Lunch & Learn with the LINK

Navigating and Advocating Through Your Transplant Journey

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You are the captain of your health team

- Studies tell us that patients (and loved ones of cancer patients) who learn about their disease and are actively involved in their medical care, have a better quality of life. Some studies even suggest they may have better outcomes as well.
Learning how to communicate what needs you have and helping the team to understand your wishes/concerns will only help your team understand how to best work with you. Some things are not in your control, however, the quality of your life improves when you have a voice in things that are.
For example

You decide how aggressive you are willing to have your treatment

Which side effects you can tolerate

Where you want to be treated (Insurance can affect but you decide)

Would you like a second opinion

Who you choose to share what information with

Who is able to make decisions for you if there is an emergency

Who is on your team

ETC.......
Resource for Discovering Your Needs

https://www.canceradvocacy.org/resources/knowyourself/
Your team

Caregivers/ Spouse/Family
Doctor(s)
Nurse(s)
Oncology Social Workers
Financial Counselors
Nutritionist
Clergy
Community Resources
National Organizations
Peer Mentors
And others...
Who has your back? Your Caregiver

Your caregiver has to be able to be tapped in when you reach your limit, be a second set of ears at appointments, be a secretary, be an amateur health aide, and know how to get support for themselves.
Ways to advocate for yourself with your doctor

What information do I need to help me make a decision about treatment?
What information do you use to make treatment recommendations for me?
What are your realistic goals for my treatment?
What are the chances that I can be cured?
What are my chances of a long-term response with good quality of life?
Are there clinical trials available to me?
How will I feel during treatment? Will I be able to work?
How will I take care of my family? Travel? Can I be around young children?
What help will I need in managing the side effects of treatment? When and for how long?
Should I consider a second opinion regarding my diagnosis and treatment?
Are there different approaches to treating my kind of cancer?

From NCCS
Doctors give their best

They give you their medical expertise, research, and years of experience, but they cannot predict the future or how your journey will unfold. You ultimately choose how you want to proceed based on the advice they give.
Nurses

Amazing educators
Knowledgeable regarding tips for symptom management
Often experts at making complicated medical discussions more understandable
Usually more accessible than the doctors are
Oncology Social Workers

- Provide individual/family counseling
- Offer support groups
- Are advocates when you feel your voice is not being heard
- Connect you with resources within your community/nationally that can help you meet your needs
  - (Ex: financial concerns, transport, medication assistance, copay assistance, help in the home, etc.)
- Educators
- Assist patients with applying for disability/assistance programs
Great Resources for Common Needs

https://www.cancercare.org/helpinghand

Find Assistance from Organizations
Providing Financial or Practical Help

- Diagnosis
- Zip Code

Please select one or more types of assistance:
- Camps/Retreats
- Co-Pays
- Dental
- Eyeglasses
- Fertility
- Financial Assistance
- Food
- Genetic Testing
- Hearing Aids
- Home Care
- Housing
- Legal
- Lodging
- Meal Delivery
- Medical Equipment/Supplies
- Medication
- Nutritional Supplements
- Prostheses
- Reconstruction
- Scholarships
- Screening
- Transplants
- Transportation
- Utilities
- Wigs
- Wish Fulfillment

Optional - Select a specific population:
- Children
- Teens
- Young Adults
More resources...

www.cancerfac.org
Local service or volunteer organizations such as Catholic Charities, Jewish Social Services, the Lions Club, Lutheran Social Services, the Salvation Army, and others may offer financial assistance. Some of these organizations offer grants to help cover the cost of treatment and other expenses, while others help with specific services or products, such as travel or medications. A social worker or an Internet search can provide you with a list of organizations. Many hospitals and clinics also maintain a list of service organizations in the community.
Local Resources

The American Cancer Society (800-227-2345) and the local United Way office can also direct people to services in their community.

The Department of Social Services in your city or county may provide food, housing, and other general assistance services. Sometimes they may offer direct financial assistance. Check the local telephone directory or online for contact information.

Community-based groups, such as local churches, synagogues, mosques, and lodges may also provide assistance for people with cancer, sometimes even if the person is not a member of that particular organization or religion. Some hospitals also have private funds available for patients in need.
Financial, Legal, and Insurance

https://triagecancer.org/

TRIAGE CANCER

...helping navigate cancer survivorship
Prescription Help

www.needymeds.org

Has all prescription assistance programs and applications online.
Talk to someone who has been through a transplant or has been a caregiver, and is able to lend an ear, answer questions, and help you feed the hope needed to go through this process.
Support Groups

- CancerCare, Inc.
  www.cancercare.org

  CancerCare is a national non-profit organization that provides free professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved.

- The Leukemia & Lymphoma Society
  www.lls.org

  The Leukemia & Lymphoma Society is the world’s largest voluntary health organization dedicated to funding blood cancer research, education and patient services. They offer financial assistance, support programs, educational programs and more.
If you decide you want to see a counselor, ask your social worker who he or she might refer. You can also go on Psychology Today and pick one by specialty, what takes your insurance, and you can read their profile. You can even email them ahead of time to try to interview and see if it is a good fit.

www.psychologytoday.com
Think Outside the Box

Where is help available and thus, where can I shift funds from to help me get what I need.

Any unique scenarios to consider?
Thank you

Feel free to reach out if you need more assistance
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