Caregivers: Quarterback, Cheerleaders and Caring for Self

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Care Partners Tour of Duty

“Becoming a care partner is similar to enlisting in the military. Both are a call to duty and similarly neither enlistee has any idea what their enlistment will require of them. However, there are some striking differences as well. One clear difference is that before agreeing to enlist in military service a person usually takes time to weigh the pros and cons. The decision to enlist as a care partner or caregiver is often done with no time for thought.”

Other differences are:

- No defined term for your tour of duty
- You are not assigned to your position based on your occupational specialty
- There is no plan in place to move up the ranks
- And the biggest difference is usually this duty comes with no financial or medical benefits.

Activity

- Words that come to mind when you think of yourself in relation to the person you are caring for/supporting

- Think of words that reflect both the challenges and opportunities that your role brings


stress
traumatic
Fatigue
theory
incident
caregivers
trauma
Compassion
help
risk
family
among
critical
cause
health
welfare
secondary
post-traumatic
fatigue
compassion
Figley
burnout
helpers
traumatized
situation
experience
services
working
symptoms
disorder
awareness
much
due
medicine
self-care
event
study
caregiver
disaster
project
hypersensitivity
time
Hasan
child
emotional
helping
care
professionals
others
people

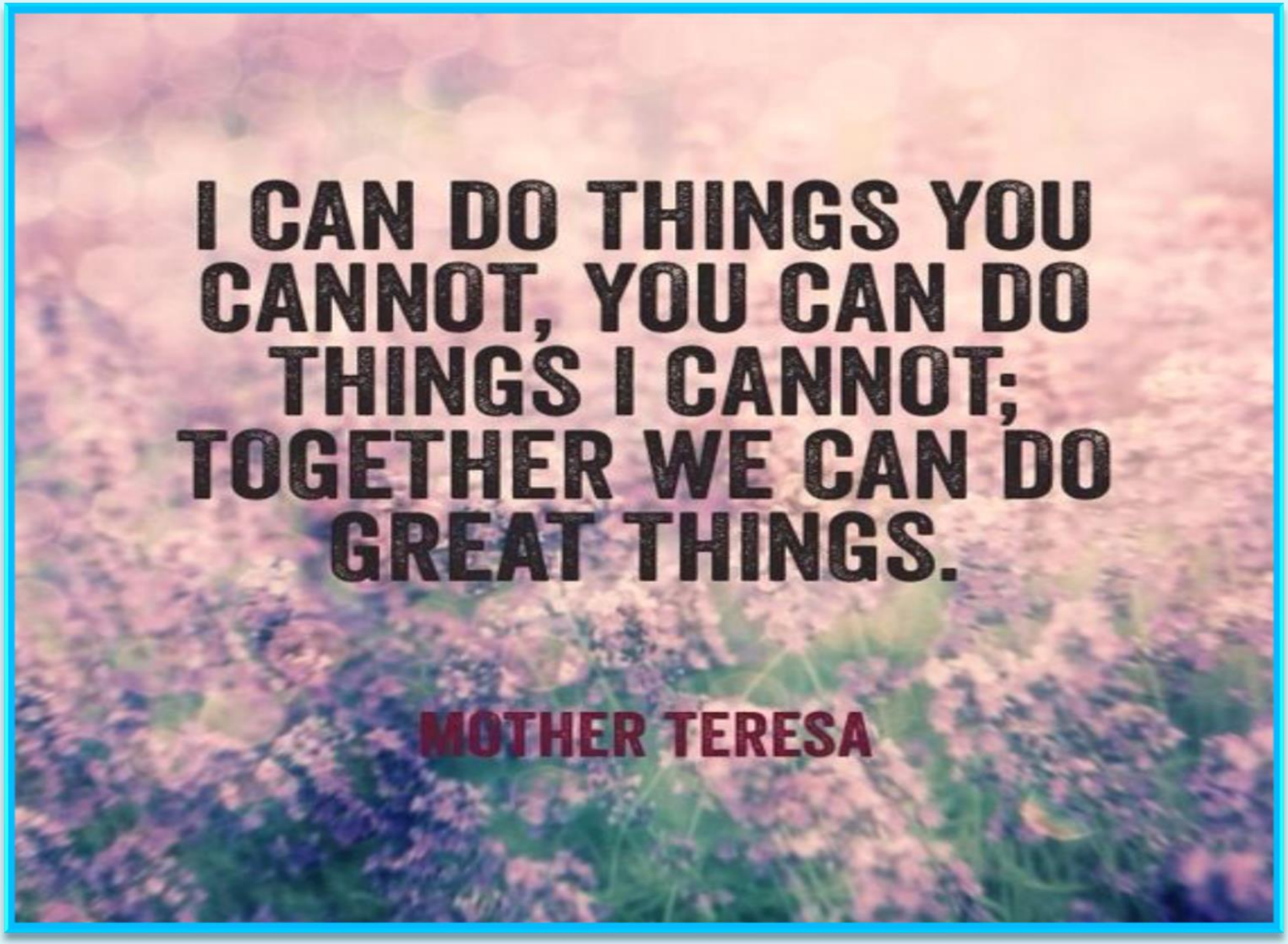
Caregiver Path

- Preparing –
  information gathering
- Care Partnering -
  researching, supporting
- Caregiving –
  daily involvement,
  adjustment of roles

Care Partnering

- "Care partnership implies a balance of care – that opportunities to give as well as receive are abundant and experienced by everyone in the care relationship."
- When two people partner in care, they can each grow as individuals and therefore each feel uniquely useful and helpful.
- Such interdependent relationships emphasize the strengths and gifts or talents of each person and from this is the opportunity to learn and grow.

➢ Eden Alternative



I CAN DO THINGS YOU CANNOT, YOU CAN DO THINGS I CANNOT; TOGETHER WE CAN DO GREAT THINGS.

MOTHER TERESA

Caregiving

- Caregiving is the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological, or developmental needs.
- Caring for others generally takes on three forms:
  - Instrumental (Quarterback)
  - Emotional (Cheerleader)
  - Informational caring (Student/teacher)

➢ Work and Family Research Network

The "We Disease"

- Both report similar reactions to a new diagnosis
- Feelings of hopelessness or depression, anxiety, fear and uncertainty
- The *quality* of the relationship and how you cope as a team differentiates who can transform the experience into positive growth from those who respond in despair, hopelessness and fear
- "Dyadic coping"

Dyadic Coping

- Your ability to cope together with the stresses
- A stress management process whereby partners either ignore or react to each other's stress signals to adapt to the diagnosis and return to a pre-illness level of wellbeing
- Dependent on understanding each other and communication between you

Reflection/Communication

Consider your relational style:

- Are you a “processor” or a “fixer”?
- What does this mean for you within the context of facing this diagnosis?

The Impact

- What is the most important change in your life since the diagnosis?
- What things are you handling well?
- What things are you handling less well?
- Is there anything positive for you that may have resulted from the cancer?
- What do you expect of each other?

Caregivers – the facts

(Statistics Canada Trend Report, 2008)

- 85% found the satisfaction of providing care far outweighs the disadvantages
- 10% found it a burden
- have higher rates of insomnia, anxiety, fatigue, poor appetite and depression
- the average length of caregiving is 4.3 years
- 60% of all caregivers either work or have worked while providing care and 62% of those have had to adjust their work schedule

Caregiver’s unmet needs:

- finding time for myself (35%)
- managing emotional and physical stress (29%)
- balancing work and family responsibilities (29%)
- 1 in 5 caregivers say they need help talking with doctors and other HC professionals

Common thoughts…

- How long before the shoe drops?
- How can I handle the constant uncertainty?
- How can I live in the “Here and Now”?
- How can I gain more control of the situation?
- Friends and family don’t always understand the symptoms, how can we express it to them?
- How can we maintain a normal life?

Common Thoughts and feelings

- I find myself thinking about all the bad things in my life
- How can I manage everything?
- Am I getting Burned out?
- I feel guilty for taking breaks or having fun
- I can’t tend to my own needs because I am needed here

Common Thoughts and feelings

Continued

- How can I get away from feeling that Cancer is our entire life?
- My partner and I seem to just “blow up” at the littlest things
- How can I be strong for my partner while coping with my own reactions?

Signs of “burn-out”

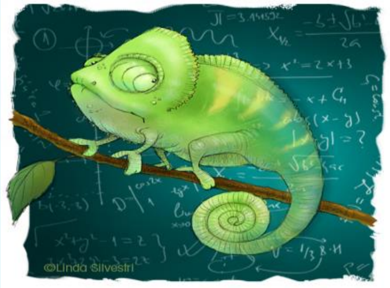
- Irritability and a low tolerance for frustration
- Constant exhaustion
- Problems sleeping
- Decreased interest in activities you used to enjoy
- Social isolation
- Recurring feelings of guilt and/or anxiety

"Caregiving is hard work. Caregiving is pain. Caregiving is loving and giving and sharing. Caregiving is accepting and learning new things and going on, and on, and on. Caregiving is lots of questions and very few answers. Caregiving is being out of the mainstream."

National Family Caregivers Association and the National Alliance for Caregiving

3 Ways to deal with stress

- Adapt



- Alter

- Avoid

National Family Caregiver's Association created **4 key messages**

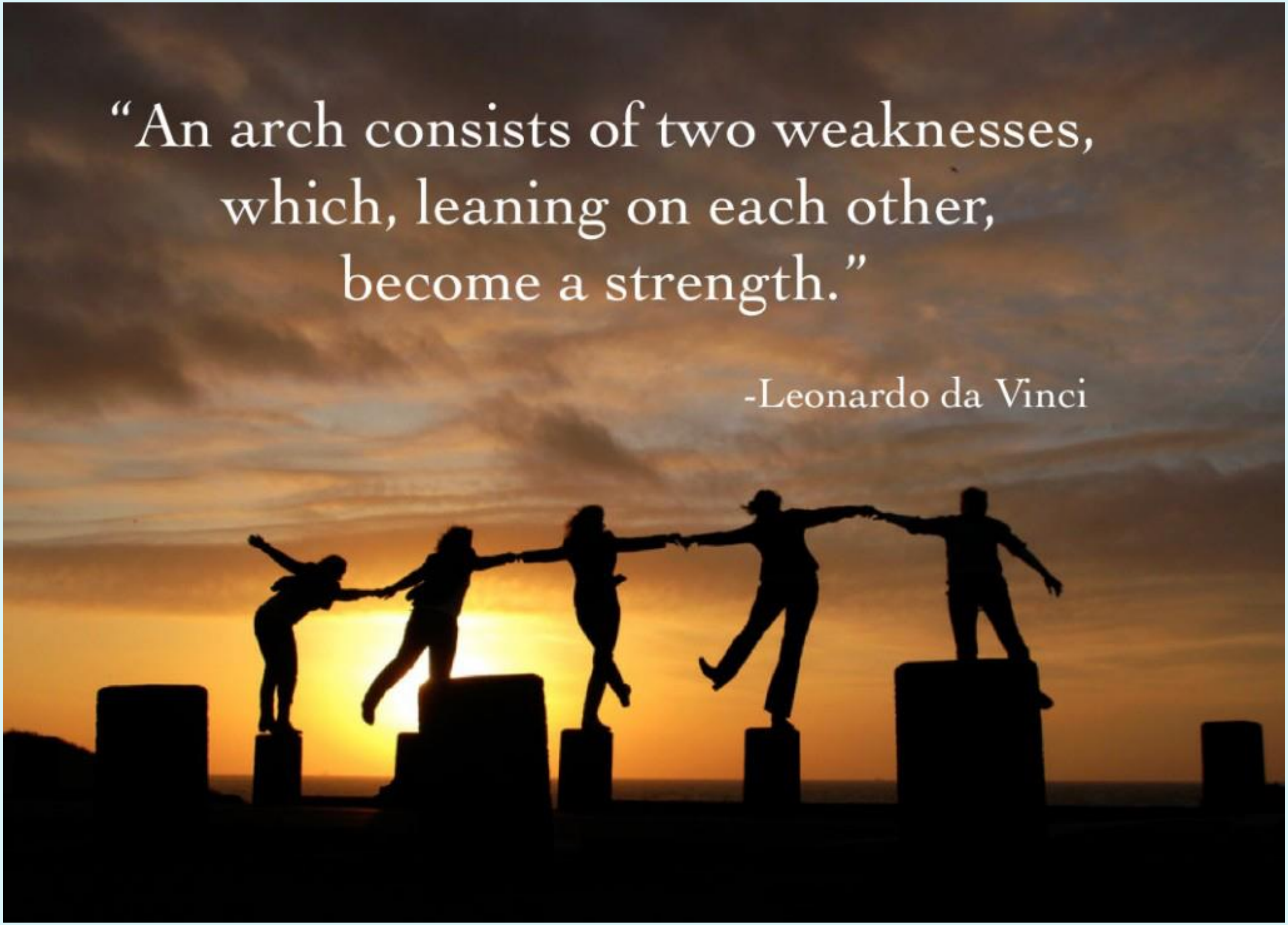
- **Believe in yourself** – trust your instincts, listen to your inner voice
- **Protect your health** – this is not a luxury, it's a necessity. You cannot look after anyone if you get sick or rundown.
- **Reach out for help** – asking for help is a sign of strength. Caregiving is not a one-person job. Help comes in various forms (physical help, education, emotional support)
- **Speak up for your rights** – you have the right for education, better support, better communication, community resource

Final Thoughts

- Anticipate – know yourself
- Communicate – speak to others
- Reach out – accept help
  - self-care

In closing…

Cancer is a family disease; one that takes a team of involved and supportive loved ones to help an individual thrive. However in most cases the bulk of the responsibility falls with one main care partner. For this individual, life is changed forever when their loved one is diagnosed and they must take on many new roles. They have a demanding job involving compromise, encouragement and strength.



"An arch consists of two weaknesses,
which, leaning on each other,
become a strength."

-Leonardo da Vinci

Thank You!
Questions?