



## World Stroke Organization Post-stroke spasticity survey

# Spasticity<sup>1,2</sup>

A stroke can damage how nerves control the muscles. This can lead to muscles becoming stiff, tightening up or resisting stretching. This is known as spasticity. With spasticity, muscles have increased tone (tension or contraction) and become very tight. Spasticity can cause a permanent shortening of the muscles, known as a contracture. About one in four survivors of stroke have spasticity.

Spasticity can cause chronic pain and severely impact stroke survivors' mobility and ability to carry out self-care activities. And without active intervention it can get worse, or trigger other, secondary, impacts such as ligament damage and pressure sores.

Although spasticity cannot be cured it can be treated through:

- physiotherapy exercises and stretches
- muscle braces, casts and splints
- injections of certain medications such botulinum toxin
- medications such as muscle relaxant



1. https://www.stroke.org/-/media/Stroke-Files/Support-Group-Resources/Spasticity-After-Stroke-Fact-Sheet.pdf

2. https://www.stroke.org.uk/stroke/effects/physical/spasticity-and-contractures

## Survey

In 2024, the World Stroke Organization (WSO) carried out a survey with people affected by post-stroke spasticity. The aims of this survey were to find out:

- what survivors of stroke and carers knew about post-stroke spasticity, and how they learned about it,
- what treatments stroke survivors with spasticity had and what the barriers were to accessing treatment,
- what levels of understanding or discrimination people with post-stroke spasticity experience.

Survivors of stroke and Stroke Support Organizations (SSOs) gave feedback on the survey design. The survey was shared by email, in the WSO newsletter, and through social media. The survey was available in English, Spanish, French, Romanian, Portuguese and Chinese.



## **Respondent demographics**

#### **Region and country**

#### Q: In which country do you live?

We received responses from 300 people from 41 countries. The region with the most respondents was Africa (62). The country with the most respondents was Canada (34).

Region	Respondents	%	Region	Respondents	%
Africa	62	21%	Europe	60	20%
Asia	37	12%	North America	54	18%
Australasia	36	12%	South America & the Caribbean	51	17%

#### Number of respondents by country



#### **Connection to stroke**

#### Q: I am

- A survivor of stroke living with spasticity
- A carer, friend or family member of a survivor of stroke living with spasticity

Seventy-four per cent (222/300) of respondents are survivors of stroke and 26% (78/300) are a carer, friend or family member.



#### Gender

#### Q: What is your gender?

Male: 137 Female: 160 Did not say: 3

Of the respondents who are survivors of stroke, 51% (114/222) are male, 48% (106/222) are female and 1% (2/222) did not say.

Of the respondents who are a carer, friend or family member, 29.5% (23/78) are male, 69% (54/78) are female and 1.5% (1/78) did not say.

#### Survivors of stroke respondents



#### Carer, friend or family member respondents



#### Age

#### Q: What is your age?

The majority of respondents were aged over 45. Two respondents did not say.



#### Time since stroke

## Q: When did you, your friend or family member experience a stroke? (the most recent if more than one stroke has been experienced)

The majority of respondents (61%, 183/300) had their stroke within the last five years.



#### Time since stroke

# Employment

#### Pre and post stroke status

## Q: What was your (if you experienced a stroke) or your friend's/family member's employment/education status before and after the stroke?

Eighty per cent (239/300) of respondents stated they were in employment or were selfemployed before their stroke. However, only 17% (40/239) of these respondents said they were employed or self-employed after their stroke. Of the respondents who only indicated they were employed (171/300), 19% (32/171) stated they were employed after their stroke. Of the respondents who only indicated they were self-employed before the stroke (45/300), 13% (6/45) said they were self-employed after the stroke. Of the respondents who stated they were both employed and self-employed (23/300) before the stroke, 9% (2/23) said they were employed or self-employed after the stroke.

There was a corresponding rise in those who stated they were unable to work or medically retired after the stroke, from 5%, (16/300) to 45% (135/300). There was no significant change in respondents who stated that they undertook unpaid care or looking after children or relatives before stroke (36/300) and after stroke (38/300). The number of respondents who stated that they were retired, increased from 11% (32/300) to 34% (103/300) after stroke. The number of respondents who stated that they volunteered increased from 11% (33/300) before stroke to 20% (60/300) after stroke.



#### **Respondent employment status**

#### Pre and post stroke employment status by gender

Forty-nine per cent (116/237) of respondents that said they were in employment or were selfemployed before their stroke, were male and 51% (121/237) were female. After their stroke, 18% (21/116) of males said they were in employment or were self- employed and 16% (19/121) of females.



#### Pre and post stroke employment status by age

Seventy-seven per cent (183/238) of respondents that said they were in employment or were self- employed before their stroke, were between the ages of 35 – 64 years. After their stroke, 17% (31/183) of respondents in this age range said they were in employment or were self-employed.

#### Employed before stroke (aged 35-64)

Employed after stroke (aged 35-64)



#### Pre and post stroke employment status by time since stroke

Sixty-two per cent (147/238) of respondents that said they were in employment or were selfemployed before the stroke had a stroke within the last five years. Twenty per cent (29/147) of these respondents said they were in employment or self-employed after the stroke. Thirty-eight percent (90/238) of respondents that said they were in employment or were selfemployed before the stroke had a stroke within 10 years or more. Twelve per cent (11/90) of these respondents said they were employed or self-employed after the stroke.



## Knowledge

Q: At the time of your or your friend's/family member's stroke, how much do you agree with the following statements?

#### I knew that spasticity is an effect of stroke

Fifty-three per cent (160/300) of people in our survey agreed, or strongly agreed, that at the time of their or their friend's/family member's stroke, they knew spasticity is an effect of stroke. Twenty-nine per cent (88/300) disagreed, or strongly disagreed.



### Q: Since the time of your or your friend's/family member's stroke how has your knowledge changed?

#### I know that spasticity is an effect of stroke

Since the time of their or their friend or family member's stroke, 78% (234/300) of respondents said their level of knowledge that spasticity is an effect of stroke had increased.



This pattern in regard to knowledge at the time of stroke and its increase since the stroke is consistent across the knowledge questions.

#### I knew how stroke can cause spasticity

Forty-eight per cent (144/300) of people in our survey agreed, or strongly agreed, that at the time of their or their friend's/family member's stroke, they knew how stroke can cause spasticity. Thirty-five percent (105/300) disagreed or strongly disagreed. Since the time of their or their friend or family member's stroke, 74% (221/300) of respondents said their level of knowledge that spasticity is an effect of stroke had increased.



#### I knew that spasticity can cause muscles to contract

Fifty-three percent (159/300) of people in our survey agreed, or strongly agreed, that at the time of their or their friend's/family member's stroke, they knew that spasticity can cause muscles to contract. Twenty-nine per cent (86/300) disagreed or strongly disagreed. Since the time of their or their friend or family member's stroke, 74% (222/300) of respondents said their level of knowledge that spasticity can cause muscles to contract had increased.

At time of stroke: disagreed or strongly disagreed At time of stroke: agreed or strongly agreed 53% 29% Post-stroke: Increased knowledge 74%



#### I knew that spasticity can cause muscles to spasm

Fifty-one per cent (152/300) of people in our survey agreed, or strongly agreed, that at the time of their or their friend's/family member's stroke, they knew that spasticity can cause muscles to spasm. Thirty per cent (90/300) disagreed or strongly disagreed. Since the time of their or their friend or family member's stroke, 72% (217/300) of respondents said their level of knowledge that spasticity can cause muscles to spasm had increased.



#### At time of stroke: disagreed or strongly disagreed



30%

#### I knew how spasticity could be treated

The pattern found in levels of knowledge about the effects of spasticity does not continue in relation to knowledge of treatment. Thirty per cent (90/300) of people in our survey agreed, or strongly agreed, that at the time of their or their friend's/family member's stroke, that they knew how spasticity could be treated. Forty per cent (120/300) disagreed or strongly disagreed.



#### Respondent knowledge of how spasticity can be treated

#### I know how spasticity could be treated

Since the time of their or their friend or family member's stroke, 60% (180/300) of respondents said their level of knowledge of how spasticity can be treated has increased. Twenty-six per cent (79/300) of respondents said this knowledge of treatment has stayed the same.



#### Increase in knowledge of how spasticity can be treated

# Information

### Q: At the time of your or your friend's/family member's stroke where did you find information about post-stroke spasticity?

The most common answer to the source of information for people in our survey was medical professionals – doctors and allied health professionals (40% of all answers, 261/654). Family, friends, other stroke survivors and stroke support organizations were also a significant source of information (35%, 226/654). Internet searches were a more common source of information (18%, 119/654) than printed materials (7%, 48/654).

#### Information source





#### Information source by region

Medical professionals were the most common source of information identified by people in our survey from Africa, Asia, Australasia and South America and the Caribbean. However, in Europe and North America, family, friends, other stroke survivors and stroke support organizations were the most common sources of information identified.

	Doctors and Allied Health Professionals	Family, friends, other stroke survivors and SSOs
Africa	<b>39%</b> (46/118)	36% (42/118)
Asia	<b>41%</b> (38/92)	36% (33/92)
Australasia	<b>49%</b> (32/69)	23% (16/69)
Europe	36% (50/137)	<b>39%</b> (53/137)
North America	34 % (39/114)	<b>39%</b> (45/114)
South America & the Caribbean	<b>39%</b> (44/113)	33% (37/113)

Internet searches were a more common source of information than printed materials in hospitals and clinics in all regions except Australasia.

	Printed materials in hospitals and clinics	Internet searches
Africa	6% (7/118)	<b>19%</b> (23/118)
Asia	4% (4/92)	<b>18%</b> (17/92)
Australasia	<b>14%</b> (10/69)	13% (9/69)
Europe	4% (6/137)	<b>20%</b> (28/137)
North America	11% (13/114)	<b>15%</b> (17/114)
South America & the Caribbean	6% (7/113)	<b>22%</b> (25/113)

When asked what other information resources would have been helpful, some respondents called for more exercise guides online, more regular follow-ups with stroke specialists, the use of plain language, and including carers and loved ones in information sharing.

"Webpages specific to spasticity being a 'stroke effect', more talk about it from doctors and hospitals, more physical resources" "Type of exercises, impact of exercises, benefit of exercises, how long to continue exercises, type of equipment that can be used at home, side effects of medication for spasticity"

"A more frank conversation with the health professionals immediately after the stroke would have helped me"



## Therapy, treatment and support

## Q: What spasticity therapy/treatment/support was available, and did it help you or your friend/family member?

The majority of people who responded to the questions about treatment, felt that their treatment was helpful.

#### Physiotherapy

Physiotherapy was the treatment that the most respondents commented on (162). Seventy- six per cent (123/162) of the people who commented on physiotherapy, said it was available and helpful. Seven per cent (11/162) said it was not available, but they would have liked it.



#### **Botulinum Toxin Type A**

Thirty per cent (42/138) of respondents who commented on Botulinum Toxin Type A said it was available and helpful. Fifteen per cent (20/138) said it was not available, but they would have liked it.



#### **Medication**

Medication was the treatment least commented on in the survey (119). Thirty-nine per cent (47/119) of respondents who commented said it was available and helpful. Eleven per cent (13/119) said it was not available, but they would have liked it.





#### Splinting and casting

Twenty-three per cent (29/123) of respondents who commented on splinting and casting said that it was available, and it helped them. Twelve per cent (15/123) said it was not available, but they would have liked it.



#### Contact with a support organization or group

Forty-seven per cent (72/154) of respondents who commented on stroke organizations or groups said they were available and helpful. Nineteen per cent (29/154) said this was not available, but they would have liked it to be.



# Therapy, treatment and support by region

#### Physiotherapy

Africa had the highest number of respondents that commented on physiotherapy and North America had the lowest. In each of the regions, the majority of people (60% or more) that commented on physiotherapy said it was available, and it helped.

	Yes, and this helped	Yes, but it did not help me	No, but I would have liked this
Africa	79% (34/43)	12% (5/43)	7% (3/43)
Asia	78% (18/23)	17% (4/23)	4% (1/23)
Australasia	68% (15/22)	23% (5/22)	5% (1/22)
Europe	79% (31/39)	8% (3/39)	5% (2/39)
North America	60% (9/15)	20% (3/15)	13% (2/15)
South America & Caribbean	80% (16/20)	5% (1/20)	10% (2/20)



#### **Botulinum Toxin Type A**

North America had the highest number of respondents that commented on Botulinum Toxin Type A and Australasia the lowest number. Less than half of respondents in all regions that answered this question said it was available, and it helped.

	Yes, and this helped	Yes, but it did not help me	No, but I would have liked this
Africa	22% (6/27)	4% (1/27)	19% (5/27)
Asia	26% (5/19)	11% (2/19)	11% (2/19)
Australasia	24% (4/17)	12% (2/17)	6% (1/17)
Europe	28% (7/25)	16% (4/25)	16% (4/25)
North America	38% (11/29)	17% (5/29)	14% (4/29)
South America & Caribbean	43% (9/21)	24% (5/21)	19% (4/21)

#### **Medication**

Africa had the highest number of respondents that commented on medication. Africa was the only region where more than half (58%) of the respondents who commented on medication said it was available, and it helped. Over a third of respondents in Australasia said medication was available, but did not help. Over a quarter (27%) of respondents in Asia said medication was not available and they would have liked this.

	Yes, and this helped	Yes, but it did not help me	No, but I would have liked this
Africa	58% (18/31)	16% (5/31)	6% (2/31)
Asia	33% (5/15)	7% (1/15)	27% (4/15)
Australasia	24% (4/17)	35% (6/17)	12% (2/17)
Europe	39% (7/18)	22% (4/18)	11% (2/18)
North America	26% (6/23)	9% (2/23)	9% (2/23)
South America & Caribbean	47% (7/15)	7% (1/15)	7% (1/15)

#### **Splints and casts**

Africa had the highest number of respondents that commented on splints and casts. In all regions except Europe (4%), more than a fifth of respondents said splints and casts were available, and this helped, with nearly a third in North America responding in this way. Nearly a quarter (23%) of respondents from Africa said splints and casting were not available, but they would have liked this.

	Yes, and this helped	Yes, but it did not help me	No, but I would have liked this
Africa	31% (8/26)	3% (1/26)	23% (6/26)
Asia	21% (4/19)	26% (5/19)	16% (3/19)
Australasia	29% (5/17)	0% (0/17)	12% (2/17)
Europe	4% (1/25)	36% (9/25)	12% (3/25)
North America	32% (8/25)	24% (6/25)	0% (0/25)
South America & Caribbean	27% (3/11)	9% (1/11)	9% (1/11)

#### Support organizations or groups

Again, Africa had the highest number of respondents that commented on support organizations or groups. In all regions, more than a quarter of people who responded said support organizations or groups were available, and they helped, the highest was in South America and the Caribbean with almost two thirds (65%). In Australasia, over a third of respondents (38%) said support organizations or groups were not available, but they would have liked this.

	Yes, and this helped	Yes, but it did not help me	No, but I would have liked this
Africa	58% (19/33)	6% (2/33)	15% (5/33)
Asia	48% (10/21)	14% (3/21)	5% (1/21)
Australasia	29% (7/24)	13% (3/24)	38% (9/24)
Europe	29% (7/24)	8% (2/24)	20% (5/24)
North America	46 (12/26)	15% (4/26)	19% (5/26)
South America & Caribbean	65% (17/26)	4% (1/26)	15% (4/26)

## Access to treatment

Q: Please state how much you agree with the following statements:

- Treatment could not be accessed because of a lack of information about where to go
- Treatment could not be accessed because no transport was available
- Treatment could not be accessed because of a lack of money to pay for it
- Treatment could not be accessed because services were not available near by

Just over a half of respondents who answered this question agreed or strongly agreed that treatment could not be accessed because of a lack of information about where to go (52%, 153/294), because of a lack of money to pay for it (51%, 146/289) or because services were not available nearby (51%, 149/292). Just over a third (34%, 97/285) of respondents who answered this question said treatment could not be accessed because no transport was available.



#### Barriers to access to treatment

#### Access to treatment by region

The majority of respondents who answered this question in Africa (65%), Asia (65%) and Europe (53%) strongly agreed or agreed that treatment could not be accessed because of a lack of information about where to go. This was almost half in Australasia (46%) and North America (47%). Over a third of respondents in Africa (44%), Asia (41%) and Europe (38%) strongly agreed or agreed that treatment could not be accessed because of transport, and this was almost a third in North America (32%). Africa (70%) had the highest number of respondents that strongly agreed or agreed that a lack of money impacted on access to treatment. This was over half in Asia (52%) and over or almost a third in all other regions. The majority of respondents in Africa (62%), Asia (60%) and Europe (58%) strongly agreed or agreed that treatment could not be accessed because of a lack of money impacted or agreed that treatment could not be accessed because of respondents in Africa (62%), Asia (60%) and Europe (58%) strongly agreed or agreed that treatment could not be accessed because services were not available nearby. This was also over a third in the three other regions.

Strongly agree and agree				
	Lack of information	No transport	Lack of money	Not available near by
Africa	65% (39/60)	44% (26/59)	70% (42/60)	62% (37/60)
Asia	65% (24/37)	41% (14/34)	52% (17/33)	60% (21/35)
Australasia	46% (16/35)	29% (10/35)	32% (11/34)	34% (12/35)
Europe	53% (31/59)	38% (22/58)	48% (29/60)	58% (35/60)
North America	47% (25/53)	32% (16/50)	44% (23/52)	40% (21/53)
South America & Caribbean	36% (18/50)	19% (9/48)	48% (24/50)	47% (23/49)



# Friends, family and community response

#### Understanding

Q: How much do you agree with the following statements?

- There is a lack of understanding about the cause of spasticity among my friends and family
- There is a lack of understanding about the cause of spasticity from employers and in the workplace
- There is a lack of understanding about the cause of spasticity in the general population

Eighty-one per cent (237/294) of respondents who answered strongly agreed or agreed that there is a lack of understanding about the cause of spasticity among their friends and family. Sixty-seven per cent (195/289) of respondents who answered strongly agreed or agreed that there is a lack of understanding about the cause of spasticity from employers and in the workplace. Eighty-four per cent (245/292) of respondents who answered strongly agreed or agreed or agreed that there is a lack of understanding about the cause of spasticity from employers and in the workplace. Eighty-four per cent (245/292) of respondents who answered strongly agreed or agreed that there is a lack of understanding about the cause of spasticity in the general population.



#### Understanding about the cause of spasticity

#### Understanding by region

In all regions, over three quarters of respondents strongly agreed or agreed that there is a lack of understanding about the cause of spasticity among their friends and family, with the highest number in Europe (83%, 50/60). The majority of respondents from Africa, Asia, Europe and South America and the Caribbean strongly agreed or agreed that there is a lack of understanding about the cause of spasticity from employers and in the workplace. This was nearer to half in Australasia and North America. In these two regions, a significant number of respondents said they neither agreed nor disagreed or were unsure whether there is a lack of understanding about the cause of spasticity from employers and in the workplace (51% in North America and 46% in Australasia). In all regions, over three quarters of respondents strongly agreed or agreed that there is a lack of understanding about the there is a lack of understanding about the cause of spasticity from employers and in the workplace (51% in North America and 46% in Australasia). In all regions, over three quarters of respondents strongly agreed or agreed that there is a lack of understanding about the cause of spasticity in the general population, with the highest number in Asia (89%).

Strongly agree and agree				
	Lack of under- standing among my friends and family Lack of understand- ing among employers and in the workplace		Lack of under- standing in the general population	
Africa	80% (48/60)	77% (44/57)	82% (49/60)	
Asia	81% (29/36)	69% (24/35)	89% (32/36)	
Australasia	80% (28/35)	51% (18/35)	80% (28/35)	
Europe	83% (50/60)	80% (47/59)	87% (52/60)	
North America	77% (40/52)	47% (25/53)	79% (41/52)	
South America & Caribbean	82% (42/51)	74% (37/50)	88% (43/49)	

#### Discrimination

Q: How much do you agree with the following statements?

- People with spasticity experience discrimination from employers and in the workplace
- People with spasticity experience discrimination from the general population

Forty-five percent (130/291) of respondents who answered this question strongly agreed or agreed that people with spasticity experience discrimination from employers and in the workplace. Almost a quarter (71/291) of respondents neither agreed nor disagreed and one fifth (60/291) were unsure. Fifty-eight per cent (170/291) of respondents who answered this question strongly agreed or agreed that people with spasticity experience discrimination from the general population. A little over a fifth (65/292) of respondents neither agreed nor disagreed.



#### **Experience of discrimination**

#### **Discrimination by region**

Half or more of respondents in Africa (58%) and Europe (50%) strongly agreed or agreed that people with spasticity experience discrimination from employers and in the workplace. While this was less than half in the other regions, a significant number of respondents across all regions said they neither agreed nor disagreed or were unsure that people with spasticity experience discrimination from employers and in the workplace. This was as high as 66% in North America. The majority of respondents from Africa, Australasia, Europe and South America and the Caribbean said they strongly agreed or agreed that people with spasticity experience discrimination from the general population. In North America more people said they neither agreed or were unsure (50%, 26/52) than said they strongly agreed or agreed.

	People with spasticity experience discrimination from employers and in the workplace		People with spasticity experience discrimination from the general population	
	Strongly agree / Agree	Neither agree or disagree / not sure	Strongly agree / Agree	Neither agree or disagree / not sure
Africa	58% (33/57)	26% (15/57)	72% (43/60)	22% 13/60)
Asia	39% (14/36)	56% (20/36)	49% (17/35)	43% (15/35)
Australasia	46% (16/35)	51% (18/35)	63% (22/35)	29% (10/35)
Europe	50% (30/60)	38% (23/60)	67% (40/60)	27% (16/60)
North America	26% (14/53)	66% (35/53)	40% (21/52)	50% (26/52)
South America & Caribbean	46% (23/50)	40% (20/50)	54% (27/50)	30% (15/50)



## Conclusion

While the number of respondents in this survey is relatively small, it does give some insight into respondents' knowledge of spasticity, source of information, availability and access to treatment, and what levels of understanding or discrimination people with post-stroke spasticity experience.

The survey found that knowledge of spasticity and its effects increased with experience of stroke. While knowledge of treatment also increased, the increase was not as high as with other areas of knowledge.

The most common source of information for people in our survey was medical professionals. However, family, friends, other stroke survivors and support organizations were also a significant source of information. Internet searches were a more common source of information than printed materials.

The survey found a major negative impact on employment among the respondents. Only 17% (40/239) of respondents who said they were employed or self-employed before their stroke said they were after their stroke.

In some regions, the majority of respondents said treatment could not be accessed because of a lack of information about where to go, a lack of transport, a lack of money and services were not available nearby. These were also barriers for significant numbers for people across all regions. Considering that many people with spasticity experience chronic pain due to their condition, addressing these barriers is vital in ensuring quality of life after stroke.

Respondents in all regions reported high levels of ignorance and discrimination about spasticity among their friends and family, employers and the general population. The stigma attached to the types of disability caused by post-stroke spasticity needs to be challenged.

The role of doctors and allied health professionals in providing information and increasing understanding of spasticity is demonstrated in the survey. Regular follow ups with medical professionals are essential to ensure good levels of treatment. The need for signposting to information, engagement with employers and raising public awareness are also indicated in this survey. The role of other stroke survivors and SSOs is also shown to be an important and beneficial source of support in this survey. With the decline in importance of printed information materials, there is a priority to ensure that there are accurate and helpful resources of information and advice available on the internet.

#### Areas for WSO action are:

- To continue to highlight the work of SSOs in supporting people to manage the effects of stroke, including spasticity.
- To identify the best sites, videos and other resources with evidence-based information and guidance.
- To reduce the stigma associated with post-stroke spasticity by sharing individual and community success stories.

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