



**World Stroke  
Organization**

Stroke Association Support Network Ghana



2020

**Global Stroke Bill of Rights Toolkit**



# Background

Stroke is a leading cause of death in developed and developing countries and a major cause of disability. There are over 13.7 million new strokes each year. Globally, one in four people over age 25 will have a stroke in their lifetime. There are over 80 million people currently living who have experienced a stroke globally. Five and a half-million people die of stroke annually.



Acha Memorial Foundation Nigeria

## Behind these numbers are real lives

Despite these shocking statistics, many people affected by stroke are unable to access the treatments, rehabilitation and support that would provide them with the greatest chance of a good recovery and a healthier, more productive and independent life.

The Global Stroke Bill of Rights is an important priority for the World Stroke Organization. These rights identify the aspects of care that are important for ALL stroke survivors and caregivers from across the world.

It is a tool that can be used by individuals and organizations to communicate with stroke care providers and with governments and their agencies about what people affected by stroke think are the most important things in their recovery. Many aspects of care considered important by those affected by stroke, and included in this document, have been shown to reduce death and disability after stroke.

The Global Stroke Bill of Rights is not a legal document. It is a guide to the elements of stroke care, that are important to stroke survivors and care givers to drive the

best possible outcomes and experiences associated with stroke.

The Global Stroke Bill of Rights was developed by a group of stroke survivors and caregivers from each region of the world. They were supported by a larger group of survivors and caregivers and by thousands more from different countries, cultures and languages who completed surveys to understand if there are any differences in different parts of the world. Their responses demonstrated that what is considered to be important in stroke recovery is consistent regardless of where people affected by stroke live.

The issues identified through this process are outlined in the Global Stroke Bill of Rights, listed according to the importance survivors and caregivers placed on them.

We have created this toolkit to help individuals and organizations best use the Global Stroke Bill of Rights to help improve access to care for people affected by stroke, better diagnosis and treatment of stroke which ultimately leading to improvements in stroke care and support across the globe.



# About the Toolkit

This toolkit is designed to help stroke and patient organizations share and use the Global Stroke Bill of Rights. Our goal is to inform all stroke survivors and caregivers of their rights.



## Frequently Asked Questions



### 1. Who has the Global Stroke Bill of Rights been developed for?

The Global Stroke Bill of Rights was developed for use by survivors, caregivers, stroke organizations, patient advocacy groups, health professionals or anyone who is interested in working to improve stroke prevention awareness, care and support in all parts of the world. It is a tool that can guide, and support advocacy for, the best stroke prevention awareness, care and support for stroke survivors and caregivers and the public.

### 2. Who developed the Stroke Bill of Rights?

The Global Stroke Bill of Rights was developed by a group of stroke survivors and caregivers from each region of the world. They were supported by a larger group of survivors and caregivers and by thousands more from different countries, cultures and languages who completed surveys to understand if there are any differences in different parts of the world. Their responses demonstrated that what is considered to be important in stroke recovery is consistent regardless of where people affected by stroke live.

The development of the Global Stroke Bill of Rights was supported by World Stroke Organization as part of its commitment to improving stroke care around the world.

### 3. Why was the Global Stroke Bill of Rights developed?

The Global Stroke Bill of Rights was developed to document aspects of stroke care that are important to people affected by stroke and their caregivers. It was designed to ensure that planning on stroke care improvements considers the evidence for particular approaches, but also takes into account the aspects of care that have the greatest impact on those who are affected by stroke, survivors as well as those who care for them. It was developed based on aspects of stroke care and support that have been shown to improve stroke outcomes and that directly may affect recovery and the rehabilitation experience.

### 4. What is the role of the World Stroke Organization in taking the Global Stroke Bill of Rights forward?

The World Stroke Organization will encourage its members to use the Global Stroke Bill of Rights within their countries. The WSO will distribute the Global Stroke Bill of Rights through media channels, its networks and the WSO website. The WSO will also use the Global Stroke Bill of Rights in considering priorities for its own work, and in the work it does advocating for change in international forums.

## 5. Who has responsibility for using the Global Stroke Bill of Rights?

We all have responsibility for using the Global Stroke Bill of Rights. Individuals and organizations can use it to elevate the key components of each aspect of stroke care and reinforce to stroke care providers and governments the importance of ensuring that stroke survivors throughout the world are able to access the treatment, information and support they need and from which they benefit.

## 6. What can I do if I do not get the care outlined in the Global Stroke Bill of Rights?

Each country will have its own way of improving stroke care. In many instances this will start with a conversation between the hospital or individual providing care. This document can be used in these conversations. If you have a local stroke support organization or patient advocacy organization, they may also be able to help. The WSO has a list of stroke support organizations on its website.

## 7. Is this a legal document?

The Global Stroke Bill of Rights is not a legal document and cannot be used to mandate that care has to be delivered, or delivered in a particular way. It is a document where stroke survivors and caregivers have outlined the aspects of care they think are important in their recovery after stroke. The rights that survivors and caregivers have identified are consistent with basic human rights that are overseen by international law.

## 8. Can this document be modified?

In some parts of the world, organizations may modify the global document or develop a local Stroke Bill of Rights. If an organisation develops a local Stroke Bill of Rights to suit their local needs, we encourage them to ensure it is developed by stroke survivors and caregivers. If the local Stroke Bill of Rights draws on the Global Stroke Bill of Rights, the original document should be referenced as follows: *This document is based on the World Stroke Organization Global Stroke Bill of Rights, released 22 October, 2014.*

If an organisation uses the Global Stroke Bill of Rights and wants to add local brands to it, this is possible to do by inserting the local brand on the bottom right hand corner of the document.

## 9. Is there evidence that the things in the Global Stroke Bill of Rights make a difference?

Many of things that stroke survivors and caregivers have identified as important have been shown through research, to reduce the burden of stroke by reducing death and disability. For example, a rapid diagnosis may increase the likelihood of patients receiving clot busting drugs such as thrombolysis and there is good evidence that care on a stroke unit, by a specialised team, increases chances of survival and independence. Many of the aspects of care outlined in the Global Stroke Bill of Rights are also recommended in the World Stroke Organization Global Stroke Guidelines and Roadmap to Quality Stroke Care available on the WSO website.

## 10. Is the Global Stroke Bill of Rights supported by any intergovernmental organizations?

The issues raised in the Global Stroke Bill of Rights are aligned with the World Health Organization Global Action Plan for Prevention and Control of Non-Communicable Diseases 2013-2020, the United Nations Sustainable Development Goals, as well as the United Nations Resolutions on Prevention and Control of Non-Communicable Diseases issued 2011 and 2014. Stroke belongs to the prioritized non-communicable diseases, which also include heart disease, cancer, diabetes, pulmonary disease, and many neurological diseases. Member states have made commitments to implement these documents in their countries. Many of the rights outlined are consistent with the principles of the above documents, in particular those relating to a human rights approach, an equity-based approach, empowerment of people and communities and evidence based strategies.



## Key Messages



Stroke survivors have the right to receive the best care, be informed and prepared, and be supported throughout their recovery.



The Global Stroke Bill of Rights can be used by survivors, their caregivers, and others to advocate for the best care and support possible.



Stroke is a leading cause of death and a major cause of disability in all countries around the world.



# For Organizations

## 1. Engage Volunteers, Staff, Partners and Stakeholders

- **Partner with Stroke Support Organizations**
  - + Ask stroke support organization leaders to raise awareness of the Global Stroke Bill of Rights among their members.
  - + Suggest that organizations use the Global Stroke Bill of Rights as part of their communications on World Stroke Day.
  - + Ask organizations to gather stories from their members about how their rights have or have not been protected and use these stories to highlight the importance of the Global Stroke Bill of Rights with decision makers.
- **Host a Stroke Training Workshop**
  - + Provide stroke education for key professionals such as stroke coordinators, nurses, rehabilitation health professionals and more. You can share the Global Stroke Bill of Rights during this workshop and develop action plans for how they can take action in their own work to protect rights and also take action to influence decision makers.
- **Partner with Public Service**
  - + Partner with public service entities and other organizations such as emergency medical services organizations, consumer advocacy groups, local high schools, etc. to distribute materials throughout your community.
- **Get all your staff to be champions for the Global Stroke Bill of Rights**
  - + Ensure your employees know all about what it is, why it was developed and where to find it if they are asked about it.
  - + Include in internal newsletters and updates.
  - + Encourage senior staff to champion the Global Stroke Bill of Rights.
  - + Add a tag to employees email signatures promoting the Global Stroke Bill of Rights.





## 2. Engage Community Leaders

- **Ask Your Public and Government Leadership to Issue a World Stroke Day Proclamation**
  - + Invite your elected officials to proclaim October 29th as World Stroke Day.
  - + Encourage all community members to share the Global Stroke Bill of Rights, make it easy for them to get a copy of the document by providing links.
- **Ask Community Leaders to Spread the Word about Stroke**
  - + Churches, community centers, even local beauty salons and barbershops can be effective venues for reaching out to your community.
  - + Contact ministers, community leaders and local civic leaders and encourage them to conduct stroke outreach to their members.
  - + Provide community leaders with educational materials and information on stroke to make it easy for them to partner with you. Download free materials at website link.
- **Connect with Local Hospitals**
  - + Encourage them to promote stroke awareness activities for their employees and at community events. Ask them to create stroke displays on World Stroke Day.

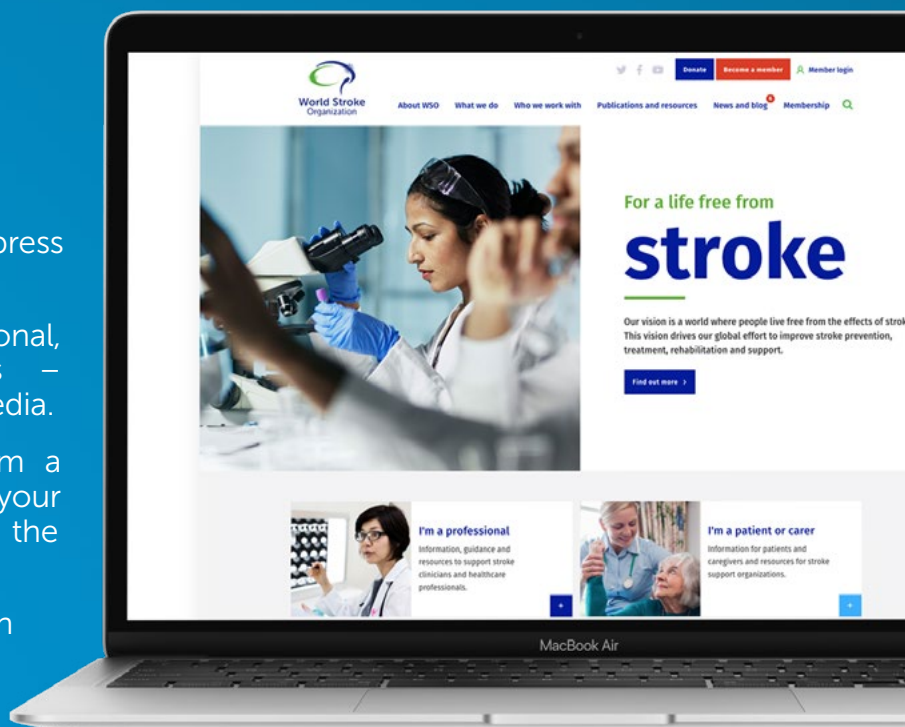
## 3. Take Your Message to the Community

- **Share the Global Stroke Bill of Rights**
  - + Include the Global Stroke Bill of Rights infographic in your social media channels, website, and email communication.
  - + Email the Global Stroke Bill of Rights to stroke survivors.
  - + Email campaign to health professionals with a call to action "Tell your patients about the Global Stroke Bill of rights".
  - + Put it up on the wall in the lunch-room and the foyer and other places visitors will see it.
  - + Link it to prevention messages (e.g. Signs of stroke messages like FAST).



- **Use the Media**

- + Host a press conference/press event.
- + Media releases – target national, regional and local outlets – medical/health and general media.
- + Consider an oped piece from a prominent stroke survivor that your media advisors could place in the press or online.
- + Highlight stroke survivors in local stories around the Global Stroke Bill of Rights.



- **Coordinate with Health Education Programs and Healthcare Systems**

- + Your community healthcare systems may have health education programs. Provide these programs with brochures and informative items to include in their education packages. Be sure to include information about where to go for more information, website link.
- + Include the Global Stroke Bill of Rights in relevant kits provided to stroke survivors in hospitals or sent from your organization.

- **Work with Health Advocates and Educators**

- + Coordinate with your local health care providers and other health-focused groups to have booths, educational sessions, and presentations on stroke.
- + Invite your mayor or other officials to your event to issue a proclamation, discuss the Global Stroke Bill of Rights and conduct a press event.

- **Find high profile stroke survivors who can be advocates for you and for the Global Stroke Bill of Rights**

- **Spread the message with digital and social media**

- + Post onto social media – Facebook and Twitter, retweet and repost WSO materials and those from other organizations. Even if you develop your own messages always use the #strokeBOR.
- + Include on LinkedIn if your organization has a profile there.
- + Feature the Global Stroke Bill of Rights, and how it can support those affected by stroke on your website and in newsletters to members.



# For Individuals

## 1. Advocate for the best care

- + Share the Global Stroke Bill of Rights with your friends and family. Ask them to be your advocate as needed in the securing your rights.
- + Discuss the Global Stroke Bill of Rights with your doctor and other health professionals and discuss how you might ensure you may get the best care.
- + Use the Global Stroke Bill of Rights when you talk to your local government representative
- + Discuss at stroke group meetings or other forums you may attend.

## 2. Drive community awareness

- + Share this with your community leaders to drive awareness of the rights of stroke survivors. Ask them to put up posters
- + Personalize the Global Stroke Bill of Rights using your story and see if you can get your local paper interested in a writing a story. Use photos of survivors in your stories and newsletter articles
- + Use the Global Stroke Bill of Rights promotion materials on your Facebook page throughout October to help spread the word

# The Global Stroke Bill of Rights and relationship to the core United Nations Human Rights instruments

We believe that a person anywhere in the world who has had a stroke has the right to:	Relevant international human rights law
A rapid diagnosis so he/she can be treated quickly.	<p>Article 12.1 and 12.2(d) International Covenant on Economic Social and Cultural Rights (ICESCR) 1966, Committee on Economic Social and Cultural Rights (CESCR) General Comment No 14 (2000); Article 24 Convention on the Rights of the Child.</p> <p>*NB, The obligations of the ICESCR are subject to the limitation of Article 2(1) which provides that each state part to the treaty “undertakes to take steps, to the maximum of its available resources, with a view to achieving progressively the full realisation of the rights recognised in the present Convent and by all appropriate means, including particularly the adoption of legislative measures.”</p>
Receive treatment by a specialist team at all stages of his/her journey (in hospital and during rehabilitation).	Article 12 ICESCR, CESCR General Comment No 14 (2000); Article 24 Convention on the Rights of the Child
Be fully informed about what has happened to him/her and about living with stroke for as long as he/she requires it.	<p><i>“Health information is a determinant of the right to the highest attainable standard of health (Article 12.1 ICESCR) and access to such information is protected by the right to exchange and impart information (Article 19.2 International Covenant on Civil and Political Rights (ICCPR))”</i></p> <p>Article 21 – Freedom of expression and opinion and access to information Convention on the rights of persons with disabilities.</p>
Receive care that is well coordinated	Article 12.1 ICESCR, CESCR General Comment No 14 (2000), Article 24 Convention on the Rights of the Child.
Be provided with hope for the best possible recovery he/she can make now and into the future.	
Access treatment regardless of financial situation, gender, culture or place that he/she lives.	Article 5(iv) International Convention on the Elimination of All Forms of Racial Discrimination (ICERD); Article 2(2) ICESCSR; General comment 14; Article 3 ICESCR; Article 12(1) of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW); Article 24 Convention on the Rights of the Child.

<sup>4</sup> The table lists state obligations under international treaty law that relates to the varying elements of the stroke survivors’ rights statement. In addition, the United Nations Universal Declaration of Human Rights 1948 (a non-legally binding document) states “Everyone has the right to a standards of living adequate for the health and well-being of himself and of his family, including food clothing, housing and medical care and necessary social services” and emphasizes the interrelated, indivisible and interdependent nature of the right to health with other rights and freedoms.



<p>Be informed about the signs of stroke so he/she can recognise one if he/she is having one.</p>	<p>"Health information is a determinant of the right to the highest attainable standard of health (Article 12.1 ICESCR) and access to such information is protected by the right to exchange and impart information (Article 19.2 International Covenant on Civil and Political Rights (ICCPR)"</p> <p>Article 21 Convention on the Rights of Persons with Disabilities</p>
<p>Treatment that is right for him/her as an individual considering his/her age, gender, culture, goals and my changing needs over time.</p>	<p>Article 12 ICESCR, CESCR General Comment No 14 (2000); Article 24 Convention on the Rights of the Child.</p> <p>*See above re limitation to available state resources.</p> <p>Article 5(iv) International Convention on the Elimination of All Forms of Racial Discrimination (ICERD); Article 2(2) ICESCR; General comment 14; Article 3 ICESCR; Article 12(1) of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)</p>
<p>Psychological and emotional support in a form that best meets his/her needs.</p>	<p>Article 12.1 ICESCR, CESCR General Comment No 14 (2000), Article 24 Convention on the Rights of the Child.</p>
<p>Be included in all aspects of society regardless of any disability he/she may have.</p>	<p>Article 2 ICESCR; Article 29 and 30 Convention on the Rights of Persons with Disabilities</p>
<p>Support (financial or otherwise) to ensure he/she is cared for in the longer term.</p>	<p>Article 9 ICESCR (right to social security); Article 11 (right to adequate standard of living), Article 12.1 ICESCR, CESCR General Comment No 14 (2000)</p>
<p>Be supported to return to work and/or to other activities he/she may choose to participate in after his/her stroke.</p>	<p>ICESCR Part III Article 6 (1)(2); Article 27 Convention on the Rights of Persons with Disabilities.</p>
<p>Access to formal and informal advocacy to assist me with access to the services he/she needs</p>	<p>Article 12.1 ICESCR, CESCR General Comment No 14 (2000); Article 26 Convention on the Rights of Persons with Disabilities.</p>
<p>Be connected to other stroke survivors so he/she may gain and provide support in his/her recovery from stroke.</p>	<p>Article 26 Convention on the Rights of Persons with Disabilities.</p>



**World Stroke  
Organization**

World Stroke Organization  
7, rue Francois Versonnex  
PO Box 6053  
CH 1211 Geneva 6, Switzerland  
[www.world-stroke.org](http://www.world-stroke.org)