

## A pioneering model for brain injury rehabilitation

*Brain injuries have devastating long-term consequences, not only to individuals, but to their families and society as a whole. We know now the brain is capable of more repair than previously understood and new research highlights the need for a different approach which includes physical exercise in the outdoors, group work and socialisation.*

*Lake District Calvert Trust (LDCT) has pioneered disability adventure for 40 years. Now, with leading clinicians and academics, it is developing the new approach to brain injury rehabilitation so desperately needed. This will focus on 'learning through doing' in the outdoors, supported by a multidisciplinary team in a purpose-built residential centre. It will marry the latest thinking in neurology with LDCT's expertise in life-changing outdoor challenges. This innovative rehabilitation centre will help people with ABI reach their full potential for recovery, improving their physical and psychological wellbeing, and increasing their confidence and independence.*



### Summary

In recent years, LDCT has seen a growing demand for support for brain injury rehabilitation. Acquired Brain Injury (ABI) occurs either through a traumatic injury or neurological event and has profound long-term consequences, not only for individuals, but for their families and society as a whole. Existing wisdom held that improvements were unlikely after 6 months, but recent evidence suggests that the brain is capable of more repair than previously understood. This research highlights the need for a new holistic approach to rehabilitation, encompassing physical exercise, experiential learning, and support in developing a new self-concept after a life-changing injury.

In response to the research, LDCT has been working with leading clinicians and academics to develop an Acquired Brain Injury (ABI) centre. This will bring together for the first time cutting edge neurological research with LDCT's expertise in accessible outdoor activities. The programme in this ground-breaking centre will support ABI survivors to reach their optimum physical, psychological and socio-functional abilities. We thus seek to become the UK's first and leading intensive ABI rehab centre, underpinned by combining traditional multi-disciplinary clinical therapies with physical activity in the outdoors. By partnering with experts in the field, we will develop an authoritative voice in this sector, not only transforming our own services, but also creating a replicable model to improve the treatment of ABI in the UK as a whole.

## Brain Injuries – The Need

With some 900,000 attendances each year at A&E for head injury and 160,000 hospital in-patient admissions (Centre for Mental Health, 2016), there is a substantial need for rehabilitation following a significant brain injury. Whilst detailed data is not consolidated nationally, studies suggest there are up to 1.3M people (aged 16 to 74) in the UK living with long-term disabilities as a result of a traumatic head injury. As improved acute care means more people survive initial injury, this is a problem that will grow over time.

Injuries to the brain happen through external trauma (e.g. vehicle or industrial accident) or when the brain is starved of oxygen (e.g. through a stroke or brain tumour). The injuries damage our control centre, reducing cognitive and executive function, ability to function socially, and self-worth. This results in long-term, severe disability which is largely invisible, poorly understood, and which has devastating effects both for survivors and their carers. Amongst those living in the UK with the effects of a brain injury, evidence shows that:

- Mental health problems are double that of the general population
- Substance abuse is a problem for one in two
- Life expectancy is substantially reduced

There are clear interactions between the psychological and physical impacts of ABI, making this a particularly difficult condition to manage. Research shows high rates of loneliness and burden to the family, and strong links to offending behaviour and imprisonment (likely owing to reduced self-regulation and socialisation). The social cost of ABI in the UK is estimated at £15bn per year, through loss of employment, crime and the cost of social care. Improved trauma care means many more people are surviving accidents: yet effective long-term care for the growing number of survivors has not caught up. Consequently, people are left with little support and at significant risk. There is a real need for an innovative care model to tackle this issue.

## The proposed ABI Centre

Ongoing brain injury rehabilitation has usually been task-oriented, with people working with occupational therapists to practice skills. The existing consensus held that change was unlikely beyond 6 months post-injury and this has left a legacy of basic long-term support. We plan to provide a residential ABI centre for people in the post-acute phase, making use of cutting edge research on what works for this group. Alongside our expert advisors, we have identified factors which are likely to lead to significantly improved outcomes:

- **Physical exercise** reinforces the adaptive processes of the brain post injury: helping the brain ‘scaffold’ to compensate for damage. It also improves people’s mental health, outlook and wellbeing.
- **Outdoor Activities** have been demonstrated to improve people’s understanding of themselves and their abilities, post brain injury, with long-lasting benefits.

Currently there are no facilities available to comprehensively address this critical formula following the initial rehabilitation post injury. LDCT’s ground-breaking new centre is based on these proven elements, while also placing people in groups (this has been identified as key) to undertake challenging outdoor activities. These will combine experiential learning (including practical skills for independent living) with sustained physical exercise (the latter supporting the brain’s response to the former). Recognising the programme will be physically and cognitively tiring, rest days will be programmed twice per week. Supervision will be provided 24 hours a day including overnight for the duration of the programme or course. Overall, the programme will deliver, for the first time, the holistic, forward-looking and effective rehabilitation so severely needed.



LDCT is committed to providing person-centred care to the people we work with and we aim to offer three different types rehabilitation support to meet a range of needs: long term residential rehabilitation, specialist short courses (5 day or weekend), and day-centre provision in partnership with other charities to offer non-residential support to the local community.

The ABI centre will be based in one of LDCT's existing properties, Old Windebrowe, for which planning permission has been obtained. Due to the nature of the rehabilitation programme and participants, it is essential that the new ABI Centre is established as separate from our existing facilities. Experts have visited Old Windebrowe and believe that, with capital investment and redevelopment, it will be an ideal location for the Centre. This will also allow us to make use of an existing building.

Support for the ABI centre is enthusiastic from potential users and other stakeholders alike. We have conducted a broad independent research consultation with professional stakeholders, a second user-focused consultation with potential service users and their families, and promising pilot sessions with service users.

#### Key outputs:

- A 10 bed residential centre, with a multidisciplinary team
- A 12-24 week rehabilitation programme with defined goals
- Specialised 5 day or weekend courses: to try out or as a refresher
- Intensive rehabilitation for c.100 people each year, or 1,000 over 10 years
- Day support for those living with brain injury locally
- 6-monthly follow-up support to help evaluate progress and set new goals

#### Evaluation

In quantifying and disseminating the lessons from this venture, we are fortunate to have secured the support of Newcastle University. This will enable us to conduct a thorough and credible evaluation of the approach over the first three years.

This process will involve monitoring numbers, demographics and characteristics of beneficiaries and the creation of an evaluation framework. The framework will include clinical measures, quantitative and qualitative feedback, including self-report and observations by staff and clinicians. A number of validated

questionnaires have been used in previous research with ABI survivors and we will make use of these to ensure that our evaluation is comparable against existing measures. We will also fund a PhD to study the longitudinal impact of this work at a rigorous academic standard.

We will share the outcomes of this body of research and the lessons we learn in the process widely to ensure that the learning from our ABI unit can be applied to support people with ABI further afield.

### About the Lake District Calvert Trust

Experience and research demonstrate the physical and emotional benefits of physical challenge, groupwork and thrill – yet disabled people are too often excluded. Our mission is to enable people with disabilities to achieve their potential through the challenge of adventurous activities in the countryside supporting them to develop, change perceptions and make positive and lasting changes to their lives. We offer:

- Enrichment of their lives through adventure, confidence building and personal achievement.
- Chances to enjoy countryside of exceptional natural beauty
- Opportunities to relax as well as participate in course activity
- Enjoyment of recreational activities that can be transferred into everyday living
- Personal development and rehabilitation leading to integration

Based near Keswick, LDCT has been a pioneer and leader in the field of accessible adventure for 40 years. As a specialist outdoor activity centre with unparalleled facilities, we support over 3000 residential visitors from across the UK each year, including whole groups of disabled people and those whose severe and complex needs mean they can't use other centres. We support people to take part in challenging activities, enabling them, alongside families and friends, to achieve their potential. Our courses take people beyond what they thought possible, and result in physical benefits alongside increased skills, confidence and feelings of self-efficacy. A full programme of adapted, accessible activities includes mountaineering, water sports, horse riding, our high ropes course and socialising.

Every residential visitor completes an evaluation form, with support if necessary. These are overwhelmingly positive, highlighting perceived benefits in mental and physical wellbeing. To understand the impact of our services more deeply, we funded a PhD (completed 2014) which showed 4 broad benefits: New experiences that would otherwise be out of reach; Physiological and health benefits both immediate and also with potential to spur participants on to continue activity at home; Social and interpersonal, including developing self-confidence, self-esteem and independence, and learning and practicing social skills; And affective which included raised mood, the creation of positive feelings, overcoming fears and a changed outlook on life.

