

CARING FOR THE CML FAMILY CAREGIVER

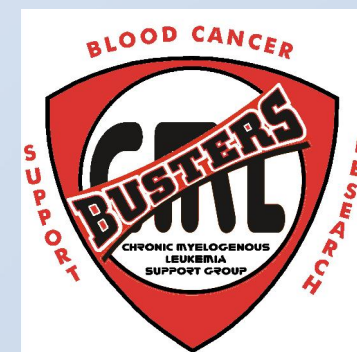
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CML Busters Family Support Group of California, USA

17 year CML family caregiver

29 year Type 1 diabetic patient

Advocacy Session #3
Best practice in patient advocacy
#CMLHZ19



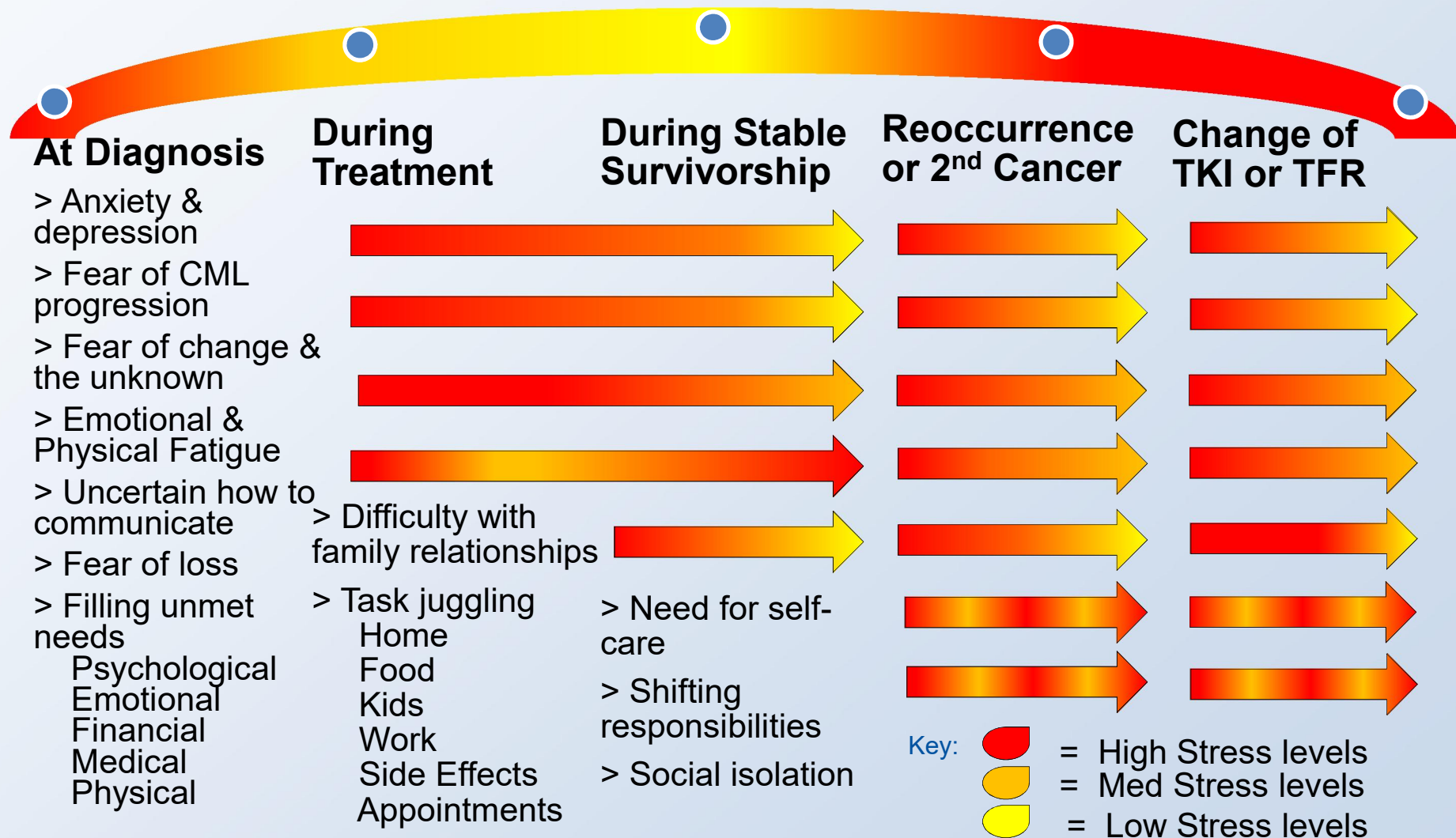
What is a CML Volunteer Caregiver?

“An unpaid/non-professional friend or family member who provides any help or emotional support in the face of a CML diagnosis and/or its treatment.” (3)

Facts the Who and Why:

1. There are an estimated 2.5 million CML caregivers providing services to ~500,000 CML patients worldwide today. (avg 4-5 caregivers / CML patient) (1) (5)
2. 28% of caregivers have higher risks for clinical depression, hypertension, heart disease or alcohol/drug abuse. (2)
3. Each caregiver / family member and the patient are affected mutually throughout the arc of the illness. (2)

The arc to independence showing caregiver pressures



Changing roles in the face of CML diagnosis and treatment

“The patient takes the treatments and the caregiver suffers the load of family responsibilities in silence” - CML caregiver 2019

CML treatment affects the whole family..

- ✓ Caregivers often will sacrifice their own health
- ✓ Caregivers also need to be educated
- ✓ Caregivers may provide a variety of services while continuing with their regular responsibilities
- ✓ Caregivers which take up the slack 7/24 may BREAK without the tools to cope
- ✓ Children may pickup on parents stress ques

The CML Caregiver Care Initiative plan

“Fear & Anxiety” are born out of loss of control or the unknown

“Depression” is born from the unresolved loss of control or lack of knowledge.

The *Caregiver Care initiative* plan:

1. Create a CML Caregivers Guidebook
2. Provide direct support opportunities early after diagnosis
3. Mentor the caregiver and patient
4. Provide additional resource links
5. Encourage caregiver self-care and respite
6. Appreciate caregivers by some special form of recognition

Sample of areas to address in a Caregiver Guidebook? (4)

1. What is CML and what are the current treatment options?
2. How CML diagnosis and treatment options affect others?
3. How CML treatments affect the patient?
4. Communications between CML patient and healthcare team?
5. As a caregiver, what can I do to best help the CML patient?
6. Caregiving during treatment – Am I prepared?
7. Nutrition and side-effects management
8. Legal and financial issues and management
9. Healthcare team management
10. Caregiver self-care management
11. Dealing with reoccurrence or a 2nd cancer diagnosis
12. Dealing with switching therapies / TFR issues

Appendix: Worksheets, Logs, Aids & Tools for caring

Worksheets, Logs & Aids included in the Caregiver Guidebook?

- | | | | |
|----|---|-----|---|
| 1 | Emergency Room (ER) Plan* | 10a | PCR History Log |
| 2a | Alternative Caregiver Plan | 10b | CBC Blood Test log |
| 2b | Weather Emergency Plan* | 11 | Chore Chart* |
| 3a | Medication / Side-Effects Log | 12 | Meal Planning* |
| 3b | TKI Compliance Log | 13 | Grocery List* |
| 3c | Daily Journal* | 14 | Food Intake and Side-Effect Log* |
| 4. | Questions for Caregivers to Ask the Patient | 15 | Insurance Call Log (US only)* |
| 5. | Healthcare Team Contact List* | 16 | Understanding Your Patient Health Plan (US only)* |
| 6a | Appointment Calendar by Month* | 17 | Insurance Appeal Tracking Form (US only)* |
| 6b | Appointment Calendar by Week* | 18 | Budget and Finance Plan* |
| 6c | Appointment Details* | 19 | Financial Assistance Record* |
| 7 | Questions for the Healthcare Team | 20 | Caregiver Self-Health Plan |
| 8 | Medical History and Drug List* | 21 | Caregiver T.A.S.K. Plan |
| 9 | Immunization Record Log* | 22 | Planning for Travel with CML |

* From the LLS Caregiver Workbook (4)

An example...the **T-A-S-K** tool

4 Yes/No questions to help assess Caregiver distress (2)

T ools?	Do you have what you need (the tools) to provide the best care possible to your cancer patient?
A ble to juggle?	Are you able to juggle your caregiver responsibilities with your other day-to-day responsibilities?
S elf-Care?	Are you taking care of yourself?
K eeping spirits up?	Are you keeping your spirits up?

Caregivers who answer “**No**” to any of the above questions may be at risk for caregiver strain and psychological distress.

What Support Groups provide...

Help for caregivers and families in understanding and addressing many issues over the full arc of chronic cancer treatments:

- ✓ **Experience** with the impact of CML treatment options
- ✓ **Experience** with the impact of changing roles and responsibilities of the patient/caregiver team
- ✓ **Experience** in handling new challenges and changes in the family dynamic
- ✓ **Reliable up-to-date information** resources for CML treatments and options
- ✓ **Coping tools and experiences** to help with time and stress management
- ✓ **Confidence through CML stories** show Caregivers and Patients that they are not alone!

Anticipated benefits of the Caregiver Care Initiative

- ✓ Reduce fear, anxiety and depression
- ✓ Reduce fears of CML cancer progression
- ✓ Help manage emotional and physical fatigue
- ✓ Strengthen Doctor-Patient-Caregiver relationships and communications
- ✓ Regain feeling of control over life (normalize)
- ✓ Stabilize family dynamics (normalize)
- ✓ Restore hope and confidence
- ✓ Empower patient and caregiver
- ✓ Improved patient healthcare outcomes

Thank You for your attention!

Sources and Acknowledgements:

- (1) “Cancer as a chronic disease”,
Jane Louise Phillips, RN, PhD, David C Currow, MPH, FRACP
Collegian (2010) 17, pp 47-56
- (2) “The Impact of Caregiving on the Psychological Well-Being of Family Caregivers and Cancer Patients”,
Laurel L. Northhouse, PhD, RN, FANN, Maria C. Katapodi PhD, RN, Ann M. Schafenacker, RN MSN and Denise Weiss, FNP, BS
Seminars on Oncology Nursing, Vol 28, No 4 November 2012 pp 236-245
- (3) Thanks to Joannie Clements, Gail Sperling, and Lisa Machado, CML Busters Family Support Group of California members and leadership for their commitment to families with CML worldwide over the past 16 years.
- (4) Special thanks to the Leukemia & Lymphoma Society for input from their upcoming general blood cancer Caregiver Guide
- (5) SEER and WHO population and cancer databases