



Winter 2023

Stroke News

For everyone affected by stroke

Stroke
Association

"Stroke happens to
the whole family."

**How stroke impacted
Alex and Adebisi's
family life**

This issue:

- Advice on relationship changes after stroke
- Support our Thriving after stroke campaign
- Getting financial help with adapting your home

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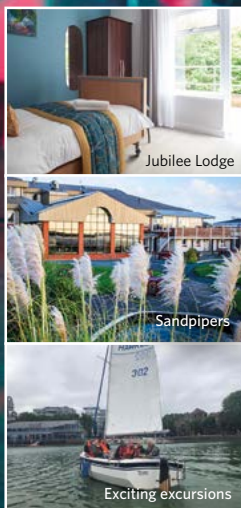
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Editor's letter

In this issue, we explore the impact of stroke on families and family life.

When someone has a stroke, the effects ripple out to everyone around them too. When our cover star, Alex, had a stroke, his life and the lives of his wife, Adebisi, and their two young children, changed overnight. On page 8, Alex and Adebisi explain how stroke affected their family, and how they're learning to adapt together.

Then on page 24, Elizabeth tells us how her dad's strokes changed the lives of her family and inspired her to fundraise to help others. Rebecca talks about her experiences as the parent of a childhood stroke survivor

and offers advice for all families living with stroke (page 30). And our Stroke Helpline Team share guidance on relationship changes after stroke (page 14).

Also, find out why it's important to take your medication after a stroke (page 28). And explore the financial help available for home adaptations (page 42).

I hope you enjoy this issue.



Christine Webster, Editor

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Over to you

My husband had a stroke in the the summer. It happened during early hours before I went to work. He woke up and realised his grip on his right side was not strong. I called 999 and the ambulance was with us in minutes. I was so scared.

In hospital, he got a lot of support with physio and is working on his motor skills. He gets tired very fast, but I've read this is normal.

We've had good and bad days since it happened, but the Stroke Association have been amazing. I've had so much support, especially during the low moments.

Life has changed but we're taking each day as it comes. At times, I feel so frustrated as I don't know what to do and how to manage my emotions. My husband doesn't talk about how he feels as he said his focus is to get better.

I want to be there for him, and I don't want us to grow apart. But I know we have to respect each other's time and space. This is new for us both and we're processing this in our own ways.

Message shared by a carer on our online forum

Stroke Helpline: **0303 3033 100**

Find your local services, clubs and groups: **stroke.org.uk/support**

Join our online community: **mystrokeguide.com**

Find information about stroke: **stroke.org.uk/publications**



Do you have something to share?

Email **strokenews@stroke.org.uk** or write to us at Stroke News, Stroke Association, 1 Sterling Business Park, Salthouse Road, Brackmills, Northampton, NN4 7EX.

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Juliet with Sir Bob Neill



From our Chief Executive

A stroke affects every part of your life. And, as we explore in this issue, stroke survivors and their loved ones often need support to understand and adapt to what's happened to them.

Life after stroke support services, like ours, are a vital part of this, providing the assistance that many need to rebuild their lives.

However, thousands still don't have access to this vital support. This is having a catastrophic impact on people affected by stroke and adding stress to the health and care system.

In October, we held a parliamentary reception to launch our 'Thriving after stroke' report. Featuring stories such as Julie's (page 18), our report highlights the difference that life after stroke support services can make.

It also draws attention to the patchy and inadequate provision of these services and puts pressure on local health systems to prioritise them for people recently affected by stroke.

It was great to see so many health and care professionals, corporate partners, stroke survivors and parliamentarians supporting our event and this cause. We'll be working with them to spur action to improve access to these vital services across the UK.

Every stroke survivor deserves to have the support in place to thrive, not just survive, after their stroke. And you can help. Please read our report and support our campaign at stroke.org.uk/thriving

Juliet Bouverie OBE

No "I" in stroke

"There is no "I" in stroke. Yes, the stroke happens medically to one person, but it affects the whole family."

Alex and Adebisi were on a family holiday in Lagos, Nigeria, with their four-year-old daughter, Velma, and four-month-old son, Sebastian, when Alex had a stroke in June 2022.

"I was at a club with my cousins when I lost vision in my right eye," remembers Alex. "Then I realised I couldn't find my right arm. It felt like the volume in the club had increased dramatically. Next thing I know it all faded to black."

Alex was taken to hospital by his cousins, where he had brain surgery to remove a clot and stop a bleed.

"I had no idea what a stroke was, and I didn't think it happened to young people," says his wife, Adebisi. "He had machines breathing for him for about three days. When he woke up, his whole right side was gone.

He couldn't speak and he had very short-term memory.

"The next six weeks were so difficult. I'd stay in hospital for about 14 hours and spend the nights with him. Then I'd go home, shower and play with Velma. I had to be positive at home for Velma and at the hospital for Alex. It was a lot physically and mentally for all of us.

"Velma missed her daddy so much. When I took her to visit Alex, she was so excited, but she quickly picked up on how much things had changed. She had to adapt to Daddy not liking loud noises, learn what arm he could use, and not to hug him when he wasn't prepared.

"When Alex came home from hospital, the first thing Velma said was, 'Now that Daddy's home, do I still have to be brave?' It just broke our hearts."

"Velma missed her daddy so much. When I took her to visit Alex, she was so excited, but she quickly picked up on how much things had changed."





Before, Alex had been a busy project manager and hands-on dad. But the stroke left him with weakness in his right arm, sensitivity to noises and smells, and arm spasms. This had a big impact on what he was able to do at home.

"I was extremely emotional in the first six months," says Alex. "I was in my head a lot, thinking about how I wanted to show up for my family, and to help my wife who now shouldered the whole family's burdens, plus my care."

Taking on all the family responsibilities took its toll on Adebisi too. "Basic hygiene became difficult as I did not have the time between full-time

work, school runs, looking after a newborn, supporting Alex and domestic chores," she says.

"I lost myself for the year of his stroke and I am only just recovering now. As a carer, it's so crucial to find time to recharge yourself, otherwise you cannot continue to give to those you love.

"Our local Stroke Association Coordinator, Lydia, was a massive help. She provided me with a lot of information on what Alex was going through. She even chased up the GP and other teams on my behalf so I could focus on Alex."

"The Stroke Association's visits were invaluable," says Alex. "At times they felt like therapy,



other times an informative lesson, a coaching session – whatever I needed.

"They also validated how I was feeling in the early days, which meant so much back then because I felt no one else understood."

Although Alex still has challenges following his stroke, he is recovering well, and together, he and his family are adapting to life after stroke.

"Velma's been amazing," says Adebisi. "She knows what Alex is working on and will often come to me and say, 'Mummy, I saw Daddy using his right hand today.' And we'll have a little clap together.

"Even our son, who's too young to know what's happening, seems to act differently with Alex. He knows you take your time with Daddy and don't yell too much."

"The stroke has changed me, but I find ways around it," says Alex. "It's important to come to terms with who you are now. Don't hold on too much to what you could do. Take it as it is and forge a new path, find new things you love."



We're here to support everyone affected by stroke. Contact us on **0303 3033 100**, **helpline@stroke.org.uk** or visit **stroke.org.uk/support** for information and guidance.

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Relationship changes after stroke

A stroke can be life-changing for you and those around you. The psychological effects of stroke, the sudden change in familial roles and the stress of caregiving can put strain on relationships. But there are some practical things you can do to help.

Lucy Sherman from our Stroke Helpline shares some guidance:

Caring for my loved one has changed our relationship. What can we do to maintain the relationship we had before?

Becoming a carer can significantly change family roles. What was an equal relationship, can become complicated when your loved one needs ongoing support. This can be very unsettling, stressful and overwhelming for all involved.

But setting time aside to do things that put you back into your roles as a couple, parent and child, or

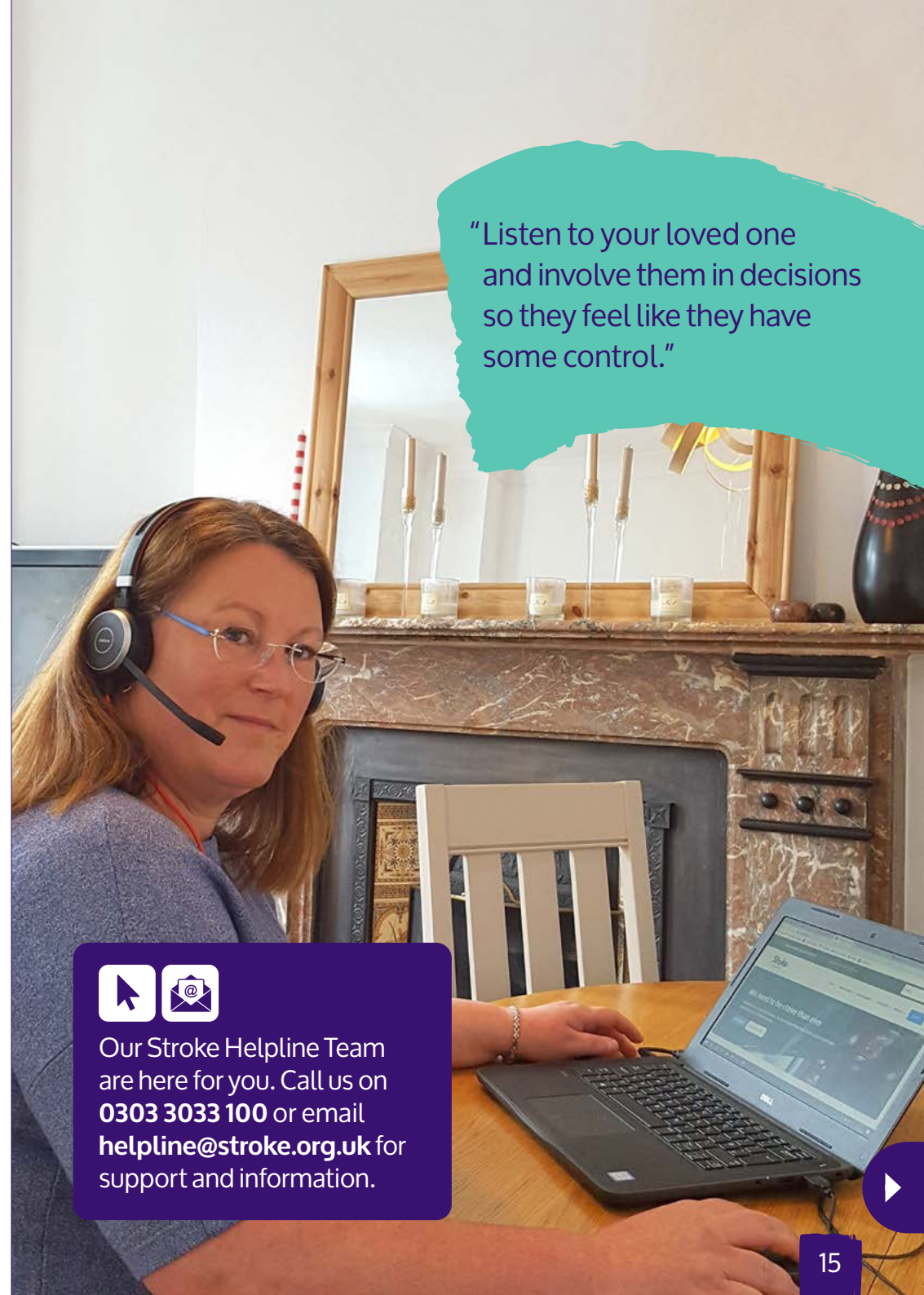
friends, rather than carer and cared for, can make a big difference. For example, perhaps you always did the crossword, or watched a football match together.

Finding ways to make your relationship more equal can also help. Such as finding new, more manageable tasks that the person who's had a stroke can do to help re-build their confidence.

Listen to your loved one and involve them in decisions so they feel like they have some control. For example, even if they can't make their own lunch, they may still want to choose what they have to eat.

Work out what your boundaries are too. How can you ensure you aren't being over-protective of a stroke survivor or being taken for granted as a carer? Be honest about your feelings and allow others to do the same.

"Listen to your loved one and involve them in decisions so they feel like they have some control."



Our Stroke Helpline Team are here for you. Call us on **0303 3033 100** or email **helpline@stroke.org.uk** for support and information.



Q I get more angry, emotional and low since my stroke and it's affecting my relationships. What can I do about it?

Emotional and behavioural changes are common after a stroke. You'll probably find these feelings improve or get easier to manage over time. But if you find your behaviour is impacting on other people, talk to your GP. They can refer you for talking therapies, such as cognitive behavioural therapy or counselling with a trained mental

health specialist or prescribe medications that can help.

It can be hard for the people around you if they feel you've changed. They may also need some support to help them understand what's happened to you. Talk to them to work out what triggers your behaviour changes and how you can avoid it. You could also agree a word, phrase or sign that your loved ones can use to let you know that you are behaving inappropriately. Or agree that they leave you alone for 15 minutes.



Top tips:

✓ **Talk to each other** - Having an honest conversation about what you are both finding difficult is the first step to making changes. Set aside a time to talk when you won't be interrupted and take it in turns to talk and listen carefully to each other.

✓ **Talk to others** - Connecting with people who know what you're going through can be a big help. Stroke survivor and carer groups are a good way to meet others to get advice and support.

Our Here For You service also connects people affected by stroke with trained volunteers who understand.

✓ **Ask for support** - Contacting your GP or local authority to find out about services in your area or seeking advice about practical and financial matters can help you feel more in control. Age UK ([ageuk.org.uk](https://www.ageuk.org.uk)) and Citizens Advice ([citizensadvice.org.uk](https://www.citizensadvice.org.uk)) can also help you to navigate local services and check what's available.

Thriving after stroke

Life after stroke support is a vital part of recovery. These support services enable people to thrive, not just survive, after their stroke by providing information and help with regaining their independence, reducing their risk of a further stroke, and improving their confidence and physical and mental wellbeing.

However, too often, support suddenly ends when a stroke survivor leaves hospital, leaving them feeling abandoned.

Julie, 55, from Bury, was discharged from hospital without support when she had a stroke on 1 June 2023.

"I was given my medication but then simply told to go home," says Julie. "It was very odd getting home without any knowledge of what happens next. I felt left upstream without a paddle.

"A couple of weeks later, I still hadn't heard anything from the stroke nurses or community

stroke team. I thought, 'Is that it? Have they just dropped me off home and left me?' It was very lonely and quite scary."

Julie is a full-time carer for her daughter, who has complex needs and is in her 20s. They were at home together one morning when Julie realised something was wrong.

"A few days before, I'd felt pins and needles in my left cheek. Later that week, I got up and found I couldn't tie my dressing gown. I went to put my earrings in and really struggled. My left hand wasn't doing what it was meant to be doing."



"I thought, 'Is that it? Have they just dropped me off home and left me?' It was very lonely and quite scary."



Stroke Association Support Coordinator, Jo, with Julie



Concerned, Julie called her doctor who told her to ring an ambulance. She was taken to Fairfield Hospital where she was diagnosed as having had a stroke. She then had surgery at Oldham Hospital and was discharged the next day.

When Julie got home, she received a letter about our support service in Bury. Worried about her next steps, she decided to get in touch with us. From that point, everything changed.

"I made contact with the Stroke Association and I received a lovely email back from Jo – one of the Stroke Association Support Coordinators – who has supported me since then.

"Jo reached out to the district stroke nurses and connected me with the community stroke team. It turned out that I'd been missed off the system.

"Suddenly, I had a physiotherapist, stroke nurses and an occupational therapist all come out to see me. I couldn't have been more looked after by them."

Jo also put Julie in contact with services to help her get adapted cutlery so she can eat with her hand weakness, and aids for her bathroom to support her mobility.

"Emotionally, it's been really good to have the Stroke Association's support. I've had lots of calls and emails from Jo. She visits me at home too, to see how I am

and talk through my questions. She's been my safety net.

"Jo also speaks with my daughter to see how she's feeling. Though I'm a carer for my daughter, she is able to use the telephone and I know she would be comfortable to call Jo on my behalf if she needed to because she has met

her and knows that Jo's support benefits me.

"Jo is able to be there to support me for as long as I need, which is great just now because I don't think I'm ready to be without her yet. The journey hasn't ended and I know the Stroke Association will be there for my future steps."



Sadly, too many people don't have access to ongoing life after stroke support services like ours after their stroke. We are calling on all UK health providers and decision-makers to recognise the value of life after stroke support, and ensure support meets the national guidelines so everyone who has a stroke can benefit. You can read our report at stroke.org.uk/thriving

Your voice matters, so please get involved. Visit stroke.org.uk/campaigns to join our Campaigns Network. Or email campaigns@stroke.org.uk to learn more about how you can campaign for life after stroke services in your area.

Freedom to move

Being active after stroke can be as simple as building movement into your day-to-day activities at home to help improve your physical and mental health.

Maria Knight, 53, had an active job as a healthcare assistant before she had a severe bleed on the brain that caused left-sided weakness in her leg, arm and hand. She has drop foot and needs to wear a splint on her left leg.

At first Maria relied on a zimmer frame but has slowly built up her strength and now uses a quad stick – a walking cane with four small feet for stability. One of her first milestones was managing to walk the path from her front door to the road.

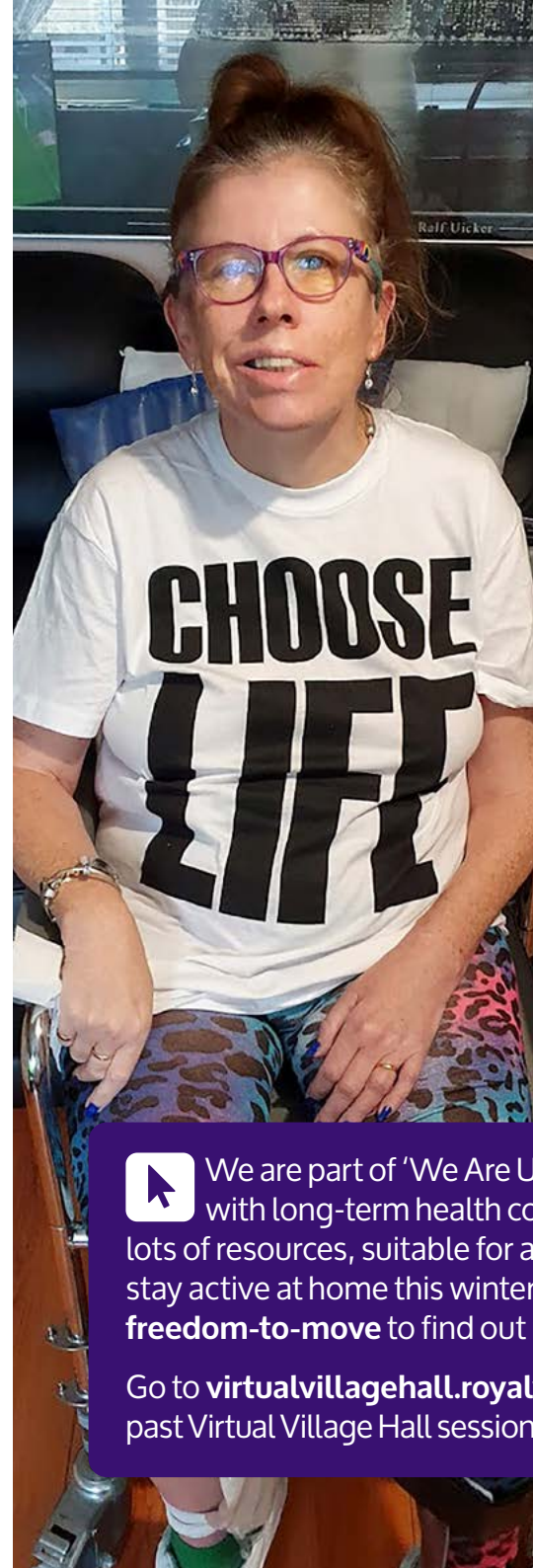
"I was frightened of doing it, but the rehab team were brilliant. They taught me breathing

exercises to calm my nerves and relax me. It took me ten minutes to walk to the car and back, but I did it and it was exhilarating.

"I decided that my stroke is not going to define me. It's a new chapter in my life, and with determination and exercise I can get through this."

Maria now keeps active at home however she can. "I do exercises on the bottom step of my staircase – 100 steps up to heaven and down to hell, with breaks in between! And I walk with my quad stick whenever I can, especially in the garden.

"Being active has been paramount to my physical and mental health. Moving independently and not having to rely on my husband helps me feel like I'm slowly getting back to me. It's ongoing and can be a struggle, especially if I'm ill. But when I'm well, I want to move as much as possible."



Recently, Maria took part in the 'We Are Undefeatable Freedom to Move Challenge' hosted on the Royal Voluntary Service's Virtual Village Hall, which aimed to encourage people to build activity into their daily lives.

The Virtual Village Hall is an online activity hub to help people stay physically and mentally active. From crafts to Zumba, singing to meditation, there are more than 900 sessions available to view online.

"I joined a few of the exercise sessions and found them challenging but helpful, especially the stretching exercises," says Maria. "It gave me the chance to do activities I'd not tried before at home with no judgement. It was well worth doing and very motivating."

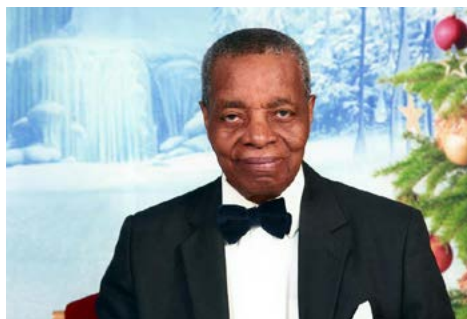


We are part of 'We Are Undefeatable', who support people with long-term health conditions to get active. They have lots of resources, suitable for all levels of mobility, to help you stay active at home this winter. Visit weareundefeatable.co.uk/freedom-to-move to find out more and have a go.

Go to virtualvillagehall.royalvoluntaryservice.org.uk to watch past Virtual Village Hall sessions and to sign up to future live classes.

Fundraising in Dad's memory

Elizabeth Kwenorley's dad, Daniel, sadly passed away in June 2022, aged 77. He'd had multiple strokes throughout his life, which had a huge impact on him and his family. Now, Elizabeth is committed to fundraising in his memory.



"I was very close to my dad. He was my best friend," says Elizabeth. "He spent a lot of time with me and my sister. At weekends, we'd go to a specific branch of KFC in Clapham Junction – that was our spot. Every Saturday morning, he'd buy the newspaper and croissants for the house. That was our little routine.

"Dad had strokes before I was born and when I was quite young, so I think he'd always lived a life affected by them. But it wasn't until 2009 that we saw the affects manifesting.

"I was 11. I had gone to sleep in my dad's room because I'd had

an argument with my sister. All of a sudden, I heard a crash. I woke up and Dad was on the floor. My sister and I called an ambulance. When we got to hospital, they explained he'd had a stroke."

The stroke affected Daniel's mobility, leaving him reliant on a walking stick or frame to get around. This had a huge impact on their family life.

"I became a young carer, assisting my mum with Dad's care. Sometimes I didn't go out with my friends because I wanted to stay home with my dad. Or I'd arrive late because I was doing something for him.



Elizabeth (left) with her sister and mum during her walk

But it didn't feel like a burden because he was so great. It became the new norm.

"It was more difficult to get him outside of the house, so the KFC, croissants and the newspapers stopped.

"But there was still life to live. I remember my mum took him to a church camp in Brighton. She was so happy talking about how they were just sitting by the beach eating fish and chips – like something out of a film! We also went to Ghana to see family.

It was nice to see him with people he loved."

Then in 2019, Daniel had a severe stroke that left him bed bound, unable to walk or speak. His family continued to care for him, but sadly his health declined, and he died on Father's Day 2022.

To mark her dad's birthday in March 2023, Elizabeth decided to walk 77,000 steps, 1,000 for every year of his life, and raise money for others affected by stroke.

"Setting up my JustGiving page was simple. Then the lovely Charlotte, from the Stroke Association's Fundraising Team, got in touch to see how I was doing. Her support really made me excited about it."

"The walk was a long but beautiful day. I walked across London, visiting sites connected to my dad, including the Ghanaian Embassy."

"Fundraising in Dad's memory helped me process my grief. It allowed me to focus on my dad and show my thanks for his life."

"Knowing that the money is going to a charity who focus on something that's had a massive impact on my dad's life, and my life, felt great. And I want to continue fundraising next year."



Paying tribute to a loved one through fundraising is a meaningful way to honour their memory. Visit stroke.org.uk/in-memory-giving or call **0300 3300 740** to find out more.

If you'd like support with grief and bereavement, we're here to help. Please call our Stroke Helpline on **0303 3033 100** or visit stroke.org.uk/bereavement

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Taking medication to reduce your risk of stroke



After a stroke, doctors often prescribe medication, as well as lifestyle changes, to help reduce your risk of another stroke. Dr David Buckle, a GP and one of our charity's trustees, tells us more about these preventative medications, and why it's important to take them.

Q How do doctors know what will reduce my risk of another stroke?

Your doctor will consider whether your stroke was caused by a clot or a bleed and why it happened. They'll then prescribe medication aimed at reducing the risk of it happening again. They'll also consider other health conditions you have, other medications you're already on and your age.

Q What medicines are prescribed?

If you have a stroke caused by a clot in your brain (an ischaemic stroke), doctors will usually prescribe "blood-thinners", to reduce the risk of clots forming in your blood.

There are two types:

- Antiplatelets, for example clopidogrel, aspirin or dipyridamole, are usually given just after a stroke or TIA. They stop platelets (small, sticky cells in the blood) from clotting inside your body.
- If your stroke was caused by a heart condition, like atrial fibrillation, doctors may move you on to anticoagulants (such as apixaban) to reduce the long-term risk of unwanted clots.

Most strokes are caused by a blood clot. If your stroke was caused by a bleed, the doctors will have searched for a treatable cause.



Whatever the cause of your stroke, it is important to make lifestyle changes as well as keeping up with your medication. For example, reducing your blood pressure by exercising regularly, eating a healthier diet and stopping smoking.



Stroke Prevention Day is on 25 January 2024. You can help stop stroke by encouraging your loved ones to check their pulse for an irregular rhythm. Visit stroke.org.uk/SPD24 or call 0300 3300 740 to learn more.

Q Should I still be taking medication even when I feel better?

Blood-thinners typically won't make you feel different because they're prescribed to reduce your risk of future strokes, rather than to help you recover from anything. It's important that you keep taking them for as long as you've been prescribed them.

However, as with all medications, they can cause side effects. If you have side effects, please don't stop taking your medication because it is reducing your chance of another stroke. Contact your GP, pharmacist or 111 for advice.

You should have regular checks while taking blood-thinners. If you have questions about your medication, keep taking it but ask your GP or pharmacist to talk to you about it and make sure it's still the best one for you.

A parent's perspective

Rebecca's son, Jacob, had a stroke before he was born. Here, she shares her experiences and advice for parents of childhood stroke survivors, and families of all ages living with the impact of stroke:

"Initially after his birth, Jacob seemed fine. Then he stopped breathing twice and started having seizures. It was terrifying.

"We were told Jacob had had a stroke and might not ever walk or talk. The medical staff stressed that, at Jacob's age, the brain can rapidly repair itself and that his outcome could be much better. But although the words were going in, I felt like I was watching from outside my body.

"Jacob is now nine. He is so funny and loving – he brings light to any room! He walks, but it came slowly and not without its hurdles. New

challenges are always coming our way. We struggle with behaviour problems and he's been held behind at school. But we wouldn't change Jacob for the world.

"Jacob doesn't fully understand what happened to him. He knows his brain is "poorly" and we must work with him to make it better. He's always eager to try, and we're so proud of him.

"We go through periods of progress and stagnation. This can feel daunting, but it's important to look at where you started and see where you are now. All progress is a huge step forward.

"My perspective has also shifted. At the start, I felt lost – like time was sealed and his whole life was determined by the stroke. But that isn't true. Life has so many twists and turns and it's important to have hope. Although Jacob could end up needing care for life, I'm more hopeful for the journey ahead.



"Remember that your journey is your journey, no two are the same. Where you are now may not be where you are in a year.

"As a parent or a carer, look after and make time for yourself. Therapy can also be very beneficial – it made the world of difference for me."

"And find people who will support you. It's not a journey you can face alone. It can take you to breaking point. Please find someone to listen to you, as you'll need them in your times of doubt and anxiety. I love that the Stroke Association has a dedicated childhood stroke support team and Parent-to-Parent support, so people can find someone they can relate to. These services will be so beneficial for many. I know they would have been for me."



We're here to help children and their families to live their best possible lives after stroke. Visit stroke.org.uk/childhoodstroke to find out more.

If you care for a stroke survivor of any age and need support, please call our Stroke Helpline on **0303 3033 100**.

Exploring the long-term effects of cognitive changes

People can experience a range of changes to their mood and thinking over a long time following their stroke.

Until now, research has only followed people for up to 12 months after their stroke. This means we don't have enough information about how these problems may change beyond a year to be able to predict how they can expect to recover and respond to treatment.



Professor Nele Demeyere and her team have recently completed a Stroke Association

-funded study, known as Ox-Chronic, following stroke survivors for three years to find out how stroke affects mood and thinking in the long term.

"We had 105 stroke survivors take part, who'd had a stroke at least one year ago," says Nele. "We met each person to carry out detailed neuropsychology assessments twice, one year apart. We asked them to do clinical interviews and questionnaires so we could measure quality of life and psychological effects such as depression and fatigue.

"We also asked carers to fill out a questionnaire to give us a fuller picture of the long-term impacts of stroke.

"We received enormous support from stroke survivors in this research. We had stroke representatives, like Trevor (page 34), on our study oversight



Grace Chiu, Ox-Chronic researcher, working with a stroke survivor taking part in the study

committees, who reviewed all of our materials to help us ensure they were accessible.

"They also helped us to organise an outreach event in September 2022 for our participants and the general public, providing guidance on materials and giving talks on their experiences of the research.

"Our results found that most people had fewer cognitive difficulties over time. However, many still had problems, particularly with fatigue and mood, long after their stroke, which impacted their quality of life.

"This shows that there is hope for long-term life after stroke as we see that recovery can continue

past the first year. But there are still people who need long-term, dedicated support.

"Psychological changes need to be monitored in the long term, and more research is needed into improving these outcomes.

"We're now using our data to help answer questions that will enable scientists to develop treatments and coping strategies to help stroke survivors and their families plan for the future.

"Our research will also help to inform NHS and policy makers to treat stroke as an ongoing condition and help everyone to understand that the psychological aspects matter."

Trevor giving a talk at a research outreach event



Visit stroke.org.uk/research-involvement to find out how you can help to shape stroke research.

Trevor's story:

"While I was in hospital after my stroke, someone from Oxford University asked if I wanted to take part in tests they were trialling to see how cognition is affected after stroke.

"I found it interesting and helpful for my recovery as the tests showed me where my limitations were and what I needed to work on. I was asked to carry on helping with the research after I left hospital and said 'Yes' as I thought it might help people in the future.

"Since then, I've volunteered in stroke research projects both as a participant and as a stroke patient representative, helping with setting up new research projects.

"For Ox-Chronic, I was a participant and also sat on the management team. Although the discussions were quite technical at times, they were very interesting. We were often asked about what we thought or felt about ideas for the project.

"I enjoyed the experience very much. Ox-Chronic shows that you do continue to improve after a stroke, but you also need support. Hopefully the government will take notice."

Stroke destroys lives

Stroke can happen to anyone of any age and the impact for them and their families can be devastating. We are dedicated to helping people affected by stroke to rebuild their lives.

If you can, please support others whose lives have been changed by stroke. You can make a donation by visiting stroke.org.uk/donating, by calling us on **0300 3300 740** or by completing the form below.

I enclose my total gift of £

Funds raised will go towards vital services and pioneering research to help rebuild the lives of people affected by stroke.

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Please detach this form and return it to us using the envelope enclosed, or post it to:
Stroke Association, Bumpers Way, Bumpers Farm, Chippenham SN14 6NG



Keeping in touch

We would love to send you information about the difference you can make to families affected by stroke through campaigning, volunteering, donating and through your own fundraising. Please tell us how you'd like us to stay in touch by filling in your details below.

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Determined to adapt

Having a stroke at 28 threw Deya's life and future into disarray.

"I was married, we'd just bought our house, and everything was falling into place with work," says Deya. "Then, in June 2012, I had the stroke.

"In the ambulance I started thinking about how my husband and I wanted to start a family. I thought, 'I'm too young to die.'"

Deya had a brain bleed that caused left-sided weakness and limited movement in her left hand. She spent three months in hospital receiving physiotherapy. But it wasn't until she returned home that the emotional impact of the stroke hit her.

"When I got home, reality sunk in. I couldn't go up the stairs properly. Everything took time, like having a shower or putting on clothes. The day-to-day things you'd normally do with ease, I couldn't do. It brought me down.

"I didn't want to move back in with family because we'd just bought our house. That motivated me to learn to do things without any help. I didn't want to give up."

When Deya found out she was pregnant with her first son, she was elated but anxious about how she'd cope.

"I'd think about things like how I was going to do nappies with one hand. But I was determined to find ways to adapt.

"When my son arrived, I managed to do most things. But at times I felt very self-conscious. I avoided going to baby classes. I couldn't do activities like lifting the babies up while singing songs. It was heartbreaking and isolating."

Nevertheless, Deya continued to find ways to stay independent.

By the time her second son was born in 2018, she'd developed many methods to do daily tasks herself. She even got back to driving with a specially adapted car.

During the pandemic, all Deya had been through with her stroke started to impact her mental health. Her GP referred her for counselling.

"Speaking to a counsellor about my stroke is the best thing I've done. It's like I'd been grieving for what I'd lost. It really helped me.

"I still have days where it's hard not to compare how it was in a past life, but it's about managing what you are capable of doing."

Deya's now helping to raise awareness that strokes can happen at any age. "When I had my stroke, there weren't many young people speaking out about it. So I just felt alone.

"It can feel like the end of the world, but with the right support and people to talk to you can get through it. If you have had a stroke, please accept any help that is offered. There is life after stroke."



To find out more about the support we offer visit stroke.org.uk/support



"I felt supported, listened to and recognised"

Having a stroke can be overwhelming. Whether it's happened to you or someone close to you, it can leave you feeling frightened, confused and isolated.

Our confidential Stroke Helpline is here to support everyone affected by stroke. You can talk to one of our Support Line Officers at any point in your stroke recovery journey.



Louise called the Stroke Helpline after she had a stroke when she was only 31.

"One day I was fine, the next day I was confined to a wheelchair," says Louise.

"Although I had support from my family and friends, I didn't have anyone who understood why I was sad, angry and felt 20 emotions in one minute. I felt very alone and isolated. "I'd tried searching for help but was told there wasn't

anything available for me because of my age. Then my mum saw an advert for the Stroke Association on Facebook.

"I was very low and depressed, so I rang the Helpline as a last hope. They saved my life. They helped me to see a better path.

"I phoned them a few times for support. The Support Line Officers understood why I felt the way I felt, despite the fact that I'd got my right leg working and could walk with a crutch now. They helped me to understand that I was grieving my old body, but it wasn't all doom and gloom, there was light at the end of the tunnel.

"They just said: 'You've had a stroke and we're here to help and support you anyway we can'. I felt supported, listened to and recognised.



"After speaking to the Helpline a few times, they recommended a Stroke Cafe on Zoom that was run by stroke survivors. I wasn't expecting much to be honest. But within five minutes I felt so welcomed and loved. I now volunteer as the leader of the cafe. I try to make sure that everyone is listened to.

"I want to get my story out there and make folk realise stroke isn't an old person's disease. And for anyone like me that's feeling the way I felt, there is help out there – an organisation that will put its arm round you and support you."



Thank you to our partners, Buzz Bingo, who've donated £57,882 to fund a Support Line Officer for the next two years. This will enable us to help more stroke survivors through the Stroke Helpline, Stroke Association Connect and the Childhood Stroke Support Service.



Our confidential Stroke Helpline is here to support anyone affected by stroke in the UK, including family and friends. If you have a question or need to talk, email us on helpline@stroke.org.uk or call **0303 3033 100**.

Help with the cost of home adaptations

If you have a disability after a stroke, you may need to make changes to your home so you can continue living there safely and as independently as possible. Financial support may be available to help with this.



Assessing your needs

First of all, your care and accommodation needs should be assessed by your local authority. The assessments are free and are usually done by an occupational therapist or social worker. They can visit you at home to see whether you need any equipment or adaptations to make life safer and easier.



Funding small adaptations

Your assessment might suggest equipment or minor alterations that could help you at home, such as installing grab rails or getting a raised toilet seat.

If you live in England, your local council should provide these free of charge, up to the value of £1,000. In Scotland, this is up to £1,500.

This assessment should be arranged as part of the hospital discharge process. But if your stroke was a while ago or your needs have changed, you can contact your local authority's adult social care team directly to ask for an assessment.



Funding larger adaptations

If you need a larger alteration, such as widening doors or installing a wet room, the Disabled Facilities Grant (gov.uk/disabled-facilities-grants) is available through local authorities in England, Wales and Northern Ireland.

In Wales, minor adaptations should be provided for free, but you might be asked to pay towards some disability equipment, depending on your circumstances. In Northern Ireland, your local trust will decide whether they'll provide funding or if you have to pay for it.

This grant is means tested, so you could be asked to pay for some of the work.

In Scotland, you can apply to your local authority's Scheme of Assistance for help. See citizensadvice.org.uk/scotland/housing/repairs-and-improvements-s



Other sources of funding and advice

- **Home Improvement Agencies (HIA)** – help with home adaptations and grant applications in England. Visit findmyhia.org.uk or call **0300 124 0315**.
- **Care and Repair** – help with adaptations and funding information. Contact careandrepairsctotland.co.uk (Scotland) or careandrepair.org.uk (Wales).
- **Disability Grants** – lists grants available around the UK. Visit disability-grants.org
- **Independence at Home** – offers grants for adaptations and equipment. Visit independenceathome.org.uk



Find out more about financial support for changes to your home at stroke.org.uk/accommodation. Or call our Stroke Helpline on **0303 3033 100**.

Puzzles

Puzzles can be a fun way to exercise your mind and improve concentration, understanding and memory.

Word search

K Q M K B C C D F
C E A Z P L O Q B
O H K Q G A U T E
R J A Z Z S N E I
G U P K D S T A S
V O L A V I R G V
P O N E Z C Y G U
F C A H P A O E H
E S O U L L P R N

ROCK	COUNTRY
POP	DANCE
JAZZ	REGGAE
BLUES	FOLK
CLASSICAL	SOUL

Across

- 1 Holier-than-thou (13)
- 8 Young chap (3)
- 9 Civilian dress (5)
- 10 Repair (3)
- 11 Etiquette (3,4,5)
- 13 Fighting (6)
- 15 Wine shop (6)
- 17 Dictionary creation (12)
- 20 Fermentation vessel (3)
- 21 Lyric poetry's muse (5)
- 22 Knight's title (3)
- 23 Small scattered amounts (5,3,5)

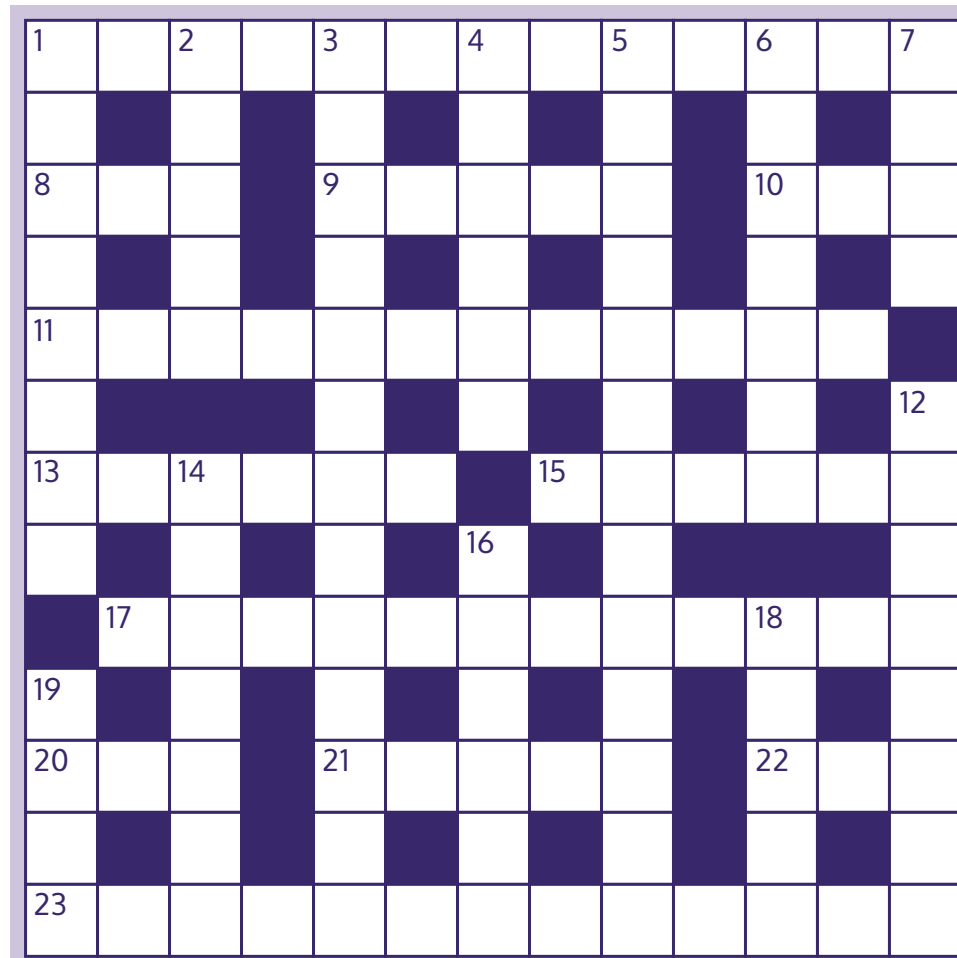
Lottery

For your chance to win £1,000 every week, play the Stroke Association Charity Lottery. Find out more at lottery.stroke.org.uk

Solutions
see page 50

Down

- 1 Seasonal turning point (8)
- 2 Poke (5)
- 3 Impermanence (13)
- 4 Annoyed (6)
- 5 Locality (13)
- 6 Crime (7)
- 7 Alluring (4)
- 12 Nautical ropes (8)
- 14 Experts (7)
- 16 Realm (6)
- 18 Italian food staple (5)
- 19 Very keen (4)



With thanks to The Times/News Syndication who granted us rights to this crossword.

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Rebuilding lives after stroke

Our charity supports people to live the best life they can after stroke. But rebuilding lives is a team effort and we need your help. A huge thank you to everyone who has gone the extra mile to fundraise, volunteer and campaign with us. Your support means we can reach even more people who need us.



Wayne Ewing

A big thank you to Wayne Ewing, who raised over £4,400 by skydiving 15,000ft – despite being terrified of heights! Wayne wanted to do something outside of his comfort zone to raise money for us and local stroke group, Nailsea Stroke Survivors Club, who have supported his sister, Sarah, since her stroke in 2020.

Shelia Thomson

Congratulations to the amazing Shelia Thomson who, at 93, flew on the zip wire over the Eden Project and raised £2,000. Sheila had a stroke last year and wanted to do something daring as a thank you for the support she received, and to show there is life after stroke.



Photo ©BBC



Find out what events we've got coming up on page 50 or make a donation at stroke.org.uk/donating

How does your donation help?



£10 supports our Helpline to answer a call from someone who urgently needs support after a life-changing stroke.



£25 could be part of a hardship grant for a stroke survivor who is struggling to pay for basics like food and clothing.



£50 could help us be there for children and families through our Childhood Stroke Support.



Warlingham Rugby Club

Thank you to all the team at Warlingham Rugby Club who have been fundraising for us at their classic car show for the last two years, raising an incredible £18,932.97.



Volunteer spotlight

Geoff Crook is Vice Chair of the Blackwood Stroke Support Group.

"I joined the group in 2020, after having two strokes in June 2019. I started volunteering during Covid, helping to set up a Zoom group so we could continue meeting online and carried on when we went back to face-to-face.

"I thoroughly enjoy my role. I get so much pleasure in seeing new friendships form and how much people change when at the group.

"As a stroke survivor, I can help other stroke survivors with my experience. Being a volunteer has given me a purpose – to help others to navigate the difficult path between 'Why me?' and 'This is now the new me.'"

Find out how you can volunteer at stroke.org.uk/yoursupport

Join Team Stroke

Get involved and fundraise at home, or join us at exciting events around the UK:



London Winter Walk 27-28 January 2024

Start the new year with a 10k, half marathon or marathon walking challenge, taking in the highlights of the Thames and many of London's landmarks. Get 25% off the registration fee when you sign up for Stroke Association at **ultrachallenge.com/london-winter-walk**

Skip for Stroke 1-29 February 2024

Skip for 15 minutes a day in February to raise vital funds for stroke survivors and their families. Join our Skip for Stroke Facebook group to chat to other participants. Visit **stroke.org.uk/skip** to sign up and get your free skipping rope!

Stride for Stroke

Honour each of the 1.3 million stroke survivors by challenging yourself to walk 1.3 million steps over 130 days, (that's 10,000 steps a day!) at a time and place that suits you. Go to **stroke.org.uk/stride** to sign up.

For more events and ways to get involved in our work, see **stroke.org.uk**

Crossword solution

Across: 1 Sanctimonious, 8 Lad, 9 Mufti, 10 Fix, 11 The done thing, 13 Combat, 15 Bodega, 17 Lexicography, 20 Vat, 21 Erato, 22 Sir, 23 Dribs and drabs

Down: 1 Solstice, 2 Nudge, 3 Temporariness, 4 Miffed, 5 Neighbourhood, 6 Offence, 7 Sexy, 12 Halyards, 14 Maestri, 16 Domain, 18 Pasta, 19 Avid

K	Q	M	K	B	C	C	D	F
C	E	A	Z	P	L	O	Q	B
O	H	K	Q	G	A	U	T	E
R	J	A	Z	Z	S	N	E	I
G	U	P	K	D	S	T	A	S
V	O	L	A	V	I	R	G	V
P	O	N	E	Z	C	Y	G	U
F	C	A	H	P	A	O	E	H
E	S	O	U	L	L	P	R	N

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*OML Patient Survey 2022



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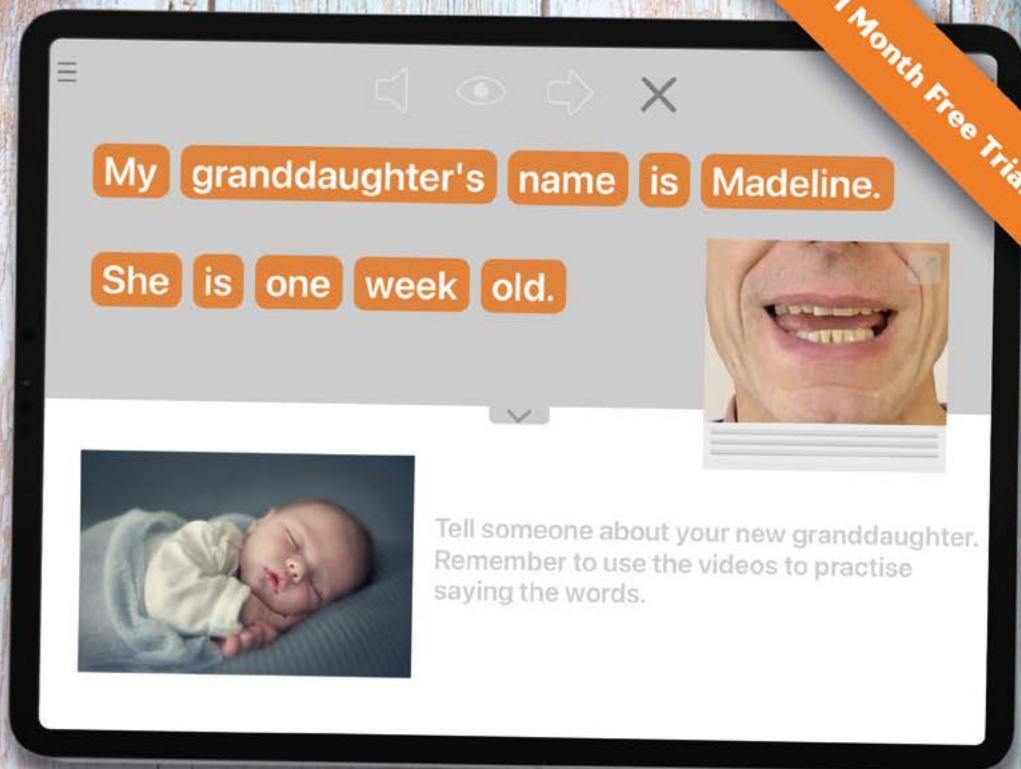
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