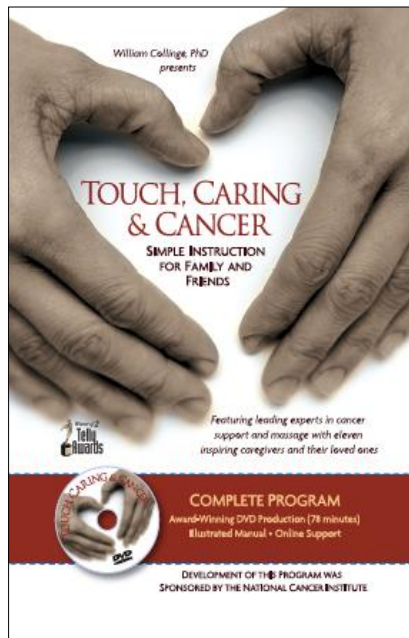


# ***Touch, Caring and Cancer***

## ***Simple Instruction for Family and Friends***



## **Guide for Professionals**

### **In Cancer Centers, Hospice Programs and Other Palliative Care Settings**

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## CONTENTS

Introduction - 2

Film Discussion Guide - 3

    Purpose of the Film - 3

    Using the Film in Group Settings - 3

    Facilitating Group Discussion - 4

    Leading Practice in a Group - 5

Program Planning: Reaching Families - 7

    New Patient Welcome/Orientation Packets - 7

    Distribution to Individual Families by Staff - 8

    Resource Libraries - 8

    Support Groups - 8

    Family Programs, Workshops and Retreats - 9

    Reaching Underserved and Minority Populations - 9

Strategies for Funding - 11

    Grateful Patient/Grateful Family - 11

    Champions of Integrative Care - 11

    Development Office - 11

    Sponsors - 12

    General Funds - 12

    Research Grants - 12

Consultation and Training Opportunities - 14

    Program Development - 14

    Massage and Cancer - 14

    Integrating Touch into Nursing Practice – 14

    Contact Information - 15

## INTRODUCTION

*The Touch, Caring and Cancer Program* represents a major advance in the availability of palliative care for people with cancer. The program empowers family and friends to be active participants in a loved one's care, overcome feelings of helplessness, enjoy new satisfaction in caregiving, and deepen their sense of connection with one another. Relationship-based caring can take its rightful place in the center of a truly holistic and integrative approach.

Developed through research sponsored by the National Cancer Institute, the program was evaluated in a randomized controlled trial that found care partners could significantly reduce symptoms and side effects of treatment in patients simply by following the instruction provided in the video and accompanying manual.<sup>1</sup>

This award-winning, evidence-based program was released to the public in December 2009. It is now being used at leading cancer centers, hospice programs and other palliative care settings in the US, the UK and Australia.

This Program Guide is intended for health care practitioners and administrators who are in a planning role for development of integrative medicine and palliative care services. It offers you alternative strategies and suggestions for implementing the program in your unique setting. It contains four sections: (1) Video Discussion Guide, (2) Program Planning, (3) Strategies for Funding, and (4) Consultation and Training Opportunities.



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<sup>1</sup>Collinge W, Kahn J, Walton T, Kozak L, Bauer-Wu S, Fletcher K, Yarnold P, Soltysik R. Touch, Caring, and Cancer: randomized controlled trial of a multimedia caregiver education program. *Supportive Care in Cancer*. 2013 May;21(5):1405-14 ([free online open access](#)).

## VIDEO DISCUSSION GUIDE

This guide is intended to help leaders of support groups, workshops and in-service trainings to facilitate group discussion of *Touch, Caring and Cancer* and the concept of touch as a way to enhance caregiving. While the video was designed and tested in autonomous use by families at home, it can also be used in support groups for patients or caregivers as well as groups where both parties in the relationship are present.

### PURPOSE OF THE INSTRUCTION

The video is designed first and foremost as a *psychoeducational* intervention. While instruction in techniques of touch and massage is helpful and will be easy to follow, the more important aspects of the program are the permission and encouragement to use touch. The instruction addresses questions people may have about their own abilities to use touch effectively, safety, communication between giver and recipient, realistic expectations, preparation and frame of mind when using touch in caregiving.

For these reasons it is important that the program not be misrepresented as “a massage video”, or instruction in “oncology massage” or “massage therapy.” The hands-on techniques are offered as means of connection and communication with the patient—as ways of expressing caring. The real emphasis is on quality of relationship and communication through touch, and technique is secondary.



The techniques that are taught are for the purpose of comfort and relaxation only. They involve light and uncomplicated methods. The fact that such simple touch can lead to significant reductions in symptom levels speaks to the untapped potential of family and friends to improve patients’ quality of life by including this form of support in their caring.

### USING THE PROGRAM IN GROUP SETTINGS

The full program is 78 minutes. If time permits, the ideal way to present it is with a *complete viewing*, after which there can be discussion and, if desired, practice of some of the techniques. Watching the full program also assures viewers will see “Closing Thoughts”, the final chapter, which presents some important and evocative material for discussion regarding the relationships between participants in the film. For example, the feelings expressed by Carol toward use of massage with her father are a rich stimulus for group discussion.

If complete viewing is not possible in one session, then the Menu allows the program to be easily viewed in chapters in the recommended order. The chapter lengths are shown below. There are natural breaks in the flow of content from one

chapter to the next.

The program could be shown over a series of support group meetings. For example, a group could plan to show one or two chapters a week. This affords the opportunity for the group to maintain its familiar support group process, and incorporate the program in smaller pieces so as not to take up an entire meeting.

Program Menu			
Chapter	Duration	Chapter	Duration
Introduction	10:57	The Head & Face	4:07
Safety	5:13	The Neck	4:57
Preparation	13:54	Shoulders/Back	7:12
Setting the Scene		The Hands	7:47
Positioning		The Feet	6:53
Communication		Acupressure	4:20
Frame of Mind		Closing Thoughts	7:33
Centering			

Viewing the program in segments this way also allows more focused discussion and practice following individual chapters. For example, one group session could play the chapter on hand massage, and attendees could practice the techniques with each other for a few minutes after watching that chapter.

The Menu also allows you to select and repeat individual chapters for review as desired.

**FACILITATING GROUP DISCUSSION**

After viewing the program, viewers should be offered the opportunity to discuss their reactions to what they have just seen, and any thoughts about the potential use of touch in their own relationship with a patient or caregiver.



Watching the film evokes strong emotion in some viewers. The expressions of love and compassion shown between patients and caregivers can be quite powerful, and some viewers may even become tearful. There is enough diversity in the cast that many viewers may see someone with whom they can identify. Emotional responses may be a good point of discussion later, but of course only for those who are comfortable disclosing their feelings to the group.

For some there may be a recognition that touch has been lacking in their relationship or their caregiving, and this could be a source of discomfort that they might not feel ready to share. Thus it is important that everyone feels free to speak or not speak as they wish.

Some simple guidelines for discussion are as follows:

- Remind everyone to observe confidentiality about anything that is expressed in the meeting
- Ask everyone to make sure there is enough time for anyone to speak who wants to
- Remind everyone that there are no wrong reactions to the film
- Assure everyone that this is just one form of caregiving and that it may or may not be their “cup of tea”, so there is no pressure to use it

### Sample Discussion Questions

- What were your reactions to the film?
- Do you think this is something you could do?
- Who in the film did you identify with? Whose story was similar to yours?
- Do you think your partner might join you in something like this?
- What did you like most about the film?
- What concerns were brought up for you in watching the film?
- How has touch been part of your caregiving up to now?
- How do you think using these techniques might affect your relationship?
- Is this something you would like to do?
- What would you hope to gain from it?
- How would you bring up this topic with your partner?
- Would you be able to say “no” to your partner at times you didn’t feel like giving or receiving touch?

Keep in mind that self-expression through discussion can be highly beneficial regardless of what is being expressed, and that there are no wrong feelings or reactions.

### LEADING PRACTICE IN A GROUP

If time permits, and if you can plan for it, offer the opportunity to group participants to spend a few minutes practicing techniques. There should be no pressure for everyone to participate; some may prefer to simply observe, and it should be made clear that this is completely acceptable.

For those who would like to have the experience, almost all the techniques taught can be done with recipients seated in chairs. It is easy to introduce people to the use of hand massage, neck and shoulder contact, and even head and face techniques using chairs.

Prior to introducing any techniques, however, be sure and lead the group in a centering exercise to help them access a state of loving kindness and presence before making contact through touch.



### The First Time

For the first time, you might want to introduce use of touch by simply having the recipient seated in a chair with the giver standing behind. After the guided centering exercise, invite the giver to very slowly and gently place his or her hands on the recipient's shoulders. Resting the hands lightly there, encourage the givers to remain aware of their breathing, their centering, and their intention to feel loving kindness toward the recipient. Encourage the recipients to remain aware of their breathing, their own centering, and their own intention to be receptive to what is being offered to them.

After a few minutes of this light contact, invite the givers to slowly release contact, and then have the two switch roles. Repeat the process beginning with the centering exercise, then the gentle contact, holding lightly for a couple of minutes, then releasing. This can be followed by the givers taking their seats again and the two sharing their experiences with each other.

As the leader you can invite them to discuss the following questions:

- What was it like being the giver?
- What was it like being the recipient?
- Were you able to stay centered?
- Did you feel any self-consciousness or concerns about giving or receiving?

After the dyads have responded to these questions with each other, invite the whole group to re-assemble and share any observations they would like with the group.

The process described above is a way of introducing touch in a “non-technique-oriented” way, so that people can focus on the more central experience of presence and not be concerned about technique. This will underscore the importance of presence as the key to successful and satisfying use of touch in caregiving. In future sessions you can use the same protocol to practice the individual techniques taught in the program, but always reminding participants that presence is the most important ingredient.



### Future Sessions

If you and your participants would like to incorporate a little touch practice in each session, you can do so by choosing one technique each time for just a few minutes of practice. If you can show the video chapter on that technique first, this will be helpful since repeated exposure will reinforce the instruction. In time the group may evolve beyond the need to review video instruction, although when new participants join the group it would be helpful to them.

Keep in mind that some of your participants, particularly those living alone, may receive very little or even no touch in their lives. Ultimately, touch can become a satisfying and rewarding element of a support group experience.



## PROGRAM PLANNING: REACHING FAMILIES

The program was designed and tested as a free-standing, at-home program that does not depend on professionals to teach or supervise the methods used. This was an important goal of the project because most patients and families do not have the resources or convenient access to professionals to provide this form of instruction or supportive care regularly. The NCI evaluation study demonstrated that users were able to understand and apply the instruction—including the safety precautions material—autonomously in home use.

One important instruction *does* involve staff, however: Users are directed to go over the “Precautions Checklist” in the manual with a staff member so they are clear about what safety precautions apply to their patient. Thus we encourage you to be aware of who is using the program, and be available for this brief consult to the partner.



Below are described several strategies organizations can use for disseminating the program to patient families. More will be added in future versions of this guide as we receive new ideas from users.

### NEW PATIENT WELCOME/ORIENTATION PACKETS

Many settings give free welcome or orientation packets or kits to new patients and families coming for care. Such welcome packages often include printed materials, relaxation tools, and information about other products or services from which the patient and family may benefit. *The Touch, Caring and Cancer Program* is suitable for distribution in this way in the form of an **organizational coupon code** with which patients and families can access the program at no cost.

This will enable users to stream the program on any device, whether a computer, tablet or mobile phone, or home TV with casting, a particularly convenient way to access the program on a phone or tablet.

If your setting can offer access to the program in its welcome materials, we would encourage you to have your staff become familiar with it so they can proactively encourage its use during follow-up visits and support the family if they have questions about it.

Because the program presents a new concept to many care partners, some may not realize the potential value to themselves and their patients if they simply find a promo code in a packet mixed with other materials. Staff members can help families by drawing attention to the program and giving specific encouragement to explore it as a resource to benefit both the partner and the patient.

### DISTRIBUTION TO INDIVIDUAL FAMILIES BY STAFF

Another model currently being used is the distribution directly to families by support staff. Some settings have social workers that can offer families access at the time of their initial psychosocial assessment, or in subsequent meetings where supportive counseling or therapy takes place. This allows a personal conversation in which the staff member can explain how the program may address specific needs of a patient and family.

For example, if pain is the predominant symptom, staff can explain to the couple that simple use of techniques taught in the program may enable the care partner to help reduce pain. In follow-up sessions the staff member can then provide on-going encouragement for practice at home.

For inpatient settings, nursing staff may introduce the information about the program to families and encourage accessing it in the hospital room during visits. This provides the opportunity for staff to quickly review the Precautions Checklist with the family (this can be printed in hard copy and handed out, or viewed in the PDF of the manual) prior to giving out access to streaming the program. This way care partners can use some of their visiting time for active rather than passive support of their loved one.

This can make visits far more rewarding for both the patient and the partner. For example, rather than watching television or movies, the dyad can watch the program on a mobile device, view the manual, and practice the techniques right there on the hospital bed or on a chair in the room. An advantage of hospital beds is that the elevation and angle can be adjusted so the care partner can be as comfortable as possible while using the techniques. The importance of care partner positioning is directly discussed in the video and manual.

### RESOURCE LIBRARIES

Resource libraries often have computers connected to the internet. This is an opportunity for users to preview the program to see if it is of interest to them. Either the preview or the actual Introduction (about 5 minutes) will be enough to make clear to viewers what the program is about and that it is intended for them. Library staff can help by encouraging visitors to watch the preview or Introduction.

For families who do not have adequate bandwidth at home, partners can learn by watching the program on a device in the hospital or resource library during visits—perhaps while their patient is resting or receiving treatment elsewhere in the facility.

### SUPPORT GROUPS

The full program is suitable for viewing in support group meetings of patients, care partners, and families. These are especially good opportunities for viewing because they allow group discussion that can be facilitated by a staff member. Patients and partners can ask questions and be helped to understand the safety-



related content with the help of a staff member.

Some of the techniques can be practiced right there in the meeting, such as hand massage, hand sandwich, light touch, etc. Through group practice, staff can facilitate discussion of people's experiences and encourage communication between patient and partner about what feels good, what is working, and what pressures are comfortable.

It would be optimal in this situation to have multiple coupon codes available to give out so that viewers can explore the material at home after being introduced to it. An on-going group will afford opportunities to reinforce practice and discuss questions about use of the techniques should they arise. In this way a "support group" can become a "healing group."

### **FAMILY PROGRAMS, WORKSHOPS AND RETREATS**

Your setting can sponsor an event such as a seminar, workshop or retreat for families in which the program is shown and then participants are guided in discussing their thoughts and feelings in response to it. This can be followed by guided practice of selected techniques from the instruction.

The participation of staff from multiple disciplines can make this approach even more effective. For example:

- A social worker may have special skills to offer in terms of facilitating group discussion, and particularly exploration of attitudes toward touch and caregiving in the couple's relationship.
- A nurse or physician can contribute special expertise in understanding patients' medical conditions and appropriate safety precautions.
- A massage therapist is ideally suited to give guidance in using touch-based techniques—including giving care partners the "felt experience" of how various pressures and strokes feel. Many settings have massage therapists with specific training in oncology massage, but, while helpful, this is not necessary to assist with such instruction due to the simplicity of what is being taught.



Some settings have distributed access to the program to attendees at the end of a workshop. Others may rely on having viewing equipment in their resource library, so families who attended a program can continue exploring the instruction over time.

### **REACHING UNDERSERVED AND MINORITY POPULATIONS**

If your setting serves ethnic or linguistic minorities, the program may be a welcome resource for them. The families depicted in the video and manual include white, African American, Asian and Hispanic/Latino participants, and these groups were also represented in the evaluation study. The program is available in English, Spanish, Mandarin, Cantonese and Vietnamese. The manual is available in English, Spanish, Chinese and Vietnamese versions.

Special programs can be organized for underserved groups who attend your

setting. For example, one large cancer center held a one-day workshop just for Chinese speaking families to introduce the program. Oncology massage therapists and interpreters were present and the group watched the program together, followed by discussion and practice. At the end of the day the families were sent home with access to the program on their own.



## STRATEGIES FOR FUNDING

The cost of the program is much less than a single massage by a licensed practitioner. Nevertheless, there may be a need in your setting to secure funding for access codes since it may not be covered under normal operating budgets. There are several pathways that can be used to fund the program for patients.

### GRATEFUL PATIENT/GRATEFUL FAMILY

Complementary and integrative therapies are widely used and appreciated by cancer patients. Often grateful patients or families who have benefited from these therapies want to donate funds to make them available to others. It is not uncommon for support staff to be asked by patients or families how they can “give back” or do something to benefit other families, out of gratitude for the care they received in that setting.



In one cancer center, the survivors of a deceased patient accepted donations in his memory and earmarked them specifically for making *The Touch, Caring and Cancer Program* available to families coming there for treatment. The actual donations were made to the organization’s development department, but the family directed how the funds were to be used. A large number of copies of the program were purchased and distributed directly to families individually by support staff.

### CHAMPIONS OF INTEGRATIVE CARE

Some donors have the specific ambition to promote the concept of integrative care. This may be out of personal experience of benefit, for philosophical reasons (a desire to promote “high touch” medicine), or out of a desire to make complementary therapies available to others who cannot afford them.

These champions of integrative care sometimes take big and bold steps like funding the building of a whole new facility or program devoted to complementary therapies. However, on a much smaller scale, they may just as well see great potential in the family as a resource for providing integrative care beginning at home. The values of strengthening families and home-based caring may appeal to donors who would like to support a low cost but high impact project such as this.

### DEVELOPMENT OFFICE

The development office of your organization raises funds to support its mission. Often the development funds are taken up by infrastructure or basic organizational needs, but there can also be latitude to direct some funding for special projects to enhance patient care. These decisions are of course made at the policy level, but the

input and influence of clinical staff—particularly those in leadership positions—may help obtain support for special projects such as this.

Keep in mind that organizational budgets often are dealing in hundreds of thousands to millions of dollars. A family resource offering like this program may be on the order of a few hundred dollars, yet it can have a strong positive impact on the quality of life of patients and families.

Again, advocacy of the concept by senior staff can have a real impact, so it will be important to sell them on the value of this program for your population. *By far most effective way to get their buy-in is for them to actually view the program* (or at least the preview on the [partnersinhealing.net](http://partnersinhealing.net) website). Because it is a unique concept compared to what the organization has dealt with previously, direct viewing is necessary in order to grasp the impact on families. Once they see it, it will be much easier to argue the justification for funding.

### SPONSORS

Sometimes there is an individual or an organization that would like to sponsor access to the program for families attending a cancer center or hospice. The benefit of sponsorship is that, if they wish, they can be recognized for their contribution. This may help to build their reputation in the community or advance their own mission.



One approach to such recognition is that a welcome letter written by the sponsor on their letterhead can be inserted inside patient or family information packets with a promo code and explanation included, with messaging such as “With the compliments of...” or “Presented by...”.

### GENERAL FUNDS

Your organization may have the resources in its general budget to make the program available to your families. Given its extremely low cost, you may have success, particularly with the support of other senior staff, appealing to administration to make funds available for this. Again, however, because of its uniqueness, it may be important for them to actually view the program before they will have sufficient understanding of what it is about.

### RESEARCH GRANTS

Donor organizations are sometimes more willing to give funds for a research project, or at least a project with a research component, than simply funding a product or service. If you plan a research project you may be able to get funding for a number of users or families. Most funders are not looking for a highly complicated study; rather, they are interested in basic but meaningful feedback about how the program has affected real people’s lives and how it could become self-sustaining. Think of a small research grant as seed money, as it could be just a first step to a



larger request once you have some data that demonstrates the value of the program to families in your setting.

Consider asking your development office what donor organizations they can suggest that might support a small research project. Research grants sometimes include funds for overhead and salary as well as materials. The overhead and salary portions would be looked upon positively by your organization. This could be added incentive for your administration to support you in the application.



Another way to have a study conducted is as part of a degree program. A student (whether an employee or from an outside institution) in need of a project to complete a degree might do a study of impact of the program with families at your site. Thus the student might be donating his or her time, and funds might only be needed for the materials.

## RESEARCH REFERENCES

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## CONSULTATION AND TRAINING OPPORTUNITIES

Several contributors to the development of the *Touch, Caring and Cancer Program* are available for consultation and educational opportunities for your organization and the population you serve. Opportunities include professional continuing education, grand rounds presentations, conference presentations, family workshops and retreats. Examples:

**Program Development.** Consultation is available from the Integrative Palliative Care Institute (IPCI) for organizations and institutions wishing to develop programs of integrative oncology. IPCI was formed by William Collinge and Leila Kozak through an NCI research project that developed an online CE/CME program for health care providers in the evidence-based use of integrative therapies in palliative care. Drs. Collinge and Kozak are available to consult on program development strategies including models of integrative care, credentialing of providers, approaches to economic sustainability, evaluation, and grant-writing assistance.

**Massage and Cancer.** Continuing education programs are available for massage therapists as well as non-therapists in the background and applications of massage in cancer care. This can include ways of integrating the *Touch, Caring and Cancer Program* alongside formal services to dramatically increase patient and care partner satisfaction.

**Integrating Touch into Nursing Practice.** Continuing education offerings for nurses are available which focus on ways that nurses can improve patient care and enhance job satisfaction through the use of touch in their interactions with patients during nursing care.

Consultants available include:

- William Collinge, PhD, MPH, director of *The Touch, Caring and Cancer Program*, is an NIH researcher and clinical social worker whose work focuses on integrative palliative care and caregiver education. He is associate director of the [Integrative Palliative Care Institute](#), has led group programs and retreats internationally and authored four books, including *Partners in Healing* (Shambhala, 2008).
- Leila Kozak, PhD, is Director of the [Integrative Palliative Care Institute](#), adjunct clinical faculty at the University of Washington Department of Family Medicine, and formerly a post-doctoral fellow in palliative care research at the VA Puget Sound Medical Center where she used *The Touch, Caring and Cancer Program* with veterans and their families. A native Spanish speaker, she is also involved in several international efforts to promote complementary therapies in palliative care.
- Tracy Walton, MS, NCTMB, one of the lead instructors in the program, is a massage therapy researcher, author, and internationally recognized expert in



oncology massage training. She is author of the text *Medical Conditions in Massage Therapy* (Lippincott Williams & Wilkins, 2010).

- Mary Malinski, BA, RN, LMT, HN-BC, is a former nurse educator with Providence Health and Services (Portland, OR), an oncology massage therapist, and founder of the Red Bear Program for bringing touch back into nursing care. She directed the Providence Cancer Center component of the *Touch, Caring and Cancer* research project.

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