

Communicating a Diagnosis of Alzheimer's Disease (AD):

A conversation between
HCPs, patients, and their
loved ones

Disclaimer



This resource was developed by Eli Lilly and Company and Dr. Sharon Cohen, MD, and Prof. Katherine Rankin, PhD, who are experts in Alzheimer's Disease. This work was inspired by established peer reviewed research but created based on the participants' perspectives and opinions as well as from data on file from multiple Lilly advisory settings.

What Are the Historical Barriers to Communicating the Diagnosis of AD?

Communicating a **serious diagnosis without diagnostic certainty**

Communicating a **complex diagnosis that requires substantial time** on the part of the HCP

Communicating the **diagnosis of a serious disease** which will **limit independence** and which **impacts quality of life**

Communicating a diagnosis of a disabling disease for which there are **insufficient treatment options**

Communicating the **information to someone with a cognitive disorder** and/or **lack of insight**, potentially resulting in misunderstanding, inability to retain or act on the information provided

Communicating the **diagnosis not only to the patient, but also to their loved ones** whose lives are also affected by the diagnosis

Dubois B et al. *J Alzheimers Dis.* 2016;49:617-31.

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Why Is It Important to Communicate the Diagnosis of AD?

To validate patients and loved ones concerns and to **provide clear and helpful information**

To help patients and loved ones **understand the clinical presentation**, and to learn skills that are critical for coping with the disease

To give patients and loved ones the chance to plan ahead and to obtain disease-specific advice regarding **support in everyday life**

To facilitate patient **access to pharmacological and non-pharmacological treatment**

Rasmussen J et al. *Degener Neurol Neuromuscul Dis*. 2019;9:123-30.

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Communication Toolkit for HCPs

Goal of this toolkit:

To enable HCPs to be better equipped to have a conversation with their patients about a diagnosis of Alzheimer's disease (AD)

Limitations: Please note, the toolkit is not meant to cover non-AD dementia, diagnostic procedures, interpretation of diagnostic results, or similar.



OBJECTIVES:

- 1 To provide a clear protocol to guide the communication of the diagnosis of AD to patients with early symptomatic AD¹⁻³.
- 2 To help clinicians explain the AD diagnosis to their patients in a clear, simple, patient-oriented manner, considering the patient's possible cognitive limitations, and involving their loved ones in the discussion.
- 3 To provide recommendations utilizing evidence-based principles of empathic communication⁴.
- 4 To provide scripts detailing how to communicate different messages about the diagnosis of AD.

1. Baile WF et al. *Oncologist*. 2000;5(4):302-11. 2. Maksymowicz S et al. *Neurol Sci*. 2022;43(7):4257-65. 3. Vandekieft GK et al. *Am Fam Physician*. 2001;64(12):1975-78. 4. Derksen F et al. *Br J Gen Pract*. 2013;63(606):76-84. This resource was developed by Eli Lilly and Company and Dr. Sharon Cohen, MD, and Prof. Katherine Rankin, PhD, who are experts in Alzheimer's Disease. This work was inspired by established peer reviewed research but created based on the participants' perspectives and opinions as well as from data on file from multiple Lilly advisory settings.

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ENABLE HONEST CONVERSATION WITH EMPATHY



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OPEN THE CONVERSATION



BUILDING EMPATHY



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SUMMARY AND NEXT STEPS

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- 3 _____

Section 1

PLAN AHEAD



Ensure the Appropriate Setting



Try to ensure that at least one loved one is included in the conversation with the patient, this way the family is informed so they can take steps to support the patient.



Organize a private room or area.



Allocate enough time for the conversation. At least 15-20 minutes is recommended, in order to allow the patient and family time to react and to ask their questions.



Review the supportive data and have it available.



Limit potential distracting noises or interruptions and switch electronic devices to silent mode.

In case of more complex patient conditions (e.g. psychiatric comorbidities, behavioral problems), evaluate the need for a multidisciplinary approach with other relevant health professionals (psychiatrist, psychologist, social worker).





Section 2

OPEN THE CONVERSATION



Open the Conversation and Identify Relevant Information

CONSIDERATIONS

- Start with an introduction.
- Make and maintain eye contact with the patient and loved ones.
- Try to be fully present. Genuine interest in the other person can increase trust.
- Assess the patient's and loved ones' goals and expectations for the visit.
- Identify if anything relevant happened or if anything has significantly changed since the last visit (e.g. cognitive concerns, personality changes, stress factors).
- Use open-ended questions.
- Communication including questions should be short and easy to understand.



EXAMPLES

"Is there anything that has changed since the last time that we met?"

"What is your understanding of your current condition?"

"I see... Go on... Are there other questions?"

These are just examples which you can modify to fit your patient.

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Section 3

BUILDING EMPATHY



Purpose of Section 3 – Building Empathy

This section is a refresher of core communication skills and reviews **the importance of the interaction with the patient in the diagnosis conversation** and includes additional perspectives that may help to optimize the dialogue.

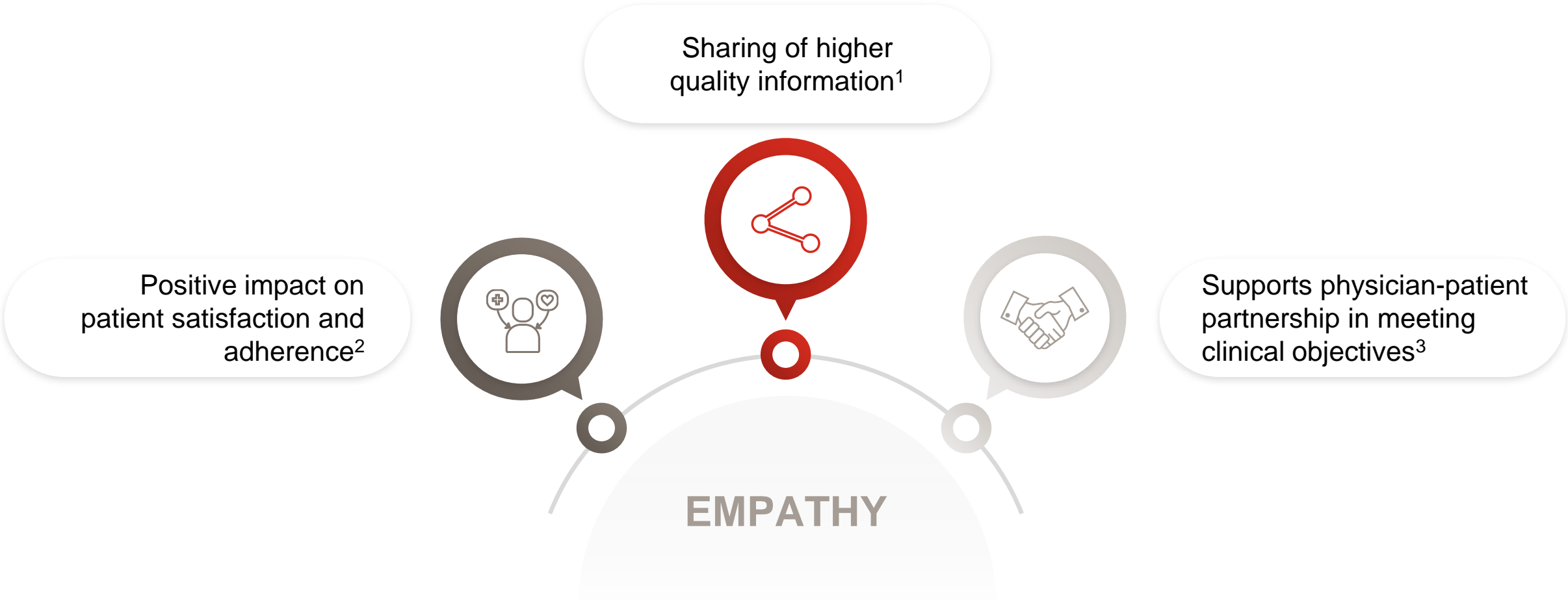
Expressing empathy in the patient-physician communication is important to help build patient trust, calm anxiety, and improve health outcomes¹.

1. Derksen F et al. *Br J Gen Pract.* 2013;63(606):76-84.

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Benefits of Empathy in Patient Communication



1. Kim SS et al. *Eval Health Prof.* 2004;27:237-51. 2. Shields CG et al. *Patient Educ Couns.* 2005;57:232-38. 3. Zachariae R et al. *Br J Cancer.* 2003;88:658-65.
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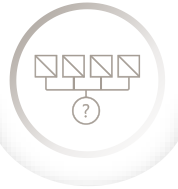
Building and Communicating Empathy



Stop and address questions as they arise.



Use empathic statements to recognize the patient's emotions.



Ask exploratory questions to help understand.



In addition to the patient's words pay attention to their gestures, facial expressions, and tone of voice.



Validate responses to help the patient realize their feelings are important.



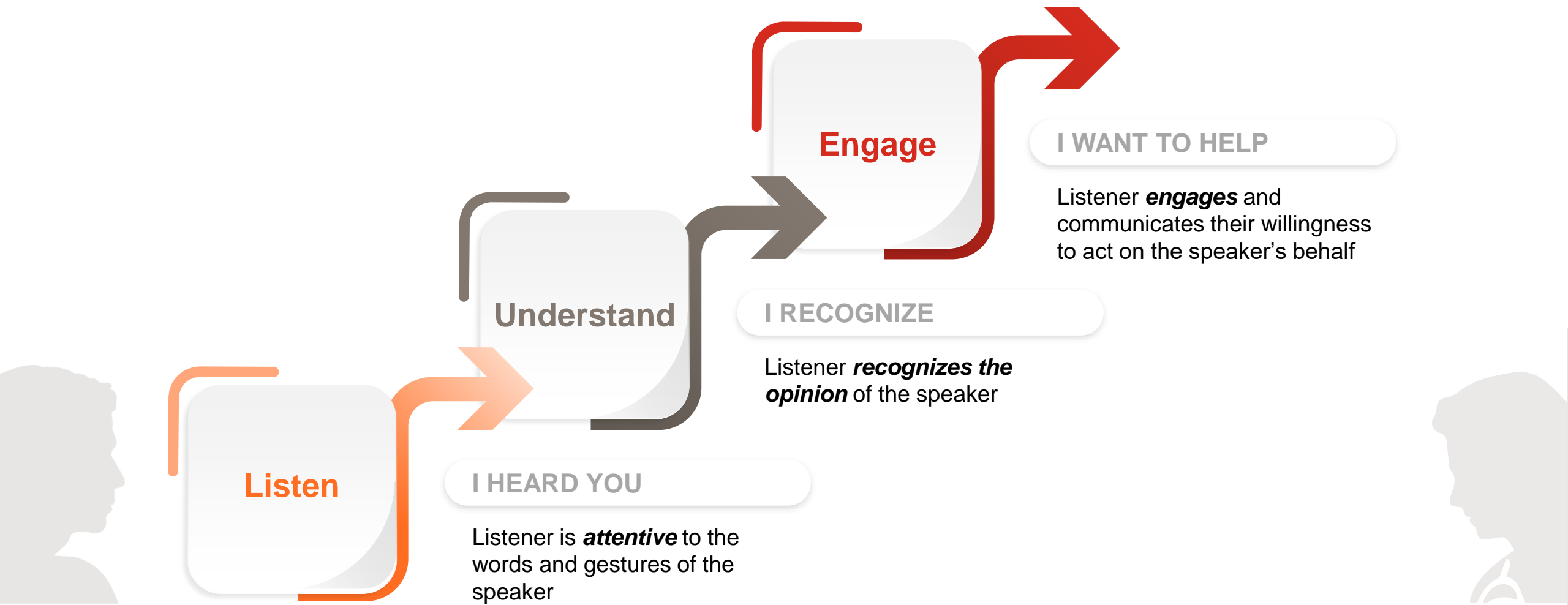
Communicate willingness to act on the patient's behalf.

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Step Up Empathy Language



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The 3 Steps in Practice

Step 1 – Listen

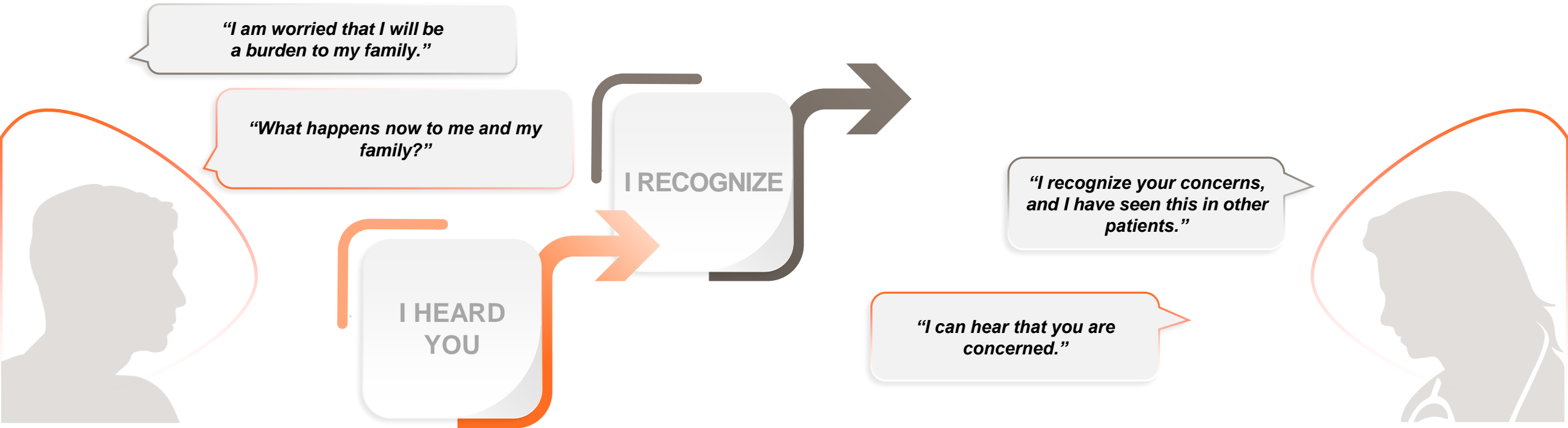


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The 3 Steps in Practice

Step 2 – Understand

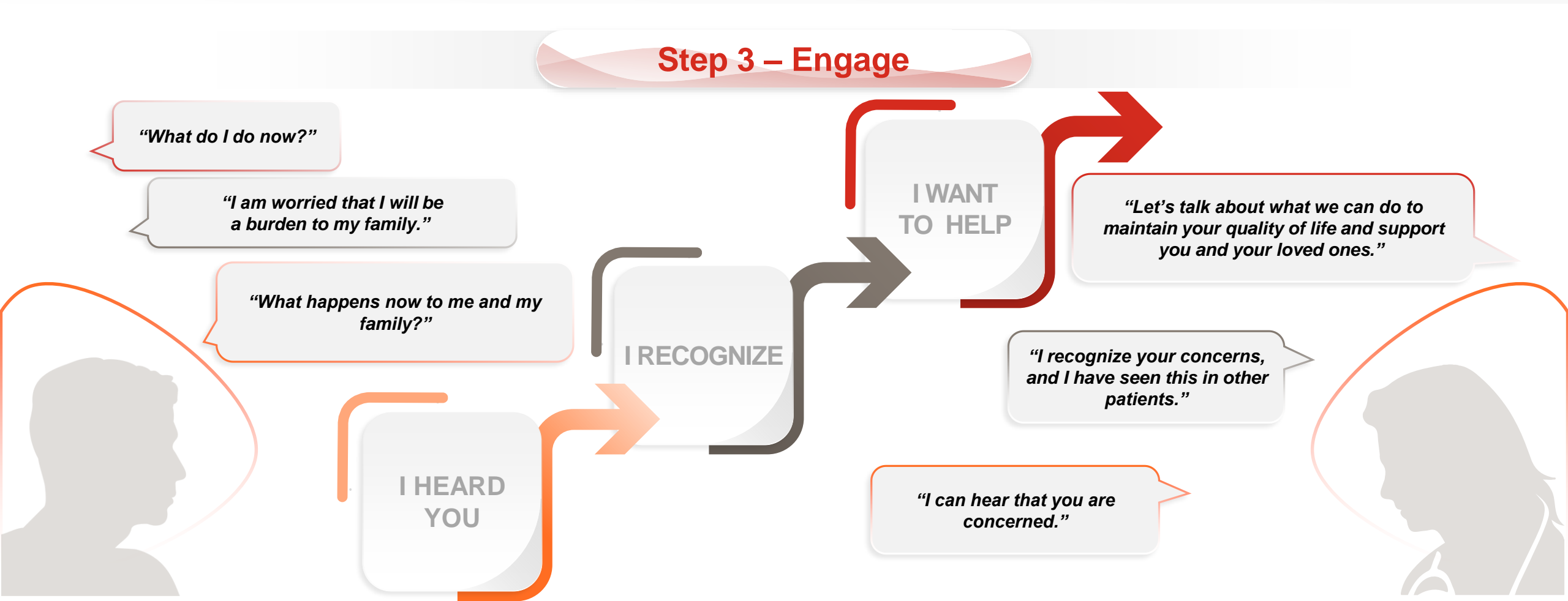


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Section 4

COMMUNICATING THE DIAGNOSIS OF AD



Communicating the Diagnosis of AD

BEST PRACTICES

- ▶ Reserve enough time to be able to answer any questions.
- ▶ Briefly summarize events leading up to this point.
- ▶ Consider the stage of the disease and the individual's specific challenges. It is important to repeat important points, but also to regularly check the patient's understanding and retention. The Teach-Back method may help in this.
- ▶ Consider that some individuals will want to learn more details about their test results and the disease itself, while others will feel overwhelmed by too much detail.
- ▶ If the patient was not accompanied by another person, offer the patient another follow-up meeting together with their loved ones or ask permission to follow up with family.

GENERAL ADVICE

- ▶ Use nonmedical terms and avoid jargon.
- ▶ Use mental / visual imagery whenever possible.
- ▶ Avoid language with negative associations.
- ▶ Communicate to the patient and their loved ones that you are taking their concerns seriously.
- ▶ Be hopeful, but realistic.
- ▶ Ensure the patient understands that the HCP is here to support them.
- ▶ If the patient does not understand what you are saying, try saying it in a slightly different way instead.



Communicating the Diagnosis of AD

? EXAMPLES

“Based on all the collected information and the results on the different tests and the image of the brain (MRI, CT), we can confirm you have mild dementia due to Alzheimer’s disease. Alzheimer’s disease is a disease in which certain brain cells no longer function normally.”



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Communicating the Diagnosis of AD



EXAMPLES



"You do have problems with your memory and thinking, that are affecting your ability to carry out some activities independently (eg, paying bills, managing household). This is not a normal part of aging. However, there are many things you are still able to do. We want you to continue to do everything that you want to do and can do, safely for as long as possible."

"We know that in people with Alzheimer's disease, there are some changes in the brain that may start to occur many years before you experience any symptoms. Because of this, your brain is not working as well as it used to."



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Communicating the Diagnosis of AD

? EXAMPLES



“At this point, you are in the early stages of Alzheimer’s disease. It is good we diagnosed it early, because this will give you and your family time to make important choices and plan for your future.”



“You do not have to go through this process alone; I will be there to support you.”

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Communicating the Diagnosis of AD

» HOW TO GO ABOUT BEING HOPEFUL, BUT REALISTIC

CONSIDERATIONS

Remind the patient that they are early in the disease process. They can still make many choices for themselves about how they wish to conduct their affairs, and what they want for their present and future care.

Encourage the patient to invite a loved one to their appointments, if one is not already involved, as this can be helpful for recalling information and for general patient support.



EXAMPLES

"It is challenging to deal with this disease on your own, so I will be here to guide you and connect you to different services that will give you helpful support."

"I have some ideas about how to help you continue to enjoy the things you love to do for as long as possible."

"Although we are not able to cure your disease, there are things we can do to help you maintain your independence and quality of life for as long as possible."

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Teach-Back in Patient Communication

WHAT IS IT?

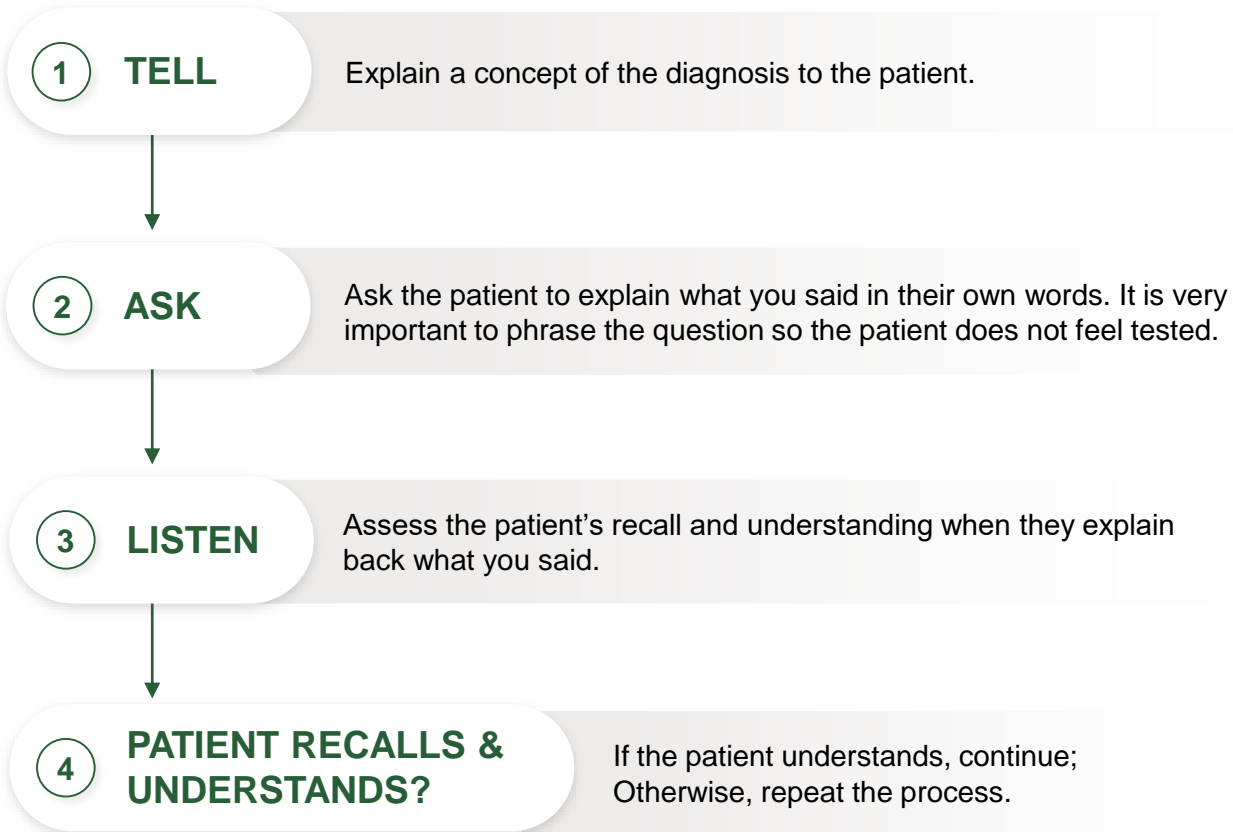
Teach-Back is a method that may already be used in your clinical practice, or maybe it is a new concept to you. It is a way to confirm what the patient understands, using their own words. The method creates an opportunity for communication in which the HCP shares information and then asks the patient to recall and confirm their understanding before adding any new information.

BENEFITS

- Improves patient's comprehension.
- Reduces the chances of misinformation.
- Improves effectiveness and efficiency in patient communication.



Teach-Back in Patient Communication



? EXAMPLES

"I know we talked about a lot of things, and sometimes I talk fast. I want to be sure I communicated this clearly – can you tell me what you understood about this, in your own words?"

"I know we talked about a lot of things. Your loved one wasn't able to be with us today. When your loved one asks you what we talked about, what are you going to tell them?"



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Communicating the Diagnosis of AD

EXAMPLES

“I know this is a lot of information; what questions do you have so far?”

“Is there anything that does not make sense to you and that you would like to talk about?”



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Section 5

SUMMARY AND NEXT STEPS



Summary & Next Steps

CONSIDERATIONS

- Summarize the news to facilitate understanding.
- Set a plan for follow-up (referrals, further tests, treatment options).
- Offer a means of contact if additional questions arise.



EXAMPLES

“Even though there is no cure for Alzheimer’s disease, we do have some treatment options that may help with your quality of life.”

“Ok, let me summarize the most important takeaways...”

“Please feel free to reach out if additional questions arise.”

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