European
Life After
Stroke
Forum

# Lived experience of acalculia after stroke

#### Colin Jenkinson

Person with lived experience United Kingdom





## Lived experience of acalculia after stroke

## by Colin Jenkinson

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## **Conflict of Interest Statement**

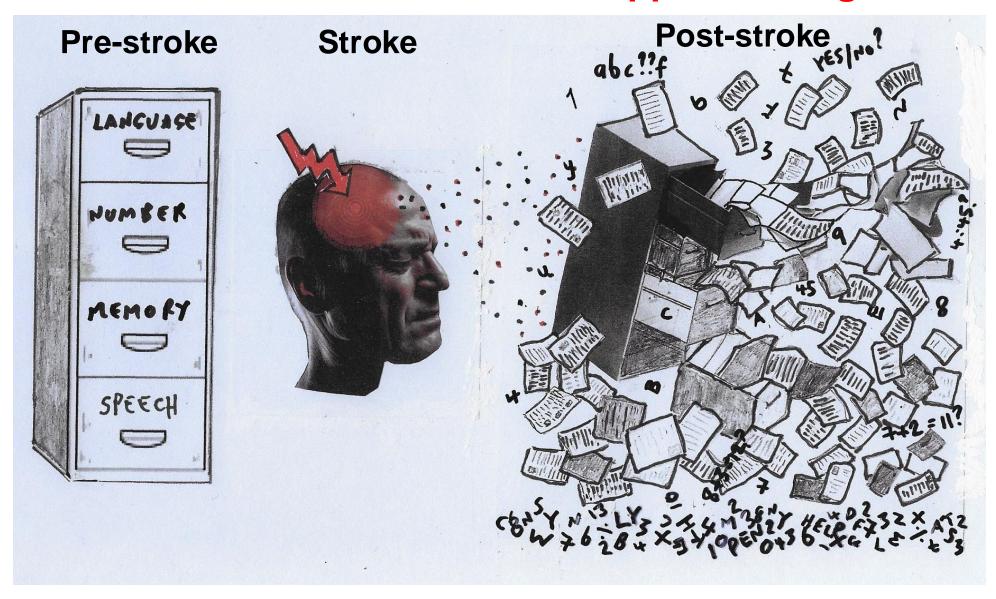
There are no conflicts of interest to declare.

### Introduction

- From Hertfordshire, UK
- Maths tutor <u>before</u> stroke in 2016
- Post-stroke: aphasia and acalculia.



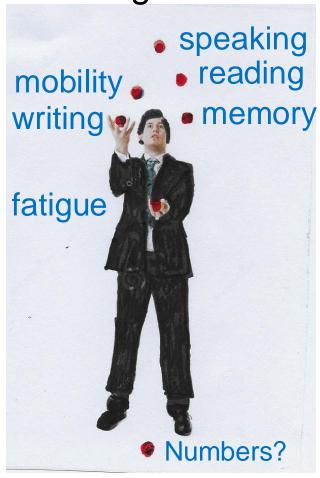
## When the words and numbers stopped making sense



## I needed help to overcome my problems with numeracy

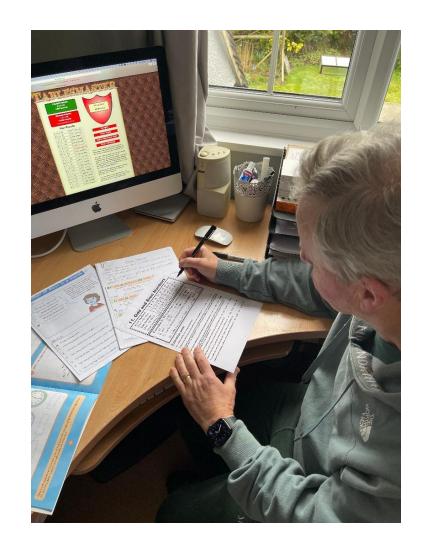
- Priority: re-learning speaking, reading, writing
- Could not teach for 2 years
- Support for numeracy very limited
- I needed help
- Problems with numbers were not routinely screened for
- Eventually regained enough speech and language to take the next step

Making choices



## I needed help to overcome my problems with numeracy

Developed my own strategies to re-learn number skills



### What did I do?

- Listed 'lost' numeracy skills
- Designed and wrote worksheets including:
  - techniques
  - information
  - exercises
  - Returned to maths teaching 2018 unaware of condition called acalculia.

## Sample worksheets

#### **Approximating Numbers**

Approximate means 'near enough'. It is a rough guide. Example:  $9 \times 98$  when calculated comes to 882 exactly. For 'easy numbers' we make the 98 into 100.

 $9 \times 100$  would give an Approximate Answer of 900.

Round Numbers give a 'near enough' answer by taking the number up or down to the nearest Power of ten.

To the nearest 10

432 would be → 430

To the nearest 100

167 would be → 200

To the nearest 1,000

3,400 would be  $\rightarrow$  3,000

A Number of <u>5 or more</u> Rounds Up; <u>4 or less</u> Rounds Down. Example: 25 would round up to 30 (nearest ten).

| Exercise 1 | Round these numbers to the: |               | Score |
|------------|-----------------------------|---------------|-------|
| Nearest 10 | Nearest 100                 | Nearest 1,000 |       |
| 1) 26      | 3) 348                      | 5) 2,500      |       |
| 2) 555     | 4) 177                      | 6) 6,366      |       |

9) 303 - 148 ≈ ...... 10) 605 ÷ 21 ≈ ......

(11) ROUPD THESE OFF TO THE NEAREST 10:

(a) 776 ... (b) 594 ... (c) 85 ... (o) 27...

(12) ROUTE THESE HUMBERS OFF TO THE WEAREST HUMBED:

(a) 3626 ... (b) 750 ... (c) 256 ... (0) 2951 ...

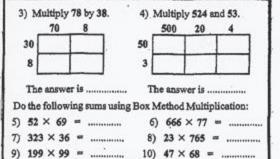
(13) WHAT IS AN APPROXIMATE ANSWER FOR 996 x 31? ...

(14) WHAT IS AN APPROXIMATE ANSWER FOR 807: 49?...

**Box Method Multiplication** 

Box Method Multiplication is another way of Multiplying. Example: Multiply 155 by 19. Step 1 Step 2 Multiply the numbers at the top Draw a box 3 squares by 2 squares (this is a 3 digit by 2 digit sum). Split and the numbers at the side and the numbers into their hundreds, tens put the answer in each box. and units along the top and down the 100 side. 155 = 100 + 50 + 5 1000 500 19 = 10 + 9450 900 1000 500 50 Step 3 900 Take the numbers from the box and write them 450 down, lining up the units on the right. Then 45 + Add up the numbers. 2945 The answer is 2945

| Multiply 342 and 21. |       | <ol><li>Multiply 39 by 15.</li></ol> |    |    |   |
|----------------------|-------|--------------------------------------|----|----|---|
| 3                    | 00 40 | 2                                    |    | 30 | 9 |
| 00                   |       |                                      | 10 |    |   |
| 1                    |       |                                      | 5  |    |   |



## **UK Stroke Assembly 2018**

- Met a stroke-survivor researcher
- Maths teacher before stroke, had aphasia, stroke did not affect her maths
- I thought my maths problems were related to language problems
- She promised to 'investigate'
- Emailed me on my birthday about 'acalculia'
- Changed my post-stroke life forever...

## What is acalculia? (pronounced EY-KAL-KOOL-EE-AH)

acquired disability, following stroke / brain injury

affects 30-65% of survivors

involves:

difficulty processing numbers and /or number words, performing mathematical calculations, understanding quantities

acalculia and aphasia can exist separately.

## Symptoms of acalculia to look out for:

- Anxiety and frustration around numeracy (and avoidance)
- Difficulty estimating
- Cannot count reliably
- Reliance on 'counting-on' strategies
- Writing number digits the wrong way round
- Inconsistent results in addition, subtraction, multiplication
   & division
- Difficulty reading clocks
- Sequencing issues
- Difficulty with times tables and mental arithmetic

## I became passionate about acalculia

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A OPEN ACCESS Check for updates

#### Worked with scientists in Manchester

16 stroke survivors with acalculia and carers.

#### The Publication

#### Co-author:

'A qualitative study into the experience of living with acalculia after stroke and other forms of acquired brain-injury' Neuropsychological Rehabilitation 2023

#### A qualitative study into the experience of living with acalculia after stroke and other forms of acquired brain

Yael Benn <sup>6</sup>, Mark Jayes <sup>6</sup>, Martin Casassus<sup>a,d</sup>, Marney Williams<sup>e</sup>, Colin Jenkinson<sup>e</sup>, Ellen McGowan<sup>f</sup> and Paul Conroy <sup>©9</sup>

<sup>a</sup>Department of Psychology, Manchester Metropolitan University, Manchester, UK; <sup>b</sup>Department of Health Professions, Manchester Metropolitan University, Manchester, UK; 4Honorary Research Fellow, School of Health and Related Research, University of Sheffield, Sheffield, UK: dUniversidad Autónoma de Chile, Providencia, Región Metropolitana, Chile; ePCPI (Patient, Carer & Public Involvement) contributor, UK; Pennine Care NHS Foundation Trust, Greater Manchester and Derbyshire, UK; <sup>9</sup>School of Health Sciences, University of Manchester, Manchester, UK

Acalculia, an acquired disability following a brain injury, involves difficulty processing numerical information and/or calculations. Acalculia is not routinely screened for, and as a result there is a lack of understanding about the nature and prevalence and the impact of the condition. This qualitative study was initiated by stroke survivors with a strong interest in acalculia. Sixteen stroke/brain injury survivors with acalculia and seven carers were interviewed using semi-structured online interviews. Participants ranged in age, gender, time post-onset, country of residence and numeracy level prior to brain injury. Data were analysed using thematic analysis. Three main themes were identified: Awareness and Diagnosis; Emotional and Practical Impact (independence); Support, Coping Strategies and Selftraining. Participants and carers repeatedly referred to the lack of awareness and treatment for acalculia and the impact acalculia has had on their lives and independence. Practical impacts included managing money, making appointments, using timetables, organizing social activities and employment, and managing medication. Our results highlight the urgent need to develop suitable assessments and interventions for acalculia and the scope for this to be Patient, Carer and Public involvement (PCPI)-led. The data also reveal useful strategies and suggestions regarding effective timing, targets and approaches for intervention.

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Acalculia; stroke; brain injury; aphasia; rehabilitation

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Substantial unmet clinical need for the management of acalculia

Acalculia is not routinely screened (after stroke)

The condition is under-diagnosed

The condition is inadequately treated

## Acalculia has a big impact on:

- everyday life
- telling and reading the time
- following recipes
- banking / using money
- shopping
- going places
- employment
- independence and wellbeing

- Profound emotional impact
- Frustration and embarrassment by everyday problems involving numbers.
- Feeling dependent on family / carers

Thinking that no-one can help them

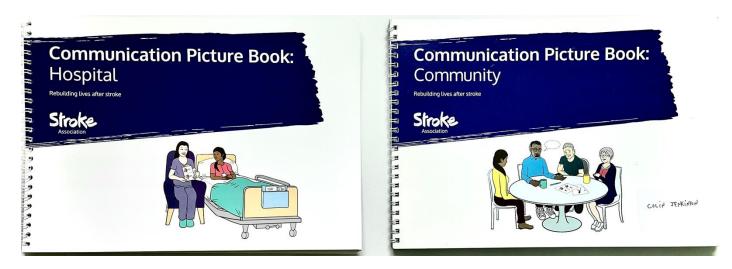
### **Urgent** need to:

- increase awareness of acalculia amongst stroke survivors and professionals
- develop suitable interventions for rehabilitation of numerical skills

## Making things better

UK Stroke Association projects

2 booklets supporting people with aphasia and acalculia in hospitals and community, plus 'aphasia friendly' booklets



With scientists in Manchester, plans for toolkit to help professionals assess numeracy level with their patients and carers.

## I would like to finish by saying...

No stroke survivor should be left without help for acalculia

There is life after stroke, we can help make things better for others

What is the next step?