

STROKE MANIFESTO

Irish Heart Foundation Stroke Manifesto

One in five people in Ireland will have a stroke at some time in their life.

Until recently, many believed stroke was a disease for which little or nothing could be done. We now know that strokes are among the most preventable and treatable of all diseases.

But hundreds of people are dying each year when their lives could be saved. And hundreds more are living with permanent disability for the want of vital service improvements.

What are the effects of inadequate services?

Fact: Around 10,000 people will have a stroke in Ireland this year. Over 2,000 will die and thousands more will be left disabled. But a significant proportion of this death and disability is avoidable.

Fact: Less than one in three acute hospitals has a stroke unit – if all acute hospitals had a stroke unit up to 500 lives a year could be saved.

Fact: At least 15 per cent of strokes are misdiagnosed – that's over 1,500 cases a year.

Fact: Less than 3% of stroke patients received the life-saving clot buster treatment, thrombolysis, in the 12 months to April this year. Almost half of our acute hospitals cannot provide the treatment at all. Many that do can only provide thrombolysis during office hours or on an intermittent basis.

Fact: Just one in four patients were recorded as having received acute rehabilitation, according to Irish Heart Foundation research. Tens of thousands of people who return home or require nursing home care after a stroke receive rehabilitation and support services that are under-resourced and poorly co-ordinated.

All this means the place, time and day of a stroke largely determines whether you recover, die, or live the rest of your life with a disability. Where patients live will also dictate whether they receive the rehabilitation and support they need after leaving hospital.

For many who survive with disabilities after being unable to access prompt treatment, there is a double injustice. The lack of availability of acute rehabilitation means that many people must live with avoidable or unduly severe disabilities.

Won't better stroke services cost too much?

We believe that providing a high quality network of national stroke services, co-ordinating prevention, hospital and community care could be cost neutral,

or save the State money. Even now our stroke services cost the State an estimated €422 million a year. Making the necessary improvements would reduce the cost of institutional care, the length of hospital stay and the rate of readmission.

How can change be secured?

We are asking people – regardless of whether their lives have yet been touched by stroke – to join our campaign urging the Government to implement the measures that will eliminate avoidable death and disability from stroke. Most of these are contained in a report by experts appointed by Health Minister Mary Harney called the Cardiovascular Health Policy Group.

We are calling on the Government to implement 16 recommendations:

Preventing Stroke

Up to 50% of strokes are preventable. This means that 5,000 strokes a year and 1,000 deaths could be avoided if people took simple steps to cut down on their risk. But very few people are aware they can dramatically reduce their chances of having a stroke.

Stroke Fact: A stroke is a brain attack. It is caused by a blockage of a blood vessel or haemorrhage that stops the flow of blood to the brain. This can damage or destroy brain cells which will affect body functions or mental processes.

Stroke Fact: A TIA is also known as a mini-stroke. It may cause a brief loss of vision, loss of speech, or weakness on one side of the body and is a warning sign that a full stroke may be imminent.

MANIFESTO POINT 1

WE CALL ON THE
GOVERNMENT TO DELIVER
A MAJOR PROGRAMME
TO EDUCATE THE PUBLIC
ON HOW TO REDUCE
THEIR RISK OF HAVING A
STROKE OR A TRANSIENT
ISCHAEMIC ATTACK (TIA).

Stroke as a Medical Emergency

Most people don't know that immediate medical treatment after stroke can make the difference between recovery, death or permanent dependency. Irish Heart Foundation research shows that the vast majority of people would not know if they were having a stroke. And less than half would ring an ambulance if they knew they were having a stroke. Greater awareness would save many lives by getting more people into hospital quicker.

MANIFESTO POINT 2

WE CALL ON THE GOVERNMENT TO SUPPORT A NATIONAL CAMPAIGN TO INCREASE PUBLIC AWARENESS OF THE WARNING SIGNS OF STROKE AND TO ENSURE STROKE IS RECOGNISED AS A MEDICAL EMERGENCY.

Stroke Unit Care

The provision of stroke units in acute hospitals could reduce death and dependency rates by 20% - saving up to 500 lives a year and sparing hundreds more from disabilities requiring long-term institutional care.

Stroke Fact: Stroke is the third biggest killer in Ireland – claiming more lives than breast cancer, lung cancer and bowel cancer combined. It is also the biggest cause of acquired disability.

MANIFESTO POINT 3
WE CALL ON THE
GOVERNMENT TO
ENSURE THAT EVERY
HOSPITAL ADMITTING
PATIENTS WITH ACUTE
STROKE HAS A PROPERLY
STAFFED AND FULLY
RESOURCED STROKE
UNIT.

Stroke Unit Standards

Any dilution in the definition of what constitutes a stroke unit, or any operational failure to comply with international standards, especially in relation to capacity, staffing and equipment will reduce their effectiveness and cost lives.

MANIFESTO POINT 4
WE CALL ON THE
GOVERNMENT TO ENSURE
THE HSE COMPLIES
WITH EUROPEAN STROKE
ORGANISATION GUIDELINES
IN THE DELIVERY OF A
NATIONAL NETWORK OF
STROKE UNITS AND TO
CONTINUALLY MONITOR
COMPLIANCE WITH THESE
STANDARDS.

Clot-busting Treatment

Treatment with clot-busting drugs – thrombolysis – prevents death and disability from stroke, but must be delivered to eligible patients within 3 hours. In the 12 months to April 2009 less than 3% of stroke patients received the treatment. Thrombolysis is currently provided to stroke patients at just over half of the country's acute hospitals, but in many of these only on a 9am-5pm Monday-Friday basis.

Stroke Fact: Thrombolysis dissolves blood clots that cause strokes by blocking the supply of blood to the brain.

**MANIFESTO POINT 5
WE CALL ON THE
GOVERNMENT TO
URGENTLY DELIVER
24/7 AVAILABILITY OF
THROMBOLYSIS TO
ALL SUITABLE STROKE
PATIENTS.**

Emergency Services

The average stroke destroys two million brain cells every minute. Trained ambulance staff, telemedicine support and properly equipped ambulances and emergency departments are crucial to the prompt treatment of stroke patients.

Stroke Fact: Only 5% of patients are admitted to hospital within two hours of stroke onset. After two hours a patient's chance of recovering with little or no disability is greatly reduced.

MANIFESTO POINT 6
WE CALL ON THE
GOVERNMENT TO
GUARANTEE THAT
EMERGENCY SERVICES
ARE EQUIPPED AND
EMPOWERED TO DEAL
WITH ACUTE STROKES.

Consultant Stroke Physicians

There are 27 lead stroke consultants in Irish acute hospitals. However, there are as few as three whose clinical remit is given over substantially to stroke.

This shortage of specialists is exacerbated by the fact that stroke can be difficult to identify. At least 15% of strokes and half of TIAs are currently misdiagnosed in Ireland. The failure to provide the correct diagnosis in over 1,500 cases carries devastating consequences for patients.

MANIFESTO POINT 7
WE CALL ON THE
GOVERNMENT TO
APPOINT MORE
CONSULTANT STROKE
PHYSICIANS TO PROVIDE
GREATER EXPERTISE
IN THE DIAGNOSIS AND
TREATMENT OF STROKE.

TIA Clinics

Patients who suffer TIAs or mini-strokes are at much greater risk of having a full stroke. Even though TIA services can reduce repeat mini-strokes or strokes by 80%, they are provided in just one in every six acute hospitals in Ireland.

MANIFESTO POINT 8
WE CALL ON THE
GOVERNMENT TO PROVIDE
CONSULTANT-LED RAPID
ACCESS TIA CLINICS ON
A REGIONAL BASIS THAT
ARE OPEN SEVEN DAYS
A WEEK.

Rehabilitation Services

Acute rehabilitation is not available to the vast majority of stroke patients which causes unnecessary suffering to thousands of people each year.

Each patient should be entitled to receive a minimum of 45 minutes of required rehabilitation 5-7 days a week for as long as it is needed. This should include physiotherapy, occupational therapy, clinical psychology, speech and language therapy and nutrition and dietetic input provided by both hospital and community based stroke teams.

Stroke Fact: Irish data showed that less than half of stroke patients were seen by a physiotherapist within 72 hours of admission and only one-in-four were assessed by an occupational therapist within seven days of admission.

MANIFESTO POINT 9
WE CALL ON THE
GOVERNMENT TO
GIVE EVERY PATIENT
AN ENTITLEMENT TO
APPROPRIATE LEVELS
OF SHORT AND LONG
TERM REHABILITATION
IN HOSPITAL AND IN
THE COMMUNITY.

Planned Discharge and After-care

Continuing care and long-term recovery programmes are haphazardly organised or do not exist. Patients should receive a co-ordinated service that ensures:

- Rehabilitation that is planned from the day of hospital admission
- A full needs assessment supporting discharge home
- Clear structures for collaboration between hospital and community stroke staff
- Access to stroke rehabilitation in the community
- Access to relevant information and advice, along with a contact person after discharge from hospital
- Aftercare and long-term support for people suffering lasting disability
- For those requiring nursing home care, access to full therapist and support services

MANIFESTO POINT 10

WE CALL ON THE GOVERNMENT TO ENSURE THE RIGHT OF EACH PATIENT TO A PLANNED AND TIMELY TRANSITION FROM HOSPITAL TO THEIR HOME OR RESIDENTIAL CARE. WE ALSO URGE THAT LONG-TERM INSTITUTIONAL CARE SHOULD ONLY BE PROVIDED ON THE BASIS OF MEDICAL AND SOCIAL NEED, NEVER BECAUSE OF INADEQUATE COMMUNITY SERVICES OR SUPPORTS.

Regional Stroke Co-ordination and Implementation Supervision

Just as there are regional cancer co-ordinators, the complexity of stroke means that regional co-ordinators must be appointed to ensure that preventive, pre-hospital, hospital and community services are working together and developing and meeting targets on excellence in stroke care.

MANIFESTO POINT 11
WE CALL ON THE
GOVERNMENT TO
APPOINT REGIONAL
STROKE CO-ORDINATORS
WITH RESPONSIBILITY
FOR ENSURING THAT
STROKE SERVICES ARE
MEETING THE NEEDS
OF PEOPLE WHO HAVE
HAD A STROKE IN EVERY
COMMUNITY IN IRELAND.

Tackling Age Discrimination

Age-related inequities are common within stroke services. In some locations over-65s do not receive rehabilitation services, whilst in others under-65s are ineligible for community services.

Stroke Fact: Anyone can have a stroke, even babies and children. Two-thirds of strokes are suffered by over-65s, but every year around 3,500 people aged under-65 have a stroke.

MANIFESTO POINT 12

WE CALL ON THE
GOVERNMENT TO
ELIMINATE AGE
DISCRIMINATION FROM
STROKE SERVICES.

THESE SHOULD ALWAYS
BE PROVIDED ON
THE BASIS OF
INDIVIDUAL NEED.

Patients' Charter

Most people don't know that high quality stroke services can save lives, reduce disability and improve the rate of recovery from stroke. Many are also unaware of what services will best aid their recovery.

MANIFESTO POINT 13

WE CALL ON THE GOVERNMENT TO ENSURE THE ADOPTION OF A CHARTER TO INFORM ALL STROKE PATIENTS, THEIR FAMILIES AND CARERS EXACTLY WHAT THEIR ENTITLEMENTS ARE IN RELATION TO HOSPITAL TREATMENT, CARE AND REHABILITATION.

Stroke Register

A stroke register will help ensure that stroke services operate as effectively as possible. Collecting basic data on stroke patients will assist with planning and monitoring of performance that can have a major impact on patient outcomes and the overall quality of services.

Stroke Fact: Patient Registries – such as the National Cancer Registry – which record the numbers, types and treatment outcomes of patients – assist in planning and evaluation of healthcare and can ensure that patients receive high quality care.

MANIFESTO POINT 14
WE CALL ON THE
GOVERNMENT TO
PRIORITISE THE
DEVELOPMENT OF
A NATIONAL STROKE
REGISTER.

Social and Vocational Supports

Social and vocational supports must be available to help people put their lives back together after stroke. For example, everyone should have access to a stroke support group. In addition, financial assistance such as housing adaptations grants can make the difference between living at home and institutionalisation. Support to return to work, or undergo re-training can determine whether a person can return to the workforce. These supports are not just crucial in human terms, they can save the State money.

MANIFESTO POINT 15

WE CALL ON THE GOVERNMENT TO ENSURE THAT SOCIAL AND VOCATIONAL SUPPORTS ARE AVAILABLE ENABLING STROKE PATIENTS TO ACHIEVE THE BEST POSSIBLE QUALITY OF LIFE AFTER THEIR STROKE. WE ALSO CALL FOR STATE ASSISTANCE TO ENSURE THAT EVERYONE WHO HAS HAD A STROKE HAS ACCESS TO A PROPERLY-RESOURCED SUPPORT GROUP.

Supporting Carers

Carers carry a huge burden in helping people to put their lives back together after stroke.

MANIFESTO POINT 16
WE CALL ON THE
GOVERNMENT TO ADDRESS
THE SOCIAL, EMOTIONAL
AND PRACTICAL NEEDS
OF CARERS IN SUPPORTING
STROKE SURVIVORS.

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