



# The trials and tribulations of peer-led burns support initiatives in Australia:

## Are we ‘throwing the baby out with the bath water’?

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# What is Peer Support?

“...a system of **giving and receiving** help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful”. (Mead, Hill and Curtis 2001)

## Self-Help Groups

“...voluntary small group structures for mutual aid in the accomplishment of a specific purpose...usually formed by peers who have come together for **mutual assistance** in satisfying a common need, overcoming a common handicap or life disrupting problem and bringing about desired social and/or personal change”.

(Katz and Bender 1976)

# The Evidence Base for Peer Support

- ✓ Spinal Cord Injury (Elliot et al 1992)
- ✓ Melanoma (Fauzy et al 1996)
- ✓ HIV (Fontaine et al 1997)
- ✓ Cardiac Event (Hildingh & Fridlund 2001)
- ✓ Traumatic Brain Injury (Hibbard et al 2002)
- ✓ Breast Cancer (Cameron et al 2007)
- ✓ Multiple Sclerosis (Jadid Milani et al 2015)
- ✓ Diabetes (Deng et al 2016)
- ✓ Mental Illness (Vayshenker et al 2016)



# The Evidence Base for Burns Peer Support

- ✓ Williams et al 2000
- ✓ Chedekal & Tolias 2001
- ✓ Badger & Royse 2010
- ✓ Davis et al 2014
- ✓ Kornhaber et al 2015
- ✓ Grieve et al 2016



# Peer Support can...

- ✓ Provide an example of a path to recovery
- ✓ Be empowering
- ✓ Offer hope
- ✓ Sense of 'belongingness'
- ✓ Sense of meaning
- ✓ "...provides the perspective of someone who has walked the walk".

**NOT** a replacement for professional counselling or therapy but instrumental in  
**SUPPLEMENTING** and **AUGMENTING** burn after-care.

# Various Methods of Peer Support Delivery

- Informal contacts – incidental, casual
- Informational materials – booklets, info sheets, online info
- Short-term intense programs – forums, retreats, camps
- Virtual / distance interactive activities – social media, chat rooms, web-based discussions
- Planned individual peer support – trained peers
- Facilitated support groups – hospital/other agency offered support groups facilitated by a trained peer supporter and/ professional
- Structured peer support programs – organisational infrastructure, systematic oversight, formalised referral process, screening and training for peer supporters

Badger et al 2017

# Australia's Recent Peer Support History

## Burns Foundation Australia

- Based in NSW
- Set up by a burns carer
- Peer-led retreats
- Difficulties with financial accountability → folded ~2011
- Rebranded as...

## Peter Hughes Burn Foundation

- Based in WA
- Set up by a burns survivor
- Peer-led retreats
- Fraudulent activity → folded ~2014

## Julian Burton Burns Trust

- Based in SA
- Set up by a burns survivor
- Formalised DGR structure and rigorous organisational structure
- Clinician-delivered national education and support forums
- Planned wind down 2018



# Burns Peer Support Programs – Going Strong

Kids Foundation (Vic) <https://kidsfoundation.org.au/>

SHARE program (NSW) <https://www.aci.health.nsw.gov.au/networks/burn-injury/about/share-peer-support-program>

Burns Support Foundation (NSW) <http://burnssupportfoundation.org.au/>

Burn Support Group (NZ) <http://www.burns.org.nz/>

Camp Oz (Qld)

Beyond Burns Facebook Forums (Aust) <https://www.facebook.com/BeyondBurns/>

Other unit-specific peer support programs?

International programs (eg Phoenix Society, Katie Piper Foundation, Changing Faces)

## Up and Coming...



## Beyond Burns

Beyond Burns is a platform that supports burn survivors launching in 2018.

STAY UPDATED ON FACEBOOK





# Challenges Encountered by Peer-led Groups

- Difficulty securing engagement with and support from clinicians in the burns units to market programs to new patients.
- Fundraising difficulties – ‘donor fatigue’
- Lack of financial accountability
- Resulting poor publicity
- Risk management concerns eg substance misuse at retreats and lack of clinical skills to appropriate respond to those in distress

# Burnslife

Started up by a group of burns survivors, carers and volunteers in 2014

Identified need for;

- ★ mutual support and encouragement
- ★ information
- ★ resources

Clinician engagement

Auspiced by the hospital foundation

Fundraising effectiveness

- **Multiple programs**

- ★ Weekly co-facilitated social group
- ★ Monthly education and support forum
- ★ Welcome and discharge packs
- ★ Donated equipment to burns unit
- ★ Community education
- ★ Written resources for burns survivors
- ★ Social Media and e-mailing list
- ★ Annual national education and support forum



# Risk Management

- Formalised governance
  - Financial accountability
  - Consistent branding
  - Collaborative communication
  - Responsiveness to clinician and consumer concerns
  - Risk assessment and mitigation
- Consideration of clinical implications of all programs
    - Infection control and patient safety
    - Emotional and psychological safety
    - Privacy and confidentiality
    - Adherence to clinically endorsed care
    - Trauma-informed care



# The Challenges

- Early wariness of the 'renegades'
- Peer supporters 'move on'
- Tension between informality and risk management
- Time-poor volunteers
- Not a substitute for professional assessment, counselling and psychotherapy
- Not for everyone...

# The Opportunity

What is happening in your unit?

What are your views about peer support?

What's happening anyway – how are you managing the risks involved?

What do you know about existing programs and services nationally and internationally?

How are you consistently informing your patients about the peer support services available to them?

How are you meeting your NSQHSS obligations for partnering with consumers?



**Partnering with Consumers**, which describes the systems and strategies to create a person-centred health system by including patients in shared decision making, to ensure that patients are partners in their own care, and that consumers are involved in the development and design of quality health care.

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# Thank you...

and questions...

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