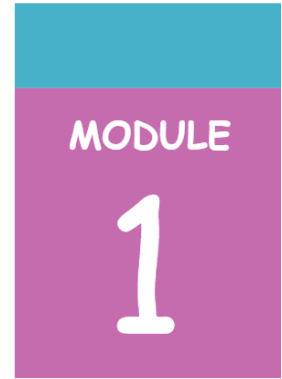


# iSupport For Young People

## Module 1 Introduction to dementia



### INTRODUCTION TO DEMENTIA

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## Introduction to dementia

### **Why is this session important?**

Dementia is a disease that can be overwhelming for the person with dementia, but also for the person that helps care for them. There are many myths about dementia and learning more will help explain some common misunderstandings.

### **How will this session help me?**

This session helps you to understand the basics of what dementia is and how it affects someone. This information is essential when you help care for someone who has dementia.

### **What will I learn?**

1. What is dementia?
2. What causes dementia?
3. What happens to people with dementia as the disease progresses?
4. What to do if you think that the person you help care for has dementia?
5. How to reach out for help?
6. What is the focus of this manual?

### **1. What is dementia?**

- Dementia occurs as a result of a disease process that increasingly damages the brain over time.
- Dementia affects all groups of society and is not linked to social class, gender, ethnic group, or geographic location.
- Dementia is not a part of normal ageing. Although dementia is more common among older people, younger people can also be affected.

## **2. What causes dementia?**

Dementia is caused by a number of diseases which destroy nerve cells and damage the brain, as outlined below.

### **Alzheimer's disease**

Alzheimer's disease is the most common cause of dementia. It destroys brain cells and nerves, disrupting the chemicals that carry messages in the brain, particularly those responsible for storing memories.

### **Vascular dementia**

Vascular dementia occurs where blood vessels are damaged, the supply of oxygen to the brain fails and as a result, brain cells die. The symptoms of vascular dementia can occur either suddenly, following a stroke, or over time, through a series of small strokes. Vascular dementia accounts for 20%-30% of all cases of dementia.

### **Lewy Body Dementia**

Lewy Body Dementia is an umbrella term that includes Dementia with Lewy Bodies and Parkinson's Disease Dementia. It can affect thinking and memory, and also cause visual hallucinations (seeing things that are not there), as well as movement changes similar to Parkinson's disease. It is the second most common form of degenerative dementia and can present in different ways which means that it can be difficult to diagnose.

### **Fronto-temporal dementia**

In fronto-temporal dementia - also known as Pick's disease - damage is usually concentrated in the front part of the brain. This group of dementias mainly affects personality and behaviour or language and speech.

### **Rarer causes of dementia**

There are many other rarer causes of dementia, such as alcohol-related dementia and dementia due to HIV/AIDS.

### 3. What happens to people with dementia as the disease progresses?

Every person is unique, and dementia affects people differently. No two people will develop the same difficulties in exactly the same way. It is not just the brain damage that determines how dementia affects someone, but also other factors including an individual's personality, life course, general health and functioning, and living environment.

#### 1. Check your understanding

##### What happens to people with dementia?

People with dementia often forget things or have trouble with their memory. Select the answer that you think is most likely.

- True
- False

## 1. Check your understanding

### What happens to people with dementia?

Although not always the case, people with dementia often forget things or have trouble with their memory.

✓ True: This is the most likely answer.

✗ False: This is the least likely answer.

The right answer is that people with dementia often forget things or have trouble with their memory.

## Dementia has stages



Dementia symptoms can range from minor difficulties with thinking, learning, language or small changes in personality to severe difficulties that make it impossible to manage daily activities without help. It can be helpful to view dementia as a series of stages to understand the illness. However, it is important to understand that not all people with dementia will have all symptoms and some of the symptoms

may only appear at one stage of the disease.

In the early stage, people with dementia may have memory problems, become disoriented with respect to time, lost in familiar places and show difficulties making decisions.

As dementia progresses to the middle stage, people with dementia may become very forgetful and in need of help with daily activities such as shopping, dressing, and washing.

In the late stage, people with dementia may not recognise relatives or friends anymore. They may display changes in behaviour that can be upsetting and distressing to the person with dementia and those around them.

## 1. Activity

Here are some common things that may happen to people with dementia. Do you think that your family member/friend/the person that you help care for experiences any of the following?

*Please select all that apply.*

Does the person you care for...		Examples
Have trouble remembering things that happened minutes before?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Forgetting recent events</li> <li>• Repeating questions</li> </ul>
Find it difficult to perform daily activities?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Money management</li> <li>• Shopping</li> <li>• Preparing dinner</li> </ul>
Struggle to identify time or place?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Forgetting the date and time of appointments</li> </ul>
Communicate differently than they did before?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Difficulty expressing oneself</li> <li>• Difficulty finding the right words</li> </ul>
Misplace things?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Not finding common objects, such as keys</li> <li>• Suspecting things are stolen</li> </ul>
Withdraw socially?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Not meeting friends as much as they used to</li> <li>• Spending more time at home</li> </ul>
Show changes in feelings or personality?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> <li>• Having a lot of ups and downs</li> <li>• Becoming more anxious than before</li> </ul>

#### 4. What to do if you think that the person you help care for has dementia?



If you or your parents/grandparents think that a family member or friend may have dementia, a good first step is to make sure that they see a medical doctor. The first thing the doctor will do is examine how their body and their brain is functioning. The doctor wants to find out if the person's memory problems are really part of dementia or are part of something else.

One important point to rule out is whether the person's memory problems are caused by other treatable conditions such as depression, urinary tract infection, medication side effects or lack of vitamins.

#### **Remember**

Just because a person has one or two of the symptoms listed in Activity 1 doesn't mean they have dementia. It is important to identify whether the person's symptoms are part of dementia or are part of something else. Only a medical doctor can do this.

#### 5. How to reach out for help?



It is important to realise that you and your family, alone, are not going to be able to provide all the support that the person living with dementia needs, especially not as things get more complex over time. And that is OK. So, make sure you reach out to other family members and friends. You and your parents

can also maybe talk to the school to explain the situation as they might be able to help. There are also charities and professional organisations that are very helpful and support young people in a similar situation to yours.

In many countries there are organisations that can be very helpful. You can try to contact your local Alzheimer's Association to find out what support is available in your area that could benefit the person you help care for as well as yourself.

You can find more information going to the website of the Alzheimer's Association in your country: <https://www.alzint.org/our-members/member-associations/>

## 6. What is the focus of this manual?



This manual is for you, as a young person that lives in a family affected by dementia.

We know that dementia can be overwhelming, and we hope iSupport for Young People can give you information and ideas to cope better. It is also really important that you take care of yourself and iSupport for Young People will show you how. We know there is a lot of information in this manual, go through it at your own pace in your own time, one bit at a time, however it suits you best!

### Keep in Mind

- Dementia affects a person's brain.
- Dementia is common, especially in older people.
- Dementia is a disease, not a part of ageing.
- As a first step it is important to see a medical doctor, if possible.
- It is important for you to take care of yourself, not only the person you help care for.

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