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The LIFE group

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# Supporting community-based exercise in long-term neurological conditions: experience from the Long-term Individual Fitness Enablement (LIFE) project

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## The LIFE group

### Abstract

**Background:** Patients with long-term neurological conditions often have low levels of physical activity and participation in exercise. Exercise referral schemes have been introduced in the UK to encourage physical activity in sedentary and clinical populations but typically exclude patients with long-term neurological conditions. We have developed and evaluated an exercise support system for people with long-term neurological disability, called the Physical Activity Support System, to enable them to use local gym facilities safely and effectively.

**The intervention:** We describe the Physical Activity Support System for people with long-term neurological conditions and provide data on the use of this system in a phase II randomized controlled study trial. The system has five key components: access and transport advice, the fitness instructor, the gym, health professional support and how to exercise safely.

**Results:** Ninety-nine patients with a range of long-term neurological conditions used six different community exercise facilities in Oxfordshire and Birmingham. Average gym attendance was one session per week for 12 weeks. Participants required an average of three 1-hour face-to-face physiotherapy contacts to achieve this. The average direct cost for the support system was £275.

**Conclusions:** The scheme achieved comparable exercise participation to standard GP exercise referral schemes operating in the same centres and offers a relatively cheap, practical and feasible system for supporting people with long-term neurological conditions.

### Keywords

Exercise, physical activity, neurological diseases, neuromuscular diseases

## Introduction

Participation in regular physical activity improves health and well-being.<sup>1–4</sup> Accordingly, governments worldwide have introduced programmes to encourage physical activity.<sup>5</sup> In the

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UK exercise referral schemes have been introduced to encourage physical activity in sedentary and clinical populations.<sup>6,7</sup> These community-based schemes are typically designed for clients who can be safely supported in standard exercise facilities. However, attaining a physically active lifestyle in people with long-term neurological conditions can be difficult. These conditions may present with varying underlying pathology, physical and cognitive impairments and patients are often deterred from using community facilities and standard exercise referral schemes.<sup>8,9</sup> It is therefore unsurprising that people with long-term neurological conditions are found to have low levels of physical activity and participation in exercise, although when they are questioned they express a desire to be active<sup>8,9</sup> and to comply with government advice.<sup>6</sup>

People with long-term neurological conditions fall outside current UK exercise referral schemes, but the 2006 National Institute for Health and Clinical Excellence (NICE) Public Health Intervention Guidance, recently confirmed by the UK Minister of State for Health<sup>10</sup> specifically urges commissioners, practitioners and policy makers to provide exercise prescription for these patients; even though they may not be able to exercise for the recommended 30 minutes moderate activity on at least five days a week.<sup>11</sup> While the importance and case for enabling individuals to be active is clear,<sup>6</sup> how best to facilitate an ongoing physically active lifestyle is not known.

The UK's NICE guidelines emphasize that practitioners, policy makers and commissioners should only endorse exercise referral schemes that are part of rigorously designed and controlled research studies in order to develop and evaluate more effective approaches to increasing exercise in long-term conditions.<sup>11</sup> We have therefore set out to develop and evaluate an exercise support system for people with long-term neurological conditions. The system is called the Physical Activity Support System and is intended to enable people with long-term neurological conditions to use local gym facilities safely and effectively. The system has

recently been evaluated in a phase II randomized controlled trial in 99 patients with long-term neurological conditions, and this trial and its results are described elsewhere.<sup>12</sup>

This paper describes a community-based exercise support system for long-term neurological conditions. We first describe the system used in the study trial and then give our recommendations and suggested improvements to the system in the discussion. We also provide some data on gym attendance, the amount of health professional (physiotherapist) time spent in supporting patients within the support system and the confidence patients have to continue to exercise after the intervention. However we start with a brief overview of the supporting evidence.

### Evidence base for the support system

The support system was developed using evidence from focus groups<sup>9</sup> with providers and patients, from theoretical exercise models for healthy and minority populations,<sup>13,14</sup> from NICE guidance for exercise referral schemes<sup>11</sup> and from published experimental quantitative and qualitative studies on helping people with long-term neurological conditions to exercise in the community.<sup>7,15,16</sup>

A successful system should build on factors that facilitate exercise and overcome barriers to exercise. People with a disability have specifically identified the following barriers for exercise:

- Practical and organizational factors – a lack of suitable local gyms that can be accessed easily and safely<sup>9,17,18</sup>
- Equipment – a lack of equipment suitable for and usable by disabled people<sup>17,18</sup>
- Transport – often unavailable, inappropriate and costly<sup>9</sup>
- Negative personal experiences and attitudes – fear and embarrassment of exercising (especially in the presence of obviously fit and healthy people)<sup>19</sup>
- Perceptions that fitness instructors will lack knowledge about their condition and how to

help them participate in exercise safely and effectively.<sup>9</sup>

People with a disability have specifically identified the following facilitators for exercise:

- Positive personal attitudes<sup>20–22</sup>
- Individually tailored gym programmes<sup>23</sup>
- An exercise place that actively supports people with similar conditions and disabilities<sup>22,23</sup>
- An exercise programme that considers individual motivators for exercise, not necessarily assuming individuals will be motivated by factors such as weight control, body shape or keeping fit.<sup>23,24</sup>

We therefore designed a system that was intended to minimize the difficulties generated by the barriers and to ensure that as much facilitation occurred as possible.

## The intervention

The support system comprises five key components. These are described in a complementary exercise handbook that is given to the patient.<sup>25</sup> The handbook additionally provides practical advice with specific sections on why someone should exercise (emphasizing their personal benefits), and on the general principles governing how to exercise.

The five key components of the system are:

1. Access and transport
2. The fitness instructor
3. The gym
4. Health professional support (physiotherapist)
5. How to exercise safely.

## Access and transport

One of the major barriers to undertaking exercise is the difficulty in accessing suitable facilities. Access and transport issues are addressed both in the handbook and by the supporting

physiotherapist. Our pilot research<sup>9</sup> highlighted that patients often delayed starting exercise programmes or failed to initiate exercising because of various concerns, including: how to get the gym, how to find their way around the building and/or how to access changing rooms and toilets.

Thus the handbook covers practical issues including where to find the gym; how to use local voluntary car services, taxis, or public transport; and where to park. In addition the physiotherapist could also help patients decide on the best route to their local gym by providing further advice and transport options.

The costs of attending a gym have been highlighted as a barrier to exercise participation,<sup>9</sup> and in order not to discriminate against patients with a low income, travel and gym costs were paid in this study. As far as possible patients were encouraged to use transport that could be sustainable (i.e. that would be practical and affordable after completion of the project).

We noted that ensuring patients had straightforward easy travel and access to the gym was important in getting them started. Advice and practical transport solutions ranged from supplying directions and maps, to organizing and meeting the transport service at the patient's house. Transport choices varied from public transport to car and taxi services. It must be emphasized that all expenses were covered by the study; taxi transport would rarely be sustained outside a study.

## The fitness instructor

Patients are often concerned that a non-medical fitness instructor may not understand their condition and thus may offer inappropriate advice. Conversely, many fitness instructors lack confidence and knowledge in advising people with long-term neurological conditions.

Research evidence from long-term neurological conditions,<sup>4</sup> the American College of Medicine and the American Heart Association

guidance for the elderly and adults with chronic conditions<sup>26</sup> confirm that exercise programmes should contain aerobic and anaerobic components and should encourage participation in cardiovascular, skill, flexibility, muscle endurance and strengthening exercises. There is guidance on safe effective doses of these exercise components but the minimal or optimal doses of these fitness components for people with long-term neurological conditions have not been established.<sup>27</sup>

The handbook provides information on what the patient can expect from the instructor at their first appointment, including how they will be supported in exercising. Patients are encouraged to express their hopes and fears, and their health and fitness needs and they are reassured the fitness instructor will work with them to design their own, individual exercise programme.<sup>28</sup>

This study used fitness instructors on the UK Register of Exercise Professionals, level 3 or above (<http://www.exerciseregister.org/>). The fitness instructors were responsible for assessing and prescribing exercise programmes in the gym. Each patient undertook a safety screening assessment with the fitness instructor using a standardized pre-activity readiness questionnaire (PAR-Q).<sup>29</sup> The fitness instructors then designed an appropriate exercise programme, taking into account the patient's wishes, health and fitness needs.

Each patient was shown how to carry out individual exercises and use the equipment safely. The patient, fitness instructor and physiotherapist established which equipment was accessible and usable or, if necessary, how to adapt equipment for them. The programme routinely contained cardiovascular, flexibility, muscle endurance and strengthening exercises programmed at an appropriate intensity, duration, frequency and progression according to exercise prescription principals.<sup>26,30</sup> Fitness instructors monitored patients and progressed or changed programmes as and when needed.

During the first few exercise sessions patients were monitored for possible adverse events (such as the development of ischaemic cardiac pain or

musculoskeletal injury) according to American College of Sports Medicine guidelines for exercise in clinical groups.<sup>26,30</sup>

We noted that it seemed important to the patients that they went to the gym with the physiotherapist who they had spoken to on the phone. Similarly, accompanying the patient around the gym showing them where to go and introducing them to gym staff helped patients become more confident.

### The gym/fitness centre

Another major concern of patients is that the gym will not have suitable fitness equipment – and some do not. This was overcome by using Inclusive Fitness Initiative gyms to deliver the intervention (<http://www.inclusivefitness.org/>). The UK Inclusive Fitness Initiative is a charitable project that focuses on creating a structure to support both disabled and non-disabled people to exercise. Accreditation for the Inclusive Fitness Initiative programme requires the gym to fulfil certain criteria, including building access, equipment and staff training. However, Inclusive Fitness Initiative gyms are not available in all settings and other facilities should be appropriate as long as they meet access, equipment and staff attitude parameters set out by the UK Equality Act.<sup>31</sup>

In general the gym should have the following features:

- Easy access – There should always be good access to the gym and fitness area with changing rooms and toilet facilities for everyone whatever impairments they may have.
- Appropriate fitness equipment – There should be fitness equipment suitable for people with a range of disabilities. Fitness equipment should include adaptable or removable seats for people in wheelchairs and, room to manoeuvre around equipment.
- Facilities to ensure good communication – Exercise facilities should include induction loops for the hearing impaired and appropriate signs for visually impaired people, and

email, internet or phone systems to enable easy booking of exercise sessions. Staff at the exercise facility should have been provided with disability awareness training to ensure they are able to communicate with disabled people and listen to their needs.

- The ability to tailor and monitor exercise – Fitness instructors should be appropriately qualified to prescribe, monitor and adapt exercising programmes.

We also found that gym staff often provided ongoing support to patients by meeting them in the car park and escorting them to the gym, viewing it as part of their role in enabling that person to exercise.

## Health professional

Patients with long-term neurological conditions are familiar and comfortable with being treated by medical practitioners and therapists, but are less confident in the skills of other people, including fitness instructors. Our pilot work suggested that physiotherapy support at the start of exercising at a community gym was vital<sup>9</sup> and patients with different long-term neurological conditions specifically endorsed physiotherapists as their preferred professional.<sup>9</sup>

The study physiotherapist was responsible for arranging and attending the first appointment with the patient. Furthermore they ensured the patient had the exercise handbook and information on how to get to the gym and they were a point of contact for the patient and fitness instructor whenever additional support or information on exercise for long-term conditions was needed.

The physiotherapist should have specialist knowledge, assessment and treatment skills for long-term neurological conditions and should be experienced in exercise delivery. The goal is for the physiotherapist to ensure the patient's exercises are safely and effectively undertaken as independently as possible without the need for one-to-one support.

## How to exercise safely

There is very little practical written information for patients, fitness instructors and medical professionals on exercising with a long-term neurological condition. The handbook contains practical advice on how patients can exercise safely and get the maximum benefit of exercise; including when, how much and how often.

## The handbook

The handbook is given to each person, and it is also available ([www.brookes.ac.uk/lifesci/lifepass](http://www.brookes.ac.uk/lifesci/lifepass)) on the internet.<sup>9</sup> The handbook covers many different aspects of exercising, trying to overcome many of the barriers and to facilitate sustained participation in exercise. Some example extracts are given below.

### *Fitting exercise into life's routine*

You now need to work out how it will fit in with your daily routine. This will be different for everyone. You may eventually exercise for about 20–30 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.

### *Setting realistic exercise-related goals*

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

### *Symptoms that may arise after exercise*

**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.

### Answering frequently asked questions

**How much exercise should I do each week?** The British Heart Foundation recommends five sessions, of 30 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 10 minutes that is still a great start.

**Will the exercise be painful?** The exercise you do at the gym should not be painful. You should not get any pain while 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. If you do overdo it don't panic, ask the advice of the fitness instructor, rest for a couple of days and then return to exercise, but do a bit less than the last time.

### Results from the LIFE study<sup>12</sup>

Ninety-nine patients with a range of long-term neurological conditions (including multiple sclerosis, Parkinson's disease, motor neuron disease, cerebral palsy and a number of neuromuscular conditions) participated in the study. Here we

report routinely collected data on gym attendance (number), the amount of physiotherapist time spent in supporting patients (number of contacts, and minutes) and the confidence of patients in continuing to exercise after the intervention (satisfaction questionnaire).

Average gym attendance was one session per week for 12 weeks, with 44 people attending once a week for the 12 weeks. After the end of the study 33 patients were still exercising.

Table 1 shows the number of face-to-face and distance (phone/email) sessions and the amount of time spent in each of these sessions. The physiotherapist gave an average of three 1-hour face-to-face and three 5–20 minute phone calls per patient.

Patients were asked in a questionnaire to rate components of the support system. Table 2

**Table 1.** Physiotherapist support sessions

	Face-to-face sessions		Distance sessions	
	Number	Advice time (min)	Support time (min)	Advice time (min)
Average	3	27	33	12
SD	3	37	33	24
Min	1	1	1	0
Max	11	300	555	145

**Table 2.** How important were the following factors to your ability to participate in the exercise intervention?

N = 26 responses	Very	Quite	Neither	Not very	Not at all
Parking	46.1	15.3	19.2	7.7	11.5
Access	50	38.5	7.7	3.8	0
Staff attitude	65.4	26.9	7.7	0	0
Equipment	46.2	50	0	3.8	0
Support of FP	50	41.7	4.2	0	4.2
Support of HP	33.3	45.8	16.7	0	4.2
People in gym	16	16	40	24	4
Travel costs	38.5	23.1	19.2	7.7	11.5

Attitudes to each category of support reported as a percentage (%) of total replies. HP, health professional; FP, fitness professional.

shows the most highly rated factors ('quite' and 'very important') affecting participation were: centre staff attitudes access, equipment, the fitness professional support, access, equipment and the health professional support.

Patients were asked how confident they were in exercising. Answers were scored between 0 (not confident) and 10 (very confident). Of the 47 replies, 39 (84%) patients rated their confidence as 6/10 or better.

Finally, patients were asked if they were continuing to exercise after the end of the whole study: of 76 replies, 17 reported they had stopped exercising, 26 were continuing to exercise either in the same, a different centre or at home. Thirty-three were undecided about whether to continue exercising.

## Discussion

The specialized system for increasing participation by people with disabling neurological and neuromuscular conditions in exercise was associated with results similar to that achieved in primary care populations by other UK Exercise Referral Schemes.<sup>10</sup> The effects upon health and well-being were evaluated in a randomized trial reported separately.<sup>12</sup>

Using recent calculations of unit costs for health and social care<sup>32</sup> the approximate direct cost per patient for delivering the exercise support system was £180 for the physiotherapist (using the higher £45/hour figure for 4 hours contact) and £60 for the gym (12 × £5 per gym session). It is estimated if the system was initiated as per UK exercise referral schemes it may incur a general practitioner (GP) cost to initiate the referral, encountering a further £35 for a GP contact of 12 minutes. In total, the support system delivery could cost an average of £275 per referral for the initial 12 weeks.

This system has been developed using the best available evidence on factors that must be considered when trying to increase exercise in people with a disability. However some limitations should be recognized.

First the evidence base is relatively limited, and is primarily based upon associations. There is very little evidence on whether changing any of the individual barriers or facilitators actually alter participation in exercise. Furthermore the actual evidence guiding advice on the amount and types of exercise that are safe and/or effective is extremely limited. Thus this package should be considered as being based on the best available evidence but this may not have been good enough to design an effective package.

Second, it should be recognized that perhaps the most important practical factor is money. Getting to and attending a gym costs money, and transport costs for people with a disability are higher than for other people. At the same time disabled people usually have lower levels of income, and are often unable to drive or even use a normal car. This is probably always going to be the most significant barrier to sustained participation in community exercise.

### Clinical messages

- A programme designed to facilitate exercise in gyms by people with neurological and neuromuscular disability has been designed and is available on the web.
- The direct costs to the health care system are about £300 (€400, \$400) per patient for 12 weeks.

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