www.irishheart.ie www.stroke.ie



STROKE REHABILITATION



One in five people have a stroke at some time in their life. Stroke can strike at any age. It could happen to you, a friend or family member.

Knowing what a stroke can do to a person can help to reduce its impact.

Until recently many people, including doctors, believed that little or nothing could be done after a person had a stroke. We now know that strokes can be treated. If the right actions are taken quickly after a stroke, a person may not have major long term disability.





Recognising the symptoms of stroke and getting medical treatment immediately is important.

This leaflet explains:

- · The effects of a stroke.
- Stroke rehabilitation.

FACT: Stroke can affect people in many different ways. Some people who survive a stroke make a near complete recovery with only minor disabilities. Some people will have a disability but will recover the ability to do certain tasks. Other people may have severe and permanent disabilities.

Discharge from hospital

Before you leave hospital, members of your stroke team should carry out a full assessment of your needs. It is important that a social worker is involved in providing information on the services and supports that will be available when you leave hospital. Whether you are leaving hospital to go home or to a nursing home, it is essential that you have access to the care you need.

When you are ready to leave hospital, you will need information about your rehabilitation, medicines and treatment. Your medical team will have information about community services, including support groups in your area. It is important that your family and friends and anyone else supporting you also get this information.

What should happen when you leave the hospital?

- You will get the contact details for your stroke team, in case you have any questions after you leave hospital.
- Members of your stroke team will talk to your General Practitioner (GP) about your requirements and medicine.
- Your GP and the public health nurse will continue to monitor you medically, along with your stroke doctor.
- If you need rehabilitation after you leave hospital, this should be available up until you have reached your rehabilitation goals or when you have made all the improvements possible.

Recovery

"Rehabilitation for me is about coming up against a brick wall when you can't do something. And then you get through that wall and you're off again. Then you get to another wall and you have to work to get over that. It makes it easier the more walls you get over."

Tommy Hankey, 63, Sandyford, Dublin

Doctors still don't have a full understanding of how the brain recovers after a stroke. There is still a lot to learn. Some brain cells may only be temporarily damaged, and may start working again. In some cases the brain makes up for the damaged cells and re-organises how it works. Sometimes, a section of the brain takes over from another area damaged by stroke.

Recovery varies from person to person – some may make a complete recovery, while others may be left with some disabilities or difficulties in some areas. Some people often make a lot of recovery during the first year, but recovery can continue long after this. The recovery time is different for each person but generally takes longer with more severe strokes. Recovery is a gradual process as the brain takes time to heal. Rehabilitation can help this recovery.

Rehabilitation is the process where a person who has had an illness regains their skills so that they can be as independent as possible. Rehabilitation after a stroke may mean learning to walk, or to speak clearly.

Rehabilitation

Rehabilitation should start in the hospital where you and your family work with the different therapists and medical professionals in your stroke team. A stroke team is made up of many different healthcare professionals including:

- Doctors
- Nurses
- Physiotherapists
- Speech and language therapists
- · Occupational therapists
- Clinical psychologists
- Social workers
- Dietitians
- · Orthoptists (vision)
- You and your family and friends are very important members of the team.

Rehabilitation is about getting your normal life back and achieving the best level of independence you can. This is done by:

- · Relearning skills and abilities.
- Learning new skills.
- · Adapting to the limitations caused by stroke.
- Finding social, emotional and practical support at home and in the community.

Rehabilitation includes helping you with skills such as:

- Day-to-day activities, for example, walking, dressing, washing, cooking, returning to work and driving.
- · Balance and mobility.
- Use of your arm and hand.
- · Speech and talking.
- Swallowing safely.
- · Adapting to healthy eating habits and lifestyle.

- · Thinking and understanding.
- · Memory.
- · Reading and writing.
- · Sight.
- · Well-being and happiness.

The rehabilitation programme will vary from person to person and depends on your symptoms. Different members of the stroke team will work with you to improve skills in a variety of areas.

The stroke team will try to get a clear understanding of what your life was like before your stroke by speaking to you, your family and your carers. All team members should work together with you to set goals in your rehabilitation so that you may get back to doing the things you enjoyed before the stroke.

It is vital that you put the most effort you can into rehabilitation to increase your chances of a better recovery. Rehabilitation is an ongoing process and for some may take many years.

Where does rehabilitation occur?

Research suggests that the best in-patient care for stroke is provided in a stroke unit or a comprehensive rehabilitation unit. However some hospitals do not have a specific rehabilitation ward so you may be cared for in a general medical ward.

When you are ready to leave hospital, the team working with you will develop a care plan to help you when you go home or to a nursing home. This is often called discharge planning.

The plan will include arrangements for you to receive any care you need at home, equipment and support to link in with services which are available in the community. Members of the rehabilitation team will discuss decisions about the different stages of your rehabilitation with you and your family. If this doesn't happen, ask questions, or get a family member or friend to ask. It is important that you understand the plan for the future.

Depending on the severity of the stroke, rehabilitation options include:

- A rehabilitation ward in the hospital (in-patient).
- The National Rehabilitation Hospital, Dun Laoghaire, Co. Dublin.
- · Community therapy (home visits).
- Your home with outpatient therapy in the hospital or in a rehabilitation service.
- A long-term care facility that provides therapy and skilled nursing care.

If indicated, everyone with stroke should get at least 45 minutes of rehabilitation 5 to 7 days a week for as long as it is needed. Not everyone needs this level of rehabilitation. The amount and intensity of rehabilitation that each person needs will be different. Rehabilitation includes physiotherapy, occupational therapy, clinical psychology, speech and language therapy and, nutrition and dietetic advice from both hospital and community based teams. Some services may not be able to offer this level of intensity due to a lack of staff or other resources.

Your age may be a factor in whether or not you are entitled to receive some rehabilitation and support services.



Rehabilitation in the community

Recovery from stroke requires you and a team of health professionals to work together. In some parts of Ireland not all of the people that make up a stroke team will be available.

This team is made up of:

GP (General Practitioner) - is the doctor you see most regularly after you leave hospital. The GP will look after any problems you have, make sure your medicine is working correctly and may refer you to a hospital consultant or to therapists when you need specific help.

Public health nurse - gives useful advice on managing any difficulties you have in your basic care at home. The public health nurse can also provide you with practical aids and help to arrange personal care if you need it. The public health nurse carries out a nursing assessment, provides nursing interventions and can refer you to other healthcare services as required.

Physiotherapist - helps you with your physical recovery to enable you to regain as much movement as possible. Often, the physiotherapist will help you to do exercises to improve your mobility, balance or the use of your affected arm and will give advice about the best positions for you to sit and sleep in.

Occupational therapist (OT) - works to help you become as independent as possible in your daily life, including working, socialising, leisure activities and driving. If you are having difficulty in any of these areas, the OT will work with you to put together a treatment programme. The OT may also visit your home to see what alterations or equipment you need to help you to be as independent as possible.

Speech and language therapist (SLT) - works with you on any speech and communication difficulties you are having, and helps you to find the best way of communicating with friends and family. The SLT may also give you exercises to improve your speech and use of words and language. The SLT will also help you to manage any problems swallowing your food and drinks.

Dietitian - looks at your diet and nutritional requirements. The dietitian will monitor what you are eating and will advise you about the food and drinks which suit your particular needs. They will give you advice to help you maintain a healthy lifestyle. If you need to receive all or part of your nutrition by a feeding tube, the dietitian will devise a suitable feeding plan to meet your needs and will monitor your progress.

Social worker - helps you and your family with the emotional impact of your stroke. The social worker will support you and provide a link to all the different therapists and medical professionals you are working with. They can also refer you to services that you might find helpful and give you advice in areas such as your finances, employment, housing or care needs.

Clinical psychologist - helps you to improve your thinking skills, such as attention span, memory and reasoning and helps you to adjust to the big changes which the stroke may have on your day-to-day life.

Your family and friends support and encourage you during the different stages of recovery, help you build up your confidence and encourage you to be as independent as possible.

Common physical problems after a stroke

"There wasn't a lot that they could do for Billy given the length of time before he received medical treatment. The damage was very severe. His right side was badly affected. His arm and leg are paralysed. He lost the power of speech and his ability to read and write."

Breda Mulholland speaking on behalf of her brother Billy Mulholland (61), Galway.

- Weakness of one side of the body (hemiparesis).
- · Weakness or drooping of the face.
- Changes in sensation, for example numbness, pins and needles.
- · Balance problems.
- Tiredness.
- · Loss of field of vision to one side.
- Coordination difficulties.
- Difficulties knowing right from left or judging depth and distance.



Assessment and treatment planning is vital, this should happen in the hospital soon after your stroke. The therapy will then be tailored to your specific needs depending on the level of weakness in your limbs. It may include:

- Practising to roll in bed, sitting up, standing up, walking or using your hand and arm.
- Exercises to improve your strength, sensation (ability to sense or feel things), coordination or fitness.
- Using machines to help strengthen your muscles, for example, a treadmill or an exercise bike. These will help reduce swelling and stiffness, reduce pain and give you information about how you are doing.
 Some machines also give you support as you walk, such as the harness support system.
- Stretching or supporting your muscles to reduce their stiffness or pain.
- Teaching you how to safely walk with the help of certain aids, such as a walking frame or stick.
- Helping you to limit the use of your good arm to encourage you to use the affected arm.

You may begin treatment by doing small guided movements and practising simple tasks. As your strength builds up, these movements will become larger and the physiotherapist will introduce more complicated exercises to encourage both sides of your body to work together. This will prevent you from overusing the side of your body that is unaffected by the stroke.

Your family members may be involved in the treatment so they can help you with your exercises at home. The physiotherapist may also show your carer or family member safe ways to help you move in bed or to walk. The physiotherapist may give you an individual exercise programme to help your muscles work as well as possible.

Swallowing difficulties

FACT: Swallowing difficulties affect about 50% of people who have a stroke.

Dysphagia is the medical term for difficulty swallowing. A swallow test is one of the first hospital assessments you will have. It involves seeing if you can swallow a little bit of water without choking or coughing.

The damage to your brain caused by stroke may make eating and drinking difficult. This is because your muscles for chewing and swallowing can be weakened, especially in the early stages after stroke. It is common to have a feeding tube in the early stages, to provide nutrition, fluids and medicines. You may have tubes through your nose or through your abdomen. These tubes can be easily removed if and when you are able to eat and drink sufficiently and no longer need the feeding tube. You may have an x-ray of your throat to see what your swallowing difficulties are and what types of food and drink are safe for you to eat. This x-ray is performed by the speech & language therapist (SLT).

The speech and language therapist will also provide special swallowing therapy and advice to help you eat and drink safely. The SLT will teach you how to sit correctly and proper eating methods to prevent food and drink from getting into your windpipe. If you have serious swallowing difficulties, the feeding tube will have to stay in place in order for you to get the nourishment you need.

Nutrition

A dietitian will give you advice to make sure you are getting the best nutrition to help you recover. The nutritionist or dietitian will make sure that you are getting the nourishment you need by assessing your nutritional requirements, monitoring what food you eat and educating you on the type of food and drink that is appropriate for your needs.

If you need a feeding tube, either because you have a swallowing problem or you're not eating enough, the dietitian will design a feeding plan to suit your needs. He or she will monitor you and adjust the plan as you improve.

Weight changes can happen after a stroke so it is important that you eat healthily when you leave hospital. Eating a healthy variety of foods including plenty of fruit and vegetables, may help you prevent another stroke. If you have diabetes, high cholesterol or high blood pressure, remember to follow the eating plan your dietitian has designed for you. Some practical tips for you to maintain a healthy stable weight:

- Be a healthy weight. You may need to lose or to gain weight after a stroke.
- Eat a balanced variety of foods including plenty of fruit and vegetables.
- Eat plenty of fibre-rich foods to prevent constipation.
- · Drink plenty of liquids.

If you need more advice on healthy eating, ask your GP or hospital consultant to refer you to a dietitian. See our booklet, *Healthy eating*, for more information. You can also contact the Irish Heart Foundation's National Heart and Stroke Helpline on Locall 1890 432 787.

Communication difficulties

"I found it difficult not to be able to talk to people in the way I would have been able to before. When I came out of hospital I wanted to explain to people how I felt and help them to know how to react to me. I wrote down on a piece of paper how I was feeling and I used to give it to people I met."

Tommy Hankey, 63, Sandyford, Dublin.

After a stroke you may have problems communicating with others because you do not understand the words that they are saying, or because you cannot find the right words to express yourself fully.

Some people may completely lose the ability to speak, but can still understand what is being said to them. The ability to read and spell and write may also be affected. When a person has problems understanding and using words and sentences, which affect their ability to communicate, this problem is called aphasia.

Some common features of aphasia are:

- Mixing up yes and no.
- Saying one word but meaning another, for example saying brother instead of sister.
- Getting stuck on a word or phrase over and over again.
- Following only parts of a conversation.
- Being easily distracted by noise.
- · Automatic swearing.
- Slow responses, taking a bit more time to understand what is being said.
- Words on the tip of your tongue.
- · Speaking but not making much sense.

For others speech may become slurred and difficult to understand because the nerves and muscles of speech have been damaged. Sometimes one side of the face and tongue is paralysed or weak and can affect speech. This problem is called dysarthria. Speech and language therapy can help you to recognise words or find other ways to communicate, like using gestures, word-and-picture charts, symbols and computers. The SLT will also show your family and friends ways of communicating with you which make it easier to get your message across.

Visual problems

Stroke causes double vision, blurred vision or partial blindness. Some people cannot see to the left or right and this causes difficulty with balance, co-ordination or recognising familiar things or people.

- Your physiotherapist and OT can help with movement and with exercises to compensate for, or cope with, areas of blindness.
- A psychologist will help you with problems processing information like recognising things and people.
- An ophthalmologist or optician can recommend visual aids like glasses.
- An orthoptist can help with eye-movement problems and explain ways of coping with reading difficulties.

Emotional problems

The two most common psychological conditions that people experience after a stroke are:

- Depression many people experience intense bouts of crying and feel hopeless and withdrawn from social activities.
- Anxiety disorder many people experience general feelings of fear and anxiety, often mixed with intense, uncontrolled feelings of anxiety (anxiety attack).

These may be caused by the change in your life after the stroke or, by the physical damage caused to your brain by the stroke itself. Feelings of anger, despair, frustration and grief are all normal for people who have had a stroke. Life changes that follow a stroke such as changes to relationships, work, finances and dealing with the loss of abilities and confidence can lead to anxiety and depression.

If you are experiencing these problems, do not suffer alone. Both depression and anxiety can be treated using psychological therapies where you can learn to cope with and understand these feelings. Contact your GP or medical social worker to get a referral to a clinical psychologist or psychiatrist for expert advice.

FACT: One third of people develop depression after their stroke (UK Stroke Strategy).

Bladder and bowel control

It is common for people to have difficulty controlling their bladder or bowel after a stroke. This is known as incontinence. For many people this control will come back over time.

- A nurse or continence advisor can show you exercises to help with your bladder retraining, including pelvic floor exercises to strengthen muscles.
- The physiotherapist can teach you exercises to improve your walking and to use a commode or toilet.
- The occupational therapist (OT) can advise on how your house can be adapted and what equipment would make it easier for you to use the toilet.

Occasionally, you may need a tube (catheter) inserted to help drain your bladder. If you need this, it should be done every now and then, rather than inserted for long periods of time.

Dealing with day-to-day activities

"The way I see it is that I used to be able to do things and now I'm learning how to do those things again but I mightn't do it 100% perfect."

Noel, 64, Nutgrove, Dublin.

The problems with movement, coordination and perception following a stroke can make it difficult to perform everyday tasks like washing, dressing, eating and going up stairs. The occupational therapist and physiotherapist work to help you become as independent as possible in your daily life, leisure activities, working, driving and socialising to the best level possible.

If you have cognitive problems following your stroke such as, problems thinking, remembering and concentrating, the OT will work with you to improve these things. This may involve:

- · Using memory aids like diaries and lists.
- Practising physical or mental skills through crafts and board games.
- Giving advice to your family members like keeping instructions short and reducing the amount of distractions when you are communicating.

You may find that you have difficulty with some dayto-day activities. By talking to your care team, you can find ways to make them easier.

Standing and walking can be made easier with simple changes such as, wearing shoes which have good support and rearranging the furniture in your home. Walking up and down stairs can be difficult, but fitting handrails or a stair lift can make it easier. You may need to use a stick, a walking frame or a wheelchair. If needed, an occupational therapist (OT) can advise you about the use of a wheelchair.



Getting out of chairs or your bed – standing up from sitting in chairs or getting out of bed can be difficult. An occupational therapist can advise on the best types of chairs and mattresses for you to use. Your physiotherapist can show you the best transfer technique to help you move about.

Dressing – you may find putting on and taking off clothes difficult. Occupational therapists can advise on simple procedures which can make dressing easier, such as putting your weak arm or leg into clothes first and using shoehorns.

Eating – sometimes you may feel clumsy or awkward using a knife and fork. Using utensils with thick handles can help, as can non-slip mats which stop your plate from moving around the table.

Washing and grooming – again there are many helpful tips an OT can give you which will may make it easier, such as using a walk-in shower.

Going to the toilet – if your toilet is upstairs and you find it difficult to walk, you might use a commode or move your toilet downstairs. You might also need to have rails fitted in the bathroom. Talk to your public health nurse and your OT about what you could do.

Many of the adaptations to your home or the equipment you need can be purchased using a Housing Adaptation Grant. These grants are provided by your Local Authority. Ask your social worker about how you could apply for a grant or call the National Heart and Stroke Helpline on Locall 1890 432 787.

Support in your home

After your stroke, you might need to get extra help around the house or with your personal care. There are different services in different areas.

Your GP or public health nurse can give you information on services available in your area.

These may include:

- · Home help.
- · Care assistants.
- · Meals on wheels.
- Respite in a specialised centre to give carers a short break.

Sometimes a person may need more care than they can receive at home. If this is the case, your social worker can help you to think about the type of care which would be suitable for you, from sheltered accommodation, to residential care in a nursing home or 24-hour nursing care.

Organisations providing support

There are organisations in the community which can help as you settle in to your life after stroke:

Day hospitals are generally in the grounds of a larger hospital. They care for mainly older people who are well enough to live at home but who need regular medical care or the services of the hospital therapists. When you leave hospital arrangements may be made for you to go to the day hospital if this is necessary.

Day centres provide an important social outlet – the opportunity to meet other people who have had a stroke or other illnesses, and may offer activities such as painting, swimming, and outings. They do not provide medical care and generally do not have therapists providing rehabilitation.

Stroke support groups help people who have had a stroke to meet up and discuss common issues. Groups often meet once a month and many also organise social activities and outings. Visit www.stroke.ie or contact the National Heart and Stroke Helpline on Locall 1890 432 787 for information on stroke groups in your area.

Financial support

Many people who have had a stroke will be entitled to receive social welfare payments. Payments are made by the Department of Social and Family Affairs and the Health Service Executive (HSE).

You can qualify for certain payments if you are sick for just a short time. For other payments you need to show that you have an illness or disability that will last longer than one year.

You should discuss your entitlements with your social worker. He or she can help you to contact your local social welfare office or local health office. You can also get information on the different types of payments and grants available from the Citizens Information Board.

Driving

If you would like to start driving again, you must tell your motor licensing authority and your insurance company that you have had a stroke. You will then need a medical report from your doctor describing any disabilities your stroke has caused.

In some cases, your doctor will not allow you to return to driving, for example if you have epilepsy or seizures and a particular type of sight loss called hemianopia. If you or your family has concerns that your stroke has affected your ability to drive, talk to a member of your care team and an on-road driving assessment may be arranged for you.

If you drive a commercial or public-service vehicle, current Irish driving regulations are very restrictive after a stroke. Even if you recover enough to start driving your private car, only in exceptional circumstances will you be able to go back to commercial or public service driving. For more information, talk to your consultant and your care team about this.

Sex after stroke

Sex is an important and normal part of people's lives. It is natural to feel concerned about whether you will be able to have sex after a stroke. You may be worried about whether you will be physically able to have sex or you could be concerned about changes to your appearance which make you feel less attractive. Low mood and depression can also affect your desire for sex.

The good news is that the ability to have sex is rarely damaged by a stroke and sex is unlikely to cause another stroke. At the same time it might take a while to get back to a satisfying sexual relationship and you might have to make some changes, depending on how your stroke has affected your physical movement.

It is very normal to have questions about sex and your care team will be happy to discuss any concerns with you. Alternatively, you can contact the National Heart and Stroke Helpline on Locall 1890 432 787.

Getting back to work

"When I went back to work people were very supportive. But because I don't have physical signs of my stroke people can tend to forget. They might correct my grammar or something like that. They forget that mixing up words is a result of my stroke."

Marie Walsh, 34, Clonsilla, Dublin.

Once you have begun to recover and have developed ways of managing the changes and difficulties caused by your stroke, you might start to think about going back to work.

It may be possible for you to return to work part time or full time, or maybe to a different job with your previous employer, or even a new job with a new employer.

Talk to your care team about the best way to approach your employer about going back to work. The law says that employers must make reasonable adjustments to help you to return to work after your stroke. They may need to make some adaptations to your workplace, such as getting a new type of office chair or a computer. You might also need to change the way you work if, for example, your stroke has affected your ability to manage equipment which is relevant to your job.

If you will not be returning to your previous employer you could undertake a vocational assessment to look at other types of work you might be able to do. Talk to your OT who will be able to provide you with information on what assessment services are available.

You could also talk to FÁS, the training and employment agency (www.fas.ie) which offers employment support schemes and workplace adaptation grants.

Looking after the people caring for you

As you move on from your stroke you will hopefully continue to receive support and care from your family and friends.

You will probably want to support your carers in their caring role. You can encourage them to take time for themselves to do the things they enjoy and to talk to and get involved with organisations which support carers.

You could also use respite services where you will receive care for a short period in a respite centre and your carers can take a short break from their caring duties.

Tips to helping you with your rehabilitation It is important to focus on your recovery and stay as positive as possible.

- Practise the tasks therapists have taught you between sessions – but don't exhaust yourself.
- Understand what each task is designed to do and why you are practising each task. This will help to keep you motivated.
- Remember that progress can be slow as recovery is a gradual thing.
- Talk to your doctors, nurses and therapists about any concerns or questions you have.
- Try to eat healthily.
- If you can, try to do some physical activity within your limitations. Your care team can give you advice on activities that would be suitable for you.

Useful contacts

Irish Heart Foundation

National Heart & Stroke Charity

Tel: 01 668 5001

National Heart and Stroke Helpline

Mon-Fri 10am-5pm: Locall 1890 432 787

Email: info@irishheart.ie or advocacy@irishheart.ie

Website: www.stroke.ie or www.irishheart.ie

Volunteer Stroke Scheme

Support groups for stroke patients

Tel: 01 4559036

Website: www.strokescheme.ie

Carers Association of Ireland

Services nationwide for family carers

Tel: 057 9322920

Email: info@carersireland.com Website: www.carersireland.com

BRÍ Ireland supports and advocates for all those

with acquired brain injury.

Tel: 01 235 5501

Email: info@briireland.ie Website: www.briireland.ie

Caring for Carers

Semi-state body with information for carers.

Tel: 065 68 66515

Website: www.caringforcarers.ie

Acquired Brain Injury Ireland – community supports

for people affected by acquired brain injury.

Tel: 01 280 4164

Website: www.abiireland.ie

Headway – specialise in brain injury rehabilitation

after illnesses such as strokes.

Tel: Locall 1890 200 278 Email: info@headway.ie Website: www.headway.ie

National Rehabilitation Hospital

Dun Laoghaire Co. Dublin

Tel: 01 235 5000 Website: www.nrh.ie

Citizens Information Centres

Information, advice and advocacy on a range of public and social services.

public and social services.

Locall 1890 777 121 or 021 452 1600. Website: www.citizensinformation.ie

Please make a donation today

The Irish Heart Foundation is Ireland's national charity dedicated to the reduction of death and disability from heart disease and stroke. Over 90% of our funding comes from public and business donations. We depend on your goodwill and generosity to continue our work.

If you found this booklet useful, please help our charity to continue to provide heart & stroke information by donating today.

You can make your donation today:

By post: Irish Heart Foundation,

50 Ringsend Road, Dublin 4

Online: www.irishheart.ie

By phone: 01 6685001

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Irish Heart Foundation. 50 Ringsend Road, Dublin 4

Phone: +353 1 668 5001 ax: +353 1 668 5896 Email: info@irishheart.ie

Locall 1890 432 787 Monday to Friday 10am to 5pm

www.irishheart.ie www.stroke.ie





The Irish Heart Foundation is the national charity fighting heart disease and stroke and relies on charitable donations for 90 per cent of its funding. We support, educate and train people to save lives, campaign for patients, promote positive health strategies, support research and provide vital public information. We need your support – through donations, as a volunteer or on our training courses.

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