

“CHATS”

Children Helped by Adults to Talk about Stroke



Information and Suggestions for Parents
and Other Adults

By Dr. Áine Connolly & Ms. Wendy Moynan

Illustrated by Caroline Hyland



Tallaght
University
Hospital

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Foreword



Almost 25% of strokes in Ireland occur in age groups where people are very likely to be active parents with young dependants. The National Stroke Strategy 2022-2026 emphasises the importance of recognising the impact on the children of adults who have suffered a stroke and the need to have supportive, accessible sources of information for children. It also recognises the

need for stroke services to have practical guidance and resources available to communicate and address the anxieties and fears of their children after such a traumatic event.

Children Helped by Adults to Talk about Stroke (CHATS) has been put together by Dr. Áine Connolly, Principal Clinical Psychologist and Ms. Wendy Moynan, Social Work Team Leader. Together they have years of experience helping patients, families and children in Tallaght University Hospital (TUH) to navigate the difficult adjustment after stroke. Created with the help of families who have experienced a stroke, the resource is a valuable educational and practical guide for parents and other adults. It was developed as a quality improvement project under the skilful guidance of Mary Hickey, Project Coach and Quality Improvement Lead, TUH. It was supported by a grant from The Meath Foundation. It has been beautifully illustrated by Caroline Hyland and there has been considerable input from Alison Baker Kerrigan, Arts and Health Department, TUH.

The National Clinical Programme for Stroke appreciates the development of this initiative. It encourages all stroke services to be especially aware of the vulnerability and needs of children of stroke patients for information and time to express their feelings about what has happened. It recognises the needs of adults for guidance and resources to help them communicate effectively on the subject of stroke. We would encourage heightened awareness and the development of a care pathway in all situations where children could be impacted by stroke, to include access to counselling and the CHATS or similar such educational and communication resource, for our patients and their children.

I wish to congratulate all the team involved in this thoughtful and valuable project.

A handwritten signature in black ink, reading 'Rónán Collins'.

Professor Rónán Collins

Clinical Lead National Stroke Programme

Comments

Comments from families

"I feel this booklet would have been such a help to myself and the boys if we had it and am sure it will be for people in similar situations."

"It's wonderful, I cried reading it as I wish I'd had this booklet when I had my stroke."

"My son was 13 when I had my stroke and I wish we'd had this book to explain to him what had happened at the time. Reading this book you realise you are not alone at this scary time".

Comment from the Ombudsman for Children

"This booklet will help to improve the lives of many Children and Young People (CYP) who will experience a loved one after a stroke. That, in turn, will undoubtedly help the person with stroke and their adult family members in their journeys because if the CYP are more aware, secure and understanding of the situation then the focus on recovery can be much easier for the adults".

Niall Muldoon

Ombudsman for Children



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Introduction

This booklet has been developed by Dr. Áine Connolly, Principal Clinical Psychologist and Ms. Wendy Moynan, Social Work Team Leader. They have worked for many years with stroke patients and their families. Through this work they have seen that parents and other adults want to support their children and young people (CYP) when a significant person in their lives has had a stroke. However they were unable to find a resource to help adults talk to and support their CYP in the early days of an admission to an acute hospital.

For this reason, using available evidence, they developed this booklet with the aim to help adults:

- Recognise the importance of communicating with CYP after a stroke.
- Talk to their CYP about what has happened.
- Understand how CYP may react.
- Support their CYP.

Who is this booklet for?

This booklet is for parents, grandparents, aunts, uncles or any adult who is caring for, or working with, a child or young person (CYP) where an adult close to them has experienced a stroke and is in hospital.

Acknowledgements

Aine and Wendy would like to thank and acknowledge the following people without whom this resource would not have been possible.

- Members of the Irish Heart Foundation's Young Stroke Survivors Network and in particular Programme Lead Helena Heffernan.
- The stroke multi-disciplinary team in Tallaght University Hospital.
- The Meath Foundation who generously funded this project.
- Caroline Hyland, Illustrator.
- Alison Baker Kerrigan, Arts & Health Department, Tallaght University Hospital.
- Mary Hickey, Project Coach & Quality Improvement Lead, Tallaght University Hospital.
- Joanne Coffey, Communications Department, Tallaght University Hospital.
- Helen Gibbons, Senior Counselling Psychologist, Children's Health Ireland at Tallaght.
- Denis M. Baker Graphic Designer at www.tudco.ie.



Section 1 Impact of Stroke



The sudden impact of Stroke

A stroke is a sudden event which gives no time to prepare yourself or your children.

As children and young people (CYP) try to make sense of what has happened they can have many different reactions. It is quite normal to be upset or distressed. CYP may feel confused, sad, worried, guilty, angry or any combination of these and other feelings. However, research tells us that children do better when they are given information at a level they can understand and have support from a trusted adult.

Look after yourself as well

The first thing to acknowledge is that it can be a stressful and challenging time for you and other adults in the children or young people's (CYP) lives. We often put CYP first but it is very important that you look after yourself too. You may feel torn between being at the hospital and spending time at home. To help you decide how to manage your time, be guided by the hospital staff about whether it is okay to take time away from the hospital.



Throughout this book you will see this picture. Inside each picture we have put some self-care suggestions that have been made by families who have experienced stroke and ourselves.

These are suggestions only and you will have your own ideas about what would help.

"Don't forget to have your own safe place too and something to continue as before, a swim, a walk, a good book"

Starting out

You may not feel confident talking to your CYP but:

Remember

- You know your CYP best.
- Having a stroke doesn't change the fact that you are the child's mother, father, grandfather, aunt etc.
- You will do so much by simply being your usual caring self.
- You won't always get things right but that's okay.
- You can ask another adult to help you if needed.

Section 2 Why Talk?

Sometimes parents and carers try to protect children and young people (CYP) by avoiding talking about the stroke. However, communicating with them about the stroke is an important part of supporting them.

Reasons to talk:

- Even very young children will notice changes in your behaviour and mood and know something has happened.
- CYP benefit from getting honest information in a way they can understand according to their age.
- It is better for CYP to get accurate information from an adult they know and trust.
- Talking can help to prevent misunderstandings e.g. some CYP may think the stroke was their fault.
- Talking can help CYP find the words to explain how they feel and understand that their feelings are normal.
- Talking can help prepare CYP to talk to other people about what has happened, if they want to.



If not given any or accurate information children may:

- Try to figure it out themselves because they feel they cannot ask.
- Make up stories to fill in the blanks that can be more frightening than the reality.
- Accidentally overhear information which can be upsetting.
- Get inaccurate information from people who don't have the facts.
- Search the internet and find information that is not relevant or accurate.
- Wonder what else they are not being told and lose trust.

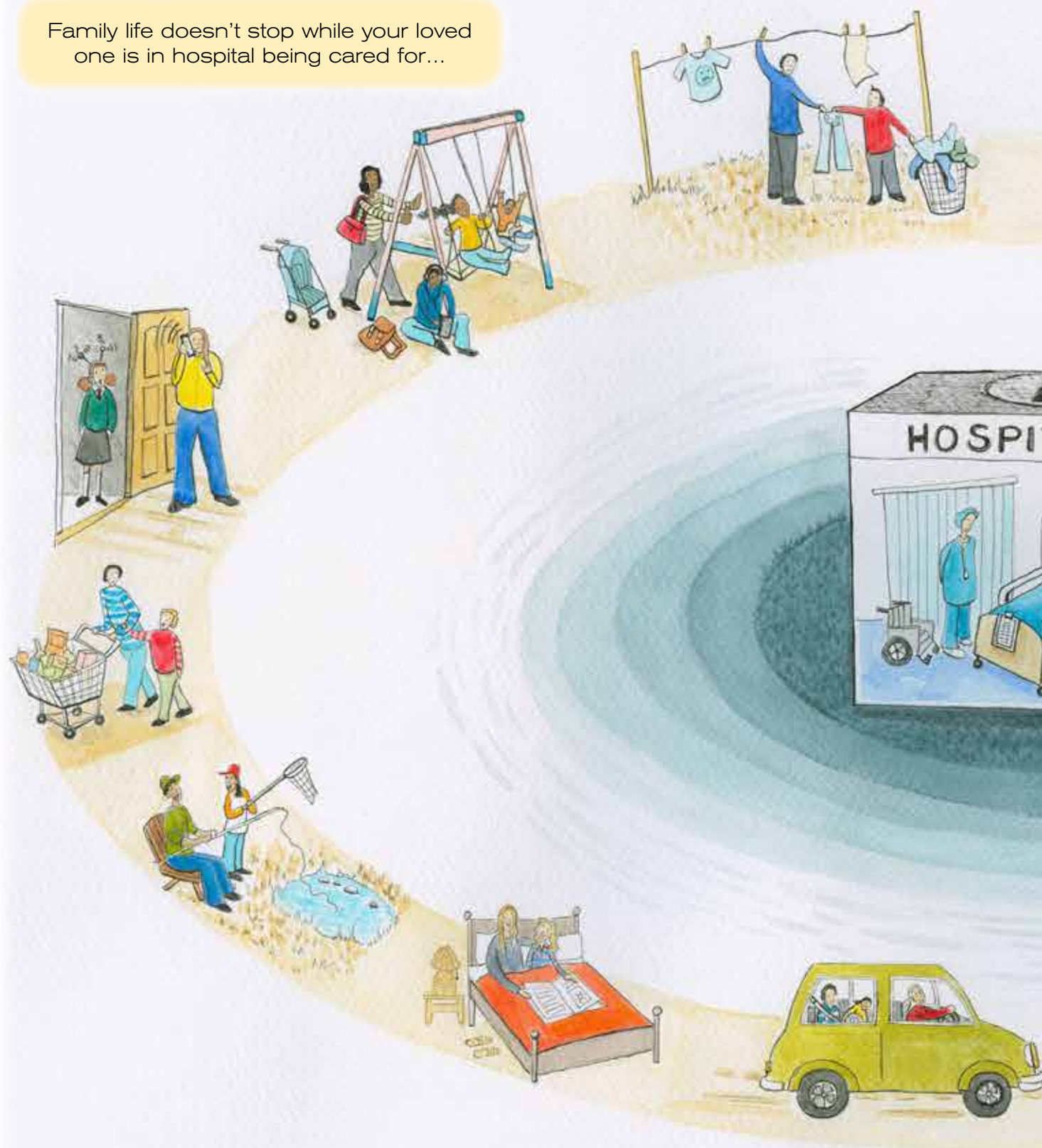
What Children and Young People (CYP) say They Want

Research by Dalton et al., (2019) tells us that when a parent had a serious illness CYP said they wanted:

- Information as early as possible.
- To talk to someone who knows what is going on.
- To know what is wrong, what treatment there is and if the person will get better.
- To be told if things get worse.
- To be able to ask questions without upsetting people.
- To know what feelings they may have (and that these are okay).
- Time to process information.
- To know what they can do to help.
- Healthcare professionals to be proactive in giving information.



Family life doesn't stop while your loved one is in hospital being cared for...





Everyday life offers an opportunity to check-in with your child and ask...

'Is everything OK?'

Section 3 Before talking think about...

*Appendix explains the way in which children understand illness

1. The ages of the children and young people (*see appendix).



2. You don't have to have all the answers but reassure that you will continue to get as much information as possible.



3. Telling is not a one off event - use opportunities in day to day life to talk.



4. Be honest and reassure where you can.



Keep normal routines



5. Pick a good time.
For You: when less stressed and tired.
For CYP: you will know the best times.



6. Be alert to listening ears.



7. Reassure the CYP that they did not cause the stroke to happen.



8. Retain hope.
"Things may never be the same but they do get better."

Section 4 Explaining Stroke

To explain stroke to your children and young people (CYP) you need to have some understanding of stroke yourself.

Put simply a stroke is an injury to the brain.

The injury is caused by either:

- 1) A bleed in the brain – a haemorrhagic stroke.
- 2) A blockage in the brain – an ischemic stroke.

The left side of the brain controls the right side of the body.

A stroke on the left side of the brain affects the right side of the body.

The right side of the brain controls the left side of the body.

A stroke on the right side of the brain affects the left side of the body.

A stroke at the base of the brain can affect either or both sides of the body.

Every stroke is different. A stroke can impact one or more of the following:

- Being able to feel or move part of the body e.g. face, arm and leg.
- Speech.
- Swallow.
- What the person can see.
- Cognition-e.g. concentration, being able to understand and remember information.
- Emotions.
- Control of bladder and bowels.
- Energy.

The stroke team are there to help you understand how the stroke has affected your family member and to try to find out why the stroke happened.



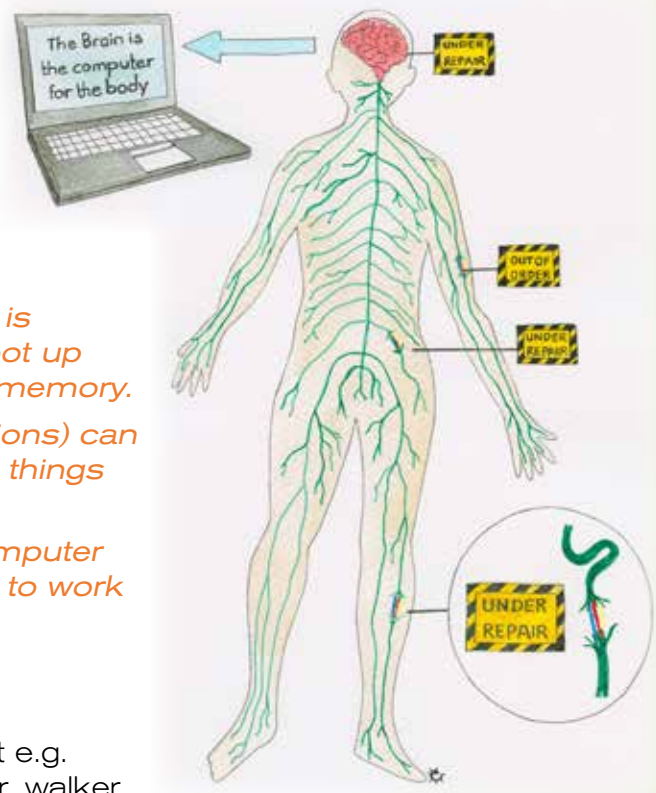
**Ask questions
if you don't
understand**

How do I explain it?

There is no right or wrong way to explain stroke to children and young people (CYP). Keep it simple and try not to use too many medical words.

One way to explain is:

- *Your brain is inside your head. The brain is like a computer that controls everything you do.*
- *Different parts of the brain do different things like help you to see, talk, and walk. It is where your thoughts and feelings happen.*
- *When a stroke happens, part of the brain is damaged. Like a computer, it may not boot up properly, it may be slower and have less memory.*
- *Sometimes the brain (computer connections) can find a way around the injury/damage and things might begin to improve.*
- *The stroke rehabilitation team are like computer engineers helping to get the connections to work again.*



It is important to talk about:

- The effects of stroke that are easier to spot e.g. arm, leg not working and use of wheelchair, walker or stick.
- The effects that are sometimes harder to see such as difficulties with remembering, concentrating, vision, reading, writing, energy levels, and managing emotions.

CYP may want to know:

- Why did the stroke happen?
- Could it happen to them or somebody else?
- Will it happen again?
- Are there ways to prevent another stroke?

Remember you don't have to have all the answers.

In terms of recovery, CYP need to know that this may take time and sometimes things don't get 100% fixed. However, the computer still works and person with stroke can learn new ways of doing things.

Be careful not to overload your child with information about stroke at any one time as you can make many opportunities to talk.



Introducing the Stroke Team

Your children and young people (CYP) may ask you questions about who is looking after and helping the person with stroke (PWS). There are many people on the stroke team who may be involved in the care and treatment of a patient after a stroke.

The following text explains the role of each member of the stroke team.

The orange text gives ideas as to how to talk to a child about what each team member does.

The Medical Team:

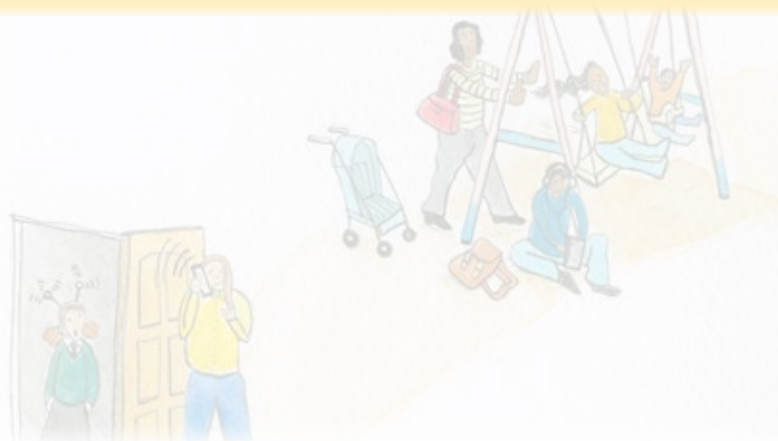
The team is led by a Consultant with a special interest in stroke. They will recommend appropriate treatment and medications depending on the type and severity of the stroke. They will try to find out what caused the stroke and give advice on how to stop it happening again.

"The doctor is checking in on Dad today and might change his tablets or medicine."

The Speech and Language Therapist:

Helps with problems related to speech, talking, writing, reading and understanding words (aphasia). They also treat swallowing difficulties, helping to improve the swallow and give advice about eating and drinking safely.

"Depending on the messages coming from the brain some days Dad might say more words and on other days he might be very quiet."



The Nursing Team:

Provide 24 hour care working closely with the doctors to monitor the condition of the person with stroke (PWS). They give medicine and, if needed, give help with washing dressing and going to the bathroom. They act as a link between the family and the stroke team.

There are also Clinical Nurse Specialists who will support and provide education to you and your family in all aspects of the stroke.

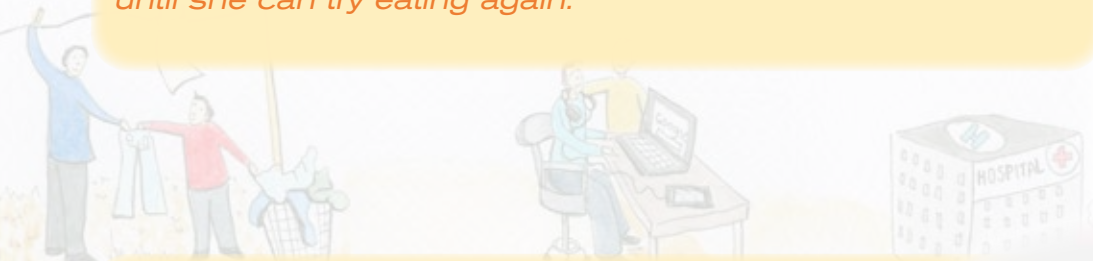
"Mum cannot do everything she used to, so the nurse is helping her to wash and dress until she is able to do this herself."



The Dietitian:

Suggests ways the person can eat as well as possible to help them recover. This may be using regular food, food that needs to be specially made so it goes down the right way, supplements in a bottle that can give a boost, or food in a tube if the person cannot eat for some reason.

"Granny isn't able to swallow so the Dietitian has organised food through a tube that goes from her nose into her tummy until she can try eating again."



The Psychologist:

Helps people whose thinking, emotions or behaviour may have been affected by the stroke. They will help the person and family to understand and come to terms with the impact of the stroke. They may also assess memory and concentration after stroke.

"Your Dad can't always tell you or explain what is going on inside. He is not able to smile properly because the muscles on one side of his face are not working but it doesn't mean he isn't happy for you."



Introducing the Stroke Team (continued)



The Social Worker:

Offers emotional support to the person with stroke (PWS) and family. They can give information about benefits and entitlements. They can help co-ordinate meetings with the stroke team to review progress and make a plan for after the hospital. They advocate and can refer to a wide variety of community services if needed.

"Your Mum is sad that this has happened and she cannot be with you. The Social Worker will be talking to her about how she is feeling and can organise help for her at home if needed."



The Physiotherapist:

Helps the person to regain movement in their legs and arms, and helps to reduce pain and stiffness. They give advice on exercise and positioning to aid recovery and might work on sitting balance, standing, walking or arm movement.

"Daddy's leg and arms are not getting a proper signal from his brain so the physiotherapist is helping him to learn how to balance, stand, walk and move his arm."



The Occupational Therapist:

Helps people relearn the things they need to do everyday like washing and dressing. They also teach people how to find new ways of doing things and give advice about making their home as suitable as possible to their needs after stroke. They may also assess memory and concentration.

"Mum's arm is not working as well as it did. The Occupational Therapist is helping her to learn new ways of doing things."

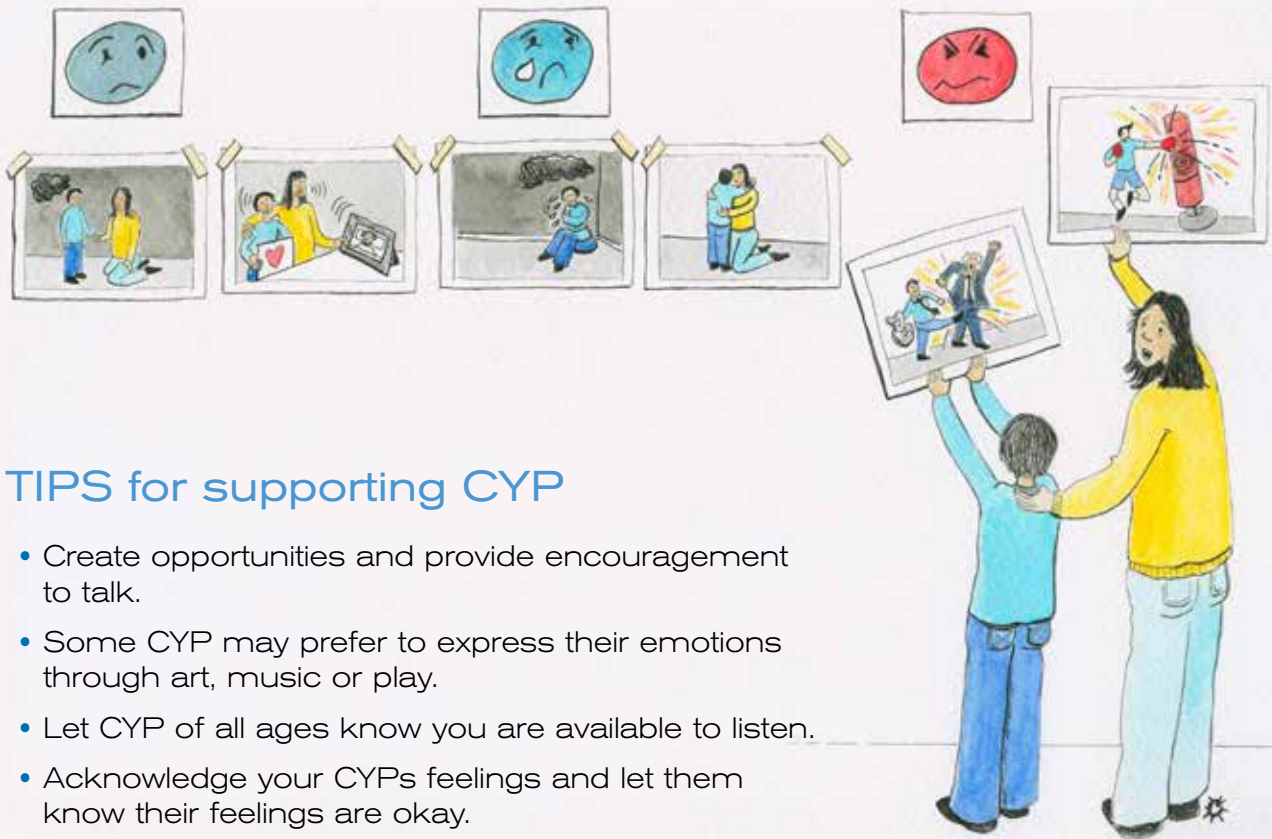


Section 5 How do I Support my Child or Young Person (CYP)?

Every family and child will have different needs. Experiencing distress following a stroke is very normal for a CYP.

They may show their distress through:

- Stronger feelings e.g. of anger, worry or sadness.
- Physical symptoms e.g. unexplained pain, poor sleeping.
- New behaviours e.g. clinginess, acting out, poor schoolwork, or avoiding activities.



TIPS for supporting CYP

- Create opportunities and provide encouragement to talk.
- Some CYP may prefer to express their emotions through art, music or play.
- Let CYP of all ages know you are available to listen.
- Acknowledge your CYPs feelings and let them know their feelings are okay.
- Use feeling words yourself as this helps CYP name and understand their own feelings.
- Let them tell you what they are worried about.
- Listen to their fears and let them know that you will get through this situation together.
- Try to make make some one to one time for each child.
- Check in regularly – in particular with the quieter child.

**Allow others
to help**

Routines

- CYP benefit from keeping to their normal routines like mealtimes, school, after school activities, play times and sleep times. This is one practical area where family and friends can help.
- If routines change explain what is happening and who will be looking after the CYP. This is especially important for younger children.

Networks

- Link in with your CYP's networks/supports e.g. schools, sports clubs, mental health, additional needs or other child support services.
- Keep the networks updated. It is helpful if all adults have the same information so that the CYP does not get confused.
- Help the CYP think about the adults they have in their network who they might want to talk to for support.

When to seek more help

Most CYP will find that their emotions settle. However some may have difficulties that don't go away. If this is the case and you are worried, then you may want to seek advice or professional help. A good starting point is to speak to a member of the Stroke Team or your GP.



Section 6 Keeping in touch with the Person with Stroke (PWS) in Hospital



Give the child or young person (CYP) a choice about how they would like to keep in contact. Some ideas include drawing pictures, making cards, sending photos and videocalls. It can be good to plan video calls at a regular time that suits the family and hospital routine and provides predictability to the CYP.

Remember calls don't always have to be a conversation but can just give the PWS a chance to be involved in normal family activities e.g. mealtimes. It is okay to set some clear routines and boundaries around the contacts that work for you at home.



Section 7 Visiting the Hospital

You will need to check if children are allowed to visit as there may be some restrictions.

if the person with stroke is well enough a visit can be reassuring for the child or young person as what they might imagine may be worse than the reality. However, they should be given the option to opt in or out, especially if the person with stroke is very ill.

**Accept
kindness
from others**

Before visiting

- Talk to the CYP about how they are feeling about a visit.
- Decide the length of the visit based on the age(s) of the CYP.
- Check with staff about the best time e.g. when ward less busy, before/after therapy, when staff around for support.
- Ask if there are family friendly spaces off the ward e.g. a day room, garden or café.
- Tell the CYP how the PWS will look e.g. in wheelchair, have a tube in nose.
- Prepare CYP for what the PWS may be able or not able to do e.g. speak well, walk, smile.
- If communication is affected, ask to speak to the Speech and Language Therapist about what would help.
- Bring some activities to encourage interaction e.g. bubbles, colouring books, books, or tablet.
- Let the CYP know they can change their mind about visiting.
- Consider bringing a relative or friend to support you with the CYP.

On the day

- Check with staff if there have been any changes for the PWS for which you need to prepare the CYP.
- Remember if your CYP is quiet during the visit they are probably trying to figure out what is going on.
- Arrange an agreed word they can use if they want to leave.

After visiting

- Allow time for questions at the pace the CYP may want to ask them.
- CYP can think back to the visit. They may ask questions or show reactions soon after or a sometimes a long time after the visit. This is normal.



Appendix



Children and Young People's (CYP) Understanding of Illness

A child's age and developmental stage will affect how they make sense of the stroke and react. If your child has any additional needs this may also affect how they make sense of the stroke and react.

The following table gives information about how children at different ages might typically understand and react to an illness of someone close to them. It also highlights some of the common needs at different ages.

However, every CYP is different and this information is provided for general guidance only.

Age	Understanding of illness	What CYP's need
0-3	<ul style="list-style-type: none">• Very limited understanding of illness and death.• Verbal skills developing.• Experience the world primarily through their senses.• Sensitive to change and if someone is not present.• Affected by the emotions of those around them.	<ul style="list-style-type: none">• Attention, love, hugs.• Known alternative carer(s).• Routine maintained.• Familiar surroundings.• To visit PWS in hospital if they want and it is possible.
3-6	<ul style="list-style-type: none">• No sense of time.• Beginning to develop an awareness of illness and death.• Don't understand how and why things happen.• Ask questions repeatedly/randomly.• Very active imagination.• Express upset verbally and non-verbally e.g.<ul style="list-style-type: none">Clinging.Bedwetting.Thumb sucking.Trouble sleeping.Become quiet and withdrawn.	<ul style="list-style-type: none">• Attention, love, hugs.• Known alternative carer(s).• Routine maintained.• Familiar surroundings.• Activities e.g. playing, drawing.• To visit PWS in hospital if they want and it is possible.

6-12	<ul style="list-style-type: none"> • Think logically, like facts, have reasoning skills. • Ask questions repeatedly/randomly. • More knowledge about the body + how it works. • Understand illness as part of body not working properly. • 6-9 years starting to understand death is permanent. • 9-12 years understand death is permanent + can happen to anyone. • May worry that someone else will get ill/die. • Express upset verbally and non-verbally e.g. <ul style="list-style-type: none"> Quiet and withdrawn. Physical reactions, upset tummy, poor sleeping. Losing skills they previously had e.g bedwetting. Angry at patient. Pick fight at school/refuse to go to school. Use play to act out feelings about the illness. 	<ul style="list-style-type: none"> • Attention, love, hugs. • Ongoing information & updates. • Known alternative carer. • Familiar surroundings. • Routines maintained. • Vent feelings/anger (fear) in controlled way. • Activities: playing, art, writing it down. • To visit PWS in hospital if they want and it is possible.
12 and older	<ul style="list-style-type: none"> • Understand more than they can handle emotionally. • Likely to have experienced illness/death of someone they know. • Like to be kept in the loop, want information about treatment + prognosis. • Want to help if can. • Peers are very important. • Express upset by verbally and non verbally e.g. <ul style="list-style-type: none"> Can rebel – self destructive behaviour/risk taking. Quiet and withdrawn. Poor concentration at school. 	<ul style="list-style-type: none"> • Encouragement to express their feelings and ask questions. • Acknowledgement of their practical help. • Routines maintained. • Rules maintained. • Activities keeping a journal, music. • Be able to help but not given adult responsibilities. • To visit PWS in hospital if they want and it is possible.



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