

Primary progressive aphasia (PPA)



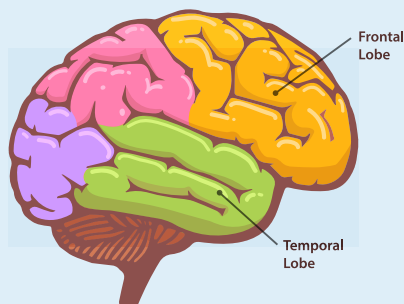
dementia
understand together

DSiDC
Dementia Services Information
and Development Centre

Primary progressive aphasia (PPA)

Primary progressive aphasia (PPA) is a neurological brain condition that affects your ability to communicate. It is a rare type of dementia that can occur with frontotemporal dementia (FTD) or Alzheimer's disease.

PPA is caused by changes to the parts of your brain called the frontal and temporal lobes. These are the **speech and language centres** of your brain. They help you to communicate, talk, read, write and understand.





Symptoms of PPA

Symptoms vary from person to person, but may include some of the following:

- › Having difficulty in finding the right word or name
- › Using one word in place of another
(for example, saying 'dog' instead of 'cat')
- › Putting words in the wrong order
- › Speaking slowly or hesitantly
- › Pronouncing words incorrectly
- › Having trouble in understanding words or sentences
- › Not keeping up in a conversation
- › Having difficulties with reading and writing

PPA is progressive, which means the difficulties get worse. As time goes on, you may notice some trouble with other mental skills such as thinking, memory and decision making. Mood, personality and behaviour may also change.



Types of PPA

There are three main types of PPA:

- › Non-fluent variant PPA (nfvPPA)
- › Semantic variant PPA (svPPA)
- › Logopenic variant PPA (lvPPA)

Some people may have more than one type of PPA.

Non-fluent variant PPA (nfvPPA)

If you have nfvPPA, you lose full control of the muscles that you use to form speech sounds or pronounce words properly. This is called apraxia of speech.

- › You know what you want to say, but you can't always find or pronounce the words you want to use.
- › Talking becomes more hesitant and less fluent. You may need to speak more slowly.
- › Understanding complex sentences can be a challenge.

Semantic variant PPA (svPPA)

SvPPA is a language disorder where you have trouble in understanding the meanings of words.

- › You may find you don't know the names of things, so you have to come up with different words or phrases. This problem gradually gets worse, making it hard to say what you want to say.
- › You may also have trouble understanding other people's words and grasping what they are talking about.
- › You may find communication aids useful – for example, your phone, photos or a wordlist.

Logopenic variant PPA (lvPPA)

If you have lvPPA, you have trouble in finding the right words. You can understand what you hear or read and can speak fluently in good grammatical sentences, but you may struggle to find particular words.

- › With key words missing, it may be hard for people to know what you are saying.
- › You may have difficulty in repeating words or phrases accurately.
- › LvPPA is linked to Alzheimer's disease.



Progression

PPA gets worse over time. How quickly it progresses is different for each person. As PPA progresses, it is likely to affect your memory and the way you think. You will need more support as time goes on.

Deciding when to tell family and friends about your condition is your own personal choice. Once they know about it, they will be able to give you support and encouragement.

Treatment

PPA has no cure, but various types of treatment can help you cope with it.

The two main types of treatment are:

- › Speech and language therapy
- › Medicine

Speech and language therapy

A **speech and language therapist (SLT)** can help you to cope with communication difficulties and everyday conversations. This will help you to lead a confident and independent life.

The SLT will:

- › Assess your communication abilities
- › Identify your strengths and weaknesses
- › Explain what is going on with your PPA
- › Suggest different ways you can communicate
- › Show you how to use aids to help you communicate, such as your phone, ID card, photos or a notebook
- › Provide one-to-one or group therapy

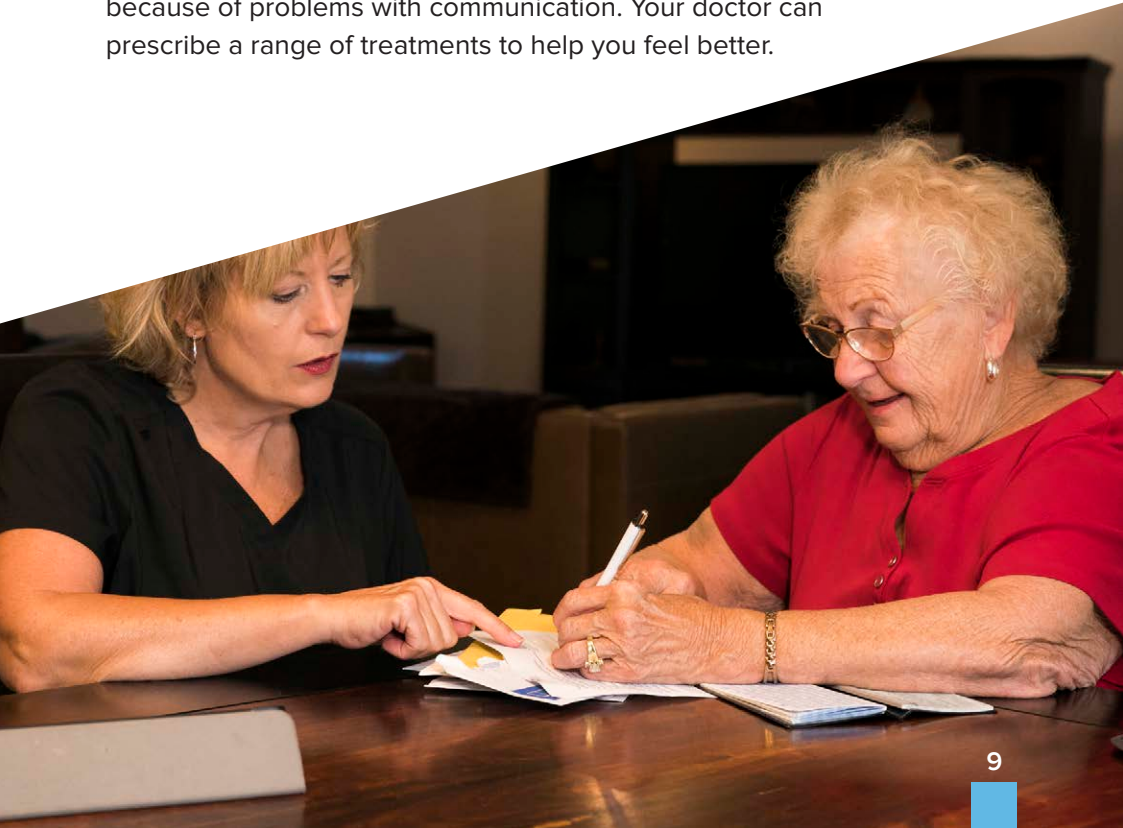
- Help your family or carers to understand your condition and how to communicate with you
- Link you up with other people who are living with PPA

To contact a speech and language therapist you should apply to your nearest Primary Care Team. You may need to ask your GP for a referral.

Medicine

If you have lvPPA, your doctor may prescribe medications called cholinesterase inhibitors. These are often used for Alzheimer's disease. They can improve nerve connections in the brain and may help you to concentrate and find key words.

Any form of PPA can make you feel depressed or anxious because of problems with communication. Your doctor can prescribe a range of treatments to help you feel better.



Living well

It is important that you and your family or carers get the information and support you need after a diagnosis of PPA. Understanding PPA helps you plan for the future.

Tips for living well with PPA:

- › Keep on the go. Moving around helps keep you healthy.
- › Carry on with your hobbies and interests.
- › Keep connected with your friends and family.
- › Look after your mental health. For example, do things you enjoy and get plenty of sleep.
- › Be aware that infections (for example, chest or urine infections) can cause serious complications. See a doctor as soon as possible if you feel unwell.
- › Look for support. Contact your public health nurse or local dementia adviser for advice.
- › Live one day at a time and aim to stay positive.



More information and support

Contact the following organisations to find out more:

The **Alzheimer Society of Ireland (ASI)** provides the main source of support for all types of dementia. For example, they provide one-to-one dementia nurse advice, online support groups and family training.

Contact ASI on

- › Freephone confidential national helpline: 1800 341 341
- › Email: helpline@alzheimer.ie
- › Website: www.alzheimer.ie

Rare Dementia Support

- › Email: contact@raredementiasupport.org or call 0044 20 3325 0828
- › Website: www.raredementiasupport.org/primary-progressive-aphasia/living-with-ppa

The **DSiDC** provides education, training and information on best practice in dementia care. For more information visit www.dementia.ie

Understand Together provides information and resources on supports for people with dementia and their carers.

- › Website: www.understandtogether.ie
- › HSE Live: 1800 700 700



Dementia Services Information and Development Centre
6th Floor, Mercer's Institute for Successful Ageing
St James's Hospital, James's Street
Dublin 8, D08 E9P6

www.dementia.ie

