. because I am brave with blood and physical pain and I can forget I am terrified of emotional pain;
68. to stay alive;
69. the fact that I am imperfect and made mistakes infuriated me;
70. because I was disgusting;

Explanations by people who self harm

72. when I felt I had been 'abandoned';

73. boredom;

74. when my thoughts needed to be stopped;

75. when I felt like a 'loser' – at least I was capable of withstanding physical pain;

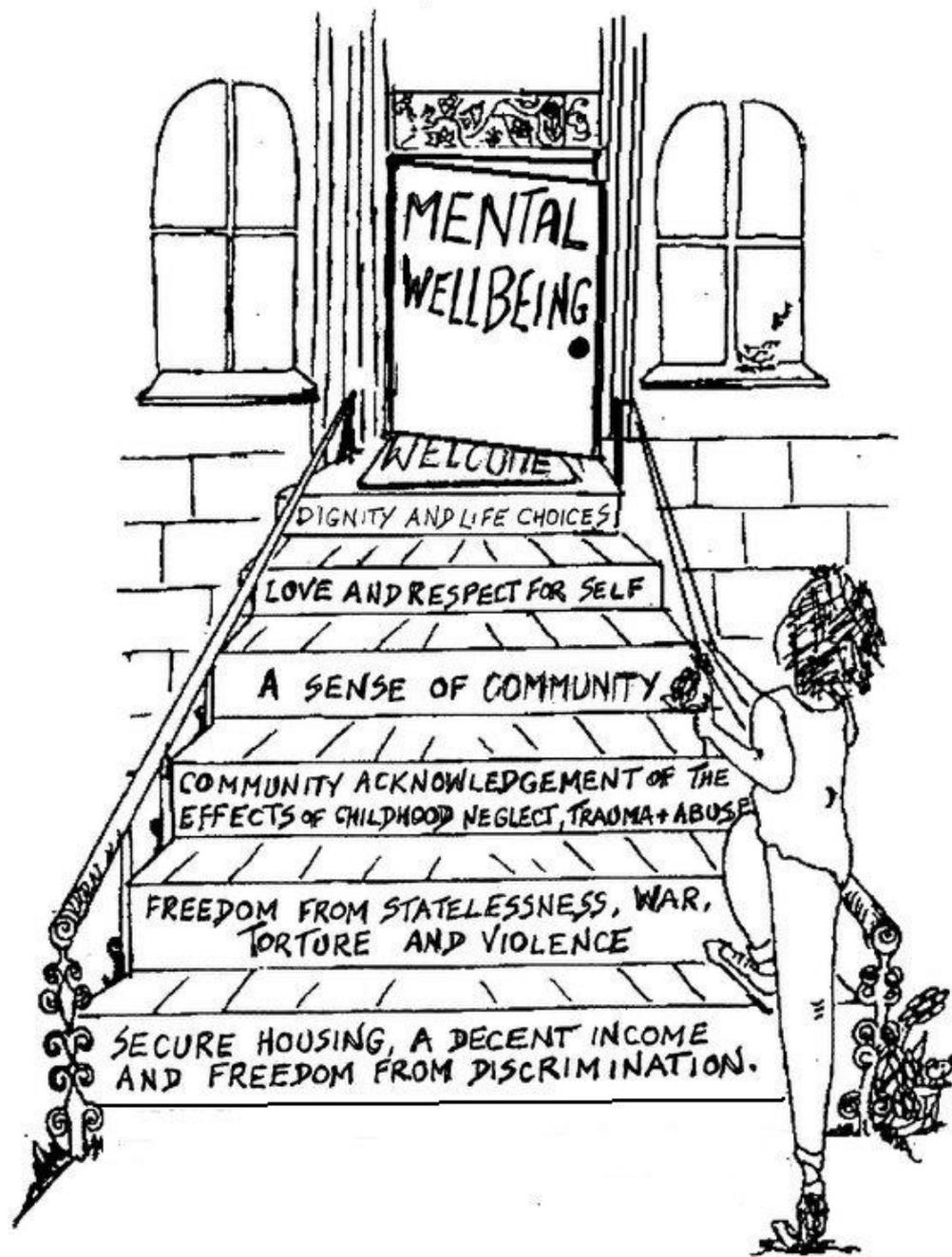
76. when I felt my identity 'dissolving'- gave me an identity to cling to;

77. because it is the only way I know I am alive;

78. because I deserve to be punished: I am bad;

Explanations by people who self harm

- 79. because it is the only way I can get the dirt and shit out of my body;
- 80. I self harm when I dissociate: it's a way to keep grounded;
- 81. because I don't know what else to do when I am desperate;
- 82. because I need someone to help me sometimes and they won't listen to me when I ask for help;
- 83. because I am really angry sometimes and it's better to hurt myself than to hurt someone else;
- 84. I self harm because I don't have the right words inside me.



MENTAL
WELLBEING

WELCOME

DIGNITY AND LIFE CHOICES

LOVE AND RESPECT FOR SELF

A SENSE OF COMMUNITY

COMMUNITY ACKNOWLEDGEMENT OF THE
EFFECTS OF CHILDHOOD NEGLECT, TRAUMA + ABUSE

FREEDOM FROM STATELESSNESS, WAR,
TORTURE AND VIOLENCE

SECURE HOUSING, A DECENT INCOME
AND FREEDOM FROM DISCRIMINATION.

HARM MINIMISATION

- **As Part of a Therapeutic Program clinicians need to teach us about:**
- **Anatomy;**
- **First aid.**
- The first assumption is that we are not always so absently driven to self harm that we can't utilise an improved knowledge of anatomy to try and ensure we cut ourselves, for example, in a place where we won't nick a major artery.
- The second assumption is that our need to self harm is a really long lasting and difficult problem for us and that it will happen again but that often the feelings and distress that drive the self harm stop immediately after we cut or burn or whatever we do. At this time we are understood and trusted to be capable of using our knowledge of first aid to help ourselves.

- **Benefits:**
- minimises physical harm;
- imperative for those who have been treated appallingly in A&E and will no longer seek emergency assistance;
- enables us to have greater control over our lives (empowering);
- shows respect for the choices we make, including 'staying alive' through self-harm.

<http://sirius-project.org/2011/06/02/first-aid-and-harm-reduction/>

Harm Minimisation

- “It [harm minimisation] means a way of accepting and a way of talking about self harm that does not devalue people who self harm. It’s a way forward that can help people feel supported rather than chastised. Perhaps it might help medical and psychiatric staff feel less helpless when working with people who self harm. It means that maybe other people will have more positive experiences of services and not feel like a failure because they can’t stop.” Consumer 2007

IMPORTANCE OF LANGUAGE

- *Traditional orthodoxy about 'who knows', 'who is seen to know' and 'who should know' depends on our relationship to the world. Even as we construct meaning through language we ourselves are constructed as social beings by language. Too often we fail to acknowledge or even recognise that meanings are relative and do not dwell in the words themselves but in the social, cultural and historical contexts in which words are used. (Olsen, A 2007)*

Language and clinical relationships



- Some of the most judgemental language used in 'the system' is reserved for people who self-harm;
- "slashers", 'self-harmers', 'wilfully immature.. and so on.
- For consumers language is often the essence of the worker relationship and that relationship, for some, provides the only possibility of something else to hope for in their lives.
- What is not said is as important as what is said.
- People who self harm use Freedom of Information Legislation frequently. Even though it often hurts it's better to 'know thy enemy'. And that's how people think about it. Often for very good reason.

Some of the main language issues For consumers who self-harm

- **For people who self harm there are many words that are offensive but a couple of concepts are worth singling out:**
 1. **'Deliberate'** – many of us say that when we 'self harm' the urge, the degree of pain, the shadow of shame are so commanding that the act is not deliberate.
 2. **'Mini suicidal gesture'** (or words like it). This is courting fate. Sometimes huge efforts are made to only do a 'little bit' of harm instead of what our brains are yelling at us to do and when this is dismissed with zilch respect for the huge effort that has been made it is likely we will do something worse.
 3. **Not a 'real'** (sic) mental illness or not a 'real' attempt to self harm, etc. What's 'real' – what's not 'real': this affects many people who self harm and often causes more self harm as people start to believe they have to prove they are 'real' by self-harming. People are regularly refused mental health services when they don't have a 'real' something, so self-harming becomes a terrible life style with everyone judging and no one helping.
 4. **'Just behavioural'** is another use of blatantly judgemental and unacceptable language. It's dismissive, blaming, crude, pointless and a very big problem for many of us who self harm.

Language is the tool we use to think; therefore it is critical to the way we practice...

- 'the borderline'/'the schizophrenic'
- 'they', 'them', 'those' (othering)
- 'the narcissist'/'the narcissist personality'
- 'difficult cohort of females'
- 'slashers'
- 'mini suicidal gesture'
- 'acting out attempts'
- 'manipulative'/'attention seeking'
- 'non-socially sanctioned self harm'
- 'unconscious non-compliance'
- 'these difficult females'
- 'wilfully immature'
- 'Case Studies', 'cases', 'difficult cases'
- 'just behavioural'
- 'self mutilation'
- 'this population of clients'
- 'working with this population'
- 'managing these clients'
- 'Therapy-Interfering behaviours'
- 'other clinical populations'
- 'perception of abandonment'
- 'the suicidal patient'
- 'termination of therapy'
- 'caught committing deliberate self harm'
- 'para-suicidal events'
- 'difficulty engaging properly with the therapist'
- 'treatment resistant condition'
- 'Intentional' self harm

LANGUAGE IS POWER

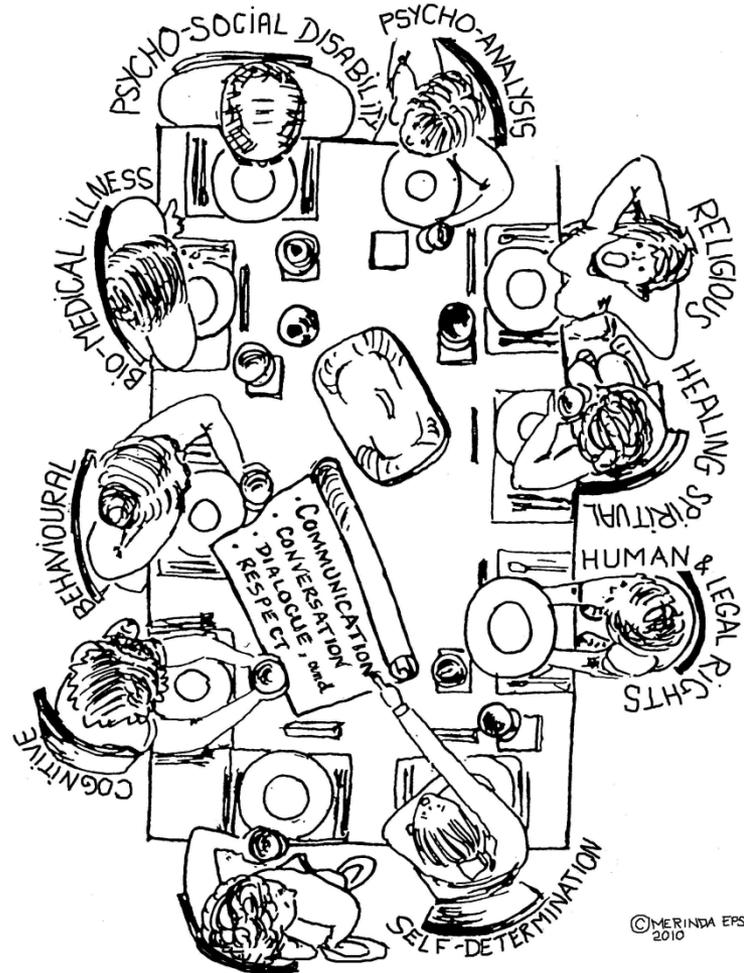
Language is power. The dominant discourse is not the consumer one. This causes major problems. Those with power don't know they have it most of the time and those who don't have it are acutely aware of it most of the time.

Language is a major challenge for 'science'

Often, even consumer-language aware researchers are forced to using disgustingly judgemental language by ethics committees. Researchers beware. Consumers hear and read your language too. You're not so rarefied that this language escapes us and it has a capacity to harm.

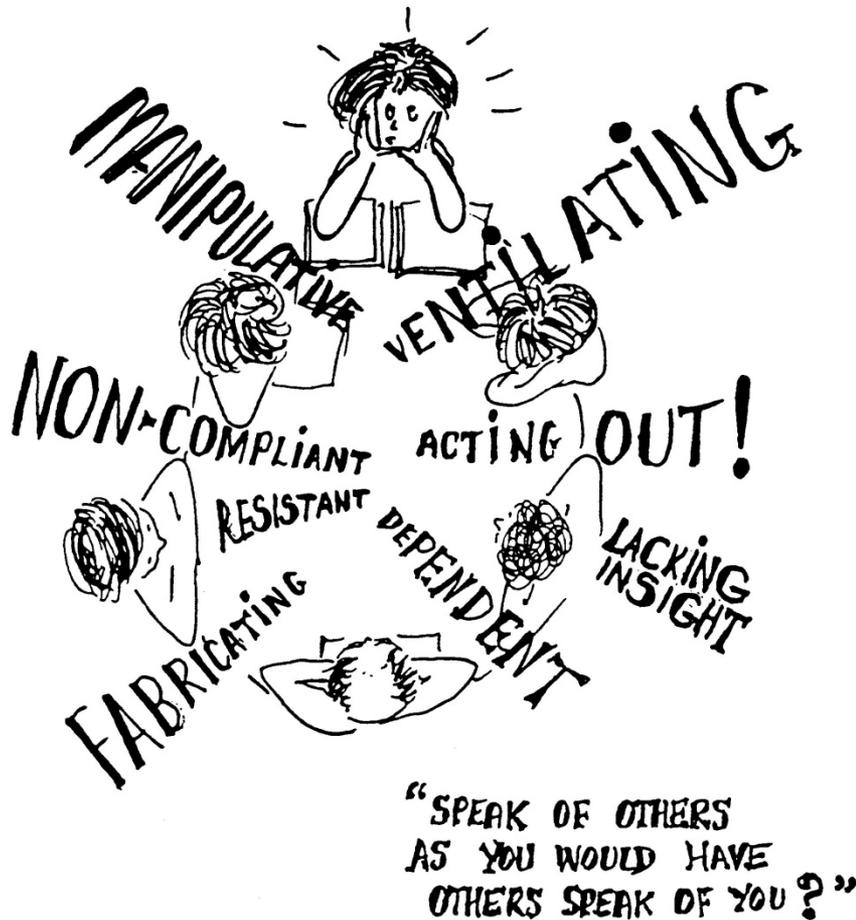
For people who self-harm language is particularly challenging. As consumer leaders we are sometime reticent to encourage people who self harm to seek out the literature because the words that are used are potentially damaging. Nobody wants to read some of the awful nonsense that is written about us as 'self-harmers' (sic).

THE FIRST SUPPER



**BRINGING THE DIS-COURSES
TO OUR TABLE**

People First language...

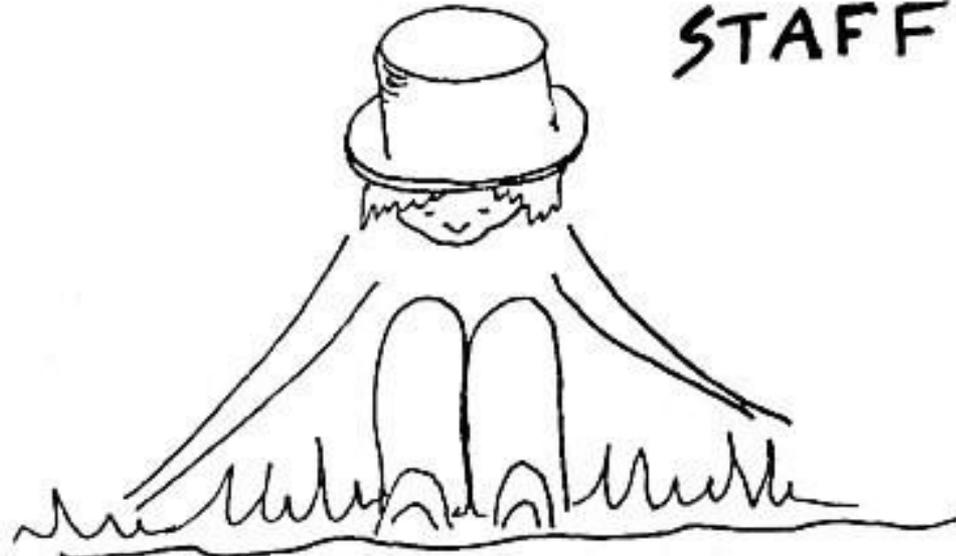


- **People who**... feel shame acutely and chronically
- **People who**... self harm
- **People who**... cut themselves

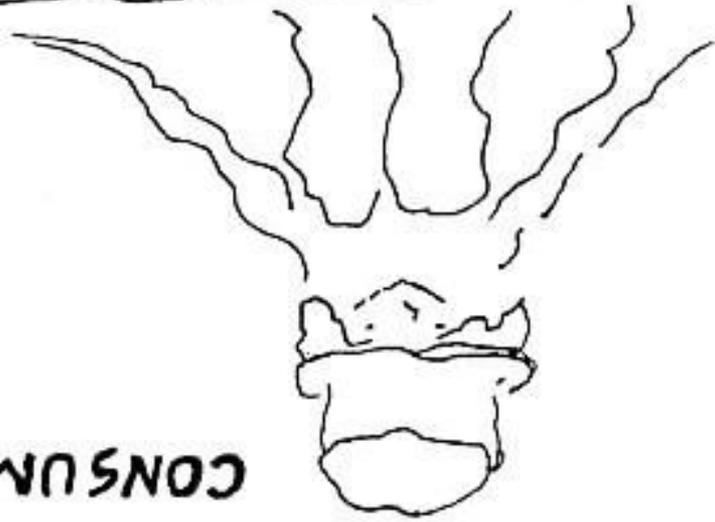
WORDS MATTER, Harold Maio and Sylvia Caras

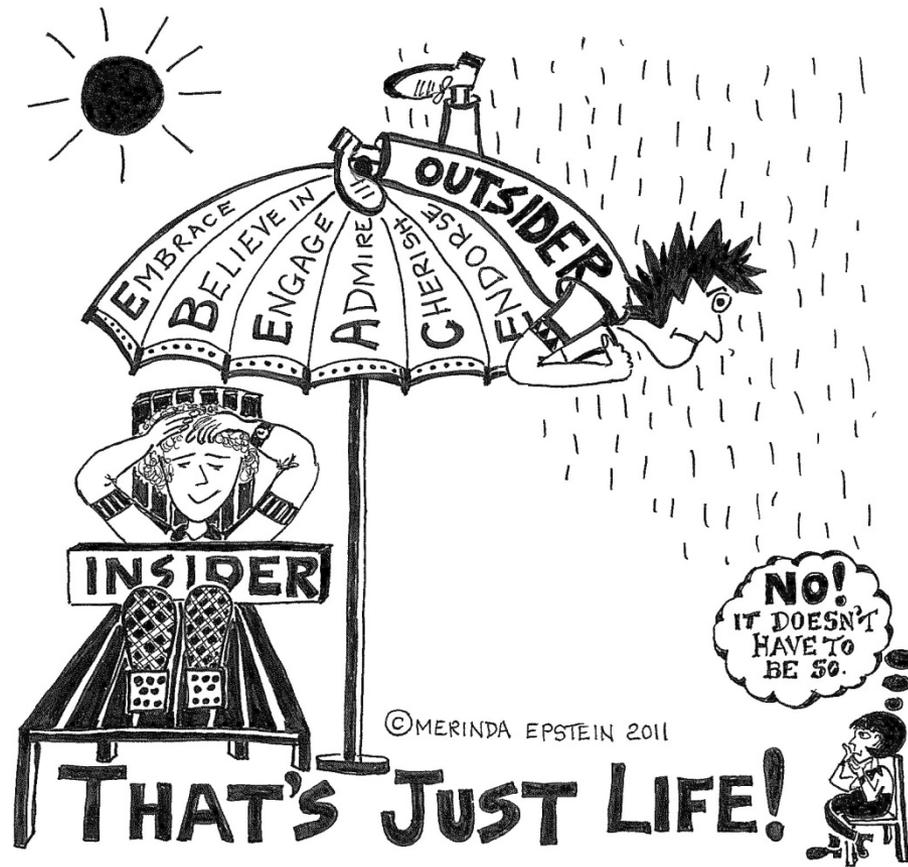
<http://www.peoplewho.org/documents/wordsmatter.htm>

STAFF



CONSUMERS





Chrissy's Story



**If you have come to help me,
You are wasting your time...
But if you have come because
your
liberation is bound up with mine,
Then let us work together.**

*Lilla Watson
Aboriginal Educator*

Bill of Rights for People who Self Harm

by Deb Martinson

- <http://palace.net/~llama/psych/brights.html>
- Deb Martinson is famous for her work in the area of self-harm. Her Bill of Rights should be displayed in all places where people who self harm come for help.
 1. **The right to caring, humane medical treatment.**
 2. **The right to participate fully in decisions about emergency psychiatric treatment (so long as no one's life is in immediate danger).**
 3. **The right to body privacy.**
 4. **The right to have the feelings behind the Self Injury validated.**

Bill of Rights for People who Self Harm

by Deb Martinson

- 5. The right to disclose to whom they choose only what they choose.**
- 6. The right to choose what coping mechanisms they will use.**
- 7. The right to have care providers who do not allow their feelings about Self-injury to distort the therapy.**
- 8. The right to have the role Self-injury has played as a coping mechanism validated.**
- 9. The right not to be automatically considered a dangerous person simply because of self-inflicted injury.**
- 10. The right to have self-injury regarded as an attempt to communicate, not manipulate.**

Nicole Emerson

- *On Tuesday afternoon I had the opportunity to momentarily gaze at the tattoo - "Psychotic and Proud" - of our keynote speaker, Ron Coleman. At first this prompted me to wonder whether the day will come when women with the so-called borderline personality disorder are able to display the marks of 'self harm' (their memorial to sexual violence perhaps) with such unfettered pride. But this hyperbole, this 'disavowed rage' perhaps, also reminded me of the unhelpful (if intriguing) battle between competing oppressions: illness versus disorder, addiction versus mental illness ... which, in the end, works to construct a hierarchy of shame that replicates the very psychiatric practice we should be critiquing.*
- *(Emerson 2006, An exploratory study: the gendered nature of discourses related to "borderline personality disorder" (BPD), unpublished PhD study*

www.ourconsumerplace.com.au/

