

# RESPITE REIMAGINED

An innovative approach to the future of integrated health, social care and leisure



### 1 MILLION people in Scotland are living with a neurological condition

100,000 experience disability as a result of a neurological condition

## **A PROSPECTUS** FOR INVESTMENT IN THE FUTURE

Three hundred breaks a year at Leuchie tell us that many people in Scotland have unimaginably difficult lives, through no fault of their own. This is because our health and care services are not designed to meet their needs and are overstretched. The number of people facing these challenges is growing and will continue to do so. The lives of many families demand a forward-thinking response.

Leuchie has been at the forefront of health and care for 60 years. Today we are delivering transformational breaks in a highly regulated environment, through our in-house, neuroexperienced team of nurses, physiotherapist, occupational therapists, technology experts and carers. We are unique in the way we blend short breaks and services, and our care provision is recognised as exemplary by our regulator and our guests.

We are ambitious to do more, for more people, because the need is growing fast, and must not be left unmet. This is a prospectus for investment in a future that reimagines respite as an enabling service which thinks beyond the break, leads to better lives and addresses gaps in our National Health Service and social care fabric.

Please contact me or any of our team to find out how you could support our mission to transform lives now.



Mark Bevan, CEO Leuchie House, North Berwick EH39 5NT Mbevan@leuchiehouse.org.uk 01620 892864

## **SUPPORT OUR** MISSION TO TRANSFORM LIVES

The people we support have an urgent need and our organisation is over subscribed. Despite this, our funding is fragile. It costs almost twice as much as we can recover in fees to deliver vital services which transform lives, not just during the break but for long afterwards.

If we are to continue to meet this growing demand and transform the way people affected by multiple sclerosis, stroke, Parkinson's disease and MND live then we need help. You may be able to offer that help in a variety of ways..



'Coming to Leuchie is the highlight of her year and makes a huge difference to her life.'

> Sister and carer of a guest at Leuchie



## SCOTLAND'S SOCIO-ECONOMIC CHALLENGES AND THE FUTURE OF CARE



"Recent years
have seen many
organisations struggle
with the challenges
which circumstances
have presented. In
Leuchie I see an
organisation which has
the imagination to look
beyond the challenges
and to do more, for
more people by seeking
out the opportunities to
do things differently."

#### **Willie Watt**

Chair Scottish National
Investment Bank

Scotland can proudly boast of some of the most progressive science, social care, and government policies in the world. Alongside this, however, the nation is faced with some of the world's highest incidences of neurological conditions.

As the population ages and medical developments enable people to live longer with multiple and complex needs, pressure continues to mount on struggling health and social care services and families.

By 2050, a quarter of the population will be of pensionable age, and population growth will stall. This raises questions about who will care for our aging society and how can we derive the maximum benefit from the money we spend on health care?

Faced with this challenge, the Scottish Government has set an ambitious agenda, through its Neurological Action Plan, Stroke Improvement Plan and more recently, the intention to create a National Care Service. The government has also put carers' needs for a break at the heart of its plans.

However, public budgets are already growing exponentially to keep up with demand and, exacerbated by the Covid-19 pandemic, the number of family members who need to care for a loved one has risen sharply to what the government now estimates to be 1.1 million in Scotland.

This is a situation which is untenable. The statistics speak for themselves. We believe there is a compelling need to invest in innovative new ways of meeting the need for respite while offering more people a more holistic, integrated approach.

## RESPITE **MATTERS**

Thousands of family members in Scotland are exhausted by providing physical care for a loved one, care that the state would otherwise have to fund. While a short break from caring is recognised as essential, few receive a service. As Maggie, a Leuchie quest said, 'you have given me back my hope in tomorrow.' What happens to the cared-for individual during that break has at times proved to be a blind spot.

For example, Iain, aged 45, found himself placed in a temporarily vacant respite bed in an older people's home, where the average age was in the mid-80s and most residents had dementia. He described the experience as being 'like torture'. This is a completely unsuitable environment and undermines the case for respite as many carers forgo a break to avoid placing their loved ones in such circumstances.

Scotland must provide a range of settings that suit the health needs and circumstances of the individual and their family. This could be a group setting with support such as provided in Leuchie House or an accessible self-catering accommodation for all the family, such as Denis Duncan House, the relaxing holiday cottage in which we are now offering short breaks from care.

Beyond this, we need to consider whether the time spent on a break can leave a legacy that endures beyond the break itself. A new vision of respite could contribute to delivering wider health and social care outcomes.

"As a GP I understand the importance of a break for people with neurological conditions and their family carers. As a Trustee of the charity, I have seen firsthand how the team at Leuchie improve health outcomes and family wellbeing. Without the support provided by Leuchie carers would struggle to cope resulting in increased pressure on the NHS and social care."

#### **Maria Duffy**

GP and Leuchie Trustee

The number of UNPAID **CARERS** in Scotland has risen to 1.1 MILLION





# **OUR EXPERIENCE OUR EXPERTISE**

Leuchie House is a national respite charity dedicated to supporting families living with the long-term effects of a neurological condition such as multiple sclerosis (MS), Motor Neurone Disease (MND) and the effects of stroke through individualised short respite breaks, and by providing hundreds of essential breaks for carers each year.

We aim to be more than just a change of caring environment and instead offer a wonderful holiday experience, enabled by our 24hour nursing and care team.

But it is not simply a place to relax, important though that is. Many tell us that they feel deeply vulnerable at home, and that they live without the support they need. As one guest said 'when I come through the gates to Leuchie I feel reassured that I will be safe for a short while. Leuchie is the only place I can relax.'

We can do this because we have worked with people living with neurological conditions and their families and carers at Leuchie House for more than 60 years.

Leuchie has always been pioneering, adaptable and able to use our relationship with guests and specialist knowledge to find solutions for people. Based on providing challenging and complex respite for more than 300 families a year, we can also foresee systemic challenges ahead and we can be a part of the solution to these too. We are collaborative and forward-thinking when it comes to influencing policy and practice.



"Leuchie House has been a real lifeline for hundreds of families since becoming an independent charity. Since then, staff and volunteers have continued to provide support that has improved the lives of thousands of people with MS and other neurological conditions."

#### Paul McLennan

MSP for East Lothian

#### **SECTOR LEADING CARE**

In 2020 the Care Inspectorate awarded Leuchie House the highest possible grade of 6 in four out of the five measures of quality.





We place the uppermost importance in supporting and developing our team and talent at Leuchie. We are committed to exceeding the living wage and are proud to have an exceptional level of staff retention.

Sue is one shining example of how we get behind our team to help them realise their potential and thrive in their chosen career. Sue initially joined us as a housekeeper before we supported her to work in care. She then went on to study hard for her nursing degree, which included work placements at Leuchie. Sue graduated and is now a fully qualified, valued member of our fabulous nursing team.

#### WHAT WE HAVE ACHIEVED IN NUMBERS

40,000 nights of respite provided

Over 2000 assessments and treatments/referrals have prevented hospital and high tariff health admissions

For every £1 spent at Leuchie by Scottish Government **£6** is generated by Leuchie and spent on delivering Government Health and Social Care priorities

Between 2017 and 2022, we treated 277 pressure **sores**... saving the NHS over £277K over the past 5 years

In 2020 and 2021 alone, we treated almost 1 urinary tract infection (UTI) per week at Leuchie, preventing hospitalisation and saving the NHS over £50,000 in the last year





"It's the team that makes Leuchie a special place. Their skill, dedication and ability to work across disciplines is a model for any winning team that's trying to make a difference, not just to individuals' lives, but to how health and social care could be delivered across Scotland"

**Gavin Hastings OBE** Patron, Leuchie House

# GOING BEYOND THE BREAK

It is no longer enough for people to depend on health and social care services for short breaks from care, as they became more rationed and less accessible, and further strained by the pressure of the Covid-19 pandemic.

## 'When he's at Leuchie, I get time to recuperate, it's really a lifeline. Without Leuchie House I would really struggle now.'

Lucia, wife of David, a guest at Leuchie

The pandemic has accelerated the need to invest in care services that are progressive and forward thinking. Embedded within the government's policy direction is the intent to improve the whole experience of carers and those who are cared for. It is time to learn from past experience and use this evidence to create a legacy of improved health outcomes which last and extend beyond the short break itself.

At Leuchie, we have reimagined what is possible, and embraced a bold new empowering approach which draws on the experiences of our guests and their families, involving them in the design of new ways of providing respite and services which look beyond simply offering a short break.

#### Our aim is to continue transforming the lives of more people, not only within Leuchie House, but beyond our walls.

With investment Leuchie can build a positive future, by reaching out beyond its walls and using its expertise and base as a beacon of excellence and as a test bed for developing future care initiatives for all of Scotland.

It is critical to the future of healthcare services, to families in desperate need right now and for the public purse, that we re-imagine respite and short breaks from care. The following are just a few examples of how Leuchie is doing this:

- Self-catering accommodation
- Health clinics
- Care at home
- Enabling technology



New and innovative approaches to respite can deliver outcomes beyond the break that improve the provision of co-ordinated health and social care in Scotland.

As a result, people living with a neurological condition, and the loved ones who care for them, will:

#### **OUTCOME 1**

Be empowered to live more independently and self-manage

#### **OUTCOME 2**

Have greater access to allied health care services, focussed on a preventative and enabling approach

#### **OUTCOME 3**

Be supported as their condition progresses and their health care needs change

#### **OUTCOME 4**

Experience improved confidence and a renewed sense of self

#### **OUTCOME 5**

Participate and inform research which shapes the future of health and social care

#### **OUTCOME 6**

Experience regular breaks from their usual care routines, in the way they need

#### **NEUROLOGICAL CONDITIONS** account for up to 20% of acute medical admissions



"The NHS needs all of our help and it has been a privilege to see Leuchie offering services which do just that. In providing expert healthcare to people with Neurological conditions throughout Scotland, Leuchie provides a service which no one Health Board could deliver. At the same time Leuchie improves lives and adds value to Scotland's health economy."

#### Sir David Tweedie

Former Chair of the **International Accounting** Standards Committee



Leuchie has invested significantly in expanding its leadership, in line with our ambition to do more for more people, within and outside our walls.

In 2022 we will use our 60 years of expertise to support the delivery of the **Scottish Government's** policy for carers and for all people in Scotland living with a neurological condition and through a range of innovative services.

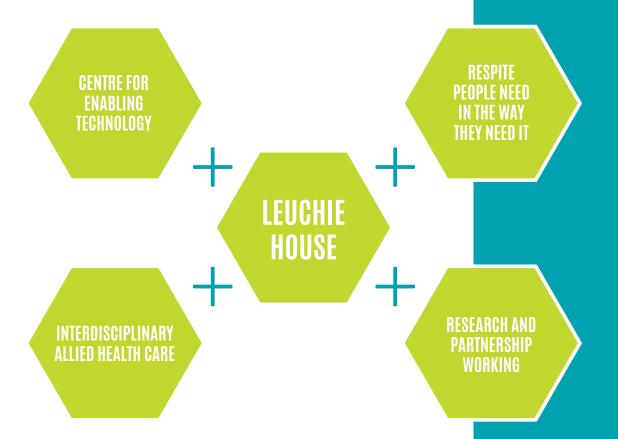
## INTERDISCIPLINARY ALLIED **HEALTH CARE**

We are growing and developing our neuro-experienced health and care team, who already do a brilliant job of working with our guests and their families, and their local health team and national agencies, to equip families for the future.

We are the only short break service in Scotland which features an AHP (Allied Health Professional) assessment as a part of our core offer. This unique position, in being able to assess individuals throughout the duration of their break, and over multiple years as many people return to Leuchie for further respite is highly valued by guests. We support our guests with a holistic assessment of their health and wellbeing at the start and through the duration of their break to identify and resolve issues before they become complex and debilitating.

We are equipped to provide wheelchair and equipment assessments, weighing, pressure mapping and positioning advice, physiotherapy and moving and handling support. We will also begin delivering specialised nursing clinics on condition management and wellbeing. Based on these, we make referrals to community health professionals for ongoing care and support where required.

Our allied health team of nurses, physiotherapists and occupational therapists are filling an important gap in health services and reducing the demand and cost to our NHS and other statutory services.



Leuchie nurses offer expertise in identifying early stage pressures sores, common in people who use wheelchairs and who find it difficult to change their posture. While the nurses may provide early treatment, our Physiotherapist can use our state-of-the-art digital pressure mapping systems to prevent the condition worsening.

Working with our Occupational Therapist, posture and support can be addressed, and guests given increased comfort and treatment which prevents pressure sores worsening and leading to hospital treatment. In this and other ways our integrated Allied Health and Technology Teams help to provide value beyond the break.





"Leuchie offers a unique and wonderful service which is much needed in Scotland and enjoyed by those who use it."

#### **Kevin Woods**

Former Director General of Health and Chief Executive NHS Scotland

# RESPITE PEOPLE NEED, IN THE WAY THEY NEED IT



Looking beyond our walls, we understand that a range of settings is needed to support the circumstances of the individual and their

Offering accessible holidays beyond Leuchie House itself, we can now provide additional self-catering holiday accommodation at Denis Duncan House - our new fully accessible cottage on the Firth of Forth. This facility offers families greater freedom and independence and a chance to spend quality time together in a beautiful setting.

Informed by our visitors' feedback and wishes, our skilled Guest Engagement team continues to tailor and expand our range of activities to stimulate interests, increase social interaction and improve wellbeing.

Whether it's a trip to the seaside, a gallery or garden centre, or access to a wheelchair assessment and the range of services provided by our allied healthcare team, we want guests to get the holiday and wellbeing experience they desire.



Our use of enabling technology is an example of ensuring we equip guests to live more independently when they return home from Leuchie. Through his work with our technology team Bob described himself as 'escaping the black hole that I was compelled to live in.'

Our specialist team set Bob up with voice-activated controls using off the shelf technology adapted by us to him, and his life has changed immeasurably. He now switches on lights, opens curtains, turns on the TV/radio and calls friends all with the control of his voice.





## **CENTRE FOR ENABLING TECHNOLOGY**

Leuchie's vision is a world in which the independent potential of everyone living with a neurological condition is maximised by harnessing technology. Our experience shows us that this gives carers back time, lowers risk and reduces the cost of care. Building on this vision, we have embarked on a journey towards establishing the Centre for Enabling Technology within Leuchie House.

We now offer 1-2-1 digital skills sessions and assistive technology workshops for guests. We have integrated SMART technology into all of our respite bedrooms and created a SMART flat comprising a kitchen, living area, bedroom and ensuite bathroom which will allow families to test and trial available technologies and products for themselves.

Because we can welcome people to stay at Leuchie overnight, we can undertake the kind of

assessments which are impossible in a few hours in a home setting. We can learn about an individual's priorities and capabilities and go through the lengthy process of identifying, adapting and training both people and technology to return independence.

The benefits impact the individual in tangible ways, and also reduce the burden of care on loved ones and on society at large.

Over time, as we assess more guests and visitors, we will build a profile database, matching people's conditions and the way they present with the technology that most suit their needs. This will mean that people will not have to physically visit our facility and allow Leuchie to provide outreach support.

## **RESEARCH AND** PARTNERSHIP WORKING

We support roughly 300 quests per year whose conditions present in similar ways and who stay with us for between 4 and 11 nights. This offers a great opportunity for our guests to participate in shaping future services and products.

With this in mind, we have committed to two partnerships:

#### FEATHER, UNIVERSITY OF EDINBURGH, SCHOOL OF INFORMATICS

Beginning August 2022, we will be a part of a project, FEATHER, to trial the development of a health monitoring system for early detection of urinary infections. As a respite centre for people where nearly 80% of our guests use a urinary catheter and are at increased risk of infection. We are keenly aware of how uncomfortable these infections can be for our guests and if left undetected, they can be life threatening.

Our Head of Technology will become a member of the project's advisory panel, and we will open the opportunity for 10 guests to evaluate and help co-design the prototype. Our Nursing and Care and Enabling Technology Team will host the researchers and help to facilitate their interaction with our guests.

#### THE NATIONAL ROBOTARIUM, HFRIOT WATT UNIVERSITY

This University, Private Sector and Government hub for robotic innovation is our latest partner.

They have agreed to undertake trials of everyday robotic equipment with guests while in Leuchie. Guests will help codesign robots that bring them greater independence, reduce care risks and free their loved ones from basic care tasks.

Our first joint venture is to test a SMART trolley which can be programmed to find and attend to guests at certain times using pressures sensors to note the removal of items, such as medication or fluids. The robot is customisable and will be on trial for development.



"Our partnership with Leuchie will allow us to work collaboratively with their technology and healthcare team, guests and carers to develop assisted living technology that truly works for users."

**Professor Lynne Baillie** Head of the Assisted Living Lab, National Robotarium



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