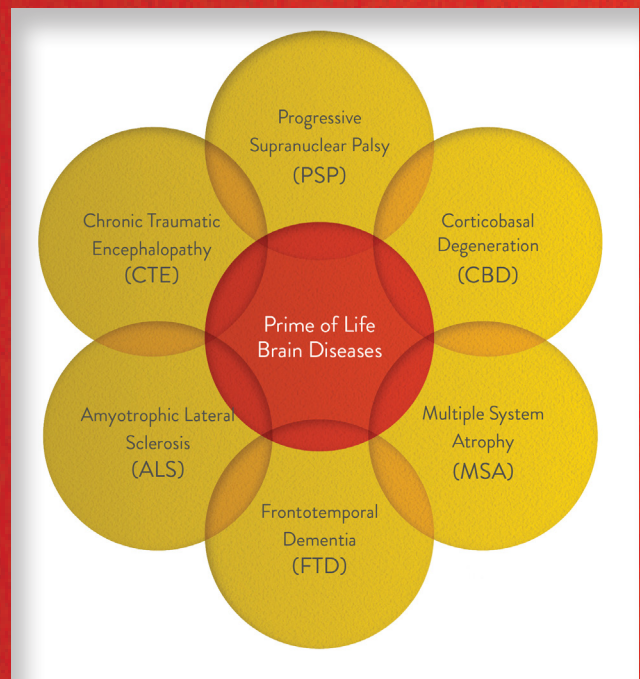


Your mission of hope.

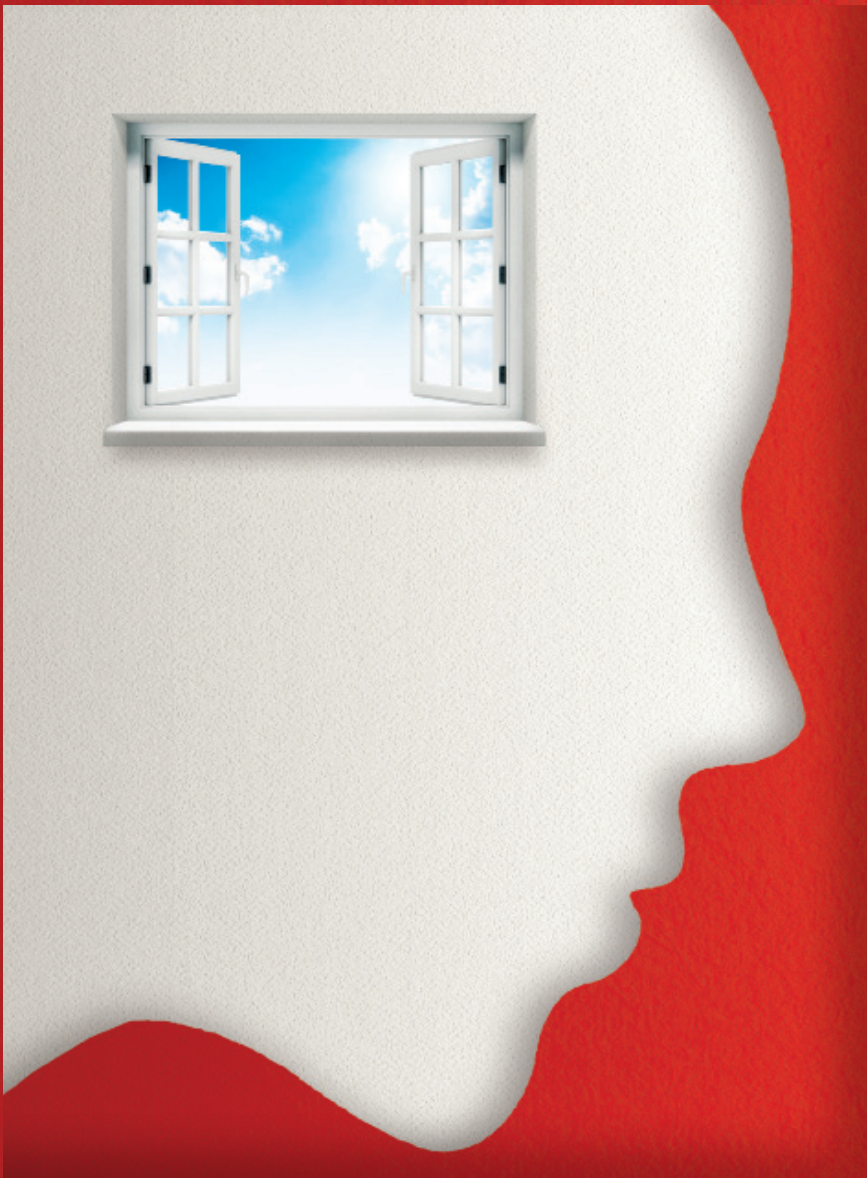


EFFECTIVE LEADERSHIP
OF SUPPORT GROUPS
FOR PATIENTS AND FAMILIES

by

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2017 Edition



INTRODUCTION

THE MISSION OF CUREPSP

Awareness, education, care and cure for devastating prime of life neurodegenerative diseases.

DEDICATION

This manual is dedicated to all the CurePSP support group leaders past and present who have the courage and vision to embrace the challenge of helping others.

DISCLAIMER: A support group is a helpful resource, however neither changes to medication or treatment plans should be undertaken without first discussing them with your physician.

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CHAPTER ONE

The Group



CHAPTER ONE: THE GROUP

What is a CurePSP support group?

A CurePSP support group is a voluntary gathering of people who share common experiences, situations or problems related to living with a prime of life disease such as PSP, CBD and MSA. Group members offer each other emotional and practical support and reduce the sense of isolation that is associated with rare brain diseases.

Who attends CurePSP support group meetings?

A very diverse group of people attend these groups. Brain diseases are not specific to any race, gender, socioeconomic group or religious background. As it true of most support groups, there is a common bond: people whose lives are significantly affected by PSP and related brain disorders. Due to the mature discussions that take place during the meetings, the appropriate age for persons attending the meetings are 18 years and older.

The following types of individuals can be involved in attending support group meetings. Many groups involve both the person with the disease and family members/significant others, since sharing mutual concerns and perspectives can often be especially helpful. In addition, the mix of both persons with the disease and families broadens the groups' ability to reach out and help a greater number of people. Attendance is often better for the meetings, since a larger segment of people are invited.

However, some group meetings are just for family members or patients separately, creating a welcome haven for individuals to share their personal point of view as to how they experience dealing with their loved ones.

A primary task is for the facilitator to decide whether the meetings should be limited to persons with the disease and family members, persons with the disease alone, or family members only. This decision is related directly to the stated purpose of the group. The purpose of the support group is to help people who have had first-hand experience with PSP and other prime of life diseases to develop new and existing methods of coping with the problems associated with these diseases.

THE TYPES OF PARTICIPANTS MAY INCLUDE:

- Those who have the disease themselves.

They may be involved in treatment with a doctor and they may or may not be on medications. Others may be at the beginning of the process of getting help, and may be in great need of support and information about the disease.

- Family members that care for someone with PSP or a related disease.

Their loved one may be in a hospital, living at home, or in an alternative living arrangement.

- Typically, a group will have new people attending each meeting.

It is not essential to attend a certain number of consecutive sessions. People come when they can, when they feel a need or interest, and when they are ready.

Professionals may be invited to attend support groups; for example, nurses, social workers, physicians – anyone who serves as a “paid helper” attempting to provide assistance to persons with these diseases and families. It is important to involve professionals and the community at large through planning educational programs about issues related to prime of life diseases. These can be arranged depending on the group members’ needs. Such meetings are vital in order to increase public awareness and the availability of resources to people with brain disease and their families.

What happens at meetings?

The meetings provide the opportunity to share information and mutual support. There may be group sharing without a specific agenda, a planned program with literature provided, or an open discussion surrounding a topic of interest. Whatever the format for a particular meeting, there is always an opportunity for personal sharing.

The purpose of the support group is to help people who have had first-hand experience with disease on the prime of life spectrum, to develop new and existing methods of coping with the problems associated with these diseases.

WHAT DO PEOPLE LEARN?

- Information about PSP and related neurodegenerative brain diseases.

What are typical symptoms? What constitutes a thorough evaluation and diagnosis? How do these diseases vary from person to person? What can be expected as the disease progresses? What treatment options and/or clinical trials exist?

- Information about available resources in the community.

Where do I go for help? What disability benefits are available and how do I apply? What options are available for respite care? What if I have to admit my loved one to a nursing home?

- Information about identifying methods of coping.

What if there is no help at times? What if there is family conflict, or lack of understanding on the part of well-meaning relatives and friends? How do family members deal with the possibility of needing to place a loved one into a nursing home?

Feelings of anger, fear, guilt, frustration, and grief interfere with decision-making. Talking about feelings with others helps to sort things out. Through sharing together, people help each other appreciate the range of responses to situations, their growing knowledge of the disease and ability to make use of practical coping strategies.

CHAPTER ONE: THE GROUP

How does meeting together have an impact on the community?

BY MEETING TOGETHER, PEOPLE ARE MAKING A CHANGE
IN THEIR COMMUNITY THROUGH:

- Encouraging the development of community resources.

People are functioning as a community resource by meeting together. The group provides people with an opportunity for support. Through discussions, the services for people with brain diseases and their families are evaluated. Education/support groups are initiated for people and families affected by these diseases. The organized expression of need offers direction, encouragement, and justification to social service and health agencies in a position to develop and potentially fund programs.

- Encouraging professional education.

In addition to learning from guest speakers invited to the meetings, the speakers are educated as well. A well-informed professional can learn about the diseases by sharing with those most directly affected by it. In this manner, guest speakers become better informed, more aware of the concerns of people living with brain diseases, and thus better equipped to help people with the diseases and their families.

- Promoting research.

Research into new treatments and causes of brain diseases will improve the quality of the lives of people dealing with the diseases. As community awareness and recognition of brain diseases as a high-cost, widespread public health problem increases, allocation of funds to research may increase.

What is important to know about choosing a meeting place and time?

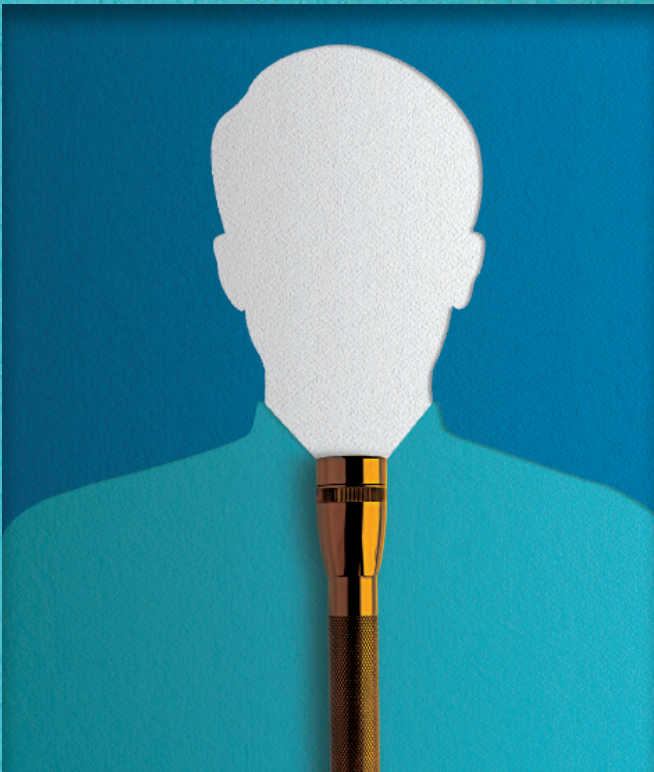
A regular time and place is important. Rather than meeting in someone's home, a central location on a public transportation route is optimal. Typical meeting sites include rooms at churches or synagogues, civic auditoriums, college classrooms, library conference rooms and hospital conference rooms. Meetings are held at any convenient location that offers the use of the facility without charge. Some locations such as libraries charge a fee; however, there are many others that can be found that will not.

The time that groups meet varies dependent on participants' needs. Some groups meet once a month on a weeknight. Other groups might meet at lunchtime or on a weekend, if this time is more convenient. Whatever the time that is chosen, it is important that the time be regular and consistent. For example, the second Tuesday of the month at 7 P.M. lets others know that they can always count on this meeting time. The meeting should have a beginning and end time of an hour and one-half.

It is very important to respect people's time by beginning and ending the meeting promptly. These time boundaries allow people to more easily fit the group into their lives since they know definitively when it will be and how long it will last.

CHAPTER TWO

The Leader



CHAPTER TWO: THE LEADER

Who provides leadership?

The group as a whole is responsible for its supportive and informative functions. However, one or preferably two people are needed to provide organization, continuity and stability for the group. These people are called “facilitators.” It is ideal to have at least two people as facilitators in case of sickness, vacations, etc. Their goal is to help identify certain tasks to be accomplished, to delegate to volunteers, and to follow-up to be sure that necessary arrangements for the group have been made.

The first two tasks listed below are the most critical: the others are important as the group develops if it wants to broaden its role and its goals. However, it is more than enough for a support group to meet and simply share together during its meeting time without the organization of educational meetings.

1. Welcoming and integrating new members.

It is important to make an effort to link newcomers with longer-term members. Designate a person to greet and welcome new people. In addition, arrange the seats in a circle with longer-term members interspersed with the newcomers. Another useful method is a buddy system in which one of the longer-term members can approach a newcomer at the end of the meeting and offer support as needed. This may include giving the new person the telephone number and the choice of calling.

2. Securing room space and arranging the room as needed for the meeting. Reserve the meeting room well in advance.

For a typical support group meeting, arrange the seating in a circle. If a special program is planned, arrive 30 minutes before the meeting to set up any literature, refreshments, chairs and audio-visual equipment. (Some agencies may provide a special meeting place and equipment.)

3. Initiating ideas and identifying needs for planning programs so as to meet the needs of newcomers and longer-term members.

Some support groups do not request special programs. Sharing information and experiences in the support groups satisfies their need for support and education. However, some support groups desire speakers to address various educational topics. Some of the educational programs may need to be repeated to benefit newcomers and longer-term members. A topic needs to be decided on, and guest speakers contacted. Topics may include issues such as:

(See Appendix E on page 43 for additional suggestions for program topics.)

4. Sending meeting reminder notices is optional.

Prepare a flyer or public service announcement (PSA) to your local newspaper on a monthly basis. Post flyers in libraries and on community bulletin boards. Use electronic options, ie. bulletin boards, Face Book, websites. If you know of a physician who treats patients who have these diseases, ask to put up information in the waiting room. You can also ask CurePSP for educational materials to leave in waiting rooms.

5. Planning special events for advocacy, fundraising or a social event.

Look for people who have the ability and enthusiasm for working on the project, and designate a chair person to oversee the special activity.

The goal is to get others involved and not to do everything yourself!

What are characteristics that make a group leader a good facilitator?

The group must share leadership in order to encourage other people to feel a sense of commitment to the group and its purpose. The purpose of the group needs to be clear to the facilitator and group participants. To be a facilitator, a person does not need to be a “super organizer” or “as strong as a rock.” The facilitator needs to have an ability to show compassion, and ability to listen in a nonjudgmental manner. Additional characteristics of a support group facilitator that are valued highly are dependability, reliability, and a democratic approach to facilitating the group such that everything the person says and does communicates that the group is “the group’s group.” Everyone in the group has a lot to say and the group needs to value each individual by providing each of them an opportunity to talk. However, there are situations when the facilitator needs to have the confidence to take the risk of setting expectations and boundaries as needed in the group.

As a facilitator, you need to have a healthy respect for your own limitations and not feel guilty about them. For example, you don’t need to be the one to introduce a guest speaker in front of a large group if you do not feel comfortable. You can ask someone else to be the “program moderator” for the meeting.

Due to the demands on people with these diseases and their families, consider rotating leadership among group members. If one person does it all, burn-out can occur, and the group may not continue on. Group members will feel empowered when asked to help the facilitator. Group members that take part in helping with the group share a feeling of personal contribution and group spirit. The best facilitator is one who considers the group as a whole as well as each individual. Since it is good for the group to have members participate in leadership, encourage others to benefit from Cure PSP’s training resources. Group members will feel empowered by functioning in the group facilitator role.

How do I know if I’m the kind of person who can be a good facilitator?

YOU WILL NEVER TRULY KNOW WITHOUT TRYING, HOWEVER THE FOLLOWING KEY POINTS CAN HELP YOU DECIDE:

- Facilitators need to be prepared to provide continuity.

Group development is not enormously time consuming, but you must be willing to attend the monthly meetings for at least a year. Group participants will come sporadically, depending on life circumstances and personal needs. The facilitator must make a commitment to be at the meetings continuously to provide a sense of stability and continuity. Of course, in case of emergency or pre-planned absence, the co-facilitator or a veteran member of the group can assume responsibility.

- Facilitators do not have to be experts on brain disorders, but they should have a basic knowledge of the diseases and current research developments.

If you do not have the knowledge, you should be willing to learn. An important role of a facilitator is to link people up with information sources. It is okay to say, “*I don’t know, but you may find the answer by contacting Cure PSP...*” Your ability to respond to basic questions can be developed by reading, from other group members, and from resource people that you involve with the group.

CHAPTER TWO: THE LEADER

- Facilitators need to have a basic knowledge about local community resources that could be helpful to the person with the disease and family members.

You need to share information, without being a lecturer. You do not have to be outspoken, charismatic or an entertainer. Some of the best facilitators are quiet, soft-spoken, and maintain a low profile. You should never talk more than any other member of the group in quantity.

- Facilitators need to like people and be interested in them.

People have a need to tell their backgrounds and share their experiences without being judged. Individuals need time to ventilate, but someone needs to take control of the meeting when an individual dominates the interaction with their problems. Problems need to be discussed in detail, but enough time must be available to focus on solutions to the problems at hand.

- Facilitators need to be able to delegate to others.

If you provide leadership plus enthusiasm and motivation about the importance of the group, other group participants will want to help and be involved.

- Facilitators need to be positive in their outlook about problem solving.

It is true that there are some extremely difficult problems to deal with for people facing brain diseases. However, finding solutions to problems can only be accomplished by using a hopeful frame of mind. For those people who have been experiencing long-term pressures and progressive losses, positive thinking may be a tough task. To a great extent, the atmosphere of the group will be influenced by the attitude of the facilitator.

What are the group guidelines to ensure healthy group functioning?

Group guidelines are norms, or rules, that the group follows. These standards give group members a clear list of behaviors that are central to a healthy group. If people are given the opportunity to communicate according to well-defined expectations, they will respond accordingly. When a group member violates a rule, or has difficulty in this area, a gentle reminder can be made about the importance of adhering to the group guideline. Setting these guidelines is an important part of the group introduction. (See page for the content of the “Introduction.”) Some facilitators like to supplement their verbal list of these guidelines with a written list. (See Appendix on page for “Support Group Guidelines.”)

What are some issues for the support group facilitator to remember?

Facilitators have genuine concern for individuals with brain disease and their families. They are able to empathize with others and communicate openly and honestly while maintaining control over their emotional behavior.

The primary role of the facilitator is to encourage positive interaction that will provide the opportunity for each group participant to feel supported and satisfied with the meeting. The facilitator should encourage a participative experience with mutual sharing and support in a nonjudgmental setting. The whole group will feel each individual's experience in the group.

What are some basic rules to remember as a leader?

IT IS IMPORTANT TO FOLLOW SOME BASIC RULES TO REMEMBER
IN THIS TYPE OF LEADERSHIP ROLE:

- You are a participant/observer in the group.

This refers to taking part in the group while simultaneously being able to step back and monitor what is happening in the group. This skill includes the ability to be aware of your own thoughts, emotions, assumptions, and biases about people; to accurately gauge how other people are reacting to each other and to you; and to pay attention to what is happening with each individual, as well as with the group as a whole.

- Staying Calm and Centered.

Another important skill is the ability to remain calm in the presence of intense feelings. Since a key function of a support group is to provide a place where emotions can be safely expressed, the facilitator must be able to tolerate and support the expression of these feelings without minimizing, running away from, or trying to fix them. Being able to bear your own intense emotions will allow you to remain calm when group members become very emotional, and will help you model this accepting behavior for others in the group.

- Provide safety by fostering a friendly, supportive, trustworthy, atmosphere.

This is accomplished by enforcing the purpose of the group and the group guidelines.

- Encourage participation of all members in the group.

Not every member feels comfortable immediately sharing with the group. The facilitator should help members participate by inviting a quiet member into the discussion. For example, *“Sharon, do you have anything you would like to add?”*

- Keep the meeting on focus.

Direct conversation back to the purpose of the group when necessary.

- Be an active listener by being sensitive to what is and is not said.

Detect nonverbal behavior that might be helpful to verbalize through feedback. If you think the group has ignored an important point, go back to it and bring it up to the group.

- Handle problems.

Members may try to monopolize the discussion, recommend inappropriate coping strategies, question others aggressively, disrupt the flow of conversation, be judgmental toward another member, or violate group guidelines. A good facilitator deals with these situations immediately, directly, and tactfully.

- Encourage self-esteem.

Let members know their sharing is important to the group and that each individual is a valuable part of the group. Do not permit personal attacks on any group member during group meetings.

CHAPTER TWO: THE LEADER

- Be flexible.

The group participants' needs for the meeting may be different than your own.

- Speak clearly so that others can hear you well.

- Be prepared for difficult feelings.

These feelings are not directed toward you personally or any other group participant. The individual who is expressing anger needs to know how the anger comes across to others, and how it makes you feel. However, talking about feelings of anger is different from behaving in an angry way.

(See section on, "What are some special problems that can interfere with group cohesiveness, and what should the facilitator do?" page 18.)

- Avoid making judgments about others.

As soon as people feel judged, honest communication is shut down. People are not coping in a "good" or "bad" way. They are doing the best they can, and are attending a support group meeting for more help and support! They will not benefit from other people's suggestions if they feel judged or put down.

- Create a safe atmosphere.

Establish the expectation of confidentiality and define what this means with the group. The group should be able to trust that everything that is discussed is personal and stays within the group.

- Be clear with the group members that a support group is not a substitute for professional treatment.

If an individual needs more help and support than the group can provide, encourage the person to consult a doctor or therapist.

- Foster personal responsibility in the group.

Create an atmosphere that communicates by what you do and say that the group is not yours. Each person is an equal member and is responsible for the group's welfare. Though you are aware of the skills needed to facilitate constructive interaction and will use them as needed, you are a group participant like everyone else. It is the group's group!

- Facilitators are role models for the group.

The group will mimic the facilitator's behavior, leadership characteristics and group management skills.

- Provide hope.

When the discussion is honest, open, and supportive, we promote understanding and awareness that will help channel resources into the most effective and efficient research developments for those with brain diseases.

- Empower each other.

As members of the group serve as helpers to others, they will feel empowered to take control of their own situation. A person needing help and support will at some point become the person giving help and support to others.

- Follow your instincts.

If you are uncomfortable with a comment by a group member, you can bet that someone else is too. Do not be afraid to question a statement, communicate your discomfort, or comment on a problem you observe in the group. Your honest behavior will illicit respect from other members and will promote caring and consideration of each person in the group.

What is the best way to give feedback to group members?

It is always important to be honest when letting another individual know what you think or feel. Remember too, you are only one member of the group who will be responding to others – it is not all up to you!

HELPFUL HINTS FOR PROVIDING FEEDBACK INCLUDE:

- Providing feedback as soon as possible.

Do not allow too much time to pass between a situation that you want to address and your response.

- Be nonjudgmental in your response.

Describe how you feel about what was said.

- Check with the other person to make sure that he hears and understand what you said.

Take time to clarify your point.

- Do not force your thoughts onto others.

Be satisfied that you have communicated to an individual who may not be ready to hear you. In time, you are persistent, caring, honest, and genuine, you will help that person understand, Feedback is most useful when asked for, not imposed.

- Be a good listener.

Since listening is rarely an innate characteristic, one must learn the skill through considerable practice. Listening implies trying to hear what is being said from the other person's frame of reference. This cannot be done if the listener is in a hurry, is disinterested, or is otherwise preoccupied. In order to hear a message from the other person's perspective, a great deal of empathy is necessary. Listening to feelings as well as words means that the subtle as well as the obvious message is addressed. For example, a member might be telling the group that her life is completely free of concern regarding her disease.

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Although she responds with the words that communicate that things are fine, her tone of voice is low and she is avoiding eye contact. The message you hear may be that this person is not feeling fine about life now, or that things are really not going particularly well. She may be reluctant to say how things are really going until she feels more comfortable with the group. If you respond to the lack of consistency between the words and the nonverbal message by saying something like, “Are you really having no concerns at all?”, you may find that she will respond more freely to a sincerely directed question. Or perhaps she is not ready to share her feeling yet with the group. That is okay.

Accept people for who they are, and where they are in the process of grief and self-growth. Respect how others feel instead of trying to make them change. The need for change must be self-perceived and self-initiated.

How do you become a more effective communicator in the group?

A FACILITATOR'S ABILITY TO COMMUNICATE EFFECTIVELY CAN BE INCREASED BY TAKING SOME OR ALL OF THESE STEPS:

- Be simple.
Use words and phrases that are chosen according to the vocabulary and understanding level of the listener(s).
- Convey sincere concern.
This can be initiated by listening to a person's message and trying to hear it from the other person's perspective. Give full attention to the person speaking, and be sure to make eye contact. When possible, use the person's first name.
- Consider the timing of the feedback.
Timing is crucial for effective communication. People hear messages accurately only when they are ready to do so. Monitor the feelings of the group by being aware of the level of anxiety, comfort, fear, or security. Evaluate your response accordingly.
- Put the talker at ease.
Help the person feel free to talk. Be patient: look and act interested. Allow the person to speak without interruption. Give indication of hearing what they have said by nodding your head or saying “yes.” People may need this response to encourage them to go on.
- Avoid argument and criticism.
This puts a person on the defensive. The person may get angry or “clam up” and not hear what is being said. A person who is angry may interpret the wrong meaning from words. People have a right to their opinions without criticism and isolation. To show a person you are listening, ask questions for further explanation.
- Summarize what has been said.
Repetition ensures that if one part of the message is not heard, then repeating it is likely to provide the necessary information. A summary of the important points discussed helps to provide direction for the group.

- Be careful of how much you are talking.

You cannot listen if you are talking. A helpful gauge is to not talk more than the other group members. It is not up to you to do all of the responding. When you are not talking, another member of the group will be encouraged to do so.

- When it is appropriate to say, “I’m sorry,” do not hesitate to do so.

In situations such as when a misunderstanding occurs with someone, a genuine apology is helpful to the individual involved and will be appreciated by the entire group. By saying, “I’m sorry,” you will show the group that you care about others and you will role model that it is okay to be imperfect and to recognize that in yourself. It will also allow the group to relax in their communications together and not be afraid to “say the wrong thing.” Forgiveness is an important component of forming trust in the group.

Now that I am a facilitator of a group, what will I do to help the group provide and generate information?

In group facilitation, there are a number of key points to highlight, some of which have already been mentioned. Due to the significance of these techniques, it is important to review them.

- As a facilitator, your role is somewhat different than that of a group member. Most of all, you will encourage interaction in the group. You might raise questions that others don’t ask, comment on differing opinions in the group, comment on other people’s interpretations without necessarily voicing agreement, and prevent incorrect information from being disseminated. Make an effort to encourage group interaction versus a dialogue between you and group participants.
- Though you are a facilitator, you do not necessarily have the “best” or “only” solution to a problem. Caution people about “good” and “bad” or “black” and “white” solutions. Your behavior will be copied by others, so exhibit the same open mind that you encourage others to demonstrate. Although you do not control the “right” answers, you need to correct gross misinformation. Encourage people to discuss any questions about medical information with their doctor.
- You should not tell people how they should feel or act. You can respond to other people’s feelings sincerely and empathetically, giving opinions and suggestions if appropriate.
- If someone is making a long wordy statement, politely interrupt by asking for a specific point.
- It is helpful if you encourage people to talk about their own personal experiences versus using statements about “everybody else,” and “most other people.”
- If there is strong disagreement about the meaning of a word, or people’s ideas, encourage the discussion of the feelings behind these strong reactions.
- Summarize the discussion periodically to provide direction and focus for the group.

CHAPTER TWO: THE LEADER

What are the most important things to remember about co-facilitating?

When two facilitators work together, they can assist each other during difficult times dealing with these diseases. Absence from the group, and lack of time and energy of organizing responsibilities can be compensated for by the second facilitator. As long as the facilitators foster joint relationships among group participants, the support group will benefit from the co-facilitator relationship.

When there are two facilitators leading the group it is very important they spend considerable time and effort communicating with each other. The relationship between facilitators is a crucial factor in running an effective support group. The facilitators need to be able to exchange ideas honestly about the group and feelings about each of their leadership styles.

If they have a healthy respect for each other, the facilitators will develop a “we” feeling about group leadership. When the group members perceive a healthy mutual respect and honest communication between the facilitators, they will respond in the same manner with each other.

CONSIDERING THE FOLLOWING POINTS CAN HELP TO CREATE AN EFFECTIVE TEAM:

- Co-facilitators must talk with their partners.

The importance of communication between the co-facilitators cannot be underestimated. They must talk to each other – before, during, and after the group meeting. To accomplish this goal the co-facilitators must allocate some time before the group begins. This pre-group meeting can serve to clarify what happened in the last meeting, as well as what goals are planned for this meeting. Communicating with each other during the group meeting can serve as role modeling for group members. Some period of time immediately after the meeting should be arranged when the co-facilitators can critique the group’s progress and their own relationship.

- Co-facilitators need to review the group issues, movement of the group and themselves.

The majority of the post-meeting time is often used to talk about the issues and goals that members have discussed in the group meeting. However, it is essential that enough time be allotted to discuss the co-facilitators’ relationship. Issues which need discussion are, for example, how well the two facilitators work together, what they agree and disagree on, and what changes they both need to make.

- Co-facilitators need to know their own assets and limitations; building on the assets of their partners’ rather than exploiting their limitations.

In order to understand the assets and limitations of one’s self it is necessary to get and give feedback. Again, open communication is the key. The co-facilitators must build on each other’s assets in the group and this is best accomplished through immediate feedback on what was useful for the group. A positive comment might include, “*You really helped out when you explained about Debbie’s concern about her family. I was at a loss as to what to say.*” A small comment can have a powerful effect on the co-facilitator relationship.

- Co-facilitators need to resist competitive temptations to be “number one” facilitator in the group.

At some point in the group, one facilitator may feel just a little better than the other facilitator. This can become a destructive influence within the relationship and for the group as a whole. It is imperative that both facilitators view the group as a shared responsibility and function as a team.

- Co-facilitators need to clarify unclear messages sent by the partner.

Unclear communication between co-facilitators, whether it occurs during the pre-group meeting, the actual meeting, or the post-group meeting, needs to be clarified. During the group, one facilitator can ask for clarification of a message sent by the partner. What is unclear to the co-facilitator may be unclear to the group members also. By asking for clarification within the group, the facilitators demonstrate by example that it is acceptable to do so.

- Co-facilitators must share honest feelings with their partners.

This key point cannot be underestimated. It is imperative that feelings are shared between co-facilitators. For example, when one facilitator monopolizes the group meeting, it is important that the partner be honest and address the issue. Resentments quickly occur if co-facilitators hold their feelings waiting to see if it occurs again. The problems will not just go away.

- Co-facilitators must practice what they preach.

As facilitators, you are trying to help people feel comfortable sharing feelings honestly and setting goals together. If two facilitators are working together, they need to practice with each other, what they would like to see the group do.

What is the best approach to choosing a co-facilitator?

The most effective way to find a co-facilitator is to look for a person from within the group. If there is someone who has shown an interest in helping, or an individual that you think would be a good facilitator, talk with the person privately. If you do not have someone in mind to be a co-facilitator, but you need some help, ask the group as a whole during a meeting. Remember it is the group's group. People will be quicker to want to be part of the group as helps if they are given the opportunities to do so.

How does the group screen its' members?

In a CurePSP support group it is helpful, when possible, to screen the calls prior to the group meeting so that the facilitator has spoken ahead of time to the people who are planning to attend. Since these groups are meant for persons with prime of life diseases such as PSP, CBD and MSA and caregivers, the facilitator will want to be certain those are the people who will be attending.

INCLUDE THE FOLLOWING POINTS IN THE MEMBER PRE-SCREENING PHONE CALL:

- Ask the callers if they were diagnosed with a prime of life brain disease or have a family member with the disease.
- Explain the purpose of the group to callers. For example, *"Our group functions as a support group for persons with PSP and other neurodegenerative diseases and/or caregivers/family members. The group is composed of patients and caregivers/family who want to share experiences with others. We do not give advice; we share our experiences."*

CHAPTER TWO: THE LEADER

Should there be an introduction and a summary for a support group meeting?

It is important to provide a clear introduction at the beginning of the meeting, and a clear summary at the end of the group meeting. Before the meeting begins, the facilitators should decide who will do the introduction and who will summarize the meeting.

INTRODUCTION:

During the introduction, the following should be conveyed: your name, your co-facilitator's name, the time of the meetings, the purpose of the group, a statement about confidentiality, your role as facilitator(s), and a reminder about the guidelines for the group meeting. The guidelines will include: personal experiences and suggestions are shared versus advice; helping, sharing, problem solving, nonjudgmental behavior, versus negative or critical behavior towards others. The Go-Round is the next stage of the group, when each person introduces themselves to the group and answers several questions posed by the facilitator: what is your name; and what has brought you to the group meeting today.

SUMMARY:

There are two methods of accomplishing the "summary." The first method involves the group facilitator taking the full responsibility for the summary. In this case, about 5-10 minutes before the end of the group meeting time, the facilitator should let the group know that the time of the meeting is almost finished. Then briefly present a summary of the issues discussed during the meeting. You can ask the group members if there are any issues that you left out in your summary.

The second method involves the group facilitator initiating the idea that the group do the summary together. This is an especially helpful method because it involves cooperation among all group members. Anytime the facilitator can involve the group, it is best to do so. Using this approach, about 5-10 minutes before the end of the group meeting time, the facilitator should let the group know the time for this meeting is almost finished. Then the facilitator gives the directive to summarize the meeting. Each group member around the circle can share something that was helpful about this meeting or something that they will remember; something that was positive, something useful, etc.

In both methods of accomplishing the summary, this is not a time for new issues to be discussed, only to summarize what has been said. If anyone brings up a new issue at this time, let them know that this is important to talk about, and ask them to bring it up at the next meeting. If it is urgent, ask to talk with the person after the meeting. Thank people for coming and participating in the group, and remind them of the date and time of the next group meeting.

As a facilitator, what are the skills that I should use in an effort to encourage positive interaction?

IN FACILITATING EFFECTIVE GROUP FUNCTIONING IT IS BEST TO PROMOTE A POSITIVE ENVIRONMENT FOR GROUP MEMBERS USING THE FOLLOWING SKILLS:

Questioning – To prompt a discussion or to expand one that's already begun, as open-ended questions. *"How has this last week been for you?"* or, *"Are there any other thoughts on that issue?"* Avoid questions that can be answered simply "yes" or "no."

Inviting Participation – To ask individual members if they would like to participate; involving all members in the discussion, *"Amy, would you like to add to that?"*

Validating emotions – When the facilitator hears underlying themes of anger, guilt, shame, and other difficult emotions, explicitly ask whether members of the group have ever felt this way. Then go on to reinforce that this is a normal and common response for people to experience in this situation. *"You're not alone in feeling angry. I can see how the situation would make you angry."* This helps assure members, especially newcomers that these feelings are experienced by others in a similar situation.

Handling Silence – To take a reflective and natural pause before moving on, don't be afraid to just let it be when that happens. If you restrain your impulse to fill the silence with your own comments, the group will do this in an appropriate fashion. This will allow you to stay in the background as much as possible, rather than taking over.

Eye Contact – To look at all members of the group as individuals are talking. This encourages interaction among the whole group. People will look toward others too instead of maintaining a focus on the facilitator.

Refocusing – If the group strays to an irrelevant or inappropriate topic, the facilitator needs to refocus the conversation. One way would be to say, *"I'm sorry I've allowed the group to stray from the topic. Let's refocus on the loss we've experienced."*

Restating – To rephrase a statement in order to clarify or to simplify what a member has said. *"So, Lou, what you are saying is...."*

Modeling Good Communication – Non-verbal cues that indicate attentive listening are very powerful in helping members to feel understood and heard. *"Yes, I see what you mean"* or *"I appreciate your sharing that...."* or *"That must have been very difficult for you."*

Linking – To relate what one person is saying or doing to the concerns of another person; helping to build bridges between members of the group. *"Mary, the issue you bring up reminds me of a situation that Al has spoken about before. Al, can you talk about that?"*

Information seeking – To explore alternative points of view by encouraging members to access information from professionals, books, articles and other resources that contain valuable and accurate information. *"What if we each explore that question between now and the next meeting?"*

CHAPTER TWO: THE LEADER

As a facilitator, what are the skills that I should use to deal with problem behaviors?

A support group for patients with brain diseases and/or caregivers, like any group is made up of individuals with unique personality characteristics, habits, and behaviors. Typically, group members will be accepting and supportive toward one another. However, there may be times when the behavior of one or more group members will interfere with the constructive interaction between group members.

USE THESE SKILLS TO ASSESS WHETHER THE BEHAVIOR IS DISRUPTIVE AND DO SOMETHING ABOUT IT:

Active Listening – To listen to the content of the conversation of an individual as well as their gestures, changes in expression and overall body language. This skill requires hearing what is not being said, the underlying feelings. Each individual has an effect on the group as a whole, so listen to and observe the behavior and the feeling tone of the group.

Blocking – Using sensitivity and directness, interrupt counterproductive behaviors as soon as you notice without attacking the person. *“Judy, we don’t use profanity in the group. It is understandable that you are angry. Can you express your feeling in a way that is respectful to others here?”*

Reinforcing Group Guidelines – During the introduction of the meeting, guidelines are verbalized for the group in order to keep the meeting safe and constructive for all group members. Some groups choose to put these guidelines in writing in addition to verbalizing them.

(See Appendix C for a list of these guidelines.)

It is also important to include:

“For us to be a supportive, caring group, it is important that we care for one another versus be judgmental or harsh. For example, it is appropriate to express feeling but only in a way that is helpful, not hurtful to anyone in the group.”

“A support group is a place to share experiences based on living and coping on a daily basis with these diseases, so that making suggestions to one another is helpful versus giving advice. The only time to give advice is to encourage an individual to discuss and issue with their doctor or other health professional.”

“Since we have a limited period of time, 90 minutes, we will begin and end on time. So that everyone in the group has a chance to participate we need to give each other the time to talk. If a person is dominating the discussion, I may need to ask the group member to listen so as to give another person a chance to talk.”

“I” Statements – To communicate honest feelings via the first person. *“I feel upset about....”*

How does a group develop cohesiveness among its members?

Group cohesiveness refers to the individual members' attraction to the group or the degree to which they wish to remain in the group. It is the glue that holds the group together.

SOME REASONS FOR ATTRACTION TO A GROUP INCLUDE:

- The purpose of the group and the members are compatible and clearly specified.
- The group has a sensitive, committed facilitator.
- The reputation of the group indicates the group successfully achieves its' purpose.
- The group is small enough to permit members to have their opinions heard and discussed with others.
- The members support and help each other by sharing experiences, and overcome obstacles to personal growth and development.
- The facilitator asks for help. In situations where you are unsure of how to respond to an individual in the group or to the group as a whole, ask the group for help. By asking for help, the group will see you as someone who has confidence in the group's ability to solve its own problems. They will feel empowered by your belief in the group and will rise to the occasion.

What if I move or decide not to facilitate the group anymore?

There are many personal reasons for needing to move on from facilitating the group. After many years, sometimes people need a break or want to move on to another volunteer endeavor. Sickness or a move to a different geographic location can also be factors.

WHEN A FACILITATOR MUST DEPART FROM THE GROUP, THE BEST METHOD TO ENABLE THE GROUP TO CONTINUE IS AS FOLLOWS:

- Let the group know several months ahead of your departure.
- Ask someone in the group who you trust to take over the leadership role.
- If there is no one that you feel strongly about asking, ask the group if someone would consider being the facilitator so the group can continue on.
- Encourage the individual to contact CurePSP and benefit from the training resources that are available through the organization.
- Co-facilitate with the current facilitator for several meetings to give the new facilitator help and support.

CHAPTER TWO: THE LEADER

What are some special problems that interfere with group cohesiveness, and what should the facilitator do?

Due to the nature of any group, there will be problems that the facilitator needs to be prepared to deal with at any time. These problem behaviors will interfere with the flow of the group discussion and will create tension and discomfort among group members. For this reason, these behaviors need to be managed promptly and effectively.

How does the facilitator deal with monopolizing behavior?

Monopolizing behavior, taking up a disproportionate share of the group's time, seemingly unaware of the behavior, is the most common problematic behavior in groups. It is important to distinguish *problematic* monopolizing behavior from those occasions where a particular member legitimately needs some extra time and attention.

For example, a brand new member who is very recently bereaved may need to talk at some length, and most seasoned survivors will remember back to their own early days and be very understanding and supportive. Similarly, groups are usually very tolerant of a member who's going through an especially difficult time and needs more time to talk than usual. Monopolizing behavior only becomes problematic when an individual regularly dominates the discussion without regard to their fellow group members' need to talk.

Related problematic behaviors include:

- interrupting
- offering advice versus suggestions and sharing experiences
- being judgmental
- projecting own experiences onto others
- challenging others' opinions or beliefs in an angry manner
- proselytizing (trying to influence others to do what they have done)
- disrupting the meeting (consistently being late to the meeting, getting off the topic, engaging in side conversations with other members)
- competing with the facilitator (offering information and trying to take control of the meeting)

But how is it best to intervene? When a behavior is a violation of one of the Group Guidelines, they are best handled by simply referring back to the Guidelines, which you have read at the beginning of the meeting during the introduction.

Example: Susan repeatedly takes over the conversation, bringing the discussion back to her own story and telling other members how they should feel. The facilitator first tries to redirect the discussion back to the group by saying, *“Let me interrupt you there, Susan, and let’s see if others have some thoughts about this problem.”* This works for awhile, but later in the meeting Susan interrupts and gives advice. Being more directive, the facilitator says, *“Susan, I see that you are trying to help Lynn by telling her your opinions about what she should do. One of the guidelines of our group is that people do best when they can hear about the experiences of others, rather than getting advice, so please talk about your own experience instead when Lynn is finished talking about hers.”*

Note that when the facilitator acknowledges the person’s well-meaning intentions, it is more likely that the facilitator’s comments will be heard and respected. However, sometimes it will be necessary to intervene repeatedly as is indicated in the example above.

Here are some additional suggestions for redirecting problem behaviors:

- *“It sounds like this has been very painful for you. I’d like to interrupt you now, Tom, and see whether others in the group have felt similarly and how they have dealt with it.”*
- *“Let’s let Ella finish and then hear your thoughts.”*
- *“I hear that you have very strong feelings about what she is saying, but it’s important that each person is supported to grieve in their own way.”*
- *“I know it’s natural for us all to want to share the benefit of our own experiences, but let’s give Sally an opportunity to talk and let us listen to her. Sally, would that be helpful to you?”*

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CHAPTER TWO: THE LEADER

How should the facilitator handle crying during the group meeting?

Due to the many problems that living with a neurodegenerative disease imposes on the patient and family, there will be many moments of sadness within the group. The act of sharing these experiences will generate many emotions among group members. Crying will most likely occur as a release of pent up feelings and should never be discouraged. The group may be one of the few places where people can truly show their feelings among others who truly understand.

FACILITATORS CAN GIVE SUPPORT TO CRYING INDIVIDUALS BY DOING THE FOLLOWING:

- When you notice an individual in the group crying, do not ignore the behavior. Acknowledge that the person feels sad or bad, and ask if the person would like to talk about these feelings with the group.
- If the person declines, or cannot talk due to crying, show some form of physical comfort or you may encourage a person sitting nearby to be comforting.
- Let the person know that you and the group care. *“It is okay to cry. We are here with you and we care.”*
- Offer the option for the individual to take a break from the group with another group member. *“If you would feel more comfortable, one of us could take a walk with you and return to the group when you are ready.”*
- Do not force the person to talk, only encourage individuals if they are able to share their feelings. Remember, individuals may not be sure exactly why they are crying.
- Perhaps the individual is crying due to something said in the group and was reminded of their own difficult situation. However, it could be that the crying was brought on by something said by another group member. Be sensitive to how others are feeling and try to put yourself in their position. If another group member gives negative feedback to an individual, intervene by acknowledging the harshness of their response. Encourage a better way of helping the person by giving a positive message to help them feel better about themselves.
- Using the group to help, give positive feedback to the crying individual for releasing pent-up emotions/tension, and expressing their feelings in the group.

How should the facilitator handle people talking at once during the group meeting?

Since most people tend to be better at talking than listening and the content of these meetings generate a lot of emotion, people may all talk at once in an effort to be heard. If this happens, it is helpful to mention that people should talk one at a time. Setting this guideline reminds people that they will each have a chance to talk, and they can be listened to best if they talk one at a time.

IF PEOPLE BEGIN TO TALK AT ONCE,
THE FACILITATOR SHOULD DO THE FOLLOWING:

- Being gentle but firm, intervene immediately by reminding the group that people need to talk one at a time. If the talking at once continues, interrupt and point out that no one can be heard if people talk over each other.
- Several people talking at once may indicate high emotion surrounding a topic that people are discussing. Be attentive to the topic being discussed at the time, and point this out to the group. For example, “It seems like the lack of treatments for these disease is of great distress to all of us. Look at how angry people are – everyone is talking at once.”

It is important to set limits on people talking at once from the start, since it is a habit that can cause the group to become ineffective as a safe, open place to share, and where everyone gets the opportunity to be heard. With consistent limit setting, people will respect the guideline for listening to one another and you will find yourself not having to handle this problem anymore.

How should the facilitator handle group discussions about individual physicians during the meeting?

It is natural for group members to talk about physicians and other medical professionals as part of their discussion about methods of coping with these diseases. Generally, physicians, medical professionals, and other health providers may be mentioned in conversation. However, when specific names are given, it is important to remind the group that it is best for the group not to discuss specific individuals. There are many factors to consider in choosing a physician or other medical professional. Focusing the group on a discussion about how to constructively make this choice is most helpful.

How should the facilitator handle a group member who appears to be under the influence of alcohol?

It is important to prevent behaviors that might be difficult to deal with in the group meeting by spotting problems as soon as possible. It is best to address unusual or out of control behavior on the part of any individual who enters the room before the meeting begins. Some of the behaviors you might notice if a person has been drinking are the smell of alcohol, impairment in gait or balance, and/abnormalities in speech or volume of speech. Take the person aside, preferably before the meeting begins, and let them know you are concerned and emphasize the group guideline about being under the influence of alcohol. Let the member know that you would like them to come back to the meeting at another time, but it would be best not to attend tonight. You may need to discuss an alternative to driving home by him/herself.

CHAPTER TWO: THE LEADER

How should the facilitator handle help-resisting behavior in the group?

“Help-resisting” behavior refers to actions on the part of an individual that indicate not wanting to help oneself, or accept help from others. This behavior may be seen by a person continuously asking for help, but then responding with, “Yes, but....”, or “I know, but I tried that already and....”.

One of the conditions of the group is for mutual sharing and problem solving, not necessarily for people to be committed to following the group’s suggestions. It is up to the individual to try alternative solutions to problems, and the responsibility lies within the individual.

However, it can be frustrating and demoralizing to the group when an individual takes the group’s time repeatedly for help, and does not seem to be satisfied with the group’s suggestions.

FACILITATORS CAN HELP THE GROUP AND INDIVIDUALS RESISTING HELP BY DOING THE FOLLOWING:

- Recognize that each of us is at a different degree of readiness in our ability to deal with our own issues. Accept that we cannot change anyone else, only ourselves. Psychotherapy can be very helpful when we need to work through some of our own issues with change and transition but need some help to accomplish that goal.
- It may be that the individual resisting help does not even realize this pattern. With the help of the group, point out that the individual seems to respond negatively to every option raised by the group.
- Let the individual know how it makes you feel to have your ideas “shot down.” Encourage other group members to share their feelings in a constructive manner.
- Be positive and supportive about the individual’s ability to ask the group for help. Encourage the person to continue talking.
- Keep in mind the help-resisting behavior may be a cover up for the person’s fear of trying an alternative; or grief about facing a loss of independence.
- There may be one very small step that the person is able to decide to take.
- Ask the individual to try to come up with one alternative that might be a suggestion for someone else with the same issue.
- Encourage the individual to continue to ask for help, but to try to acknowledge the usefulness of other people’s suggestions.

What if multiple family members want to attend the same group meeting?

Complicated family dynamics can sometimes arise when multiple family members attend the same group meeting. It is not unusual for several members of the same family to come together, particularly in areas where there may not be another group for miles around. This is generally not a problem, and can even provide a positive setting for family members to support one another. However, there can also be drawbacks to having members of the same family attend the group together. Some family members may feel inhibited about speaking freely with another family member present. Also, family problems that are unrelated to their loved one's brain disease (i.e., marital conflict) can also negatively affect how family members interact in a group setting.

If this happens it's important to remind the individuals (either during the meeting or after, based on whichever seems more appropriate in the situation), that the group needs to be a safe and comfortable environment for all members. Perhaps the family members should consider attending separately, taking turns coming to the group meetings. It might also be useful to recommend that they consider whether the group is able to meet their needs fully, and whether family or individual counseling might also be worth their consideration.

What if there is tension or anger between group members?

On occasion, conflicts may arise between unrelated group members, whether it is due to a personality clash or another reason. If the situation begins to interfere with the constructive functioning of the group, the first step is to refer back to the Group Guidelines. If this doesn't work, it may be necessary to speak privately with each of the members to explore whether they feel they can continue with the group in a productive and mutually respectful way.

If group members have conflicting views, it is not a problem as long as the facilitator pays close attention to make sure that no one's beliefs are being negated or criticized. If this happens, it is important that the facilitator interrupt the group and remind members of the Group Guideline to respect everyone's individual opinions and views.

Why is it important to avoid giving advice in the support group?

As a support group whose purpose is to share experiences based on personal experience, the most effective approach to doing this is through sharing first-hand experiences or through offering suggestions, for example, "*My experience has been...*" or "*Have you thought of...*"

It is important to avoid telling each other what should be done as this can be received in a defensive way. Also, we leave advice-giving to the medical professionals. We need to be sure to set clear boundaries between what is supportive suggestions and what is medical advice. Support groups are offered as an adjunct to medical advice but do not take its place. We want to ensure that support groups have a positive reputation in the community. Physicians and other professionals will not refer people to these groups if there are unclear boundaries about support groups versus medical care.

CHAPTER THREE

The Meeting

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How do I plan and publicize the first meeting?

- Once you begin to think about the location for the group, CurePSP can help you identify where and when other groups meet in your community and those in your surrounding areas. This is important so that there are a variety of groups available in different community locations, and also to ensure that you will generate an adequate turn-out for your meetings.
- CurePSP can help you with your publicity efforts by promoting on social media channels, their website and through our regular mailing programs to patients and families affected by prime of life brain diseases. CurePSP will help through continuous referral to people that call for support group information.
- Publish notices in the event calendars of local newspapers.
- Place notices in church/synagogue bulletins.
- Put up posters in public places, such as supermarkets, libraries, service organizations, as well as using the internet for publicity.
- Contact your local radio station about announcing your meetings.
- Place notices in publications offered by the venue hosting the group.

MEETING NOTICES SHOULD ALWAYS INCLUDE:

- Purpose of the group
- Address of venue
- Date of the meeting
- Time of the meeting
- Your phone number and a number for the meeting venue if possible
- Any information related to parking or other accommodations.

WHEN TALKING TO INTERESTED CALLERS ABOUT THE GROUP, BE SURE TO ENGAGE THEM BY DOING THE FOLLOWING:

- Ask them if they, or someone they know, has been diagnosed with a prime of life brain disease.
- Discuss the purpose of the support group and why coming to the group would be beneficial.
- Remind them of the time and place of the meeting.
- Be sure they have directions to the meeting and the room number where the meeting will be held.
- Ask them if they know of other people who might be interested in attending that you could contact or that they might invite.
- Thank them for their interest and let them know you are looking forward to meeting them.

CHAPTER THREE: THE MEETING

HOLD THE FIRST SUPPORT GROUP MEETING:

At the first meeting, arrive early and make sure there is adequate seating and that the physical setting of the room is conducive to a comfortable meeting. Be sure to think about seating arrangements since this can exert a strong influence on group dynamics. The seating for a support group should be arranged to facilitate group conversation; in a circle rather than in classroom style. With the seats positioned in a circle, each participant can easily make eye contact as well as putting everyone on equal footing.

At this initial meeting, you should not be overly concerned with initiating ideas for tasks and future meetings. Your objective is to develop a core group of participants who want to continue to meet together.

Begin the meeting with introductions. The facilitator should explain that the purpose of the meeting is to give the participants the opportunity to form the support group. Explain that a support group is composed of people with a common problem helping themselves and each other. By participating in a support group there is a mutual helping relationship established between group members. Explain that this is not a place for seriously troubled persons to receive extensive help, but a place for persons who are emotionally able to talk about painful situations in their lives. Be clear that it does not take the place of medical care that may be needed, but can serve as a supportive adjunct to treatment.

Take the time to share your situation regarding dealing with the disease, as a patient, family member, or caregiver. Express your reasons for wanting to participate in a support group, and your personal expectations for the group. After taking this brief time for an introduction, it is important to let everyone introduce themselves and discuss what brought them to the group meeting and what they hope to gain from it. This should be done on a voluntary basis, with the facilitator listening and encouraging others to listen in an accepting, nonjudgmental manner. Do not feel that you have to solve people's problems as they mention them. In addition to their personal stories, encourage people to talk about what they would like to gain from participating in the group.

Direction that you give should be toward identifying individuals' common purpose for the group's meetings. For example, sharing problems and concerns related to prime of life brain diseases, educational programs by guest speakers, sharing information, community resources, etc. If the group can find a general consensus about what participants feel the group can do, you will be on your way to forming a solid and lasting group. However, don't expect to arrive at a consensus among all group members at the first meeting. It may take a few meetings before the participants feel comfortable and open up to the group.

Remember, the most important agenda of this first meeting is to help make everyone feel comfortable with the group. The meeting time and place, length of the meeting, and any other similar items will need to be discussed. It is a good idea to maintain the same meeting place and time so that prospective and absent members will know exactly when and where to come. It is wise to refrain from doing any more business at a meeting than is necessary since the major purpose is to provide an opportunity for sharing. However, it is important to announce any upcoming events of interest, educational programs, or research updates, etc.

As the meeting progresses, people may share experiences that are frustrating and stressful. They may give each other helpful hints about how to deal with a particular problem. For many, this may be the first time they have had the opportunity to share in an accepting and nonjudgmental setting. The group may share ideas and suggest helpful resources. This enables the person in need of help to leave the meeting with a feeling of hope.

An important issue that the group facilitator must be aware of is that they do not come to think of the group as their own. Just because a person helps to organize meetings and facilitate sharing, does not mean that person should be a dominant figure. The support group can only succeed if everyone shares and molds activity toward the interest of the whole group. The group's continued vitality must be the major interest of all the members.

About 5-10 minutes before the end of the meeting, the facilitator should be prepared to initiate the summary of the key points discussed at the meeting. (See page for discussion of the "Summary".) The facilitator should be ready to confirm the date and time for the next meeting. This is also a good time to pass around the completed sign-in sheet, if people haven't yet signed it, with the option of exchanging phone numbers or email addresses as people want to do so. Thank everyone for attending. Feel free to ask participants who are able, to help with clean up.

At this initial meeting, you will have succeeded if you can provide a comfortable and open place to share concerns about living with PSP and related prime of life brain diseases, as a patient, family member and/or caregiver. Through the sharing of experience, if participants feel as if they have been helped or have helped others, the meeting should be considered a success.

CHECKLIST AND AGENDA FOR SUPPORT GROUP MEETINGS:

- Set up area to display educational materials
- Have sign-in sheet available and sign your own name to get it started
- Place seats in a circle
- Welcome and introductions
- Define and discuss the purpose of a support group.
- Briefly remind the group about confidentiality, that everything shared in the group stays in the group.
- Explain the group guidelines.
- Go around the circle and ask people to briefly introduce themselves and what brought them to the meeting; and personal goals/expectations for the group.
- After the introductions, ask a question to encourage sharing and interaction around the circle. Make it clear that everyone is welcome to join in the discussion and that everyone will have an opportunity to share.
- Approximately ten minutes before the meeting ends, have the group summarize the issues discussed, by going around the circle asking each member to highlight one helpful thing they will take away from the meeting.
- Announce upcoming events that may be of interest, educational programs, research updates, etc.
- Remind the group of the next meeting date and time.
- Pass around the completed sign-in sheet and encourage sharing contact information as people desire.
- Thank everyone.

CHAPTER THREE: THE MEETING

What factors are necessary in order to keep the group developing over time?

After the first meeting, facilitators will naturally be concerned with keeping the meetings going. As always, the primary purpose of each meeting is to provide help and support to participants dealing with prime of life brain diseases. Keep the focus on the group purpose – to share experiences with one another. Factors that continue to be of great importance to maintaining the group are: a central location, regularly scheduled meetings, meetings that begin and end on the announced schedule, and between 6-12 individuals for optimal group participation. It is important to note that group attendance is something that grows over time.

Despite your efforts to avoid becoming bogged down with business during the meetings, there are several items that will need to be attended to on a regular basis. If these things are properly dealt with, they will help your group keep going and continue growing.

RECOMMENDED ACTIONS FOR GROUP GROWTH:

- It is essential at every group meeting that all participants sign the attendance record, located in the appendices in this manual. Keep a list at the door and remind people to sign it for the purpose of keeping a mailing list. This will enable the group to contact members if there is a change in time or location of the meeting due to a weather or other problems. When special programs are planned and announcements need to be made, telephone networking is a time saving system of communication. With this record, a phone tree can easily be established when verbal communications are necessary. A phone tree or network is organized by each person in the group having preassigned persons to call. One person, perhaps the support group facilitator, begins by calling two or three other persons. These persons will, in turn, call two or three persons, etc. Through this mechanism the entire support group mailing list can be contacted without one person spending many hours on the phone.
- Keep public relations going. Make sure that there are continuing announcements about your meetings. CurePSP materials can assist you in publicizing your group. Local hospital neurology departments should know about your meetings so that neurologists and other health professionals can act as referral sources. Posters and flyers can be printed for additional publicity.
- CurePSP provides training and support for facilitators whether they're starting a new group or keeping a group going over time. If your group is struggling with attendance, please contact our office manager at 347-294-2871.

What is the best format to use for running the group meetings?

At this point you will find you have a group of people uniting together on a regular basis to discuss problems they are experiencing related to their own or loved one's brain disease. Your next task is to make the content of the meetings as productive as possible.

The major reason for meeting is sharing. You may not want to do this all the time, but never stray too far or too long from this simple and basic function of the meetings.

It has been the experience of many support groups that at any meeting a process will take place in which the persons most in need of support will be speaking the most, with the others providing support as necessary. While every person should have the chance to talk, those with the greatest need will take the greater share of the time. Others should be encouraged to provide feedback including any similar experiences, alternative solutions, and support. Those providing support will surely feel helped by virtue of their having been helpful themselves.

The potential problem that is that one or two of the same people may tend to dominate the discussion meeting after meeting. The group can clarify how much time should be allocated to each individual, so others get the opportunity for feedback, suggestions, and support. The group facilitators may need to set limits if the same people continuously monopolize the meeting.

The group must also decide what percentage of time should be allocated to just sharing problems and concerns. Depending upon members' needs, some groups allocate the whole group meeting time for sharing. Other groups designate certain meetings for discussion of topics, or special educational programs. Some of these activities may be worth special publicity efforts, since people who might be uncomfortable coming to a "sharing" meeting may feel more comfortable attending a lecture or programmed meeting. There is no correct answer about what is the best format for a particular group's meeting. The group must decide for itself what is best for them. No two groups are alike; therefore, their needs and goals will differ.

SPECIAL EVENTS IN ADDITION TO REGULAR GROUP MEETINGS MAY INCLUDE THE FOLLOWING:

- Professional speakers from the community. Seek physicians and other health professionals who might be able to provide useful information and suggestions about dealing with prime of life diseases. Health professionals may be eager to provide lectures or lead discussions since the opportunity gives them exposure. Cure PSP is available for your assistance with ideas for speakers.
(For some suggestions of educational program topics see Appendix E on page 43.)
- Learn and share community resources. A valuable project might be for group members to work on learning about what resources are available in the community for people affected by these diseases. Often, people are unaware of resources available right in their own communities, and this activity has the potential to be of great help to participants.
- Use programmed materials. There are many written and digital materials that can be used to provide information to people dealing with prime of life brain diseases. Many of these materials can be accessed by contacting the CurePSP office, or the CurePSP website at www.curepsp.org

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- If you are considering using material written by a source other than CurePSP please share the material with CurePSP to make sure it is accurate.
- Focus on specific topics. At some meetings you may want to pick one or more topics and discuss how they affect each person in the group. You may find that using these topics as starters can lead easily and naturally into valuable sharing of concerns and needs. Returning to the discussion of the initial topic can always be utilized as needed.

Caution: Be careful of depending too much on structured meetings at the expense of unstructured sharing and support. However, these ideas are an excellent addition to the meetings, as long as there is always a central place for sharing and discussion.

(See Appendix E for Discussion Topics, page 43.)

How does the facilitator cultivate an ongoing source of referrals to the group?

After your first several meetings, a drop-off in group attendance may occur and should not be interpreted as a sign of failure. In addition, keep in mind that at each meeting you will have approximately 25 to 50 percent newcomers. This is to be expected since people attend support group meetings for a variety of reasons. Some come once, some come a few times a year, some attend every meeting, and some don't come at all. However, it is vital that people know you are there, and that the meetings occur as scheduled. Family members and those with prime of life brain diseases will find security in this knowledge.

Since meeting attendance may fluctuate, and since you will continually want to reach the people affected, you need to begin to cultivate referral sources. A major goal should be to try to reach newly diagnosed families. It would be ideal if at the time a patient is given the diagnosis of a PSP, CBD or related diseases, they are advised of available resources, including support groups. One of the major ways of reaching these families is through referral sources.

It is recommended you align yourself with a medical ally – a specific neurologist or hospital, or an organization such as CurePSP, to lend credibility to the group in the medical community. This assists in getting other physicians and health professionals to refer families to the group. In addition, establishing this collaborative relationship contributes to the combining of resources available to help people in the community.

This network of referring physicians and medical professionals can also be a potential resource in that they may be willing to present, or they may know of other possible presenters. This will strengthen the caring network and further educate the professional community about the needs of people with rare brain diseases and their families.

A simple straightforward letter can be sent to potential sources of referrals with basic information about PSP, CBD, and other rare brain diseases. A simple, straightforward letter with basic information about PSP and related prime of life brain diseases can be sent to healthcare professionals, who may refer patients to the group. Professionals feel more comfortable in referring patients when they have the facilitator's name, have spoken with the facilitator, and have some confidence in the quality of the group. Again, remember the importance of inviting guest speakers to meetings.

How can the support group contribute to educating others in the community?

Support groups for neurodegenerative brain diseases grow by reaching out to others, and by spreading knowledge and understanding about PSP, CBD, MSA and other prime of life brain diseases. Reaching out to others can be accomplished by leaving an informational brochure about the disease in a public library, community center, or healthcare center. Outreach does not necessarily have to be a formal presentation.

However, some people who are part of the group may enjoy public speaking and have a special talent at communicating their personal experience. A support group of people with brain diseases and/or their family members can develop a small core of speakers available to address community and professional groups about their experiences. These speakers can give brief presentations about rare brain diseases, support group activities, and available resources. It has a tremendous impact for a person affected by this disease to say, “Let me tell you what happened in my family.....”

By addressing community and professional groups, the support group achieves recognition as a viable community resource. Many community groups such as the Kiwanis Club, Rotary and faith groups, are looking for program speakers. They appreciate a layperson who calls and says, “May we provide a program for your group? This is a most important topic, and we feel your group is an influential one that reaches many people.....”

It is important to have an outline prepared that emphasizes some basic information about prime of life brain diseases that the audience will understand. Some advance preparation and practice for the speaker is important in order to refine the talk and to build the speaker’s confidence.

CurePSP can help provide you with brochures and informational materials. Remember, many people will not be looking for a lot of detail. They will remember your sincere and concerned attitude, the personal experience you shared with them, and that they took home a brochure about these brain diseases. If they heard something about the group, they will find you when they need you!

Support group members can also be involved in professional education. It is helpful to have health professionals (nurses, psychologists, social workers, physicians, neurologists, etc.) knowledgeable about your group. Most of these professionals are members of professional associations, and they have contacts with other colleagues involved with these associations. The professional associations and hospital departments often have monthly meetings, and in-service education programs. Your group can ask to have “Rare Brain Diseases and Support for People affected by these Diseases” as a program topic. Knowledgeable professionals can also be enlisted to cover technical information emphasizing that group’s focus. Do not underestimate that a panel of persons who have a brain disease or family members can discuss their experiences and be an invaluable addition. Professionals are very interested in what people with personal experience have to say.

A professional teamed with a person with the disease is also important role modeling. Their interaction sets the stage for better collaboration between professionals and people experiencing the effects of these diseases on a daily basis.

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How should the facilitator encourage group members to volunteer to help?

If a group has been started by one or two facilitators, there may not seem to be a need for help, initially. However, as the group grows, and people want to become more involved, it is important to the group's health and continuation to allow others to help. For this reason, it is important that the group facilitators believe from the start, that they will need the group members' help in order to make the group a successful experience. The group needs to see from the facilitators' behavior the emphasis on the group as a shared responsibility.

Some groups rotate leadership after a certain number of meetings, and this can be an effective model to follow in order to avoid one or two people from shouldering all leadership responsibilities.

The group must make the decision about what leadership model will work best for them. Often group leaders are disappointed at the lack of volunteer help from group members. It seems the tasks always fall upon a few people, and it is difficult and discouraging to be "doing all the work." This can generate frustration and anger from those that feel burdened, and this can create a poor atmosphere for the support group.

Slow down and take one step at a time. The goal isn't necessarily to get things done fast, but to encourage many people in group to foster a feeling of ownership. You must be willing to take time to ask and to delegate to others. Often, people do want to help with a task, or to share an opinion which may give guidance. However, people will not see the need if the facilitator is "taking care of everything." In addition, if group goals and activities expand, the facilitator will burn out or try to limit the growth of the group in order to maintain control. Build a basis for support and growth!

WHEN ASKING GROUP MEMBERS TO VOLUNTEER, IT IS IMPORTANT TO KEEP CERTAIN FACTORS IN MIND:

- Many people and families are genuinely burdened with the responsibilities they are trying to meet. They may not have the time, energy, or desire to take on extra tasks.
- Many people come to the support group to gain strength, and receive and give help to others. This is the primary goal of a support group. The thought of taking on more responsibilities can be overwhelming.
- The support group is a volunteer effort. There will always be more work and not enough people to get the work done. Not all volunteers must come to group meetings. Friends, professionals, and others may wish to help with the tasks of the group.

Be realistic with your goals. During the first year, you may want to accomplish many things; however, the group participants may prioritize their monthly meetings of sharing as their goal. Planning and holding 10 to 12 support group meetings in one year is quite an accomplishment. Perhaps a "committee" may meet one to three times to plan educational programs for the upcoming year.

Be sure your group isn't trying to do too much at one time. There is a lot to be done, but be selective. Too many activities and not enough volunteers can mean that you are spreading your efforts in too many different directions and can lead to disappointments if, for example, attendance is low.

If you can generate one to five individuals to volunteer to help during the first year of the support group, you will have made a good start. Realistically, you and a few others will need to do the necessary work at first, and others will become involved as the group grows and progresses.

Lastly, some people may be more likely to agree to volunteer if they are asked to help in a very limited way, for example by bringing refreshments or helping with room set-up.

How does the group develop a newsletter as a vehicle for communication?

Over the course of time, as group developments occur, group members may have more information to share and may wish to do so on a regular basis. A single page newsletter can be a simple way of fostering communication and visibility in the community.

NEWSLETTER CONTENT MAY INCLUDE THE FOLLOWING:

- Calendar: Dates, location, time, and topics for upcoming support group meetings
- Notice of special events: fundraising events or workshops
- Suggestions: Tips mentioned by group members at meetings. Items pulled from articles read
- Experiences: Comments made by people at meetings, in emails and letters, personal writings, etc. which involve feelings and reactions of those coping with a rare brain disease. Be sure to get permission to use individual names
- Research studies: Information about research studies going on; and updates about research progress
- Recognition of volunteers: With permission from the individual, a volunteer's name printed in the newsletter may be an important sign of thanks to an individual
- Donations: List of contributors
- Community education and outreach accomplished and upcoming: Listing of any special awareness activities planned on a national and local level; community groups addressed; and names of volunteer speakers; Professional education events at which the group was represented
- Available resources: Books and articles to read

The newsletter can be an important way to document the group's activities and development. The newsletter will serve as a morale builder too. It is easy to lose sight of all the ways that the group has contributed to raising community and professional awareness, developing resources, and giving valuable support to people with brain diseases and family member. Written documentation encourages feelings of "look what we've done," and creates group confidence in the capacity for further success.

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What are the benefits of one-to-one networks to individuals in the support group?

One goal of the support group should be to link people with particular concerns to others who share those interests. For instance, linking a woman awaiting a nursing home placement with someone who has recently been through the same process. Two people with these diseases that live in adjacent neighborhoods may want to know of each other so they can carpool to meetings. A spouse whose husband was just diagnosed with a prime of life brain disease may want to talk with another wife who was diagnosed at a similar age.

Sometimes family members and individuals with these diseases reach crisis points during which they need to pick up the phone and talk with someone else dealing with similar problems. Emotional support is needed at the time – even if it is 3 p.m. on a Saturday, and the next support group meeting is not for another week. Members unable to attend a meeting often appreciate being called or “checked on.” Other people enjoy meeting people affected by these diseases that they can socialize with, since family and friends sometimes drop off.

The support group often has outcomes that people may not be aware of initially – individual friendships can develop. Even though some people do not attend group meetings regularly, their initial contact with the group may enable them to find other ways to meet their needs. Some people feel uncomfortable sharing in a group setting, but are able to more easily open up to another person on a one-to-one basis. There is great comfort and strength found in understanding each other’s problems.

Try to foster linkages between group members by introducing people with the disease, and family members at meetings. Developing a mailing/phone/email list with names, addresses, and phone numbers for distribution with the group can act as a saving grace for some individuals. Be sure to ask for the group’s permission before developing and distributing the list. The “telephone tree” is another tool that can be used to establish links between individuals in the group between meeting times. However, people should be encouraged to feel free to say, “Now isn’t a good time for me to talk. Please call another person.”

The mutual benefits of one-to-one networks can be great. Many people will find this kind of support a helpful addition to the support group meetings. For those who have only minimal contact with meetings, the one-to-one support networks make a big difference to the quality of their lives.

CHAPTER FOUR

The Appendices

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APPENDIX A: BASIC FACTS ABOUT PSP, CBD AND MSA

CurePSP focuses on three prime of life neurodegenerative diseases:

Progressive supranuclear palsy (PSP)

Affects roughly 17,500 people in the United States; only 25% are accurately diagnosed. Symptoms include loss of balance, changes in personality, weakened downward eye movements, slurred speech, difficulty swallowing.

Corticobasal degeneration (CBD)

Affects 2,000-3,000 people in the United States; only 25% are accurately diagnosed. Symptoms include difficulty with balance and speech, stiffness or clumsiness in upper or lower extremities, dementia.

Multiple system atrophy (MSA)

Affects roughly 13,000 people in the United States; only 25% are accurately diagnosed. Symptoms include excessive changes in blood pressure when altering position (sitting, standing, lying down), impaired speech and difficulty swallowing, breathing and eating.

All diseases lead to progressive decline, and, although symptomatic treatment exists, there is no known cause or cure.

- For all three diseases, it is very rare for two cases to occur in the same family. However, subtle genetic influences are present for all three, and researchers are using these genetic “risk factors” to help discover the other factors in the causes of these diseases.
- Another important point that applies to all three diseases is that, while there is still no cure, many of the symptoms can respond to prescription or over-the-counter medications and to nonmedication treatment. In this way, patients with PSP, CBD and MSA can delay disability and improve the quality of their lives.

PROGRESSIVE SUPRANUCLEAR PALSY is a brain disease in the category of “neurodegenerative” diseases along with Alzheimer’s, Parkinson’s and Lou Gehrig’s diseases. In PSP, cells in some areas of the brain accumulate clumps of a protein called “tau” and gradually die off. Those cells control walking, balance, mobility, vision, speech, swallowing, sleep and behavior.

In the U.S., around 17,500 people have been diagnosed with PSP, a number similar to that of better-known Lou Gehrig’s disease (ALS). PSP’s average age of onset is 63, but rare cases have started in the early 40s. It is slightly more common in men than women, but PSP has no known geographical, occupational or racial preference. PSP is often misdiagnosed as Parkinson’s disease because of the general slowing of movement.

It can also be mistaken for dementia or Alzheimer’s disease because of changes in mood, intellect, memory and personality. Survival after the initial symptoms averages 7.4 years, with the milder “PSP-parkinsonism” variety progressing more slowly than the more severe “Richardson’s syndrome” variety. Currently there is no treatment or cure for PSP although research is very active.

CORTICOBASAL DEGENERATION is also a neurodegenerative brain disease. Almost the same set of symptoms occurs in CBD as in PSP, but the emphasis is on limb movement rather than on gait and balance, and in CBD the symptoms are highly asymmetric (worse on one side than the other).

Only about 2,000 – 3,000 people in the United States have CBD, of whom only 500-750 are correctly diagnosed. The average age of onset is similar to that of PSP. Initial symptoms are often stiffness, shakiness, jerkiness, slowness and clumsiness in one upper or lower extremity. Eventually the symptoms will affect the entire body. Other initial symptoms may include difficulty with speech generation, articulation, controlling the muscles of the face and mouth and walking and balance difficulties. A person with CBD will usually become immobile due to rigidity within five years of symptom onset. Research continues despite the rarity of the condition, and there is currently no cure.

MULTIPLE SYSTEM ATROPHY is a disease of the brain and spinal cord. The protein that accumulates in the brain cells, alpha-synuclein, is the same as in Parkinson’s, rather than the tau protein that accumulates in PSP and CBD.

The “MSA-parkinsonism” form can resemble Parkinson’s disease for years, but usually with more balance loss. The other form is “MSA-cerebellar,” where there is a coarse tremor and drunken-appearing gait and speech. People with MSA also have important impairment of the autonomic nervous system, which controls blood pressure, the digestive system and the bladder. The result is usually dizziness or fainting, constipation, urinary urgency or incontinence.

MSA also can affect sleep in important ways, causing obstructive sleep apnea or other forms of insomnia. Like PSP and CBD, MSA is rare, affecting about 13,000 in the U.S. The average age of onset is usually the early 50s, a bit younger than PSP or CBD. Survival after onset averages about seven years. While there is no current treatment or cure, MSA research is ongoing.

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APPENDIX B: EXPECTATIONS OF FACILITATORS OF CUREPSP SUPPORT GROUPS

Some prospective facilitators become discouraged at the idea that too much will be expected of them by both CurePSP and a group's members. Actually, CurePSP has basic requirements of support groups and support group leaders, and much flexibility is afforded to the facilitator running the group.

CurePSP would like support group leaders and their groups to:

- Meet regularly, preferably monthly, but the facilitator(s) and the group decide what is best
- Decide if meetings will be for patients, carepartners, or both
- Stay in contact with group members between meetings, preferably by email, to increase a sense of connection
- Possess a basic knowledge of PSP, CBD, MSA and related brain diseases, with a willingness to learn more
- Let CurePSP staff know if more materials are needed for group meetings
- Use the sign-in sheet at every meeting and return to CurePSP (see instructions on form)
- Let CurePSP staff know if attendance is low or if help is needed with any other aspect of running the group

CurePSP will help support group facilitators and their groups by:

- Promoting the group to local people in the area that are in the organization's database via email, while also listing the group on the website
- Supplying the group and leader with educational materials on prime of life brain diseases, and any other information that may be useful to the group
- Listing the group in all the informational packets that are sent to patients, families, and health care providers
- Communicating with leaders regularly via email on topics of interest that can be shared with the group
- Providing monthly "train the trainer" conference calls to allow leaders to ask questions and share ideas

APPENDIX C: SUPPORT GROUP GUIDELINES

- Share the Air. Share the time in the group letting everyone who wishes to speak have an equal opportunity to do so.
- One person speaks at a time. Let each person have an opportunity to speak so that we can all hear them, free from interruption.
- What is said here, stays here. Confidentiality is very important to opening up and sharing concerns.
- Differences of opinion are OK. We are all entitled to our point of view, without judgment or criticism.
- Use “I” language. “What I did when faced with a problem....” Avoid giving advice, or providing solutions. Sharing your experience is far more helpful and respectful.
- We are all equal. Accept differences that are cultural, religious, ethnic, social and racial. We promote acceptance.
- We are here to care and help each other. We are a support group.

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APPENDIX D: FOR GROUP FACILITATORS

THE PRIMARY GOAL OF A FACILITATOR:

To promote and foster a safe environment for people to share their feelings.

Refrain From Giving Advice:

- Remind group members not to give advice.
- Responses should take the form of an “I” statement.
- Utilize personal experiences in responding to another group member when offering support, encouragement, and suggestions.

A Red Flag Should Go Off When:

- You say, “You Should...”
- When you hear a group member say, “You Should..”

Remember, in a support group, people are coming for fellowship and support, even when discussions branch into medical questions.

APPENDIX E: DISCUSSION TOPICS

Whether you are looking for a speaker or just a way to encourage people to interact, having some topics handy can be helpful. Some recommendations from facilitators include:

- Community Resources: Day Care, Home Health Care
- Respite Care
- Staying active despite the disease
- Learning to ask for help
- Laughter and Humor
- How to avoid becoming isolated
- Help for behavior problems
- Communicating effectively with your physician
- Stress Management
- When to take the car keys away
- Levels of loss as the disease progresses
- What it's like to get the diagnosis
- Preserving self-esteem
- Coping with holidays and special family events
- Travelling with a person with a prime of life brain disease
- Changing roles and responsibilities for carepartners
- Managing time away from your loved one
- Improving communication
- Changing sexuality
- Normal and Abnormal aging
- Home Emergencies: What to do when the unexpected happens
- Research Updates
- The nursing home decision
- Long Distance Caregiving
- Parent/Adult Child Relationships
- Personal Growth in spite of the disease
- How to talk to family and friends about the diagnosis
- Disability: What benefits are available and how to apply
- How to cope with lack of sleep
- What is hospice and how can it help?

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APPENDIX F: SUPPORT GROUP SIGN-IN SHEET

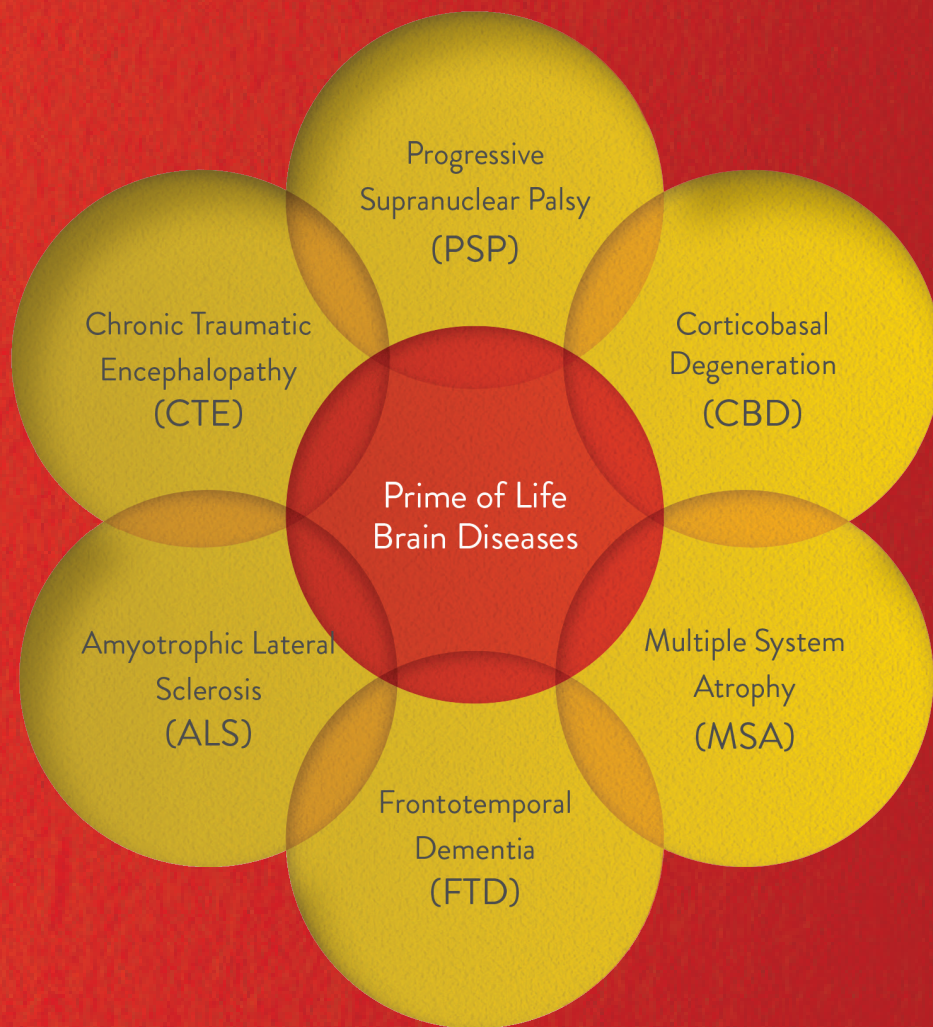
FACILITATOR

CITY/STATE

DATE



NAME	ADDRESS	EMAIL	PHONE	DIAGNOSIS





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