

**STROKE**  
**MANIFESTO**  
**2017**



**Irish Heart**

*We are United for Stroke*



United for Stroke is the commitment we, at the Irish Heart Foundation, make to support stroke survivors. Many people do not realise that stroke and heart disease are connected and that many of the risk factors are the same. The Irish Heart Foundation is here for stroke survivors all around Ireland, providing support through dedicated local support groups and a national nurse Helpline. Through our work in stroke we raise awareness of stroke symptoms through our Act FAST message and we raise awareness of the connection between heart health and stroke prevention. 1 in 5 people will have a stroke in their lifetime, most are over 65 years, but stroke can strike at any age. Through our advocacy, we campaign for better services to improve care for patients.

## Irish Heart Foundation Stroke Manifesto

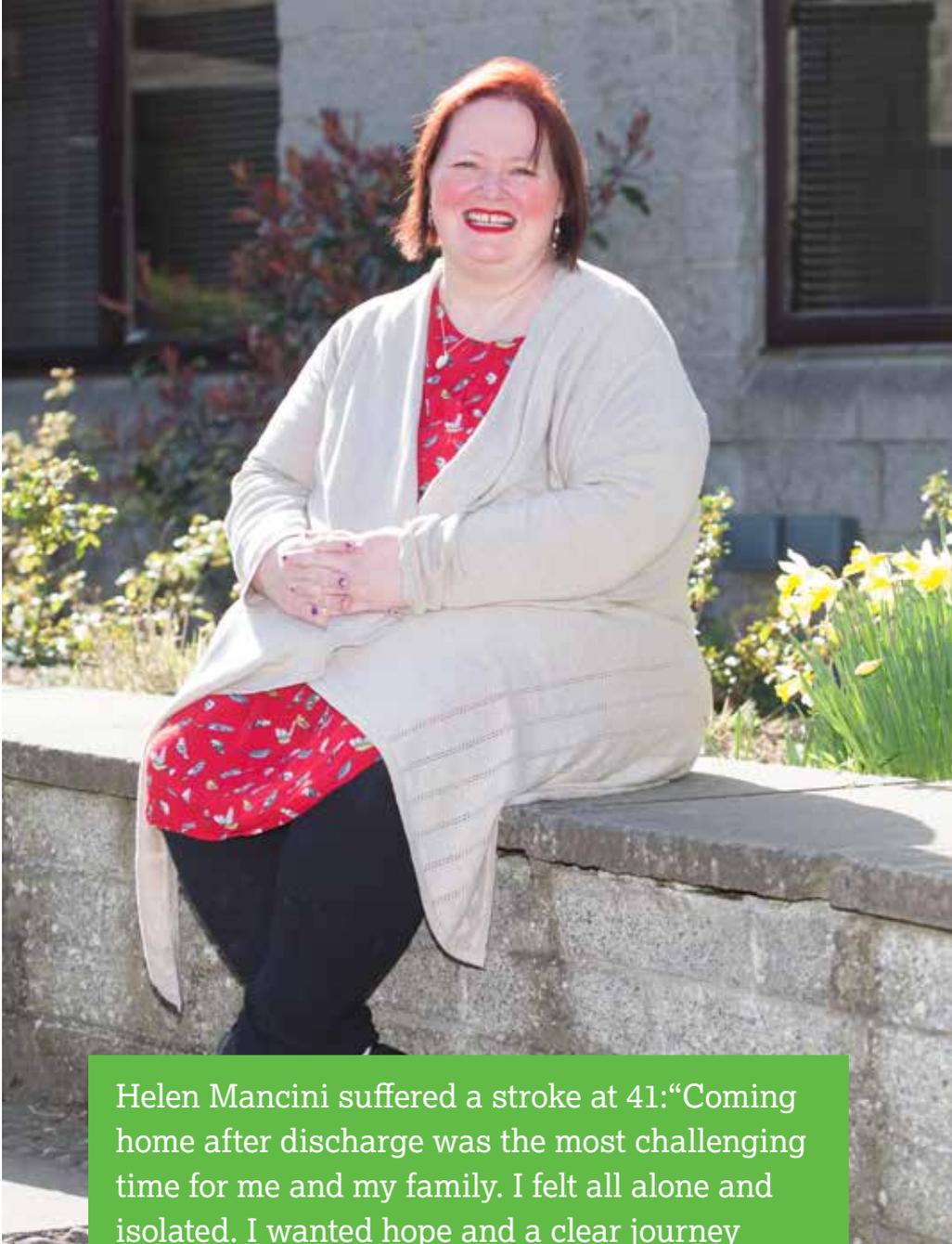
The rate of death and permanent severe disability from stroke in Ireland has been reduced dramatically in recent years.

But hundreds of people are still dying every year when their lives could be saved.

And thousands more are not receiving basic services that would enable them to make the most of life after stroke. In cold print this may read like an inconvenience. In fact, deficits in acute, rehabilitation and community services are devastating lives.

Stroke is unlike any other disease. It can hit anyone, of any age at any time. If it doesn't kill you, it can rob you of your power of speech, of sight and swallow; it can leave you paralysed, incontinent and forced to spend the rest of your life dependent on others to carry out the smallest and most personal tasks.

Modest additional investment in hospital and community services would have a life-changing impact on many people. And yet they continue to suffer. Even when we can prove the services they are being denied are cost effective.



Helen Mancini suffered a stroke at 41: “Coming home after discharge was the most challenging time for me and my family. I felt all alone and isolated. I wanted hope and a clear journey ahead of me but there was none offered.”

## What are the effects of inadequate services?

**FACT:** Over 7,000 people will be hospitalised due to stroke in Ireland this year. At least 1,800 will die. But one in every six of these lives could be saved through acute service improvements that it’s accepted would not only reduce mortality, but also cut health service costs.

**FACT:** Just half of stroke patients in Ireland receive any of their treatment in a stroke unit – currently the most effective lifesaving and quality of life restoring intervention for the disease. Some hospitals have more serious service deficits than others, but every centre treating acute stroke fails to meet minimum international standards on the provision of acute rehabilitation services.

**FACT:** Over 3,000 stroke patients every year are being denied a potentially better outcome because of the HSE’s failure to roll out Early Supported Discharge programmes nationally that could also free up 24,000 bed days a year in our struggling hospital system by providing therapy in people’s homes rather than hospital.

**FACT:** The State spends up to 60 times more on nursing home care for stroke survivors than the community rehabilitation services that can keep them living in their homes. As a result Ireland’s 50,000 stroke survivors receive the equivalent of less than two physiotherapy sessions a year for what can be complex physical, communication and psychological difficulties caused by their brain injury.

## Won't better stroke services cost too much?

The HSE's National Stroke Programme has proved it's cheaper to deliver stroke services well than to deliver them badly. Improved outcomes from the development of the stroke unit network and of clot busting thrombolysis treatment resulted in estimated savings of €150 million in the first three years of the programme alone, through reductions in the need for nursing home places and in average length of stay in acute hospitals.

In reality, there is no shortage of State spending on stroke. The problem is where the money goes. ESRI research shows that out of a direct cost of stroke to the State of up to €557 million a year, as much as €414 million is spent on nursing home care and less than €7 million on the community rehabilitation that can help keep stroke survivors living at home.

In effect, the State waits until after it can best assist stroke sufferers to recover before spending any real money on them.

## What do we want?

If you have a stroke in Ireland today, you face being effectively abandoned by society and the State after your discharge from hospital. Whilst services are provided to those with other life threatening conditions regardless of cost, stroke sufferers often have to pay for their long-term care with their house and other assets. Yet the Fair Deal scheme has provided little or no assistance to keep stroke survivors living in their own homes. Meanwhile, in nursing homes there is virtually no access to even basic therapy services, unless residents can afford to pay extra themselves.

We want a truly fair deal for stroke sufferers. This entails up-front investment by the State in acute, rehabilitation and other community services and supports that will save lives, improve quality of life and continue to cut health service costs, particularly through reduced nursing home requirement.

We are only asking for investment in services we can prove will pay their way and that some of the net savings will be used to support services for people with severe disabilities which will be hugely beneficial, but not cost saving.

This can be achieved by Government implementing the following recommendations. These have been endorsed by the Irish Heart Foundation Council on Stroke which includes all the professional bodies representing those who deliver stroke care. These measures are clear, simple, easily monitored to ensure efficiency, cost effective and achievable in a short timeframe.

## Manifesto Point 1

**We call on the Government to ensure that every hospital treating patients with acute stroke has a properly resourced stroke unit.**

Only 29% of stroke patients are admitted directly to a stroke unit and almost half do not receive any treatment in a unit during their hospital stay. Nearly a quarter of hospitals providing acute care do not meet minimum organisational standards and three of these do not have any of the infrastructure in place required for a stroke unit.

In addition, there are staffing deficits of over 30% in nursing, 50% for physiotherapists, 61% for occupational therapists, 69% for clinical nutrition and 31% for speech and language therapists, whilst only 44% of hospitals have any access to a medical social worker and 19% have access to a neuropsychologist.

Meeting basic minimum service levels will save lives and restore a better quality of life for many stroke sufferers, whilst increasing the savings on nursing home care already secured by the HSE's National Stroke Programme.

**A stroke unit is a discrete area in a hospital where stroke patients are cared for by a multidisciplinary team which specialises in stroke care. The core team consists of doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, dieticians, therapy assistants, psychologists and social workers**

## Manifesto Point 2

**We call on the Government to ensure the standardisation of 24/7 clot-busting thrombolysis treatment in every hospital treating acute stroke.**

Ireland's thrombolysis rate of 11% is high by international standards. But the rate of delivery of the clot-busting treatment still fluctuates wildly across the hospital network from 0% to 37% according to national audit results. This means that in some parts of the country service deficits are costing lives and leaving others to endure disability that is unduly severe and protracted.

Standardising thrombolysis services is an essential element of eliminating avoidable death and disability from stroke in Ireland. All patients who present to hospital in time should have access to thrombolysis when appropriate.

## Manifesto Point 3

**We call on the Government to ensure that endovascular stroke centres providing emergency clot removal treatment called thrombectomy are developed in conjunction with emergency services to provide access for all suitable stroke victims regardless of location.**

International clinical trials found that thrombectomy reduces stroke mortality by half and almost doubles the rate of positive life-changing outcomes.

The concentration of expertise and other resources required to deliver thrombectomy dictates that the only feasible way to develop the service is through centres of excellence.

At present a two centre strategy, incorporating Beaumont Hospital and Cork University Hospital, will deliver the greatest good for the greatest number.

This must be resourced and supported by revamped ambulance and air ambulance services to admit eligible patients countrywide up to 12 hours after symptom onset.

## Manifesto Point 4

**We call on the Government to resource stroke units so that patients who suffer TIA receive immediate investigation, assessment and treatment to prevent further stroke occurring.**

Patients who suffer TIAs or mini strokes are at much greater risk of having a full stroke. Less than half the hospitals treating acute stroke provide services to assess minor strokes and TIAs within 24 hours, even though rapid treatment can reduce repeat mini strokes or full strokes by 80%.

## Manifesto Point 5

**We call on the Government to give every patient an entitlement to timely access to appropriate levels of in-hospital rehabilitation.**

Acute rehabilitation is insufficient for the vast majority of patients. This results in disability that is unnecessarily severe or prolonged for many people trying to rebuild their lives after stroke.

Post-acute inpatient rehabilitation is also grossly under-resourced and should be developed regionally and nationally, including by increasing capacity at the National Rehabilitation Hospital and creating four regional rehabilitation centres.

Each stroke 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, medical social work and nutrition and dietetic input.

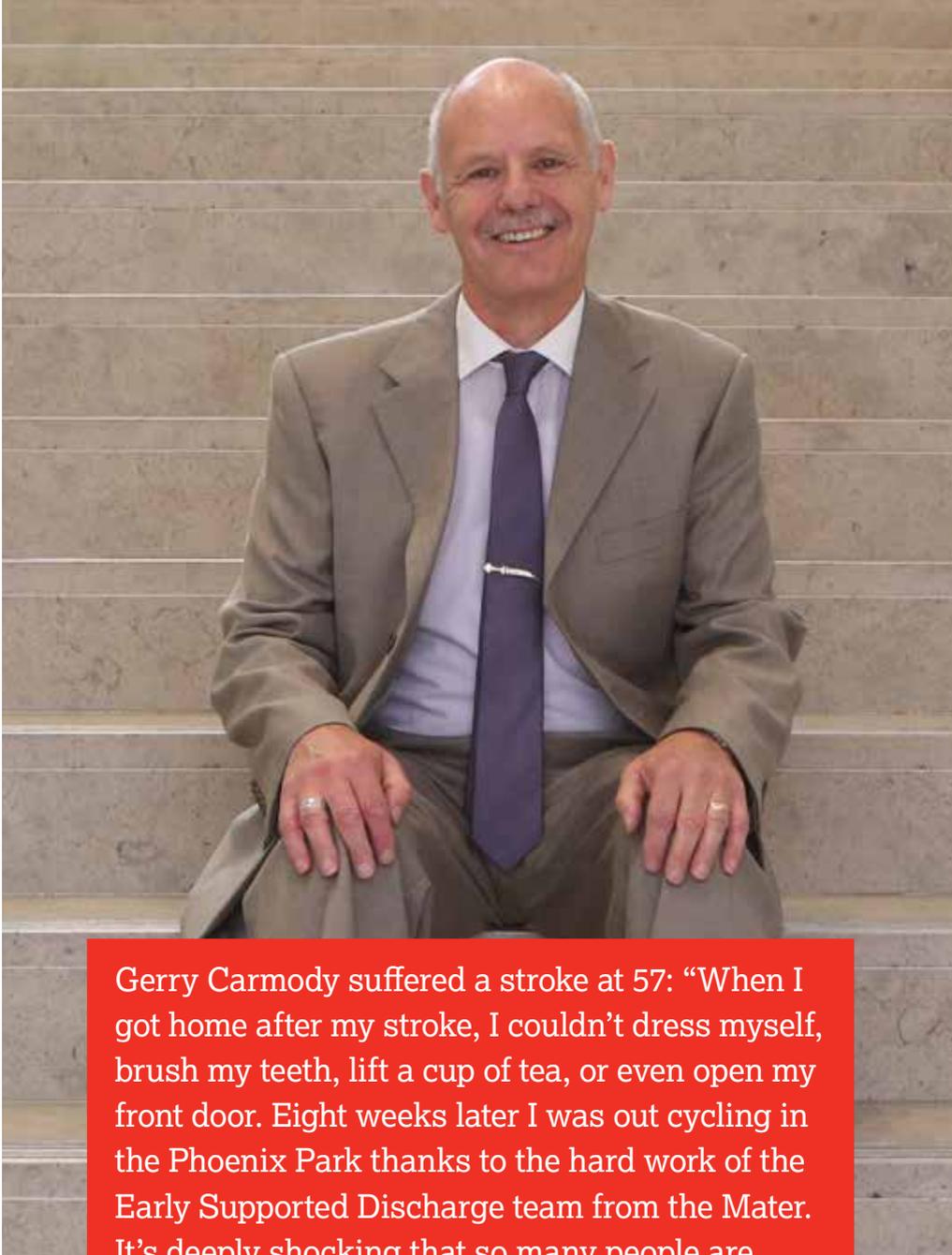
## Manifesto Point 6

**We call on the Government to roll out Early Supported Discharge programmes nationally for stroke patients to improve patient outcomes and free up acute hospital beds.**

ESRI research shows that over half of all stroke survivors – more than 3,000 people a year – could benefit from Early Supported Discharge (ESD), a programme providing specialist therapy in people's own homes rather than in hospital.

Such programmes represent a basic form of care internationally and would free up some 24,000 hospital bed days annually, as well as reducing length of hospital stay for stroke patients by a third. Using data from around the world and from poorly resourced Irish pilot sites, the ESRI concluded that ESD could improve outcomes for large numbers of patients at a cost saving to the State.

**Early Supported Discharge is an intensive approach to rehabilitation that involves patients receiving therapy services such as physiotherapy and speech and language therapy in their own homes, rather than in hospital. Evidence from Ireland and internationally shows it improves the likelihood of a good recovery, is cheaper than keeping people in hospital and frees up beds for those who need them most.**



Gerry Carmody suffered a stroke at 57: “When I got home after my stroke, I couldn’t dress myself, brush my teeth, lift a cup of tea, or even open my front door. Eight weeks later I was out cycling in the Phoenix Park thanks to the hard work of the Early Supported Discharge team from the Mater. It’s deeply shocking that so many people are being denied this life changing service.”

## Manifesto Point 7

**We call on the Government to ensure that stroke survivors are no longer abandoned after leaving hospital by developing community rehabilitation services with equality of access nationally and a process to monitor delivery.**

The fear of the future facing stroke survivors as they learn to live with their brain injury is exacerbated by the widespread dearth of vital rehabilitation services throughout the country. To improve the recovery of stroke survivors, the following are required:

- The Minister for Health should outline the entitlement of stroke survivors to rehabilitation services and develop a system to monitor and improve these services with set objectives and timeframes.
- Discharge planning processes should be improved to ensure that all stroke sufferers leaving hospital have a rehabilitation plan in place and a hospital/community stroke liaison worker to assist them.
- Properly resourced and staffed community neuro-rehabilitation teams should be established in each of the nine Community Healthcare Organisations.

- Investment should be made in long-term rehabilitation specific services in the community to provide lifelong support in appropriate settings.
- Age barriers to rehabilitation and long-term care services should be removed.
- Stroke sufferers living in nursing homes should be entitled to rehabilitation services without having to pay for them privately.



Jillian Ennis O'Boyle who suffered her first stroke at 32: "Leaving hospital care is like falling off a cliff. After that initial burst, the help you get is diluted. They want to discharge you as soon as possible. The minute you go out of the system, you're down at the back of the queue."

## Manifesto Point 8

**We call on the Government to create a legal entitlement to homecare where appropriate for stroke survivors of all ages.**

Stroke survivors are regularly discharged from hospital without the necessary supports, or continue to occupy an acute bed until a homecare package is available even though keeping patients in these beds costs up to 15 times more. In other cases patients are inappropriately discharged to nursing homes. This frees up hospital beds, but the cost to the State is far higher than providing a homecare package and the patient loses all access to therapy.

Even when homecare packages are secured they are often inadequate and the Fair Deal scheme has provided no assistance for the vast majority of stroke survivors who want to remain living at home.

Although under-65s now account for one in every four strokes, they do not qualify for the Fair Deal. Home care packages are also administered by the HSE's older person's services and are not tailored to the specific needs of people who could be living with the effects of stroke for decades.

The current system is not only piecemeal and overly complex, it is wasteful and inhumane. We need a right to homecare for stroke survivors of all ages to be enshrined in law, providing the basis for a caring and sustainable system that finally meets their needs and wishes.



Tony and Margaret O'Connell. "Like most people I would have moved mountains to ensure my wife Margaret could come home with me after her stroke. I gave up my job, changed my lifestyle, adapted our house, as we just wanted her home with her family. This wasn't easy, but it makes so much sense – the state must step in and help people live at home with loved ones for as long as possible."

## Manifesto Point 9

**We call on the Government to deliver funding for a properly resourced Stroke Register, along with a rolling audit cycle incorporating acute, rehabilitation and community services every three years to ensure that service deficits are identified and addressed.**

There is no monitoring of compliance with minimum standards in one third of hospitals treating stroke. The current Stroke Register receives no dedicated funding and operates in about two-thirds of hospitals in addition to the official duties of overworked stroke care teams. In comparison the National Cancer Registry has over 50 dedicated full-time and part-time staff. Meanwhile national stroke services have recently been audited for just the second time ever. On both occasions the audit could not have been undertaken without funding from the Irish Heart Foundation.

## Manifesto Point 10

**We call on the Government to invest in stroke prevention and particularly through awareness and screening programmes for high blood pressure and atrial fibrillation.**

High blood pressure and atrial fibrillation are the most important controllable risk factors for stroke. About three out of four people who have a stroke for the first time have high blood pressure. And an irregular atrial heart rhythm — a condition called atrial fibrillation — is present in about one third of strokes in Ireland. By identifying these conditions early the majority of these strokes can be prevented.

## Manifesto Point 11

**We call on the Government to support an ongoing national campaign to increase public awareness of the warning signs of stroke and to ensure stroke is recognised as a medical emergency.**

In the aftermath of the Irish Heart Foundation's FAST campaign, public awareness of the warning signs of stroke almost trebled to 87%.

This resulted in a huge increase in the numbers of stroke patients getting to hospital within the time window to receive potentially lifesaving clot-busting treatment. Since the campaign ended, the knowledge of stroke signs and the need to act FAST has fallen back, resulting in fewer patients getting to hospital in time to benefit from potentially lifesaving treatment.

**The F.A.S.T. acronym stands for:**

**Face** – has their face fallen on one side? Can they smile?

**Arms** – can they raise both arms and keep them there?

**Speech** – is their speech slurred?

**Time** – time to call 999 if you see any one of these signs



Dylan McKenna who saved the life of his father, Thomas (pictured right), when he was just three years old. Dylan acted FAST to get help for his Dad after he suffered a stroke in the family home. But many people don't. The average stroke destroys two million brain cells every minute, yet scores of people die every year because they didn't get to hospital in time to receive lifesaving treatment.

## Manifesto Point 12

**We call on the Government to ensure that stroke survivors receive the supports they need to make a contribution to society matching their abilities, including through employment and all areas of active citizenship.**

Some 62% of working age stroke survivors have not returned to full-time employment one year after their stroke. They require more support to maximise their ability to make the move back to being productive members of society. Others who cannot work, or who are past retirement age also need access to social and emotional supports to make the most of life after stroke and ensure they can live fulfilled lives in their own communities for as long as possible.



**Irish Heart**

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