



**COLLECTIVE OF SELF HELP GROUPS INC.
(COSHG)**

**Chronic Illness Peer Support Forum
1 & 2 April, 2014**

**Report 'Closing the Gaps'
Identifying the Issues and
Exploring Solutions**

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About COSHG

The Collective of Self Help Groups (COSHG) is the longest operating self help group state wide peak body in Australia. For over 37 years COSHG has assisted health condition and chronic illness support groups and is well placed to validate the benefits of chronic health peer support groups.

COSHG has traditionally worked with those groups who are not resourced or have little in the way of resources often dependent on their members' contributions in time and funds. These groups are also referred to as support, mutual aid or peer support groups.

Our understanding of the value and benefits of peer support for those individuals seeking others who are 'in the same boat' is profound. This understanding is not only based on our longevity but also on the diversity of groups that we have supported and the networks we have participated in (local, interstate and with equivalent organisations overseas).

COSHG's awareness of group issues is intrinsically linked to our community development philosophy of inclusive and collaborative practice. This approach applies to individuals, groups and organisations that interact with COSHG including those we have supported in the process of setting up their group and as participants at our workshops, information sessions and events.

We have well proven expertise in identifying the aspects and issues that contribute to the running of successful groups and in identifying the means to address issues that arise in starting and maintaining groups.

Although the majority of groups COSHG works with are by far health condition related, COSHG is able to bring a broader knowledge to its work in recognising the common factors that affect support groups regardless of the specific issue that bring those with a common interest together to form groups.

The Forum

The intention of this project was to bring together chronic illness peer support groups, workers from chronic illness specific organisations, carers and all those with an interest in peer support and chronic illness. The forum explored and recorded common factors (needs, issues and gaps) of chronic illness peer support groups and their members by providing opportunities for participants to express their issues in a collaborative and inclusive manner.

This forum was presented in a format that allowed participants' voices to be heard and listened to in a safe and welcoming environment and to gather and validate anecdotal evidence that forms much of the qualitative evidence that is well understood within support groups and the sector. Evidence that is far too often not recognised considered or acknowledged within medical and health professions and government bodies.

This report provides an overview of the program content.

Descriptions and Definitions

COSHG definitions

- 1. Self help/support groups** are made up of those who come together of their own volition to address a common issue. Groups may be very diverse in nature and focus and are member founded and member run. The members choose the way the group operates, whether it is group that focuses specifically on advocacy, social activities, speaker presentations, raising community awareness, campaigning, information sharing or a mixture of these and more. Many groups are standalone while others although independent may have access to an umbrella organisation with a specific worker allocated to provide information and other resources but has no involvement in running the group.
- 2. Supported groups** are those who are brought together for peer support and are facilitated by a non-member (professional or otherwise) as part of a program or service that is run by an agency or organisation. Participants may have varying input into the content and/or the manner in which meetings are run. On occasion self help groups will evolve in their own right from supported groups as a means of continuing the value and benefits gained from meeting with their peers.
- 3. Online groups** can be particularly useful for those who are isolated e.g. geographically or by the nature of their illness. Internet based groups provide an alternative from face to face meetings and have the ability to fill a gap for those seeking others in the same boat which may not otherwise be filled. For example for those with rare genetic conditions where there are limited numbers with the condition in a state, country or even globally. Online groups can be a means of communicating, sharing information and experience in order to gain understanding and knowledge from each other in living with their mutual condition.
- 4. Intentional peer support groups**
This is a more recent label for a type of group which appears to be particularly associated to mental health services. To find out more about Intentional groups see: www.intentionalpeersupport.org (note there are many other definitions available on the internet)

Definitions of Chronic Illness

1. Chronic Illness Alliance www.chronicillness.org.au

"...an illness that is permanent or lasts a long time. It may get slowly worse over time. It may lead to death, or it may finally go away. It may cause permanent changes to the body. It will certainly affect the person's quality of life."

2. Australian Government Department of Health

www.health.gov.au/internet/main/publishing.nsf/Content/chronic#def

Chronic disease has been defined ¹as illness that is prolonged in duration, does not often resolve spontaneously, and is rarely cured completely. Chronic diseases are complex and varied in terms of their nature, how they are caused and the extent of their impact on the community. While some chronic diseases make large contributions to premature death, others contribute more to disability. Features common to most chronic diseases include:

- complex causality, with multiple factors leading to their onset
- a long development period, for which there may be no symptoms
- a prolonged course of illness, perhaps leading to other health complications
- associated functional impairment or disability.

¹Australian Institute of Health and Welfare (2012).

Risk factors contributing to chronic disease, page 5.

3. Better Health Channel www.betterhealth.vic.gov.au

A chronic or long-term illness means having to adjust to the demands of the illness and the therapy used to treat the condition. There may be additional stresses, since chronic illness might change the way you live, see yourself and relate to others.

Characteristics of a chronic illness

Chronic illnesses are mostly characterised by:

- Complex causes
- Many risk factors
- Long latency periods (time between exposure to the illness and feeling its effects)
- A long illness
- Functional impairment or disability.

'Closing the Gaps' Program

Managing your condition

Identifying issues

Exploring solutions

Sharing experiences & learning from others

Date: Tuesday 1 & Wednesday 2 April 2014

Venue: Ross House, Hayden Raysmith Room, Lvl 4, 247-251 Flinders Lane Melbourne

Day 1 Tuesday 1st April 2014

Guest Speaker - Positive Women Vic.

Our guest speaker Michelle Wesley, Support Co-ordinator at Positive Women will begin the forum with a talk on the experience of being HIV positive.

Q&A session – Living with a chronic health condition - Identifying common issues

This session encourages participants to identify and share common and systemic issues in conversation with a panel of experienced self help group & health sector network members.

Workshops – Exploring your issues

In group settings - the opportunity to explore and expand on those issues raised in the Q & A session which impacts your group, you as an individual or as a worker in the health sector.

Day 2 Wednesday 2 April 2014

Life experience - Personal stories

Introduction to Mindfulness with practitioner Steve Brown. Using Mindfulness to help manage stress and difficult emotions and the three ways in which mindfulness achieves its outcomes.

Workshop - Exploring the issues – Benefits of Self Help/Peer Support Groups.

We come together to look at the issues we identified on Day 1 and discuss the benefits self help and peer support groups contribute to those with a chronic illness.

Wrap up - What are the positives we can take away?



The Collective of Self Help Groups Inc. (COSHG)
acknowledges the support of the Victorian Government

Guest Speakers

Michelle Wesley, Positive Women Vic. - Michelle is the Support Co-ordinator at Positive Women and is also one of Positive Women's listed speakers on the experience of HIV positive diagnosis. Michelle's work brings her into contact with many HIV positive women from all walks of life, each living productive lives; studying, working, having children, achieving. Positive Women Victoria is a support information and advocacy organisation for HIV positive women. www.positivewomen.org.au

Liz Telford - Liz is a founding member of Post Polio Victoria (PPV) and has extensive experience contributing to advocacy relating to Polio and Post Polio Syndrome. www.postpoliovictoria.org.au

Steve Brown - Introduction to Mindfulness - Steve has post-graduate training in Family Therapy and grief and loss counselling and has worked as a counsellor and social worker in Melbourne for over twenty five years. For the past 18 years he has been teaching meditation and mindfulness to groups and individuals and utilising meditation and mindfulness techniques in his counselling practice. More recently Steve has been interested in the neurobiological consequences of various aspects of culture and lifestyle for emotion regulation, especially stress, anxiety and depression. www.beingpresent.com.au

The Power of the Personal Story

There were many life experience stories presented at the forum from both presenters and participants. We also interviewed Christine Hunt from Mornington Better Breathers Support Group who took us on the journey of the founding of the group with her late husband Reg Hunt. Christine related how the group grew and what it came to mean to its members, how being part of the group was not only about sharing information but clearly showed the improvement in well-being and overcame the sense of isolation that dealing with their chronic condition had brought about.

Michelle Wesley

The forum began with our guest speaker Michelle Wesley. Michelle's presentation relating personal experience acquiring and living with HIV was very powerful. It was a presentation that set the scene of much of the forum highlighting what we were to see and hear again and again - the power of the personal story. It showed clearly how others, no matter the nature of the condition they have, can often identify with the impacts others living with differing chronic illnesses face. Recognising many of the consequences of living with a chronic illness are the same or similar and there are many common factors.

Michelle's capacity to explore the impact of HIV and AIDS diagnosis and to create awareness of the issues that the diagnosis involves was heightened by her work as a peer support co-ordinator which has enhanced her ability to state the benefits of peer support. "Research suggests that the provision of peer support and the sharing of experiences can be beneficial to emotional well-being. Better emotional well-being

improves physical health something that is very important for women living with HIV”.

Nearly three decades has passed since the extract below raised the issues that were being recognised in 1985... Michelle’s presentation highlighted much of the journey for those with the diagnosis in the intervening years.

“Acquired Immune Deficiency Syndrome occupies a unique position in our medical and social history. It has created massive individual and collective trauma in the various ‘at risk’ groups and to a lesser extent in society in general. It poses a bewildering array of dilemmas, problems and difficult decisions...

There are so many interlocking and hazardous problems involved in the AIDS phenomenon that we need to try and divide the problem by a variety of means. Some divide the medical issues from the lesser ‘social issues’. I don’t believe this is one medical condition that can be divorced from its social context. We need to know the medicine to fight the organism but we also need social understanding of the groups that appear at high risk to make the fight as effective as possible.”

‘Health Action’ News Journal of the Health Issues Centre September / October 1985. Pages 22 to 24. Phil Carswell President, Victorian AIDS Council. (Edited version of a talk given to the St. Vincent’s Bioethics Conference, April 1985. (full article available in COSHG library collection)

Liz Telford

We asked Liz to present at the forum after writing a timely newsletter article on her recent experience of an emergency trip to hospital.

Polio and Post Polio support groups in Australia have been very active in researching and making available information on the effects of their condition. As a consequence when Liz found herself requiring emergency surgery (unrelated to PPS), she was well armed with verbal and printed information regarding any potential impacts on her surgery and recovery. However the information was largely ignored. Liz’s article “In case of Emergency” on her experience is in Polio OZ newsletter Vol 4 Issue 1. March 2014 Autumn edition can found on the Polio Australia website: www.polioaustralia.org.au. The following is an extract.

“In Case of Emergency. . .

Last year I found myself in a very vulnerable and frightening situation. I was in the hospital in great pain, minutes away from emergency surgery and facing an anaesthetist who, when asked by my husband and me to read a brochure prepared by Polio Services Victoria on the issues facing polio survivors and respiratory issues, rolled her eyes...

...Since being diagnosed with post polio syndrome, I have been provided with a wallet sized “polio information card” that polio self help groups have developed with short-hand essential post polio information to provide to doctors we are being treated by. I have often wondered who will read such a card and under what circumstances. I have

found it hard enough to discuss the post polio implications with doctors when I'm fully awake and alert as I have found that doctors are not always receptive. Will anyone notice and pull this card out of my wallet if I'm hurt in an accident and unconscious? Or is it something that can only be useful if I can hand it over and explain? It is just not reasonable to expect the patient to take this much responsibility for educating doctors. Furthermore, even if I take this responsibility upon myself, it won't be effective if medical staff are unaware of or not interested in the complex issues involved"...

Q & A Panel Members

Trish Fallon - Co-ordinator, Self Help Queensland (SHQ)

Trish has spent the last 15 years at SHQ, a not for profit community organisation comprised of a wide network of Self Help and Support Groups throughout Queensland, SHQ works to build the capacity of groups to assist members to improve their health and wellbeing. Founded on community development principles SHQ supports, promotes and helps develop the Self Help Sector in Queensland.
www.selfhelpqld.org.au

Bel Harper - Peer Support Projects, Chronic Illness Alliance (CIA)

Bel's role at the CIA is managing projects relating to peer support and productive ageing. The aim of the Alliance is to build a better focus in health policy and health services for all people with chronic illnesses. It does this through education and research projects. **www.chronicillness.org.au**

Esther Lim - Project Officer Consumer Participation Projects, Health Issues Centre (HIC)

Esther's role at Health Issues Centre is to lead the Empowering Participation Program. The project aims to build the capacity of consumers, carers, health services and condition-specific organisations to collaborate and develop strong partnerships to improve health care planning and delivery. Esther also provides support to the Rural Health Consumer Participation Project which aims to foster consumer participation across rural Victorian health services. **www.healthissuescentre.org.au**

Amanda Plowright - Executive Director, Self Help Organisations United Together (SHOUT) ACT

Amanda Plowright has been working for SHOUT for over 10 years in various capacities. Since 2009 she has been the Executive Director. Amanda has been involved in the delivery of Chronic Disease Self-Management programs with ACT Health and is a peer leader for the Living a Healthy Life with Long Term Conditions course developed by Stanford University. SHOUT is working together with the ACT community to promote the philosophy and practice of self-help by speaking with a

united voice to provide support and resources, which develop and sustain groups.
www.shout.org.au

Yvonne Waite - Program Co-ordinator, Parent-to-Parent Gippsland (Noah's Ark)

Yvonne's work encompasses the extensive area of Gippsland and offers services to parents, families and professionals working with children aged from infancy to eighteen years old with disabilities and developmental delays.

www.noahsarkinc.org.au/what-we-do/parent-to-parent-gippsland

Q & A session – Living with a chronic health condition - Identifying common issues

This session encouraged participants to identify and share common and systemic issues in conversation with a panel of experienced self help group & health sector network members. The key issues that were identified were explored more fully in workshops and discussions over the two days of the forum.

The main themes that arose were:

1. Power – patients and the medical professions
2. The power of the personal story
3. The various models of self help and peer support and what they contribute to being part of a group
4. Providing evidence - qualitative and quantitative
5. Juggling limited funding and resources and the impacts on the sector and groups

Workshops

In the workshops, participants had the opportunity to expand on those issues raised in the Q & A session.

For the two workshops which ran simultaneously on the first day, we asked the participants to record key words from the issues they identified and discussed. These were used as 'bricks' which were put together to create a wall to represent the issues and gaps we would continue to explore in the forum.

Workshop One

Self Help and Peer Support Group Models

In this workshop the various models of self help and peer support groups and the contribution they make were discussed. There was acknowledgement that there was room for all models and participants will have different needs that will be met by different models.

Groups overcome isolation people finding people with like experiences

Informal groups meet with no specific agenda for each meeting sharing information based on experience that members may be unlikely to get from service providers.

What members want guide the group – their choice

Different types of groups meet different needs in different communities.

- Some groups may need a facilitator or a driver from either within the group or from outside the group.

Place for all models of support groups to co-exist

- Support as you like it
- Groups should be non-judgmental and observe privacy and confidentiality

Online groups, email forums and chat sites

- These need quality mediation and safety rules
- Those who wish to participate need to investigate whether the site is appropriate for them.

Peers support programs that will last for 6 weeks or so and out of those programs at the end may develop a social group or an ongoing support group in its own right.

Ages and stages for groups

- Recognition of an initial need for group to form and last for its natural life if that need is met.
- The group may choose to reform at a later stage when there is a need to get together again. E.g. different stages of an illness
- Some groups need succession plans
- Groups need new blood and ideas over time
- Need clearly defined visions to make them work
- Have individual plans and rules that suit the nature of the group
- Be non-judgemental, inclusive and aware of privacy and confidentiality issues for all members

OTHER SPECIFICS OF SELF HELP GROUP PARTICIPATION

In addition to the cognitive and behavioral restructuring that occurs, three less technical or clinical, but very beneficial results of participating in self-help groups should be mentioned. They are: *de-stigmatization of the problem, increase in social contacts, and the opportunity for members to feel valued by making a persona contribution to the group.* None of these specific benefits can be easily achieved through professional help alone!

Partners in Wellness – Self Help Groups and Professionals. Page 8.

Alfred HJ. Katz D.S.W. Department of Mental Health. State of California 1987

(This publication is in the COSHG library collection)

Workshop two -Health professional and patient relationships

Time

The difficulty of having sufficient time to build those relationships, that trust and rapport with health professionals. Strategies- to take a support person and/or book a double session to give extra time.

Trust

Trust in relationships to go in both directions - between the person and their health professional. May need to shop for appropriate doctor for own needs to make that connection based on trust. Patients are a bundle of relationships not just symptoms.

Partnerships

Partnership is not ultimately two individuals in a room talking at one another, but actually building partnerships and having a shared responsibility. Some people want the doctor to be an expert and blindly help.

Doctors and patients to communicate and talk about the issues facing the patient. Medicos need to have information but cannot keep up to date with information on specific conditions

The potential for a doctor and their patient to have a discussion regarding some sites that are reputable as sources of information. Patients may look at those sites and bring that info back to discuss with GP. This becomes a contractual negotiation to enable both parties to have a fruitful dialogue with quality evidence.

Medical bubble

Medical agenda items often override the interaction and the engagement with the patient.

Technology

Medicos can focus on the technology and the technical processes rather than the person that they are working with.

Lack of acknowledgment- Medicos are actually human too and they do really appreciate a gesture of appreciation and positive feedback.

How to relate to Medicare locals?

Concern expressed about Medicare locals. What is community engagement? A challenge that lies ahead of us.

Health Professionals frame education – Formal support groups and education reflect health professionals' frames not person's needs. There is a need to get training

to be really responsive to consumer perspectives. Challenge to get health professionals to really listen and incorporate those perspectives. Sometimes need advocates

Rights and responsibilities

Both health professionals and patients /clients being aware of those shared rights and responsibilities.

- You do have to know about your own condition and your own body.
- Some conditions it is the patient responsibility to inform medical professionals but often medical staff are not open, they are not good at collaborative care

We are the experts of our own body!

We need our own health diary/health records to present to health professionals

Motivation for both sides to drive some of the change we want.

Cultural changes

- Some positive things are happening
- Younger medical professions generation wanting to gain knowledge re "other side"
- Taking an information sheet for going into hospital including key info regarding illness abilities/assistance required. (This would be good for nursing staff too.)
- Some institutions are including training in community approaches and practice

Support Groups and health professions

Perceptions

Perceptions we carry into clinical relationships. Perceptions that health professionals will have suspicion about self help groups being a just whinge fest for example, rather than having a vital role in supporting people emotionally and potentially with education as well, e.g. won't listen to a just a consumer.

Evidence and Value

Anecdotal and qualitative data is often not valued by professionals.

Data collection

Building quantitative data collections not just the qualitative evidence that we tend to collect. Data collections by groups e.g. secondary factors which may influence medical research

Credibility of support groups.

- Need to address the myths and facts
- Self help groups could educate each other by networking between groups
- Some groups run "newly diagnosed" information sessions

- Medical patron for support group does not have to attend but review material
- Inviting people of note to be on boards especially if high profile
- Invite speaker (expert) then invite onto board
- Manage agenda for time availability then ask for their connections, accommodate them

Firstly we have to know there is a huge imbalance of power between health service providers and users or potential users. The very word 'patient' represents a passive role with things being done to the individual.

Collective of Self Help Groups Submission to Health Department Victoria Health Services Complaints Act 1986

What does a support group mean for you?

For the last session of the forum we gathered together to highlight the aspects that participants felt were beneficial in being part of a group in dealing with chronic health issues. These are their words in response to the question, 'what does a support group mean for you?'

- Everything
- Not isolated. Not alone. Not the only one
- Connecting with others
- Information sharing
- Respected in an unaccepting world
- Raising community awareness
- Groups are not considered as 'sexy'
- Not resourced enough
- Provide self-reflection
- Banks of wisdom and knowledge
- Offer practical day to day solutions
- Government funds from flow on effect
- Don't have to explain – like minded/similar needs
- Learn from each other
- Life experience
- Time with own 'kind'
- Opportunity to learn the 'language'
- Understanding
- Fun
- Purpose, common factors
- Belonging, encouraging
- Like a family
- Strategies that groups share
- Reduce re-admissions to hospitals

- Self help groups can collect own data
- May choose to participate in medical trials appropriate to their condition
- Participation can give hope
- Aid future management of illness
- Families coping
- Reduce stress and mental health consequences
- Support beyond focus issue to other emotional areas of members lives
- Validation
- Provide road maps
- Variety and diversity of members and groups
- Wish doctor had told me about self help groups
- Different aspects of lives
- What supports self help groups?
- Inclusiveness
- Safety
- Empowerment and growth
- Social engagement
- Confidentiality, privacy from SHG to organisation
- Ground work
- Guest speakers
- Knowledge, skills, expertise
- Are valuable resources
- Credibility
- Achievable
- Personal gain

Funding and resourcing

A theme that emerged during the two days of the forum was the issue of funding and resourcing of the peer support sector. This was often related to the evidence of the value and contribution self help and support groups make to their members' sense of well-being and in raising community awareness.

This concern was emphasised by the recent defunding of Self Help Queensland (with over three decades experience assisting countless groups across the state to form and thrive).

- We need evidence to support the effectiveness of self help/peer support
- We need to build on the evidence and create further alliances to do this
- Very hard to measure support
- There is lots of work still to be done