

## CHAPTER 15

# Malecare

## Twenty Years of Innovation and Service to Gay and Bisexual Men and Transgender Women with Prostate Cancer

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### CHAPTER SUMMARY

This chapter tells the story of the world's leading gay, bisexual, and transgender (GBT) prostate cancer psychosocial support group network, Malecare. Challenged to develop the world's first prostate cancer support group for gay men, a small group of social workers and psychologists developed a set of unique modalities to help GBT people with the psychosocial and sexual stressors associated with prostate cancer diagnosis and treatment. A new nonprofit organization called Malecare was formed to create novel programs, using those new interventions to help underserved men diagnosed with cancer. During the last two decades, Malecare has become a source of medical innovation, health-care change, and psychosocial understanding for all men diagnosed with cancer throughout the world.

### KEY TERMS

bisexual cancer, bisexual health, gay cancer, gay health, LGBT cancer, LGBT health, prostate cancer, psychosocial, support groups, transgender cancer, transgender health

### BEGINNINGS

I am a social worker. During the mid-1990s, I was working in European refugee resettlement camps. It was rewarding, sleep-depriving, and honorable work to help torture survivors from lesser-developed countries find their footing in prosperous and safer societies. One day I got

a letter from my dad saying that he had prostate cancer. Not knowing what that meant and not being able to get him to talk about it on the phone, I dropped everything and returned home. I soon learned that he wasn't going to die anytime soon, but that he did have an advanced stage of his disease and would need extensive help with treatment navigation.

My dad was brilliant at doing things for others, crap at helping himself. I thought he needed other men his own age to talk to about his health. I thought a cancer group might be a good opportunity for him to have some conversation and an outlet for venting. I wanted him to see that he, as well as other men, could continue to live enjoyable and worthy lives with their cancer. Unfortunately, he and I shared a common complaint—we both hate commuting, and the nearest prostate cancer support group was nearly an hour away.

I thought: I'm a social worker, I can start a group. I joined with a national prostate cancer patient organization and started a prostate cancer support group at a local hospital. So in November 1997 my dad and about 30 other men sat in a hospital auditorium while I introduced a urologist to talk about prostate cancer. Then I offered to meet with the men in a smaller group setting after the lecture. Few took me up on the offer. My dad grew weary and stopped attending after the second meeting.

My dad's presentation of self seemed familiar to me because it was similar to that of the refugees I had been helping in the resettlement camps. Like a refugee, he was dealing with a type of adjustment disorder and the stressors that are unique to adults with sudden life changes. For him, and other men, this once-a-month so-called support group that I led was useless. More frequent and reliably scheduled group meetings that engage and provide psychosocial support would be better, in a style similar to what we used in the resettlement camps. Unfortunately, in 1997 there were no cancer survivor support group models that matched what I was looking for. So I developed one.

## **THE SUPPORT GROUP**

We were based in a hospital in lower Manhattan in New York City, so there were many men happy to find a support group that they could easily attend after work. Men, many of whom attended with their wives, would stay for the lecture but leave before we could develop a more open-to-everyone kind of conversation. Also, I noticed that there were several men who seemed much more uncomfortable than others. I wanted to understand why. During the last of our lecture-style meetings,

I gathered four of them and asked. One was notably quite vocal about not feeling comfortable being out in the group. Another said that the only reason he was sticking around to talk with me was because I had brought up anal insertive sex as being different from vaginal insertive sex.

These four men and I sat around talking about prostate cancer from a gay man's perspective. They talked about all sorts of things that were totally outside the heterosexual experience of prostate cancer. Specifically, the men had concerns about sexual identity and integrity relative to androgen deprivation treatment, which is similar to the punishment foisted on gay men in England during the 1940s, 1950s, and 1960s. They mentioned discomfort even in talking about cancer with gay friends when everyone in the New York gay community was focused on HIV/AIDS activism. They worried about the entirety of their sexual identities being disrupted as a consequence of prostate cancer treatment and the unique psychosocial challenges that disruption presents. And they recounted the extraordinary challenges generated by heterosexual presumption by the medical community. Most prevalent of all was their experience of a total lack of recognition of men who have sex with men as a unique psychosocial cohort that was experiencing prostate cancer. Then and there, I understood that what was needed was a group meeting just for men who enjoy sex with men. As we discussed what a support group for gay men with prostate cancer might look like, I remember saying a phrase I think I may have been the first to utter, "gay psycho-oncology," and seeing a brightness restored to all four men's faces.

By then it was 1998. I sent a letter to the national organization that we were affiliated with, asking if its members knew of any other gay men's groups and requesting that they list our meeting, specifically, as a gay men's group. We didn't expect the reaction we received. There was no discussion; they just kicked us out. Our New York City group was removed from the organization's support group directory, and we no longer received copies of its newsletter. Despite numerous phone calls to the organization's home office and to the president of its board of directors, I never received an explanation.

## **MALECARE BEGINS**

Because I was determined to continue the gay men's prostate cancer support group, I thought it would be essential to have a formal and legal foundation for my work. I started a nonprofit organization called Malecare. I placed flyers in community centers, gay bars, and elsewhere,

and I had success in attracting new men to the group. Around late 1999, several social workers and psychologists joined me as volunteers in helping run Malecare. We were all convinced we were onto something unique and thoroughly helpful.

The monthly lecture-and-breakout-group model in use by many cancer support groups other than Malecare quickly proved inadequate for helping gay men diagnosed with prostate cancer. In my view, monthly lectures offered by prostate support groups then and now often offer only a modicum of support and are more like marketing events, not only for doctors and hospitals seeking new patients, but also for pharmaceutical companies that view support groups as vehicles for promoting their products.

A man in need of psychosocial support needs meetings that occur more frequently than once a month. Imagine missing one meeting and having to wait at least another full month until the next. Cancer doesn't afford that much time for waiting. Also, lectures are not support groups. Lectures generally consist of an individual speaker delivering an informative talk for the majority of the scheduled time. The audience sits facing the speaker, rather than each other. Audience members usually get to ask a question and not much else. Lectures rarely afford men the opportunity to share their stories at length or to interact with each other in any depth. A helpful support group is five to fifteen men, sitting around a table, being led in conversation about their cancer by a social worker or psychologist, for 90 minutes. That was the first of several innovative modalities that Malecare would bring to the prostate cancer patient community in the United States.

## **BECOMING A NATIONAL ORGANIZATION**

Around 2001 many people were saying that they read about Malecare on the Internet. Dozens of clinicians around the United States asked if they could copy or affiliate with our work. Many more social workers and psychologists volunteered to build and maintain Malecare. As our groups became more refined, we developed simple protocols that could easily be taught via Skype or phone calls to clinicians outside New York City. For example, one Malecare innovation was to have first-time attendees speak first, starting them off with the request "In 90 seconds or less, tell us why you are here." Obviously, everyone takes more than 90 seconds to share his story and hear comments from the other group members. We found that getting the new guy (or guys) to speak first

relieved both individual and group anxiety and more efficiently integrated the new guy into the body of the existing group.

Using this very-simple-to-teach system, Malecare has created a network of in-person, patient-centered psychosocial support groups in the United States and an online support group network that is accessible throughout the world. Our quality maintenance and patient-safety assurance have allowed hospitals and community health centers to be accepting and inviting of our groups. Also, our unique group modality differentiates Malecare as an organization of substance, leadership, and innovation, which gives our local hosts the benefits of association with a well-regarded national brand.

### **COLLABORATION**

On a very cold Saturday afternoon in 2012, I was sitting in a daylong prostate cancer conference in New York City. Several doctors spoke to an audience of 50 or so patients. The conference closed with a talk by David Sandoe, a wonderful man from Australia, who spoke about how he had surgery and, despite impotence, was having a wonderful relationship with his wife. "No worries, mate. . . . When you lose your ejaculate after surgery, there's no more mess." So I guessed that this guy and his wife didn't care about ejaculate. David sat down at a table to enjoy a cup of coffee and I went over to join him, introducing myself as a support group leader, just like himself. Did he understand that it might be difficult for the gay men in the audience to relate to what he was saying? I asked this with constrained arrogance. "Oh, you know, I think you are right," he responded, "but I didn't know that there were any gay men in the audience. I guess it is not quite right for me to have assumed that."

David was a patient member of the Prostate Cancer Foundation of Australia (PCFA). We then began a long conversation, perhaps two hours long, about gay and bisexual men (GBM) and prostate cancer survivorship. From that conversation, Malecare's first major international collaboration was born. Starting in 2013, the PCFA, in partnership with Malecare in the United States, established six gay men's support groups. They also developed booklets covering diagnosis, treatment, side effects, and well-being specifically for GBM.<sup>1</sup> This collaboration has become a model that lent itself to collaborations with similar organizations in the United States, Canada, and the United Kingdom, along with emerging prostate cancer organizations from Iceland to South Africa. Because of these collaborations, Malecare saw the value of creating an

alliance of prostate cancer organizations from around the world, to share cross-border treatment opportunities and strategies for inclusion of all men in access to care. The Global Prostate Cancer Alliance was founded by Malecare as a free and open system of communication among like-minded, nonprofit patient-helping organizations.

## **TRANSGENDER WOMEN**

Some time in 2000 I was working part-time as a social worker with a community-based mental health organization. One of my clients was an older transgender woman who had difficulty sleeping because of frequent urination. She had resisted suggestions to see a urologist about prostate cancer, mostly, in her reasoning, because she was not a man and did not see any reason to get tested for “men’s things.” That she still had a “men’s thing,” meaning a prostate, crystallized a toxic dynamic faced by many older transgender women (TGW): a struggle to reconcile the realities of anatomy with the truth of their identity and gender.

We worked for half a year together as her symptoms, including lower back pain, got worse and worse. A few months of consultations and tests brought her to a diagnosis and the beginning of treatment for metastatic prostate cancer. Her initial treatment required 40 days of radiation spread over eight weeks. She complied with the treatment but had one nonnegotiable demand: that her treatment be scheduled as the very first appointment of the day, so that she could minimize waiting room contact with men diagnosed with prostate cancer. She was able to seek treatment as long as she could see herself as a woman diagnosed with prostate cancer rather than as a woman diagnosed with a man’s cancer. This requirement created an interesting issue for prostate cancer support group attendance. To her, attending a gay men’s group was just as toxic as attending a straight man’s group.

So Malecare developed what we believe is the first support group for transgender women. Unfortunately, in the year 2000 we could attract only two women to attend the group. An online group failed to develop a critical mass, too. We started to wonder if a broader approach might be more sustainable and equally helpful—a psychosocial support group to which all LGBT cancer survivors would be welcome.

## **MALECARE AND THE NATIONAL LGBT CANCER PROJECT**

We asked our patient community and ourselves what psychosocial commonalities might exist for all lesbian, gay, bisexual, and transgender

cancer survivors. After three years of effort, we developed a deep understanding of which stressors and psychosocial challenges could be helped in a well-managed LGBT cancer survivor support group. One of the challenges involved community identity. In 2004 women could readily find lesbian-focused cancer support, and GBM could find quality gay and bisexual support in Malecare. But many men and women felt themselves a part of something larger. We found that the phrases “LGBT cancer survivor” and “LGBT psycho-oncology” resonated deeply and helped restore the dignity of LGBT-identifying cancer survivors. Social workers, psychologists, and oncologists with whom we spoke thought that our ideas about LGBT cancer survivors as a unique cohort were innovative and potentially helpful.

So in 2005 Malecare founded the National LGBT Cancer Project, the world’s first nonprofit organization focused on LGBT cancer survivorship. We created online support groups, using the brand Out With Cancer. We helped several community cancer centers across the United States form in-person Out With Cancer groups, using our training for their staff. The National LGBT Cancer Project has been replicated around the world, and we could not be more proud. People will copy good things, and, with rare exception, that is good for everyone.

## **WORKING WITH PHARMACEUTICAL COMPANIES**

Malecare honors pharmaceutical companies that create treatments that save our lives. We believe it is our responsibility to advocate for these same companies’ marketing their treatments in equitable and affordable ways, with a no-compromise goal of universal access to healthcare. Several times a year pharmaceutical companies, biologic and genetic test developers, and medical device manufacturers ask heads of patient-focused nonprofits, like Malecare, to review potential marketing materials for consumers.

Almost all the materials I reviewed seemed to target white, middle-class men and their age-appropriate wives. A telling moment for me was the time I handed a pharmaceutical company’s marketing person one of Malecare’s brochures, which shows a gay couple with their son. The marketing person complimented Malecare on our novel approach, showing a set of “brothers” engaged in prostate cancer awareness. Upon hearing that the image was that of a partnered couple and their son, that same marketing person said, “Is that possible?” Though we

were speaking in a major American city around 2003 or 2004, she didn't understand that gay men could raise children.

A marketing person for a major company was clueless about a major segment of her market—which, from Malecare's perspective, meant that a major pharmaceutical company did not have a concern about gay men who use their products, even after two decades of HIV/AIDS awareness. That company simply was not doing market research on our community. Did they not care? Certainly they expected to sell their product to gay men. But pharmaceutical marketing people seem to assume that gay men would be responsive to heterosexually positioned materials because they were so used to seeing such materials.

Malecare identified three issues regarding our mission to make pharmaceutical companies more responsive to our community:

1. To alter the way prostate cancer treatments are marketed so that gay men are included both in imagery and in texts
2. To acknowledge unique stressors for gay men in support materials
3. To improve identification and accrual of gay and bisexual men in clinical trials

We gave ourselves five years, from 2005 to 2010, to achieve tangible results.

As of May 2017, our efforts have had good outcomes with some companies, and disappointing or null results with others. For the latter group of companies, gay and bisexual men continue to be irrelevant. All those companies' prostate cancer marketing materials are purely heterocentric, and they do absolutely no outreach to the GBM community or even offer support to our work, as they do to all other prostate cancer organizations. We suggest that patients test out all prostate cancer websites with a simple search for the term *gay*.

## **RESEARCH**

Early on, we saw the need to innovate and lead a marketing effort for more research regarding GBM and TGW with prostate cancer. We did not have a clue what disparities, if any, might exist, but we knew it was important to find out. And our support group attendees wanted to know, too. Many men entered our groups, happy for the comradeship and ease

of conversation, but confused about whether there was something about being gay that might make prostate cancer a truly different experience.

Because we were being asked to help accrue patients for clinical trials, it was an easy proposition to demand that the trials include demographic questions about gender, sexual identity, and type of relationship a participant was involved in. Remarkably, we were refused at every turn. Not one clinical trial manager empathized with our requests. In fact, almost all were quite adamant that the differentiation would prove irrelevant. Most toxic was the fact that many of the researchers voiced homophobic concerns that the mere inclusion of a question regarding sexual identity would dissuade further participation in their research study. Researchers thought they were in safe territory in ignoring Malecare, as long as we focused only on gay men.

So, to fight back, some time around 2003 I changed our mission goal to say that Malecare is working to become the world's leading non-profit organization for men's cancer survivorship. We needed authority and muscle power. The authority would come from our own self-funded research, and the muscle would come from size.

We were determined to become large in numbers of group attendees. To do that, we began to develop additional support groups that would be inclusive of men of all sexual identities. Malecare was and still is one of the very few organizations to conduct weekly 90-minute, sit-around-a-table-and-share group meetings. We found a niche ready to fill. And fill it we did, very quickly building our census to nearly three times the size of the next-largest competing nonprofit. We were also the first large nonprofit organization to identify men with advanced-stage prostate cancer as a cohort with unique psychosocial and treatment issues. Our advanced-stage support groups increased our size by an additional third.

Starting around 2008, Malecare had a massive database of patients, all eager to share their thoughts and experiences with the hope of improving treatment outcomes. Researchers were knocking at our door several times a month. But, getting GBM and TGW investigative criteria inserted into survey and clinical research remained a huge challenge. Researchers who agreed to work with Malecare under our terms saw their subject accrual completed in short order. Researchers also said that they found valuable insights from Malecare's group leadership and our deep understanding of the psychosocial issues of our group attendees.

We thought we were making progress, but between 2009 and 2012 an interesting problem emerged. As Malecare patients saw the papers that were produced from those early studies, they stopped participating in research. From focus groups of our group attendees we learned that our men were angry that Malecare was not mentioned as a partner in almost all the papers. They felt that if Malecare was not mentioned, then they as individual patients were not credited or acknowledged. It was a surprise to me and our staff that these men were participating not only to improve treatments, but also to build awareness of support groups in and of themselves. And they were right to feel that way.

These men wanted other men to find the same helpful value in Malecare groups that they had found, and they simply were not going to participate in anything that would not further that goal. Our staff and I decided that Malecare would participate only in research in which we felt we could provide significant input into all aspects of the particular investigation. We sought to have one or more of our staff as co-investigators and to ensure that our contributions would constitute more than subject accrual assistance. Malecare is a ready and able community partner to all researchers who respect our organization collegially, and we can now demonstrate through numerous published papers and high-level grant awards that our inclusion benefits everyone.

## **INNOVATION AND THE FUTURE**

Malecare is now positioned as one of the world's leading prostate cancer patient organizations. During the last 20 years, we've learned that partnerships and collaborations are the fastest and most equitable and sustainable method of spreading our work around the world. From our Global Prostate Cancer Alliance we've learned that engagement of international prostate cancer coalition stakeholders and organizations from many disciplines, from consumer to doctor, advocate to minister of health, nurse to researcher, helps facilitate program implementation. Malecare works with nonprofit organizations that are already working within local communities. We offer training and support materials to these organizations and help with marketing and promotion. We stay connected with these local nonprofits in keeping with our theme of "treating locally, connecting globally." In this way prostate cancer patients from communities of all sizes and locations share information and support, across borders and without fear.

Our strong suit is collaborating in innovative programming and promoting new thinking about prostate cancer. In 2011 we began a research program called Start a Cure, which has led to several peer-reviewed papers, abstracts, posters, one patent, and one patent pending.\*

Our online support group network is one of the largest in the world. And our technical innovations, such as Cancergraph (a clinical trial, accrual, mobile app system, and patient side-effect recording device), help thousands.

Twenty years ago, Malecare played a key role in initiating the field of gay psycho-oncology and LGBT psycho-oncology, which are now respected fields of research in which brilliant investigators develop new modalities to help patients. For the next 20 years, Malecare will continue to find ways to increase access to healthcare and to advocate for prostate cancer treatments that are effective, affordable, and morbidity-free. The spine of our mission remains the same as when we started: to reduce fear and ease adjustment to the diagnosis and to restore dignity and happiness to all men diagnosed with prostate cancer and, with our research program and CancerGraph, to survivors of all cancer types.

## REFERENCE

1. Prostate Cancer Foundation of Australia. Prostate cancer pack: Information for gay and bisexual men. 2014; [www.prostate.org.au/awareness/for-recently-diagnosed-men-and-their-families/gay-and-bisexual-men/download-information/](http://www.prostate.org.au/awareness/for-recently-diagnosed-men-and-their-families/gay-and-bisexual-men/download-information/).

\* U.S. Patent no. 9,168,002, October 27, 2015: A device and method for real-time simultaneous measurement of radiation at specific parts of the body. Understanding cumulative radiation exposure in people undergoing ionizing radiation for diagnostics and medical treatment is essential in reducing secondary tumors from primary radiation therapy. U.S. Provisional Patent Application no. 62/370,092, September 7, 2016: Mobile health-monitoring Cancergraph, a symptom and side-effect recording and reporting mobile app, patent pending.