

# CDF Support Group

## Facilitator Manual



Celiac Disease Foundation

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Welcome CDF Support Group Facilitator,

On behalf of Celiac Disease Foundation (CDF), I want to thank you for your interest in working with CDF as a support group facilitator.

This CDF Support Group Facilitator Manual will provide the necessary knowledge, forms, and tools you will need to successfully run a CDF Support Group. In order to provide the highest quality program, facilitators are also required to follow the CDF Support Group Policies found in the Appendix of this manual.

I truly appreciate your time and commitment. Your efforts will have a significant and positive impact on people's lives as they learn to cope with celiac disease and other gluten-related disorders. In addition, you are fulfilling a vital component of the CDF mission: to provide a supportive and educational environment to the people living with celiac disease and to their families, caregivers, and loved ones.

Thank you for making a difference in your community!

Warmest Regards,



Marilyn G. Geller  
Chief Executive Officer

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## About Celiac Disease Foundation

### *Mission Statement and Program Objectives*

Celiac Disease Foundation (CDF) is the nation's leading voluntary health organization dedicated to driving diagnosis for celiac disease and other gluten-related disorders through advocacy, education, and advancing research.

CDF energetically pursues its mission statement through five program objectives:

- Advocates for increased public and private sector support for screening of celiac disease and gluten-related disorders.
- Heightens public awareness of the impact of undiagnosed and untreated celiac disease and other gluten-related disorders.
- Provides financial support to researchers and camps to children on the gluten-free diet through CDF's grassroots fundraising program, CDF Team gluten-free™.
- Translates research findings into medically sound information and programs for people with celiac disease and other gluten-related disorders, their families, physicians, and other health professionals.
- Supports individuals with celiac disease and other gluten-related disorders, as well as their families, caregivers, and loved ones.

CDF has a national network of local chapters that provide programs and services to help people with celiac disease and other gluten-related disorders. These include:

### *Education Programs*

- Booklets and fact sheets on all aspects of living and coping with celiac disease and other gluten-related disorders.
- Electronic newsletters containing updates on celiac disease research, living with celiac disease, public policy issues, and local events and activities of interest to people with celiac disease.
- INSIGHT® Magazine, the only national publication for people with celiac disease and other gluten-related disorders, their families, and caregivers that provides health and wellness features, lifestyle articles, research summaries, clinical updates, and more.
- Education programs to provide updates on developments in research, treatment, and coping with celiac disease and other gluten-related disorders.
- Website ([www.celiac.org](http://www.celiac.org)) which provides the latest information on living with celiac disease and other gluten-related disorders, including breaking news, research study participation opportunities, and healthcare practitioner and gluten-free marketplace directories.

### *Support Services*

- Orientation seminars for people newly diagnosed with celiac disease and other gluten-related disorders.
- Support groups for people who want help from others facing similar challenges.

- Health educators to answer questions and connect people with resources and other services, who can be reached at [info@celiac.org](mailto:info@celiac.org), and 818-716-1513 during normal business hours, 9:30 a.m. to 5:30 p.m. PST.

## CDF Support Group Philosophy

People with celiac disease and other gluten-related disorders often feel alone with their disease and the everyday struggles that the disease brings to their lives, especially during meal times. The philosophy of CDF support groups is to provide a warm and caring environment where people with celiac disease and other gluten-related disorders, their family members, caregivers, and loved ones can share their experiences, methods of coping, and insights into living with this chronic illness. Knowing that others share this journey offers comfort and reassurance. CDF support groups encourage people to adhere to a strict gluten-free diet and provide a comfortable learning environment to help them develop the best coping strategies to reduce stress that often accompanies living with this chronic illness.

### A Support Group IS:

- A self-help group; it is usually organized by people who share a particular challenge or life situation. CDF support groups are open to people with celiac disease and other gluten-related disorders, their family members, caregivers, and loved ones who gather periodically to share common concerns.
- A place for people with celiac disease and other gluten-related disorders to be themselves and come to terms with a diagnosis of celiac disease or another gluten-related disorder and the way their disease affects them as individuals.
- A source of information, which includes CDF educational materials and community resources.
- A place to confidentially share, learn, and help others. Group members discover a place where they can receive information that is accurate and up-to-date, as well as come to terms with living with chronic illness.

### A Support Group is NOT:

- A professional counseling or therapy group. If the facilitator perceives that a person needs more help than a support group can provide, the facilitator can talk to that person privately and suggest that he or she contact his or her health care provider about any health issues that may need to be addressed. The facilitator must not provide individual referrals.
- A substitute for medical treatment or health counseling. The facilitator must not give medical advice.
- A replacement for family and friends, or other close relationships. However, participating in a support group may help lighten the burden of living with celiac disease or another gluten-related disorder, and allow relationships outside of the group to be less stressful.
- For everybody. The idea of a support group may make some people uncomfortable. Some people prefer different types of support at different times in their lives, depending on a variety of factors. One may not want to share his or her health problems with others, and listening to other people's problems may be too stressful. A newly diagnosed individual may not be ready to attend a support group.

- A cure. It won't make celiac disease or gluten sensitivity go away, but it can help people with feelings of helplessness and address their fears.

### **Goals of a CDF Support Group**

- Provide an accepting and safe learning environment so that support group members are able to express their feelings and concerns and develop appropriate skills to cope with chronic illness.
- Provide comfort and reassurance to those who feel alone in their disease.
- Provide current and accurate information about celiac disease and other gluten-related disorders.
- Help group members come to terms with the fear of living with celiac disease and other gluten-related disorders and gain confidence in learning to cope.
- Encourage group members to share their health issues, including any change or worsening of symptoms and disease management concerns, with their doctors and other members of their health care team.
- Assist group members, through guided and effective group interaction, in adjusting to changes in lifestyle that can help them cope and better manage living with celiac disease and other gluten-related disorders.
- Provide a positive social support system where a peer support network can develop.

### **Value of a Support Group**

#### **Sharing**

People with celiac disease and other gluten-related disorders may not be able to share with family and friends just how difficult it can be to live with the day-to-day struggles of a chronic illness. Sharing their stories and experiences, openly and honestly with others “who have been there” can help decrease a sense of isolation and helplessness, and promote a renewed sense of well-being. Many lifestyle adjustments are often necessary to live successfully with celiac disease and other gluten-related disorders. The exchange of information in a support group can help members process this change.

#### **Peer Support and Friendship**

Most people with celiac disease and other gluten-related disorders experience any number of lifestyle adjustments. Most people who come to a support group are in the process of trying to understand their diagnosis and are looking for emotional support. Members can support and help one another in coping with the medical and social aspects of the disease. Through peer support and friendship, group members can find the courage to begin creating a “new normal” — a life that has changed due to chronic illness, but is still fulfilling and rewarding. Peer support and friendships enable members to give help as well as receive help.

#### **Information and Education**

Successfully managing celiac disease and other gluten-related disorders starts with awareness, and awareness starts with having current, accurate, and experience-based information. Through guided discussions, group members can become more aware of their particular symptoms and how celiac disease or another gluten-related disorder is affecting them. They can become more

conscious of what they need to do to prevent being exposed to gluten and how to take care of themselves to be as healthy as possible. They can become more aware of the tension and stress that often accompany chronic illness, as well as coping strategies and techniques to reduce that stress.

A support group is a good place to get accurate, up-to-date information about celiac disease and other gluten-related disorders, the disease process, the symptoms, disease management, forms of treatment, and research. A support group can also be a good place to learn about related issues of disability income, accessibility, employment concerns, stress management, community health resources, etc. Appropriate, professional guest speakers may be invited to the meetings as approved by CDF or the Chapter to talk about these or other related issues as they pertain to the needs of support group members.

### **Why Support Groups Work**

- No one knows better than someone “who has been there” how the understanding and empathy inherent in support groups can provide a sense of relief to members.
- Support group members can help others develop new insights about living with a chronic illness such as celiac disease and other gluten-related disorders.
- Support group members can help each other understand that coping is not a single behavior, but a collection of many strategies and behaviors that develop over time.
- Support groups allow members to accept their diagnoses in a way that makes sense to them.
- Support groups allow members to take small steps which make adjusting to living with a chronic illness easier. Small, steady changes with validation from peers can help make adjusting to a life with chronic illness easier.

### **CDF Support Group Facilitator Criteria**

CDF Support Group Facilitator Training ensures participant understanding of how to effectively and successfully run a CDF Support Group, and reinforces that facilitators must comply with CDF Support Group Policies. Support Group facilitators have an opportunity to touch the lives of people with celiac disease and other gluten-related disorders and make a meaningful difference in their own lives.

CDF Support Group facilitators should have a true desire to help people with celiac disease and other gluten-related disorders and their families, in addition to having a basic understanding of celiac disease and other gluten-related disorders and how they can affect the body. CDF has many educational resources in a variety of topic areas and formats that facilitators should read to learn about the complexities of celiac disease and other gluten-related disorders. CDF appreciates its Support Group facilitators and their efforts in working to help others adjust to a life changed by celiac disease and other gluten-related disorders.

*Facilitators need to:*

1. Submit a CDF Support Group Facilitator Application.
2. Be interviewed and selected by CDF or the Chapter.
3. Attend CDF Support Group Facilitator Training. Thereafter, participation in “refresher” sessions is strongly encouraged.



4. Sign the CDF Support Group Facilitator Agreement.
5. Understand and be compliant with CDF Support Group Policies.
6. Commit to a one-year term of service as a facilitator.
7. Actively seek a trained co-facilitator for the support group.
8. Stay in monthly or more frequent contact with CDF or the Chapter, as required.

## **An Effective Facilitator**

A support group needs a facilitator who has a different role than support group members. A facilitator's job is to be aware of how group members are working together to assure that the group can accomplish its goals. An effective facilitator guides group interaction according to guidelines set forth in this manual and balances individual needs with group needs. While it may be challenging at times, it can also be very rewarding.

The support group facilitator is responsible for guiding and protecting the support group process. Therefore, effective support group facilitators will often need to set limits, including time limits, and introduce topics for discussion or education programs. For example, limits should be placed on facilitator dependency. The facilitator must set limits on member access to the facilitator's personal time.

The Seven Step Facilitator Process provides a general framework for the support group process. A good understanding of the Seven Step Facilitator Process will help the facilitator run an effective support group.

## **The Seven Step Facilitator Process**

### **1) Setting Climate**

- a) Setting the climate involves allowing people to feel as though they can participate comfortably and communicate easily.
- b) The facilitator's job is to establish a safe climate for the healthy exchange of information.
- c) A facilitator who respects all members for their integrity and worth will create an atmosphere of friendliness and cooperation, informality and freedom.
- d) Another equally important part of setting the climate is to help the group to communicate effectively. The facilitator maintains an informal and friendly atmosphere in which full participation and cooperation can be achieved.
- e) The facilitator initiates discussion and stimulates participation.
- f) The facilitator works to ensure that opinions of all group members are heard and understood, even if not all participants agree.

### **2) Mutual Planning**

- a) Everyone plays a role in the decisions of the group. Groups work better when the planning is shared among members.
- b) The support group facilitator should set the precedent of sharing tasks and primary responsibilities to get group members involved in helping the group stay organized. In the short run it may seem easier for the facilitator to do most of the tasks, but such a pattern is very easily set and quite hard to break; the facilitator then becomes the "best person to

do it” at the cost of member joint ownership. Sharing tasks and responsibilities can help members connect with each other.

### **3) Assessing Needs**

- a) The facilitator takes special responsibility for being sensitive to the need for definition or clarification of goals and purposes.
- b) Assessing needs is an important step that allows individuals to feel as though their needs are important and that their needs will be met.
- c) Many support groups spend the first few sessions simply discussing common concerns and giving members a chance to get to know one another. This is the time in which support group facilitators can assess the needs of the group.
- d) Once the group needs are assessed, an agenda or meeting schedule can be outlined which includes discussion or program topics that will address these needs.

### **4) Forming Objectives**

- a) The support group facilitator helps group members form objectives to help achieve their goals individually and as a group. However, there must be some common ground in the support group; otherwise, individuals may not get what they are looking for.
- b) It is up to the facilitator to assure that each member’s needs are assessed and understood by the group. The group must then come to some sort of an agreement on what the common objectives of the group will be – and those objectives need to take into account everyone’s needs.

### **5) Designing**

- a) The facilitator helps the group determine its course of action and conduct. In other words, the facilitator helps the group to reflect on its problems and assesses needs to determine what procedures might provide the best outcomes, such as open discussion, role playing, professional speakers, or a special time for socializing.
- b) Though the facilitator should never be in the position of making decisions for others, he or she should feel free to raise questions and make suggestions. The facilitator should not allow her/himself to be put in the position of making decisions for others.

### **6) Implementing**

- a) The facilitator cultivates a sense of shared responsibility for the implementation of the group. The facilitator should encourage members to contribute their skills and talents. However, the facilitator has the primary responsibility to carry out the necessary tasks to successfully get a support group “up and running.”
- b) A co-facilitator is encouraged and can help the facilitator with many tasks and functions. The co-facilitator should help arrange and run support group meetings a few times to ensure the continuity of the support group when the facilitator is not available.
- c) Once the group is established, the support group facilitator – based on input from group members – may ask individual people to help with specific tasks and projects.

### **7) Evaluation**

- a) The facilitator has a special responsibility to coach the group in becoming aware of the processes as well as the content of its work, and to evaluate these processes objectively so that the group can improve on them.

- b) The facilitator helps the members of the group to learn from their experience. By developing the habit of looking not only at what they are doing, but also how they are doing it, members of a group can improve their ways of working together.
- c) The evaluation process will involve several factors such as attendance, participation, staying on track, group feelings and respect, accomplishment of goals, attitudes toward the group facilitator, and members' attitudes at the conclusion of a meeting.
- d) Facilitators are getting results when:
  1. Individuals feel they belong to the group.
  2. Members improve their ability to function and feel better about living with celiac disease and other gluten-related disorders.
  3. Members have developed strategies to cope better with a chronic illness.

## Qualities of an Effective CDF Support Group Facilitator

In addition to concrete skills, there are a number of important qualities that can help the facilitator lead an effective support group. Throughout the process of starting and running a support group, hard work will help the facilitator strengthen these qualities and even develop new qualities as the group also grows and develops.

*Integrity, Self Knowledge, and Awareness:* First and foremost, facilitators who share the same life situation as the group (facilitators who also have celiac disease or another gluten-related disorder) need to evaluate where they are with their illness, and separate their own illness from their role as facilitators. Facilitators also need to be aware of their own values and attitudes that they may bring to the support group and recognize that these values may differ from those of others in the support group.

*Commitment:* The facilitator must have a strong sense of CDF and its mission, and believe in and be committed to the CDF support group philosophy.

*Creativity:* The facilitator should be able to create and maintain an atmosphere for sharing, support, and education. The facilitator needs to use creativity to keep meetings interesting and worthwhile.

*Patience:* Facilitators need to be comfortable with group silence. Facilitators need to allow group members to take the time that they need for appropriate group interaction and processing.

*Understanding:* The facilitator needs to understand and be sensitive to the fact that celiac disease and other gluten-related disorders affect people differently, and people react to the diagnosis and living with celiac disease and other gluten-related disorders differently. Understanding and empathy (not sympathy) can help enable the group to improve relationships that enhance group processes.

## Facilitator Responsibilities

- Complete the application process, complete CDF Support Group Training, and sign the CDF Support Group Facilitator Agreement.
- Attend the CDF National Conference Leaders Workshop each spring in Los Angeles, California.

- Responsibly educate himself/herself about CDF and its mission, and have a general knowledge of and understanding about celiac disease and other gluten-related disorders.
- Work continually with CDF or the Chapter to plan and organize a support group for those affected by celiac disease and other gluten-related disorders.
- Prepare for and implement a support group according to CDF Support Group Policies (see Appendix).
- Understand the purpose of a support group and be willing to protect the purpose and goals of a celiac disease and other gluten-related disorders support group, as well as the integrity of the group.
- Guide the group in identifying its goals and keeping the group focused on those goals and tasks in order to enable effective sharing and learning.
- Maintain the value of a support group by facilitating appropriate sharing, peer support, and friendship, and providing accurate and up-to-date information.
- Serve as a good role model and practice positive coping skills.

## Facilitator Skills

A skilled facilitator will have a good sense of direction and a clear perception of immediate, as well as long-range, support group goals. Positive leadership helps the support group to develop and function more effectively. A support group facilitator needs to develop strong leadership skills in order to implement and guide the support group process so the group can provide the best support possible to people living with celiac disease and other gluten-related disorders, their families, caregivers, and loved ones. While it can be very difficult at times, it can also be very rewarding when individuals, and the group as a whole, succeed in accomplishing their goals and are able to make effective lifestyle changes to live better with a chronic illness. The following skills are important and can help to ensure a more productive group process.

### 1) Organization

- a) A skilled facilitator needs to have the ability to organize a safe, warm, and caring support group environment.
- b) A well-run support group requires sound planning, structure, and a sense of direction to help move the group forward.
- c) A good organizer is able to help the group sort out what is important and meaningful to group members so they can form and clarify their own goals to live better with chronic illness.
- d) A good organizer has the ability to maintain focus on the essence of ideas and periodically pull together the related parts of group discussions, helping group members organize thoughts and ideas to improve group interactions and build synergy.
- e) A good organizer does not make all of the decisions all of the time, but knows when to share and delegate responsibilities that are in the best interest of the group.

### 2) Effective communication

- a) Effective communication can be described as sharing information, providing feedback among group members, and having meaningful interaction that provides effective understanding of group discussions.

- b) Personal styles, personalities, emotions, cultural differences, and circumstances of a given situation can all influence communication. Self-awareness is an important factor in helping people to communicate with others.
- c) Effective communication is achieved when the facilitator and group members are able to articulate thoughts effectively. However, expressing and articulating thoughts clearly can be very difficult in a support group setting where people are dealing with emotions and various symptoms of their illness.
- d) Taking the time to listen and reflect on the content of what is being said – being a good listener.
- e) Finding purpose and intent in what is being said.
- f) Demonstrating that you are listening through eye contact, head nodding, etc.
- g) Obtain clarification by repeating the content or by asking a follow-up question that starts with, “Are you saying...?”
- h) Pay attention to what is not being verbalized, such as body language.
- i) Be patient and give the speaker time to say all that he or she needs to say.

Some ineffective communication skills are:

- I. Not listening*
- II. Not making eye contact*
- III. Appearing bored or distracted*
- IV. Interrupting the speaker*
- V. Taking away from the speaker’s message with side talk*
- VI. Not responding to, or ignoring the speaker*
- VII. Minimizing or dismissing the ideas and/or problems of the speaker*

### **3) Intervention**

- a) Facilitator intervention is a critical skill that guides group interaction and the entire support group process. For example, a facilitator may interrupt group discussion in order to change a behavior or keep discussion focused and on track to improve group functioning. Very specific interventions will be addressed in the next section. A skilled facilitator knows when to interrupt the support group process in order to protect the purpose and goals of the group.
- b) Appropriate intervention may be necessary to address conflicts or problem behaviors that threaten the effectiveness of the group.
- c) Appropriate interventions can help to broaden or limit participation and move the group forward.
- d) Appropriate interventions can help the group process stay organized.
- e) Appropriate interventions help the group members to participate more effectively in group discussions and move toward more effective outcomes.

### **4) Processing**

- a) People come to a support group meeting to achieve something, so awareness of the group’s work is a very important part of every group meeting. A skilled facilitator has the ability to help the group examine their shared thoughts, ideas, and experiences. People come to a support group with various experiences that they share with each other. Group processing, the reflection and interpretation of group interaction, generates feedback, awareness, and new learning. The facilitator moves the process along through good organization and communication, appropriate interventions, and problem solving.

- b) People come to a celiac disease and other gluten-related disorders support group and recreate their “living with celiac disease and other gluten-related disorders experiences” through interacting openly and honestly with each other.
- c) During the meeting, group members listen, interpret, and generalize what they hear from each other and provide feedback.
- d) Through group processing, members learn that they are not alone and they find comfort in learning that others have had similar difficulties and are able to offer new insights about coping. They have the opportunity to apply new learning that makes sense to them. Through applied new learning, group members will bring back new experiences to the group.

## 5) Problem Solving and Decision Making

A skilled facilitator has the ability to help the support group members develop techniques and strategies to solve problems and make good decisions. The idea is to recognize problems, decide how to deal with problems in the group in the best way possible, and move forward. Sometimes it is difficult to determine a problematic situation, but if something doesn't feel right, it should probably be addressed. Important steps in problem solving and making good decisions include:

- a) Observing a behavior or a particular need that is problematic.
- b) Ask yourself: Is there something that is making the group uncomfortable or keeping the group from moving forward?
- c) Clarifying the problem with the group. Ask members to describe what they think is the real problem.
- d) Ask the group: What should be happening and what should not be happening?  
Formulating possible solutions and assessing the value of possible solutions.
- e) Ask yourself: What are some possible solutions and how will they improve the situation?
- f) Choosing the most valuable solution and putting it into action.
- g) Ask yourself: What solution will benefit the most members of the group? Getting feedback from group members and evaluating the effectiveness of the action taken to address the problem.
- h) Ask yourself: Were the outcomes of the action effective?

## Planning and Organizing a CDF Support Group

Once you and CDF or the Chapter decide that you should start a support group, you have met the facilitator criteria, and you understand the CDF Support Group Policies, the next step is to work with CDF or the Chapter to plan and organize a support group and get it “up and running.” In addition to helping you plan and organize a group, CDF or the Chapter may also be helpful in identifying a core group of people (two or three others) interested in helping you start a support group.

## How Support Groups Get Started

Every support group has its own story about how it began. The group that you are starting will also have its own unique beginning. A person with celiac disease or another gluten-related disorder, caregiver, or health care professional who sees the need for a group and is willing and able to take on the responsibility can plan, organize, and implement a support group. Some scenarios include:

- Someone with celiac disease or another gluten-related disorder contacts CDF or the Chapter looking for a support group, but learns that there are none in the area. He or she then expresses an interest in starting a group. This is the most common situation.
- A family member or caregiver understands that connecting with others in the same life situation may lighten the burden of the illness for those who have the disease as well as their family members.
- A health professional, such as a social worker, nurse, or mental health professional, realizes that a celiac disease and other gluten-related disorders support group would be beneficial in the community and contacts CDF or the Chapter for information about starting a support group for persons affected by celiac disease and other gluten-related disorders.
- Someone has a friend with celiac disease or another gluten-related disorder, but in order to give support, he or she needs to have some understanding about celiac disease and other gluten-related disorders and how the illness can affect people, and how to cope with celiac disease and other gluten-related disorders. A friend who understands celiac disease and other gluten-related disorders can lend valuable support.

## A Few Things to Consider

Starting a CDF Support Group takes time and energy, but the benefits are worth the investment. If you have celiac disease or another gluten-related disorder, it is important to be aware of how your illness is affecting you and whether taking on the responsibility of a support group might add to the stress of your illness. On the other hand, working on developing an effective support group and helping others can be a great learning experience and very rewarding.

Starting a support group requires a reasonable amount of planning, organizing, and preparing for each meeting. Please keep in mind the following:

- Starting and developing a support group is an ongoing commitment.
- Keeping a support group “up and running” is not a one person job. Working with a co-facilitator to help meet the demands of organizing and running an effective support group can make the experience more enjoyable and prevent burnout. Effectively delegating tasks is important.
- Starting a support group can have many positive effects and can change your life. In fact, you may find yourself becoming a “celiac disease and other gluten-related disorders advocate” in your community.

## Meeting Location, Time, and Frequency

### *Location*

It is important to pick a location that will serve the greatest number of people. For example, should the group be more centrally located, or outside of a metropolitan area? Participants should not have to travel far to a support group, and the location and facility should be convenient for participants. CDF or the Chapter may have some good location suggestions based on their membership database. CDF or the Chapter must review and approve the meeting location of a support group.

## *A Safe Place*

Usually a meeting room can be found for use free of charge, but may require a contractual agreement for liability purposes. Meeting spaces may sometimes require a fee, and that must be approved by CDF or the Chapter. It is essential that CDF or the Chapter be involved in any contracts that occur and must co-sign along with the facilitator. Meetings should take place in convenient and public locations (not in private homes) that provide a comfortable and safe environment and necessary physical accommodations. Some places where support group meetings may be held include:

- Hospital meeting rooms
- YMCA or YWCA Senior Centers
- Public libraries
- Rehabilitation centers
- A community room at a local mall
- Local CDF Chapter meeting rooms
- Churches, synagogues, or other places of worship (note that this is simply a location for a meeting and the support group is not affiliated with any religious beliefs).

Be sure to visit a potential meeting place before deciding to use it. The location must be accessible to those with disabilities as defined by the Americans with Disabilities Act. Contact the meeting facility approximately one week in advance of each meeting to confirm the meeting space.

Here are some things to consider when looking at a potential meeting place:

- Is the parking lot close to the entrance? Do people have to pay to park?
- Are the building entrances, exits, bathrooms, and meeting space easily accessible, handicapped-accessible, and well lit? Is there an elevator if needed?
- How large is the room? Will it accommodate wheelchairs? Will the room ensure privacy of the group?
- Is the room quiet, or will the noise from other building activities and the surrounding area be disturbing?
- Is the room adequately ventilated, heated, and/or air conditioned for year-round comfort?
- Are you able to alter the lighting for people with light sensitivity?
- Can you gain access to the building and meeting room outside of conventional business hours to set up before the meeting?
- Are there any security issues?
- Is there a closet where the group can store supplies and literature? Can you bring in refreshments?
- Are there chairs and a table already in the room, or will you have to set up chairs and a table for every meeting? Can the room be set up for guest speakers? Is audiovisual equipment available to the group?
- Would the facility be willing to help your group to advertise its presence there? Is there a requirement for liability insurance?



## *Time*

The facilitator should be aware of his or her availability as well as the availability of potential support group members. The facilitator can ask participants at the first meeting about convenient meeting times. The day of the week and the time of day are important factors and should be consistent so people can plan ahead and make necessary arrangements. The day and the time of support group meetings should reflect what is best for the majority of group members. Here are some things to consider:

- Certain routines and commitments such as work, school, and/or childcare may preclude daytime participation for some members, especially during the work week.
- Night-time meetings require additional considerations for safety and public transportation issues. There may be more transportation options during daytime hours. It may be helpful to check public transportation schedules in the area.
- Older individuals with celiac disease and other gluten-related disorders might prefer a daytime meeting in order to avoid driving at night.
- When looking at weekends it is important to consider the religious differences within the group, especially when it comes to Sabbath observances.
- Typically, support groups will meet from an hour to two hours. A group that meets for an hour and a half (no more than two hours) is reasonable and allows/respects group process and it respects individual time and commitment. However, support group facilitators should suggest a reasonable amount of time for group meetings and give group members the opportunity to determine a time frame that is reasonable and agreeable to the group as a whole.

## *Frequency*

How often a support group meets is an important consideration. Most support groups meet monthly. Monthly meetings are far enough apart so that they are not too stressful, yet close enough together to allow people to get to know each other and provide consistency. Some groups may meet more often if there are special circumstances and group members are seeking extra support. The frequency of support group meetings should be agreeable to all members of the group. Well-attended support groups have consistent meeting times and publish a yearly or at least a six-month schedule of meeting times and topics.

## **Type of Meeting and Format**

CDF support groups are open to people with celiac disease and other gluten-related disorders, their family members, caregivers, and loved ones only. They can be ongoing or meet for a set period of time. Participants will change from time to time and people will come to the group with various needs. When new members come to the support group meeting, they will add new perspectives; therefore, relationships within the group may change. Typically, support groups have fewer than 20 members. However, a group with six to eight (no more than ten) members is a good size for the purpose of the group and for a more focused discussion within a particular time limit.

Facilitators are responsible for structuring and guiding the group format. Although meeting formats may vary from time to time depending on the needs and composition of the group, the

initial and ongoing format for a support group is often similar to the following, where the facilitator:

- Starts the meeting on time.
- Opens the meeting by introducing her/himself and extending a warm welcome to group members.
- Provides a brief orientation to the support group (e.g. the group's purpose, how it functions, the facilitator's role, meeting format, etc.).
- Asks participants to introduce themselves and briefly share their situations and what they would like to accomplish by participating in the support group. If this is not the first meeting, the facilitator may ask participants to share how they have been feeling since the last meeting.
- Guides the group in establishing and complying with ground rules, or revising as needed.
- Introduces the discussion topic and guides group discussion, making sure that everyone has the opportunity to share information and contribute to the discussion.
- Summarizes group interaction before the meeting comes to a close. This is a good time to ask members to briefly share what they got out of the meeting.
- Reminds members of the next meeting and asks if the discussion topic for the next meeting is still agreeable
- Thanks everyone for coming and closes the meeting on time.

## Meeting Topics

*Topic information presented at support group meetings must conform with information displayed at [celiac.org](http://celiac.org); Support Group Facilitators may only provide information related to celiac disease or its treatment that is found at [celiac.org](http://celiac.org) or on a CDF Medical Advisory Board member's website. If you would like to introduce new information, please direct your inquiry to the National Office at [info@celiac.org](mailto:info@celiac.org) for approval by the CDF Medical Advisory Board.*

All meetings, even open discussion meetings, should have a topic to help the group focus. In the beginning, the group meeting topic might be *Getting Acquainted* or *Sharing Your Celiac Disease or Other Gluten-Related Disorder Story*. As the group grows, a variety of topics can help meet the needs of group members. It is important to allow group members to help determine meeting structure and topics. The following topics can be used for open discussion, or they can be addressed by a guest speaker. A possible guest speaker could be a gastroenterologist or other medical specialist, a registered dietician or nutritionist, a pharmacist, or a licensed mental health professional, depending on the topic.

The Support Group Meeting Planner helps facilitators plan for the year of support group meetings, topics, and guest speakers (see Appendix). As the support group progresses and its needs change, topics may have to be adjusted accordingly. We encourage you to share the planner with CDF or the Chapter upon completion and throughout the year.

Some suggested topics:

### **Understanding celiac disease and other gluten-related disorders**

- Common symptoms of celiac disease and other gluten-related disorders
- How can celiac disease and other gluten-related disorders affect the body?
- What causes celiac disease and other gluten-related disorders?

- Diagnosing celiac disease and other gluten-related disorders
- Why does a diagnosis of celiac disease and other gluten-related disorders take so long?
- How are celiac disease and other gluten-related disorders diagnosed? What do diagnostic tests mean?

### **Treating celiac disease and other gluten-related disorders**

- How to manage the gluten-free diet
- Successfully managing celiac disease and other gluten-related disorders in partnership with your doctor and health care team
- Preparing for a visit with your health care provider

### **Living with celiac disease and other gluten-related disorders**

- Emotional reactions to living with celiac disease and other gluten-related disorders
- Depression
- Living with memory loss and “celiac disease and other gluten-related disorders fog”
- Living with chronic pain (pain management)
- How can people with celiac disease and other gluten-related disorders deal with extreme fatigue?
- Diet and nutrition for people with celiac disease and other gluten-related disorders
- Celiac disease and other gluten-related disorders and intimacy

### **Coping with celiac disease and other gluten-related disorders**

- Explaining celiac disease and other gluten-related disorders to family and friends
- Celiac disease and other gluten-related disorders on the job
- Lifestyle changes
- How has celiac disease and other gluten-related disorders changed your life?
- Stress management
- How is the support group helping you?
- Strengths gained from coping with celiac disease and other gluten-related disorders

## **Support Group Promotion**

Building awareness about your group is critical in order to generate interest and attract members to develop the group. Publicity should begin at least four to six weeks prior to the group meeting to:

- Provide information about the purpose of the support group and whom it may benefit.
- Building trust in support groups begins with the very first contact, whether it is through news releases or articles, a one-to-one personal contact, the telephone, or a group meeting. Every contact with a potential member should be characterized by a nonjudgmental attitude, empathy, understanding, and concern.
- Reach out to the community to let people newly diagnosed with celiac disease and other gluten-related disorders and other potential new members know that the support group exists and how they can join the group.
- Remind established members of upcoming meetings and expand the membership of future group meetings.

## *How to Promote Your Support Group*

Maintaining the integrity of the CDF brand is critical when conducting any kind of public awareness or promotion. The public relies on CDF as the most credible and trusted authority for information on celiac disease and other gluten-related disorders. In order to continue to meet that expectation, promotional materials must be high quality, accurate, and consistent with CDF's colors and brand. To assist Chapters and support group facilitators in promoting their support group, the following tools have been developed, consistent with CDF's brand (and can be found in the Appendix of this manual):

- Flyer
- Postcard
- Print Advertisement
- Calendar Notice

CDF or the Chapter can provide the facilitator with these materials in electronic form. The Chapter logo may be added and the time, date, and location may be customized.

Below are some suggested strategies and tips to help you get started promoting your support group within your community.

### *Media*

Getting your support group listed in community newspapers, local radio event calendars, and other media outlets is a great way to increase visibility for your support group and attract a new audience. Most newspapers, for example, have a calendar and events editor responsible for the community calendar. You can contact media outlets and ask them for the appropriate contacts.

Editors should be emailed or faxed the calendar notice with all of the relevant details including date, time, location, and any guest speakers for the upcoming support group meeting.

### *Advertising*

The sample print advertisement provided is currently sized to ¼ page. Each newspaper has its own size and format specifications, and the ad will need to be modified to meet its requirements. Do not discount advertising just because there is a cost associated. Some weekly community newspapers have affordable rates. Targeting your advertising is instrumental in successfully recruiting participants. Identify publications that target the specific community where your support group is located.

### *Community Outreach*

There are a number of organizations and places within your community that you can work with and ask for support in publicizing your support group. You can ask these groups to post flyers, publish the information on their website, or include it in their electronic or printed newsletters. Some community newspapers have calendars in which you can post an advertisement for your meeting free of charge.

Recommended organizations and places include:

- Hospitals and community clinics
- Local health departments
- Offices of gastroenterologists and physicians
- Churches, synagogues, or other places of worship
- Libraries
- Pharmacies
- Coffee shops
- Other community based health and advocacy organizations including NAACP, La Raza, Urban League, local medical associations, and local community health coalitions.

We also encourage you to do some homework and to research organizations online! Many communities have health coalitions and organizations unique to that community.

### *Events*

Distribute flyers or postcards at local events such as health fairs and community festivals. Summer is a great time to find out what events and festivals are going on in your community and where you might be able to promote your support group.

### *Mailings*

A 4 X 6 sample postcard has been provided for Chapters and support group facilitators as an example of something to mail their constituents. If postcard mailing is something from which your support group might benefit, the National office can create a version for you using our logo, which you can then distribute to your constituents. Do not forget to mail the postcard to previous attendees.

### *Online/Website*

- Post support group meeting information in CDF Chapter E-newsletters and websites. Chapters with a Facebook or Twitter account are encouraged to use these tools as a way to promote their support groups.
- Chapters and support group facilitators should also ask constituents, friends, family, etc. to help spread the word about the support group through email or Facebook.

Support group facilitators should contact CDF or the Chapter with any questions regarding the materials provided, or how to further promote support group meetings.

## **The Support Group Meeting**

### **Before the Meeting**

A facilitator can help the meeting get off to a good start by being prepared. Adequate preparation before the meeting can help you, as the facilitator, to feel more relaxed and confident about getting the meeting started. A good sense of organization and direction can help group members feel at ease, especially if this is the first meeting. Think about what you want to accomplish and how you might achieve your goals.

Have a good understanding of the meeting topic. Develop a few questions that reflect this topic to use in initiating group discussion. Look at your questions and prioritize them. Are the questions clear? How might they help keep the discussion focused? Use open-ended questions that will draw out thoughts and feelings rather than questions leading to a simple yes or no response.

For a new group, the topic might be *Understanding Celiac Disease and Other Gluten-Related Disorders*, *Adjusting to a Diagnosis of Celiac Disease or Other Gluten-Related Disorder*, or *How Celiac Disease and Other Gluten-Related Disorders Affect You*. Some helpful questions to initiate open discussion include:

- Trying to reach a diagnosis of celiac disease or other gluten-related disorder isn't always easy. What were some of the challenges that you faced?
- At the time of your diagnosis, how did you feel? How do you feel now?
- How is celiac disease or other gluten-related disorder affecting you?
- What has been the reaction of your family?

For a more established group, the topic might be *Living with Celiac Disease and Other Gluten-Related Disorders* or *Successfully Living with Celiac Disease and Other Gluten-Related Disorders*. You can reflect on the group's experiences and ideas and share CDF educational materials. Some helpful questions to initiate discussion may include:

- How has living with celiac disease or other gluten-related disorders changed important things in your life?
- What are some of your strengths gained from coping with celiac disease or other gluten-related disorders?
- How have our group meetings been helpful?
- In past group meetings we have talked about the reactions of family and friends to your diagnosis. Have the reactions of family and friends changed over time?

### *Preparation for a Guest Speaker*

The facilitator must get preapproval from CDF or the Chapter on all guest speakers at support group meetings. Guest speakers must be relevant to the topic of discussion and provide education to support group members, but **must not directly recruit volunteers for clinical trials, sell a product, or offer therapy**. A facilitator should submit the Guest Speaker Request Form at least four weeks in advance of the proposed presentation (see Appendix). If you have arranged for a guest speaker, you will have some additional tasks to do before the support group meeting.

- Call the speaker to remind him or her about the meeting, the time, and location.
- Ask the speaker if he or she needs directions and if there is anything that you can do to help make the experience more enjoyable.
- Let the speaker know approximately how many people will be attending and the amount of time that has been arranged for the presentation. Speakers will usually take questions at the end of their presentations, so you can ask how he or she would like to handle questions and answers at the end of the presentation and plan accordingly.
- Make arrangements for audio/visual equipment as needed and make sure that it is in place before the meeting. You will want to test the equipment before the meeting starts.

- Ask the speaker for information that you can use to properly introduce the speaker. This may include a resume or CV that you can then provide copies of to the support group members.

### *Just Before the Meeting*

Creating a safe, warm, and caring environment starts before the meeting. Members need to feel comfortable in order to participate effectively. The following tasks are important to make sure the meeting is set up to start on time. The facilitator can ask the co-facilitator(s) or other group members to help.

- The facilitator should arrive at the meeting place well before the meeting is scheduled to make sure that the room is open, clean, and well lit, and that the temperature is comfortable.
- If the room is inside a large building, for example, you will need to post a sign at the main entrance directing people to the meeting room. Or, as a welcoming gesture, a volunteer can greet people at the main entrance and guide them to the meeting room.
- Seating in the room (usually in a circle) should be arranged so that members can maintain eye contact at all times, which provides a sense of connection from the start.
- Support Group Meeting Sign-in Sheet and Support Group New Member Registration Forms should be easily accessible, and appropriate education materials should be neatly arranged on a table for dissemination (see Appendix.)
- Light refreshments can make the environment feel more social and help people relax.
- Refreshments should be set up before the meeting so the meeting can start on time. Refreshments must be gluten-free as defined by the FDA rule. A listing of ingredients is helpful, as members tend to have other food sensitivities.
- As the meeting is about to begin, double-check any security issues.

### *Registration and Sign-in Process*

Facilitators are asked to follow the registration and sign-in process to enable accurate communication with support group members and to ensure complete reporting of outreach. This process is important in keeping personal information confidential. No personal information is shared with outside parties unless the participant chooses to do so.

The following forms are used in this process (see Appendix):

- Meeting Sign-in Sheet – signed by every attendee at each meeting, collected, and secured by the facilitator in his or her personal records for the duration of the support group. It will not be collected by CDF or the Chapter.
- New Member Registration Form – given to each new member to complete at his/her first meeting, collected, and secured by the facilitator in his/her personal records. These forms will be attached to the Support Group Meeting Report.
- Support Group Meeting Report – completed by the facilitator at the end of each meeting to capture important outreach data, and submitted to CDF or the Chapter upon request.

Given that society is increasingly more concerned about privacy issues, in particular as they relate to an individual's health, CDF is taking a much more conservative approach when dealing with support group meeting sign-in. While organizations such as CDF are not currently impacted

by the Health Insurance Portability and Accountability Act (HIPAA) regulations, in the interest of individuals with celiac disease and other gluten-related disorders who are involved in support groups, CDF places protecting a person's personal information at the center of our support group attendance strategy.

Confidentiality is a must for all support groups in order to create a safe and welcoming environment. Below are a few important things to consider about confidentiality. Group members may choose to exchange names and phone numbers among themselves. It should be made clear that no one is required to do so and that any exchange of information shall not be given to outsiders. This policy may be especially important to newcomers who have not shared their diagnosis with others (e.g., friends, employers, etc.).

A support group is not a place for pharmaceutical representatives, company representatives, or the media. Someone seeking a celiac disease and other gluten-related disorders story or a particular project, for example, needs to be referred to CDF or the Chapter for information. Allowing someone who is not part of the group to attend a support group meeting compromises the caring and trusting environment of the support group. It is the responsibility of the facilitator to protect the group environment.

Individual personal problems, such as divorce or financial difficulties, for example, should not be the focus of group discussion. Personal problems of members must not be discussed outside of the group. Group members shall not provide personal advice to other group members, but information about appropriate community resources may be helpful.

The names and phone numbers of support group facilitators are sometimes included in meeting notices and media releases. It is possible that a facilitator may receive a call from a sales or marketing person asking for names and addresses of group members, or asking if he or she may attend a group meeting. The support group is not a place for sales and marketing, and the names and addresses of group members are confidential and may not be provided, no matter what product or service is being marketed. The facilitator can ask that information about a particular product or service be sent to CDF or the Chapter. It is the policy of CDF not to make recommendations concerning medications or products concerning the treatment of celiac disease and other gluten-related disorders.

A facilitator may not speak to a support group member's family or friend without the support group member being present.

### **Opening the Meeting**

Over time, and as group members continue to participate in the support group, they will usually develop a secure set of expectations regarding the opening, running, and closing of group meetings. Familiar expectations can help group members feel more at ease. The following tasks will help open a support group meeting in an orderly manner.

#### *Welcome and Facilitator Introduction*

Every meeting should start on time. It is important to respect everyone's time. As the group facilitator, you should introduce yourself, extend a warm welcome to the group, and share what



your role is as a facilitator. The way a facilitator opens the support group meeting can be an indicator of how well the rest of the meeting will proceed. This is a good time to ask if everyone was able to sign the Support Group Meeting Sign-In Sheet and if new members were able to fill out the Support Group New Member Registration Form, and to address any other housekeeping issues, as well as any other announcements that CDF or the Chapter has asked the facilitator to relay to the support group members. It is also a good time to ask if everyone is comfortable; if not, find out if there is anything that would help to make the group more comfortable before getting started.

### *Group Introductions*

Go around the room and allow each person to introduce him or herself. If this is the first meeting, members may want to share if they are newly diagnosed or how long they have been living with celiac disease or another gluten-related disorder or caring for someone with celiac disease or another gluten-related disorder. They can volunteer to share what brought them to the support group and what they hope to gain from the group. If this is not the first meeting, the facilitator may ask members to share briefly how they have been doing since the last meeting. Group introductions help people get settled in and become engaged. Remember that each member will interact at his or her own pace, and the facilitator should be accommodating towards people who may not want to share personal information right away.

Facilitators should also be accommodating toward new members to help them have a positive experience. Remember to acknowledge new members and be aware that they may need a clear understanding of group expectations. Consider asking an established member to offer additional attention and support to the new member. New members need to feel valued and they may need a little time to orient to the group. Before moving on, ask new members if they have any questions about the group.

Learning the names of group members is important. Address a group member by her name instead of “the lady on the right....” If the group is large, using nametags can be helpful.

### *Support Group Purpose and Goals*

Take a minute or two to remind the group about the purpose of the support group, what a support group is and is not. Briefly share the goals and the value of a support group with the members. The group is a place for people affected by celiac disease and other gluten-related disorders to come and be themselves and come to terms with their diagnosis and the way celiac disease or other gluten-related disorders is affecting them as individuals. The group is a place to share and learn from each other about the best coping strategies to reduce the tension and stress that often accompanies living with celiac disease and other gluten-related disorders.

### *Ground Rules*

An effective support group needs to have established ground rules. Generally, if members have the opportunity to participate in determining ground rules that are specific to their group, they will respectfully assume ownership for the rules that guide the effectiveness of their group. Group members should be reminded of the ground rules at the beginning of each meeting.

Confidentiality must be understood and agreeable to group members. One of the most important ground rules is that what is said and expressed within the group should not leave the group. Additionally, any information which might individually identify a group member should never be discussed outside of the group. In order to maintain a safe and caring environment, it is essential that the CDF Support Group Policies on privacy be followed. Group members should be reminded about the confidentiality policy at the beginning of every group meeting. The facilitator should ask to be informed about any breaches in confidentiality.

### *Additional Important Ground Rules*

- Group members will respect and listen carefully to all members, accept feelings, not engage in side conversations, and not be judgmental.
- Group members are here to express their own experiences, rather than those of someone else who is not present.
- Emotions are a healthy part of coping. Group members are encouraged to reveal as much or as little as they wish about their illness; it is acceptable to share both positive and negative feelings within the group.
- Avoid extensive advice giving; group members should focus on sharing and support. No one may offer or formally recommend medical or treatment advice.
- If another person has expressed a need or concern, allow the group to support them before expressing your own need or concern.
- It is important that each member's differing needs and values are respected and the group remains a safe place where people can be themselves and come to terms with their illness in their own way.

After providing ground rules, the facilitator should introduce the discussion topic and initiate discussion using prepared questions. This is a good time to ask group members one thing they would like to accomplish during the meeting, given the topic.

### **During the Meeting**

#### *Facilitator Awareness of Group Processing and Experiential Learning*

Support and group processing is about support group members listening to what is being said and interpreting and reflecting on what they hear. The idea is for members to consider what is being shared and how it might pertain to them, apply this new learning and then bring back their learned experiences to the group. In other words, effective group processing can help members become more aware of how their illness is affecting them and how they can apply new learning outside of the group to reduce the tension and stress that often accompanies living with celiac disease and other gluten-related disorders. It encourages them to come back to the group to, once again, share how they have handled problems based on what they have accomplished in the support group.

Open discussion at group meetings has a particular purpose. The exchange of information is really an active approach to finding “best coping strategies” to live with a chronic illness, such as celiac disease and other gluten-related disorders. The exchange of information through guided open discussion can provide various perspectives to living with celiac disease and other gluten-

related disorders. Open discussion also helps people to actively deal with their emotions, thus allowing a creative learning process to develop.

During the meeting, help the group chart its course and accomplish its goals by helping the group stay focused and complete mutually agreed upon tasks. It is the facilitator's responsibility to create and maintain an emotionally safe environment, that is, an environment that accepts people as they are and provides understanding, support, friendship, and shared learning. What happens during a support group meeting will determine the effectiveness and value of a support group.

### *Group Development Through Support and Group Processing*

The stages of group development, known as Forming, Storming, Norming, and Performing, were proposed and published by Dr. Bruce Tuckman many years ago. He determined that specific phases, or developmental sequences, were necessary for a group of people to become a functioning team that could accomplish important goals. Tuckman's model became the basis for other models of team development. Whatever terms are used by experts to describe the development of groups, the basic concepts of awareness and acceptance of group goals, peer support, and effective group interactions are important to the success of the support group. Dr. Tuckman's group phase concepts as applied to celiac disease and other gluten-related disorders support groups are explained in detail.

#### *Forming: Coming together and forming a support group*

Initially, group members simply come together as individuals and begin to get to know each other and begin to talk about the purpose and goals of the support group.

Members may not be clear about what is expected and they may have some concerns about whether or not they fit in. Group members are usually looking for information. Group members will usually decide how safe the group is before they decide how much of themselves they will disclose and how much of their celiac disease and other gluten-related disorders experiences they will share. They slowly get to know each other by sharing similarities and differences about their diagnoses and living with celiac disease and other gluten-related disorders.

There may be awkward moments as members try to determine a comfort level before they are willing to take risks and share personal information.

Members will usually look to the facilitator for a sense of direction or approval.

In general, group members are busy gathering information and forming impressions.

#### *Storming: A period of unrest*

Group members may question goals. There may be disagreement about how the group functions.

In general, members usually share their individual thoughts and feelings more openly and there may be disagreements.

There may be resistance to group discussion and activities; competition and conflict are also common. The facilitator may be aware of differences in personalities and personal values.

There may be individual struggles about wanting to get more involved, but still some reservation about how much to share with the group.

A period of unrest in group development will be challenging and the group may lose focus on its goals; however, storming is necessary to the growth of the group. The facilitator will need to take the time and patience to resolve conflict, to help the group be mindful of support group goals, and to carefully guide group interaction in order to move forward.

#### *Norming: Working together*

This is a time in which group members are more focused on building cohesion and developing mutual respect.

The group settles down, focuses on its goals, and works to resolve differences. Relationships are valued. Members help each other to cope with living with chronic illness through peer support and more constructive sharing.

#### *Performing: Accomplishing goals, individually and as a group*

Group members work to accomplish their goals more effectively and identify with the group as a whole.

The group functions more smoothly, the group environment is positive, and group interactions are productive.

#### *Effective Facilitation: Helping the group move forward*

##### *Some Helpful Tips*

Facilitators are responsible for supporting the strengths of individual members and maintaining an atmosphere in which members support each other.

People usually will assume different roles within groups. Facilitators should allow members as many constructive roles as possible. For example, some group members may be better than others at helping with group conflict.

Facilitators warmly encourage everyone to participate, giving recognition for contribution and demonstrating acceptance and openness to ideas of others. However, not all members will be ready to participate, and that's okay.

Facilitators guide the sharing of information and keep the group focused and on track.

Facilitators guide members in understanding their differences, search for common elements in conflict, and use problem solving techniques to try and reconcile disagreements. What may be

helpful to one member may not be helpful to another member. The facilitator needs to help members respect differences.

Facilitators ease tensions within the group by making sure that the support group maintains a safe and comfortable environment and that open discussion is appropriate. Suggesting a break at the right time can provide an enjoyable time for members to connect further with each other. Encourage a sense of humor but de-emphasize inappropriate humor and clowning around.

Facilitators listen and serve as interested audiences for all members, are receptive to everyone's ideas, and help other group members to be receptive to everyone's ideas.

Facilitators accept and support openness of all group members, reinforcing appropriate risk taking and encouraging respect of individuality.

Facilitators demonstrate good communication skills to help ensure that each group member understands what other members are saying. If someone has trouble making a point or communicating an idea, take a moment to help the group member clarify the point. The facilitator may ask other group members if they can help restate the issue. If restating the issue creates conflict, spell out the points of disagreement so the whole group can help settle the difference.

The facilitator and group members **must not diagnose, recommend treatment, or recommend a specific health care provider**. There are many details about a person's medical history that may not be shared with the group.

To ensure effective communication, the facilitator must:

- Use open-ended questions to initiate and guide discussion to help the group process move along. Closed-ended questions can be answered with a simple yes or no. Open-ended questions encourage members to express their thoughts and feelings, and stimulate an exchange of information. For example, "What is everyone's reaction to..." instead of "Does everyone agree?"
- Maintain eye contact with participants. By simply looking at someone and smiling, you help that person participate, even if the member hasn't said anything for a while.
- Be aware of group energy and individual relationships. Glance around the room frequently to check expressions and body language. Be aware of members who are inattentive or appear uncomfortable, and figure out the best way to engage them.
- Let one person talk at a time. If someone does not get to finish a point, go back to that person. If someone tries to contribute, but can't get into the conversation, give that person the chance to contribute to the discussion using the appropriate interventions.
- Listen so that you can give feedback, extend support, and call attention to similar or conflicting points of view.
- Let members speak first. Any questions directed to you should be redirected back to the group. For example, "What do the rest of you think?"
- Discourage monopolizing of discussions.
- Be able to recognize behaviors that block communication.

### *Challenging Behaviors You Might Encounter*

- One or two members doing most of the talking.
- One or two members competing to see who has the greatest story.
- Someone trying to get the group to be overly sympathetic to his/her situation.
- Disrupting the work of the group by inappropriately joking around.
- Seeking attention by excessive talking, loud talking, talking over others, extreme ideas, or unusual behavior.
- Wandering from the topic of discussion, whispering to others, or acting indifferent or passive to group interactions.
- Criticizing or blaming others, or showing hostility toward the group.
- Introducing personal experiences unrelated to the discussion topic.
- Attempting to get others to accept one's personal values and beliefs, and rejecting others' ideas without consideration.

### *Facilitator Interventions*

Interventions by the facilitator may be necessary to correct the course of the group process to improve individual or group behavior. This will strengthen group interaction and functioning, and will help the group stay on track and move forward.

Usually it is the support group facilitator who intervenes, but when group members intervene appropriately, it indicates group development. For example, a member of the group may make an observation, ask a question, or ask for redirection. Or a group member may offer information that helps the group evaluate itself. An intervention may be as simple as taking a minute or two to reflect, or it can be more involved. Intervention can include asking the right questions, providing constructive feedback, validating feelings, or providing information.

An intervention is *valid* when it:

- Protects the purpose of the support group
- Brings awareness to a situation that may impact the effectiveness of the group
- Helps the group self-examine support group goals
- Helps address conflict
- Helps the group process move forward
- Encourages all members to participate and express thoughts and feelings appropriately

An intervention is *invalid* when it:

- Is not relevant to the situation at hand
- Is used for the purpose of sounding superior and showing one's expertise to the group

- Does not enhance the group process
- Encourages behaviors that move the group away from constructive interaction

### *When to Intervene*

As the facilitator, you need to intervene when you sense that group interaction and group processing is at risk. When you feel the need to intervene, take a minute or two to reflect, stay calm and focused on the situation at hand, and intervene.

### *Some General Guidelines*

Even for the most prepared and seasoned support group facilitator, mistakes are inevitable. Taking risks, however, is necessary and will enhance your ability to be an effective facilitator and stimulate group development. Being an effective facilitator is not about how many or how few mistakes are made, but is about how much and how fast one learns. *Effective facilitators need to practice their intervention skills.*

Practice “permission based” interventions. For example, “May I offer an alternative?” or “May I offer a few suggestions?”

When responding to negativity, be selective and offer constructive interventions. An intervention needs to be clearly stated and sincere.

An intervention should move an individual or the group forward. Keep interventions brief and to the point.

Focus on behaviors, and not individual personalities.

Intervention is not about sounding superior or threatening. Rather, it requires using a calm, friendly tone of voice, and offering comfort and reassurance.

### *Sample Interventions*

The facilitator must make sure that each person has a chance to speak and is heard. Some people speak more slowly, or more softly, than others. It is okay for the Support Group facilitator to assist, but not to speak for that person. Sample interventions are included in the Appendix.

### *Assessing Your Intervention Skills*

As a facilitator, evaluating how you intervene and how you facilitate support group meetings should be ongoing. Using the following questions, it may be very helpful to maintain a journal for a while until you are comfortable with your facilitation and intervention skills.

How did you feel right after you intervened?

What were the consequences of your intervention? What happened? What should not have happened?

What would have made the intervention more effective?

*What Should a Facilitator Avoid?*

- Overemotional identification with difficult experiences of members and/or inappropriate expressions of sympathy around them
- A patronizing manner
- The temptation to give ready answers, to lecture, to convince, to persuade, or to withhold
- The need to be right or to be omnipotent as an authority
- The need to excessively reassure members that they are achieving
- Functioning solely as a parliamentarian, or dominating the group
- Pushing her or his personal agenda
- Sharing too much or competing information about her or his personal experiences
- Siding with various group members
- Offering inappropriate information, such as treatment advice or non-CDF approved materials

### **Closing a Meeting**

*Close on time.* A good rule is the 15-minute reminder rule. Let the group know that the meeting is approaching the last 15 minutes and that you would like to use that time to summarize the content of the meeting and call attention to any unanswered questions.

*The group should help bring the meeting to a close.* For example, the facilitator can suggest going around the room and asking members for their closing remarks. The facilitator might ask members to share how the meeting was for them, what was most helpful to them, or recommendations for the next meeting.

*Ask the group if the topic that was discussed needs more attention and further discussion at the next meeting.* Are there any loose ends that need to be taken up at the next meeting? No one should leave the group feeling as though his or her needs were ignored.

*Remind members about CDF printed materials.* Every group meeting should have an information table with CDF materials.

*Remind members about the date and time of the next meeting.* Encourage group members to tell their physicians about the support group and others who may be interested in the group.



*Make sure that everyone in attendance is accounted for on the Support Group Meeting Sign-In Sheet; this will be important for evaluation and reporting. Members may exchange contact information with each other, but they may not provide names of members to anyone outside of the group without the member's permission. Confidentiality is a MUST.*

*Thank everyone for coming to the group and for sharing and supporting each other. Make an effort to connect with anyone in the group who did not share openly.*

*After the meeting, the facilitator should reflect on how the meeting went, perhaps with the co-facilitator. You may wish to utilize a journal again to answer the following questions:*

- Did people seem comfortable?
- Did everyone get a chance to participate?
- Were the proposed topics adequately covered?
- What, if anything, needs to be done differently at the next meeting to enhance group interaction, allowing the meeting to be more effective?

## **Meeting the Challenge**

One challenge in starting and sustaining a support group is bringing together enough people affected by celiac disease and other gluten-related disorders who are willing to share the “ups and downs” of their illness, and who are committed to attending the support group long enough to experience and benefit from effective relationships and support group development. The success of a support group also depends on whether or not members are achieving their goals and experiencing helpful new learning. And, most certainly, the success of a support group is determined by how well the facilitator anticipates and copes with all of the challenges that come with organizing, implementing, and facilitating a support group.

## **Group Attendance**

There are many reasons why people may stop attending a support group. It is not unusual for some members to come and go depending on their circumstances. Facilitators should keep in touch with support group members in between meetings to bring them information or to touch base to remind them that a meeting is coming up. However, below are some factors that may influence the ebb and flow of support group attendance.

- One or two sessions might be enough for some individuals.
- They may be physically unable to attend a support group because of the way celiac disease and other gluten-related disorders are affecting them.
- They may not want to be known as a person with celiac disease and other gluten-related disorders.
- They may feel that the need for a support group is a sign of weakness. Their new identity as a person with celiac disease and other gluten-related disorders can be emotionally overwhelming. Cultural beliefs and values may not support participation in a support group.

- They may experience anger, disbelief, or denial upon being diagnosed with a chronic illness.
- They prefer to deal with their illness privately.
- They prefer sharing information about their illness, and about how the illness is affecting them, with family and friends.
- Support groups are not for everyone.
- Support group goals did not meet their expectations.
- They found that some group members made them uncomfortable.
- Some people with celiac disease and other gluten-related disorders come to a group hoping to change it to fit their needs and are disappointed.
- After attending a few meetings, a participant may become overwhelmed and may need some time to reflect on his or her situation before coming back to the group.
- Issues that consistently disrupt group interaction, such as severe depression, anxiety, or other mental health issues can add more stress and tension for people already dealing with the stress that often accompanies living with celiac disease and other gluten-related disorders.
- A change in health status (improved health or deteriorating health) or other circumstances.
- They may have received what they wanted from the group and have no further need to attend.
- Lack of meeting organization and poor facilitation of the support group can keep people from coming back.

## Assessment and Evaluation

It is important to assess and evaluate the effectiveness of your support group and facilitation skills on a regular basis. This ensures that all CDF Support Groups consistently deliver high value to people with celiac disease and other gluten-related disorders, their families, caregivers, and loved ones.

On a biannual basis, facilitators will distribute the Support Group Assessment Form to members to solicit their anonymous feedback on group dynamics and topics. The facilitator will then submit these assessments to CDF or the Chapter (see Appendix.) Collectively, the facilitator and CDF or the Chapter will review the feedback and determine any appropriate responses and modifications.

On an annual basis, CDF or the Chapter may formally evaluate a support group facilitator utilizing the Facilitator Evaluation Form. This also creates an opportunity for CDF, the Chapter, and the facilitator to reflect and report on effectiveness as well as goals for the coming year (see Appendix)

## **When Support Groups Work Well**

An effective CDF Support Group facilitator is instrumental in delivering CDF's mission to support those affected by celiac disease and other gluten-related disorders. Becoming a skilled facilitator starts with your facilitation training. However, as you learn more about working with the celiac disease and other gluten-related disorders community and guiding constructive support group meetings, you will help your members to grow and achieve positive coping skills. Everything you have learned in this manual enables you to demonstrate best practices for facilitating effective group interaction that helps members become more aware of how the illness affects them, lifestyle changes that can help them stay as healthy as possible, and behaviors and techniques that make living with celiac disease and other gluten-related disorders easier.

## **Appendix: Tools and Forms**

### **Table of Contents**

CDF Support Group Policies

CDF Support Group Forms

- Assessment

- Facilitator Evaluation

- Guest Speaker Request

- Meeting Planner

- Meeting Report

- Meeting Sign-In Sheet

- New Member Registration

CDF Support Group Tool

- Facilitator Intervention Tool

CDF Support Group Templates

- Meeting Calendar Notice Template

- Meeting Notice Flyer Template

- Meeting Notice Postcard Template

- Meeting Notice Print Ad Template

The following CDF Support Group Policies support the mission and core values of CDF. They are written for both CDF nationally managed support groups (hereby referred to as “CDF”) and CDF Chapter sponsored support groups. Policies are listed by category.

The purpose of Celiac Disease Foundation Support Groups is to provide current and reliable celiac disease and other gluten-related disorders information and to assist group members to adjust to a life with celiac disease and other gluten-related disorders. Celiac disease and other gluten-related disorders support groups are open to those with celiac disease and other gluten-related disorders, their family members, caregivers, and loved ones, and shall be implemented by a facilitator who has been trained by CDF.

Chapters shall use these CDF Support Group Policies governing the formation and operation of support groups and may create additional policies that help govern support groups within each Chapter area.

### **Operations**

Support groups are approved and established as a direct service by either CDF or CDF Chapters.

CDF and Chapters may terminate a support group as deemed appropriate.

Each support group shall have at least one CDF trained facilitator. In addition, a CDF trained co-facilitator is strongly encouraged. Anyone interested in becoming a support group facilitator must comply with the following process:

- CDF or the Chapter must screen and interview applicants.
- The applicant must complete a CDF or Chapter Support Group Facilitator Application.
- The applicant must complete a Background Check. If the initial application is approved, the applicant must complete CDF Support Group Facilitator Training.
- Following CDF Support Group Facilitator Training, the facilitator receives a Certificate of Completion.
- Following receipt of the CDF Facilitator Training Certificate, CDF or the Chapter shall determine final approval of the facilitator’s support group and meeting location.
- The applicant then must sign a CDF or Chapter Facilitator Agreement. The facilitator must agree to conduct a support group for at least one year.
- The facilitator must agree to facilitate a minimum of eight support group meetings per year.
- The facilitator must agree to attend the CDF National Conference Leaders Workshop each spring in Los Angeles, California.

CDF or the Chapter is responsible for assigning facilitators to support groups.

CDF or the Chapter must approve any and all guest speakers at support group meetings.

- Guest speakers must be relevant to the topic of discussion and provide education to support group members.
- Guest speakers may provide education but must not directly recruit volunteers for clinical trials.

All meeting locations must be accessible to those with disabilities as defined by the Americans with Disabilities Act.

Any agreement required to obtain meeting space, such as proof of insurance, must be pre-approved and signed by CDF or the Chapter.

Facilitators are responsible for sending all required forms to the National Office by mail or email to: [info@celiac.org](mailto:info@celiac.org), including, but not limited to: the CDF Support Group Assessment, Guest Speaker Request Form, Meeting Report, and New Member Registration. The Meeting Report and New Member Registration forms must be submitted to National no later than one week following the meeting.

#### *Policy on Reporting*

CDF and the Chapters shall require quarterly activity reporting from each facilitator on attendance, topic of discussion, type of support group, and any guest speakers.

#### *Policy on Evaluations*

Each Support Group Facilitator will be evaluated annually either by their Chapter or by a representative from National. Each Support Group Facilitator will also be evaluated by their support group members biannually by June 30<sup>th</sup> and December 31<sup>st</sup>. Each Support Group Assessment Form must then be sent to National no later than one week after the June 30<sup>th</sup> and December 31<sup>st</sup> deadlines.

#### *Policy on Finances*

Any projected support group expenses such as room rentals, educational materials, and/or speaker fees fall under the responsibility of CDF or the Chapter. The facilitator must obtain prior approval for these expenses. Moreover, facilitators must obtain prior approval of any requested expenditures and use of funds designated for CDF or Chapter Support Group Programs.

#### *Creating and Terminating a Support Group*

A support group should be created by CDF as a response to a community need, rather than the request of any one particular individual. The decision as to who will lead the group is at the sole discretion of CDF. Location and meeting times of the group should be approved in advance by CDF.

CDF or the Chapter secures and approves the meeting location based on established criteria, such as handicapped accessibility, safety, etc.

CDF may decide to disband or move the location of a support group for a variety of reasons, including:

- Attendance issues
- Resignation of the facilitator
- Difficulties in accessing meeting location
- The combining of two support groups

CDF or the Chapter may terminate a facilitator based on outcomes such as poor performance or non-compliance with CDF Support Group Policies.

### *Selection of a Facilitator*

CDF or the Chapter should ensure that anyone interested in becoming a facilitator is screened and interviewed and completes all necessary paperwork before being considered.

CDF or the Chapter requires a facilitator to undergo CDF standardized training to conduct a celiac disease and other gluten-related disorders support group.

It is recommended that facilitators exhibit empathy towards people with celiac disease and other gluten-related disorders gained through personal or professional experiences, and have experience in one of the following:

- Peer to peer support
- Group facilitation
- Counseling
- Social work
- Another health related profession

If a new facilitator is not already knowledgeable about celiac disease and other gluten-related disorders, CDF or the Chapter should provide celiac disease and other gluten-related disorders education, including recommended reading.

CDF or the Chapter provides facilitators ongoing education and updated information on celiac disease and other gluten-related disorders with CDF approved content.

### *Reporting and Evaluation*

While quarterly reporting is required of all support group facilitators, CDF or the Chapter may request more frequent reporting on attendance, topic of discussion, type of support group, and any guest speakers.

Facilitators should inform support group members that any and all information collected is solely for the purpose of CDF or the Chapter, and will be kept confidential.

## **Privacy**

CDF protects the privacy and confidentiality of people who participate in support groups.

- Each new attendee must sign a CDF-provided New Member Registration Form that includes privacy and confidentiality information.
- CDF, the Chapter, the support group facilitator, or support group members shall not share support group member information with outside organizations, companies, the media, or individuals.

If CDF or the Chapters offer telephone or online support, CDF and the Chapters must abide by CDF's Privacy Policy to protect the confidentiality of support group members.

### *Protecting Privacy of Support Group Members*

Member information will be entered into a database, which is used to send CDF or Chapter communications, such as E-newsletters. However, the member will always have the opportunity to opt out of receiving such communications.

The facilitator should ensure that the support group is open to only people with celiac disease and other gluten-related disorders, their families, caregivers, and loved ones.

## **Medications/Treatments/Products**

CDF trained support group facilitators do not make referrals to physicians or other health professionals, and do not make recommendations concerning medications and products for the treatment of celiac disease and other gluten-related disorders. The facilitator may not offer medical or treatment advice. The facilitator may refer support group members to the CDF Healthcare Practitioner Directory for a list of health professionals in their area.

CDF does not endorse products or services. Support group facilitators or members may not market or sell products or services within the support group, and support groups must be protected from the sales and marketing of products or services by outside groups. Speakers must not promote products or services.

### *Providing Referrals*

Members may discuss diagnosis, treatment, and living with celiac disease and other gluten-related disorders topics within the support group meeting where physicians or other health professionals are mentioned. However, the facilitator should indicate that they do not make a recommendation for or referral to a specific physician or healthcare professional.

Members may discuss medications during support group meetings. The facilitator should inform support group members that such discussion is not a recommendation or endorsement.

The facilitator may not offer medical or treatment advice. The facilitator should inform members that only their physicians or healthcare teams can offer such advice.



## *Speaker Selection and Content*

The facilitator should discuss and obtain agreement from the speaker that the purpose of the talk is solely for educational purposes and may not involve marketing a product or service. In addition, the speaker may not directly recruit members to volunteer for clinical trials.

For example, a nurse educator from a biotechnology, pharmaceutical, or other organization may be a speaker for an event or request to speak to a group about celiac disease and other gluten-related disorders or treatments related to celiac disease and other gluten-related disorders. Not only is planned content to be reviewed and approved by CDF, but he or she may only provide direct educational information on the topic as a whole, and not promote a product or service directly.

If the speaker has an FDA-approved treatment for celiac disease and other gluten-related disorders, he or she may only discuss the treatment in the context of all treatments used for celiac disease and other gluten-related disorders.

Speakers can answer questions from support group members about products, services, or clinical trials, but should keep their remarks general and based on providing education and awareness.

The Guest Speaker Request Form must be completed and submitted to National at least four weeks prior to the proposed guest speaker's presentation.

## **Fundraising**

The purpose of a support group meeting is to provide a supportive and educational environment to people living with celiac disease and other gluten-related disorders as well as their loved ones and caregivers, not to raise funds. If individual support group members wish to participate in CDF or Chapter sponsored fundraising activities, they can elect to do so. Any other fundraising efforts must be pre-approved, and funds will be managed by CDF or the Chapter.

Support group members may want to individually support CDF or the Chapter and are encouraged to do so; however, support group members are not required to participate in fundraising activities.

Members may not solicit or raise funds for the operations of CDF support groups. However, if support group members wish to contribute to the sustainability of CDF or Chapter support groups, they may designate their gifts accordingly.

Support group leaders and members may join CDF Team Gluten-Free and create fundraising pages on behalf of CDF. Support group leaders may also create a Team, which includes support group members. Support group leaders who raise \$1,500 or more annually may be reimbursed for their travel expenses for the CDF National Conference.

## **Promotion**

Facilitators can promote their support groups for the purpose of attracting members and keeping them informed. Only the templates provided in this Support Group Facilitator Manual may be

used for promoting your support group. These materials include a postcard, flyer, calendar notice, and advertisement. Any additional promotional materials must be pre- approved by CDF or the Chapter.

All promotional materials and strategies must adhere to CDF's current policies for use of the CDF logo and website.

Online or virtual support groups are not considered best practice or recommended at this time. Some support groups have tried them with limited success. CDF needs to fully evaluate their effectiveness, and develop a separate program and format that would provide the same support and information as in a regular support group.

CDF and Chapters will promote their respective support groups via their celiac.org website pages. Support groups are not to create their own website separate from celiac.org.

CDF and Chapters will create Facebook pages and Twitter accounts or other social media for their support groups. Support groups are not to create their own pages or accounts separate from those created for them.

Facebook postings and Tweets can include:

- CDF information on celiac disease and gluten-related disorders – only CDF-approved information may be posted regarding diagnosis, treatment, and research.
- Pictures from events the support group hosted or participated in (permission to post photos must be obtained from the individuals).
- Reminders about meetings and events.
- Questions to get feedback from members.
- Articles featuring the efforts of different members.
- Information about upcoming local Celiac Disease Foundation events and volunteer opportunities.
- Any other successes the support group may have.

Before the facilitator distributes promotional materials, final copies should be provided to CDF or the Chapter.



## CDF SUPPORT GROUP ASSESSMENT

This assessment gives support group members the opportunity to provide feedback on the facilitator, as well as the overall support group.

Name of Support Group \_\_\_\_\_ Date \_\_\_\_\_

**Approximately how many times in the past 12 months did you attend support group meetings?** \_\_\_\_\_

Please indicate the extent to which you agree with the following statements.	Strongly agree	Agree	Disagree	Strongly disagree
My experience in this support group overall is satisfactory.				
The support group is an accepting, safe, and caring environment.				
Members are able to comfortably express their feelings and concerns about the way celiac disease and other gluten-related disorders affect them.				
Support group members seem connected and listen to each other with understanding.				
Open discussion topics are helpful and relevant to celiac disease and other gluten-related disorders.				
I have learned that I am not alone in my disease. Group interactions and peer support have helped me become more aware of coping strategies to reduce stress and live better with celiac disease and other gluten-related disorders.				
The support group provides updated materials from CDF that are helpful.				
I have gained new insights and a broader perspective about living and coping with celiac disease and other gluten-related disorders.				
The support group facilitator starts group meetings on time and reminds members about support group goals and important ground rules, including confidentiality.				

The support group facilitator has good leadership skills and a good sense of support group goals.				
The support group facilitator is attentive to group needs and supports all group members.				

	1	2	3	4
Please indicate the extent to which you agree with the following statements.	Strongly agree	Agree	Disagree	Strongly disagree
The support group facilitator encourages all group members to participate in open discussions and the decision-making process.				
The facilitator is able to help guide group discussions and keep discussions on track; he/she helps members process shared thoughts, ideas, and experiences.				
The facilitator is able to effectively help the group with conflict.				
The facilitator is a good listener.				
The facilitator and group members do not provide medical advice.				
The facilitator is able to help group members summarize points of discussion toward the end of the meeting, and then closes the meeting on time.				
As a member of this support group, I am accomplishing my goals.				
I appreciate this support group as a safe and non-threatening place for celiac disease and other gluten-related disorders information and constructive sharing.				

*Optional:*

Describe/share any particular concerns that you have about the support group.

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Describe/share how the support group has been particularly helpful to you.

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## CDF SUPPORT GROUP FACILITATOR EVALUATION

This form allows CDF or CDF Chapters to evaluate the Support Group Facilitator. This is also an opportunity for the Support Group Facilitator to provide feedback on the CDF Support Group Program. The Yes/No questions should be filled out by CDF or the CDF Chapter. After completion, the supervisor and facilitator should discuss the answers and then use the open-ended questions to prompt a dialogue about the support group program. The supervisor will document all discussion and keep the evaluation on file.

	Yes	No	Comments
The facilitator is knowledgeable about celiac disease and other gluten-related disorders, and has attended any refresher courses offered by CDF or the CDF Chapter. The facilitator keeps support group members updated on the latest celiac disease and other gluten-related disorders information the chapter has previously provided.			
Meetings are held in a safe, convenient, public location on a regular basis.			
All guest speakers are pre-approved by CDF or the Chapter, and support group meeting topics are appropriate.			
The facilitator always respects the confidentiality of members and open discussion. The facilitator does not share member information with outside organizations, companies, the media, or non-members.			
The facilitator does not offer medical or treatment advice, and does not make referrals to physicians or other health professionals, nor does the facilitator make recommendations concerning medications and products for the treatment of celiac disease and other gluten-related disorders.			
The facilitator, in collaboration with CDF or the CDF Chapter, is effective in promoting the support group, resulting in a steady or increasing attendance.			
The facilitator timely submits all reports, including the New Member Registrations, Meeting Summary Reports, and Annual Support Group Evaluations.			

The facilitator follows all other CDF Support Group Policies.			
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What accomplishments has the facilitator experienced during this past year in facilitating his/her support group?

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What aspects of the support group and/or facilitation might be goals for growth and development for next year?

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What other CDF volunteer activities has the facilitator been involved in?

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What additional direction, consultation, or programmatic support does the facilitator wish CDF or the CDF Chapter would provide to aide in the group's success?

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What specific topics or areas of professional growth would the facilitator like covered in potential future facilitator refresher courses?

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Additional comments:

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Name and location of support group

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Facilitator Name \_\_\_\_\_ Signature \_\_\_\_\_  
Date \_\_\_\_\_

Supervisor Name \_\_\_\_\_ Signature \_\_\_\_\_  
 Date \_\_\_\_\_

 <p><b>Celiac Disease FOUNDATION</b> celiac.org</p>	<p align="center"><b>CDF SUPPORT GROUP GUEST SPEAKER REQUEST</b></p>
<p>Please fill out and submit to CDF or the Chapter at least four weeks in advance of the proposed guest speaker's presentation.</p>	
Support Group	
Support Group Facilitator	
Speaker and Professional Title	
Speaker's Organization	
Address	
City, State, ZIP Code	
Phone	
Email	
Title of Presentation	
Will this speaker be presenting at your regularly scheduled meeting?	<p align="center">Yes <input type="checkbox"/>                      No <input type="checkbox"/></p>
If not, please state the date, time and location	
<p><b>How did you find this speaker?</b></p>	
<p><b>Please provide a description of any extra help you will need for the meeting and speaker including educational materials and flyers. CDF or the Chapter will subsequently contact you to discuss how they can help you prepare for the meeting.</b></p>	

CDF or Chapter Staff Signature \_\_\_\_\_

Title \_\_\_\_\_

Date of Approval \_\_\_\_\_

 <p><b>Celiac Disease FOUNDATION</b> celiac.org</p>	<b>CDF SUPPORT GROUP MEETING PLANNER</b>
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Utilize this planner to help map out your topics and speakers for the year and consult with CDF or the Chapter.

Fiscal Year \_\_\_\_\_

Support Group \_\_\_\_\_

Facilitator \_\_\_\_\_

<b>Month /Date</b>	<b>Topic</b>	<b>Video or Guest Speaker</b>
January		
February		
March		
April		
May		
June		
July		
August		
September		
October		
November		
December		





## CDF SUPPORT GROUP MEETING REPORT

Facilitators should fill out this form shortly after each meeting and submit according to the instruction of CDF or the CDF Chapter. Please be sure to attach all New Member Registration Forms when turning in this report.

Support Group Name:	
Facilitator Name:	
Meeting Date:	
Please circle the type of support group held:	General    Women    Men    Teens    Caregivers    Online Teleconference    Other (please identify: _____)
Number of attendees:	
Please provide a brief summary of topics discussed: <i>(do not include member names or confidential information shared among group members)</i>	
Additional comments and/or follow-up action needed:	



## CDF SUPPORT GROUP MEETING SIGN-IN SHEET

New and returning members should sign-in here. This sign-in sheet is confidential and for record-keeping purposes only. CDF or the Chapter will never share your name or information with outside parties.

Facilitator: \_\_\_\_\_

Location: \_\_\_\_\_ Date: \_\_\_\_\_

### Member First and Last Name (please print)

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## CDF SUPPORT GROUP NEW MEMBER REGISTRATION

If you have never attended a CDF Support Group, please fill out the following registration form and give to the Support Group facilitator.

Celiac Disease Foundation and Chapter affiliates provide support groups for two reasons:

1. *To assist and support group members in developing skills in coping and living with a chronic illness.*
2. *To foster open discussion of how celiac disease and other gluten-related disorders affect our lives and assist members in developing self-management skills.*

A support group is not designed to provide professional psychotherapy or counseling. Celiac Disease Foundation (CDF) Support Group facilitators have a desire to help others. All facilitators have received special CDF training by a professional in how to provide support in a non-threatening environment. Some are trained professionals. Although this is **not** a therapy group, out of respect for participants, **confidentiality is a must**. All information and dialogue is confidential and shall not be discussed or revealed outside the group.

The opinions and statements expressed by the group members or its facilitator do not necessarily reflect the opinions or positions of Celiac Disease Foundation or its affiliated Chapters.

CDF, the Chapter, the support group facilitator, nor support group members shall share support group member information with outside organizations, companies, the media, or individuals. Member contact information will only be used to notify an individual of any changes to future support group meeting times and location and for CDF and Chapter mailing and e-newsletter distribution unless members choose opt out.

Name of Support Group \_\_\_\_\_

New Member Name \_\_\_\_\_

Address \_\_\_\_\_

Phone Number \_\_\_\_\_

Email Address \_\_\_\_\_

By signing below, I acknowledge that I have read all of the information above and agree to abide by the confidentiality and privacy rules of CDF Support Groups.

Signature \_\_\_\_\_ Date \_\_\_\_\_

Interventions by the facilitator may be necessary to correct the course of the group process to improve individual or group behavior. Here are some suggested interventions.

### **Paraphrasing to emphasize important points**

“Mary, you seem comfortable with the idea based on your experience, but I sense that some of you have some concerns about...”

“What I hear you saying is that we need to discuss this issue further at our next meeting.”

### **Calling awareness to the overall tone of the group**

“The group today has expressed a lot of anger. Do we need to take some time to gain a better understanding of everyone’s feelings?”

“The group seems quieter today than usual. Would anyone care to elaborate?”

### **Calling awareness to a specific undesired behavior or situation**

“Several people are asking questions at the same time. Everyone’s question is important. May we address them one at a time, starting with Mary?” (Permission based)

“The group seems to have strayed from our discussion topic. May we get back to sharing how everyone feels about...?”

### **Expression of feelings**

“I’m confused as to where our discussion is heading.”

“I’m feeling uncomfortable about where our discussion is going.”

### **Observations**

“I noticed that everyone participated today and shared some deep and personal feelings about living with their illness. How did it feel to share your experiences?”

“Mary, I appreciate your story, but now everyone seems quiet. Can we take a few minutes to reflect and talk about how everyone is feeling? Is that okay with you, Mary?”

### **Processing**

“Can we go around the room and share our thoughts and ideas, given the situation?”

“How is everyone being affected by their illness? How have your needs changed since your diagnosis?”

## **Encouraging group discussion and problem solving**

- “What does everyone think about the problem as stated? Have we clearly defined the problem?”
- “Would everyone like to share how they have addressed the issue of ...?”
- “Would anyone care to offer suggestions about what we need to discuss at our next meeting?”
- “Now that some of you have shared your thoughts and feelings, would others like to add to the discussion? How is the rest of the group feeling about...?”
- “What else do we need to address before the end of our meeting?”
- “Thank you, Mary, for sharing your experience. Has anyone had a similar experience?”
- “You have made several good points, and I am wondering if someone else might like to share their comments?”
- “Your thoughts are interesting, but I wonder if you would hold your comments for a few minutes until everyone has had an opportunity to describe their experience?”

## **Focusing and summarizing group discussion**

- “Can we take a look at where we are now in relation to our goal for this discussion?”
- “Why don’t we review important points and the progress we have made thus far in this discussion. My understanding is that... What do the rest of you think?”
- “Your comment is interesting; can you help me better understand your point of view?”

## **Moving the group forward**

- “I wonder if we have spent enough time on this aspect of the problem; should we talk more about...?”
- “Have we gone into this part of the problem far enough so that we might now shift our attention and consider this other area?”
- “Does anyone have anything further to share regarding...? If not, can we move on to ...?”
- “We have spent a lot of time on this topic and if no one has any further concerns at this time, would it be in the group’s best interest to address...”

## **Making a decision**

- “I feel that everyone is in agreement on these points. Are there any further comments?”
- “Does everyone agree that this is the best solution and that it will benefit the group?”
- “Do we need further clarification about the problem before the group makes a decision?”

## **Lending continuity**

- “Since we did not have enough time to discuss how everyone feels about \_\_\_\_\_ at our last meeting, can we take a few moments to review what we covered at our last meeting and what needs further discussion?”
- “Would someone care to suggest points that need further discussion before we move on?”

## **Helping the group evaluate itself**

- “I wonder if any of you feel that we are stuck on this point?”

- “Should we take a look at our goals to see how we are progressing?”
- “Does anyone have any suggestions as to how we can make our group meetings more meaningful?”
- “Would the group like to share how our support group meetings are helpful?”
- “What have we accomplished in our discussion up to this point?”

### **Additional sample questions**

- “I’m concerned that we’ve taken the conversation away from Mary. Can we get back to Mary’s question?”
- “Can you share how your situation is affecting you right now? You seem encouraged about the progress you’ve made.”
- “I’m confused. Can we take a few minutes to sort out everything that has been shared?”
- “Is there anything that we should deal with before we end? Is there anything that can’t wait until our next meeting?”
- “Would anyone like to respond by talking about a similar situation they’ve had?” “What choices do we have when that is the case?”
- “I’m concerned about \_\_\_\_\_ what does everyone else think?”
- “If that is your choice, would you be willing to share how you think that it will be helpful to you?”
- “Life seems especially difficult for you now. Is there something the group can do to help you?”
- “What do you do to take care of yourself?” “How does everyone feel about \_\_\_\_\_?”
- “It seems like we’re trying to fix Mary’s problem. Mary, what would be helpful to you right now?”
- “You mentioned several things. Is there one thing in particular that you would like to focus on with the group?”



CDF SUPPORT GROUP MEETING CALENDAR NOTICE TEMPLATE

Dear Editor (or Public Service Director),

We wanted to let you know about this upcoming support group for people living with celiac disease and other gluten-related disorders in < CITY> for the community calendar. Please let me know if you have any questions, or would like any additional information.

Best,  
<NAME>

**Celiac Disease and Other Gluten-Related Disorders Support Group Provides Valuable Information on Coping and Living with Celiac Disease and Other Gluten-Related Disorders**

*People with celiac disease and other gluten-related disorders, their family members, caregivers, and loved ones can share their experiences, methods of coping, and insights into living with chronic illness on a gluten-free diet.*

**When:** <Date and time> i.e. The group meets the 3rd Tuesday of each month beginning June 21, 2013

\*\*\*FOR IMMEDIATE RELEASE\*\*\*

**Where:** <Location> i.e. The group meets the 3rd Tuesday of each month beginning January 20th, 2014

**RSVP:** Space is limited. Advanced registration is recommended. To register, call <Phone> or email <Email address>

**Who:** Celiac Disease Foundation <Chapter Name> is a proud member of the CDF National Network, which is comprised of chapters, support groups, and community representatives. CDF and its National Network are focused on improving quality of life for people with celiac disease and other gluten-related disorders through programs of research, education, and advocacy.

**What:** Celiac Disease Foundation (CDF) support groups are intended to provide a warm and caring environment where people with celiac disease and other gluten-related disorders, family members, caregivers, and loved ones can share their experiences, methods of coping, and insights into living with chronic illness and following a gluten-free diet. The support group also provides current and accurate information about celiac disease and other gluten-related disorders and related issues and information about appropriate community resources.

CDF Contact Person: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

**Celiac Disease Foundation (CDF) is the nation’s leading voluntary health organization dedicated to driving diagnosis for celiac disease and other gluten-related disorders through advocacy, education and advancing research.**



## ***Celiac Support Group***

### **LIVING & COPING**

*on the gluten-free diet*

**Celiac Disease Foundation, Support Group Name**  
Meeting Notice

**DATE**

**LOCATION**

**TIME**

Celiac Disease Foundation (CDF) support groups are intended to provide a warm and caring environment where people with celiac disease, their family members, caregivers and loved ones can share their experiences, methods of coping, recipes, product reviews and insights into living with chronic illness. The support group also offers current and accurate information about celiac disease and gluten-related disorders, and appropriate community resource information.

For more information call **Phone Number** or visit **URL**





**Celiac Disease Foundation, Support Group Name**

Meeting Notice

**DATE**

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For more information call **Phone Number** or visit **URL**

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