Stroke survivors' declaration

Your guide to getting the help you need after a stroke

Northern Ireland Edition
The Stroke Association believes that everyone who has had a stroke should have the opportunity to make their best possible recovery. But, for many stroke survivors, coping with stroke can be like embarking on a journey without a map.

This declaration has been created for stroke survivors, by stroke survivors across the UK, to encourage you to be aware of the level of care and support you should expect. We hope it will help you and your family or carers to navigate the health, social care and welfare system and know what to do if your needs aren’t being met.

Every year, 150,000 people in the UK – including 4,000 people in Northern Ireland – have a stroke. For those of us affected, the impact may be profound: we may have health care, physical, psychological and other support needs resulting from the stroke that can affect our social situations, relationships and finances. Many of us have to learn to live with uncertainty and the feeling that we have lost control over our lives. This guide aims to help you regain that control and encourages you to seek help if you aren’t getting the support you need.

One of the best ways you can help yourself and others is by joining the Stroke Association’s Speak Out for Stroke (SOS) Supporters Network. The SOS Network can put you in touch with other stroke survivors as well as giving you the skills, information and confidence to campaign, volunteer and fundraise to improve your life and the lives of stroke survivors in your area. Join us at stroke.org.uk/campaigns. If you don’t have email you can still get involved – just call our helpline on 0303 303 3100 and ask to receive our free Stroke News magazine, which features campaigning news and tips.
Stroke Survivors’ Declaration

I will be given the best possible chance of recovery after my stroke

1. I can expect to be treated in a specialist stroke unit with staff who have high levels of specialist knowledge and expertise. I have the right to dignified care and support.

2. I will be involved in decisions about my own care and have personal choices about, and control over, the support I receive. Services will be designed around my need to live as well as possible for as long as possible. If I have difficulties with speaking, writing or thinking, I will be able to appoint someone to advocate on my behalf.

3. When I go home from hospital I will have specialist support.

4. I can have confidence that my health and social care teams will work effectively together so that my care is seamless and well co-ordinated.

5. I know that my health needs will be reassessed by my GP after six months and as they change. If I have a carer, they will be informed of their right to an assessment of their needs.

If you are unhappy about your care, you or a family member or friend should speak to the health care staff. You can also ask for an advocate to do this on your behalf. If you aren’t satisfied with the result, you can make a formal complaint.

Talk to your GP, social worker or rehabilitation therapist if anything is not working well.

Speak to your GP about your health care if you have not had your needs assessed. Talk to your social services or social care department about a carer’s assessment (see ‘Support for carers’ at the back of this guide).

While you are in hospital, take time to discuss your options and make sure that your choices and decisions have been noted. Ask for support from an advocate if this would help.

When you are ready to leave hospital you will receive a discharge plan setting out all the help you will need. You should be satisfied that the plan records the discussions you’ve had and the choices you’ve made. Make sure that all your questions have been answered before you go home; if not, speak to your social worker or care co-ordinator. Once you are home, if you aren’t getting the help you need, talk to your GP who is the person through whom your ongoing care and support is organised.
My family, carers and I will receive accurate and accessible information and advice

6. I will be given the information and advice I need, in the format I need, when I need it, to:
   • help me understand the effects of stroke;
   • tell me about the support that is available to help me adjust to life after stroke;
   • help me make informed decisions about my care;
   • help me explain to others the effects of my stroke.

Contact the Stroke Helpline on 0303 303 3100 (Monday to Friday, 9am-5pm) or by email: info@stroke.org.uk, or visit: stroke.org.uk for a wide range of information and support for everyone affected by stroke.

7. My mental health and physical needs will be recognised and I will be able to access the relevant support. My carers’ support needs will also be recognised.

If you would like help with your mental health, speak to your GP, consultant or social worker. They may suggest referring you for counselling or to a clinical psychologist. This is also the case for your carer. You can also discuss your physical needs – such as speech, mobility or vision – with your GP; again, they may refer you to a specialist.
8. I will be given advice on the financial benefits I can claim

➢ Get a benefit check to establish whether you’re getting all the benefits you are entitled to. You can go to an independent advice centre, such as the Citizens Advice Bureau – go online www.citizensadvice.co.uk or call 028 9026 1970 to find your nearest office. Alternatively you can use an online benefit calculator such as www.a2b.org.uk. The benefits section of NI Direct’s website is at www.nidirect.gov.uk/all-about-benefits.

9. I will be given advice on living healthily to maximise my chance of remaining well for as long as possible.

➢ Your GP can advise you on managing your medical conditions and staying well and can refer you to specialists such as a dietitian, or to exercise programmes. He or she can also talk to you about healthy lifestyle choices.

10. The impact of my stroke on my family/carers will be recognised. They will have access to appropriate information and services to help them understand and make adjustments.

➢ Your GP or social worker can talk to you and your family about the impact of your stroke and offer information and services to support you all. Call the Stroke Association on 028 9050 8020 or 0303 3033 100 to find out about our Life After Stroke services that can provide information and emotional support to the whole family.
My family, carers and I will receive timely personalised services

11. I will have access to services that will help me manage my condition so that I can regain my independence and confidence.

> Talk to your GP if you aren’t getting the help you need. Your GP is the person through whom your ongoing care is organised. Contact the Stroke Association on 028 9050 8020 or 0303 3033 100 for details of your nearest stroke support services.

12. If I am considering moving into a care home, I can be confident that staff have been trained to understand and recognise the needs of stroke survivors and that I will be encouraged to live life to the full.

> When looking for a suitable care home, ask what training staff have in caring for people with stroke and what activities and opportunities are offered to residents. The Stroke Association factsheet ‘Accommodation after stroke’ includes useful checklists of questions to ask.
All stroke survivors, their carers and families have the right to be treated equally and to participate in our communities.

13. My views and experiences will be heard and will be used to help shape future services and support for stroke survivors.

Join the Stroke Association’s campaigners’ network where you can use your experiences to help others. Go to stroke.org.uk/campaigns.

14. I can expect to participate in my community, either through employment or volunteering and be supported in doing so. If I am of working age I will have access to rehabilitation services to help me return to the workplace and my employer will be able to get advice on my returning to work, including education or training that would help me.

Tell your GP or consultant about your plans to return to work and ask for a referral to an occupational therapist (OT). The OT will draw up an action plan to help you prepare to go back to work. Speak to your employer about making arrangements and adjustments for your return to work.

If you are looking for work, speak to the Disability Employment Adviser (DEA) at your local Jobs & Benefits Office. They can help you find work or gain new skills. They can also tell you about Access to Work, a scheme that provides practical help to disabled people in the workplace by meeting some of the extra employment costs that arise from a disability.

15. My home will be adapted for my needs as they change and I will be provided with equipment that helps me to retain some independence. I will have accessible transport to remain as mobile, independent and active as possible.

Ask your GP or consultant for a referral to an occupational therapist, who can advise you on adaptations to your home and aids that can help you to be independent.

Careers Service Northern Ireland can give you careers advice over the telephone on 0300 200 7820, or visit www.nidirect.gov.uk/careers.

Your local volunteer centre may also have opportunities; you can find out more through Volunteer Now in Northern Ireland at www.volunteernow.co.uk or on 028 9023 2020.
Call the Stroke Helpline
Our helpline is here to listen to your concerns, to support you and answer your questions, wherever you live in the UK. Helpline staff can advise you on what support is available in your area, what should be happening in hospital, and what to do if things aren’t going to plan.

Call us: 0303 3033 100
(Monday – Friday 9am-5pm)
Website: stroke.org.uk
Email: info@stroke.org.uk
From a textphone: 18001 0303 3033 100

We also have access to 'Language Line', a free telephone interpreting service.

Contact us:
Stroke Association
Rushmere House,
46 Cadogan Park,
Belfast, BT9 6HH

Telephone: 028 9050 8020
Email: northernireland@stroke.org.uk

Find out more about stroke
Factsheets and leaflets are available on all sorts of issues which affect people after stroke, from communication problems to exercise or depression. Helpline staff can send you copies, or you can download them free at stroke.org.uk. You can also order useful aids and equipment from our online shop at strokeshop.org.uk.

Further support
Support is available from the Stroke Association’s Life After Stroke services across Northern Ireland. These provide practical advice and emotional support, with a range of services including speech and language therapy, communication development groups, information, advice and support services, home visiting, self-management programmes, training and stroke prevention advice.

You may also want to join a group to meet others who have been affected by stroke. There are 17 communication-based groups across Northern Ireland and we can give you advice on other groups which may be able to support your needs.

Contact the Stroke Helpline to find out more or go to stroke.org.uk/in_your_area

Support for carers
Carers Direct is run by the NHS to help carers get the help and support they need. Call their helpline 0808 802 0202 (8am to 9pm Monday to Friday, 11am to 4pm at weekends) or visit www.nhs.uk/carersdirect. Calls are free from UK landlines and mobiles, or you can request a free call back.

Carers UK has an Advice Line for carers: 0808 808 7777 or visit www.carersuk.org for more information, including a directory of local organisations offering support to carers.

You may want to contact a local agency such as Carers Northern Ireland on 028 9043 9843 or visit www.carersuk.org/northern-ireland.

You can also contact Crossroads Caring for carers on 028 9181 4455, www.crossroadscare.co.uk or email mail@crossroadscare.co.uk.