How to get the maximum benefits from exercise

Physical Activity
For Neurological conditions

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www.ltnc.org.uk

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How to get the maximum benefits from exercise

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Physical activity for long term neurological conditions

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This manual is available in a larger font size, PDF and CD from www.
This handbook was produced as part of the Department of Health funded Long Term Individual Fitness Enablement (LIFE) research project in Oxford and Birmingham, UK.

The aim of the LIFE project was to study the benefits of exercise and physical activity in long term neurological conditions using a support package called the Physical Activity Support Scheme (PASS).

This handbook was provided to help support participants to exercise.

Following the conclusion of the project the handbook is now being made available to more people.

The handbook aims to provide you with information to help you to exercise more easily and achieve the health benefits that exercise can bring and advice on how to plan your exercise routine.

It includes information on why and how exercise can help you and some answers to frequently asked questions.
There are ten million people in the UK living with a neurological condition. These conditions affect all ages and people. These conditions may affect mobility, balance, strength, flexibility, thinking, coordination. This booklet is aimed at enabling you to exercise and participate in physical activities in the community.
Introduction

Why Exercise?
- Physical activity is a broad term that includes any movement, from participating in sport to washing up. Exercise is physical activity that targets aspects of everyday function such as strength, endurance and flexibility.

Why Exercise?
- Exercise is good for you.
- Regular exercise has health benefits for everyone and it can be an enjoyable social activity too.

Why is it good for me?
- Regular exercise can improve the strength and condition of muscles and joints in your body that can help to increase your flexibility.
- Exercise is good for your heart and lungs and can help make your breathing more efficient and easier.
- Exercise strengthens bones and can help prevent osteoporosis.
- Exercise can help improve emotional health as well as physical health enhancing your mood which in turn can improve your quality of life.
- Regular exercise alongside a healthy balanced diet can help with digestion, sleep, losing weight and controlling blood pressure.
- Exercise affects your mood and even moderate amounts can help with depression, fatigue and improve energy levels.
- Exercise can be enjoyable and is a good way to spend time with your friends.
- Exercise can help clear your mind allowing you to be more focused and can increase your concentration.
- Exercise is good for your heart, keeping it healthy and it can also help to increase your stamina.

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How can we help you to exercise?
As someone with a neurological condition you may have had limited access to participation in exercise or physical activities. This may have been due to very simple reasons such as finding a suitable exercise facility or difficulty getting to a gym due to transport issues. Perhaps it may be a lack of confidence in the benefits of exercise or not being confident the people in a fitness gym/centre will know about your condition and how you can safely exercise.

Whatever the reason you may have received short periods of hospital-based rehabilitation but found there is little community activity or focus on helping people like yourself to continue to stay fit and healthy.

Most of us have some sense that the benefits of being fit and healthy include:
- **Encouragement from a local fitness instructor**
- **Martin gets specific guidance from a physiotherapist**

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active are positive for all and we want to be as mobile as possible as this can enable us to maintain our independence, social and family life but it can be difficult to access the right information and find help.

Recently we have been involved in research collaboration between people with neurological disabilities, and health and fitness professionals experienced in helping them to exercise effectively. We have listened to everyone and as a result developed this handbook that we hope will help you to take part and enjoy exercise in your community.

This handbook aims to provide you with information to help you to access fitness facilities and exercise more easily. It is a guide to helping you with some of the problems we’ve come across such as transport and entering new/strange buildings. It also aims to help you with overcoming other obstacles to exercise that we can all identify with – for example not wanting to exercise on our own, not being able to find the time, or needing someone to look after loved ones while we are away from home.

Hopefully the information in this handbook will help you find it a less daunting experience to get involved in exercise.

We have listened to what you need and this is what you have told us will help you exercise

1. ✔ Advice on access and transport
2. ✔ Fitness instructors
3. ✔ Gym facilities
4. ✔ Medical and physiotherapy advice
5. ✔ How to exercise safely – practical tips and advice

Physical Activity for Long Term Conditions.

1. ✔ Advice on access and transport

Transport is often a major factor in accessing different leisure and social activities. With constraints on most NHS services we do understand that getting out and about is often very difficult and often needs to be paid for. We don’t have all the answers but we hope to offer you some advice and information on how you may get to and from the gym. You may be able to travel by car or get a lift with a family member or friend.
Your local GP service may be able to provide you with information on local volunteer car services and, council transport schemes such as Dial-a-ride are often available and should be listed in local telephone directories or, on the county council web sites. We have found that travelling with / without a companion in a taxi is sometimes more cost effective and may work for you, it all depends how far you have to travel. It's worth exploring local taxi services as they often operate community services such as ‘school-runs’ for families.

2. Fitness instructor

The fitness instructor at the gym or exercise facility will individually assess you and take into account your goals and prescribe your exercise programme. They will ask you a series of questions related to you and your health to see if there is anything they need to check with your doctor first.

The instructors will be qualified in the discipline(s) they instruct and often listed with the Register of Exercise Professionals. It is expected that fitness instructors will be qualified in awards that fulfill the criteria ‘Supervising Exercise with Disabled People’ or ‘Exercise Programming with Disabled People’ (YMCAfit). This level of qualification ensures instructors have adequate knowledge enabling safe exercise prescription and supervision for a range of clients.

The fitness instructor will work with you to ‘tailor’ your exercise programme to your goals and promote your independent use of the gym as far as possible.

3. The gym

Generally we have recommended Inclusive Fitness Initiative (IFI) Gyms but not all parts of the UK have access to these facilities. In this instance you can contact your local gym, GP or physiotherapy service and get some advice as to suitable facilities in your locality.

Information on IFI gyms closest to you are listed in the back of this handbook and can also be accessed on the web site: www.inclusivefitness.org
However the Disability Discrimination Act (2005) does provide legislation for exercise facilities to ensure appropriate modifications are in place for disabled persons to use facilities such that there is equal access for all persons to exercise. In general gyms are expected to provide:

- **Access** – there should always be good physical access to the gym and fitness area with changing rooms and toilet facilities for everyone.

- **Fitness equipment** – there will be a range of fitness equipment suitable for you to use for your exercise programme.

- **Communication** – exercise facilities should include induction loops for the hearing impaired, appropriate signage for visually impaired users and email, internet or phone systems to book exercise sessions.

- **Monitoring** – facilities should monitor how well they understand the needs of clients when exercising.

4. **Medical and physiotherapy advice**

   For each area in the UK this will likely be different and depend on access to services though you will always have access to your GP for any concerns you may have when considering starting to exercise. Indeed it may be the case that the fitness instructor would like confirmation from your GP that it is safe for you to carry out an exercise programme as it involves exercising your heart.

   In some circumstances you may find it helpful if a specialist physiotherapist who knows about your condition is able to visit the gym with you. A physiotherapist would be able to offer advice on how to use the equipment more easily e.g. if you have a tight hand or foot that needs holding in place or advice on how hard to exercise.

   Therefore if you have contact with the physiotherapy service they may be able to help. Alternatively your GP or neurologist (if you have one) may be able to request physiotherapy services. This will be different for everyone but it’s worth asking.
Preparing to exercise

Now that you have made the decision to be involved in exercise

Congratulations!

You now need to work out how it will fit in with your daily routine. This will be different for everyone.

It is likely that you may eventually exercise for about twenty to thirty minutes depending on your level of fitness and wellness but initially this may be a lot less, say five minutes and you will build up gradually.

It is likely that you may have days when you can do a bit more or you might do less. This is normal.
It is likely that it will take a period of time to travel to the gym, exercise and then get home. It may not be unreasonable to assume going to the gym could take about two hours of your day.

If you have a set routine for getting up in the morning or to get to work or start your day then try planning where exercise fits into your daily routine. Make it realistic and don’t try to fit in too much in your day.

Make it easy on yourself so that you get the maximum benefit from your gym experience.

Current guidance for healthy adults encourages people to attempt to be active most days. There is no current guidance for people with neurological conditions. You may find that it is best to start by exercising once or twice a week and see how it goes.

**Your First Session**

The first assessment session will normally last not longer than one hour. This first session will be led by the fitness instructor.

After this first assessment you will be given an exercise programme to assist you in achieving your goals. Most people find they can attend once per week but you may find time to attend more often.

**Exercise programmes**

Exercise programmes will be jointly set-up with you and based on what you would like to achieve. You should take into account the variability in your condition and how some days it is possible to do more and other days less. Listen to your body.

**Frequency** – there will be specific instructions in your programme on how much to do for each exercise.

**Intensity** – there will be specific instructions in your programme on how hard to work and what you should be working towards.

**Duration** – the programme will have time limits on the exercises so you know how much to do.

**Progression** – Working towards small goals will help you to focus and the instructors are always there to help you achieve the next goal.

Exercise can often involve helping with flexibility, balance, health and mood.
Your Goals

It will be helpful for you to discuss with the fitness instructor what you would like to achieve from your exercise program. This can be a number of things such as in the diagram above:

- Improving the strength in your legs or arms,
- Increasing your muscle flexibility,
- Losing weight,
- Being fitter,
- Or walking faster

Setting yourself a target or a goal to achieve will often help you to exercise. Like any one of us attending the gym for the first time we would look at what is realistic and set small little goals to achieve this. And, it really can be anything that you want it’s up to you!

It may simply be that you want to strengthen your legs so you can stand for longer, that you enjoy the social side of exercise, or, that you wish to be healthier and lose weight.

Keeping going

Setting realistic goals helps you to keep going and you will feel more like exercising if you are achieving your goals. It is important to vary your programme a little so that you keep yourself interested in exercising. This could involve joining a local health walk or just adjusting your day so you walk a little bit – it doesn’t always have to be the gym.

If things are getting a little difficult and you want a new challenge to help you keep going then talk to the fitness instructor. They will be able to help you.

It sometimes helps to have someone go to the gym with you. That way you can motivate each other.

Your carer or helper should always be welcome to come with you to the gym but do ask at the first session.
Exercising is different for everyone. Sometimes you can do more, sometimes less. Below is a list of the different forms of exercise and some of the symptoms you may experience when you exercise. Remember you may experience, some, all or none of these.

**Muscle endurance**

If you have muscle weakness then this may lead to muscle fatigue often as a result of lack of endurance or ability to sustain a powerful muscle contraction. Once you start to exercise then it may be that this symptom reduces as the muscle is able to use its energy more efficiently and you become more able to use it.

**Muscle strength/speed/power**

You may have reduced muscle strength, this often occurs in the shoulders, legs and ankles, which reduces your ability to move fast and powerfully at will. A strength reduction in your leg muscles can often lead to problems like getting out of a chair. Reduced muscle strength is common in people with neurological conditions. The leg tends to be affected more than the arm and weakness in certain muscle
groups may directly relate to problems with specific activities such as walking and climbing stairs. Whilst exercise cannot change your neurological condition, you may maintain your muscle strength and coordination by strengthening exercises.

Flexibility
If you have increasing difficulty moving your body alongside muscle weakness and joint stiffness then this may result in decreased flexibility.

Stiffness can occur because you are not moving or not able to move about easily. Joint stiffness is also a feature of other conditions such as arthritis, wear and tear and age. As long as you do not have pain or swelling with your joint stiffness exercise should have a positive benefit. Joints contain a small amount of fluid that acts as a lubricant, a bit like oil in the car engine, and if the joints are not moving the fluid becomes thicker and stickier which in turn makes the joints feel stiffer.

It may be that you find it harder to move your hips and knees into the correct position or bend down and tie your shoe laces. Some people have spasticity or muscles that work too hard when you aren’t even trying to work them. These spastic muscles in our experience are often weak and exercising them can help reduce the stiffness in the muscle.

Joints
The range of movement in your joints may be reduced due to stiffness or increased (hypermobile) due to muscle weakness.

Spastic, rigid muscles will reduce the range of movement at a joint due to the increased resistance to movement in the muscle. It is important to work within your comfortable range at least to begin with. Once you are familiar with the exercises you can try to stretch your joints a little further each time.

Hypermobile joints
Hypermobile joints can be a feature of muscle weakness or muscle imbalance (where the muscle one side of a joint is much stronger than the muscle the other side). If the muscle is not strong enough to fulfil one of its functions it can sometimes move too far. This can be seen for example when the knees straighten beyond a straight line and seem to ‘bend backwards’. It is important to protect the joint from this excessive extra movement if possible as it can cause pain and excessive wear and tear on the joint in the long term.

Contractures
Contractures are where the muscles are too tight and prevent a joint moving through normal range. Contractures can happen in any muscle, commonly seen at the knees and hips in people who do not walk. Contractures are very difficult to change once established and many people are given stretching exercises to do at home by physiotherapists early on in their care to try to...
Carefully balanced equipment offers support

Preventing contractures. Only extreme contractures would seriously limit exercise otherwise it is a matter of adapting the exercise to the range of movement possible.

Protecting joints
Protect joints from overstraining wherever there is altered movement due to weakness or spasticity. It may be necessary to alter the start or end position of an exercise to limit the range that you exercise through. The fitness instructor should advise you on the correct way to do an exercise. Follow the instructions carefully but also say if something does not feel right for you.

Pain
Chronic pain is very disabling and can make you tired and miserable which in turn can reduce your ability to function or cope with day to day activities. However doing nothing doesn’t help, keeping occupied is often a better solution. Exercise can help people deal with chronic pain and is known to make joints and muscles feel more comfortable. Once your exercise reaches a threshold (which is different for each person) the body makes and releases chemicals into the body that are natural painkillers and also make you feel good.

When pain levels change
If your pain levels change during your exercise session or between sessions and you are worried about this you should report it first to the fitness instructor. It might be the way that you are doing a certain exercise or you may be working a certain muscle too hard. Once these causes have been ruled out the physiotherapist would probably want to discuss with you what other steps to take to deal with or prevent the pain depending on the cause.

Fatigue
Fatigue is a feature of many long term neurological conditions. Stress, feeling low, overweight and being generally unfit can also cause fatigue.

The cause of fatigue is not clear and is probably due to a combination of things. People with mobility problems report not being able to walk and talk at the same time and say that it is very mentally tiring requiring them to keep stopping to rest.

If fatigue is a problem for you then it is important to pace yourself and to arrange to exercise at the best time of day for you.

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Will the gym and instructors know about my condition?

The fitness trainer may not know about every neurological condition, but they should have qualifications that give them an understanding of complex conditions and how to modify an exercise programme to suit your needs. Your fitness trainer should be trained to a minimum level 3 on the Register for Exercise Professionals or have the Inclusive Fitness Initiative level 2 award in Supervising Exercise with Disabled People. You can also ask for a trainer who has experience in Exercise Referral Schemes and is trained as a Referral Programme Consultant.

You may also already have a physiotherapist involved with your care or are able to access their services through your GP or Neurologist. Their advice and support along with the fitness instructor will help you to exercise.

What should I wear?

Wear something light and comfortable, probably loose fitting and may be a layer that you can remove because you may get warmer when you exercise.

Frequently Asked Questions

Group sessions are a source of fun and friendship.
you are going to be standing and walking then remember to wear sensible, supportive, well-fitting footwear and if you wear splints for walking to bring them along to the session too.

**What about my medication?**
The instructors should understand the medication you are taking and you will know when you need to take it. Some medication may affect your response to exercise and exercise in itself may affect your medication. If you are in any doubt then contact your GP or Consultant about medication.

**Should I avoid eating or drinking before exercise?**
It is not a good idea to exercise when you have just eaten a big meal but it is also not a good idea to exercise when you are hungry. It is best to leave at least an hour after a meal before exercising but if necessary have a light carbohydrate snack e.g. cereal bar. Also remember to drink water before during and after exercise.

**How much exercise should I do each week?**
The British Heart Foundation recommends five, thirty minutes per week for adults or two and a half hours per week if you prefer. Many people do not achieve this amount of exercise. However ANY exercise is better than none at all so if you can only manage ten minutes that is still a great start.

**How often should I exercise?**
Twice a week would be a good starting point. You will see a quicker response with twice a week than once a week but don’t be put off if you can only manage once a week.

There is nothing to stop you also exercising at home in addition to gym sessions if you want to however it is important to space out your exercise through the week to give your muscles time to recover from one session before doing the next one. Forty eight hours is usually enough time therefore exercising on alternate days is recommended. This brings you to three times per week.

**How much exercise should I do in a session?**
How much you can do depends on how fit you are. Your fitness trainer will assess how fit you are at your first session and start you at the right level. Remember that you can take as many rest breaks as you need to. As you get used to your exercise routine you should be able to reduce the rest breaks you need. Once you can comfortably work for ten minutes continuously you can then start to increase the time that you exercise for in any one session. Your fitness trainer will advise and support you.

**When is the best time to exercise?**
This depends on you and your lifestyle. If you get tired by the end of the day then it is probably best to exercise in the morning when you are fresh. If you work then it may be better to exercise...
straight after work on your way home. You may need to try a few different times until you find the one that suits you. Also remember that the gym will have busier and quieter times and this may influence when you choose to exercise. Generally the gym is quietest in the middle of the morning about ten thirty or eleven am.

How hard should I work?
This depends on how fit you are. The British Heart Foundation recommends you exercise at a pace to suit your fitness. You should aim for light to moderate intensity to begin with which means that you will feel warmer, possibly be aware that your heart is beating faster but still be able to hold a conversation with someone. Always ask the advice of your fitness trainer as they will be able to help here. The research evidence to date suggests that mild to moderate exercise intensities are beneficial for people with neurological conditions.

Will the exercise be painful?
The exercise you do at the gym should not be painful. You should not get any pain whilst you are exercising. You may experience some muscle aching or muscle tiredness after exercise particularly if you are not used to exercising. However these feelings should not be long lasting, they should go in two days and in fact as you continue to exercise they should be less and less obvious.

Can I do too much?
Yes, if you don’t listen to your body. If you are not used to exercising it is best to begin gently and build up gradually. If you over do it you will know because you will be very tired or perhaps your legs will feel wobbly, or you will have more difficulty doing your usual activities.

Most people over do it at some time when starting to exercise that is part of finding out what your limit is. If you do over do it don’t panic, ask the advice of the fitness trainer rest for a couple of days and then return to exercise but do a bit less than the last time.

Will I feel tired?
Exercise very often helps to improve fatigue. However to begin with you may feel more tired or you may be tired as a result of the exercise you have done. This is quite normal and this tiredness usually improves as you get used to your new level of activity. This tiredness may not be the same as the fatigue you experience with your condition. You can also expect the muscles to feel tired or aching the day after you exercise especially if you have done more than usual. This is because the muscle takes time to recover from exercise.

Should I exercise when I am unwell?
NO, no one should exercise when they are not well. If you have a temperature or an infection this will put undue stress on the body’s repair mechanisms. You should wait until your temperature has come down and you feel ‘normal’ again before you return to exercising. There are many benefits to exercising and we realise it can take a great amount of effort and planning to make it part of your lifestyle.

Always consult your GP before you start any exercise and ask about any local Exercise Referral Schemes.

Use the handbook to help you exercise.

Bibliography