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SEPL630 Ministries of Advocacy and Change

Cancer Support Ministry

 Cancer is now the second leading cause of death in America.[[1]](#footnote-1) More and more people are being diagnosed with cancer every year. Treatments for cancer are prolonging lives longer. This means people must manage through cancer diagnosis and treatments, and many will experience a life-time of follow-up appointments. Cancer isn’t choosy; it picks anyone at any time. It is an epidemic as almost forty percent of Americans will develop cancer in their lifetime.[[2]](#footnote-2) Cancer also affects more than just the person themselves. It has a ripple effect impacting the lives of many who care for their loved one. With the growing population of people affected by cancer the need for groups to support them increases. Support groups can address many things related to the journey of a cancer diagnosis including advocacy, information on care options, emotional support and more. In this paper I will address some of the issues related to cancer diagnosis as well as introduce the method that can be used to implement a ministry cancer support group that can benefit many communities included the East Stroudsburg Presbyterian Church community to which I will be implementing it in. It is my hope that this method is created in such a way that it can be replicated in any church or community that sees a need for it.

As someone who has attended and benefited from a support group and has first- hand experience of cancer diagnosis I recognize the struggles for cancer patients and their loved ones. Managing the health care system, the struggle of being stigmatized as handicapped in some way, and the struggle of managing cancer as a chronic disease which is becoming increasingly the case for many people with cancer as medicine develops better methods of treatment and longer survival rates. As people survive longer the stigmas related to cancer become more prevalent. Some types of cancer come with more stigma than others. Take lung cancer for example, many people associate lung cancer with smoking. This is understandable given the American Cancer Society’s and the general societies’ push against the tobacco industry. Propaganda against tobacco has caused an unconscious misconception that smoking is directly related with lung cancer. Now someone with lung cancer faces the looks, the preconceived notions that it was their fault they developed cancer.

Another stigma that occurs primarily for women is an effect of cancer treatments, hair loss. Most times the results of cancer treatment leaves people with bald heads sometimes even no hair anywhere including eyebrows and eyelashes. The description just mentioned is most likely the first picture in many people’s minds when they think about someone who has cancer. Again, this is a stigma of cancer that can negatively affect someone with cancer as well as their families. Society prides in beauty and this makes many people feel out of place and marginalized. Furthermore, when out in public many people stare or approach a person with cancer with words of pity often well-intentioned, but it is not always easy for the person with cancer to manage the constant awareness and awkwardness. This stigma has many women covering their head with wigs and using make-up to imitate eyebrows and eyelashes.

Another stigma that affects primarily women with breast cancer but can affect many others is disfigurement post cancer resection surgeries. Often surgeries leave people with cancer deformed beyond normal plastic surgery repairs. If the deformity is noticeable to the public it can come with stares, social avoidance by others, and people again often well-intentioned offering words of pity. Like baldness women will seek to cover up the deformities in any way possible. For people with other cancers it can be devastating because they may not be able to cover up deformities. Additionally, related to deformities are the need for colostomy bags and catheters post treatments and surgeries for cancer. These deformities leave people who have cancer with a stigma where they feel uncomfortable going into public. Since these types of medical apparatuses have negative connotations associated with them.

There is one final stigma that needs to be recognized before beginning a cancer support group. It is one that I am most familiar with in my personal story and have heard several others as well. It involves the relationship of the stigma of cancer and work. Most of the time people with cancer are unable to work through all their treatment. They are likely to need extensive time off work. Employers recognize they are also an increase cost due to the expenses they add to the employee health insurance. Some employers are kind and considerate working with the employee with cancer to do what is best for both them and the employee which could mean holding their position until they can return to work, allowing fellow co-workers to donate their sick time, working to get short term and long-term disability until the employee can either return or seek other means of income. Yet others, like as was my case, seek to find ways to terminate you without legal ramifications. What is even worse is that many cancer survivors struggle to find employment post cancer treatment if they are open about their cancer because employers know that having cancer means added cost for group health insurance, needing time off for follow-ups, and increased risk for re-occurrence. Furthermore, when someone is battling cancer they often battle increase cost combined with this loss of income forcing them on government assistance programs which also come with a stigma.[[3]](#footnote-3)

 There are scripture verses that remind us how to treat those with stigmas or who are sick. John 13:34-35 34 says I give you a new commandment, that you love one another. Just as I have loved you, you also should love one another. 35 By this everyone will know that you are my disciples, if you have love for one another.” And Matthew 25:37-40 which reminds us that “…righteous will answer him, ‘Lord, when was it that we saw you hungry and gave you food, or thirsty and gave you something to drink? 38 And when was it that we saw you a stranger and welcomed you, or naked and gave you clothing? 39 And when was it that we saw you sick or in prison and visited you?’ 40 And the king will answer them, ‘Truly I tell you, just as you did it to one of the least of these who are members of my family, you did it to me.’ Psalm 41:1 recalls that, “Happy are those who consider the weak. The Lord delivers them in the day of trouble.” Isaiah 1:17 reminds us to …Defend the oppressed. Take up the cause of the fatherless; plead the case of the widow.” The Deuteronomic law again and again instructs to take care of the widow, foreigner, orphans and those most vulnerable in society. A support group that offers emotional support, advocacy, information and more is a way of caring for the marginalized in our society. Jesus reached out to the sick who were stigmatized in their society the bleeding woman, the many lepers, people with epilepsy, and people with mental health.

 To reach those in need a method must be put in place. The method began by accessing local need which was done by reviewing an insight report, communication with local hospitals in the surrounding area of the church which would host and by exploring cancer facts related to populations. I was able to receive information from an insight report done on the area surrounding East Stroudsburg Presbyterian Church which explained that over the next decade the ESPC study area will experience the most significant increase in the adult population over 65. As pointed out in the opening paragraph those over the age 65 have an increased likeliness of developing cancer. This means that there will most likely be more people locally to ESPC that will be affected by cancer making there a greater need for a cancer support group.

As noted a second method of assessing the needs was through contacting local hospitals and researching for other local cancer support groups. According to Lehigh Valley Hospital Pocono Center (formerly Pocono Medical) Head of social work Lynne Steele at the Hughes Cancer Center, the hospital and cancer center does not offer a general cancer support group, but they do have a breast cancer support group as well as a prostate cancer support group. Additionally, they offer art therapy group and support group for patients and family of those with Lymphoma/Leukemia/Blood cancer. There was still a need for a general support group for all cancers, but not enough time or resources available for the hospital to facilitate. Lynne seemed excited by the idea of this general group and perhaps community partnership. Similarly, I researched the other local hospital St. Luke’s Monroe Campus who offers only an irregular bereavement group in that area, but who may come to offer more after their cancer center is completed and fully staffed. However, given that it is in its beginning stages there is opportunity for partnership with social workers or assigned staff associated with care groups for individuals with cancer.

 Besides the two local hospitals there is also the American Cancer Society in Stroudsburg not too far from ESPC. Inquiring what they offer in way of support groups turned up that they only offer a breast cancer support group, but they do coordinate with other types of activities that assist people with cancer. They too are open to community partnerships and were unaware of any general cancer support groups in the local area, the nearest being Allentown at the Cancer Support Community.

 The Hospitals and cancer organizations are not the only community organizations that offer programs for those affected by cancer. There used to be two hospices within a five-mile radius of ESPC who offered support groups but recently the VNA Hospice home closed its doors. Although I have not had the opportunity to connect with the other hospice yet, I am aware of their negative reputation. I also know that they offer a bereavement support group which has been attended by a member of ESPC who lost a loved one to cancer. I intend on doing further research with regards to the hospices homes and the home care/home hospice entities that serve in the local community who might be interested in partnering in the endeavor as well.

 In addition to possible community partnerships with hospices, hospitals and the ACS there is other avenues yet to be explored for partnerships. According to the Monroe County Area of Aging there are four Senior Centers in the county that meet regularly on weekdays and provide socialization, information, meals and more for seniors. One of them is located within a mile from ESPC and meets every weekday from 10-1:30. This is another opportunity for partnership and offering an opportunity to fulfil a need for the elderly they serve. Finally, tapping into a strength of ESPC’s members is the connections with the East Stroudsburg School District, Elk’s community, and Fire Department. All of which offer several connections to members of ESPC like the former Superintendent of school, a current school board member, several Elk’s members including the lead minister, a firefighter from the local fire department, as well as the fire chaplain again the lead minister. Furthermore, I have personal connections to the Cancer Support Community of the Lehigh Valley who also may be interested in partnering with me to service an area in need but with more exploration on this must be done in the future.

 After collecting information and assessing the need for a general cancer support group in the area it is important to gather information about forming a support group. Since this idea began quite a while back and I had already discussed with Bill Arnold my ideas to which he shared the same passion, he kindly shared with me the resources he had already gathered. Additionally, since I am a participant of a cancer support group at the Cancer Support Community they were willing to share with me some of their resources as well. Many of the gracious resources shared with me are listed in my bibliography for future reference or for anyone wanting to form a group like this in their community. To go into detail of each resource would be unnecessary as some of the ideas are similar. However, throughout the remainder of this paper I will offer brief descriptions of some of those resources to identify which might be most helpful in answering specific questions.

 First, is a resource from the Cancer Council of Australia. I found this resource to be one of the most helpful because it is a step by step guide in starting and maintaining a cancer support group. In this they discuss basic questions about support groups as well as tips for forming the group, troubles that may arise and how to address them, suggestions for organizing, the role of a good group leader, and forms that can be used to evaluate the group or to ensure that the privacy of the group is of utmost importance to all members.

 Another great reference or resource is also put out by an Australian entity and is for peer lead support groups. This is similarly a step-by-step guide, but it points out that depending on what type of group is needed dictates if the group should be peer lead or more professionally lead. It identifies the difference and similarities of leading versus facilitating a cancer support group. It discusses how to work through some of the details that are not always focused on when initially beginning a group such as finances, funding, dependency on the leader/facilitator especially one who may have been with the group from its beginning, being prepared, how to gather good information, questions the leader(s) should be asking themselves along the way, as well as several examples of case studies. Although both resources mentioned so far are from Australia they are a great resource for ideas and questions that are important to review when beginning any cancer support group whether peer led or professionally led, peer facilitated or professionally facilitated or a combination of the two.

 One of the most useful resources that offers a ton of information with regards to beginning, maintaining, dealing with issues that arise, and good group leading is called the *Community Tool Box* which is available through the work of the University of Kansas. This website can be used as a resource for any community interested in ways to promote community health and development. The page listed in the bibliography offers every detail with regards to beginning a peer cancer support group from the envisioning stage to beginning maintaining and ending meetings, as well as leader resources and information. It is a must read for anyone interested in starting a peer support group and was helpful as I began to develop the peer support group that will be implemented at ESPC.

 This resource among others listed in the bibliography were helpful to me as I began envisioning this cancer support group as a ministry project for an issue that is dear to my heart. It helped me in creating a vision and mission. According the *Community Tool Box* resource mentioned earlier the vision needed to be short general and concise. The vision for the group with which I will be implementing is Caring Cancer Community or CCC for short. According to the toolbox the mission is a little more involved. Therefore, this groups mission is to support anyone in the community affected by cancer helping them find ways to meet their emotional, physical, spiritual and mental well-being.

 As mentioned the *Community Tool Box* and other resources listed so far all have an aspect that helps the group leaders and facilitators understand their role how to manage the group dynamics. Training group leader(s) and facilitator(s) is my top priority and will be necessary to begin early on to ensure that there are back-ups in my absence as well as someone to hand the torch over after my time at ESPC ends. A good facilitator as well as a good leader can make or break a group and I want to have enough time for the leader(s)/facilitator(s) in training to feel comfortable with leading as well as managing conflicts that may arise from time to time. Some support groups will have the group leader also be the facilitator which will be the case as I begin the program at ESPC. This comes with its pros and cons. A pro is having the same person planning the meetings and information being the person who relays and implements it which creates continuity. However, a con is as with any program having all the responsibility on one person can be challenging and disastrous.

 According to many of the resources having a co-facilitator(s) or leader(s) is ideal. With a leader(s) and facilitator(s) the con is having to take the time outside of the group time to plan as well as manage the group, record keeping, track funding, and find necessary resources. Although some of this work can be done separately it will need to be shared collaboratively between the leader(s) and facilitator(s) before each meeting. A pro, however, is that the workload is shared. The leader and facilitator can agree to enlist either members of the group or members of the church (which some may be a part of both) to do record keeping, marketing, emails, etc. for the group and only one or the other need to meet with the extended group relaying any necessary details to the other.

 However, the most significant pro to having multiple people as facilitator(s) and leader(s) is for reflection time after group sessions. One of the most challenging parts of facilitating and leading support groups is unloading any baggage that results from the group interaction as well as listening to positive criticism on ways to improve. Having someone to discuss self-reflection with will help the leader(s) and facilitator(s) process through any struggles. The goal is to explore and resolve them out to avoid any negative impact they could have on future sessions. Since self-reflection is crucial to a successful group and initially I will be the group leader and facilitator until others are trained, I will plan a set time to reflect with my supervising minister or some other trusted knowledgeable person that can help me work through anything that may arise.

Yet, there is one aspect that must be addressed only by trained leader(s)/facilitator(s) which is meeting with individuals prior to their first meeting. This is a time when the rules of the group and confidentiality waivers should be signed. This allows the incoming members to recognize that this group’s privacy as well as their own privacy is of utmost importance to the group.

There tend to be more pros for having multiple leader(s)/facilitator(s). To assist them in their leading I came across another great resource that specifically assists leaders and facilitators in avoiding issues that may arise. This resource focuses more on cancer support groups within a church as well as offers their self-collected list of churches that offer cancer support groups. This website like many of the resources offer ideas for leading/facilitating a cancer support group, but I found several of the author, Lynn Eib’s, ideas intriguing and helpful. First, is the reminder to allow room for humor and encourage humor.[[4]](#footnote-4) I am fortunate enough to have had great examples of both positive and negative leaders and facilitators. One thing I have come to learn is that humor and laughter is necessary when dealing with such heavy topics like cancer. A good facilitator works at balancing both the lightness of humor and the heaviness of cancer discussion.

In my opinion and in the opinion of many of the resources, rules are an important aspect of a successful support group. Another point Lynn made is about rules for her support groups. She states that her “unwritten” rules which she regularly expresses are

* No using names if you share anything “bad” about a doctor or anyone else.
* No trying to “fix” other people’s problems for them. (We share what worked for us, not what others should do.)
* No divulging outside the group what’s shared in the group (respect confidentiality).
* If the cancer patient passes away, loved ones may NOT continue to attend regular meeting[[5]](#footnote-5)

I was struck mostly by three aspects of her rule statements first is the concept of unwritten rules. Many of the resources encourage written rules and reviewing over them with new members as well as periodically reminding current members if necessary. I intend to follow this format with the group I am implementing at EPSC. (See Appendix A)

 The second aspect of her list that I had not found in the other resources but is a great rule to include in implementing a cancer support group is not using names when sharing anything bad about a doctor or anyone else. What is important for a leader/facilitator to communicate to the group is that every individual’s experience is different. Finally, what struck me the most was her last unwritten rule excluding loved ones of cancer patients who have passed away. Her explanation makes me wonder if this rule is something that I should implement in my group. She with experience has explained that it changes the dynamic of the group. I have decided to discuss this with others and perhaps let the group decide whether to follow this rule.

 Another aspect Lynn Eib along with many of the resources points out is a focus on how to manage information that the group desires to learn more about. There are several resources found in *Community Tool Box* as well as several of the resources already mentioned that offer common information sought by members of other cancer support groups. Many of these resources also mention that it is important to let the group decide on presentations or information that they would like shared. Keep in mind that some group members may just desire emotional support through sharing of stories while other members might want to have additional information about advocacy or insurance management etc. Perhaps, this where having a cancer support group with leader(s) and facilitator(s) along with supporting church community can be very beneficial. Because this is where a small group or committee can address creating information sessions on topics desired by several members. This group can work with or include the leader(s)/facilitator(s) with community organizations to offer information sessions on specific cancer related topics. If the group collectively would like more information about a topic then the leader(s)/facilitator(s) can work together or with a group to bring this information directly to the group.

 During the process of gathering information about any treatments, assistance, advocacy programs, and general cancer information etc., it is important to remain neutral. Those gathering the information can start with some of the resources listed in this paper’s bibliography or find others of their own. Another great starting point is contacting the societies related to the specific type of cancer being focused on as well as the American Cancer Society which already have existing information and may be willing to come to offer information sessions at one’s location. Considering this group will be a general cancer group, the leader(s)/facilitator(s) must share any of this gathered information without bias even if it means sharing information about other local cancer support groups related to a specific cancer that may be more beneficial to them. The group member’s well-being should be most important as well as their need to feel comfortable with the decisions made throughout the course of their or their loved one’s treatments. For example, I don’t care for the American Cancer Society because of the way in which they allocate a majority of their funding to lobbying against smoking, but I know they offer programs and services that can be helpful to others. So, as a leader I would not share that opinion with the group, but if asked directly I would defer to answer them privately.

It is vital to know when certain things should or should not be shared and when or when not to share them with the group. This is also critical for the group members to understand and may be necessary for the facilitator(s) to know how to manage this. It is suggested by several of the resources to allow separate times outside of support group to gather for fellowship offering a time to share stories, jokes, and ideas not relevant to the support group setting. Some suggest once or twice a year and others suggest more periodically. The support group leaders and members should make the determination on this based on the availability, need and desire of the group.

 Another aspect that many resources mention is that leadership must decide early on how often the group will meet as well as the setting of the room. Beginning this cancer support group in a church means that the group must be aware of which rooms are available at the necessary times and what set-up options are in those spaces. It may not seem that important, but making the group comfortable and able to see one another is very significant in creating a suitable group dynamic. Ideally, the church will be available for the group to meet weekly. The frequency of meetings can be adjusted according to group or communities’ needs, keeping in mind that not all members will be able to make it every week. This is especially true in cancer support groups due to several factors related to cancer like fatigue, treatment locations, times, etc.

The resources and ideas discussed so far are possible because beginning a cancer support group has been done many times before. Although the idea of creating a cancer support group within a church is new for ESPC and for its surrounding area it is not something that other churches have not ventured into doing. I regularly view a sign at Wesley United Methodist Church for a weekly cancer support group.

Additionally, from my internet research and through the lists from several resources there are many churches and existing organizations that work with churches to form cancer support groups within their walls. There is one group that may be very suitable for churches who do not know where to begin. A program called Cancer Companions offer a paid program that provides materials for training peer support companions as well as materials for devotion, bible studies and “written exercises to help the cancer family member to explore their emotional struggles and learn methods to cope.”[[6]](#footnote-6) Keep in mind that this group is more biblically focused and may not suit the desire of the whole community. Since there is cost involved it would also need to be approved by proper channels. In addition to this group and all the resources listed there are many more cancer-related groups that may offer partnerships and free resources to beginning a local cancer support group.

 There is a vast amount of information available that can be used in beginning a cancer support group in any church. The points and resources within this paper are valuable and vital as I implement these for the CCC cancer support group at ESPC, and for others interested in implementing a group in their local church.

**Appendix A**

**General Rules for Cancer Support Group**

1. Primary is confidentiality- what is said in the group stays in the group
2. Share your personal stories not advice
3. Accept all members by being respectful and sensitive towards all members of the group
4. Avoid interrupting or having side conversations
5. No using names if your share something negative about a health care provider or anyone else.

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