

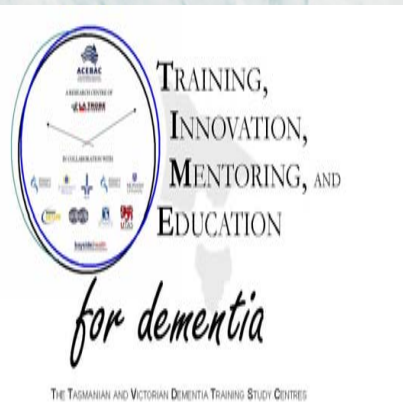
Person Centered Care: fanciful rhetoric in a climate of fear and litigation?



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What does the evidence tell us about person centered care?

- **Not much if you rely on effectiveness research**
- **Lots if you look at meaning:**
 - **Choice, respect, dignity, a sense of independence; fun; relationships; human rights...**



NOT just consulting

- **A genuine change in how we think about care**
 - Not the disease
 - Not this presentation
 - Not ‘our discipline’
 - Not our geographical space – eg acute, GP surgery, RACF, community
 - NOT what WE think is best
- **Emphasis on physical care and safety has lost sight of the person and what is significant to their experience and QoL.**



From the 'minute' to the major decisions of life and death: who should make them?

- **A computerized or paper-based care plan?**
- **Care at home or in a home?**
- **What and when to eat?**
- **To fall and break a leg or not to?**
- **To be monitored or not?**
- **To choke or not to?**
- **If and how to take medications?**
- **If/ how to express sexuality?**
- **If/ how to die?**



What can guide us?

- **YOU need evidence based practice**



So what is EBP? (Sackett et al 1997)

[EBP] ...is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine means integrating individual clinical expertise with the best available external evidence from systematic research...and client choice



Evidence Based practice?

- **The best research evidence**
- **Clinical judgement**
- **AND client choice**

- **I am going to focus on client choice**



The best evidence differs

- **Is this treatment effective?**
- **What does pain mean to this person**
- **Is it feasible to introduce a particular treatment/change**
- ...



What IS evidence?

- **Meaningfulness**
- **Many things may be effective but have no meaning for ME**
- **OR mean something different to me than to you**



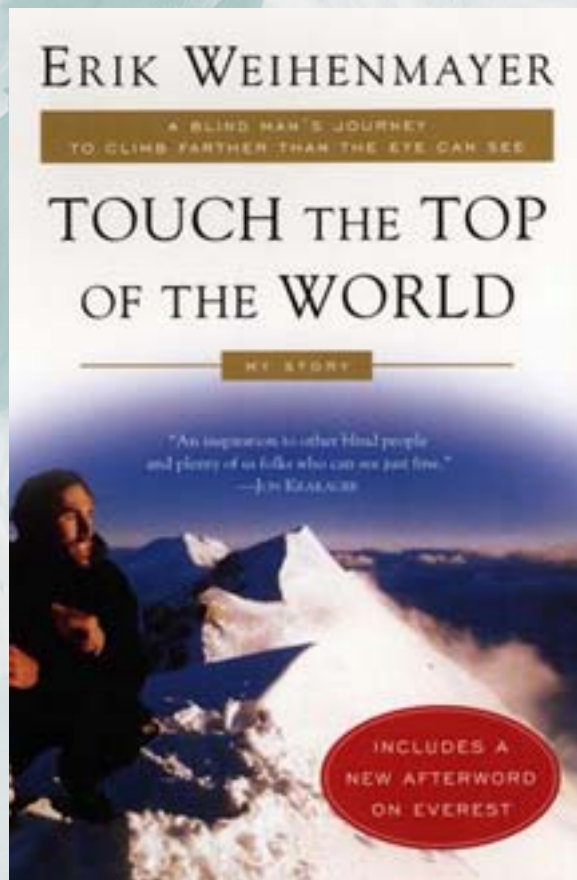
Think about your normal week

- **Do you drive a car?**
- **Take a plane?**
- **Leave electrical appliances on?**
- **Have unprotected sex?**

- **Are you overweight?**
- **Do you have the recommended exercise?**
- **Do you smoke/ drink too much/ use other drugs?**



Should he have been stopped?



Was this too big a risk?

- **A professor in a college ethics class presented his students with a problem. He said, "A man has syphilis and his wife has tuberculosis. They have had four children: one has died, the other three have what is considered to be a terminal illness. The mother is pregnant. What do you recommend?" After a spirited discussion, the majority of the class voted that she should abort the child.**
- **The Tale Of The Tardy Oxcart
Charles R. Swindoll, Word, p. 2**



Think about

- **Peter Brock**
- **Stephen Fossett**
- **Nelson Mandela**
- **Martin Luther King**
- **Roy Higgins....**

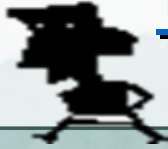


They were/ are:

- **All risk takers**
- **All admired for taking risks**
- **All take risks that some people would define as irresponsible**
- **All risking serious injury/death**
- **Should they have been restrained to protect them and save their lives?**



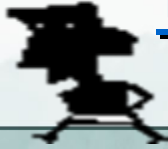
Experiencing acute 'care'



- **Ward X is very busy; The Registrar has been up all night; the phones have not stopped ringing; 2 nurses have rung in sick and the bathroom's flooding.**
- **Emmy has been aggressive, verbally abusive, impossible to shower and trying to get out of bed all night – we had no option but to restrain her to stop her hurting herself.**

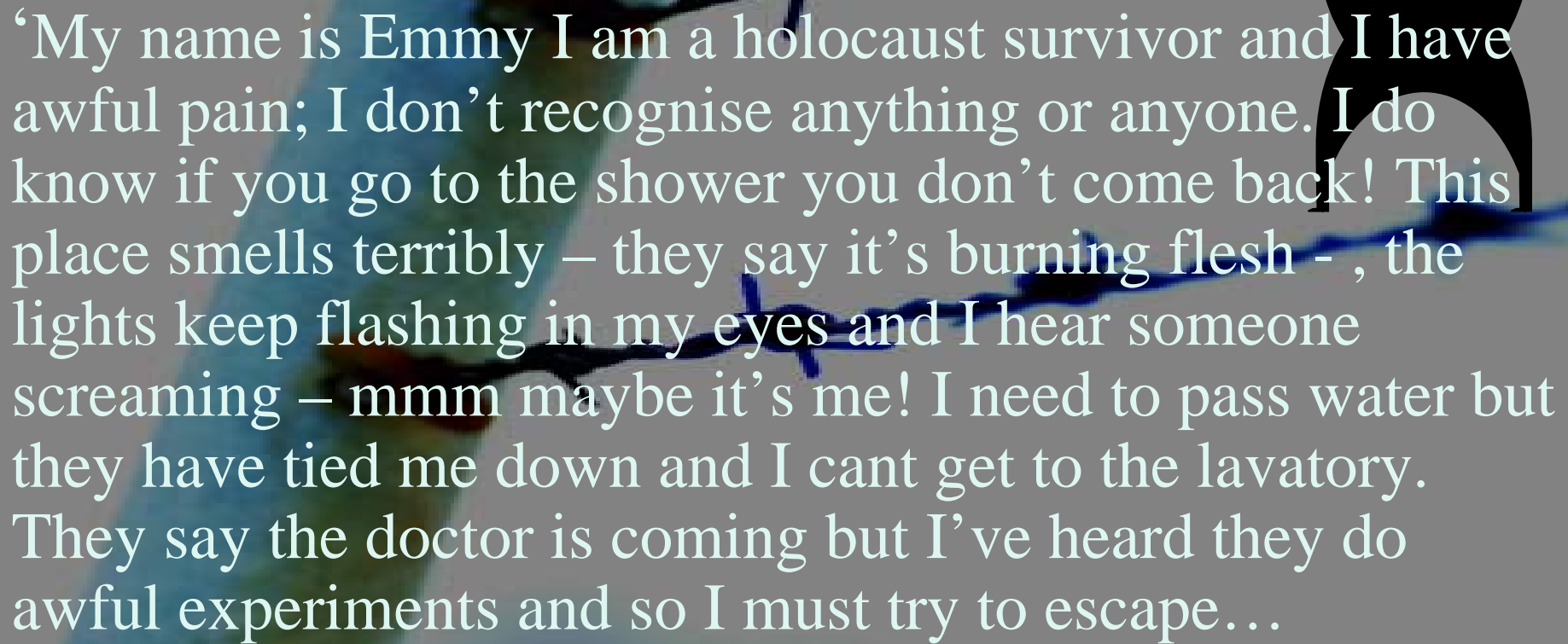


Experiencing acute 'care'

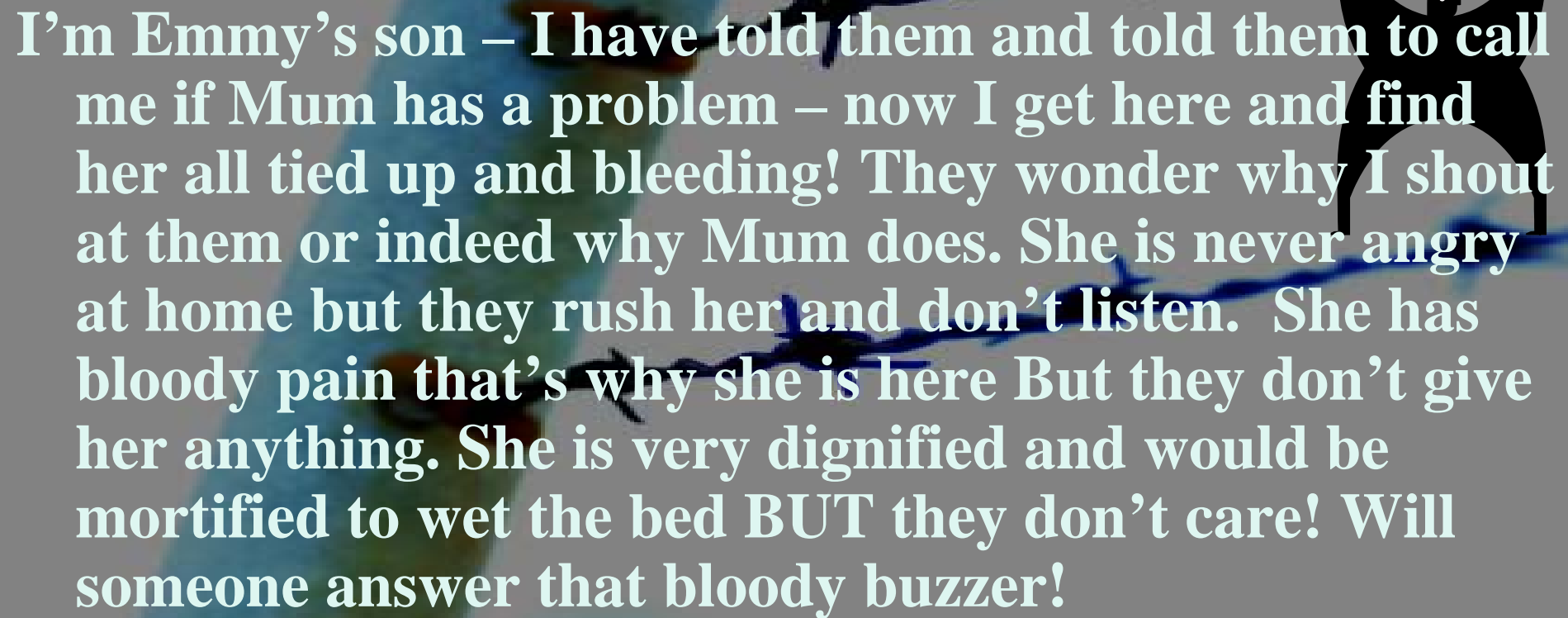


- **She nearly strangled herself in the rails so we sedated her. She then fell over the end of bed and now has a major bump on her head. The family is furious and said we should have called them earlier but we just didn't have time. We had no option but to restrain her so she would not fall again.**
- **We can't win – in trouble if she falls; in trouble if we restrain. Well we have a duty of care to stop her falling!**





‘My name is Emmy I am a holocaust survivor and I have awful pain; I don’t recognise anything or anyone. I do know if you go to the shower you don’t come back! This place smells terribly – they say it’s burning flesh - , the lights keep flashing in my eyes and I hear someone screaming – mmm maybe it’s me! I need to pass water but they have tied me down and I cant get to the lavatory. They say the doctor is coming but I’ve heard they do awful experiments and so I must try to escape...



I'm Emmy's son – I have told them and told them to call me if Mum has a problem – now I get here and find her all tied up and bleeding! They wonder why I shout at them or indeed why Mum does. She is never angry at home but they rush her and don't listen. She has bloody pain that's why she is here But they don't give her anything. She is very dignified and would be mortified to wet the bed BUT they don't care! Will someone answer that bloody buzzer!



A resident of a nursing home

- **has dementia – she makes it very clear to all when she is unhappy... she has a male visitor and staff note she is always very happy after his visits. The infrequently visiting son walks in on them engaging in sexual activity and insists the staff ban the male from visiting. They do....why?**



An 85 year old man

- **Lives in the community - he falls occasionally, does not eat really well according to current dietary standards and his house and person are perceived by health professionals to be less than hygienic. He says he is happy but his family and doctor are saying he must go into nursing home care – ‘it is the best thing for him’ – IS IT?**



A 90 year old woman

- **who is cognitively intact, a ‘frequent faller’ and who attempts to walk to the toilet on a frequent basis is restrained with lap-belt and table to protect her between toilet rounds.**
- **In every case ‘duty of care’ is invoked as the staff/family explanation**



A 93 year old man

- **Has been assessed by the speech therapist and ordered blended food; staff fear he will choke.**
- **He refuses to eat as he wants real meat!**
- **The team meeting decides he will die without a PEG**
- **HE says he would rather die if he can't enjoy a good meal**



Patient autonomy in physical restraint

Pracy P.Y. Cheung MA, RMN and
Bernard M.C. Yam MA, RN

- **‘Over the past 20 years, there has been a shift in emphasis in health care from a strong paternalistic approach to a greater concern and respect for the personal autonomy of patients (Dodds, 1996). There is also an increasing demand for an individualized approach to care which is more supportive than controlling. The awareness of patients' rights and self-determination has filtered through all medical, nursing and allied health education programmes. Its ignorance can no longer be used as an excuse for exemption of legal and ethical obligations to patient care’**



Can we have a duty of care to a physical body

- **And ignore the rights of the person?**
- **Is not the person more than their physical body?**
- **What is **person**-centred care?**
- **Respecting the whole person and their right to choice, risk, stress, independence, sense of achievement, esteem ... healthy ageing.**



What 'we' fear most about ageing

- **Loss of independence/autonomy**
- **Loss of choice/human respect**
- **Loss of control**
- **That may mean the autonomy and control to give away our control – but WE should decide.**



Risk Management (Mitchell 1994)

- in the present health care system, risk is viewed primarily as something to be eliminated, controlled and minimized. Indeed there are whole departments dedicated to risk management with no counter dedication to risk enhancement.'



Respecting Patient Choices

- **Can have Statement of Choices**
- **MEPOA**
- **Refusal of treatment**

- **Maybe these need to be used (are being used?) in relation to risks and living at home, restraint, falls, sexuality and dementia etc??**



Reith lectures (Kirkwood, 2001)

- over-protection can create or reinforce anxiety and self-doubt. If we treat old people as weak-spirited because they are frail we do them a serious injustice'
- Person centered care demands health professionals have the courage to let go some of our risk aversion and support the older person's right to take risks.



Being a Person IS taking risks Being person-centered is supporting risk

Dylan Thomas:

- Do not go gentle into that good night
- Old age should burn and rage at close of day:
- Rage, rage against the dying of the light



Selected References

1. Feingold, E & Werby, E. 1990. Supporting the independence of elderly residents through control over their environment. *Journal of Housing for the Elderly*:25-32.
2. Fiveash, B., & Nay, R., (2004) Being Active Supports Client Control Over Health Care. *Contemporary Nurse*, 17(3), 192-204.
3. Kitwood, T. 1997 *Dementia reconsidered: the person comes first*. OUP. Buckingham.
4. Kirkwood, T. 2001 Making Choices. *Reith Lectures*, ABC.
5. Koch, S2002 *The Tension between Human Rights and Protective Custody*. PhD. LTU.
6. Maher, P. 1992 Not safe at home:risk versus safety in the home. In White, G. *Ethical dilemmas in contemporary Nursing Practice*. ANA Pub:89-104.
7. Mitchell, G. (1994) The Dignity of Risk and the Right to Failure: One profile of patient-focused care, *Illuminations*, 2(4): p10.
8. Moody, H. 1998 The Cost of Autonomy, the Price of Paternalism. In Disch, R et al 1998. *Dignity and Old Age*, Haworth Press
9. NARI 2006 What is person-centred care? A literature review. DHS. Victoria.
10. Nay, R., (2004) Evidence based practice: does it benefit older people and gerontic nursing, *Geriatric Nursing*, 24(6), 2-6.
11. Nolan, M etal Beyond 'person-centred' care: a new vision for gerontological nursing. *JCN*, 13(1): 45-53
12. Nay, R. 1993. Benevolent Oppression. PhD Thesis.
13. Pracy P.Y. Cheung MA & Bernard M.C. Yam MA 2005 Patient autonomy in physical restraint. *Journal of Clinical Nursing* 14 (1): 34 doi:10.1111/j.1365-2702.2005.01145.x
14. Seligman, M 1975 *Helplessness*, WH Freeman and co, San Francisco.
15. Seligman, M 1990 *Learned Optimism* Random House, Sydney.
16. Waring, A. 2000 Constructive risk in the care of the older adult: a concept analysis. *BJN*, 9(14): 916-924.
17. Selye, H 1956 *The Stress of Life*, New York: McGraw-Hill Book Co.

