



ATTACHMENT (ONE B)

Supporting Partners Element

Summary

The Supporting Partners Programme has been operating statewide within Queensland since November 2004. The Programme is auspiced and supported by Queensland Health and the Gynaecological Cancer Society.

Supporting Partners Programme focuses on improving outcomes for women experiencing any serious illness, by improving the capacity of male partners to remain supportive throughout the course of her illness and treatment.

Supporting Partners encourages men to:

- provide effective ongoing practical and emotional support to the seriously ill woman
- seek additional resources and act as advocates
- maintain the family unit in the long term
- discuss issues and priorities with their local community and health workers

Serious illness in this context is not synonymous with end stage or terminal illness. The Supporting Partners Programme is appropriate in early or later treatment phases of an illness, when the information contained can have impact on later developments.

Background

The Gynaecological Cancer Society became aware, through its work in supporting women patients, that supportive partnering is a key issue in many families affected by cancer and associated treatment.

Serious illness is an unusually stressful time for partnerships, with poor outcomes in terms of relationship survival. Statistics obtained from national research indicate that in the wider community

- 48% of all partnerships break down
- 80% of the time, it is the women leaving the partnership

However, when gynaecological cancer is present:

- 69% of partnerships fail
- 80% of the time, it is the man leaving the partnership

It is the belief of the Society that these statistics are not unique to gynaecological cancer, but represent a general reality within serious illness in women. Therefore the Society sought and obtained funding to establish an educational and support programme for the male partners of women living with cancer (and other serious illness).

Primary funding support for the Program has come from Queensland Health with significant additional funding from the Society to ensure complete state-wide coverage..

Initial Planning Process

In late October 2005 the Society engaged Gabriel Monson of Carer Support and Training to coordinate the program. Gabriel has a background in palliative care family support counselling, as well as group facilitation and production of community services training materials.

As Project Coordinator Ms. Monson has responsibility for the Programme's implementation including:

- Development of programme strategies
- Recruitment and engagement of consultants/facilitators
- Development of resources
- Database design and upkeep
- Distribution of resources
- Liaison with other distributors such as health services and community agencies.

Consultation

Consultation concerning the content and strategy of the Programme has been ongoing. A particular emphasis was placed on involving men as consultants, in order that the Programme is relevant in content and language to men.

Male consultants to the programme have included:

- Ross Adams - *an experienced and qualified family therapist with a private practice in Family Therapy and experience with working with men in Anger Management groups*
- Barry Walton - *a counsellor and Project Manager with Relationships Australia.*
- John Allen - *a trainer with experience working with younger men in crisis.*
- Glen Guy - *founder and lecturer of the QUT Family Therapy Clinic and Masters in Counselling*
- Owen Pershouse - *Founder MENDS support groups*
- Simon Kneebone - *clinical psychologist and illustrator*
- Brad Ainge - *Designer*

- Men (to remain anonymous) - *nominated by staff of Karuna Hospice Service, Brisbane. These men had previously, or were currently, supporting women with serious illness.*

Other consultations included:

- Clinical and counselling Staff - *Karuna Hospice Service*
- Emotional Support volunteers - *Gynaecological Cancer Society women who have received treatment and are currently in remission from serious illness.*
- Adele Baldwin - *CNC Townsville Hospital*
- Barb Milne - *Mobile Women's Health Nurse*
- Alison Sparke - *Children's and Young People's Bereavement Service, Mt Olivet Hospital*

Development of Programme Strategy

Groups

Initially, psycho-educational support groups for male carers, led by male facilitators, were seen to be an appropriate format for the Programme and the initial months of the Programme involved preparing for them. At that stage the Programme aimed to reach 100 men in each of regions (Northern and Se/Urban)

Facilitators were recruited in each Pilot Region, and a Facilitator's Kit was prepared for One Day or Three Meeting formats, with session plans and supporting materials.

However, this strategy was revised within the first months of the Programme due to poor response to groups, as well as feedback from potential referral bodies. Men simply do not like attending group sessions irrespective of motivation.

Support groups may still be convened in the future where sufficient demand exists, however the overall strategy of the Programme was changed in favour of the self-paced Kit approach detailed below.

Supporting Partners Kit

The second phase of the Programme has followed a strategy of developing, producing and distributing the self-paced Supporting Partners Kits

The advantages of this strategy include:

- Maximising the accessibility and utility of the Programme to men in both urban and regional areas, without increasing demands on their time or requiring further travel
- Cost effectiveness, as many kits can be produced for the cost of running one group
- Timeliness as Kits can be given to partners at an appropriate time by concerned health and support professionals
- Confidentiality
- Appropriateness to men's preferred methods of receiving information

- Increasing the range of the Programme across broad geographical areas.
- Extending the lifespan and effectiveness of the Supporting Partners Programme beyond the end of the Pilot period (mid 2006)

Contents of Supporting Partners Kit

The Supporting Partners Kit contains 11 items including written material as well as audio and data CDs, presented in a C5 sized printed envelope, which can be distributed or mailed to participants without further repackaging.

Supporting Partners Kit is designed around the concept that:

“To be successful in any enterprise, there are 5 key areas that need to be addressed”

- Information (accurate, relevant and understandable) that aids informed decision making
- Coaching (to benefit from others experience and avoid pitfalls)
- Skills (building on current skills and acquiring new ones)
- Backup network (to support the carer to continue caring role and personally)
- Motivation

Each Kit contains 6 Booklets, 2 CD's and additional material appropriate to the end user (professional or public)

Booklets

Written material is in the form of illustrated A5 booklets, from 8 to 16 pages. Booklets are written in a conversational style and illustrated with cartoons specially commissioned from Simon Kneebone, a psychologist and cartoonist. They also provide linkages to more specialised support, such as organisations offering information and support about particular diseases, or in particular areas, such as respite care. Titles include:

- How to be a Supporting Partner
- Helping with Shock and Change
- Understanding Treatment & Cure
- How to do Relaxing Exercises
- Helping with Pain Management
- A guide to Supporting Your Children

CDs

- Change and Shock and Relaxing Exercises (readings of the above booklets)
- Information from the GCS website concerning gynaecological cancer. These are included to reflect the involvement of GCS as auspicing body, and disseminate information into the community, although the Kits are not gynaecological cancer specific, but more generic in application.

Additional material

- Tri-fold leaflet explaining the *Supporting Partners Programme*

- *Priorities Worksheet*: to clarify the situation and next steps. This worksheet can be used by partners on their own or in consultation with social workers, counsellor, or *Supporting Partners Programme* phone support
- Covering letter / information flyer for professionals or agencies (to accompany samples)

The Supporting Partners Programme also provides for the possibility of free personal support and follow up, on the phone or face-to-face at the request of supporting partners. Information on how to obtain this is included in the Kit. This has had a low take-up rate to date, however there are signs of increased usage in the future following the success of the 'Kits'.

Revisions and updates

Two minor and one major revision have been made to the Kit by June 2006:

- Initially (the first 150 copies of the Kit) a copy of *When the Woman you Love has Advanced Breast Cancer* (produced by the National Breast Cancer Centre) was included. However early feedback indicated that this was not a necessary inclusion and is no longer included as standard. Also, the Supporting Partners Kit is very appropriate to use in early or treatment phases of an illness, when the information contained can have impact on later developments.
- The number of specially commissioned cartoons was increased to convey information in a more relaxed manner.
- A complete revision has just been completed to incorporate the recommendations arising from the JCU research report.

Promotion

The Supporting Partners Kit has been promoted and distributed primarily through professional and clinical workers and agencies. This strategy is used to increase:

- Widespread distribution of the Kits using existing networks throughout Queensland
- Cost effectiveness, particularly in comparison to advertising
- Familiarity and confidence with the Kit with social workers and clinicians who can then be proactive in passing them on to women and supporting partners in their local areas
- Appropriateness of timing and suitability to individual end users, as relevant and involved workers are likely to be familiar with the needs of their clients or patients
- Ease of obtaining kits, without men having to send away or specially request them
- Ease of eventual evaluation of the programme, without compromising confidentiality or privacy of user.

Specific promotional methods have included:

Personal visits and regional tours

- Townsville
- Harvey Bay/Maryborough
- Sunshine Coast/ Gympie

- Brisbane North/ Redcliffe/ Caboolture
- Brisbane South

Mailed samples

Approx 300 samples were distributed to health facilities on the Society's mailing list. The majority of these have now been followed up with phone calls

Presentations at in-service seminars, team and regional meetings

- Carers Qld
- Ozcare
- Qld Cancer Fund
- Children's and Young Peoples Bereavement Service Stakeholders Group
- Caloundra, Gympie, Nambour, Caboolture, Royal Women's, and Logan Hospitals

Follow up phone calls

This is currently the primary promotional focus of the Programme, and is proving highly effective in establishing relationships with services and individuals in each Health District and arranging further presentations for local teams and reference groups

Liaison with information and resource agencies

- Commonwealth Carelink
- QCF (Brisbane, Cairns and Townsville)
- Children and Young People Bereavement Program
- Palliative Care Information Service

Additional promotion is currently being negotiated with:

- Media, including regional ABC radio
- Videoconferencing and video streaming
- Awareness days and regional meetings

Distribution

The Society has been distributing Supporting Partner Kits

- Through medical practitioners, hospital clinical and social work departments
- Through community agencies and information networks groups
- Directly to partners who self refer to GCS

Contacts recorded on the distribution database include

- 400 health services
- 2 community support groups
- 5 counsellors
- 22 information agencies
- 13 women's health agencies
- 12 direct referrals

Distribution Data by Region

To date, 2,600 Kits have been distributed across Queensland. Distribution data is maintained by Supporting Partners Programme Pilot Regions, which are based around Qld Health Districts, but do not precisely correspond to Qld Health Zones.

Pilot regions have been defined as:

Northern: Health Districts included in the Qld Health Pilot funding:

- Bowen, Cairns, Cape York, Charters Towers, Innisfail, Mackay, Moranbah, Mt Isa, Tablelands, Torres Strait, Townsville.
- Patients in this Pilot Region would be likely to travel to Townsville for treatment if required, although this may involve considerable travel.

SEQ/Urban: Health Districts included in the Jupiter's Casino funding:

- Bayside, Fraser Coast, Gold Coast, Gympie, Logan/Beaudesert, Redcliffe/Caboolture, Sunshine Coast, Toowoomba West Moreton
- Patients in this Pilot Region would be able to access treatment in Brisbane and return home within a day's traveling by road.

Southern Remote: Other Health Districts which are not otherwise covered by Project funding:

- Banana, Bundaberg, Central Highlands, Central West, Charleville, Gladstone, North Burnett, North Downs, Rockhampton, Roma, South Burnett, South Downs,
- Their inclusion has been funded by the Society in order make the Program available to all Queenslanders, irrespective of location.

Cross-State: Kits have also been distributed to agencies that cover the entire state, such as the Royal Flying Doctor Service, Carers Qld, Ozcare.

Interstate : Some kits have been sent to individuals and healthcare organisations in Northern NSW as they form part of the Queensland catchment area.

Pilot Region	Number Distributed as at December 2005	Health Districts
Northern	549	Bowen, Cairns, Cape York, Charters Towers, Innisfail, Mackay, Moranbah, Mt Isa, Tablelands, Torres Strait, Townsville
SEQ	877	Bayside, Fraser Coast, Gold Coast, Gympie, Logan/Beaudesert, Redcliffe/Caboolture, Sunshine Coast, Toowoomba West Moreton
Southern Remote	463	Banana, Bundaberg, Central Highlands, Central West, Charleville, Gladstone, North Burnett, North Downs, Rockhampton, Roma, South Burnett, South Downs,
Cross - State Agencies	490	
Interstate	200	Including Federal Senate Select Committee

People distributing Kits are requested to keep a record where possible of who has received them, to assist the Programme evaluation process. However, receiving a kit does not depend on providing personal information.

Projections

It was projected that using current promotional and distribution strategies, in excess of 3,000 kits would be distributed throughout Queensland in the last 18 months:

Pilot Region	Number Distributed	Total Projected
Northern	549	650
SEQ	877	1,000
Southern Remote	463	550
Cross-State Agencies	490	600

Feedback and Evaluation

Feedback has been sought throughout the Project by

- feedback slips included in each pack
- verbal feedback sought during follow up phone calls
- a formal evaluation which will begin in December 2005

Summary and Next Steps

Building on the achievements in promotion, distribution and tracking of Supporting Partners Kits so far, the final phase of the Supporting Partners Programme included:

- Ensuring that Kits mailed to clinical staff have been passed on to community and social work staff, and sending additional samples as required
- Following up distribution of samples to generate repeat orders
- Tracking whether kits are reaching general public and supporting partners or 'stopping' with professionals and agencies, who have been our main distribution path to date
- Making any necessary changes to promotion and distribution strategies, to ensure maximum benefit to the community from the Project
- Promotional Trips eg to: Gold Coast, Ipswich/Toowoomba, Central Qld, Roma/St George, FNQ coastal and inland areas eg Charter's Towers/ Mt Isa/Longreach
- Other promotional activities, such as awareness days, media interviews, conference presentations, seminars or distribution of flyers
- Review and Revision of the Kit to include additional material on Supporting Children. Changes incorporated at this Review will qualify as a Version change, so that future Kits will be recorded as Version 2
- Exploring feasibility of developing an audio CD of people's experiences
- Forming strategies for continuing useful life of the project beyond the Pilot period
- Research evaluation of the Programme
- Obtain funding to extend the Programme nationally.

ITEMISED BUDGET SUPPORTING PARTNERS NATIONAL ROLLOUT

(Year One)

Item	Function	Allocation	Comment
Supporters Partners Pack	Production of 15,000 units	\$120,000	Production & Packaging of 11 components each Pack
Supporters Partners Pack	Distribution of 15,000 units	\$ 30,000	Postage & Delivery
Staff Wages	National introduction & follow-through	\$ 60,000	Proportional Allocation
Implementation	Accommodation & travel	\$ 15,000	Proportional Allocation & includes contingency for group sessions
Administration	Infrastructure & overhead expenses	\$ 40,000	Support services, telephone, etc.
Total		\$265,000	

Over the initial five (5) year rollout phase of the Supporting Partners Programme the total expenditure would be as follows:

(Five Year)

Year	Budget	Comment
Year One (1)	\$ 265,000	Including implementation expenses
Year Two (2)	\$ 255,000	Lower implementation & travel expenses
Year Three (3)	\$ 235,000	As Above plus lower reduction numbers
Year Four (4)	\$ 235,000	Stabilised numbers and implementation costs
Year Five (5)	\$ 235,000	Stabilised numbers and implementation costs
Total	\$1,225,000	