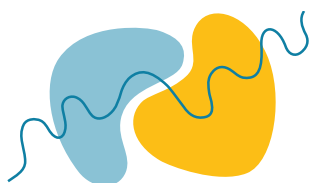
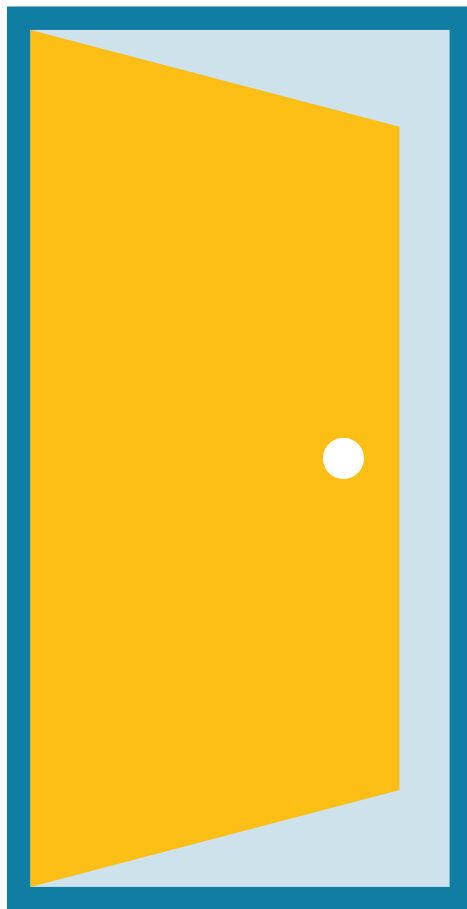
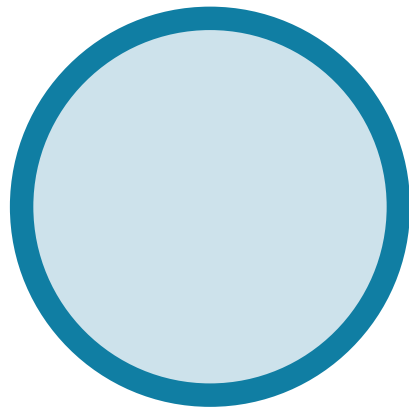


Aphasia Information Pack



connect

the communication disability network

What's this all about?

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

It covers:

2	What is aphasia?.....	2
3	What causes aphasia?.....	3
4	Different types of aphasia.....	4
6	What does aphasia feel like?.....	6
7	Top tips for communication.....	7
8	Meet people who live with aphasia.....	8
10	What carers say.....	10
11	Will I get better?	11
12	Will I have another stroke?.....	12
13	What happens next?.....	13
14	Getting support at home.....	14
15	Where do I go for help?.....	15
18	How can I get more information?.....	18
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22	Add your local information.....	22
23	QR codes: what are they and how to use them?..	23

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?



"What is aphasia?"

"Aphasia affects a person's ability to communicate with others"



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.

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"

If you have aphasia:

- you are still an **intelligent** adult
- you **know** what you **want to say**
- you can make your own **decisions**
- you are **not deaf**.

People with aphasia know what they think and feel, but can't get to the words.

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.

"Why did you get aphasia?"



"I had a **stroke** and the left side of my brain was damaged."

The **left** side of your **brain** controls many things including:

- your **right arm** and right **leg**
- language and communication.

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**.

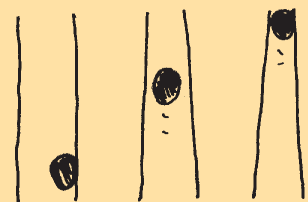
Blockages

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?

What does *aphasia* feel like?

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.....

8



How can I get more information?.....

18



Top tips for communication

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



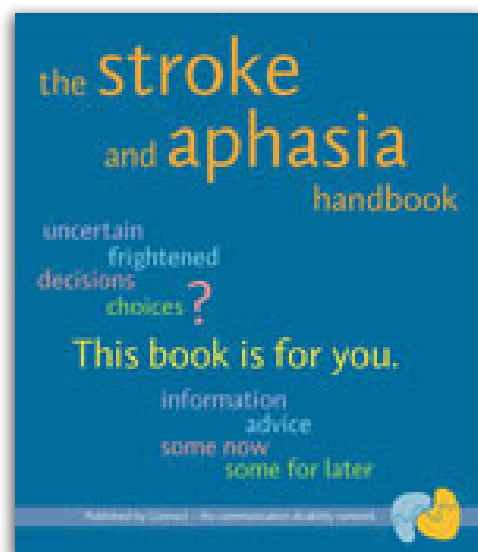
connect

the communication disability network

www.ukconnect.org

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



Aphasia
Information Pack



connect

the communication disability network

Meet people who live with aphasia

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."



"My aphasia means I sometimes sound like I have a German accent. But I am English! This is known as 'Foreign Accent Syndrome'. It was scary and distressing because as well as unexpectedly being 'disabled', suddenly I had a new 'identity'."

Elaine

Meet people who live with aphasia(continued)

"I am Debbie Lee. I live in Middlesex – little flat. Big family – nine children – two sisters were closest. Long time ago – first job in Bentalls, Kingston – worked there nine years. I met Tony 1981 – together till 1991 – still in my life. Severe stroke September 1987. Nineteen years ago very very shy – no speaking out. One word – 'duck'. Improvement – little tiny improvement for me – lots of people see me – [they say] large improvement for speaking out – blossoming! 2–3 weeks intensive speech and physio and OT – Wolfson Centre. And the City Aphasic Group before Connect – now Connect. Connect - lots of people like conversation group – comfortable, laughing and joking, friendly and warm. Lots of people, some shy, some lots of talking – different type of strokes. Facilitators – me and Carole and Wendy, helping – boost for the people. Also the treasurer".



To **hear other people** talking about aphasia visit **patient voices**

www.pilgrim.myzen.co.uk/patientvoices/naoconn.htm



Patient Voices



To **see other people's stories** click on

www.ukconnect.org/viewourdvs.aspx



Connect's DVDs

OR



Meet people with aphasia

www.ukconnect.org/meet-people-living-with-aphasia.aspx

OR

www.nhs.uk/Livewell/stroke/Pages/janestokes.aspx



NHS Choices Jane: my story

What Carers say

'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**

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



'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**

For advice see Connect's publications



Connect's Better Conversations



Connect's Caring and Coping



Connect's Stroke & Aphasia Handbook



Having a stroke: Being a parent



connect

the communication disability network

Will I get better?

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."



Will I have another 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**



What happens next?

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 **cop**ing with the effects of your stroke or brain injury



Rehabilitation does not:

- ✗ **cure** you
- ✗ **go on for ever**.

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

☎: 0207 367 0840

🖱: www.ukconnect.org/publications.aspx

Email: publications@ukconnect.org
and choose 'The stroke and
Aphasia Handbook'



Connect's Stroke &
Aphasia
Handbook

Where do I go for help?

Your communication

Your **Speech and Language Therapist**

Speech and Language Therapy department



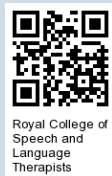
– **contact your local hospital**

Or **Royal College of Speech and Language Therapists.**

 : www.rcslt.org.uk

 : 020 7378 1200

Email: info@rcslt.org.uk



Royal College of
Speech and
Language
Therapists

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

 : www.ukconnect.org/publications
and choose the Stroke
and Aphasia Handbook



Connect's Stroke &
Aphasia
Handbook

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



NHS Choices
Aphasia

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

Where do I go for help (continued)?

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?'



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Where do I go for help (continued)?

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.

Connect

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



NHS Choices
Aphasia



Other organisations that support people with aphasia include:

Connect – the communication disability network

 : www.ukconnect.org

 : 020 7367 0840

Email : info@ukconnect.org



Connect

Speakability

 : www.speakability.org.uk

 : 0808 808 9572

Email : speakability@ speakability.org.uk



Speakability

Different Strokes

 : www.differentstrokes.co.uk

 : 0845 130 7172

Email : info@differentstrokes.co.uk



Different strokes
(for younger people)

The Stroke Association

 : www.stroke.org.uk

 : 0845 303 3100

Email : info@stroke.org.uk



The Stroke Association

Chest, Heart and Stroke Association Scotland

 : www.chss.org.uk

 : 0845 077 6000

Email : admin@chss.org.uk



Chest Heart and
Stroke Association
Scotland

Northern Ireland Chest Heart and Stroke Association

 : www.nichsa.com

 : 0845 769 7299

Email : mail@nichsa.com



Northern
Ireland Chest
Heart and
Stroke
Association

Headway

(for those with all types of brain injury including stroke)

 : www.headway.org.uk

 : 0808 800 2244

Email : helpline@headway.org.uk



Headway

How can my family get more information?

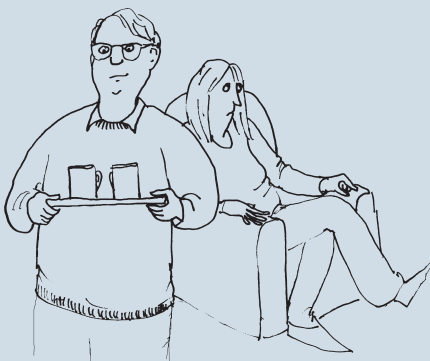
The **next few pages** are for **your partner**, or the person who lives with you or looks after you.

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**



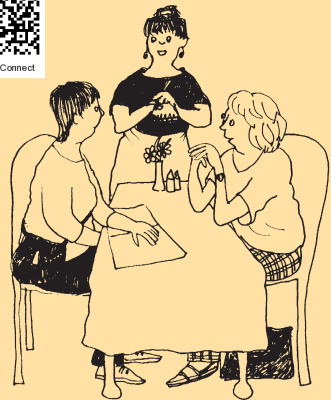
-- **Counselling**



-- 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 assesment."*



Where can my family get support?

Connect – the communication disability network

 www.ukconnect.org

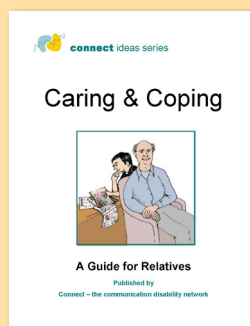
 020 7367 0840

Email : 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.

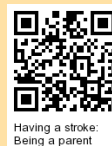
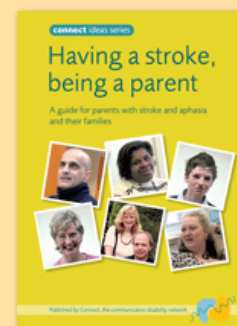
You can **read** them from our **website**.



Connect's Caring and Coping



Connect's Better Conversations



Having a stroke: Being a parent

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@speakeability.org.uk



Relate

☞ : www.relate.org.uk

☎ : 0845 456 1310

Email: enquiries@relate.org.uk

☎ : Local phone book



Relate Scotland

☞ : www.relatescotland.org.uk

☎ : 0845 119 6088

Email: enquiries@relatescotland.org.uk

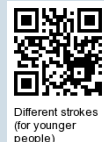


Different Strokes

☞ : 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



RADAR

☞ : www.radar.org.uk

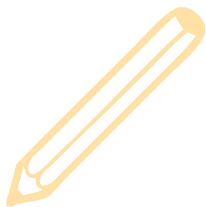
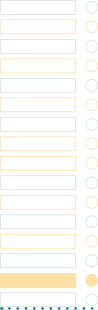
☎ : 020 7250 3222

Email: radar@radar.org.uk



Local hospital Social Services

☎ Phone book under the name of your local council



For your own local contacts or notes

Handwriting practice area with 15 sets of horizontal dashed lines for writing.



connect

the communication disability network

QR codes: what are they and how to use them

What are QR codes?

A QR code is 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 phones **camera** over the QR code

Connect

 www.ukconnect.org

 :020 7367 0840

Email: info@ukconnect.org



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