

# Communication After Stroke:

Information and support for Māori whānau with communication difficulties caused by stroke

By Karen Brewer, Clare McCann and Matire Harwood





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## About this booklet

This booklet is based on a website ([stroke.blogs.auckland.ac.nz](http://stroke.blogs.auckland.ac.nz)) created by Dr Karen Brewer. It is part of a project that was funded by The Health Research Council of New Zealand when Karen Brewer was awarded an Eru Pōmare Research Fellowship in Māori Health. Dr Matire Harwood and Dr Clare McCann were supervisors on this project.

Before creating this booklet we spent many hours listening to Māori whānau affected by stroke. Many of the suggestions come from those whānau, who were keen to share their experiences to help others. Other ideas have come from speech-language therapists who work with Māori whānau. We hope this booklet is helpful for you in your journey. If you would like to get in touch please email Karen, [k.brewer@auckland.ac.nz](mailto:k.brewer@auckland.ac.nz).

## About the authors

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*Ko Tarakeha te maunga*

*Ko Opepe te awa*

*Ko Mataatua te waka*

*Ko Whakatōhea, ko Ngaiterangi ngā iwi*

*Ko Ngai Tamahaua, ko Tauwhao ngā hapū*

*Ko Opape te marae*

*Ko Karen McLellan tōku ingoa takakau*

*Ko Karen Brewer tōku ingoa*



I am a speech-language therapist and kaupapa Māori researcher. I live in Auckland with my husband and our two young sons.

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*Kia ora*

*Nō Te Tai Tokera ahau*

*Ko Ngāpuhi te iwi, ko Ngāti Rangi, Ngāti Moerewa,*

*Māhurehure ōku hapu*

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*Ko Clare McCann tōku ingoa*

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## Acknowledgements

Thank you to the following people for assistance in this project.

Ngā mihi nui ki a koutou.

The stroke survivors and whānau members who contributed to this project. The following asked to be acknowledged by name: Jimmy Huata and Gayle Melrose, Mrs Iraani Paikea and Joanne Stewart, Peter Pirini, Toto Thompson, Debra Andrews, Juliana and Leslie Still, Pere Albert, Petti McLean, Gloria Herbert and Katarina Chapman, Lucy Bagley and Te Urutau (Doreen) Kake, Pa Tony Brown and Irene Saalea. We also acknowledge and all the individuals and whānau who preferred to remain anonymous.

Amohaere Tangitu, Lani Marama and their team at Mai i Ngā Kurī a Whārei ki Tihirau (Bay of Plenty DHB Regional Māori Health Services), Rukingi Haupapa, Ian Kaihe-Wetting and his team at Counties Manukau Health, Ngai Tamahau hapū, Paiheke McGarvey, Susan Reid and Hinemoa Elder. The speech-language therapists, Stroke Foundation community stroke advisors and managers who contributed to this project. Prof Suzanne Purdy, Whaea Julie Wade, Whaea Dolly Paul and colleagues in Speech Science and Te Kupenga Hauora Māori at The University of Auckland. Kaiawhina rangahau Te Whaawhai Taki, Waimirirangi Andrews, Te Ami Henare-Toka and Meghann Grawburg. Lois Cameron and the team at Talking Mats in Scotland. Sally Kedge, Felicity Bright and Carol Green.

The New Zealand Speech-language Therapists' Association and members of He Kete Whanaungatanga. Northland, Counties Manukau and Bay of Plenty District Health Boards. The Stroke Foundation, especially Don Scandrett and Nita Brown. Techpā Studios.

Unless otherwise stated, te reo Māori translations were provided by Pacific International Translations (PACTRANZ).

Illustrations for booklet and whāriki by Carol Green.

## **Disclaimer**

This booklet is intended to supplement, not replace, the advice of a speech-language therapist. Readers should see a speech-language therapist for individualised assessment and treatment recommendations.

This booklet is not intended as a substitute for the medical advice of physicians. The reader should regularly consult a physician in matters relating to his/her health and particularly with respect to any symptoms that may require diagnosis or medical attention.

The cartoon pictures are not intended to resemble the people quoted. Any resemblance to actual persons, living or dead, is purely coincidental.

# About stroke

The te reo Māori word for stroke is “**mate ikura roro**”. A stroke causes **brain damage**. When you have a stroke it could **damage** any **part** of your **brain**. When part of the brain gets damaged it's not able to do its job anymore. Each part of the brain does a different job, so **stroke** can look **different** in **different people**.

A stroke is a medical **emergency**. Everyone needs to learn to recognise the **signs of stroke** so they can get help quickly. The quicker you get to hospital, the better recovery can be. It helps to remember FAST. (<https://www.stroke.org.nz/fast>)

- **F** – Face drooping
- **A** – Arm weakness
- **S** – Speech difficulty
- **T** – Take action, call 111

Working towards **recovery** after stroke is called **rehabilitation**. Rehabilitation is **not** about **curing** the **stroke**. The stroke damaged parts of the brain. We **can't fix** those **damaged** parts, but **other** parts of the **brain** can **learn** to do new jobs. This is called **neuroplasticity**.

We never know for sure how much a person will **recover** after a stroke. Every **stroke** is **different**. Every **brain** is **different**. Everyone has **different** things happening in their **lives** that **impact** their **rehabilitation**. Scientists are learning new things about the brain all the time.

Some people find it **helpful** to **learn** more about **stroke**. The **Stroke Foundation** has a book called “**Life After Stroke**”, which is **free** from your Stroke Foundation Community Stroke Advisor ([www.stroke.org.nz/community-stroke-advisors](http://www.stroke.org.nz/community-stroke-advisors)).



*And how did I find out? I read Google, I read everything. I find out what's wrong with me.*

**Gloria**

Stroke survivor

# Communication problems after stroke

## Aphasia (say uh·fei·zee·uh)

Stroke can **damage** the part of the **brain** where **words** and **language** are. This is called **aphasia**. Aphasia is a problem with using **language**. People with aphasia can still **think** clearly but they **can't find** the **words** to express their thoughts. They **can** use their mouth and vocal cords to **speak**, but they **can't** always **find words** to say. **Language is not just speaking**. Language includes:

- **Speaking**
- **Understanding** what you **hear**
- **Understanding** what you **read**
- **Writing** down your ideas
- Using **numbers**

**Aphasia** can make it **difficult**, or **impossible**, to use all these parts of language. People with aphasia are still **intelligent** and they still have **good ideas**, they just find it **hard to express** themselves and understand conversations.

## Apraxia of speech (say uh·prak·see·uh)

If the stroke **damages** the part of the **brain** that controls **speech**, you can get **apraxia of speech**. Apraxia of speech is when the **message** gets **mixed up** as it travels from your brain to your mouth. Your **mouth doesn't move** the way you **want** it to and you are **not able** to **say** the **word**. Apraxia of speech is just a problem with **speech, not language**. You can still **understand** what people are saying to you, you know what to **say** and you can still **read** and **write**. It's just that your **speech is hard to understand**.

## Dysarthria (say duh·saa·three·uh)

**Dysarthria** is when you have **trouble** controlling your **breathing, vocal cords, tongue** or **lips** so your **speech is not clear**. It might be **slurred** or too **quiet** or have an unusual **tone of voice**. Dysarthria is just a problem with **speech, not language**. You are still **intelligent**. You can still **understand** what people are saying to you, you know what to **say** and you can still **read** and **write**. It's just that your **speech is hard to understand**.

## Right hemisphere language disorder

If you have a **stroke** in the **right side** of your **brain** you can get **right hemisphere language disorder**. People with right hemisphere language disorder can find it **hard to understand nonverbal cues**, like **facial expressions** and **tone of voice**. They might say **inappropriate** things or **talk** at the **wrong time**. People with right hemisphere language disorder are still **intelligent**. They just find it **hard to follow the rules of communication**.

## Difficulties in more than one area

Some stroke survivors have **more than one** communication **problem**. They have **problems** with **language** and **speech**. For example aphasia and apraxia of speech.

When you see a **speech-language therapist** they will **assess** your speech and language to find out if you have any of these communication problems.

# Speech-language therapy

## What happens in speech-language therapy?

**Speech-language therapy** is part of **rehabilitation**. Rehabilitation means working to get someone back to doing the things they used to do, as much as possible.

Speech-language therapists are part of the **rehabilitation team**. Their name is often shortened to “**SLT**”.

The SLT’s **first job** is to **get to know you** and your whānau. Then they need to **find out** what **difficulties** you are having. This is called assessment.

## Assessment

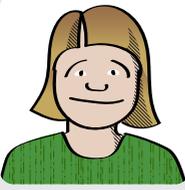
In **assessment** the SLT talks to you and your whānau about the **problems** you are having, and the **things you used to do** but have trouble doing now.

Often the SLT will ask you to do some **tasks**. These might include:

- Following instructions
- Naming pictures or things
- Describing things
- Telling a story
- Writing
- Reading

During **assessment** the SLT tries to **learn** all about what is **easy** for you and what is **hard** for you. It is important to know your strengths and weaknesses so they can make a plan for how to **help** you **improve**. The **assessments** might be **easy** and they might be **hard**.

Some of the things the SLT asks you to do might be a bit **unusual**, but assessment should **never** whakaiti or trample on your mana. If you are **not comfortable** with something the SLT asks you to do **you don’t have to do it**. You or your whānau can **talk** to your SLT **about it**, or you can talk to someone else, e.g. someone from the Māori health department of the hospital.



*It's very difficult for people, like rehab staff, to understand what the patient was like beforehand... I explained about his learning. How he learns, you know, like a lot of people learn by doing things, a lot of people are visual learners. And that's important to know how a person's going to learn.*

**Gayle**

Partner of Jimmy, Stroke survivor

## Goal setting

The SLT needs to find out what is **important** to **you** and your **whānau**. They will work with you and your whānau to learn about **who you are** and **what** you would like to **do**. Then you work together to set **goals** for what you want to achieve in **therapy**.

**Goals** need to be **specific**. If you tell the SLT “I want to be able to talk like I used to” they will help you to **break down** that goal into smaller parts and decide what to work on first.



*Why should I put energy into learning something I don't want to know anything about? I'll pick and choose what I want to do with my brain. If I want to just let it ferment it should be my right to let it... If I want to have a lazy day for instance I shouldn't be made to be, feel inadequate because I don't want to do what everyone, what they expect to me to do. The so called specialists, you know, the professionals, if I don't want to do it, I don't want to do it ... I think we've earned our, the right to choose what we want to do, and if you want to vegetate they should let us*

**Petti McLean**

Stroke survivor

## Therapy

Once you know what you **want to achieve**, there are many different ways to do it. The **three main ways** are:

- **Exercises** to try and improve your speech and language
- Practise **new ways of communicating**, e.g. writing, drawing, using gestures or technology such as an iPad
- Your **whānau** and **friends** learn new ways to communicate with you and help you communicate

Most people do all three types of rehabilitation. Even if your speech doesn't improve much, your communication will probably improve as you and your whānau learn new ways of communicating.



*It made me be able to start relating to other people, you know. Whereas I know it may not have been like that if I hadn't gone there because I would have just, you know, just sat because I couldn't speak well. I would have just sat there and just thought cos I couldn't speak. But being in a speech therapy, they teach you, you know, all these things. And there was one thing I admire about them. Today I say that to anybody. Go to speech therapist. Yeah, they'll help you in a lot of ways.*

**Iraani**  
Stroke survivor

## Different ways to do therapy

You might do **therapy** by **yourself** or in a **group**, with the **SLT**, your **whānau** or a **volunteer**.

In some areas the SLT comes to your **house** and in other areas you go to a **clinic**. Your SLT will talk with you and your whānau to **explain** what happens in your **area**.

## Whānau talk about stroke groups



*And it, it's good, the group eh, yeah, talking a lot.*

**Debra**, stroke survivor



*But it's just reassurance I guess that you're not completely isolated.*

*There are other people out there that can relate to what you're trying to say. Even how strange or way over the top it may sound to other people, it's okay. You're safe, in a very safe environment.*

**Petti McLean**, stroke survivor



*Yeah, yeah and talking and laughing, yeah, yeah.*

**Pere**, stroke survivor, saying that it's easier to talk when she is relaxed



*It's not them and us, it's us together.*

**Petti McLean**, stroke survivor

## Some people don't like being part of a group:



*So when you say you don't like to go to a stroke group, that's part of your personality, is it?*

Yes

Conversation with **Jimmy**, stroke survivor

## Whānau share what helped them

In this section Māori stroke survivors and whānau talk about their experiences of stroke recovery.



*I can remember the speech therapist saying but remember who you are. Whether you're Māori, Pākehā, remember who you are. And don't ever let that go from you because that's the way you are, that's the way you've been brought up.*

**Iraani**

Stroke survivor



*In some ways I can accept the things that I can't do, and in some ways it's good to accept what you can't do but nevertheless do everything you can do which is really important. I actually had to use my mind that I can do it, I can do it. I can lift that leg, I can lift up, I can stand. Having stand, now I can stand my left foot, then my right foot, and finally eventually get to where I'm going... Every, every step I tell my mind I can do it. And sometimes it's bloody hard to do it, but I, I don't give up.*

**Gloria**

Stroke survivor, talking about what she learnt from reading “The Power of Now”.



*Practise  
practise  
practise all  
the f-ing  
time.*

Catchphrase of **Debra**, a young stroke survivor



*I could talk.  
But I  
couldn't  
understand  
what I was  
doing. No,*

*on a scale from 10, I was down to about a 4, 3, lucky to be a 3... i wareware te reo. Yeah, I couldn't understand nothing.*

**T\_**, stroke survivor



*There's no  
one else to  
do it for me.  
Only I can  
do it myself.*

**Peter**, stroke survivor



*But it's been  
hard for my  
sister to get  
us to this  
point cos we  
had no ears.*

*We had no patience, no ears,  
and didn't want to learn. As far  
as we're concerned, you're the  
health provider kind of thingy in  
our family. You worry about it.  
Now it's like we're all keen.*

**Joanne**

Daughter of Iraani, stroke survivor



*I knew I was  
sick and I  
needed  
someone to  
fix me, and  
they if they*

*weren't gonna help, then I've  
gotta do my fix, fix myself.*

**T\_**, stroke survivor



*We're not bad. We just didn't understand back then.*

**Joanne**, daughter of Iraani, stroke survivor



*Just the fact, that basic information that, sometimes because you've had a stroke you may feel like this, or things might change*

*for you. It was alright to say, it's alright, that's normal to be upset or emotional and stuff, that's quite the norm.*

**Petti McLean**, stroke survivor

Living with the effects of a stroke, or caring for a whānau member, can be isolating. Here some whānau share their experiences.



*You certainly find out who your friends are. She had quite a huge circle of so called friends but finished up with one good one.*

**Les**, husband of Juliana, stroke survivor



*And it's just one of the things that we have to accept is caring for her at home actually is a form of isolation from other people.*

**Kathy**, daughter of Gloria, stroke survivor



*I want to go back to work. It's a boring life staying at home. It sucks man! Dunno why people, dunno how people enjoy staying at home. I find it so boring man.*

**Peter**, stroke survivor

# Speech-language therapy ideas to do at home

Sometimes you have to **wait** to see a **speech-language therapist** or you can't see them as **often** as you would like to. If this happens, there are lots of things you can do **yourself** at home.

The main thing to **remember** is to make sure the **stroke survivor** is **ok** with the activities. Some people **don't like** using **children's books** or **flash cards** because they think they are babyish. Other people are **happy to use anything**, even if it was made for children.

For some people just **getting through** the **day** is **hard** enough without worrying about doing extra mahi.

Here are some **ideas** for things to do at **home**. Everyone's stroke is **different** so some of these ideas might not be helpful for you. Choose the ideas that you think might work for you. **Remember** that it is **important** to see a **speech-language therapist** for personalised advice.

## Automatic speech

Some stroke survivors can't speak but they can use **automatic speech**, that is **kōrero** they **know** very well. Whānau can **encourage** the stroke survivor to say anything they know very well and can say without thinking, e.g.:

- Karakia
- Waiata
- Song lyrics
- Moteatea
- Chants
- Whakatauki
- Poems
- Sayings
- Bible verses

**Kia tūpato!** Because of the stroke the person might get some of the words wrong so **make sure** the **kōrero** is **safe**.

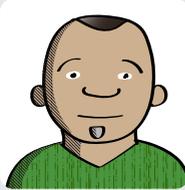


*Poetry is like a song and if you, if you sing it properly with the right rhythm, with the right words, with the sound of the words and telling the story of the poetry, it actually gives it, it makes it, it's like singing a song with the right rhythm*

**Gloria**  
Stroke survivor

## Problems finding the right word to say

Lots of stroke survivors have **problems** finding the **right word** to say. This is often called “**wordfinding difficulties**”.



*I talk with Edna a lot, but she gets too frustrated, can't get those words out. She's saying turn the TV off instead of saying turn the sound down, it's turn the tap or something like that.*

**Toto**  
Husband of Edna, stroke survivor

In this example, if Toto knows what Edna meant he could just say “Turn the TV down? Sure, I'll do that”. If he doesn't understand he could say “You said turn the TV off. Did you mean that or something else?” It is not helpful to make Edna keep trying until she says it right.

Here are some **ways to help** with wordfinding difficulties:

### Describe it

For example:

- What **colour** is it?
- What do you **use** it for?
- **Where** is it?
- If you are thinking about a **person** you might be able to say that he is your **moko** or the **person next door**.

## Use a different word

For example, if you can't find the word for “**towel**” you might say “**dry**”, or “**shower**”.

## Use pictures

Make a **book** of things that are **important** to you. A clear file folder is good for this. You can **use** this **book** to help in **conversation**, to **point** to things when you can't say the word, and to **introduce** yourself to new people.

Ideas for your book:

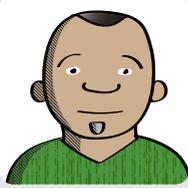
- **Photos**
- Pictures from **magazines** or **junk mail**
- **Newspaper** articles
- **Maps**
- **Tickets** from places you've been
- **Pictures** or **cards** from whānau
- Anything that is **important** to you
- Some people like to write their **pepeha** in the book, or show their pepeha using **photos**

If you have a **computer** and a **camera** or **phone** you could **print** your own photos or find pictures and maps on the **internet**.

## Reading

**Practise** reading things that you used to read, such as the **newspaper**. Start with just the **headlines** or the **captions** on photos then slowly **build up**.

If you need to **practise speaking** you could **read aloud**. Try **recording** yourself on your phone and playing it back to see how good you sounded and notice anything you need to work on.



*I make her read aloud all the time.*

**Toto**

Husband of Edna, stroke survivor



*So now when I'm actually struggling to get the words clearly I actually find it helps me a lot with language to be able to actually say it out loud. And reading out loud, even a book. I'll open a book, I'll read it out loud.*

**Gloria**

Stroke survivor

## Writing

Practise writing. Start with **simple activities** and slowly make them **harder**. Ideas for writing:

- Your **name**
- Your **address**
- Names of **whānau** members
- Other **important** words
- Keep a **diary**, even if you don't write much. Try **writing** or **drawing** a picture to show what the **weather** is like each day
- Write something that made you **happy** today
- Write **shopping** lists or **to-do** lists

If you need **help**, ask someone to **print** the words for you to **copy**.

If you have **problems** with moving your **hand** you might find it difficult to hold a pen. It can be easier to use a **felt pen**, a **pencil** with a soft lead, or write on a **whiteboard**.

## Waiata

Some stroke survivors can **sing** better than they can **talk**. Singing is a good way to **practise speech** and it can be a good way for the stroke survivor to **join in** with people.

Ways that **whānau** can **encourage** singing:

- Sing favourite waiata with a **guitar**, or **by yourself**
- Sing along with the **radio** or a **CD**

Don't worry if the stroke survivor is not able to sing with you, as Rita explains below.



*I knew the music, yeah, but I couldn't the words, no. But my father every day to play some tunes on the guitar... I couldn't speak or anything but I knew the words on the guitar but I couldn't sing. That was helpful, really helpful, and everybody came. At the [rehab] centre he was playing the guitar for everybody.*

**Rita**

Stroke survivor

## Keep your body and brain active

This page has ideas for things you can do to keep your brain and body active, and hopefully have some fun too.



*I can write slowly, write type a letter or whatever. But unless I do it every day I lose the ability ... Anything that I don't hear for a long time, or not very often, I start to lose the ability.*

**Gloria**

Stroke survivor



*Oh I propel myself in my wheelchair, I push myself in the wheelchair. I don't use the electric wheelchair, it makes you lazy man.*

**Peter**

Stroke survivor

## Ideas

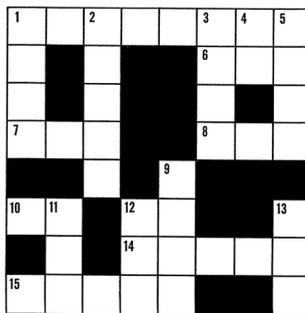
Crosswords, Sudoku, etc.

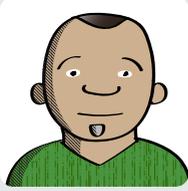
If you used to enjoy **crosswords**, **wordfinds**, **quizzes** or **Sudoku**, try doing them again. It might be much more difficult than it was before the stroke.



*She was a whizz at those crosswords and things, and yeah, we're trying to reintroduce that to her. I don't know if it'll work.*

**Joanne**, daughter of Iraani, stroke survivor





*And then she does the Sudoku every morning, so the brain's working good.*

**Toto**

Husband of Edna, Stroke survivor

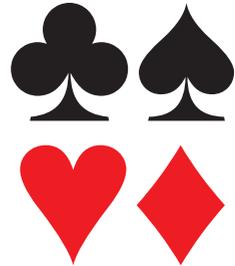
## Playing Cards

If you used to play cards, try playing again. If it's too difficult to play your usual games start with something easier. Here are some ideas.

### Sort the cards

Sort the **cards** in different ways, e.g.

- Colours
- Numbers
- Suits



### Play “memory”

- Choose some **pairs** of cards (e.g. two kings or two aces)
- Turn all the cards **face-down**
- Take turns to **turn over** two cards. If they **match** you get to keep the cards
- When all the cards are gone see who has the **most** pairs

You can make this game easier by using fewer pairs of cards and harder by adding more pairs of cards. To practise speaking, say the name of each card as you turn it over.

### Modify your usual games

When you are up to playing your usual card games like Euchre, think about ways to **make it work** for you.

If you can only use **one hand** you might **lay your cards out** on the table and use something as a **barrier** so that other people can't see them.

Try using a card games **app** on your phone.

If it is hard to say the names of the suits, or if you sometimes say it wrong, make **picture cards** with a heart, diamond, club or spade and on them so you can show people which one you mean.

## Computer games

Some people find computer games helpful. **AphasiaNZ** has computer programs and other resources you can **borrow**. Their website is at [www.aphasia.org.nz/device-loaning](http://www.aphasia.org.nz/device-loaning)



*I've got a game that goes on my computer, it's called ableX, good game eh.*

**Peter**  
Stroke survivor

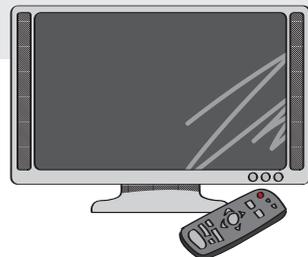
## Watching TV

You might find that you enjoy **different TV programmes**. Sport might be easier to watch than programmes with complicated stories.



*I'm now watching TV, more sport than I ever thought I would ever be such a big watcher of TV sport. But the reason is because I can, it's visual and so I can, I can kind of follow the story.*

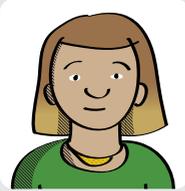
**Gloria**  
Stroke survivor



## Tamariki and Mokopuna

Find ways to play with mokopuna, even if you can't speak well or move around.

- Looking at whānau **photos**
- Looking at a picture **book**
- Watching a **DVD**
- **Joking**
- Making **music**
- Singing **songs**



*When our son was a little person he would spend one day a week with Mum and Dad at home. And they just absolutely loved having him but then that in itself presented little challenges for them too. So this boy would play with his kuia and she was really, really awesome with him though, he could poke at her, play games with her and just do things with her that some of the other mokopuna wouldn't do with her. He would call her names, he would poke her with sticks and she would just laugh, whereas if some of the other mokopuna did that she wouldn't. So they had this really, really special relationship.*

**Daughter** of a woman with stroke



# Ways for whānau to help

There are many ways that whānau and friends can help a stroke-survivor to communicate. Here are some ideas.

## Don't talk about them as if they're not there

Sometimes we don't know how much a stroke survivor can **understand**, especially if they are not able to **respond**. It's a good idea to always presume someone can **hear** and **understand** us. This means:

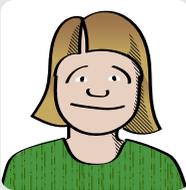
- **Talking** with them like you **usually** would
- **Including** them in the conversation
- Only talking about **things** you **want** them to **hear**



*This is what Mum said, when she had her stroke. She may not have been able to respond, like she was partly in a coma, but she said she heard everything. She could hear us arguing, she could hear everything. She remembers every conversation that was said at her bedside. She remembers Dad growling us. See what I'm saying? So she knows, but at the time she couldn't respond. And when she came through the coma and then she couldn't even do any of this, but she could hear and see everything.*

**Joanne**, daughter of Iraani, stroke survivor

Remember the **personality** of the stroke survivor. If s/he didn't talk much before that **probably won't change** with the stroke:



*Jimmy was never a conversationalist... he never used to talk, so nothing's new, and now everybody's wanting to talk and make conversation*

**Gayle**

Partner of Jimmy, stroke survivor

Some people who have had a stroke **swear**, even if they **never used to** swear. This can be **embarrassing**, especially for whānau, but try not to stress about it. Click [here](#) for a short article about how to deal with swearing.

This website has a short article about how to deal with swearing:  
[theaphasiacenter.com/2014/09/cursing-aphasia](http://theaphasiacenter.com/2014/09/cursing-aphasia)



*Swear words, swear words she could use. As clear as a bell. Yes, roll those off the tongue just like nothing, just like toffee.*

**Whānau** talking about their mother who had a stroke

## Helping people won't make them lazy

Whānau, remember that people with stroke **try** their hardest to **communicate** and they **need** your **help**. **Helping** the person to communicate will **not** make them **lazy** or make their communication problem worse.

If the message gets communicated that's ok, **don't worry** if it's **not perfect**. The most **important** thing is to make **communication** as **relaxed** and **successful** as possible.

Find out how the person with stroke likes to receive help. Some people like help to find the words and other people don't like people finishing their sentences for them.



*– She'd be going, "oh yeah, yeah, yeah", like this, and you could see, it was just on the tip of her tongue, so she knew. But then by the time she went to say something and then Dad, trying to be helpful...*

*– Put some names into her mouth.*

*– Yeah, and then she'd say "no, no, no", like this, and then she'd end up getting upset*

**Whānau** talking about their parents after their mother's stroke

People with stroke can **accidentally** say the **wrong** word. Sometimes this means that the **wrong message** gets across. Everyone needs to know about this so there aren't too many **misunderstandings**.



*With Mum's speech, she'll say "he" instead of "she", "she" instead of "he"... Or she'll talk about her eyes when she means her ears... But having lived with her I can actually either work out what she means.*

**Kathy**

Daughter of Gloria, stroke survivor

After a stroke communication can take a lot of **time** and a lot of **patience**. Try to **make time** to **communicate**. People's preferences can change after a stroke so **don't presume** you know what the stroke survivor wants. Have a **conversation** with them. Take every opportunity to communicate.

Some stroke survivors take a **long time** to **process** what they hear and then **respond**. Here are some ideas that might help:

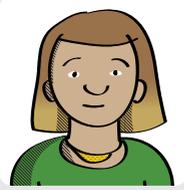
- After you have said something **keep quiet** to give it time to sink in
- If you need to **repeat** what you have said, use exactly the **same words** the second time. This means that the person doesn't have to process a whole new set of words
- Allow plenty of **time** for the stroke survivor to say what they want to say. Or as the Kaitaia Chat Group put it,

*"Shut up and wait! Don't put words in our mouths".*



*At first we were too fast for her. We'd go dadadadada, and she just looked at us blank, we knew straightaway. And so we had to, like we've all realised now we have to sit down and talk to her face, straight face, eye to eye, and then slow*

**Joanne**, daughter of Iraani, stroke survivor



*She could hold a conversation with you but that's only because, like I said before, we would allow her, we would give her the time and sort of just sit there and drink cups of tea. And when she was ready she'd go "oh yeah, and so and so, so and so". Conversations went really really well when there was only her and us and the kids*

**Daughter** of a stroke survivor

## Mirimiri

Some people find **mirimiri** or **massage** helpful.



*We even took her to do some mirimiri, our Māori side. And yeah, she did really well with that cos she's a Christian, you see. So I didn't want to go past those boundaries of Christianity and our Māori spiritual side, so I had to kind of fib and tell Mum that you're getting massage "Mum, you're going for a massage". And she goes "oh, okay". Soon as we got there they said a lot of things to her. And blimmin heck she heard it all. And she goes "it's mirimiri, eh?" And I'm like "yeah, massage in English" (laughter). And she goes, "no, they said everything right, hey?" And I went "yeah". I was glad, yeah.*

**Joanne**

Daughter of Iraani, Stroke survivor

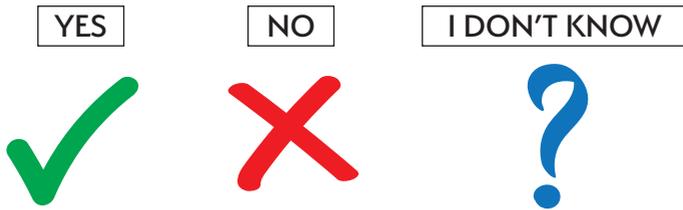
## Ask questions

There are **different kinds of questions** and some are easier to answer than others.

The **easiest** question is a **yes/no** question. These are questions that the answer is **yes, no, or don't know**. For example, “are you hungry?”

Some people with stroke accidentally say yes when they mean no, or no when they mean yes. They might not know that they made a mistake, so make sure you get the right answer.

If yes/no is not clear, draw up a piece of paper like this:



Then ask the person the question again and point to the options saying “are you hungry? Yes? (point to yes) or no? (point to no) Show me”.

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The next easiest questions have **two options**. For example, “would you like spaghetti or baked beans?”

It is easier to answer this question if the options are there, e.g. if you are holding a can of spaghetti and a can of baked beans so they can point to their choice.

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Then there are **Short answer** questions. For example, “what would you like for lunch?”

It is easier to guess the answer to these questions because you know what the topic is.

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**Open** questions usually need more than a short answer, e.g. “what shall we do tomorrow?” or “what do you think about global warming?” These are the **hardest** questions to answer when you have trouble talking.



*I used to try and guess all these things, and now I'm more saying no, no, think about what you want to tell me. And we isolate it down now, we put it into boxes until we get the right answer.*

**Gayle**

Partner of Jimmy, stroke survivor

## Putting the different types of questions together

Gayle learned how to help Jimmy to communicate by the way she asks questions. You can use these **different** types of **questions** to **help communication**. Start with very **broad** questions until you know the topic.

For example, Is it something you need? Is it about a person? Is it inside the house?

Then start to **narrow** it down.

For example, If it is about a person, is it someone in the whānau? Someone from work? Someone at the hospital?

## Plan for hui, parties and other gatherings

Most people with stroke find it **easiest** to communicate in a **quiet** place with not many people. **Events** like hui can be **hard**. Some people like to **be part of it** even if they can't talk as much as they used to, but other people **don't like to go** at all.

It might help to make a **plan** before you go. Decide:

- What you would like people to **know** about the stroke
- How people should **help** the stroke survivor to communicate
- How it is best to **communicate** this information

Try to find a **quiet place** to **rest** if it all becomes **overwhelming**. Be prepared to leave early if you need to.



*The truth is they do talk with me [but] they can't actually concentrate all the conversation on my little short sentences and whatever. And I actually enjoy the actual being part of the group. In fact it's important for me to be part of the group even if I miss half of it, because I don't always want to say, unless I'm really- sometimes I say hang on, hang on, what did you say just then?*

**Gloria**

Stroke survivor

## Keep a diary

Some whānau told us it was really helpful to keep a **diary** of what happened each day after the stroke. This can help **communication** so **visitors** know what has been happening. It is also a **record** you can look back on later to see how far you've come.



*From the day he had his stroke, I wrote in the diary every day until he left hospital... Because stroke victims can't normally remember what happened, and that was huge, quite often I'd go back and read it and think oh wow he's come from there, wow, to there! And that was really good... Mind you he probably didn't see a lot of it, but it's always there for him to read later on if he wants to*

**Gayle**

Partner of Jimmy, stroke survivor

## You can make a difference

Whānau, friends and community members make a **big difference** to people with stroke. Sometimes you can make things **worse**, even when you're trying your best:



*My progress is limited to how they deal with up home... I know about*

*what I'm um yeah but other people don't want to face that I can't do it anymore*

**Rita**, stroke survivor



*You are trying to help and here's us stopping, well, the*

*family. It's not actually the patient sometimes. It could be the family that's stopping her growth from the speech language and all that therapy.*

**Joanne**, daughter of Iraani, stroke survivor



*And my friends always for meetings for the marae and all the interests I've got my friends take and pick me up and things like that and we have heaps of conversations so that our world was upside down for a while but when I come to I um out of the hospital my friends were coming and taking me places... Yeah, was good.*

**Rita**  
Stroke survivor



*It's the families you've got to target. The patient will be fine if the families understand.*

**Joanne**

Daughter of Iraani, stroke survivor



*My only support was my family coming in every day... an invaluable support.*

**T\_\_**

Stroke survivor

## Videos available online

### Communication Problems After Stroke

**Karen Brewer**, speech-language therapist, explains the communication problems that can be caused by stroke. [youtu.be/iOkiJI3S3Jw](https://youtu.be/iOkiJI3S3Jw)

**Attitude TV** episode about stroke. The first person is Mary Brown who has aphasia. [youtu.be/kS1fXjPPIJ4](https://youtu.be/kS1fXjPPIJ4)

**The Treasure Hunt**. This is a short video made for children. It explains what happens in the brain when people with aphasia struggle to find the right words to say. [youtu.be/Gq12cMUZPg4](https://youtu.be/Gq12cMUZPg4)

**Attitude TV** episode about a young mother who had a brain bleed that gave her severe nonfluent aphasia and apraxia of speech. [youtu.be/1NTvQuiGuIs](https://youtu.be/1NTvQuiGuIs)

**Open Door** episode about aphasia. [youtu.be/HBx7g1u4las](https://youtu.be/HBx7g1u4las)

## Stories from Māori Stroke Survivors

Rita Wordsworth tells her story of stroke and aphasia

[youtu.be/X49slt9hwT4](https://youtu.be/X49slt9hwT4)

Tawhai Te Rupe tells his story of stroke

[youtu.be/cToZAhLxgVs](https://youtu.be/cToZAhLxgVs)

Kawana Timoti tells his story of stroke

[youtu.be/Bsm-lsEI4Ow](https://youtu.be/Bsm-lsEI4Ow)

Rukingi Richards tells his story of stroke (Warrant of Fitness episode)

[youtu.be/5IyMtqOLQ1M](https://youtu.be/5IyMtqOLQ1M)

Rukingi Richards' story in te reo Māori (Te Karere)

[youtu.be/KDD0j7tu-zY](https://youtu.be/KDD0j7tu-zY)

Maraea has dementia caused by a stroke (Attitude TV)

[youtu.be/Wj4nfIOuMww](https://youtu.be/Wj4nfIOuMww)

TVNZ On Demand Waka Huia Rukingi Haupapa:

[www.tvnz.co.nz/shows/waka-huia/episodes/s2019-e40](http://www.tvnz.co.nz/shows/waka-huia/episodes/s2019-e40)

## Other videos about stroke

**Attitude TV** episode about stroke, filmed at Middlemore Hospital:

[attitudelive.com/player-page/impact-stroke/](http://attitudelive.com/player-page/impact-stroke/)

A series of videos about stroke. Māori stories are near the bottom of the page

(**Stroke Foundation of New Zealand**). [www.stroke.org.nz/life-after-stroke-videos](http://www.stroke.org.nz/life-after-stroke-videos)

**Māori Television** video about stroke.

[www.maoritelevision.com/news/regional/stroke-campaign-launches-special-focus-on-maori](http://www.maoritelevision.com/news/regional/stroke-campaign-launches-special-focus-on-maori)

**FAST campaign** in English and te reo Māori

[hpa.org.nz/campaign/stroke-fast-campaign-resources](http://hpa.org.nz/campaign/stroke-fast-campaign-resources)

1 Stroke and blood pressure (NZ)

[stroke.blogs.auckland.ac.nz/files/2018/05/brain-animationv2\\_1-1i0p6sb.mp4](https://stroke.blogs.auckland.ac.nz/files/2018/05/brain-animationv2_1-1i0p6sb.mp4)

2 Explanation of stroke (NZ)

[stroke.blogs.auckland.ac.nz/files/2020/06/Blood-pressure-v3qvx8.mp4](https://stroke.blogs.auckland.ac.nz/files/2020/06/Blood-pressure-v3qvx8.mp4)

Cartoon explanation of stroke (England) [youtu.be/ryIGnzodxDs](https://youtu.be/ryIGnzodxDs)

# Links to resources

## Organisations and services



Stroke Foundation NZ

[www.stroke.org.nz](http://www.stroke.org.nz)



Aphasia New Zealand Charitable Trust  
mate ngaronga reo

Aphasia NZ

[www.aphasia.org.nz](http://www.aphasia.org.nz)



New Zealand  
Speech-language  
Therapists' Association  
Te Kāhui Kaiwhakaitiakitika  
Reo Kōrero o Aotearoa

New Zealand Speech-language

Therapists' Association

[speechtherapy.org.nz](http://speechtherapy.org.nz)



Waitemata  
District Health Board

Best Care for Everyone

Waitematā DHB Volunteer Stroke  
Scheme

[www.healthpoint.co.nz/public/  
community/waitemata-dhb-volunteer-  
stroke-scheme-regional](http://www.healthpoint.co.nz/public/community/waitemata-dhb-volunteer-stroke-scheme-regional)



Green Prescriptions

[www.healthnavigator.org.nz/healthy-  
living/g/green-prescriptions/](http://www.healthnavigator.org.nz/healthy-living/g/green-prescriptions/)

University speech-language  
therapy clinics



The University of Canterbury Speech  
and Hearing Clinic

[www.canterbury.ac.nz/science/clinics/  
speech-and-hearing-clinic/](http://www.canterbury.ac.nz/science/clinics/speech-and-hearing-clinic/)



The University of Auckland Speech-  
Language Therapy Clinic

[www.auckland.ac.nz/en/on-campus/  
facilities-and-services/university-of-  
auckland-clinics/speech-language-  
therapy-clinic.html](http://www.auckland.ac.nz/en/on-campus/facilities-and-services/university-of-auckland-clinics/speech-language-therapy-clinic.html)



UNIVERSITY OF NEW ZEALAND

Massey University Speech Language  
Therapy Clinic

[www.massey.ac.nz/massey/learning/  
departments/institute-of-education/  
speech-language-clinic/speech-  
language-clinic\\_home.cfm](http://www.massey.ac.nz/massey/learning/departments/institute-of-education/speech-language-clinic/speech-language-clinic_home.cfm)

## Information

### Australian Aphasia Rehabilitation Pathway

Australian Aphasia Rehabilitation  
Pathway  
[www.aphasiapathway.com.au](http://www.aphasiapathway.com.au)

### Stroke4Carers

Stroke for Carers  
[www.stroke4carers.org](http://www.stroke4carers.org)



> InformMe

Clinical Guidelines for Stroke  
Management  
[informme.org.au/Guidelines/  
Clinical-Guidelines-for-Stroke-  
Management-2017](http://informme.org.au/Guidelines/Clinical-Guidelines-for-Stroke-Management-2017)



New Zealand Stroke Charitable Trust  
[www.stroke.net.nz](http://www.stroke.net.nz)

### Te Reo Hāpai The Language of Enrichment

Te Reo Hāpai  
The Language of Enrichment  
[www.tepou.co.nz/uploads/files/Te\\_Reo  
Hapai/Te Reo Hāpai - The Language  
of Enrichment.pdf](http://www.tepou.co.nz/uploads/files/Te_Reo_Hapai/Te_Reo_Hapai_-_The_Language_of_Enrichment.pdf)



**THE APHASIA CENTER**  
INTENSIVE TREATMENT PROGRAM

The Aphasia Center (USA)  
[theaphasiacenter.com](http://theaphasiacenter.com)

## My Stroke Guide

My Stroke Guide  
[mystrokeguide.com](http://mystrokeguide.com)

My Stroke Guide is a self-management tool to support people who have been affected by stroke. It was designed by the UK Stroke Association, working closely with stroke survivors and family members. My Stroke Guide includes:

- 1 Information about the effects of stroke and hints and tips about how to deal with them.
- 2 Peer-to-peer support, including an extensive video library and an online forum.
- 3 Advice and signposting on the various issues people can face after stroke.

You need to create a log in to access My Stroke Guide. It is made for people in England and the UK but lots of the information is relevant to everyone affected by stroke.

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## Networking



**Stroke Support New Zealand** is an active Facebook group. This group is dedicated to stroke survivors, victims, caregivers and family members affected by stroke. This is a forum for all to discuss and share stories about your journey as a stroke survivor and let others know about information you have found helpful. The group is dedicated mainly to New Zealand residents however others are free to join.



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CC BY-NC-ND 4.0