



Cancer Support Community Urology Program

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Program Overview

- ▶ In May of 2018 Cancer Support Community created a part-time position for a Urology Program Manager with the intent to screen newly diagnosed prostate survivors from The Urology Group for distress and to provide individualized counseling, decisional counseling for individuals and their families.
- ▶ These services are offered at **no-cost** for prostate survivors and their families.
- ▶ As the program has grown and developed over the past 9 months, services have been increased to include all (advanced prostate cancer survivors and non-The Urology Group patients) and their families.

*You can make it, but it's
easier if you don't have
to do it alone.*

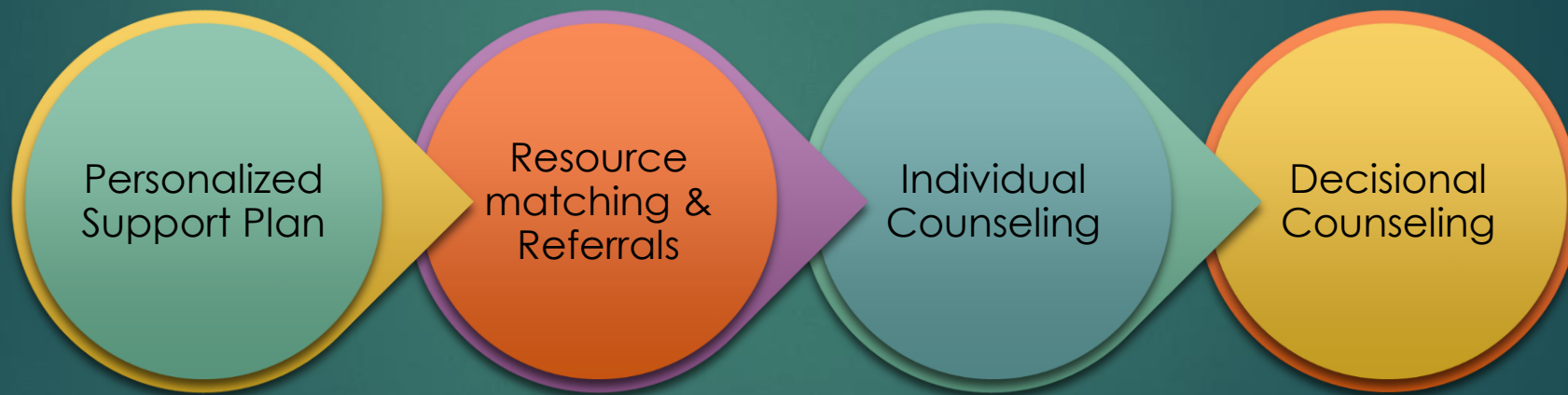
— Betty Ford



happify™

What this
means
for you

Services Offered



Personalized Support Plan

- ▶ Cancer Support Community (CSC) utilizes a confidential, validated distress screening survey to both screen cancer survivors and their family members for distress, and also to provide a personalized support plan for each person.
- ▶ The survey can be taken in person at CSC, through email, or by taking the survey in paper form.
- ▶ Each person then receives resources for the local Cincinnati area, educational information for topics that they are concerned or interested in, and recommendations for CSC programs that may be helpful.
- ▶ The survey takes about ten minutes and can be taken as often as you like.

Sample Report

My Support Care Plan

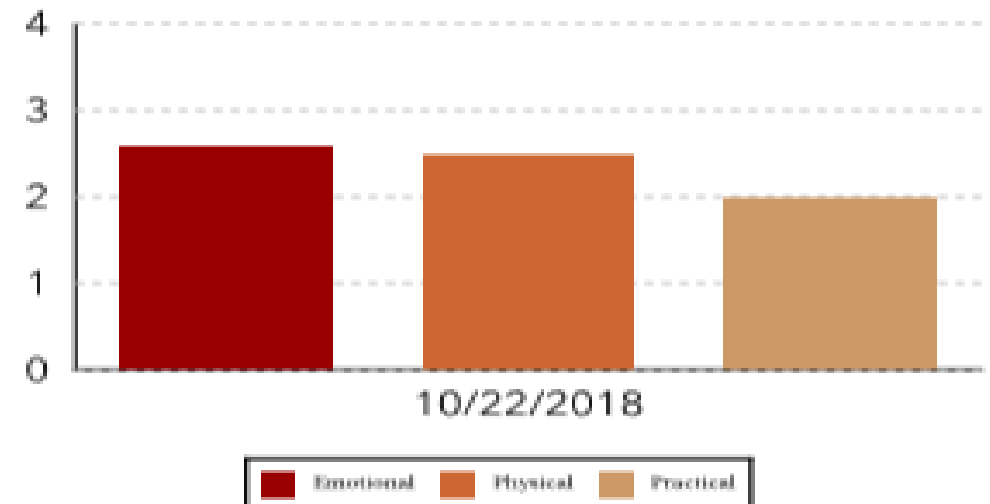
Thank you for completing your CancerSupportSource® Distress Questionnaire. This report has been created for you based on how you answered the questions. It is a guide to finding the information and supportive services that could be most useful to you at this time. The distress items listed are ones that you requested additional information. Please review the helpful tips, print and online materials provided in this report. A staff person will be happy to review this report and assist you in finding supportive resources.

Name: **rebecca IRWIN**

Date of Birth: 09/01/1978

Date of Survey: 10/22/2018

Your distress score: 36/60



Sample Report Cont.

Health insurance or money worries: please let us know how we can help you.

Having open conversations about insurance, financial concerns and the cost of cancer care are an important part of managing life with and after cancer. There may be resources that can help you reduce the financial impact of cancer. Above all, be informed and don't hesitate to ask your health care team to discuss these issues with you.



Here are some related online resources that you may want to check:

Health Insurance or Money Worries

http://www.cancersupportcommunity.org/sites/default/_pdfs/general/health-insurance-or-money-worries.pdf

Financial and Legal Information

<http://www.cancer.gov/cancertopics/coping/financial-legal>

Patient Advocate Foundation

The mission of the Patient Advocate Foundation (PAF) is to provide effective mediation and arbitration services to patients to remove obstacles to healthcare including medical debt crisis, insurance access issues and employment issues for patients with chronic, debilitating and life-threatening illnesses.

Resource Matching & Referrals

- ▶ Based on each person's individual support plan and/or personal needs, programs and local resources are provided either in a one-on-one appointment, by phone or mail.
- ▶ Since the implementation of the program, we have found that prostate cancer survivors have been most interested in education information, financial resources, and side-effect management.
- ▶ Survivors and their families are matched with CSC programs, local Cincinnati resources that may be helpful, and prostate cancer specific organizations that offer emotional, financial and educational support.
 - ▶ See Handout

Resources Continued – Educational

- ▶ **ZERO – The End of Prostate Cancer**
 - ▶ <https://zerocancer.org>
 - ▶ FB Group - ZERO Prostate Cancer Champions
- ▶ **Prostate Cancer Foundation**
 - ▶ www.pcf.org
- ▶ **Us Too** <https://www.ustoo.org/Home>

Resources Continued - Financial

▶ Financial Resources

- ▶ <https://zerocancer.org/>
- ▶ <http://www.cancer.gov/cancertopics/coping/financial-legal>
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<http://www.patientadvocate.org>
- ▶ **Patient Access Network**
<https://panfoundation.org/index.php/en/patients/how-to-apply>
- ▶ Medical Bill Financial Assistance
<http://heartstonefoundation.org/heartstone-foundation>

Resources Continued – Side Effects

- ▶ Zero – FB group
- ▶ PCIG – Man-to-Man Group
 - ▶ Educational Group
- ▶ Making Love Again, by Virginia and Keith Laken
- ▶ Kegal Trainer PFM Exercise App – Free app with reminders on your phone to do Kegal exercises.

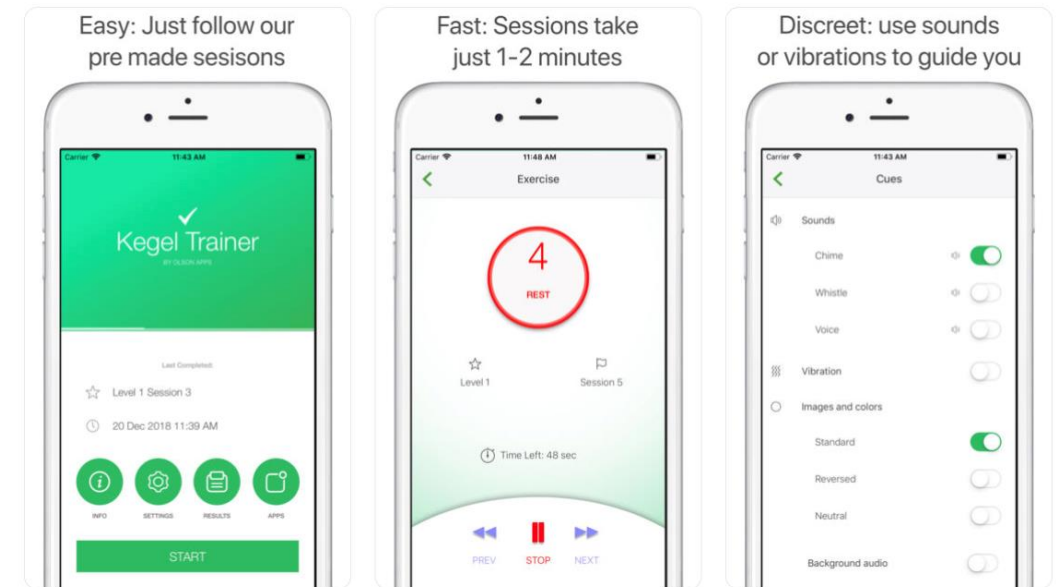


Kegel Trainer PFM Exercises

Pelvic floor exercises

★★★★☆ 609

[OPEN](#)



Individual Counseling

- ▶ No-cost, Brief Solution Focused Therapy, is provided for up to six sessions for anyone interested in working one-on-one with a therapist.
 - ▶ One initial consultation to determine needs of the individual, not included in the six sessions.
 - ▶ One initial session to determine what the individual would like to focus on, typically consisting of 1-3 brief goals. These typically surround the areas of side-effect management, feelings of sadness, worries, quality of life concerns, sleep management and life goals to improve health and wellness.
- ▶ Appointments are available Monday-Thursday at the CSC Blue Ash location, and at The Urology Group in Norwood on Wednesday afternoons.

Sometimes the
questions are
complicated
and the
answers are
simple.



Brief Solution Focused Therapy

- ▶ Solution-Focused Brief Therapy has several foundational tenets (de Shazer & Dolan, 2007).
- ▶ First, if it is working, do not fix it.
- ▶ Second, if something is working for you, do more of what works.
- ▶ Third, if it is not working, try something different.
- ▶ Fourth, small steps can often lead to bigger changes.
- ▶ Fifth, solutions are not necessarily directly related to problems. Clients do not need to sort out problems of the past.
- ▶ Sixth, problems do not happen all of the time, and these exceptions can be utilized.
- ▶ Finally, clients can define their own futures.

Decisional Counseling

- ▶ Cancer Support Community utilizes a copyrighted program called Open to Options, which was developed with an emphasis on shared decision making between the medical provider and the patient. Developed in collaboration with CSC, Dr. Jeff Belkora and Education Network to Advance Cancer Clinical Trials (ENACCT).
- ▶ “The Cancer Support Community, in collaboration with Dr. Jeff Belkora and the Education Network to Advance Cancer Clinical Trials (ENACCT), developed and evaluated the *Open to Options*™ program and its Question Listing approach to help patients communicate more effectively with their health care team in order to arrive at the treatment decision that is right for them.”
- ▶ Together with a trained, CSC clinical staff member, individuals are guided to anticipate questions from their medical provider, develop a printed question list for key medical appointments.

Decisional Counseling Cont.

- ▶ Ideal for many prostate survivors because frequently there is not a rush to treat (Active surveillance).
- ▶ This model helps patients process information when asked to anticipate their responses, questions and concerns prior to making a treatment decision.
- ▶ Results:
 - ▶ 20% decrease in anxiety
 - ▶ 60% increase in confidence
 - ▶ 37% decrease in distress

Open to Options



Questions to Discuss with My Doctor

Meeting with:
Today's Date:

Question List for Appointment with.....

MY SITUATION—key facts about my situation:

Diagnosed in September 2018. It was determined that the cancer was not aggressive, and I was placed under active surveillance with PSA tests every six months. I love to travel and future treatment options must include the ability for be able to travel. I am a very active person, who loves to exercise and being able to maintain a fitness routine is very important to me.

MY OPTIONS—my understanding of choices/options available for treatment:

If I need treatment, my options are:

Radiation x-rays, cyber knife, prostatectomy, I know all of these treatments cause incontinence and ED.

Incontinence is my most worrisome side-effect

I am concerned about my ability to obtain an erection if I receive radiation because of my young age.

NETWORK—who can help, voice and responsibilities:

My wife

My primary care provider

My urologist

My friends

My family, my brother who was diagnosed with prostate cancer and received radiation

My cousin who is an MD

Cancer Support Community

My personal Trainer

GOALS and OBJECTIVES—my concerns, priorities, values, preferences:

To be independent to travel and exercise without worrying about incontinence.

EVALUATION—my questions about how my options affect my objectives:

What are my treatment options?

What treatments will cause the least number of side-effects?

Is there anything I can do now to reduce the likelihood of incontinence?

How can we treat incontinence if and when it happens?

What options are there for Erectile Dysfunction?

How long will I have to do monitor my PSA?

What does my PSA have to reach to have to trigger a change in my treatment plan?

Can we monitor the PSA more often?

What are the newest treatments for prostate cancer?

This question list summarizes concerns as expressed by the patient. Cancer Support Community does not provide medical advice or specific treatment information. Open to Options is for information only and not intended to take the place of medical care or discussions with the health care team.



A SERVICE of the CANCER
SUPPORT COMMUNITY

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Open to Options Cont.

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News/Upcoming Events

- ▶ **NEW!! Men's Strength Training starting March 6th, 2019**

Coming Wednesdays in March, 5:30 pm - 6:15 pm

Join us for this strength training class, where we will work our full body using light weights, bands and body resistance. All fitness levels welcome! Facilitated by Emily Morgan, Personal Trainer and Cancer Exercise Specialist.

- ▶ **Reel Recovery Retreat June 3rd -5th, 2019**

- ▶ **Gentleman's Stakes 5k walk/run/snooze for dudes** <http://urologygroup.com/gentlemen-stakes/>

- ▶ Pre-race survivor's breakfast



Questions?