

# Community Health Resource Center's Cancer Buddy Program: A volunteer based support service

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# Cancer Buddy Program Training Agenda

- I. Welcome and Introductions
- II. Overview of the Cancer Buddy Program
- III. Training, Methods of Communication, Matching Process & Contact Information
- IV. Vignettes
- V. Evaluation
- VI. Appendix A-C

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Dear Volunteer Buddy,

I want to formally welcome you to the team of volunteers and offer my support to you now and throughout your journey as a "*Buddy*" with the Community Health Resource Center. Your participation in the *Cancer Buddy Program* is a tribute to who you are as a person and what is so wonderful about humanity. Giving time and attention to those now facing a cancer diagnosis is a gift of infinite proportions. The *Cancer Buddy Program* is designed to assist on multiple levels within care giving systems. Most directly, individuals matched with you will have an opportunity to tell their stories and receive words of wisdom. Additionally, healthcare professionals will have a resource to call upon in the event that their client needs assistance. The staff at the Community Health Resource Center and myself specifically will be available should you have any questions or concerns regarding any aspect of this exciting program.

Again, I welcome you to an excellent team of support providers and thank you for giving your time and energy to this important program; the *Cancer* 

## Buddy Program.

Sincerely, Scott Plymale

Scott Plymale LCSW, PhD Executive Director Community Health Resource Center

## **Cancer Buddy Program Overview**

The *Cancer Buddy Program* involves selection, training and support for volunteers who have survived cancer. Volunteers are asked to first meet with a social worker. The initial contact between a social worker and the volunteer allows the volunteer to learn about the program, matching process, support services and training schedule. After the initial meeting with a Community Health Resource Center (CHRC) social worker, the volunteer will be invited to attend a series of trainings. The *Cancer Buddy Program* training is designed to prepare volunteers for the types of situations that might develop during their volunteer experience. Inclusion in this training program allows volunteers an opportunity to learn about the resources available to cancer patients through the California Pacific Medical Center. In addition, CHRC volunteers will be invited to attend a training focused exclusively on support for newly diagnosed cancer patients receiving treatment on an outpatient basis.

The *Cancer Buddy Program* matching process is based upon diagnosis. The goal of the matching process is to connect patients recently diagnosed with a specific type of cancer with a volunteer who has lived with the same or similar diagnosis. The match will provide a framework for volunteers to communicate with the patient about the treatment process, self-care, accessing resources or simply share thoughts about a condition very few can completely understand. The volunteers will be asked about their current health and type of cancer at the outset of the volunteer process. Newly diagnosed patients are referred through oncology offices, infusion centers, American Cancer Society, the Leukemia & Lymphoma Society, oncology-radiology centers and other avenues. Once the patients are referred to CHRC's social worker, the matching process will begin.

Following the training and matching process the volunteer will be connected to a Community Health Resource Center social worker. The meeting with the social worker can occur via telephone or in person and are organized around two central elements. The first aspect of the ongoing meetings includes support to volunteers. The second element of the meetings includes sharing important and relevant information related to the *Cancer Buddy Program*. The goal of these meetings is to provide comprehensive and concrete support to volunteers as they offer their knowledge and experience to patients.

The program will continually evaluate the needs of the volunteers as well as the cancer patients. Feedback about the program is requested from all involved parties including referring oncologists, nurses, social workers, other outpatient service centers, volunteers and patients.

# Training

The training for volunteers is conducted with one of the Community Health Resource Center social workers directly involved in the Cancer Buddy Program. The training format has been modified over the previous three years to focus on critical areas related to the needs of newly diagnosed cancer patients as well as volunteers and their needs. The purpose of the training is to prepare the *Cancer Buddy Program* volunteers for experiences they may encounter during the program. The training format centers on: offering support to volunteers, informing the cancer volunteers of the resources for their match,

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communicating about sensitive topics, confidentiality, matching, diagnosing, treatments, end-of-life care and ongoing care.

# **Methods of Communication**

The CHRC *Cancer Buddy Program* is developed to support newly diagnosed cancer patients through three methods of communication. The first is by telephone. The second is by e-mail and the third is through direct face-to-face contact in the CHRC office meeting space.

Telephone communication: Telephone calls can be organized by the volunteer after the match has been made. Please keep in mind the potential cost to both yourself as well as your match. The program does not reimburse for telephone calls. It is hoped that most if not all calls will be local and affordable. The benefits of telephone communication include: flexibility in scheduling, minimal impact on physical movement and varied lengths of discussions. The drawbacks of telephone contact include: potential cost, no visual clues about a person's needs or emotional reactions and care at a distance. Other things to keep in mind when making telephone contact: Who is in the room with you as you talk with your match? How much time do you or your match have to spend on the telephone? How does the conversation start and end? How do you set up a future call or not?

E-mail communication: The near universal use of computers makes e-mail a viable option for communication. Please understand that not all computer systems have high levels of security and like most internet options, the e-mails exchanged may not be through a secure connection. In addition, similar to phone contact, email communication provides no visual clues about a person's needs or

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emotional reactions and offers care at a distance. Despite drawbacks e-mail allows for ongoing discussion between the volunteer and the match without having to coordinate a time and date for phone contact or face-to-face meetings. Additionally, information exchanged during the dialogue can be saved and accessed for reference at later dates. This is most helpful with resource referral.

Face-to-Face meetings: Volunteers are invited to meet with their match in the neutral and accessible space of the CHRC. The CHRC conference room will be reserved for face-to-face meeting opportunities. To use the meeting space simply call a CHRC social worker (415) 923-3155 and have the space reserved for the amount of time needed. The benefits of face-to-face meetings include: verbal and non-verbal means of communication, awareness of a person's physical hindrances associated with cancer and an easier rapport building process. The drawbacks of direct face-to-face contact include: availability and time to reserve the meeting space, energy getting to and from the meeting and potential emotional reactions during the meeting.

# **The Matching Process**

All matches are made based on diagnoses in order to provide the most direct level of support to the newly diagnosed patient, also known as "the match," regarding questions and/or concerns related to their cancer. The match will be referred into the program through a variety of different avenues including personal physicians, nurses, friends and family members.

Most patients referred into the program will live in the Bay Area. However, it is possible that the matches will live in Northern or Southern California or even outside of the state. It is very likely that the meetings will not occur face to face. Although the match between the volunteer and the newly diagnosed patient is based on diagnoses, the treatment, prognosis, support systems, needs, concerns and questions of the match can be very different than those of the volunteer when he/she was living with cancer.

Volunteers will first be contacted by a CHRC social worker to inform them that a newly diagnosed cancer patient has been matched with them. The referred patient will have signed a release form acknowledging that the volunteer will be informed about their condition and has the right to contact them. If the volunteer has questions about the match, the CHRC social worker will be available.

If the volunteer pairing does not work or if there are questions regarding the matching process the volunteer should contact a CHRC social worker to explain the circumstances.

# **Contact Information**

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After being contacted by the CHRC social worker you are given the name and phone number of your match. The match is referred to you based on the cancer diagnosis. After waiting a few hours you call the match. There is no answer when you make your first call. The following day you call again without an answer. When making the second call the phone rings and eventually an answering machine picks up.

- 1. What is your message for the answering machine?
- 2. Do you call a third time?
- 3. What happens if you call a third time and someone other than the volunteer picks up the telephone?

After completing the volunteer training you receive a call from a CHRC social worker with the name and telephone number of your match. You place the call a short time later. The person you are calling answers the phone. After introducing yourself as a Cancer Buddy Program volunteer, the match immediately begins to cry, telling you that they are not only struggling with cancer but they do not have money for a taxi to get to the hospital for treatments. The person you are speaking with continues to cry.

- 1. What do you say to the match?
- 2. What is your emotional response?
- 3. How do you answer their question about funding to get to the hospital?



You and your match decide that e-mail is the best way for you to communicate with one another. The release forms have been signed, HIPAA requirements have been reviewed during the volunteer training and the person you are supporting is familiar with computers and e-mail. You and your match have identified the relationship as helpful and have been engaging one another through e-mail for three months. The more recent e-mails indicated that your match was going through radiation treatments for the cancer and the prognosis was relatively good. You send a message on a Monday and do not hear back for two weeks. You decide to call rather than waiting for an e-mail response. Upon calling and asking to speak with your match you are told they passed away five days previous.

- 1. What do you say to the person on the phone?
- 2. What is your reaction?
- 3. What support do you need?
- 4. Who do you reach out to?

You and the match have been corresponding for one year by telephone. These conversations are going well as your match generally calls to stay in touch and ask questions about treatment methods and potential side effects of medications. One day the match calls and wants to thank you for your help during the year. He/she would like to meet you for the first time in person at the local coffee shop to give you a "gift." Unfortunately you are busy the afternoon your match asks for the meeting. You are free the following week but you do not tell the match this on the telephone.

- 1. What do you say when the match asks you for medical advice?
- Do you have a discussion with your match about meeting in person? If so, how?
- 3. Do you accept a gift from the match?

You and the match have chosen to correspond via e-mail. The first month of correspondence is friendly and open. Shortly thereafter the messages from the match become very hostile and threatening. It is clear that the match is upset but you are not clear why.

- 1. How do you approach this situation?
- 2. What supports are available to you through the Cancer Buddy program?
- 3. Would there be a difference in your approach if the correspondence was either by phone or face-to-face?



After two months of correspondence with the match you plan to take a vacation. The trip is in the United States and within reach of telephone or e-mail communication. You mention to the match that you will be going on vacation. The match sounds disappointed on the telephone. You ask about their disappointment and they reveal that they have a very important surgical procedure the week that you will be away. The match begins describing that no one else in their family will be able to attend this event and that they are all alone. You were aware of their isolation but not about this upcoming surgical procedure. After listening to their circumstances for thirty minutes the conversation politely comes to an end.

- 1. What do you do about the vacation plans?
- 2. What do you say regarding their feelings of isolation?
- 3. How do you feel after the conversation?

Appendix A



## **AUTHORIZATION AND CONSENT** TO RELEASE CONFIDENTIAL HEALTH INFORMATION **CANCER BUDDY PROGRAM**

I, \_\_\_\_\_, born on \_\_\_\_\_\_ (Patient Name) (Birthdate)

hereby authorize the members of the Cancer Buddy Program at the Community Health Resource Center to disclose the information I have indicated below to the volunteer buddy or match:

Please check those that apply in your situation:

1. Current or previous cancer diagnosis

2. \_\_\_\_\_ The treatment and/or service plan related to cancer

3. Other (specify)

This disclosure of information is required for the purpose of providing effective program care. This consent is valid for one year from today, unless you revoke it earlier or specify a different date to discontinue its validity:

(Optional Date)

Signed: \_\_\_\_\_\_(Your Signature)

Date:			

For minors under 18 years old, parent, guardian or conservator signature is required:

Signed: \_\_\_\_\_\_ Date:

(Parent/Guardian/Conservator Signature) (Relation to Client/Patient)

To be completed by CHRC Staff:

Witness Signature:

(Clinician Signature and Title)

Appendix B



# **Notice of Privacy Practices**

## THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED BY CHRC AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

## What this Notice is and Why it is Important:

This notice is required by law to inform you of how your health information will be protected, how CHRC may use or disclose your health information, and about your rights regarding your health information. If you have any questions about this notice, please call 415-923-3155 and ask to speak with the Executive Director.

## **Understanding Your Health Information:**

Each time you visit a CHRC staff member (nutritionist or social worker), a record of your visit is made. This record typically contains a description of your symptoms, health history, diagnosis, treatment, and a plan for future care. This information, which is often referred to as your health record, serves as a:

- Basis for planning your care and treatment
- Means of communication among the health professionals who contribute to your care
- Legal document of the care you receive
- Source of data for planning facilities, marketing healthcare services, and fundraising
- Tool with which we can assess and work to improve the care we provide

Understanding what is in your record and how your health information is used helps you to ensure its accuracy, better understand how others may access and use your health information, and make more informed decisions when authorizing disclosures to others.

## Your Health Information Rights:

You have the following rights related to your health records kept by CHRC.

Obtain a copy of this Notice - You will receive a copy of this Notice at or prior to your first visit.

Thereafter you may request a copy of this notice or any revisions from the Front Desk or by calling

415-923-3155 and asking for the Executive Director.

Authorization to use your health information - Before we use or disclose your health information, other

than as described below, we will obtain your written authorization, which you may revoke at any time to stop future use or disclosure.

Access to your health information - You may request a copy of your health information that CHRC keeps

in your health record. Your request must be submitted in writing.

Amend your health information - If you believe the information we have about you is incorrect or

incomplete, you may request that we correct or add information. Your request must be in writing.

*Request confidential communications* - You may request that when we communicate with you about your

health information, we do so in a specific way (e.g. at a certain mail address or phone number). We will make every reasonable effort to agree to your request.

*Limit our use or disclosure of your health information -* You may request in writing that we restrict the use

or disclosure of your health information for treatment or any other purpose, except when specifically

authorized by you when we are required by law or in an emergency situation in order to treat you. We

will consider your request and respond, but we are not legally required to agree if we believe your

request would interfere with our ability to treat you.

## **Our Responsibilities:**

We are required by law to protect the privacy of your health information, to establish policies and procedures that govern the behavior of our workforce and businesses associates, to provide this notice about our privacy practices, and to abide by the terms of this notice.

We reserve the right to change our policies and procedures for protecting health information. When we make a significant change in how we use or disclosure your health information, we will also change this notice. The new notice will be posted in the registration areas, and will be available at the Front Desk.

Except for the purposes related to your treatment or when otherwise permitted or required by law, we will not use or disclose your health information without your authorization. You have the right to revoke your authorization at any time. We are unable to take back any disclosure we have already made with your permission.

#### Examples of Uses and Disclosures for Treatment, Payment and Healthcare Operations

## We will use your health information to facilitate your healthcare treatment.

For example: Information obtained by members of your healthcare team will be recorded in your record

and used to determine the course of your healthcare treatment. Your provider may document in your

record his or her expectations of the members of your healthcare team. Members of your healthcare

team will then record the actions they take and their observations as appropriate. With your consent, we

will communicate a summary of our contacts with you to your primary healthcare provider.

### We will use your health information to facilitate routine healthcare operations.

**For example:** Members of our healthcare staff may use information in your record to assess the care you

have received and how your progress compares to others. This information may then be used in efforts to

improve the quality and effectiveness of the healthcare and other services we provide.

#### We will use your health information to help us educate medical staff, residents, and students.

For example: CHRC has associates with a variety of schools involved in the education of health

professionals. All staff, residents, and students must sign a confidentiality agreement before accessing

any health information maintained by CHRC.

### We will use your health information to notify your family and friends about your condition.

For example: We may use or disclose information to notify or assist in notifying a family member,

personal representative, or another person responsible for your care or your general condition. Health

professionals, using their best judgment, may disclose to a family member, other relative, close personal

friend or any other person, relevant health information to facilitate the person's ability to assist in your

care.

## **Examples of Uses and Disclosures for Other Purposes**

Appointment Reminders: We may contact you to provide appointment reminders.

*Alternative Treatments:* We may use your health information to provide you with information about

alternative treatments such as acupuncture, biofeedback, massage therapy, and stress reduction.

*Marketing:* We may use your health information to inform you about our classes, lectures, services,

treatment alternatives, or other health-related benefits and services that may be of interest to you.

*Fundraising:* We are a community-based, not-for-profit health resource center that depends extensively on

charitable support. We may use limited information about you such as your name and address to inform you of opportunities to support CHRC and its services and programs.

**Public health:** We may disclose your health information as required by law to public health or legal

authorities charged with preventing or controlling disease, injury or disability.

*To avert a serious threat to health or safety:* We may use and disclose your health when necessary to

prevent a serious threat to your health and safety or to the health and safety of the public or another person. Any disclosure would be made only to someone able to help prevent the threat.

*Correctional institution:* Should you be an inmate of a correctional institution, we may disclose to the

institution or their agents health information necessary for your health and the health and safety of other individuals.

*Law enforcement:* We may disclose your health information for law enforcement purposes as required by

law or in response to a valid subpoena, or court or administrative order.

**Business associates:** There are some services provided in our organization through contracts with business

associates. Examples include lectures given by non-CHRC healthcare professionals and support groups facilitated by contract clinicians. When these services are provided by contracted business associates, we may disclose the appropriate portions of your health information to these business associates so they can perform the job we have asked them to do. To protect your health information, however, we require all business associates to sign a confidentiality agreement verifying they will appropriately safeguard your information.

## **Special Situations:**

*Military and Veterans:* If you are a member of the armed forces, we may disclose your health information

as required by military command authorities. We may also disclose health information about foreign military personnel to the appropriate foreign military authority.

*National Security and Intelligence Activities:* We may disclose your health information to authorized

federal officials for intelligence, counterintelligence, and other national security activities authorized by law.

*Protective Services for the President and Others:* We may disclose your health information to authorized

officials so they may provide protection to the President and other governmental leaders, or conduct special investigations.

*Regulatory oversight:* We may disclose your health information to appropriate health oversight agencies,

public health authorities, or attorneys when required by law. Your health information may also be disclosed if a workforce member or business associate believes in good faith that CHRC has engaged in

unlawful conduct or has otherwise violated professional or clinical standards and are potentially endangering one or more patients, workers, or the public.

### For More Information or to Report a Problem

If you have questions, would like additional information, or want to request an updated copy of this notice, you may call 415-923-3155 and ask to speak to the Executive Director.

If you believe we have not properly protected your privacy, have violated your privacy rights, or you disagree with a decision we have made about your rights, you may contact the Executive Director of CHRC. You may also send a written complaint to the U.S. Department of Health and Human Services at 200 Independence Avenue, SW • Washington, DC 20201. CHRC will ensure that the care you receive at our center will in no way be impacted if you file a complaint.

Appendix C



## **Acknowledgement of Receipt of Privacy Practices**

Date:

I, \_\_\_\_\_\_, have received a copy of the CHRC privacy act policy. I also consent to services that I have requested from the staff of CHRC, including involvement in the Cancer Buddy Program. I acknowledge that my health information will be shared with providers within CHRC and with my volunteer match through the Cancer Buddy Program. I do not authorize the release of my health information to others outside of the Cancer Buddy Program or CHRC organization without a specific release of information completed by me.

Signature of client

Signature of witness

Signature of parent or guardian if client is under 18 years of age.

Position title of witness