



 癌症基金會

 CANCERFUND

Development of Cancer Patient Self-Help Group Experience Sharing by CancerLink

癌症病人自助組織的發展：癌協的經驗分享

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Hong Kong Cancer Fund

- The largest cancer support organisation in Hong Kong.
- Established in **1987**, our vision is to better the quality of cancer support in Hong Kong and to ensure that **no one faces cancer alone**.
- Our **network of support** strives to make life better for people touched by cancer, by addressing all aspects of the cancer journey.
- **Psychosocial care** is a key component of our work.



Our Network of Support



In the Public Hospitals:

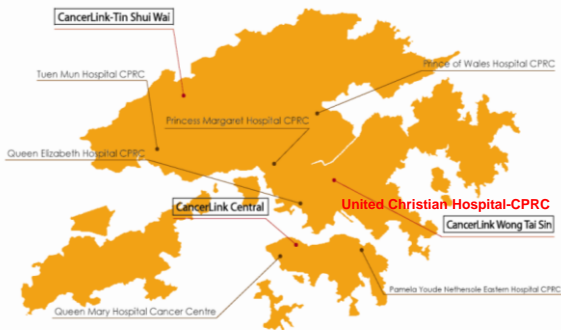
- Queen Mary Cancer Centre
- Pamela Youde Nethersole Eastern CPRC
- Queen Elizabeth CPRC
- Princess Margaret CPRC
- Tuen Mun CPRC
- Prince of Wales CPRC
- Prince of Wales Hospital Acupuncture Centre
- United Hospital CPRC

In the Community:

- CancerLink Central
- CancerLink Wong Tai Sin
- CancerLink Tin Shui Wai
- H.K. New Voice Club
- H.K. Stoma Association



Hong Kong Cancer Fund's Support Network



CancerLink Support Centres

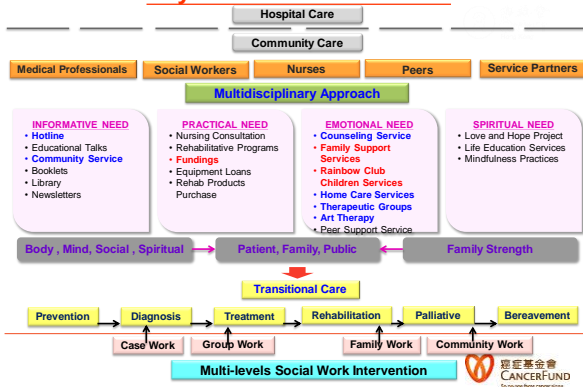
A service of Hong Kong Cancer Fund, CancerLink is a haven in the community helping people touched by cancer. Serving cancer patients, survivors, their families and friends, we address all aspects of living with cancer, be it physical, emotional or practical which include:

- Cancer Information hotline
- Nursing Consultations
- Professional Counselling
- Homecare
- Rehabilitation Programmes
- Peer Support Groups
- Psychosocial Support
- Nutrition Workshops/ Health Talks

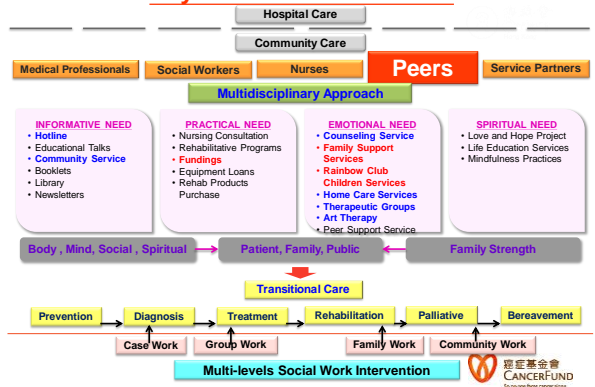
Our free and on-going cancer support services are delivered by a team of dedicated social workers, oncology nurses, guest specialists and volunteers



Psychosocial Care Model



Psychosocial Care Model



Cancer Facts

Cancer of All Sites in 2011
2011年所有癌症統計

	Incidence 發病		Mortality 死亡	
	Male 男性	Female 女性	Male 男性	Female 女性
Number of cases registered 登記個案	14,024	12,974	7,936	5,305
Male : Female ratio 男女比例	1.1	1	1.5	1
Median age (years) 年齡中位數 (歲)	68	61	72	74
Crude rate* 粗發病/死亡率*	424.6	344.3	240.3	140.8
Age-standardized rate (World)** 年齡標準化率 (世界)**	264.9	222.8	143.6	79.9
Lifetime risk before age 75 一生累積風險 (0-74歲)	1 in 4	1 in 5	1 in 8	1 in 14
Mortality : Incidence ratio 死亡:發病比例 (2007-11)	0.55	0.37		

Source: Hong Kong Cancer Registry, Hospital Authority Nov 2013



Top Five Cancer in Hong Kong 2010

Leading cancer types (both genders combined)

Rank	Site	No. in 2010	No. in 2000 (rank)
1	Lung cancer	4,480	3,952 (1)
2	Colorectal cancer	4,370	3,210 (2)
3	Breast cancer	3,025	1,932 (3)
4	Liver cancer	1,863	1,584 (4)
5	Prostate cancer	1,492	683 (7)
	All cancers	26,390	21,349



Cancer

- Cancer patients in diagnosis, treatment or rehabilitation stage may encounter information, financial, psychological and social problems

(Campbell, Phaneuf and Deane, 2003)

Obstacles

- Patients were often **unaware** of resources available to help them overcome these problems, but when they were aware, limitations in mobility, fatigue, pain, transportation problems, cost issues can be overcome.

(Jerant et al., 2009)



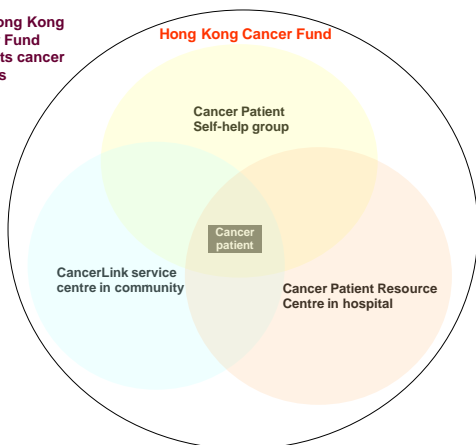
Importance of community support

- Except assessing problems and needs, assessing resources is also very important
- Every community contains effective, naturally occurring psychosocial supports and sources of coping and resilience

(Inter-Agency Standing Committee (IASC) (2007)



How Hong Kong Cancer Fund supports cancer patients



SHG as working partners

- CancerLink serves as a home and facilitator of 20 cancer patient SHGs in Hong Kong.
- We formed a network called “Friends of CancerLink” (FOC) to facilitate self-help groups to communicate and support each other.
- We assist by facilitating information exchange, providing volunteer training, meeting tangible needs and offering rehabilitation services.



Value of peer support

- Peer support, and the integration of peer relationships in the provision of health care is a concept of substantial significance to health scientists and practitioners today. (Cindy-Lee, 2002).
- The World Health Organization (1998) has identified strengthening social relationships as a health promotion strategy.
- Although scarce empirical evidence supports the effectiveness of peer support, in our experience and with strong theoretical rationale (Yalom, 1995 and Kurtz, 1997), we are sure that peer support has important function in the patient rehabilitation process.



Value of peer support

Yalom (1995) identified 11 therapeutic factors in psychotherapy groups also found in self-help groups.

- ◆--instillation of hope
- ◆--universality
- ◆--information or direct advice
- ◆--altruism
- ◆--corrective recapitulation of the primary family group
- ◆--social skills
- ◆--Imitative behavior
- ◆--Interpersonal learning
- ◆--Group cohesiveness
- ◆--catharsis
- ◆--existential factors



Value of peer support

Kurtz (1997) found that there were some helping factors common to both support and SHGs:

- Conveying information
- GivingSupport
- Imparting a sense of belonging
- Communicating experiential knowledge
- Teaching coping methods



Friends of CancerLink, FOC

	SHG name	Cancer type	Set up year
1	Hong Kong Pioneers Mutual Support Association Ltd	All	2007
2	New Voice Club of HK	CA Larynx	1984
3	HK Stoma Association	CA colon, with stoma	1979
4	Cheong Hong Club	CA colon, without stoma	1998
5	TMH Stoma Group	CA colon, with stoma	1998
6	Mutual Aid Association	NPC	1995
7	Kin Lok Club	NPC	1995
8	The Rising Sun	NPC	1995
9	Association of Relieve	NPC	1994
10	Sun Flower Network	CA Breast and Gyn	1996



Friends of CancerLink, FOC

	SHG name	Cancer type	Set up year
11	The Brightening Association	CA Breast and Gyn	1996
12	Yin Hong Club	Ca Breast	1996
13	Bauhinia Club	Ca Breast	1995
14	TWH Breast Group	Ca Breast	2009
15	Yin Chun Club	Ca Breast	1993
16	Orchid Support Group	Gynecology	2005
17	Hong Kong Bone Marrow Transplant Patients' Association	Patients who received bone marrow transplants.	1993
18	HK Adult Blood Cancer Group	Leukemia and Lymphoma	1997
19	Chinese Painting and Calligraphy at Leisure Circle	All	2000
20	Cansurvive	All-for English speaking	1987



Background of self-help groups

Target members	No. of groups
All cancer types patients	3
Colon cancer patients (with stoma and without stoma)	3
Breast cancer patients	6
Nasopharyngeal carcinoma patients	4
Blood cancer patients	2
Cervical cancer patients	1
Larynx cancer patients	1



Care and Concern Service of Self Help Groups

- There were totally 13, 491 members among 20 self-help groups.
- No. of volunteers: 870 peoples (7%)
- No. of volunteers who participated in care and concern services: 536 peoples(62%)

	Numbers of members under 500 (13 groups)	Numbers of members over 500 (7 groups)
Ratio between members and volunteers	19 : 1	25 : 1
Care and concern service coordinator	Group leaders of self help groups	Staff of self help groups



Care and Concern Service of Self Help Groups

- Patients of different cancer types and stages were served through various intervention strategies.
- All the self-help groups had conducted services in hospitals; including in-patient ward visits, on-site comfort in Oncology outpatient wards, peer support meetings for new patients and relapse patients.
- Services of the self-help groups provided in 2012-13 :

Service Items	times	attendance
Caring phone contacts	12514	14726
Home visiting, clinic and ward visiting	804	4017
Supportive / mutual aid group	1620	14031
Orientation program for new patients	115	1196



Care and Concern Service of Self Help Groups

For providing stable and long lasting care and concern service to the cancer patients, 20 SHGs arranged patients into sub-group as a function of support network, based on their characteristics such as:

- living districts of patients
- cancer type of patients
- how long the patient have been diagnosed
- the numbers of years the patients have joined the group.



Care and Concern Service of Self Help Groups

- Special care to
 - > newly-diagnosed patients
 - > relapse patients
 - > terminal stage patients
- 13 self-help groups formed special peer support teams to provide regular calls, hospitals visits and peer sharing meetings to them.



Difficulties in providing care and concern service

Difficulties of the SHGs faced	No. of groups
Not enough volunteers / loss of experienced volunteers	11
Challenges regarding inter-personal relationships	8
Difficulties in handling administrative work	8
Weakness in helping skills and techniques	7
Members felt the groups could not satisfy their needs.	3
Insufficient information on cancer and cancer service	1



Problems encountered in SHG

Referring to our working experiences and feedback from SHGs, we found that they encountered some common problems which would affect the quality of the care and concern service:

1. Depending on staff and inadequate trained volunteers when the group expanded
2. Confusion due to constant service direction shifted from personal caring to recreational programs
3. Loss of experienced volunteers because of relapse and death of volunteers
→ Quality of care and concern service decline
4. Task overload and low awareness in self-care
→ Burnout of the volunteers



Building up the model of care step by step

- For facilitating SHGs improving the quality in care and concern service, we started to develop the model of care and the following strategies were used with self help group from 2008.



Building up the model of care step by step

1. Facilitate self help groups to evaluate their care and concern system

Checklist of questions for SHGs to review their care and concern system in the retreat activities. For example,

- Did your group has any procedures to welcome new members and to understand their needs?
- Did your group has any services to support members who had special needs?
- Did your group provide on-going care to the members? How did your group up-date their status, eg health conditions?
- In the recreational programs, did your group facilitate members to know each others?



Building up the model of care step by step

2. Trained the trainers to strengthen the ability and capacity on caring

The topics of trainings included:

- How to build up relationship with members?
- How to take care of members who have special needs?
- How to help our group to set up care model?
- How to care our members in recreational program?
- How to take care of ourselves as peer volunteers?



Building up the model of care step by step

3. Proposed working procedures and workflows to help the groups strengthening care and concern systems.





Building up the model of care step by step

4. Strategies of helping SHGs to solve difficulties

- (i) Raise the volunteers understanding on the direction of SHGs and their roles in care and concern service.
- (ii) Strengthen the missions, skills and confidence of the volunteers
- (iii) Encourage volunteers as role models and help to invite members becoming volunteers
- (vi) Facilitate volunteers to show concern to members in different activities, no matter what types of cancer and what stage of cancer, help them to face cancer and build up support network
- (v) Encouraging SHG to build up relationship with service partners, including hospitals or community organizations, etc.
- (iv) Providing on-going training to keep the service qualities and morale of the volunteers.



Building up the model of care step by step

5. Provide hardware support to SHGs

- funding support
- workplace, venue of activities and office equipment
- IT support and back up
- Intranet resource corner

Building up the model of care step by step

6. Provide professional support

- advice-giving of service direction
- mentorship
- crisis intervention
- service referral



Building up the model of care step by step

7. Build up supportive network between SHGs

- Quarterly meeting of Friends of CancerLink
- Working groups for special topics, e.g. advocacy working group

Follow Up

- When we started to develop the model of care, all the SHGs shared our visions and missions.
- They actively joined in our trainings and started to evaluate their care and concern systems. However, we also concerned
 - to what extent the strategies put into practice.
 - how to evaluate the effectiveness.
 - how to share the missions not only to the volunteers but also their members.

*Further assessments and interventions would be needed.



Conclusion

- SHGs are our important collaborators in cancer patients' care.
- We hope that the cancer patients in SHGs can also receive the good quality care and concern services in their cancer journey.
- Setting up of the model of care is the starting point only, we will keep on evaluating and modifying.
- To ensure "No one faces cancer alone" under our seamless care service.



Thank You

