

A middle-aged man with short grey hair is sitting in a wheelchair. He is wearing a green polo shirt and khaki trousers. He has a gold watch on his left wrist and a blue wristband on his right wrist that says "Medical Alert DNR". A golf ball is on the joystick of his wheelchair. Behind him is a large window with a view of trees and a white door. To the right is a bright green wall.

RESPIRE: REIMAGINED

10 years of positive impact
2021

 **HOUSE**
leuchie
NATIONAL RESPITE CENTRE

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WELCOME

Our enthusiasm for having reached such a significant milestone in Leuchie's history and ambitious plans to do more in the future are slightly tempered as we pause to recognise the significant impact that the Covid-19 pandemic has had on those who we support. It has lasted much longer and had much more of an impact than any of us would have imagined.

For our guests, their isolation, need for health and care services and their wellbeing have been subject to an extreme test. Their loved ones, who provide most of their care, have been exhausted by the weighty responsibility and effort. Some guests have sadly passed away; others remain resilient and glad to have had the opportunity to come to Leuchie. We have, above all other things, seen stark evidence of the necessity of a break at Leuchie for the health and wellbeing of many people in Scotland with neurological conditions, along with their carers. Leuchie provides such a critical health service.

In their professionalism, creativity and skill the team at Leuchie has responded brilliantly to the pandemic 'call to arms'. We recognised the implications for our guests and closed to our usual respite service just ahead of the first national lock down. Leuchie quickly re-provisioned as a Step-Down service for our NHS and welcomed people who were in hospital but did not require immediate hospital treatment. This provided a much more reassuring environment and freed up hospital beds which were urgently needed.

Leuchie continued to provide this kind of support, welcoming people in from the community when their home circumstances or a break down in their care arrangements would have otherwise meant admission to hospital.

Leuchie was an early advocate for individual, risk assessed respite to re-commence in late summer



2020. We were delighted to welcome guests back to a COVID safe respite experience and to remain COVID free. This was achieved by the high degree of professional infection prevention and control and diligence of everyone at Leuchie.

Throughout the year we have been supported brilliantly by our colleagues in Scottish Government, the Health and Social Care Partnership, donors and the local community. Along with the staff team who have been magnificent, you deserve much greater thanks than we can commit to these pages.

Finally, most guests who come to Leuchie stay in touch and return. It is from you that we draw the greatest strength and support and to you we owe the greatest thanks because you continue to give us purpose, the strength to carry on and along with the odd challenge, your friendship.



Stephen Pearson
Chair of the Board
of Trustees



Mark Bevan
Chief Executive

**LEUCHIE QUICKLY
RE-PROVISIONED
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WHY RESPITE MATTERS

10%
of people living
with a neurological
condition are
disabled as a result

This has an impact on relationships with friends, colleagues and loved ones, as well as the ability to enjoy the same hobbies, work and home life.

1/5
of carers
report not
having had a
break in over
5 years

Leuchie House is Scotland's only charity dedicated to supporting families living with the long-term effects of a neurological condition.

**1.1
MILLION**
unpaid
carers in
Scotland

As Scotland's population ages and medical advances continue to enable people to live longer with multiple and complex needs, family and friends are increasingly being relied on to fulfill the role of 'unpaid carer' for their loved ones.

1 MILLION
people in
Scotland are
living with a
neurological
condition

Multiple Sclerosis, Parkinson's, Motor Neurone Disease and Stroke are just a few of the devastating conditions for which Leuchie provides high quality care and support.



Elspeth stayed at Leuchie in 2019 with her mum Alison who has MS. She wrote this poem while writer in residence with Shared Care Scotland.

WHO CARES FOR THE CARERS?

Who cares for the carers? Who gives us a break?
Let the moves move and the shakers shake
Till the system works for everyone's sake.

He's always 'my darling', make no mistake,
But I bite my nails and tear out my hair,
Don't wait for the break-down – give me a break.

Over one million in Scotland awake
knowing they're the ones who have to be there
to hold up the ceiling, for everyone's sake –

Sharing the load brings change in its wake.
Since humans are human and sainthood is rare,
Accept my reality – give us a break.

Respond to the pleas that all of us make
With phone calls, appointments, petitions and prayer,
Then stick to your promise for everyone's sake.

We're asking for funding that's fair and not fake,
For time to recover, to rest and repair,
We're unpaid carers – give us a break,
And do the right thing for everyone's sake.

Elspeth Murray



A GUEST'S PERSPECTIVE

LORRAINE AND DONNY'S STORY

"Donny and I live with our two dogs, Minnie and Molly on Seil Island on the west coast of Scotland. We were both in the RAF and have been married for over 13 years. In 2011, I received the difficult news that I had multiple sclerosis."

"For a time, Donny and I got on OK with support from local carers. As my condition progressed, caring for me took its toll on Donny. Things started to become tense between us. When he injured his back, we realised we'd reached crisis point and were both exhausted and in desperate need of a break."

"My local MS Therapy Centre in Oban told me about Leuchie and I was lucky to have the support of my social worker who helped me get the funding to go. My only wish is that I had done it sooner!"

"I was nervous at first, but Leuchie staff are so professional, understanding and caring. I wish more people understood what a gem it is. You make friendships that go beyond Leuchie. The staff, other guests and carers feel like an extended family, and they help you focus on what you can do instead of fixating on what you can't."

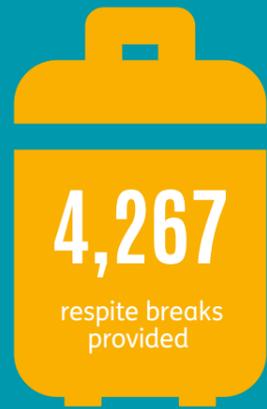
"While I'm at Leuchie, Donny gets a proper rest. When I first came, I think he felt a bit redundant and guilty, but now he understands how good it is for me, and most importantly, how good it is for us."

"Leuchie House is special - very, very special. Although you couldn't replicate it in any way, shape or form, if I won the lottery, I would want to try."

Without Leuchie House

My husband and I
would have reached
breaking point

Lorraine Reynolds, Guest
Seil Island, West coast of Scotland



A DECADE OF DIFFERENCE

Founder, Mairi O'Keefe OBE retires and becomes a Leuchie patron

Leuchie is chosen, alongside My Name's Doddie, as a charity partner for the Scottish Open

Leuchie's first digital programme, Leuchie Links, is funded

Queen's Award for Voluntary Service presentation



Run by Servite nuns as the Richard Cave MS Holiday

Leuchie House was built – still owned today by the Hamilton Dalrymple family

2021

Leuchie celebrates its 10th Anniversary

2020

Leuchie converts its service to supporting the NHS during global Covid-19 pandemic and to supporting its usual guests remotely

2019



2018

2017

2016

2015

Gavin Hastings OBE becomes Leuchie's first patron

4 July 2011

Leuchie House established as an independent charity and broadens its support for people living with a range of neurological conditions

1998-2011

Run by the MS Society



1970-98

1779



Without Leuchie House

I would really struggle now

Lucia Regan, Carer Glasgow

A CARER'S PERSPECTIVE

“My husband, David, was diagnosed with MS in his early twenties when we were engaged to be married. He told me to go, but of course I didn't. When you love someone, you don't look too far ahead.”

“MS wasn't terribly bad to us at the beginning. When David had his relapses, it was quite bad, but then unfortunately, he did deteriorate quite quickly. I'm a nurse and David was a welder in the shipyards. He had to give up work seven years after he was diagnosed, but that meant he was around more to help with our three children.”

“Leuchie has been a support to us for many years. When the children were younger, we used to go for family breaks and eventually, David started going on his own. When he's at Leuchie, I get time to recuperate and it's really a lifeline.”

“We're very self-sufficient after coping for so many years with his condition, but we recognise that we both need breaks. I know David enjoys himself when he's there, which helps me stop worrying and allows me to have a break too. I'm always glad to hear that he's been socialising in good company and enjoying the food – or his favourite outing - a pub lunch!”

“One year David did a microlight flight thanks to Leuchie, and he absolutely loved it! We would never have been able to make this happen ourselves.”

“We are so pleased to see Leuchie reach its 10-year milestone and hope that it will continue to be here for families like ours for many years to come.”

RESPITE: REIMAGINED

For over 50 years, Leuchie House has supported people living with MS and other neurological conditions. We are incredibly proud to have done this as an independent charity for the last 10 years and excited to use the valuable experience and insight gained to reimagine respite over the next 10 years, in order to support more people in more ways.



MORE SPACE TO SUPPORT MORE PEOPLE

We recently converted the lower ground wing of Leuchie House to create three additional bedrooms, taking our total from 15 to 18, and expanding a fourth bedroom to offer greater accessibility and comfort.

LEUCHIE AT HOME

We are developing a Volunteer Befriending service that will see us support families directly in their home through the help of volunteers. We'll soon be appealing for volunteers who local carers can rely on week-to-week to schedule some much-needed time for themselves while their loved one enjoys a friendly face with whom to socialise.

SELF-CATERING

We are delighted to announce that Leuchie House has received a very generous donation from the Lin Berwick Trust of Denis Duncan House, an accessible self-catering house located just down the road in the picturesque village of Dirleton.

This property will complement our respite facilities here at Leuchie, while offering people living with a neurological condition an alternative. Bookings are currently open and Leuchie will begin running the facilities from January 2022.



ENABLING TECHNOLOGY

Like so much of what is at first sight intuitively right and later backed up by exhaustive research, our work with Assistive Technology began with a simple story about one man's life.

BOB'S STORY

Bob, a former sales manager and widower lives alone. He was diagnosed with MS and quickly lost the use of his limbs. He now has some limited control from the neck upwards. He needs physical help with every imaginable activity, all day long. Alongside this loss of physical ability, Bob lost independence, self-worth and esteem. Life was a bleak succession of care tasks to which he was subjected, until he came to Leuchie and inspired this our work with enabling technology.

Bob mentioned that he didn't watch the popular TV series 'Line of Duty' because it was screened at night. When asked why night time mattered, he said that at night he was put 'in a black hole'. He went on to describe his carers putting him to bed at 8pm, because that is when they were available, switching off the lights, TV etc and leaving him until they returned at 7:30am the following morning. Leaving this man with no motor control in his 'black hole', an experience immeasurably worse than the lockdown which many of us have experienced. No contact, no Netflix, not even a phone call was possible.

We worked with Bob and our specialist team was able to set him up with voice activated controls using off the shelf technology adapted by us to him. Bob's life has changed immeasurably. He now switches on lights, opens curtains, turns on the TV/ radio, calls friends, even answers the doorbell all with the control of his voice. He has escaped his 'black hole'.



Learning from this experience, Leuchie House has worked with others in similar situations to free them from their 'black holes'. We have learned about the use of digital connectivity, technology and equipment which can literally transform lives. 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 obvious ways but they also reduce the burden of care on loved ones and on society at large. At a population level, this cannot be underestimated. We are an aging population with public spending stretched beyond anything ever previously seen. This is one area in which technology can make a massive difference at individual and societal levels.

At Leuchie, we have now integrated SMART technology into all of our respite bedrooms and created a SMART flat including a kitchen, living area, bedroom and ensuite bathroom which will allow families to test and trial available technologies and products for themselves.

THANK YOU FOR MAKING THIS POSSIBLE

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