ST E P

Start Talking Early and Plan

A Program to Increase Communication
Between Elders and Their Health Care Agents

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Introduction

There is general agreement that advance directives are valuable tools to help individuals communicate their wishes for future health care. In addition, there is agreement that it is better to complete these documents when individuals are healthy and able to approach the topic of end-of-life decision-making with as little external stress as possible.

The health care proxy, one form of advance directive, enables an individual to designate an agent to speak for him/her about health care decisions in the event the individual is not able to do so. Even when this powerful tool for safeguarding self-determination is in place, there may be unanticipated problems. These include misunderstanding about the medical circumstances under which health care agents make decisions and misunderstanding about the type of decision required. Sometimes individuals do not even tell their health care agents they have been selected. Even when the health care agent knows he/she has been selected, discussions about the individual's preferences are often never held. For those who discuss their health care wishes with their agents, the necessary details about their preferences are often not made known.

Communication between individuals and their potential health care agents is critical to effective end-of-life planning and decision-making. In order for individuals to feel comfortable naming a health care agent, and for agents to make decisions that truly reflect the individuals' wishes, people must talk about subjects that may be disturbing for them. Research has documented that there is a relationship between the ability of potential agents to accurately represent individuals' wishes and prior discussions about end-of-life planning. However, with older persons in particular, there is growing evidence that these discussions about wishes for care at the end of life are not being held.

The aim of this project was to develop an intervention to facilitate communication and understanding between older persons and their potential/designated health care agents. The project provided an educational and communication enhancement intervention program through a series of group sessions led by social workers. The intervention, targeting high functioning community-dwelling older persons and their potential/designated agents, aimed to enhance communication about end-of-life planning prior to a crisis or acute illness.
Through comparison with older persons and agents who did not participate in the program, we were able to document the success of this program. Persons who participated in the program scored significantly higher than those who did not take part in the program on measures of knowledge about the health care proxy form and the roles and responsibilities of the health care agent. In addition they scored significantly higher on an instrument that measured communication between older persons and their agents about end-of-life decisions.

This manual is intended to serve as a guide for programs wishing to help their clients begin the important process of communicating with their potential/designated agents about their wishes for health care. The curriculum is presented here exactly as we used it*. We present it this way because we have been able to demonstrate the success of this curriculum and the model we used to deliver it. We have included factors that we believe contributed to our ability to effectively deliver the program. For example, we found it helpful to provide meals prior to each group meeting. This served both as an inducement for people to come to all of the group meetings as well as a way to develop trust between the group leaders and the participants. You may find that you do not have the resources to deliver this program in the same format. While we encourage you to follow the format as closely as possible, we realize that this may not be possible. It is our belief that any efforts toward helping older persons begin discussions with potential/designated health care agents are of great value to both the older persons themselves and the relatives or friends who may someday have to speak for them. Therefore, we hope that you will find material in this manual that will be helpful to you in working toward this goal, even if you are unable to replicate the Start Talking Early and Plan (STEP) program. We do recommend that anyone who embarks on a program to help others begin discussions about end-of-life decision planning have experience in and comfort with discussing this topic.

This program was developed for use in New York. Consequently, the information about end-of-life planning in general and the health care proxy in particular is based on New York State law. If you are using this manual to guide your use of this program in another state, it is important to check for differences between your state and New York.

* We have included suggestions for what the group leader could actually say in presenting some of the material. This can, of course, be adapted to suit a leader’s individual style. We also included the suggested time to be allocated for each section of the curriculum of the second and third group meetings.
The STEP Program

The program consists of a series of three group meetings. The meetings are summarized below:

1. Small group sessions – This group of older persons and a social worker focuses on the health care proxy and the difficulties inherent in end-of-life planning. The participants receive relevant written materials to take home with them.

2A. Large group sessions - The session is held for the older persons and potential/designated agents. It includes a presentation by an interdisciplinary team of a social worker, physician, attorney, and member of the clergy*. This presentation includes information about advance directives; medical, legal, and ethical issues in end-of-life planning; the role of values; and communication issues.

2B. Small break-out groups of older persons and potential/designated agents** with a social worker are held immediately following the large group presentation. The break-out groups focus on the difficulties inherent in end-of-life planning and the process of communication between older persons and their potential/designated agents. Participants receive relevant written material, including material related to the large group session.

3. Small group sessions - This meeting of older persons, potential/designated agents and a social worker focuses on participants’ efforts to communicate about end-of-life planning.

It is important to leave sufficient time between group meetings so that participants have enough time to process and discuss the material covered. We recommend

* The use of an interdisciplinary team may be a luxury for some agencies. The material presented by the team can be delivered by one individual (possibly the social worker running the group) if (s)he has become fully informed about all aspects of the curriculum. If participants have specific questions related to their individual situations, they would be referred to their personal health care provider or clergy by the team.

** If your program has a small number of participants, a large group session may not be required. The material in group sessions 2A and 2B can be combined, with a short break if desired.
allowing for two weeks between the groups at a minimum. On the other hand, you
do not want to have so much time elapse between the groups that you lose the
momentum gained.

The curriculum for the series of three meetings follows.*

To prepare for leading the series of group interventions, the social workers
participated in two training sessions. The curriculum for these sessions is included
in the Appendix of this manual.

We recommend that group leaders be social workers who are experienced in and
comfortable with discussing end-of-life issues. The group leader should plan to be
available after the group ends in the event anyone is distressed by the material
discussed and needs to talk about his or her reaction to the discussion.

* Please note that reference is not made in the curriculum to the fact that the health care proxy
form includes a section on organ donation (optional) because that was added after this program
was completed.
Curriculum for Small Group of Older Persons

Lunch: 30 minutes
Small Group Meeting: Approximately 60 minutes
Six Participants per Group

Name tags for participants

Content outline

1) Introduction of attendees
2) Project review
3) The health care proxy and the health care agent
4) Communication: Why end-of-life planning is difficult
5) Group Closure

1) Introduction of Attendees
Format: Dialogue

Introduction of group leader and participants

2) Project Review
Format: Lecture and discussion

♦ Review of the project and key definitions
♦ Leader will elicit and answer any questions about the project.

Summary of the sessions:

First Meeting - Older persons: This is our first group meeting. The focus of this group is to encourage communication and understanding between you and your potential/designated health care agent around end-of-life planning. We will provide three sessions to help you understand the issues and help you to be more comfortable talking about end-of-life planning.
Second Meeting - Older persons, potential/designated health care agents, and interdisciplinary team panel (if an interdisciplinary team is used): The second meeting is a combination of large and small groups. The meeting begins with a discussion of end-of-life issues and includes a doctor, a lawyer, and a member of the clergy with a social worker leading the discussion. This is followed by small group discussion with you and the person you are considering as your agent to discuss end-of-life issues.

Third Meeting - Older persons and their health care agent: The third meeting is a small group. It is easier for you to talk with somebody you trust about what you would like to have done medically if you couldn’t speak for yourself. The purpose of the group is to encourage discussion about end-of-life planning between you and your potential agent and to answer any questions regarding this process.

Definition of terms:

Advance Directives: Advance directive is the general term that refers to: 1) a living will and 2) a health care proxy. These documents give instructions about the medical care in case you are unable to speak for yourself due to serious illness or incapacity.

Living Will: A living will lets you put in writing your wishes about the medical treatment you desire at the end of your life if you are unable to communicate these wishes yourself. This document is to guide your family and doctors in deciding how aggressively to use medical treatment at end of life.

* You may use only a small group if desired.
** The use of an interdisciplinary team may be a luxury for some agencies. The material presented by the team can be delivered by one individual (possibly the social worker running the group) if (s)he has become fully informed about all aspects of the curriculum. If participants have specific questions related to their individual situations, they would be referred to their personal health care provider or clergy by the team.
Health Care Proxy: The health care proxy is a document that allows you to appoint someone you trust to make decisions about your medical care if you cannot do so yourself. The person you appoint is authorized to deal with all medical situations when you cannot speak for yourself, not only end-of-life decisions. In the event you become temporarily incapacitated--after an accident, for example--as well as if you become irreversibly ill, this agent can speak for you.

3) The Health Care Proxy and The Health Care Agent
Format: Lecture and discussion

Health Care Agent role:
♦ Make medical decisions if patient loses capacity to make them on his or her own
♦ Speak for the patient only if he or she is unable to speak:
  • at end-of-life
  • if temporarily incapacitated such as after an accident
♦ Have legal authority regarding medical decisions
♦ Knowledge about patient’s wishes regarding types of treatment

Why plan now?
If you want the designated agent to make decisions for you if you are unable to speak, you need to discuss your wishes now so he/she will know what you want

Naming (potential) someone to be your health care agent
♦ What qualities does the person have that made you consider selecting him or her?
♦ Issues selecting one person over another (e.g., selecting one family member)
4) **Communication: Why end-of-life planning is difficult**

 Format: Questions posed to participants and discussion, with suggestions provided by the group leader.

**Introduction to why sometimes it is difficult.**

*(Social worker may want to read the list to begin the discussion)*

**Barriers to discussion can include:**

1. Discomfort with the subject
2. Lack of a potential agent
3. The burden placed on agents
4. Not wanting to relinquish autonomy
5. Completing an advance directive connotes personal death, raising ambivalence and fear
6. Adult children (or designated agents) do not want to discuss end-of-life planning
7. Other concerns that may come from the group

**Questions to ask the participants**

♦ End-of-life planning - why is it difficult?
♦ Why is it hard to talk about this with loved ones?
  • People are afraid they will jinx their situation; if they talk about it, then something bad may happen
  • Issues around death
♦ How to begin the conversation.
  • Don’t wait until the right moment; there never is the perfect moment
  • It is OK not to have the perfect lead-in sentence
  • Decide when and where you want to have the conversation
  • Decide if you want to speak with one individual or the whole family
• Example: I know it is upsetting, but I need to talk with you about end-of-life planning. It may be difficult now, but it will be much easier down the road if we discuss it now. Also, it will be very comforting to both of us if you know what I want and helpful to you if decisions about my care need to be made.

♦ How to deal with potential/designated agent who doesn’t want to talk about it or is uncomfortable talking about it.
♦ How to deal with your own discomfort.

5) Group Closure

♦ Summarize topics discussed
• Encourage participants to return
• Mention health care proxy form will be handed out/completed during the last meeting
♦ Encourage participants to begin the discussion with the person they are considering as their health care agent
♦ Give participants packet of material*

* Note: The materials we handed out were three booklets:
Curriculum for Large Groups of Older Persons and Agents
Dinner: 30 minutes
Large Group Meeting: 60 minutes

Content Outline
1) Welcome
2) Project review
3) Understanding advance directives and the health care proxy in particular
4) Team presentation
5) Questions from the audience
6) Summary

1) Welcome (2 minutes)
   Welcome - Introduce Team

2) Project Review (3 minutes)
   Format: Formal presentation—Team Leader
   Review of the project including definitions of health care proxy and living will
   ♦ Today: Large group meeting to discuss end-of-life issues with the panel
   ♦ Followed by small group discussion with the elders and their agents
   ♦ Final meeting will be a small group discussion with the elders and their designated proxies to discuss the process, answer questions, and bring closure to the process
3) **Understanding Advance Directives and the Health Care Proxy in Particular** (5 minutes)

   *Format: Formal presentation (relevant written material will be distributed at the end of the meeting)*

   ♦ **Definitions:**

     **Advance Directives:** *Advance directive* is the general term that refers to: 1) a living will and 2) a health care proxy. These documents give instructions about the medical care in case you are unable to speak for yourself due to serious illness or incapacity.

     **Living Will:** A *living will* lets you put in writing your wishes about the medical treatment you desire at the end of your life if you are unable to communicate these wishes yourself. This document is to guide your family and doctors in deciding how aggressively to use medical treatment at end of life.

     **Health Care Proxy:** The *health care proxy* is a document that allows you to appoint someone you trust to make decisions about your medical care if you cannot do so yourself. The person you appoint is authorized to deal with all medical situations when you cannot speak for yourself, not only end-of-life decisions. In the event you become temporarily incapacitated--after an accident, for example--as well as if you become irreversibly ill, this agent can speak for you.

     **Do-Not-Resuscitate (DNR) Order:** A *do-not-resuscitate order* is a written instruction from a physician to health-care providers telling them not to perform cardiopulmonary resuscitation or related procedures on a patient.

   ♦ **Reason for tonight’s meeting is to discuss roles and responsibilities of health care agent (general statement)**

4) **Team Presentation**

   **Medical, legal, and ethical issues in end-of-life planning** (30 minutes)

   *Format: Team presentation (relevant written material will be distributed at the end of the meeting)*
♦ **Doctor** (10 minutes) - Medical issues
  - Kinds of decisions individuals may be called upon to make
  - Do-not-resuscitate, nutrition, hydration, ventilator, surgery, role of intensive care, and any other issues
  - Clarifying the issues
  - Timing - why it is important to discuss early on in the process
  - Dealing with doctors and nurses

♦ **Lawyer** (10 minutes) - Legal issues
  - Do not need a lawyer to complete the form
  - Need two witnesses to sign health care proxy
  - Do not need to notarize the form
  - It does not deal with financial issues
  - Cannot make nutrition, hydration decisions if wishes are not known
  - Discuss where to obtain forms and who should receive a completed copy

♦ **Clergy** (10 minutes) - Values, spirituality, and ethical issues
  - The importance of our values
  - Values as a basis for decision making
    - Advantages of values worksheet and why it is a helpful tool
    - Discuss cultural and ethnic values
  - How to discuss values
  - Values and religion

5) **Questions from the Audience** (15 minutes)
   
   The Interdisciplinary Team will answer questions from the audience

6) **Summary** (5 minutes)
   
   Briefly summarize the panel discussion
   Facilitate moving elders and their designated proxies to break out groups
Curriculum for Break Out Groups of Older Persons and Agents
Small Group Meeting: 50 minutes
Dessert and Coffee Available
6-8 Participants Per Group

Content outline

1) Introductions
2) Roles and responsibilities
3) Health care proxy form
4) Questions
5) Communication: Why end-of-life planning is difficult
6) Values history
7) Group closure

1) Introductions (5 minutes)
   Format: Dialogue
   Introduction of group leader and participants

2) Roles and Responsibilities (5 minutes)
   Format: Formal review
   The health care agent **has the right** to make decisions regarding:
   1) health care decisions for the patient if he/she cannot speak
   2) artificial nutrition - if patients’ wishes are known
   3) artificial hydration (intravenous fluids) - if patients’ wishes known
   4) stopping life sustaining treatment (e.g., renal dialysis, ventilator)
   The health care agent **does not have the legal right** to:
   1) vote for the individual
   2) make financial decisions
   3) make decisions for patient if the patient still has the capacity to communicate

3) Health Care Proxy Form - (5 minutes) *Discuss items on the form only (form itself to be given out during final meeting)*
   ♦ Name
   ♦ Artificial nutrition and hydration
   ♦ Substitute person
♦ Two witnesses needed
♦ Do not need a lawyer to complete the form
♦ Does not need to be notarized
♦ The form does not deal with financial issues
♦ Can cancel health care proxy form or change designated health care agent

4) **Questions** (5 minutes)
   **Format:** Invitation to participants
   Ask participants if they have any questions

5) **Communication: Why end-of-life planning is difficult** (15 minutes)
   **Format:** Discussion (relating back to small groups with older persons)
   1) End-of-life planning - why is it difficult?
   2) Why is it hard to talk about this with loved ones?
   3) How to begin the conversation

   *Use topics from the first small group training session for additional questions*

6) **Values History:** (5 minutes) Hand out the *Values History Worksheet* (see Appendix).

   **Suggested homework:**
   ♦ Talk about end-of-life planning in whatever way is most comfortable for you
   ♦ Tell the participants they may use *The Values History Worksheet* as a tool if they wish

7) **Group Closure** (10 minutes)
   ♦ Summarize topics discussed
   ♦ Encourage participants to continue the discussion with each other
   ♦ Give educational materials to health care agent*

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* Note: These are the same materials given out to the older persons after the first group session:
Meeting 3

Curriculum for Final Small Group Meeting of Older Persons and Agents
Dinner: 30 minutes
Small Group Meeting: 60 minutes

Content outline

1) Introductions
2) Communication: Efforts to talk about end-of-life planning
3) Hand out and review the health care proxy form
4) Wrap-up
5) Group Closure

1) **Introductions** (5 minutes)
   Format: Dialogue
   Introductions/Reintroduction

2) **Communication: Efforts to Talk About End-of-Life Planning** (15 minutes)
   Format: Dialogue and questions posed by group leader
   ♦ Sharing of efforts to communicate end-of-life planning
   ♦ What has it been like?
   ♦ Were you comfortable/uncomfortable with end-of-life discussions?
   ♦ What did you do to move the conversation along? To stop it?
   ♦ Why do you think it played out this way?
   ♦ How would you like it to be different?
   ♦ What can you do to make it different?

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3) **Hand Out and Review the Health Care Proxy Form*** (15 minutes)

4) **Wrap-Up** (15 minutes)
   Format: Discussion guided by questions
   ♦ What has this experience been like for you?
   ♦ What can you do to continue the dialogue?

5) **Group Closure** (10 minutes)

You may want to be available after the group ends to assist any participants who wish to complete a health care proxy at this time.

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Appendix

Values History Worksheet

Sample New York Health Care Proxy

Sample New York Living Will

Social Worker (Group Leaders) Training
VALUES HISTORY WORKSHEET

There are several values important in decisions about end-of-life treatment and care. This section of the Values History invites you to identify your most important values.

A. Values Section:

1. **Basic Life Values**: Perhaps the most basic values concern length of versus quality of life. Which of the following statements describes your wishes?

   _____ I want to live as long as possible, regardless of the quality of life that I experience.

   _____ I do not wish my life to be prolonged by medical treatment(s) if my quality of life is unacceptable to me.

2. **Quality of Life Values**: There are many values that help us to define for ourselves the quality of life that we want to live. The following values appear to be those most frequently used to define quality of life. Review this list and check the values that are most important to your definition of quality of life. Feel free to elaborate on any of the items in the list, and to add to the list any other values that are important to you.

   _____ I want to maintain my capacity to think clearly.

   _____ I want to feel safe and secure.

   _____ I want to avoid unnecessary pain and suffering.

   _____ I want to be treated with respect.

   _____ I want to be treated with dignity when I can no longer speak for myself.

   _____ I do not want to be an unnecessary burden on my family.

   _____ I want to be able to make my own decisions.

   _____ I want to experience a comfortable dying process.

   _____ I want to be with my loved ones before I die.

   _____ I want to leave good memories of me for my loved ones.

   _____ I want to be treated in accord with my religious beliefs and traditions.

   _____ I want respect shown for my body after I die.

   _____ I want to help others by making a contribution to medical education and research.

   _____ Other values or clarification of values above: ________________________________

   ________________________________
B. Directives Section

Please circle “yes” or “no” to indicate the circumstances under which you would or would not want the interventions listed below

1. I wish to undergo cardiopulmonary resuscitation (CPR) if my heart or breathing should stop
   Yes  No  Under all circumstances
   Yes  No  If I have a severe incapacitating mental or physical illness from which there is no reasonable hope of recovery
   Yes  No  If I am in a persistent vegetative state in which I have no awareness of my surroundings and no expectation of recovery.
   Yes  No  If (please fill in) ________________________________________________________
   Yes  No  Under no circumstances

2. I wish to be placed on a breathing machine
   Yes  No  Under all circumstances
   Yes  No  If I have a severe incapacitating mental or physical illness from which there is no reasonable hope of recovery
   Yes  No  If I am in a persistent vegetative state in which I have no awareness of my surroundings and no expectation of recovery.
   Yes  No  If (please fill in) ________________________________________________________
   Yes  No  Under no circumstances

3. I wish to have a tube placed down my throat to help my breathing
   Yes  No  Under all circumstances
   Yes  No  If I have a severe incapacitating mental or physical illness from which there is no reasonable hope of recovery
   Yes  No  If I am in a persistent vegetative state in which I have no awareness of my surroundings and no expectation of recovery.
   Yes  No  If (please fill in) ________________________________________________________
   Yes  No  Under no circumstances

4. I wish to receive food artificially by a tube into a vein or the stomach. (I understand that food will be offered by mouth if I am able to take it.)
   Yes  No  Under all circumstances
   Yes  No  If I have a severe incapacitating mental or physical illness from which there is no reasonable hope of recovery
   Yes  No  If I am in a persistent vegetative state in which I have no awareness of my surroundings and no expectation of recovery.
   Yes  No  If (please fill in) ________________________________________________________
   Yes  No  Under no circumstances
5. I wish to receive fluids artificially by a tube into a vein. (I understand that fluids will be offered by mouth if I am able to take them.)
   Yes  No  Under all circumstances
   Yes  No  If I have a severe incapacitating mental or physical illness from which there is no reasonable hope of recovery
   Yes  No  If I am in a persistent vegetative state in which I have no awareness of my surroundings and no expectation of recovery.
   Yes  No  If (please fill in) __________________________________________________________
   Yes  No  Under no circumstances

6. I wish to have medications for treatment of my illness continued. (I understand that pain medication will be continued if I need it to relieve pain.)
   Yes  No  Under all circumstances
   Yes  No  If I have a severe incapacitating mental or physical illness from which there is no reasonable hope of recovery
   Yes  No  If I am in a persistent vegetative state in which I have no awareness of my surroundings and no expectation of recovery.
   Yes  No  If (please fill in) __________________________________________________________
   Yes  No  Under no circumstances

7. I wish to have kidney dialysis.
   Yes  No  Under all circumstances
   Yes  No  If I have a severe incapacitating mental or physical illness from which there is no reasonable hope of recovery
   Yes  No  If I am in a persistent vegetative state in which I have no awareness of my surroundings and no expectation of recovery.
   Yes  No  If (please fill in) __________________________________________________________
   Yes  No  Under no circumstances

8. I wish (consider any other wishes you may have) ________________________________
   Yes  No  Under all circumstances
   Yes  No  If I have a severe incapacitating mental or physical illness from which there is no reasonable hope of recovery
   Yes  No  If I am in a persistent vegetative state in which I have no awareness of my surroundings and no expectation of recovery.
   Yes  No  If (please fill in) __________________________________________________________
   Yes  No  Under no circumstances

Social Worker (Group Leaders) Training
Two Sessions
(approximately 2 hours each)

Session One

I. Introductions

2. Overview of Project
   A. Review of project
   B. Role of the social worker
      1. Group leader/facilitator
      2. Educator
      3. Facilitate communication among participants
      4. Provide support to elders through this important task

3. Education about the health care proxy
   A. Overview
      1. Hand out health care proxy and living will forms
      2. Hand out materials:
         Discuss do-not-resuscitate, artificial nutrition and hydration,
         cardiopulmonary resuscitation
   B. Case presentation and discussion
      1. Case: Understanding the range of situations when a respirator may
         be used
      2. What if scenarios?
         Ex. What if the medical staff ignores health care proxy?
   C. Values worksheet
      1. To be completed prior to first meeting
      2. Discuss reaction to worksheet
   D. Own feelings about health care proxy (each group leader should have
      completed his/her own health care proxy)

4. Running Small Groups
   A. Small group process
      1. Introduce group members to each other
      2. Make a brief, simple opening statement to clarify group purpose
      3. Obtain feedback from group if this is what they are expecting

* Note: We handed out four booklets:
1) “Advance Directives and End-Life Decisions,” available from Partnership for Caring,
2) “Talking About your Choices,” available from Partnership for Caring,
3) “Healthcare Agents: Appointing One and Being One,” available from Partnership for Caring,
4. Clarify job of the group leader:
   a. Facilitator
   b. Time keeper
   c. Stay focused on topic

5. Create a supportive culture in the group in which members feel safe
   a. Acknowledge difficulties of the topic
   b. Participants are there to share ideas; not give advice

6. Begin to encourage inter-member interaction rather than discussion between group leader and group members

5. Solicit ideas and feedback from social workers
   Participants were given a copy of the video, “Whose Death is it Anyway?” available from Partnership for Caring, to view before the next session.

Session Two

1. Introduction
   A. Overview of topics to be discussed
   B. Address questions from participants
   C. Discuss the video

2. Knowledge of curriculum to be delivered
   A. Specific information covered in small groups
   B. Knowledge about health care agents role and responsibilities
   C. Knowledge about health care proxy form
   D. Comfort discussing end-of-life planning
   E. Attitudes toward advance planning
   F. Greater communication between older persons and their agents

4. Small group process
   A. Curriculum of small groups
   B. Topics to be covered
   C. Pacing the small groups
   D. Importance of attrition
   E. After each group, please be available if someone is upset and needs further emotional support

5. Closure and Feedback