What’s this all about?

This pack contains information about aphasia. It includes this **booklet** and a **DVD**.

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This is a **QR code**

You can **use it to go directly** to

-- Websites
-- DVDs
-- Publications in this booklet

To see how – go to the **back page** of this booklet
What is aphasia?

If you have aphasia, you may find it hard to:
-- talk
-- understand others when they speak
-- read
-- write
-- use numbers and do calculations.

You may have been told that you have aphasia.

If so, you are not alone.

It is estimated that there are about 250,000 people living with aphasia in the UK (more than live with MS and Parkinson’s combined).

But aphasia is a hidden disability, so few people know about it.

People who have aphasia can think clearly. But they have difficulty getting messages in and out.

"I thought I was losing it but I know what aphasia is now"

Aphasia means you have a problem with communication.

Aphasia can be very confusing for you and your family.

Aphasia can also be called Dysphasia.

It’s invisible, and difficult to understand.

If you have aphasia, you may feel very bewildered and lonely.

It can help to meet others who are in the same situation.

It’s a good idea to talk to a speech and language therapist about your aphasia.
What causes aphasia?

Aphasia can be caused by a number of things:
-- stroke
-- injury to the brain
-- infections and inflammations of the brain
-- progressive aphasia
-- tumours in the brain.

**Stroke** is one of the most common causes of aphasia. A stroke interrupts the blood supply to the brain. The brain tissue becomes damaged.

If the left side of your brain is affected, you may have:
-- problems moving your right side.
-- language and communication problems (aphasia).

What is stroke?

A stroke happens when the blood supply to a part of the brain is suddenly **reduced**. This can happen in two ways:
blood vessels can become *blocked*, or they *leak*.

**Blockages**
A blood clot can block a blood vessel in the brain.

This can be a thrombus or an embolus.

**A thrombus** is a clot which builds up and blocks a blood vessel.

**An embolus** is a clot which forms, then breaks off and travels along a blood vessel until it gets stuck.

**Leaks**
Blood vessels can become thin or weak and begin leaking.

This is called a haemorrhage.

**An aneurysm** is a weakness or thinning in the wall of a blood vessel. If the blood vessel bursts, a **haemorrhage** happens. Blood leaks into the surrounding tissue.
Different types of aphasia

Aphasia can take many different forms. Talking, listening and understanding, reading, writing and using numbers can all be affected in different ways.

Some people have very severe aphasia. For others, it is not so bad. Different people have different types of aphasia.

You may recognise your own type of aphasia in the boxes that follow. No-one will have all of these difficulties. Aphasia can be called Dysphasia.

### Speaking and finding words

- I find it **difficult** to talk at all
- I struggle to get **every word** out
- I can’t find the **exact words** I want
- I miss out **small words**, like to and of
- I talk a lot. But what I say is difficult to follow
- I use **strange words** which sound foreign or nonsensical
- I think I am talking perfectly **well** but I am not
- I get stuck on **certain words** or phrases
- Sometimes I am very **blunt** and direct. This can **upset people**

### Listening, understanding and aphasia

I can hear, but:

- I have **difficulty** listening, and **understanding** what other people say
- I have difficulty understanding some **words**
- I have difficulty following **conversations**

I can mostly follow what others say, but it can be **harder**:

- in a **crowded** or noisy place
- when I’m **tired** or anxious
- if the other person talks too **quickly**
- or doesn’t make it clear what the **topic of conversation** is
- or uses **complicated words** or long sentences.
Different types of aphasia (continued)

Reading and aphasia

"I couldn’t read and that was a frightening thing to me. People would bring in magazines. I’d say 'thanks'... but couldn’t read them"

- Reading anything takes me a long time.
- I find it difficult to understand anything I try to read.
- I can read some words, but nothing too long or complicated.
- I can read most things, but get stuck when I have to take in details.

Writing and aphasia

- I can’t spell.
- I find it hard to plan or organise what I want to write.
- I have difficulty making grammatical sentences.
- I can’t write at all.
- I can write some letters of the word I want (but not the whole word).

Aphasia and using numbers

- Numbers and calculations are hard to deal with.
- I make mistakes with time, and money.
- I take a long time to work out bills and write out cheques.
- I get stuck working out my change.

What form does your aphasia take?
Aphasia can lead to:
- isolation
- frustration
- problems with relationships
- anxiety
- anger
- lack of confidence
- unemployment
- boredom
- depression
- uncertainty
- embarrassment
- a different way of life

Living with aphasia brings lots of **new challenges**. Communication is so **important** to life, work, relationships and leisure. It can be hard to **re-connect with life**. Many things **help you** find a **way forward**; stroke **service providers, others with aphasia** and **clear, accessible information**.

**See**
- Meet people who live with aphasia
- How can I get more information?
Making communication work
When you have aphasia, communication can be difficult.

Other people may not know what to do.
These communication tips may help.

Ten top tips for talking with people with aphasia

- Use pen and paper
- Say one thing at a time
- Don’t pretend you understand
- Don’t rush – slow down, be patient
- Draw diagrams or pictures
- Write down key words
- Relax – be natural
- Recap – check you both understand
- Ask what helps
- Reduce background noise

If you are looking for help with the computer, visit this website for ideas on what software can help.
www.aphasiasoftwarefinder.org

The Stroke And Aphasia Handbook has lots of top tips on how to help. It also includes how to help with reading and writing.

Or you can visit Connect’s website at
www.ukconnect.org/projects_32_546.aspx
What do other people say about their life with aphasia?

“Before my stroke, I was very driven and ambitious professionally. Since then, the pace of my life has slowed, allowing me more time for others, especially my family. Becoming a hands-on grandfather has been a great lesson in patience and flexibility. Now I’m less driven, but also more open-minded and open-eyed and more accepting of my own and others’ limitations. I’m grateful for the opportunity to have a second chance at life.”  

Andy

Sarah Scott was reading out loud in an English lesson when she had a stroke. She was 18 years old. Her aphasia meant she had just a few words of speech 'Yes and No'. So 18 months on, how do you spend your time?  

“Gym, riding horse, swimming, speech and language therapy, cinema, coming to Connect, talking books. Horse riding is the best.”

Do you have any tips for other people who have just acquired aphasia?

“Write words down if you can’t think of the word. Don’t just sit there, it’s not good at all. Keep busy and active and do things you like doing.”

Elaine

To hear other people talking about aphasia visit patient voices
www.pilgrim.myzen.co.uk/patientvoices/naoconn.htm

To see other people’s stories click on
www.ukconnect.org/viewourdvs.aspx
OR
OR
www.nhs.uk/Livewell/stroke/Pages/Janestokes.aspx
‘Nobody came and asked me how I was coping. Nobody did it, not a soul, and I just felt as if I was drowning really.’ Wendy

‘Going back to work part time has been like a therapy for me and it has benefited George too. It was the best thing I could have done as it has made him try things on his own and given him the confidence to go out on his own to the shops and pub.’ Pat

‘Suddenly my relationship was filled with silence. Do I run? How will we fill the emptiness? My mind stood still. Slowly I discovered that all was not lost. My man’s intelligence, sense of humour, other senses and emotions were – thank God – left intact’. Monica

‘I gradually came to realise that I had been over-caring – that he was able to cope much better than I thought. The more he did without me, the more confident he got.’ Ray

‘Taking small risks helps you to move forward – one step at a time’. Andy

‘I think he’s better now that I share more things with him… now we’re a couple again’. Jane

For advice see Connect’s publications
In the first days and weeks following a stroke, a **lot of changes** can take place.

"It's impossible to tell how much or how quickly someone will recover."

Your **brain** is **recovering** from the stroke. **Some** people recover **more** than others. Recovery **takes time**. In the **early days** after stroke, it may be **impossible** to tell how much recovery you will make.

**Some people recover** their ability to communicate **very quickly**. But for **others** recovery is a **long, slow process**.

You **may not** be able to communicate in the **same way** as you did before the stroke.

Aphasia often becomes **less of a problem** as **time passes**. Many people find ways of coping and learning to **live with it**.

**Many people** with aphasia still see signs of **progress**, even **years after** their stroke.

It's **impossible** to tell exactly how much or **how quickly** someone will recover.

**Everyone is different.** Comparing yourself with others may not help.

Sometimes, **talking doesn’t change much**, but **life still gets much better**.

**Getting better** means **different things** to different people:

-- **feeling** more relaxed and **calm**, not so **angry**
-- **doing more** and **finding a purpose**
-- learning to **talk** or read **better**
-- getting involved in **something** you **enjoy**
-- **looking forward** to a **family event**
-- helping others
-- meeting new **friends**
-- trying **new things**
-- laughing **more**
-- making **plans**.

"Some days I talk the hind legs off a donkey. Some days I can’t talk at all."

"Some people recover their ability to communicate very quickly. But for others recovery is a long, slow process."

You **may not** be able to communicate in the **same way** as you did before the stroke.

Aphasia often becomes **less of a problem** as **time passes**. Many people find ways of coping and learning to **live with it**.

**Many people** with aphasia still see signs of **progress**, even **years after** their stroke.
Many people worry about having another stroke.

**Most people** only have **one stroke**.

A **small number** of people have **more** than one stroke.

**Ask your doctor** what you can do to help prevent another stroke. But it is usually a good idea to:

--- Make sure your **blood pressure** is checked regularly

--- Eat a good **diet**

--- Try to keep your **weight** down and take regular **exercise**

--- Keep taking any **medication** prescribed

--- Stop **smoking**

--- Don’t drink too much **alcohol**

“**Aphasia doesn’t mean the end … can be a new beginning … you’ve got to think of new ways of dealing with things … you have to recognise that you are different to what you were before … and cope with that**” Sharon - person with aphasia
Rehabilitation
Most hospitals have stroke units.

These provide specialised inpatient care, treatment and rehabilitation for people who have a stroke.

Some hospitals have rehabilitation units. These are for people with a range of different conditions, including strokes and head injury.

You may have rehabilitation as an inpatient, in your own home or as an outpatient.

Some people attend a day hospital for their rehabilitation.

What is rehabilitation?
Rehabilitation enables you to:

- identify the problems you are facing
- get better, as far as possible
- get the support and assistance you need
- find ways of coping with the effects of your stroke or brain injury

What happens next?
You should always be told about any plans for your rehabilitation.
If you want to, you can be involved in setting goals and deciding when your rehabilitation will end.

The rehabilitation team might include:

- Doctor
- Nurse
- Physiotherapist
- Occupational therapist
- Speech and language therapist
- Psychologist / counsellor
- Hospital social worker

It’s your right to know what is happening and why.
Getting support at home

Many people find it a relief to get home from hospital.

But it is also a time when you come face to face with aphasia.

You may have questions about:

- Getting better and keeping well
- Managing at home
- Getting practical help
- Finding support and information

You are not alone. The next few pages tell you where to go for help and support.

"I'm relieved to be going home, but I feel a bit anxious too."

You are not alone. With the help of The Stroke and Aphasia Handbook you can find out:

- what sort of help you can get
- where to get it.

To order a stroke and aphasia handbook contact Connect

- Phone: 0207 367 0840
- Email: publications@ukconnect.org and choose ‘The stroke and Aphasia Handbook’
Where do I go for help?

Your communication

Your Speech and Language Therapist
Speech and Language Therapy department

– contact your local hospital

Or Royal College of Speech and Language Therapists.

Email: info@rcslt.org.uk

For more information on where to get help please see the Stroke and Aphasia Handbook on Connect’s website

Your health

NHS Direct
Can give you information about local services

: www.nhsdirect.nhs.uk

: 0845 4647

NHS Choices
Information from the National Health Service on conditions, treatments, local services and healthy living.

: www.nhs.uk

Your GP or health centre

-- Can tell you about local NHS therapy services

-- Can refer you to local NHS therapy

Your district nurse or health visitor

-- Can tell you what health services are available locally

-- Can arrange support for you

: Contact your GP

Your stroke care coordinator or stroke navigator

-- Can tell you what stroke services are available locally

-- Can arrange support for you

: Contact the stroke unit at your local hospital

connect
the communication disability network
Therapies once you’re home

Before you leave hospital, make sure you know – will I get more therapy?

Options:

-- You may go back to the hospital to have treatment and therapy as an outpatient.
-- You may go to a local rehabilitation unit or day hospital.
-- You may see a therapist ... at a local health centre....or in your home.
-- No further therapy may be planned. If so, you should be informed.
-- You may decide to see a therapist privately.

Managing at home – personal and social care services

Your social worker or local Social Services department should provide personal care and support if you need it at home. Social services can advise you about personal budgets and direct payments.

You can contact your hospital social worker before you go home. Or once you are home contact the local social services department.

Local phone book under name of local council

For details see pages 19, 20 & 21 of this booklet – ‘how can my family get information?’
Money and benefits

Department for Work and Pensions (DWP)
Government department providing services and information about work, and benefits (including direct payments and personal budgets).
www.dwp.gov.uk

Local disability and welfare rights groups

Scope
A charity that supports people with disabilities
www.scope.org.uk
0808 800 3333
Email: response@scope.org.uk

Jobcentre Plus
www.jobcentreplus.gov.uk
Local phone book

Other Help

Local disability and welfare rights groups

Citizens Advice Bureau
www.citizensadvice.org.uk
Local phone book

Scope
A charity that supports people with disabilities
www.scope.org.uk
0808 800 3333
Email: response@scope.org.uk

Crossroads
Caring for Carers
www.crossroads.org.uk
0845 450 0350

RADAR
www.radar.org.uk
020 7250 3222
How can I get more information?

Connect – the communication disability charity.

We are a national charity. We improve the lives of people living with aphasia and communication disability, equipping them to reconnect with life. We:

-- work in equal partnership to enable people with aphasia to develop and deliver services that they need and want
-- provide training and consultancy to a wide range of service providers
-- provide information and support to help everyone understand aphasia and its impact

You can visit us in person if you live in London, Cornwall, Gloucester or Canterbury. If you would like to have services in your local area, contact Connect. Details are on our website.

Or you can visit our website.  
☎: www.ukconnect.org  
📞: 020 7367 0840  
Email: info@ukconnect.org

NHS Choices
Information from the National Health Service on conditions, treatments, local services and healthy living.  
☎: www.nhs.uk

Other organisations that support people with aphasia include:

Connect – the communication disability network  
☎: www.ukconnect.org  
📞: 020 7367 0840  
Email: info@ukconnect.org

Speakability  
☎: www.speakability.org.uk  
📞: 0808 808 9572  
Email: speakability@ speakability.org.uk

Different Strokes  
☎: www.differentstrokes.co.uk  
📞: 0845 130 7172  
Email: info@differenstrokes.co.uk

The Stroke Association  
☎: www.stroke.org.uk  
📞: 0845 303 3100  
Email: info@stroke.org.uk

Chest, Heart and Stroke Association Scotland  
☎: www.chss.org.uk  
📞: 0845 077 6000  
Email: admin@chss.org.uk

Northern Ireland Chest Heart and Stroke Association  
☎: www.nichsa.com  
📞: 0845 769 7299  
Email: mail@nichsa.com

Headway  
(for those with all types of brain injury including stroke)  
☎: www.headway.org.uk  
📞: 0808 800 2244  
Email: helpline@headway.org.uk

NHS Choices
Information from the National Health Service on conditions, treatments, local services and healthy living.  
☎: www.nhs.uk

Speakability  
☎: www.speakability.org.uk  
📞: 0808 808 9572  
Email: speakability@ speakability.org.uk

Different Strokes  
☎: www.differentstrokes.co.uk  
📞: 0845 130 7172  
Email: info@differenstrokes.co.uk

The Stroke Association  
☎: www.stroke.org.uk  
📞: 0845 303 3100  
Email: info@stroke.org.uk

Chest, Heart and Stroke Association Scotland  
☎: www.chss.org.uk  
📞: 0845 077 6000  
Email: admin@chss.org.uk

Northern Ireland Chest Heart and Stroke Association  
☎: www.nichsa.com  
📞: 0845 769 7299  
Email: mail@nichsa.com

Headway  
(for those with all types of brain injury including stroke)  
☎: www.headway.org.uk  
📞: 0808 800 2244  
Email: helpline@headway.org.uk

NHS Choices
Information from the National Health Service on conditions, treatments, local services and healthy living.  
☎: www.nhs.uk

Speakability  
☎: www.speakability.org.uk  
📞: 0808 808 9572  
Email: speakability@ speakability.org.uk

Different Strokes  
☎: www.differentstrokes.co.uk  
📞: 0845 130 7172  
Email: info@differenstrokes.co.uk

The Stroke Association  
☎: www.stroke.org.uk  
📞: 0845 303 3100  
Email: info@stroke.org.uk

Chest, Heart and Stroke Association Scotland  
☎: www.chss.org.uk  
📞: 0845 077 6000  
Email: admin@chss.org.uk

Northern Ireland Chest Heart and Stroke Association  
☎: www.nichsa.com  
📞: 0845 769 7299  
Email: mail@nichsa.com

Headway  
(for those with all types of brain injury including stroke)  
☎: www.headway.org.uk  
📞: 0808 800 2244  
Email: helpline@headway.org.uk
How can my family get more information?

The next few pages are for your partner, or the person who lives with you or looks after you.

These pages may be helpful for you too.

When someone has a stroke and aphasia, relatives, friends and family members face many changes and challenges:
-- loneliness
-- fear: what does the future hold?
-- feeling exhausted
-- our relationship has changed
-- guilt
-- how can we talk?
-- anger and resentment
-- money worries
-- where can I get help?
-- I need someone to talk to
-- Everything is different

Some useful ideas for carers:
-- Local carers’ groups
-- Information and support from the internet
-- Counselling
-- Keeping a journal
-- Making time for yourself
-- If you don’t look after yourself, you can’t look after your partner.
-- Befriending

If you are looking after someone with aphasia at home, you might be able to get practical help and support.
How can my family get more information (continued)?

You have the right to ask Social Services for:

-- a **personal budget** or **direct payment** to help fund the care you choose
-- a **Community Care Assessment**, to work out the needs of the person with stroke and aphasia
-- a **Carer’s Assessment** to work out the needs of you, the carer.

After an **assessment**, Social Services might suggest:

-- a home help
-- shopping services
-- help to use educational, facilities and libraries
-- a place at a day centre
-- a holiday
-- meals
-- a break for you, the carer

Social Services will only suggest things they can provide.

**You** may have to **pay** for the services or **contribute** to the cost.

**Support** will **vary** from place to place.

Don’t wait for a crisis - **Act Early**

"If you are a care giver, it helps to keep a **diary** of what you do every day, to show at the assessment."

Where can my family get support?

**Connect** – the communication disability network

- [www.ukconnect.org](http://www.ukconnect.org)
- 020 7367 0840
- [Email](mailto:info@ukconnect.org)

The **Stroke And Aphasia Handbook** or the **Connect website** has more information on how to go about this.

Connect has written **guides** to support you and your family. You can **read** them from our **website**.
How can my family get information (continued)?

Speech and language therapist (SLT)
Phone book under the name of your local hospital (ask for the stroke unit)

NHS Choices (Carers Direct)
Information, advice and support for carers
: www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx

Carers UK
: www.carersuk.org
: 0808 808 7777
Email: contact via website

Princess Royal Trust for Carers
: www.carers.org
: 0844 800 4361
Email: info@carers.org

The Stroke Association
: www.stroke.org.uk
: 0845 303 3100
Email: info@stroke.org.uk

Chest, Heart and Stroke Association Scotland
: www.chss.org.uk
: 0845 077 6000
Email: admin@chss.org.uk

Northern Ireland Chest Heart and Stroke Association
: www.nichsa.com
: 0845 769 7299
Email: mail@nichsa.com

Speakability
: www.speakability.org.uk
: 0808 808 9572
Email: speakability@speakability.org.uk

Relate
: www.relate.org.uk
: 0845 456 1310
Email: enquiries@relate.org.uk

Relate Scotland
: www.relatescotland.org.uk
: 0845 119 6088
Email: enquiries@relatescotland.org.uk

Different Strokes
: www.differentstrokes.co.uk
: 0845 130 7172
Email: info@differentstrokes.co.uk

Crossroads Caring for Carers
: www.crossroads.org.uk
: 0845 450 0350
Email: contact via website

The Stroke Association
: www.stroke.org.uk
: 0845 303 3100
Email: info@stroke.org.uk

RADAR
: www.radar.org.uk
: 020 7250 3222
Email: radar@radar.org.uk

Local hospital Social Services
Phone book under the name of your local council
What are QR codes?
A QR code is a symbol.

This is a QR code.

QR codes take you directly to websites.

If you have a smartphone (Android, Blackberry or iPhone) you can use QR codes.

QR codes take you directly to:
-- websites,
-- DVDs,
-- publications in this booklet.

How do I use them?
Download an app that reads QR codes.
E.g. i-nigma (download is free).

Open the app.

Hover your phone's camera over the QR code.

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