Supporting Caregivers

Brought to you by the:

NATIONAL LEIOMYOSARCOMA FOUNDATION

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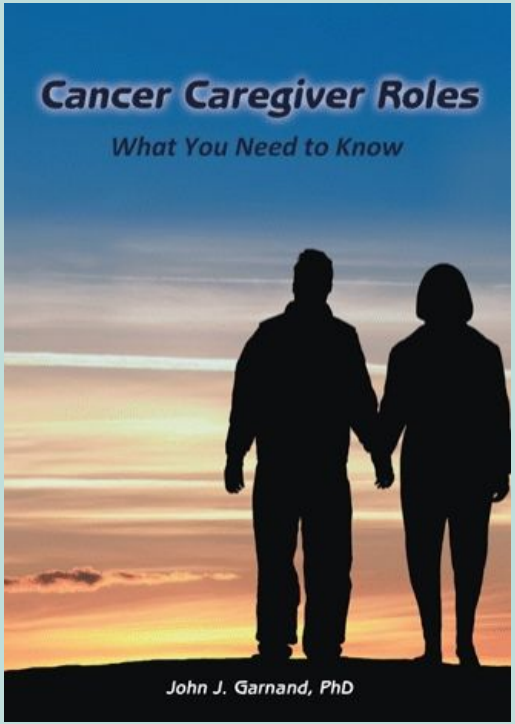
Support • Education • Advocacy • Research

Moving forward in the quest for the cure!

Profile of a Caregiver



- A spouse, parent, adult child, or a friend, co-worker, neighbor
- Many cancer treatments are given in an outpatient treatment center setting and not in hospitals.
- Day to day care of the patient receiving treatment require more involvement in the monitoring and assistance given -to enable management of side effects and communicate well with the oncology care team - in a timely manner.

Helping...

- Make sure you and your loved one review the health insurance plan currently in place to understand coverages for everything to be involved in the cancer diagnosis journey - knowing what to expect reduces stress for you both.
- Make sure that there are no lapses in insurance, that you, as caregiver, are authorized to address questions or file an appeal if the need should arise.

Resources:

- Cancer Support Community - Insurance Checklist
- The NLMSF website - insurance resources
- A guide to questions to ask during oncology appointments
- Be Your Own Best Advocate- by asking questions - it is important to come away from the appointment adequately informed.
- Taking notes or using a voice recorder (if the medical team agrees to it) is helpful to remember what was said/covered during the appointment.

Helping The Patient...

HELPING THE PATIENT PREPARE FOR ONCOLOGY APPOINTMENTS -CAREGIVERS ARE QUALITY OF CARE ADVOCATES

Usually appointments may last up to 15 minutes

As a result, it helps to be well prepared for each appointment by having well thought-out questions to ask - have them typed up and provide a copy to the oncology care team member

For Long Distance Caregiving - helpful Resource Assistance links:

https://www.cancer.net/coping-with-cancer/caring-loved-one/long-distance-caregiving- from Cancer.Net and

https://www.cancercare.org/publications/275-long-distance_caregiving - from Cancer Care

Helping...

- Discuss the possibility of accessing Integrative Medicine – to obtain guidance on nutrition, exercise, well-being consultation that is tailored to the specifics of the patient's case.
- Discuss the accessing the guidance and counsel of a social worker or nurse navigator regarding information on financial assistance, insurance coverage and issues.
- An Appointment Organizer – is available to you – compliments of the NLMSF – an aid to keep imaging studies/reports, blood lab results, and notes organized for each subsequent visit.

Caregiver Reminders...

UNDERSTANDING THE PATIENT'S JOURNEY AS A CAREGIVER

- Knowing your loved one's cancer team – the multidisciplinary sarcoma team is important to know - and what their roles are in the care protocol established for the treatment journey.
- This information can be found in the Foundation's website: https://www.cancer.net/navigating-cancer-care/cancer-basics/cancer-care-team/oncology-team
- You are part of the Advocacy component of your loved one's self-advocacy efforts going forward in all appointments.
- Always be informed about prescribed medications and any medication interactions that would affect chemotherapy especially. Be aware of radiation side effect issues and how to manage them if necessary.

Importance of a Caregiver

- As the patient's needs change, so does the role of the caregiver – during and after treatment is completed.
- The demands of being a caregiver can be challenging – balancing work and the tasks at hand
- To meet the needs of patients and the caregiver's can be challenging but rewarding.
- The caregiver is an important partner with the patient of the Oncology Care Team.

Caregivers Reminders...

- Never be shy about asking questions and expressing any concerns you may have. Good communication with the care team will always benefit and enhance your efforts as a Caregiver to be the best Caregiver you want and need to be.
- Make sure that the goals of the treatment are clear and understanding able for both the patient and for you.
- Make sure that you are guided by complete information from the sarcoma oncology care team in terms of length of time for the entire treatment cycle, and follow up visits to be involved.
- Make sure that the possible side effects and symptoms are fully discussed and how to mitigate/minimize them are fully discussed. Keep track of all that is shared in an appointment organizer or audio recorder.
- Once the treatment protocol is completed, make sure that there is a Survivorship Care Plan in place for after treatment surveillance appointments are in place for the future.
- Survivorship Care Planning guidance can be found in the Foundation website: https://nlmsf.org/survivorship-2/

Importance of a Caregiver…

YOUR WELL-BEING IS IMPORTANT IN BEING THE EFFECTIVE AND LOVING CAREGIVER YOU WANT TO BE

- The Foundation has a special “Caregiver’s Corner” devoted to the well-being of caregivers: https://nlmsf.org/caregivers-corner/
- Take time out to destress, recharge, and rebound – to affect your physical and mental health in a positive way.
- Know your limitations – what you can and cannot do. You don’t have to do it all alone. There are resources for meal preparation, house cleaning help.
    - Visit the Foundation website for resources: https://nlmsf.org/resources/

The Importance of...

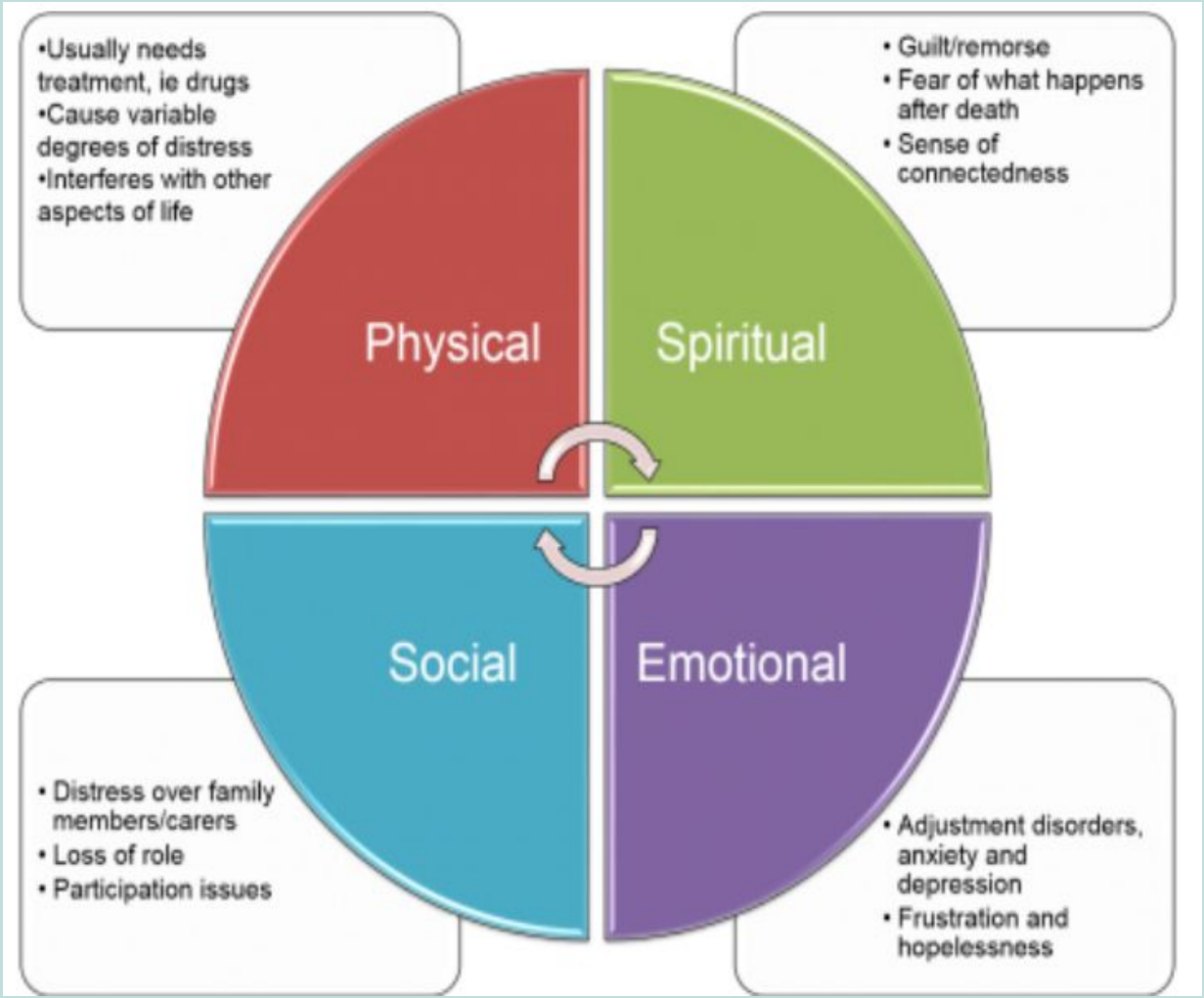
CAREGIVERS NEED THE SAME SPHERE OF SUPPORT

AS THE PATIENTS THEY ARE CARING FOR

- If any of these components below seem familiar because you have experienced them first hand, it may be helpful to reach out to a professional - whether it be in person or a telemedicine consultation.
- You have access to Integrative Medicine at a Sarcoma Center of excellence as well, to obtain assistance. You want to be your best – to be the best caregiver you can and want to be.
- Everyone in the cancer journey wants and deserves Quality of Life to the degree it is possible to attain. It will take time – it cannot all happen in a day – but patience and tenacity can get you there.

Importance of a Caregiver...

- Don’t be shy to ask for help - everyone in your sphere of support will want to be asked to help you and the loved one involved in your care.
- Making a meal, running an errand on your behalf will be rewarding for others who want to help.
- If you feel professional counseling would help you - realize that it is an option for you if you feel overwhelmed with caregiver responsibilities that are causing depression, physical or relationship issues with family members. It can be a healthy and effective way to address managing issues through this option.
- Plan on things you enjoy to take a break if someone is willing to step in and take your place for a few hours, so that you can do something just for you.


•Usually needs treatment, ie drugs
•Cause variable degrees of distress
•Interferes with other aspects of life
• Guilt/remorse
• Fear of what happens after death
• Sense of connectedness
Physical
Spiritual
Social
Emotional
• Distress over family members/carers
• Loss of role
• Participation issues
• Adjustment disorders, anxiety and depression
• Frustration and hopelessness

Take Care...

Resource Checklist (click here):

- Coping Checklist for Caregivers
- Coping Checklist for Patients
- For Long Distance Caretaking
  - From Cancer.net
  - From Cancer Care

"Do not count the days - Make the Days Count!" - Muhammad Ali

"You are the extension of an Angel's Hands and Wings" - Annie