



# Caregiver's Profile

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## Module 2: Being a caregiver

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# Who is a caregiver?

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- **Informal Care** comes from the patient's family
  - In married people, the duties of the main caregiver are usually assumed by the **spouse**.
  - In cases of widowhood, one of the **children** assumes this role, based on common social sense criteria (gender, firstborn, cohabitation).
  - Most often, **daughters or brides** end up as the main caregivers in these cases.
  - In other cases, the duties of a caregiver may be assumed by a **paid person** or an institution employee (**formal care**).



# What caregivers seek

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- **Information about dementia:**
- how long will it last?, Can it be cured? Is it hereditary? What are the stages and what to expect?
- **Answers in practical issues concerning their person**
- How am I supposed to talk to my mom? My dad is not the way he was. How will he be as he used to? When will I need help at home? My husband is isolated due to his difficulties. What should I do?
- **Support**





# Becoming a caregiver

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- Their previous role will change...
- Becoming a carer is a process



# Carergiver's profile

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- caregivers are unique people who face the same problem and therefore they have common characteristics
- They experience physical, psychological, emotional, social and financial burden





# Caregiver's Burden

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- Caregivers need help but are **unaware of their needs** due to exhaustion.
- Due to their deep care for their family member, they **neglect their needs constantly**
- Some of the effects on the carer's life is the physical ill-health, social isolation as well as **economic hardship**.
- Stress, **depressive symptoms, and grief are apparent characteristics** in their profile and most of the time are expressed in their behavior



# Caregivers need self-care

- Caregivers are **focused on caring** for their person with dementia
- They usually end up **suffering from burn-out**, depression, and stressful elevated levels
- **Self-care** is essential and refers to physical, emotional, social, and spiritual health





# How we can help carers

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- Maintain the communication with the person with dementia
- After the diagnosis, feelings of grief and sadness are apparent and isolate the person
- Talk with them and make them feel safe





# How we can help carer's

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Enhance carers:

- Promote the *psychoeducation, counseling and career's groups*
- Knowing about dementia can solve plenty of their queries prior to their psychological state
- Remind them that it is ok to ask for help
- Highlight that their feelings are important (frustration, worry, grief)
- Help them not to feel guilty about their thoughts of rest or privacy



# What is the profile of the “good enough” caregiver?

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- Up to now, we discussed the characteristics of a carer.
- Write a list of adjectives that can describe the qualities of a “good enough caregiver”.



# The “good enough” carer

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- Patience. People who need care often take longer to complete simple tasks. ...
- Empathy and understanding
- Humor
- Being Present
- Detail Oriented
- Able to Accept Help
- Willing to Set Boundaries
- Cooperative
- Assertive



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Is there an assertive way to discuss and communicate with people with dementia?

Are there ways to improve this communication?

What are the needs to draw their attention?

Are there non-verbal communication skills in dementia care?

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## Communication Skills



A real example of a

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COMMUNICATION  
GAP



# What we should avoid

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- ✓ Argue
- ✓ Try to reason
- ✓ Confront
- ✓ Remind them they forget
- ✓ Question recent memory
- ✓ Take it personally
- ✓ Avoid referring to them as they are not there



# Communication Strategies

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- Due to dementia their language communication skills are impaired at this level:
- IF Their language expression might seem strange..
- ✓ Be **patient** with them
- ✓ Treat them with **respect and dignity**



# Communication Strategies

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- ✓ Pay attention to the **body language**
- ✓ The **facial expressions** are important
- ✓ **Gestures** are a way of contact
  
- ✓ These forms of connections are important and shows us that not only talking is a form of communication
- ✓ Encourage them to communicate in any form they can



# Communication Strategies

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- ✓ Speak slow and with clear pronunciations
- ✓ Don't pressure them to answer, they need time to respond
- ✓ When they want to share something about themselves give them the time
- ✓ Avoid patronizing them or making fun of their answers
- ✓ Encourage them to share, even when the context of their answer is not coherent



# Gain their attention

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- **How do you think that we can gain the attention of a person with dementia in a respectful way?**
- Address her by name
- Identify yourself by name and relation
- Approach in a friendly way
- If she is seated, get down to her level
- Use non verbal cues -Mirror their poses and gestures-Maintain the eye contact when you are talking to them



# Gain their attention

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- Touch if it's permitted by the person or situation will help keep her focused
- Low tone of voice
- Keep it simple :-Use short sentences and simple meanings
- Try not to combine many information
- One task at a time, not many activities together



## Prior to this..

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- **Make sure that the person is not facing any hearing or sight loss** (medical tests, check the hearing aid)
- **Create the setting for a proper communication**
- Limit distractions and noise –
- turn off the radio or TV
- close the curtains or shut the door,
- or move to quieter surroundings.



# Positive conversations in dementia

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- Positive conversations in dementia
  - Respectful
  - Sensitive
  - Consistent
- Remember that an effective way of talking to someone and make them me feel nice is **using compliments**
- **Ignore the mistakes they make**
- Focus in their achievements



# Think and make a list of..

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- What type of compliments would you give to the person you take care for while you engage with him in your everyday life?



# Compliments that carers can use

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- You did well in your drawing
- I really like your outfit
- You helped a lot. Thank you.
- You are good at making sandwiches.
- It is so nice having you here.
- You are so funny.



Use them in  
different  
situations



# Communication skills rely on:

- Gaining their attention
- Using simple, small sentences
- Active Listening and empathic understanding
- Identify their body language & facial expressions
- Compliment them
- Stay positive, respectful and sensitive





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## Being a caregiver

- Can be stressful and demanding
- Is lonely
- Can be a financial burden
- Can be challenging
- Can cause depressive symptoms
- Has plenty of responsibilities





# When caring becomes a burden

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**It might be difficult for the carers to ask for help for a number of reasons**

- They don't want to burden other people
- They might be afraid that people will say no
- It is difficult for them to trust others in tasks they normally do
- Stigma-They don't want others to feel sorry for them
- It may require you to examine your own needs, educate other people about caregiving
- They are afraid of their person's reaction



# Caregiver's need help to

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- recognize their need for help and fit it into their self-image
- express their needs in an effective way avoiding passive and aggressive ways of asking help. Eg. I would appreciate your help in a way that is possible for you next week rather than “you are obligated to help me!”
- help to “map” the resources available in their environment that they could turn to **when they would be ready**
- Involve others and understand that this can be beneficial for others too
- Understand that sharing care is normal. It may allow you to do something pleasant for yourself and enjoy a well-deserved break.



# Asking for help Effectively

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- Be flexible: maybe you won't get exactly what you asked for, but you will get something that will be helpful
- Break it down into smaller parts – it's usually easier for people to say yes to a little request than to a big one.
- It's important to remember that seeking for help will not always lead to the result you want, but it is important that you feel able to ask for it.



# Asking for Help Effectively

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- Think about what you want or need and what your feelings are about the current situation.
- Describe your thoughts and feelings clearly, so that the other person can understand your point of view.
- Be honest and direct
- Keep the feelings of the other person in mind
- Give detailed information about what kind of help you need.
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# Types of help

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- The help they can get, can be of any kind
- It can be **practical** help
- It can also be an **emotional** support
- Information type support, etc.
  
- And can be given/offered/asked by several sources



# Try to make a list of needs for a carer with examples regarding types of help

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- Practical help
  - Someone to help with the bathing process



# Sources of Help

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- Family
- Friends
- Neighbors
- Care homes
- Formal Caregivers



# Family, friends or neighbors

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- Can be a source for the carer's comfort.
- They can offer their help, their support or time to aid the carer's routine and everyday tasks.
- Their support can be in an emotional care (e.g. Listen them, offer company to their relaxation)



# The role of care homes

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- When caring for a person with dementia is a struggle, there are the care homes to provide their services

There are several positive aspects for people with dementia in living there

- 1. They make and have friends close to their age
- 2. They have people caring for their medical condition 24/7
- 3. They take part to groups with other residents

In severe stages of dementia is often one way solution



# Help from a paid carer

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- Is needed when people with dementia prefer their independence and home base but are unable to live on their own
- The paid caregiver will live in the house together with the person with dementia
- Will take care of all the practical issues (bath, walks, toileting, clothing, food preparation, medication)

# Alzheimer Organizations

**Provide caregivers with a wide range of services such as:**

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- Day centers
- Support groups
- Counseling services
- Psychoeducational interventions
- Support from different professionals like doctors, psychologists, social workers, nurses

And help caregivers:

- gain knowledge about dementia
- strengthen the sense of safety and sense of belonging
- Help them create space and time for themselves



Try to name other sources of help for  
caregivers

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# Scenario

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- July is a mother of two, married woman who works in a hospital. More to this, her mother is diagnosed with Alzheimer. Her mood is low, she has no energy and is in confusion.
- What type of help do you consider that July wants?
- From whom can she receive that type of help?
- What might her needs be?



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- Thank you for your attention!