CARING FOR THE CARER

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Caring for the Carer:

- Definitions of Care and Carer
- Impact on Huntington disease in Carers life- surveys
- A journey of a Carer
- Caring for the Carer:

  Recognise the need to care the Carer and identify ways of support

Doctors diagnose, nurses heal, and caregivers make sense of it all.

— Brett H. Lewis

Care in Huntington disease

Care in Huntington disease begins as a simple task and ends up to a full-time care as the disease move on.

Main duties of a carer:

- Emotional support
- Personal care(bath, hygiene, dressing etc)
- Manage medication and transfer to doctors
- Help with food (feeding first by mouth- then gastrostomy)
- Manage the safety of the environment
- Advocate patients rights
- Manage economical issues of the patients

Carers of HD patients

- A carer, usually is someone who provides unpaid, ongoing assistance and care to a person with HD.
- Due to the hereditary nature of HD, a carer may be looking after more than one member of the family at the same time
- A carer can be anyone from a parent, child, sibling, close friend, neighbour or someone in the person's close social network.
- A carer is also a professional- that get paid to provide care for daily needs of patients in the house or a nursing home, specialised center etc.

Impact on Huntington disease in carers life

- A lot of survey about the quality of life and caregiver burden focus on different types of dementia, including Alzheimer's and Parkinson, stroke, cancer or mental illnesses
- Less attention has been paid to informal caregivers of patients with HD meanwhile, psychosocial implications of HD are much more serious and wide-ranging.
- In medical setting the HD patient is the one who draws professional attention but the family caregiver needs also attention, support and help.

Impact on Huntington disease in carers life-Surveys

- Caregivers perceive their role as 'very stressful'. Stress related mainly from the neuropsychiatric character of HD
- Role reversal from a spouse, or a parent, or a child, to a caregiver is also very distressing, especially because many carers do not feel prepared for the caregiving task and have problems with adjusting to the new roles, responsibilities and schedules
- Caregivers feel that they have lost their lives, identity and personal independence
- Most of the studies report difficulties with patients' moodiness, irritability, depression, anger, loss of memory and suicidal ideations.

Impact on Huntington disease in carers life

- Caregiver identified the stress and worry they experienced as they battled with decisions around their employment, whether they should resign from their positions and provide the level of care they determined appropriate.
- Whilst considering this, they also highlighted potential financial strain.
- Such stress is further increased by the fear that with age one's ability to take care will decrease
- Financial burden loss of income because the patients not cable to work- the carer responsible to cover the expenses of the family and also to cover medical and personal expenses of the patients.

Impact on genetic risk

- Patients feel guilt and blame themselves for being responsible for passing the disease to their offspring
- Carers are burdened by the fact that HD may develop in other family members. The most stressful is that while caring for the sick, one anticipates the disease in future generations
- Careres are strained by the responsibility to inform others about the risk of having HD
- Carers who are tested negative often experience survivor guilt(a response to an event in which someone else experienced loss but you did not)

Parents carers of children patients

- The children JHD different from other children, but there is also different from the children there were. The disease it self transform the children in the eyes of their parents.
- Parents feel devastated because the disease does not let their children be children and young adults in the short life they have
- Parents feel lonely, isolated and unable to cope.
- Feelings of guilt and anxiety especially by the parent transferring the disease
- Parents want respite care for themselves and their families but need to know that the children are being cared properly.

Young person carer

- Teenage carers express their sadness not only due to loss of relationship with the affected parent but also with the non-affected one who is absent due to professional and caring responsibilities
- Feel guilty about leaving the person they are caring- going to university, moving with a partner or even going out for the day cause guilty for not being around to help.
- Feel that should not think about their own future, but focus on the person they are caring for.
- Role reversal As the condition progresses, the young person begins to take on a more parental role in the family, filling the gap left as a result of the parent having HD.
- Looking in the mirror syndrome
- Caring for someone with HD can be difficult, tiring and stressful. It can also be emotionally challenging if you know that you are at-risk of HD or inherited the disease-causing gene.


"Caregiving
often calls us to
lean into love
we didn't know
possible."

Spouses of patients with HD

- Especially female carers and daughters in particular, are more pressured into caregiving and are expected to abandon their plans for a professional carrier where as sons often leave home to pursue their academic and professional aspirations.
- Consequently, they often feel as being restricted by their caring responsibilities and are concerned over the loss of former roles and relationships
- Apart from these important gender differences,caregivers in general feel that they have lost their lives, identity and personal independence
- Those who continue to work are also concerned about leaving the affected person at home without adequate support
- Economical problems when they stop work and start the care of their spouce. Need to apply for social funds- feelings of embarrassment, humiliation mentioned
- Worries about the children- not enough time to spend with them
- Fear, anger, guilty that the children will inherit the disease

VisitingTheGrayPlanet.com

A journey of a Carer:

Diagnosis:

Patient- 48 Years old

Wife Carer: 40 Years old

Children: 19, 17, 9 years old

Early stage:

Behavior change –become more irritated with people in the environment

The wife realise these changes –in the beginning get angry about that behaviour-couldn't accept that the disease affect his husband

'***This behaviour has nothing to do with the man I know-it was really strange for me***"

A journey of a Carer:

Early stage:

- ***'For me it was self-evident that these are my duties, there was no doubt for that so I accept the new reality and try to do my best to take care my husband.'***
- ***I had to manage job, taking care of the household and transferring children to their schools, friends etc'.***
- ***' I realise the hereditary of the disease- continuous worry about the children-if they will decide to test and the results of the test'.***
- ***'My children were in different ages and had a lot of responsibilities and worries, I had to stand by them in their different needs'.***
- ***'I decide that is very important for my children to make their dreams come true: So I promised myself that I will not let them to think that the hereditary of this disease will be an obstacle to stop their dreams'.***


FRIENDSHIP
NOW
connect
smile
healing
kindness
COMPASSION
purpose
caregiver
healthcare
patien
long term
sen
respect
trust
GR
support
LOVE
UNCONDITIONAL
nu
time
activity
mobility
dignity
family
THER
inclusion
community

A journey of a Carer:

Early stage:

She was determined to keep her job and in the main time to stay committed with the care of her family

'***The job helped me to go out of the house, remain productive and think other things as well beside the disease of my husband***'

'My employee fortunately was very supportive-understanding when the difficult days were there'

'I try to stand by my husband to keep his job as long as he could because I realized that working helped his psychology. On the other hand I was next to him and tried to prepared him that as soon as things get worse, he will have to stop work'.

A journey of a Carer:

Middle stage:

- Symptoms affect the patient's ability to work- stop the job and apply for disability pension
- Symptoms worsening, (detiorating of movements- difficulties to take care of him self in daily needs)
- ***'Difficulty to accept to get help from a paid carer. I felt that I didn't wont a 'stranger' in the house.' I didn't want a person outside the family to provide help and support'.***
- ***'Two reasons convinced me to employ a caregiver:***

✓ ***I didn't want to get my children in the position of carer'***

✓ ***I didn't want to loose my job***

- ***'Children started to go to university – I was happy that they continue with their lives and I didn't think about my self'.***

A journey of a Carer:

Middle stage:

- Economical difficulties- one salary and a lot of needs to cover
- The wife try to get support through the social funds but in the beginning they rejected the application- feel hopeless and that the society is not supportive enough
- The carer describe that even she felt embarrassed and disappointed to apply for funds for economical support she has to get over it and ask for help
- '***Family and friends were willing to help either economically or with the care of my husband but I didn't want to be a burden to others***'
- '***Sometimes when I was struggling I accepted this help and felt grateful that it was available'***.

A journey of a Carer:

Late stage (bed ridden-loss of communication)

- ***'I decided to take care of myself with little things in daily life: In summer time I go for swimming in mornings, get positive energy from the sea and come back relieved to take over the care of my husband'.***
- ***'My grandchildren create empathy for their grandfather: many times ask me with concern if the grandpa has pain and wondering if they can do something to help him'.***
- ***'In this stage of disease It is extremely difficult for me to hear him screaming.'***
- ***'Some times I am wondering why he is not 'leaving' in order to stop suffering. I feel very bad seeing him suffer. Mostly I want for him to rest and not for me and my children that we are also tired'.***

A journey of a Carer:

General comments about her experience during this journey:

- ***'I feel happy that I take care of my husband and support him- I wouldn't feel well if I didn't stand by him all these years'.***
- ***'My children told me several times throughout the years to get support from an expert and express my feelings: I reacted , I want to do it my way- I get support from my faith and from my spiritual confessor - priest.'***
- ***I thank God that helped me to stand by him'.***
- ***' Even that I didn't visit a psychologist – I strongly believe that carers and members of family have to ask for help from professionals or other persons that they feel safe to share thoughts and feelings'.***


create
healthy
space
for
yourself

CARING FOR THE CARER

- ***But just like in an airplane, you got to make sure that you put your mask on first before you help someone*."**
- **It is easy to overlook the importance of self-care because your focus is often on the person you are caring for.**
- **However, in order to effectively fulfil your role as carer, it is critical to make sure you take the time to care for yourself.**
- **If you are feeling distressed, frustrated, guilty, exhausted, or annoyed, it is important to know that these feelings are normal. If you find your role as a carer overwhelming, it may help to discuss your feelings with your GP, a psychologist, a social worker or a counsellor.**

Ask for help -Counseling

A counsellor can help by:

- suggesting strategies for managing relationships
- giving you ideas for keeping communication channels open
- advising you how to balance your caring role with your own needs.
- Suggest alternative solutions in the community to provide care to carer
- Encourage to ask help from a respite care

Find ways to rest: Respite care

Respite care is essential for all caregivers, especially to relieve stress and prevent burnout. By using respite care, you can support and strengthen your ability to continue taking care of your loved one…and yourself!

Benefits of respite care in specialized centers providing 24/7 care services

Relaxation: Families can relax, gain peace of mind and renew their energy.

Stability: Improve your family's ability to cope with daily responsibilities.

Involvement: Your loved one can become involved in group activities and be less isolated.

Enrichment: Enhance their own growth and development.

In house respite care

- provided by a friend, relative, or volunteer may have no associated costs.
- paid care by professional nurses or carers


BREATHE

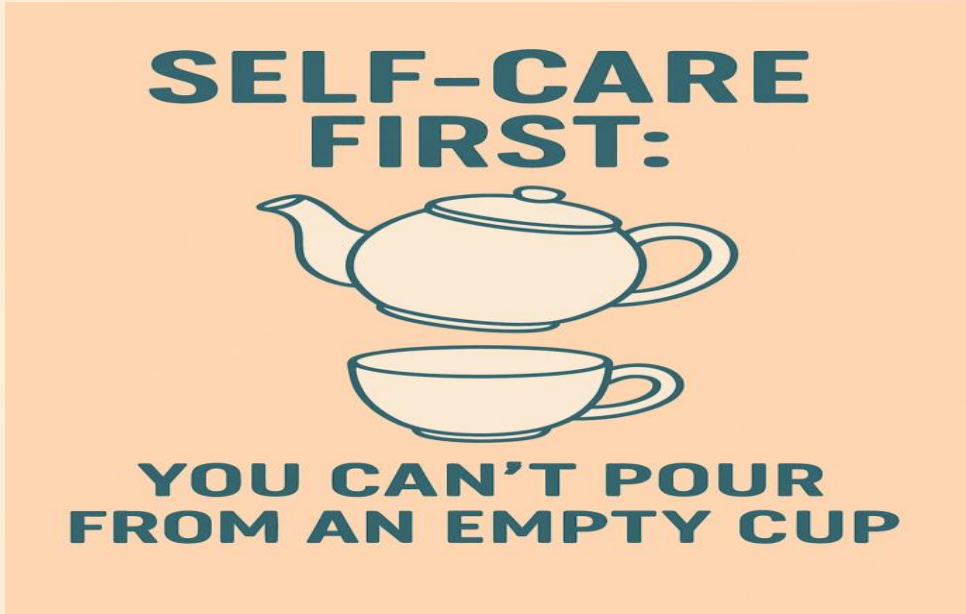
Caring for the Carer:

Helpful tips –questions that help carers to reflect on their own wellbeing:

- Am I getting enough sleep and exercise?
- Am I eating regular, well-balanced meals?
- Am I able to take time out from caring and work to pursue my own interests?
- Do I have a supportive social network?
- Do I set aside time to relax?

Caring for the Carer:

- Discuss **flexible work** options with your employer. Many employers offer flexible working arrangements. Talk to them about possible options.
- Get **someone to do your household chores**. Ask a relative or consider a local private service or access help at your local council.
- Set up a roster. Caring for your loved one could be shared by using a **roster system** if more than one person is providing care.
- Consider a regular **email update to friends and relatives**. This can keep people updated and reduce the number of phone calls to make.



MANAGE CAREGIVER STRESS

Sleep it off

Stretch it out

Express yourself

Talk it out

Share the load

Dance and sing it out

HappyHealthyCaregiver.com

Caring for the Carer:

- **Make a list of friends or relatives that can help**. A list can clarify how many others you can call on. If no one is willing, search for other solutions like a respite care, a centre for people with disabilities etc.
- **Keep a diary of issues**. This can help you keep track of issues and serve as a reminder when family meetings with the palliative team occur, or others ask for information.
- **Ask friends or relatives to prepare meals**. People are often willing to help. If this isn't possible consider a home delivery service for meals.
- **Ask a friend to stay overnight**. It may help you get a good night's sleep and provide extra company.
- **Find a hobbie**: yioga, pilates, swimming, theatre workshop setc. Commit your self and decide for the days and time
- **Go out with a friend** every week or twice a month : concert, cinema, theatre
- Search for free programs **–social events** that you can participate in the local community or the non governmental organizations

Huntington's Disease Caregiver Support

Remember to take care of your own health

Exercise

Get plenty of sleep

Make personal time for hobbies and socializing

Ask for help

Seek professional support

Caring for the Carer:

- **PARTICIPATE**
- **ASK FOR SUPPORT-GIVE SUPPORT**
- **GET AND GIVE INFORMATION**
- **SHARE-FEEL- STAY CONNECTED**

- ✓ **Participate in support groups-in your country or other countries (physical presence or online)**
- ✓ **Participate in Conferences in your countries or in European conferences (EHA Conferences)**
- ✓ **Register and actively participate in the patient organizations and associations in your country.**

Out of the box-Caring for the Carer:

Search and find **projects even if they seem unusual-** they may help and support

Example: LOGGIA PROJECT- ΑρχαοιολΟγικά:

Archaeology and wellbeing programme:

By looking at the heritage sites of the valley and exploring them through creative activities, including writing and photography, the project encouraged discussions on the broader themes relating to the recent history of the region, memory, and abandonment.

ACTIVITIES FOR PARTICIPANTS- CARERS AND MEMBERS OF FAMILIES

- Visit abandoned archaeological places
- Participate through-photography-reveal abandon places
- Participate in a workshop-connect with the abandonment of places and abandonment in disease
- Reveal feelings, share thoughts

CONNECT -PARTICIPATE-SOCIALIZE –GET TOGETHER

Connected with projects


Starting today,
remember to take care of
yourself. Sometimes you get
so busy taking care of others
that you forget that you
are important too.
lessonslearnedinlife.com

EHA CONFERENCE-ROMANIA 2025
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WHAT'S NEXT IN THIS PANEL:CHALLENGES OF CARERS

- **STIGMA**

'*The stigma of this disease is more strong than the consequences of the disease*'

- **AWARENESS**

'*It was difficult to explain my feelings to others: Its much easier to keep it yourself than sharing to people . Because, when you do, they look at you a bit askance, like you're imagining things*'

- **BELIEVE-FAITH -HOPE**

' *My believe in God and his providence for me was the most important source of power for me.*'

' *I hope that the surveys will ended up positive and cure will be available in the near future.*'

- **PROFESSIONAL SUPPORT - FRIENDS AND FAMILY SUPPORT**

'*The psychologist help me to understand things complicated in my head- I feel relief and empowered*'

'*The social worker is a professional that supports the whole family in all the way of this disease: support, refer to psychologist, counselling for the social fund, connection of the patient with sources and services in communities*"

- **STRONGER TOGETHER**

- '*My friends and other members of the family was a great support for me*"

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