

# CARING FOR THE CAREGIVERS

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**By the end of this presentation, you'll be able to identify:**

1. The meaning of caregiving
2. What features are unique to CML patient caregivers?
3. What difficulties may a CML patient caregiver be confronted with?
4. What can you do to overcome those difficulties?
5. What is the role of patient organizations regarding caregivers?

# 1. The meaning of caregiving

CARE / CURE



*Caru*  
*Cearu*



*Karo*  
*Charo*



*Cura*  
*curare*

1. Worries, troubles and anxieties

2. "Providing for the welfare of another"  
Attentive conscientiousness

Ethics of care

Two fundamental,  
but conflicting  
meanings

## Our definition:

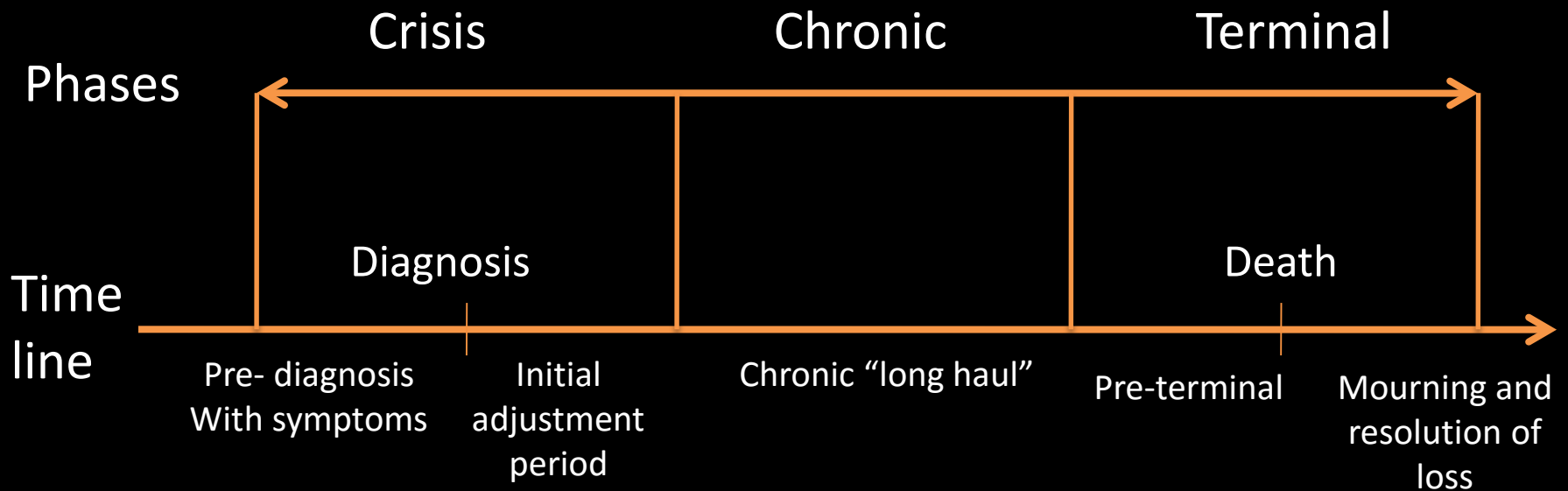
To walk along with somebody who has CML

- ✓ It is a behavior
- ✓ It does not mean “to take over” somebody (this idea could lead to some of the problems that caregivers report)
- ✓ It enables an active role for your loved one, or patient to take care of himself/herself

## 2. What features are unique to CML patient caregivers?

Variables that shape the needs of a CML patient:

1. Natural history of the disease
2. Personality of the patient / Coping style
3. Relation to the caregiver



Rational

Analytical



Directive



Socially Cautious

Socially Daring

Sensitive



Impulsive



Emotional

### 3. What difficulties may a CML patient caregiver be confronted with?

- “My relative / CML patient says that he/she doesn't want help and wishes to maintain his/her independence”
- “My relative / CML patient is in denial”
- “My relative/ CML patient does not want to take the medication”
- “I feel guilty when I am not able to do some of my duties as a caregiver”
- “I feel physically ill when helping my relative / CML patient”
- “My relative / CML patient treats me disrespectfully”

## Evidence shows that this issues can result in:

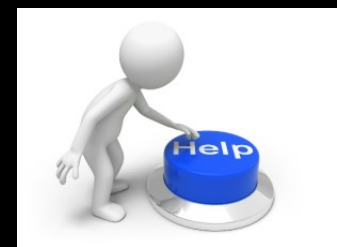
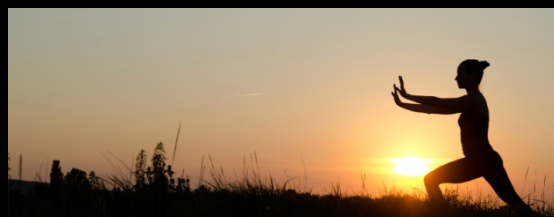
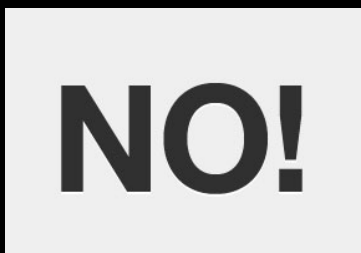
- Higher levels of depression
- Higher levels of stress and frustration
- Harmful behaviors
- Worse overall health status
- Increased risk of heart disease
- Lower levels of self-care
- Increased mortality





## 4. What can caregivers do to take care of themselves?

- Develop self-awareness
- Learn to say no (set boundaries)
- Stay active
- Have a second-line caregiver (arranged with your loved one or CML patient)
- Ask for help when you need it



## 5. Patient organizations and caregiving

- Make an assessment of caregiver needs that leads to a plan with support services
- Caregiver education
- Respite to reduce caregiver burden
- Financial support
- Be the second-line caregiver

Improved recognition and the addressing of physical and psychological symptoms among caregivers is a growing health concern and a major challenge for Public Health globally. Maintaining family caregivers healthy plays an important role in the context of current population aging and has deep ethical, social, psychological and economic consequences

## Some useful online resources:

- National Alliance for caregiving : <http://www.caregiving.org/resources/>
- Medicare: <https://www.medicare.gov/campaigns/caregiver/caregiver.html>
- Family Caregiver Alliance : <https://www.caregiver.org/>
- AARP: <http://www.aarp.org/home-family/caregiving/planning-and-resources/>
- Rosalynn Carter Institute: [http://www.rosalynncarter.org/caregiver\\_resources/](http://www.rosalynncarter.org/caregiver_resources/)
- Cruz Roja Española: <http://www.sercuidador.org/Ley-de-dependencia.html>
- Alzheimers.gov: [http://www.alzheimers.gov/espanol/caregiver\\_resources.html](http://www.alzheimers.gov/espanol/caregiver_resources.html)

# Thank you

If you have any questions, comments, or personal experience that you want to share personally with me, you can do it via e-mail to [nevescristian@gmail.com](mailto:nevescristian@gmail.com) or [cgneves@uc.cl](mailto:cgneves@uc.cl)