Acting on stroke and noncommunicable diseases

Preventing and responding to stroke to work towards Universal Health Coverage 2022



NCD Alliance

Acknowledgments

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Introduction

Prevention and control of noncommunicable diseases

Noncommunicable diseases (NCDs) are widely recognised as a major challenge to health and sustainable development in the 21st century.

They are the leading cause of death and disability worldwide, responsible for 74% of global mortality, taking 41 million lives every year¹. This exerts a heavy and growing burden on all societies, economies and health systems, with annual deaths from NCDs projected to escalate to 52 million by 2030. While this burden is worldwide, it is disproportionate, with 77% of all NCD deaths occurring in low- and middle-income countries (LMICs).



The global NCD response primarily focuses on five disease areas – cardiovascular diseases (CVD), cancers, diabetes, chronic respiratory diseases and mental and neurological conditions – that are linked to five modifiable risk factors – tobacco use, unhealthy diet, physical inactivity, harmful use of alcohol and air pollution².

Stroke is the second leading global cause of death, with 6.6 million deaths from stroke annually, and the third leading global cause of death and disability combined, with over 143 million healthy life years lost each year across the world's population. Currently, there are over 101 million people worldwide who have survived a stroke³. Given the scale of this problem, stroke can potentially affect everyone either directly or indirectly, as caregivers or family members. This is an avoidable tragedy, as stroke is not only largely preventable but identification of its symptoms and fast access to treatment can reduce mortality and improve outcomes.

Stroke is classified as a neurological disorder

In the most recent revision of the <u>International Classification of Diseases and Related Health Problems (ICD-11)</u>, stroke has officially been reclassified from a circulatory system disease to a disease of the nervous system. Cerebrovascular diseases now form a block within 'Diseases of the nervous system' and each disease item has a definition. The classification change provides increased clarity in recognizing stroke as a separate entity in the statistics. It will help advocacy to support global efforts to increase stroke awareness and improve access to stroke services and treatments. Of note, the move in the ICD-11 does not affect the separate definition of stroke as a "Cardiovascular Disease" – stroke continues to be a cardiovascular disease.

The Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders 2022-2031 was approved at the 75th session of the World Health Assembly in 2022, a landmark document addressing brain health, prevention of neurological diseases and improvement of neurological services at a global scale. The action plan has the potential to improve public health outcomes for a vast array of conditions of the central and peripheral nervous system connected to the brain, including stroke.

This policy brief focuses on stroke as a major contributor to the increasing burden of NCDs in society and the urgent need to implement effective, affordable, and widely applicable strategies to prevent and treat stroke before, during and after its occurrence. It also provides key recommendations for healthcare providers, policymakers and civil society on advocacy and implementation to improve the response to stroke and NCDs. These recommendations are based on a comprehensive approach as part of working towards Universal Health Coverage (UHC).



² NCD Alliance. Why NCDs. Accessed at: https://ncdalliance.org/why-ncds/NCDs

Valery Feigin et al. World Stroke Organization (WSO): Global Stroke Fact Sheet 2022. International Journal of Stroke. 2022. Accessed at: https://www.world-stroke.org/news-and-blog/news/wso-global-stroke-fact-sheet-2022

What is stroke?

Stroke is an NCD that occurs when the blood supply to the brain is disrupted, causing oxygen starvation, brain damage, and loss of function.

It is most frequently caused by a clot in an artery supplying blood to the brain, known as ischemia (ischemic stroke). It can also be caused by a haemorrhage (haemorrhagic stroke), which occurs when a blood vessel in the brain bursts and blood leaks into the brain⁴. Strokes can result in lasting damage, including partial or complete paralysis, difficulties with speech, comprehension, and memory/cognition. The extent and location of the damage determines the severity of the stroke, which can range from minimal to catastrophic.



Stroke is highly preventable and treatable

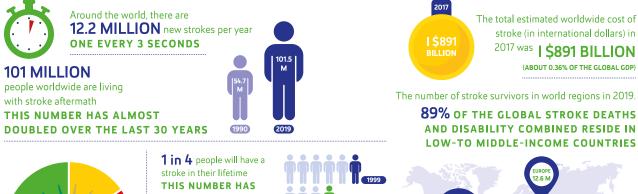
90% of strokes, as well as other NCDs, are linked to 10 modifiable risk factors that include hypertension, tobacco and alcohol consumption, physical inactivity, unhealthy diet and air pollution. Exposure to common risk factors may be augmented by rapid urbanisation, leading to low levels of physical activity and poor ambient air quality. By addressing these risk factors at an early stage through simple lifestyle changes, the majority of stroke cases can be prevented.

Every US\$1 spent on prevention of stroke and cardiovascular disease yields a return on investment of over US\$10. Overall, financing for NCD prevention and detection remains distressingly low, despite robust data demonstrating the economic benefit of investing in NCD prevention and treatment. Stroke and other NCDs lack adequate, predictable and sustained resources within health systems, and siloed priority-setting at macro- and micro-organisational levels can lead to ineffective use of available public and private health resources.

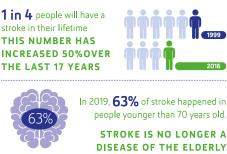
 $Source: World Stroke Organization. Stroke Advocacy Brochure. 2022. Accessed at: \underline{https://www.world-stroke.org/assets/downloads/WSO_advocacy_brochure_online_4.pdf}$

⁴ World Stroke Organization. Stroke Advocacy Brochure. Accessed at: https://www.world-stroke.org/assets/downloads/WSO_advocacy_brochure_online_4.pdf

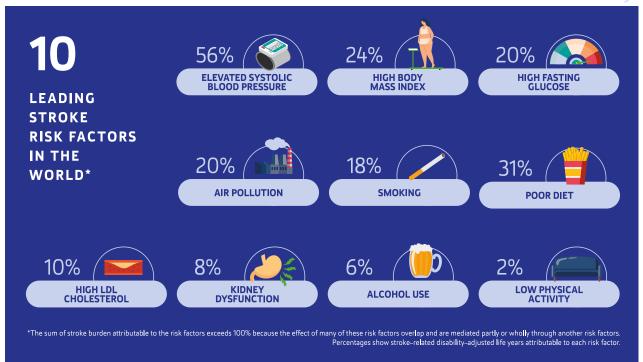
TOP TEN GLOBAL RISKS FACTORS FOR STROKE



Up to 80% of strokes and heart attacks happen in people with LOW OR MODERATE CVD **ABSOLUTE RISK**







Source: World Stroke Organization. Stroke Advocacy Brochure. Accessed at: https://www.world-stroke.org/assets/downloads/WSO_ advocacy_brochure_online_4.pdf

Moreover, stroke treatment has been revolutionised during the last two to three decades through increased access to clot-busting treatments and mechanical thrombectomy, which improve survival rates and reduce the severity of post-stroke disability. It is important that people who have a stroke have access to quality care at the correct time, no matter their resource setting.

NCD co-morbidities and the double burden of NCDs and COVID-19

Often, one individual can live with two or more NCDs, which is referred to as 'NCD co-morbidities'. The majority of people who have had a stroke live with one or more additional chronic conditions. Adding to the stark burden of NCD and stroke co-morbidities is the devastating impact of the COVID-19 pandemic. In low-, middle- and high-income countries alike, people living with NCDs have been at higher risk of COVID-19-related illness and death. Studies have estimated that 60-90% of COVID-19 deaths have been of people living with one or more NCDs, putting them at the epicentre of the crisis⁵.

NCD co-morbidities impose years of disability and financial burden on those affected, their families, health systems and national economies. In most cases, co-morbidities require higher out-of-pocket expenditures, which are often more than double for NCD co-morbidities than for a single NCD. While the prevalence of co-morbidities varies globally, it increases substantially with age in all countries, occurs at higher rates in urban areas, and disproportionately affects people living in LMICs⁶. NCD co-morbidities can occur because diseases share the same risk factors or because some diseases predispose individuals to developing others. In the case of stroke, both are possible: stroke shares risk factors with many other diseases and stroke risks can be increased by the presence of other diseases, such as diabetes.

The individual and societal impact of stroke

Stroke has an acute onset but should be seen as a chronic disease. As a neurological disorder, many survivors of stroke face long-term physical disabilities, cognitive and mental difficulties and socioeconomic consequences such as loss of work, income and independence. While stroke survivors and their caregivers have identified hope for recovery as a priority for life after stroke, this requires investment in life after stroke care and support. Family members and carers, friends and colleagues are also impacted by the effects of stroke and may need support and guidance. Some people may not recover from a stroke and will require palliative care for as long as needed to improve the quality of life of patients and their families⁷.

"Having a stroke changed my life, I could not walk or talk and I was bedridden. I lost everything - my job, I was incontinent, and crying all the time. My sister was my main carer doing everything for me, even lifting me up."

Irene Tabansi, Nigeria

⁵ NCD Alliance. A Global NCD agenda for resilience and recovery from COVID-19. 2021. Accessed at: https://ncdalliance.org/ncd-covid-19-recovery-agenda-report

⁶ Ogechukwu Augustina Asogwa et al. Multimorbidity of non-communicable diseases in low-income and middle-income countries: a systematic review and meta-analysis. BMJ Open. 2021. Accessed at: https://bmjopen.bmj.com/content/bmjopen/12/1/e049133.full.pdf

⁷ WHO. Palliative care. Accessed at: https://www.who.int/health-topics/palliative-care

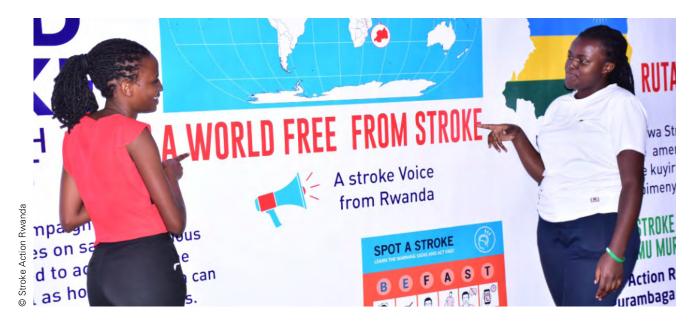
Impact of COVID-19 on NCD response and essential services: weakened health systems, disease silos and existing inequalities

Since the first landmark UN Political Declaration on NCDs in 2011, there has been a series of bold global political commitments to guide the NCD response. **This includes reducing premature NCD deaths by one-third by 2030, the commitment governments made in 2015 as part of the launch of the UN Sustainable Development Goals (SDG target 3.4).** Prior to the pandemic, fewer than 20 countries worldwide were on track to hit this target, showing that globally, health systems are ill-equipped to respond to the challenges posed by NCD co-morbidities⁷. The syndemic of COVID-19 and NCDs has only further exacerbated where NCD treatment and care is lacking.

Health systems are designed to address acute issues rather than to provide the continuous care required for complex and chronic NCDs. Individual diseases are treated with a siloed, vertical approach, which is inappropriate and ineffective for people living with NCD co-morbidities. Inequalities within and between countries are reflected in the burden of NCDs and are further highlighted by the differing toll of COVID-19 among population groups: both NCDs and COVID-19 disproportionately affect LMICs and marginalized populations who are discriminated against due to employment status, age, race, ethnicity or other factors. For marginalized people already living with stroke and other NCDs, challenges faced include limited access to healthcare and essential medicines, high out-of-pocket expenditures, limited information about prognosis, reliance on family members to provide significant post-stroke care with minimal support, and limited knowledge among health care workers.

The 2022 WHO Progress Monitor on NCDs shows that national level progress towards the 'one-third by 2030' target is insufficient and uneven in the wake of COVID-19⁸. The fourth High-Level Meeting of the United Nations General Assembly on the Prevention and Control of NCDs will take place in 2025 and will serve as an important milestone to adopt a new, ambitious and achievable Political Declaration on NCDs on the road to 2030.





⁸ NCD Alliance. WHO launches new NCD Progress Monitor. Accessed at: https://ncdalliance.org/news-events/news/who-launches-new-ncd-prog-ress-monitor

Strengthening the approach to stroke and other NCDs to build back better from COVID-19

Given the devastation caused by COVID-19 against the existing backdrop of NCD mortality, with stroke being responsible for one of the highest global death rates, it is imperative that health systems reorient from a single disease approach to integrate care packages across multiple NCDs through a holistic personcentred approach.

The integration of NCDs into Universal Health Coverage (UHC), must be at the core of national and global preparedness for future health threats. UHC ensures financial protection from high out-of-pocket payments and aims to leave no one behind, prioritising marginalised communities. Primary health care (PHC), the mechanism underpinning UHC, refers to the whole-of-society approach to health and well-being based on the needs and preferences of individuals, families and communities. It addresses the broader determinants of health and focuses on the comprehensive overview of all aspects of physical, mental and social health and wellbeing. It plays a central coordinating role in the prevention, diagnosis and long-term management of chronic diseases⁹.

UHC and the 2030 Sustainable Development Goals

UHC is a political commitment stating that the highest attainable standard of physical and mental health is a fundamental human right, and that all people should have access to quality essential health services without incurring financial hardship.

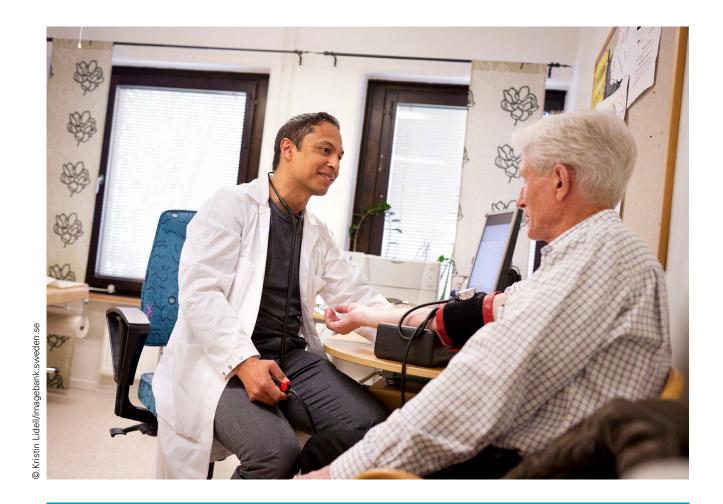
It is defined as:

- 1) **High quality essential** health services across the continuum of care are available according to need;
- 2) **Equity in access to health services**, whereby the entire population is covered, not only those who can afford services;
- 3) Financial risk protection mechanisms are in place to ensure the cost of using care does not put people at risk of financial hardship.

UHC is part of the Sustainable Development Goals (SDG target 3.8) to achieve UHC, including financial risk protection, access to quality essential health care services and access to safe, effective, quality and affordable essential medicines and vaccines for all by 2030. <u>UHC2030</u> is a powerful movement of diverse voices that convened around the 2019 UN Political Declaration on UHC to develop set of UHC key asks. The UHC2030 movement will mobilise once more ahead of the UN High-Level Meeting on UHC in 2023, where world leaders will meet to review 2023 targets set on UHC, including one billion additional people covered by UHC by 2023.

A PHC approach is important to address the prevention and treatment of stroke and NCD co-morbidities. In order to meet global political commitments on UHC, it is essential that stroke and NCDs are included in national UHC policies and packages. Despite slow progress towards UHC targets, there are existing tried-and-tested methods to effectively integrate NCDs into UHC at national level in different economic settings, enabling governments to provide care and financial protection to people living with NCDs across the whole population.

⁹ NCD Alliance. Protecting everyone, Integration of Noncommunicable Diseases into Universal Health Coverage in the Era of COVID-19. 2020. Accessed at: https://ncdalliance.org/sites/default/files/resource_files/Protecting%20Everyone_Report_Web_ENGLISH_0.pdf



UHC service coverage and inclusion of NCDs in Sweden

In Sweden, UHC is underpinned by the Swedish Health and Medical Service Act from 1982, whose objective is to ensure good health to the entire population, health on equal terms, and equitable care based on needs. PHC is the basis of the healthcare system and quality of care is recognised as high. Use of data has been ingrained into the system with 90 national disease registries in place. National clinical guidelines were introduced in 2000, and over the last five years, there has been increased collaboration across the regions, coordinated by the national government. This system is known as "knowledge-based healthcare".

Stroke prevention, management and rehabilitation

The national quality registry for stroke "Riksstroke" was established in 1994 and the first evidence-based national clinical guidelines for stroke were published in 2000 by the National Board of Health and Welfare and revised in 2005, 2009 and 2011. Stroke incidence rates in southern Sweden decreased by 33% between 2001 and 2015. In 2019, the clinical guidelines were expanded to include standardised "care processes" for acute care of stroke patients, which are currently being implemented throughout the country.

Source: NCD Alliance. Protecting everyone, Integration of Noncommunicable Diseases into Universal Health Coverage in the Era of COVID-19. 2020. Accessed at: https://ncdalliance.org/sites/default/files/resource_files/Protecting%20Everyone_Report_Web_ENGLISH_0.pdf

How can healthcare systems, policymakers and other stakeholders better integrate stroke into UHC?

It is important to consider comprehensive care for NCD integration into UHC. All chronic diseases demand the continuum of care, which includes health promotion and prevention, screening, early diagnosis, treatment and care, rehabilitation and palliative care. Comprehensive UHC ensures essential services, including essential medicines, are included in national benefit packages in order to improve the health and wellbeing of populations¹⁰.

Stroke care encompasses the full continuum of care from primordial and primary prevention to long term recovery and reintegration into the community. In many instances, a patient's psychological needs are not met once their stroke-related medical services are discontinued and many stroke survivors have difficulty readjusting to life after stroke. This lack of preparation and planning for the current and future needs of stroke patients also poses extraordinary challenges to healthcare systems that are vulnerable and ill-equipped to treat such diseases. There needs to be an emphasis placed on continuous holistic stroke care that puts patients at the core.



The World Stroke Organization (WSO) <u>Global Stroke Services Guidelines and Action Plan</u> outlines a stroke services framework that describes key phases of the continuum of stroke care, best practice recommendations and key quality indicators for each phase. This framework is accompanied by a clinical practice <u>roadmap</u> intended to guide healthcare officials, stroke care clinical groups and policymakers in establishing quality stroke care systems that incorporate the entire stroke continuum of care. This roadmap can be adapted by LMICs, where there is the most urgent need to improve access to stroke units, implement acute stroke care services and implement integrated prevention activities¹¹.

Alongside healthcare officials, it is imperative to recognise the important role that civil society organisations (CSOs) and people affected by stroke have in ensuring that stroke is integrated into comprehensive UHC packages. CSOs such as Stroke Support Organisations (SSOs) are engaged in funding stroke research, prevention awareness, supporting people affected by stroke through their recovery and advocating with and for people affected by stroke to ensure that they are at the forefront of driving improvement in access to stroke treatment and care¹².

¹⁰ Ibid. See footnote 9.

¹¹ Mayowa O Owolabi et al. The state of stroke services across the globe: Report of World Stroke Organization-World Health Organization surveys. International Journal of Stroke. 2021. Accessed at: https://pubmed.ncbi.nlm.nih.gov/33988062/

¹² World Stroke Organization. Stroke Support Organization Global Mapping. 2021. Accessed at: https://www.world-stroke.org/assets/downloads/WSO_Report_2021_01032021.pdf

Key elements within the stroke continuum of care pathway



Primary prevention of stroke

Task shifting through the development of community health workers, improved public awareness of stroke risk factors and prevention education supported by eHealth.



Stroke recognition

Knowledge of individual risk and symptoms of stroke occurrence, FAST awareness campaigns, development of stroke trained emergency healthcare.



Pre-hospital, emergency and acute inpatient stroke care

Establish and ensure access to stroke units, ensure access to essential medicines and medical devices such as thrombolysis, endovascular treatment and rehabilitation.



Stroke rehabilitation and community reintegration

Long term support for patients and carers after stroke, secondary prevention of recurrent stroke, capacity strengthening of national and local stroke support organisations, involvement of stroke survivors and caregivers in the development of policy at all levels.

Palliative stroke care

Long term support for patients and carers after stroke, appropriate end of life care.



Stroke prevention

Supporting the implementation of population-wide prevention strategies for stroke and NCDs

While stroke treatment has made great progress, the mainstay of responding to this NCD remains prevention. The majority of stroke burden is attributable to modifiable risk factors, which are common across other NCDs including dementia. Without the implementation of robust global prevention strategies, there will be approximately 200 million stroke survivors and 106 million people with dementia by 2050. Recognising the commonalities of stroke and dementia risk and the need to avoid disease silos whilst working towards UHC, WSO launched a 2020 <u>Declaration on the global prevention of stroke and dementia</u>. The declaration encourages the adoption of population-wide strategies that reduce exposure to risk factors across the lifespan of the entire population and puts the emphasis on LMICs where the stroke burden is increasing the most.

Best practice recommendations on primary stroke prevention¹³

- Abandon categorisation of people into low, moderate, and high risk and instead advocate for a holistic prevention approach for all people at risk of stroke
- Promote and implement motivational mobile technologies, e.g. WSO endorsed free Stroke Riskometer to identify individual risks and support action on lifestyle risk factors among adults
- Facilitate access to a low dose combination of generic blood pressure and lipid-lowering therapies in one polypill for middle-age and older adults with at least two behavioural or clinical stroke risk factors
- Invest in the training and deployment of community health workers to facilitate implementation of prevention strategies
- Assess the effectiveness of primary stroke prevention strategies or measures by regularly monitoring stroke incidence, mortality and prevalence at the individual and population levels.

"I was 31 at that time (of my stroke) and was earning a living as a taxi driver. I know what you are thinking: "Gosh! How can he have a stroke? He is so young." But let me share how I was living my life at that time. I was working 12 hours a day without a break. I was not a smoker, nor did I have a habit of drinking alcohol. I did, however, have high blood pressure and was not following my doctor's instructions diligently with regard to my medications."

Tam Hong Ching, Malaysia

¹³ Mayowa O Owolabi et al. Primary stroke prevention worldwide: translating evidence into action. The Lancet. 2021. Accessed at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8727355/

SSO SUCCESS STORY

Stroke Prevention Programme

National Network Heart for Heart Foundation Bulgaria



The National Network Heart for Heart Foundation named the initiative 'What is your reason for preventing a stroke?' The aim of the campaign was to raise awareness of preventing and controlling stroke risk factors by reaching people in their workplace.



Heart to Heart Foundation Bulgaria

The Foundation was able to mobilize volunteers to deliver the programme within two months to two of the largest tailoring companies in the country, and in 12 kindergartens and schools. The staff in these workplaces accessed free medical examinations and information materials. The initiative was a success: nearly 1,000 people accessed the health screening programme; 600 at the tailoring companies and 352 in the kindergartens and schools. Working in collaboration with the workplaces meant that the programme was easily accessible to the employees and an employment benefit. It also meant that the employers could continue to promote health messages in the workplace.

Source: World Stroke Organization. Stroke Support Organization Global Mapping. 2021. Accessed at: https://www.world-stroke.org/assets/downloads/WSO_Report_2021_01032021.pdf



Stroke recognition

Improving knowledge in the population of individual risk of stroke occurrence and symptoms of stroke and on the benefits of timely admission to hospital

The importance of improving public awareness of stroke, rapid recognition of its symptoms (face drooping, arm weakness, speech difficulties) and timely hospital admission amongst all healthcare professionals and members of the public should not be overlooked. It increases an individual's chances of preventing death and disability.

Best practice recommendations on stroke recognition

- Increase the awareness around the signs and symptoms of stroke and the need to act fast amongst all
 members of the public and healthcare professionals, by making use of the annual WSO World Stroke
 Day campaign and using campaign materials year-round.
- Advocate within certain geographic regions for a local emergency call number or system in place, such as 9-1-1 in the United States.

World Stroke Day Campaign¹⁴

In 2006, WSO established World Stroke Day, which takes place on October 29th every year. The global awareness day provides a coordinated global platform for the stroke community to increase public awareness of stroke symptoms and stroke prevention. In 2021, the WSO launched the two-year #Precioustime campaign aimed to raise public awareness of stroke symptoms and of the importance of seeking emergency medical treatment if stroke is suspected. This global campaign launched a simple call to action: learn the signs, say it's a stroke and save #Precioustime. **The 2021 campaign reached 2.3 billion people across the world**. Resources developed for the campaign are available in multiple languages and can be used throughout the year.



"We urge the government to scale up health care services and ensure increased awareness of risk factors and the need to act FAST among the population."

George Chimatiro, co-founder SSO, Malawi

¹⁴ World Stroke Organization. World Stroke Day. Accessed at: https://www.world-stroke.org/world-stroke-day-campaign

SSO SUCCESS STORY

World Stroke Day Event 2021

Por una vida libre de ACV Argentina



The first SSO established in Argentina, Por una vida libre de ACV (For a stroke-free life), delivered a range of activities around World Stroke Day 2021 targeting different audiences, winning the award for best campaign in a high-income country.



leart to Heart Foundation Bulgari

Activities included a virtual event aimed at stroke survivors to raise awareness around peer support and recovery activities, stroke prevention, symptom recognition and accessing treatment, with almost 1000 people registered for the event. The SSO took the message 'Hay minutos que pueden salvar vidas/Minutes can save lives' to the streets of Buenos Aires on World Stroke Day itself to increase community awareness of stroke on the ground. The SSO toured the streets in a minivan displaying the campaign posters and key campaign messages. Five actors brought the messages to life by performing the four main signs of stroke at traffic lights and distributed brochures for motorists to take home. The national campaign was a success attracting a range of stakeholders from stroke survivors to medical professionals to the general public.

Source: World Stroke Organization. Accessed at: https://www.world-stroke.org/news-and-blog/blogs/taking-the-message-hay-minutos-que-pueden-salvar-vidas-minutes-can-save-lives-to-the-streets-of-buenos-aires



Quality acute stroke care services

Timely access to appropriate stroke services and treatments

The acute stroke care phase typically begins about 24 hours after stroke onset and continues through the first five to seven days after stroke. High quality acute stroke care, involving rapid hospital admission and healthcare providers with expertise in stroke care, can reduce post-stroke morbidity and mortality by up to 30%. The timely treatment of clot-busting drugs increases the chance of a good outcome by a further 30% and clot retrieval treatment increases the chance of a good outcome by more than 50% . All acute patients with stroke should have access to treatment at hospital stroke units and to evidence-based therapies including essential medicines and medical devices.

Best practice recommendations on acute stroke care:

As part of integrating stroke into UHC with no one left behind, the implementation of stroke care guidelines across the continuum of care should be context specific. In LMICs there is lower accessibility to some of the most basic health care services, especially in rural communities. The three levels of service availability (advanced, essential and minimal services) take this into account and demonstrate that stroke services can be adapted to LMIC settings. This is especially relevant for acute stroke care as some patients may not have access to an established stroke care unit, and making the most of acute services available can make a difference to the outcomes of people who have a stroke¹⁶.

Minimal stroke care delivery	Stroke care delivery is based at a local clinic staffed predominantly by nonphysicians. Laboratory tests and diagnostic studies are scarce, and much of the emphasis is placed on bedside clinical skills, teaching, and prevention
Essential stroke care delivery	Essential stroke care delivery offers access to a CT scan, physicians, and the potential for acute thrombolytic therapy, however stroke expertise may still be difficult to access
Advanced stroke care services offer multidisciplinary stroke expertise, multimodal imaging, and comprehensive therapies.	

 $Source: World Stroke \ Organization. \ Stroke \ Advocacy \ Brochure. \ Accessed \ at: \ \underline{https://www.world-stroke.org/news-and-blog/news/wso-publishes-global-stroke-advocacy-priorities}$

"Our health camps were based in the city, and we became increasingly aware that we were only reaching those stroke patients who could travel to the foundation every month. We therefore established 'Neurology on Wheels' our project in rural areas where we travel to the resource poor areas in our van."

Dr Bindu Menon, India

¹⁵ Ibid. See footnote 5.

¹⁶ Mayowa O Owolabi et al. The state of stroke services across the globe: Report of World Stroke Organization-World Health Organization surveys. International Journal of Stroke. 2021. Accessed at: https://pubmed.ncbi.nlm.nih.gov/33988062/

SSO SUCCESS STORY

Neurology on Wheels Programme

Dr. Bindu Menon Foundation India



Neurology on Wheels is a community outreach programme for marginalized villages in India, contributing to the Foundation's mission to reduce the treatment gap for stroke and epilepsy by reaching out to resource-poor areas. In 2018 in Nellore district, there were 11 neurologists for a population of 600,000, translating to one neurologist for 50,000 people.



Dr Bindu Menon Foundatior

The programme team travels to rural villages that lack specialized neurology care and liaises with the village community to plan activities all based on the programme motto 'We Reach, We Teach, We Treat.' The activities begin with an awareness programme where community health workers are trained on stroke prevention and care so that they can act as health educators and promoters in their communities. Members of the village community are screened for hypertension and diabetes and those who have had a stroke are identified. Patients are educated regarding stroke awareness and prevention and access to medicine is supported by the foundation. Neurology on Wheels has screened more than 12,000 patients, visiting 34 villages and carrying out detection and treatment of 362 hypertension cases, 95 diabetes cases and 126 stroke cases.

Source: World Stroke Organization. Accessed at: https://www.world-stroke.org/news-and-blog/blogs/addressing-stroke-care-dis-parities-in-india



Stroke rehabilitation and recovery Improving long-term support for patients and carers after stroke

Many stroke survivors face significant challenges that include physical disability; communication difficulties; changes in how they think, feel and act; and loss of work, income, independence, and social networks. Ensuring people affected by stroke have access to neuro-rehabilitation units, and when needed to long-term rehabilitation and support, is essential for health, well-being and social participation.

Best practice recommendations on stroke rehabilitation

Healthcare providers and CSOs should invest in and advocate for the meaningful involvement of stroke survivors and caregivers in the development of national, regional and global policy. Stroke survivors and caregivers from each region of the world developed the <u>Global Stroke Bill of Rights</u> in collaboration with WSO. The Bill of Rights identifies the key aspects of care that are important across the care continuum for all stroke survivors and caregivers. It is a tool that can be used by individuals and organizations to communicate with policymakers about what people affected by stroke think are the most important things in their recovery.

Global Stroke Bill of Rights

As a person who has had a stroke **I have a right to:**



Receive the best stroke care

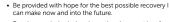
- A rapid diagnosis so I can be treated quickly.
- Receive treatment by a specialised team at all stages of my journey (in hospital and during rehabilitation).
- Receive care that is well coordinated.
- Access treatment regardless of financial situation, gender, culture or place that I live.
- Receive treatment that is right for me as an individual considering my age, gender, culture, goals and my changing needs over time.

Be informed and prepared



- Have access to full and accurate information about stroke risk factors.
- Be informed about the signs of stroke so I can recognise if I am having one.
- Be fully informed about what has happened to me and about living with stroke for as long as I require it.

Be supported in my recovery



- Receive psychological and emotional support in a form that best meets my needs.
- Be included in all aspects of society regardless of any disability I may have.
- Receive support (financial or otherwise) to ensure I am cared for in the longer term.
- Be supported to return to work and/or to other activities I may choose to participate in after my stroke.
- Get access to formal and informal advocacy to assist me with access to the services I need.
- Be connected to other stroke survivors and caregivers so I may gain and provide support in my recovery from

www.world-stroke.org

"When a family member gets sick, all the family are affected. Stroke is a sudden event and affects the whole family, who often then take on the caring responsibility. Family members are not always prepared to deal with all these changes and may end up improvising the way of caring, despite love and goodwill."

Solange Syllos, President Associação Ação AVC, Brazil



SSO SUCCESS STORY

Daily Rehabilitation Activities

National Stroke Association of Malaysia Malaysia



The National Stroke Association of Malaysia (NASAM) has eight centres across the country, all with a mission to provide affordable, stroke specific rehabilitation therapy and post-stroke support to stroke survivors and their families. Public hospitals in Malaysia cannot provide daily rehabilitation services for stroke survivors and not everyone can afford private care. NASAM's unique extended programmes provide a holistic service for stroke survivors as part of the healing process that's so crucial following a stroke.



NASAM's team of professional therapists make it a priority to ensure that the recovery journey of a stroke survivor is aimed at restoring self-esteem and dignity. Centres deliver individual and group daily rehabilitation activities that meet the physical, emotional and social needs of stroke survivors using an integrated approach that includes physiotherapy, speech therapy, occupational therapy, psychosocial support and recreational activities as well as various complementary therapies. This has been adapted to a virtual setting with Telehealth programmes and webinars. NASAM seeks to inspire and motivate stroke survivors to reach and achieve their goals. As part of this mission, NASAM held Stroke Games in 2017 and 2019. Preparation for the Games becomes a part of the activities at the centres, which organize their own teams for the event. The Games prove to stroke survivors and the general public that with rehabilitation, stroke survivors can compete, run, play games and have a fulfilling life after a stroke.

Source: World Stroke Organization. Accessed at: https://www.world-stroke.org/news-and-blog/blogs/25-years-raising-stroke-awareness-and-supporting-the-recoveryacross-malaysia

How can civil society take further action to improve healthcare for stroke and other NCDs?

CSOs, including SSOs, carry out a range of activities that are instrumental in providing access to life-saving stroke services across the continuum of care. Civil society plays a vital role in driving advocacy, building awareness and ensuring accountability across a multitude of stroke and NCD stakeholders.

Hold national governments, service providers, and international organisations accountable on their global and national commitments.

Only 38% of WHO member states explicitly included stroke in their NCD response and preparedness plans. Civil society can take actions to help to ensure that governments are held accountable for commitments made at a global level.

- The Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders 2022-2031 was adopted at the 75th Session of the World Health Assembly, with thanks to advocacy efforts from civil society including WSO and other key organisations. The action plan includes the target '75% of countries will have included neurological disorders in the UHC benefits package by 2031', an important step towards achieving UHC.
- Civil society, including <u>SSOs across the globe</u>, can work at the <u>regional and national level</u> with governments to help tailor global action plans on stroke by creating and reviewing national NCD and UHC policy to include stroke prevention and care.

Form multi-stakeholder partnerships to ensure a whole-of-society approach and drive multisectoral action.

Civil society should work with relevant private sector organisations and other stakeholders in mutually beneficial partnerships to advance public health goals and drive investment on NCDs.

- WSO partners with Boehringer Ingelheim International on the Angels Initiative, a healthcare intervention dedicated to improving stroke patients' chances of survival and a disability-free life. Since 2016, an estimated 7.5 million patients have been treated in over 6000 Angels hospitals worldwide, including more than 1400 new stroke-ready hospitals established across the world with the help of Angels.
- NCD Alliance has partnerships with NGOs, development agencies, corporates and foundations who all share a common interest in leveraging global NCD advocacy processes and platforms for stronger engagement with the global NCD community. These partners form the NCD Alliance supporters group, a unique space where all partners can exchange to drive multisectoral action on NCDs.



Raise awareness of stroke within the context of NCDs.

There are several initiatives in place to dispel misconceptions around the cost feasibility of solutions to improve access to healthcare for stroke and NCDs amongst the public and healthcare professionals.

- World Stroke Day annual campaign is spearheaded by WSO and focuses on raising public awareness of the symptoms of stroke (such as a drooping face, weakness in arms and legs and slurred speech) and that acting fast to call for help is crucial in reducing the chances of a lifelong disability.
- WSO Future Stroke Leaders Program is an initiative of the WSO to develop the technical and research skills of the next generation of stroke professionals. It is a tailored two-year program to equip a global cohort of early career clinicians and researchers with in-depth understanding of the key challenges in relation to stroke and how these challenges can be addressed within diverse stroke care systems.
- WSO World Stroke Academy is a core educational activity of the WSO and provides high-quality stroke education to healthcare professionals.

Identify local, national and regional champions that are willing to raise awareness about stroke and motivate investment to fight NCDs and build the capacity of stroke survivors and caregivers to advocate for change.

Implementing priorities and recommendations across the stroke continuum of care requires the meaningful involvement of patients who have lived experience of stroke at all decision-making levels.

- SSOs across the globe are building communities of stroke patients and their carers, aiming to empower patients to be involved in advocating for improved stroke care. SSOs encourage people with lived experience to engage in national and regional forums focused on developing stroke and NCD policy and practice.
- Global Charter on Meaningful Involvement
 of People Living with NCDs is an NCD
 Alliance advocacy tool that rallies all actors such
 as governments, international institutions, civil
 society and the private sector to put people at
 the centre and leave no one behind.



The World Stroke Organization (WSO) is the only global body with a sole focus on stroke. Through our evidence-based advocacy, education and good practice programmes we aim to prevent stroke and to reduce stroke-related deaths and disabilities worldwide. WSO has a membership of over 80 scientific and stroke support organisations around the world. We represent over 50,000 stroke experts and many more patients and caregivers worldwide, and work with them to develop and deliver our programmes.

wtwitter.com/worldstrokeorg f facebook.com/worldstrokecampaign

www.world-stroke.org



The American Stroke Association is devoted to saving people from stroke — the No. 2 cause of death in the world and a leading cause of serious disability. We team with millions of volunteers to fund innovative research, fight for stronger public health policies, and provide lifesaving tools and information to prevent and treat stroke. The Dallas-based association was created in 1998 as a division of the American Heart Association.

twitter.com/american_stroke f facebook.com/AmericanStroke

www.stroke.org



The NCD Alliance (NCDA) is a unique civil society network, uniting over 300 member organisations in more than 170 countries, dedicated to improving NCD prevention and control worldwide. Our membership is made up of a variety of NGOs, including our founding federations, national and regional NCD alliances, scientific and professional associations and academic and research institutions. NCDA has a diverse supporter base, including the World Stroke Organization and American Heart Association. Together with other strategic partners, including the WHO, the UN and governments, we work on a global, regional and national level to bring a united civil society voice to the global campaign on NCDs.

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