

## iSupport for dementia

## What is iSupport?

iSupport is an online programme that provides information and support for carers of people with dementia. It aims to help you learn about dementia and how to look after someone living with dementia. It also includes information about how to take care of yourself, so that you can continue to support the person you care for.

| iSupport is organised into five modules:          | What is a carer?  |
|---|---|
| (1) Introduction to dementia<br>(2) Being a carer | If you support or look after a parent, relative,<br>partner or friend living with dementia who<br>would find it difficult to manage without you,<br>then you might be described as 'their carer'. |
| (3) Self-care                                     |   |
| (4) Providing everyday care                       | You might feel you are doing what anyone else<br>would do for a family member or friend, so the<br>term 'carer' could feel uncomfortable.   |
| (5) Dealing with changes in people with dementia. | However, describing yourself as a carer may<br>enable you to access the help and support you<br>need for this role.   |

Dementia and mental health can come with a stigma, and it can feel hard to ask for help. This can

often lead to feeling alone and unsupported. By educating yourself and finding out what support is available, you can better help the person with dementia.



2.

#### **Useful contacts**

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## Practical tips for carers of people with dementia Providing everyday care

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#### Engage the person in personal care

- Help the person with dementia do as much as they can themselves.
- Modify the environment, for example by switching from a shower to a sponge bath.
- Be mindful of falls use a non-slip shower or bath mat.
- The person with dementia may resist when you try to help them with personal care. Be compassionate and try to understand why.



#### Toileting and continence care

- Modify the environment. This can help reduce incontinence accidents. For example, put a picture of a toilet on the bathroom door.
- Remind the person to go to the bathroom regularly.
- Consider using incontinence aids and equipment.
- Do not blame the person for accidents.



Make sure that the person is eating and drinking

- You may need to remind them to eat and drink regularly.
- Adjust their diet according to their preferences and health.





#### Establish routines

- Maintain routines similar to the ones that the person had before developing dementia.
- Be prepared to adapt routines as necessary as their abilities change over time.

#### Keep inedible items, sharp objects, household chemicals and flammable items in a safe place.

For more information see iSupport Module 4 "Providing everyday care". Adapted from <u>Providing everyday care to</u> <u>the person with dementia</u>. WHO is not responsible for the content or accuracy of this adaptation.



Practical tips for carers of people with dementia Ensuring that the person with dementia continues to receive care

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#### **Plan in advance**

- Ask the person with dementia about their care preferences, including where they would like to be cared for and by whom.
- Talk to people who would be willing to provide support if needed, for example if you can no longer provide care.
- Make a plan for the costs of future care and discuss preferences in case of more advanced care needs and end-of-life decisions.

#### Gather information

- You will need information to make informed choices. Make decisions together and talk with your family, friends, doctor and any other people close to you and the person with dementia.
- Prepare instructions that reflect the wishes of the person with dementia.



For more information see iSupport Module 2 "Being a carer". Adapted from Ensuring that the person with dementia continues to receive care. WHO is not responsible for the content or accuracy of this adaptation.



### Practical tips for carers of people with dementia Communicating information to the person with dementia

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#### Share simple facts

- Ask or tell the person with dementia one thing at a time. Use short sentences and simple words that the person with dementia can understand. Repeat information calmly.
- When needed, change from open questions to closed questions that can be answered by yes or no.
- Reduce distracting background noises such as a television or radio.



Dementia can often make communication difficult

This can have an impact on your relationship with the person you care for. It can even make them or you frustrated, sad or angry.



#### Get attention in a respectful way

- Capture the attention of the person you care for by speaking clearly, slowly and at a volume that is comfortable for them. Remember to speak face-to-face and at eye level.
- You could lightly tap their hand, arm or front of their shoulder, or call the person by their name or a nickname they recognise.



#### Try to stay in control of your feelings

- At some point, you may not understand what the person you care for is trying to say. It is important that you take the person seriously - they are trying to tell you something.
- Be patient and give them time to find their words. Pay attention to their reactions, including facial expressions and body language.



 Show compassion about the feelings that the person expresses. Saying something positive or complimenting the person can make them feel good.

For more information see iSupport Module 2 "Being a carer". Adapted from <u>Communicating information to the</u> person with dementia. WHO is not responsible for the content or accuracy of this adaptation.



### Practical tips for carers of people with dementia Caring for myself

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#### **Stay connected**

Social support is important. Talk regularly to someone you trust and who understands your situation and feelings. This might be family, friends, a community, religious or spiritual leader, a neighbour, or a volunteer.



#### **Focus on relaxation**



Consider different ways of relaxing

Relaxation makes you feel less tense. ItRelaxationcan also help you to be more effective infind nogetting tasks done and will allow you torelaxiprovide care for longer. Try to dolistensomething relaxing every day.the performed



## Changing unhelpful thoughts into helpful ones

Thoughts determine how we feel. You cannot change what happens, but you can change your response.

You can learn to think differently by changing your unhelpful thoughts into helpful ones.

It might not always be possible to change your thoughts. In these situations, try to show yourself kindness and accept these feelings without being too hard on yourself. Relaxation is different for everyone. Some people find meditating or doing a breathing exercise relaxing. Others enjoy stretching, reading a book, listening to music, or doing pleasant activities with the person they care for.



What is the event that is making me feel upset?

What are my unhelpful thoughts?

What would be a more helpful way of thinking?

How could helpful thoughts make me feel better?

For more information see iSupport Module 2 "Being a caregiver" and Module 3 "Self-care". Adapted from <u>Caring for myself</u>. WHO is not responsible for the content or accuracy of this adaptation.



## Practical tips for carers of people with dementia Responding to changes in the person with dementia

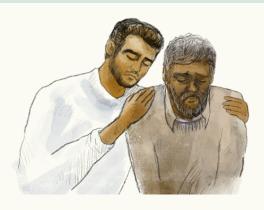
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As the disease progresses, the person with dementia may change

Changes may include agitation, depression, anxiety, becoming withdrawn or overly suspicious, having difficulty sleeping or changes in judgement. The person may also show signs of confusion, deterioration of existing cognitive problems (e.g. memory), delusions and hallucinations, repetitive behaviours or wandering.





- What does this change look like? What is your usual response to it?
- Identify whether the environment or your approach could be causing the particular symptom.
- Try different responses and approaches your first response may not always work.



# Let's take depression and anxiety as an example

- Both are common in people with dementia and can be very upsetting. Identify what these changes look like and try to determine what is making them feel depressed or anxious.
- Think about how you usually respond and what you can do to make the person with dementia feel better. For example, think of ways to make them comfortable, or encourage them to do things that they enjoy.

If the person has serious and constant mood changes or if you think that they are in danger of harming themselves, seek medical advice immediately.

For more information see iSupport Module 5 "Dealing with changes in people with dementia." Adapted from <u>Responding to changes in the person with dementia</u>. WHO is not responsible for the content or accuracy of this adaptation.



## Practical tips for carers of people with dementia Reaching out to others for help

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You are not alone

Caring for someone with dementia can be overwhelming and does not need to be a lonely experience.



Use available support services

Services, such as self-care guidance, caregiver training, respite, or informal support groups may be available within your community, or online.



#### Ask for help

- Describe your problem and what kind of help you need.
- It is not a failure to ask for help from others. By involving others, it is a way of helping the person with dementia.







#### **Consider different types of help**

You may wish to ask for practical help such as housecleaning, or preparing a meal; help doing pleasant activities with the person with dementia such as asking family members to read to the person; emotional support; or collecting information on dementia.

**For more information see iSupport Module 2 "Being a carer"**. Adapted from <u>Reaching out to others for help</u>. WHO is not responsible for the content or accuracy of this adaptation.



