

How to Start a Support Group in your Community

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- Introductions
- Why we are here today
- Housekeeping



Susan G. Komen for the Cure®

- Founded in 1982 by Nancy G. Brinker
- World's largest grassroots network of breast cancer survivors and activists
- Invested more than \$1.3B since inception
- Our promise: to save lives and end breast cancer forever.



One promise, two sisters

Our Work: Fighting breast cancer on all fronts

HOSPITAL

GOVERNMENT POLICY

RURAL AREAS

LABORATORY

URBAN AREAS

DOCTOR'S OFFICE

LOCALLY

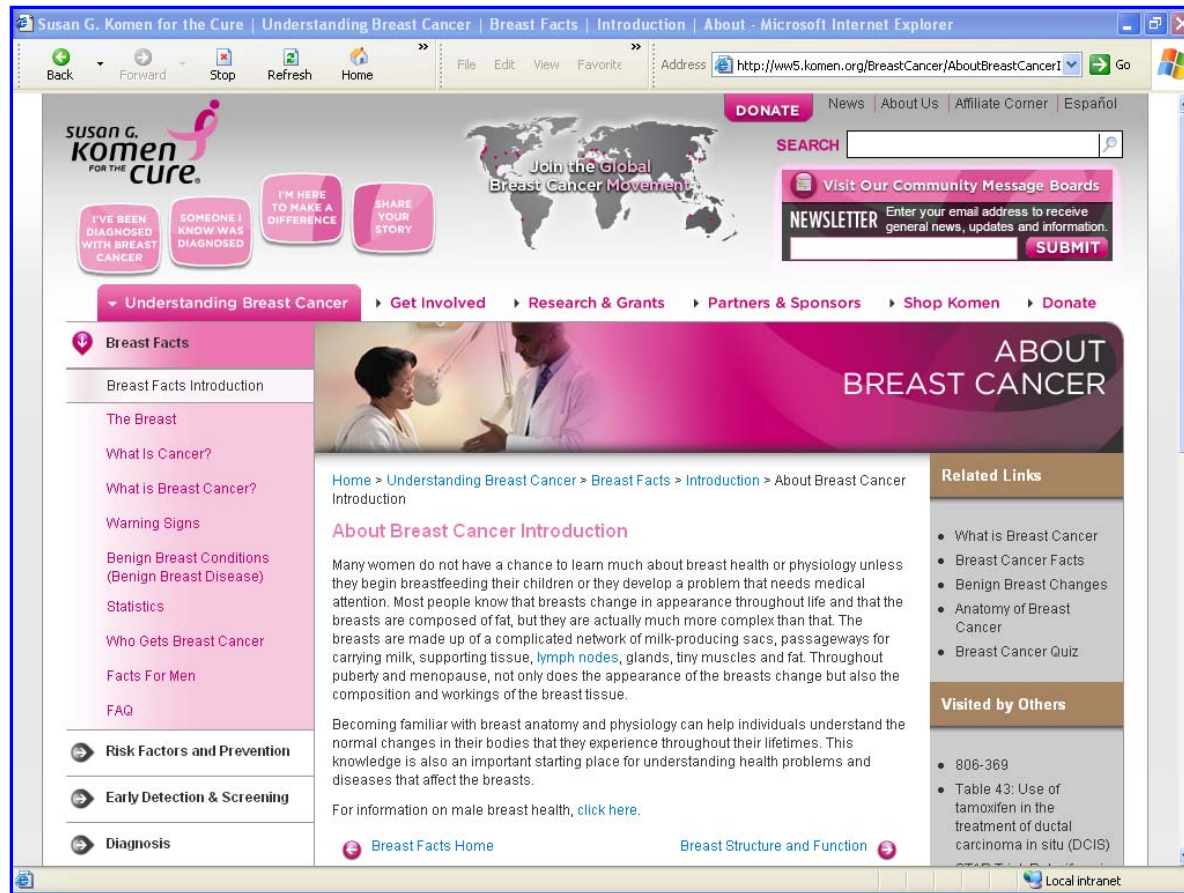
GLOBALLY



Going Global



Breast Health Resources



PURPOSE

To empower community members in the region with the knowledge and tools to start support groups within their communities.

GOALS OF TODAY'S PROGRAM

- Provide information and tools to assist in developing support groups
- Provide suggestions and ideas for starting support groups
- Provide an opportunity to discuss and think about steps that can be used for starting support groups (assess, plan, implement, evaluate, revise and modify)

LEARNING OBJECTIVES

Upon the completion of this training, you will be able to:

- Describe the purpose of support groups
- Discuss the types/structure of support groups
- Discuss the benefits of social support and the role support groups can play
- Discuss the advantages and disadvantages of each type of support group
- List the steps of a model that may be used to start, promote, maintain and sustain a support group (assess, plan, implement, evaluate, revise and modify)

AGENDA

- Introductions
- Purpose, goals and objectives
- Definition, purpose, types/structure of support groups
- Break
- Advantages and disadvantages of types of support groups
- Lunch
- Assess and plan
- Break
- Implement and evaluate
- Revise and modify
- Questions



DEFINITION OF A SUPPORT GROUP

A group of people, sometimes led by a therapist, who provide each other with information, moral support and advice on problems relating to some shared characteristic or experience.

Example: a support group for women who have had a breast cancer diagnosis.



PURPOSE OF SUPPORT GROUPS

Informational - to give accurate, unbiased information about the illness and effective ways to cope with it.

Psychosocial - to provide emotional connection when members feel isolated from friends and family and to help normalize some of the patients feelings

Practical – to provide practical solutions to shared problems

TYPES / STRUCTURE OF SUPPORT GROUPS

- Professionally led
- Lay lead
- Combination (by co-leaders) I
- Patients only
- Special patient groups – by age, diagnosis (newly diagnosed, advanced), type of treatment
- Family/partner only
- Caregiver only
- Children only
- Mixed/combination Ongoing
- Time-limited
- Drop-in as needed
- Free to participants
- Participants pay a fee
- Mandated



BENEFITS OF SOCIAL SUPPORT

Reduced:

- Anxiety
- Psychological distress
- Depression
- Feelings of pain

Improved:

- Mood
- Self-image
- Ability to cope
- Feeling of control

ROLE OF SUPPORT GROUPS

Informational benefit

- Exchange of information
- Advice from “expert” speakers

Psychosocial benefit

- Socialization
- Opportunity for patients to release powerful emotions

Practical benefit

- Exchange of ideas, experiences and coping strategies



ADVANTAGES OF PROFESSIONALLY LED SUPPORT GROUPS

- usually more formal structure
- trained and experienced to lead group
- ensures no one dominates the group
- motivates the group through difficult periods
- someone has responsibility for the running of group
- maintain a more detached position
- maintain a balance between sharing/dwelling too much on difficulties/any one topic
- enable members to discover strength
- enable members to identify and meet their own needs

DISADVANTAGES OF PROFESSIONALLY LED SUPPORT GROUPS

- poor facilitation skills can take power away from group
- may be seen as outsider and not having same understanding
- may be seen as too structured

ADVANTAGES / DISADVANTAGES OF LAY LED SUPPORT GROUPS

Advantages

- empowering
- personal experience
- members can develop new skills and abilities
- no “professional” or outside involvement
- Autonomy

Disadvantages

- negative experiences may heighten anxiety
- responsibility can lie with a few key members
- some member may dominate
- the leader may assume some ownership

ADVANTAGES / DISADVANTAGES OF COMBINATION LED SUPPORT GROUPS

Advantages

- shared responsibility
- personal experience in one of leaders
- trained facilitator

Disadvantages

- may be seen as too formal with professional facilitator
- member may not like leader has not experienced disease

ADVANTAGES / DISADVANTAGES OF PATIENT LED SUPPORT GROUPS

Advantages

- all members have shared experience
- members have sense other members understand

Disadvantages

- perspective is only of someone with disease

ADVANTAGES / DISADVANTAGES OF SPECIAL PATIENT GROUPS

Advantages

- all members have shared experience
- members have sense other members understand

Disadvantages

- perspective is only of someone with disease

ADVANTAGES / DISADVANTAGES OF FAMILY OR PARTNER ONLY GROUPS

Advantages

- safe place to express feelings
- personal experience of other family members
- support from other family members

Disadvantages

- sometimes other patient experiences are important for families to hear

ADVANTAGES / DISADVANTAGES OF CHILDREN ONLY GROUPS

Advantages

- Children learn they are not alone
- children express more freely with other children

Disadvantages

- can be important for patient to understand children's concerns

ADVANTAGES / DISADVANTAGES OF MIXED / COMBINATION GROUPS

Advantages

- support from similar members
- understanding of patients and family members

Disadvantages

- participant may be unwilling to share negative feelings

ADVANTAGES / DISADVANTAGES OF CAREGIVER ONLY SUPPORT GROUPS

Advantages

- nurses and or other caregivers give each other support
- important to hear others have same feelings

Disadvantage

- can be important for caregivers to understand patient concerns

ADVANTAGES / DISADVANTAGES OF OTHER TYPES OF SUPPORT GROUPS

Groups that are free

Advantage – may allow more members to attend

Disadvantage – members may not appreciate value of group

Groups that charge a fee

Advantage – members may perceive value if a fee is charged

Disadvantage – may eliminate some from attending

Groups that are mandated

Advantage - members must attend and may receive value

Disadvantage – members may resent having to attend and not participate
and therefore not gain

ADVANTAGES / DISADVANTAGES OF ONGOING SUPPORT GROUPS

Advantages

- members become very close and share freely
- date and time are constant and well known
- established members may help welcome new member

Disadvantages

- someone new may feel not as connected

ADVANTAGES AND CHALLENGES OF TIME LIMITED SUPPORT GROUPS

Advantages

- members may be more willing to commit for a limited time
- usually meeting agenda are set in advance
- attendees are aware of goals of the meetings

Disadvantages

- timing of meeting may not meet patient immediate needs

ADVANTAGES AND CHALLENGES OF DROP-IN SUPPORT GROUPS

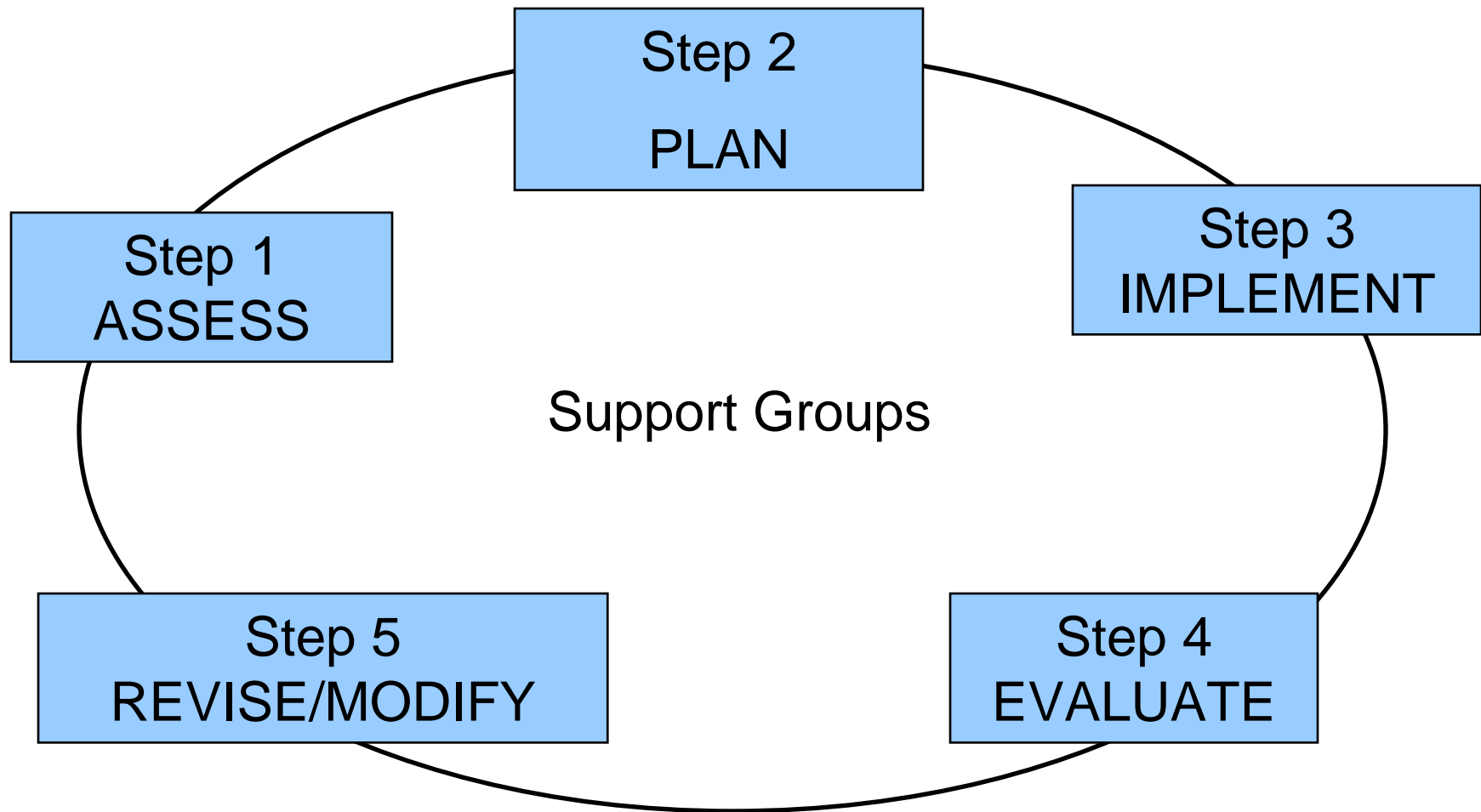
Advantages

- members do not feel an urgency to commit
- often this is a group they have attended in the past as needed

Disadvantages

- change in members may be disruptive
- drop in member will have missed much of what has happened ongoing

PLANNING MODEL



ASSESS

Process – who will be involved, who will be responsible, what is the timeline

Content – what information will be gathered



1. Gather information

- Need for a group
- Breast cancer in the community – incidence, mortality, stage at diagnosis
- People in the area – what does BC mean to them – attitudes, values and beliefs
- Likely sources of community support/resistance
- Community resources (locations, referrals, administrative support, financial, outreach)

2. Make decisions

- Process
- Content



PLAN

Process - who will be involved, who will be responsible, set timeline

Content of the plan:

- Focus/purpose – mission statement, goals, objectives
- Type/structure
- Logistics
- Marketing plan
- Record-keeping and reporting
- Evaluation plan

IMPLEMENT

Content – who will be involved and who will be responsible

Process:

- Group leaders – select and train
- Schedule/organize meetings – facilitator and logistics
- Promote and recruit
- Prepare meeting check list
- Gather resources (materials, refreshments, guests)
- Prepare for first meeting
- Make the environment welcoming
- Clarify your guidelines
- Clarify issues of confidentiality
- Clarify attendees expectations – linked to mission
- Evaluate
- Prepare records and reports

EVALUATE

Process – who will be involved and responsible

- Support group meetings themselves – by leader and participants
- Meetings/training for leaders
- Overall program

Content – type, schedule, content, process

- Formal/informal
- Schedule – after each meeting, at intervals
- Content
- Process



REVISE AND MODIFY

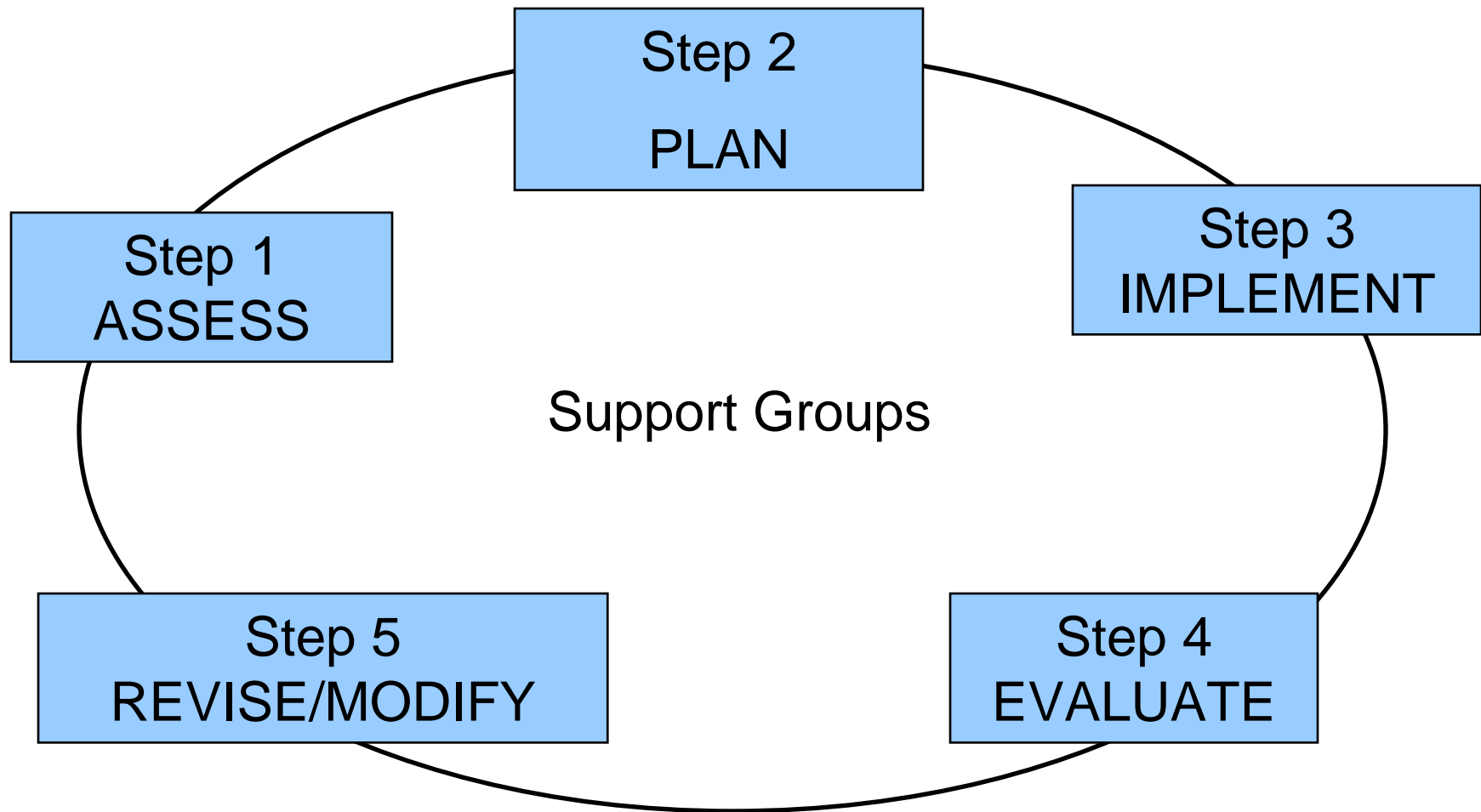
PROCESS – who will be involved and who will be responsible

CONTENT

- Constantly evaluate
- PLAN to revise and modify
- Revise as the needs of the group become clear or change
- Modify to constantly strive to meet the needs of the group



PLANNING MODEL



STAGES OF A GROUP



Stage 1 – high attendance, silent members, people who come once and never return

Be clear about your goals and guidelines.....keep calm

Stage 2 – fewer attendees, committed attendees, some dominate members

Make sure everyone has a chance to speak, be clear about your guidelines

STAGES OF A GROUP CONTD.



Stage 3 – lots of discussion, sense of trust, sense of ease, more commitment

Congratulate yourself, do evaluation to continually meet group needs.

Stage 4 –a crisis takes place, a leader becomes ill or leaves, members are feelings less secure

Keep calm, recognize the inevitable stages, discuss with group what has happened and how it feels, celebrate what you have achieved, ask group if they want to make changes

Questions



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LEARNING OBJECTIVES



Now at the completion of this training, you are able to:

- Define support groups
- Discuss the types and purpose of support groups
- Discuss the benefits of social support and the role support groups can play
- Discuss the advantages and disadvantages (challenges) of each type of support group
- List the steps that may be used to start, promote, maintain and sustain a support group (assess, plan, implement, evaluate, revise and modify)

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