September 2020

movingforward

News for people affected by Life Limiting Illnesses

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ARE YOUR PENSIONS AND INSURANCE POLICIES WRITTEN IN TRUST

TRUSTS ARE IMPORTANT VEHICLES IN HELPING PEOPLE MEET THEIR FINANCIAL GOALS AND AVOID UNNECESSARY LIABILITIES. TRUSTS CAN HELP PEOPLE AVOID TAX AND ALSO HELP PEOPLE AVOID PAYING CREDITORS LIKE BANKS OUT OF THEIR ESTATES AFTER DEATH.

Life insurance policies written into trust can pass outside a person's estate after death. This means that the life insurance monies avoid being used to pay off creditors who have claims against the estate. For example if a person had a life insurance policy worth £100,000 and an estate that had credit card debts of £20,000. If this policy was written into trust the £100,000 proceeds of the life insurance policy would be paid directly to the named beneficiaries of the trust and the £20,000 of credit card debts would have to be written off by the bank. However if the life insurance policy was not written into trust, only £80,000 of the proceeds would be payable to beneficiaries, with £20,000 being used to pay off the credit cards.

Similarly pensions written into trust can pass outside a person's estate after death. Most modern stakeholder pensions, personal pensions and occupational pensions are written into trust. However many older plans are not written into trust with proceeds being paid into the estate where they may be subject to claims by creditors. Some workplace pensions being set up at the moment may also not be written into trust.

Another advantage of placing monies into trust is that monies can be paid out faster to loved ones after death. Life insurance policies and pensions written appropriately into trust do not form part of the deceased's estate. This means that probate which can often take months or even years is not required for monies to be paid out to beneficiaries. With many solicitors now charging fees based on a percentage of an estate's value this can mean that probate costs can be significantly reduced by placing policies into trust.

It is important to seek advice regarding the appropriateness of placing policies into trust. It may not be advisable to place policies like critical illness plans or combined life and critical illness plans into trust as the person setting up the trust is likely to be a beneficiary of the plan. For example people setting up critical illness policies will want themselves to benefit from the payout in the event of them being diagnosed with a critical illness.

Placing life insurance policies and pension monies into trust is relatively simple. It is not a complex process – you simply need to think about which people you wish to be the beneficiaries of your estate after death, and which people who you wish to appoint as trustees. Trustees can be friends or professionals like solicitors. (Please note that solicitors and other professionals may charge fees for their service).

Given the advantages to be gained from having life insurance policies and pensions written into trust it is important to check whether your plans are in trust. For more information about the benefits of using trusts to protect your life insurance monies and pensions please contact St Bernard Support for further information.

LESS SURVIVABLE CANCER TASKFORCE REPORT CALLS FOR URGENT ACTION ON FASTER DIAGNOSIS

The Less Survivable Cancers Taskforce (LSCT) is calling for focus, prioritisation and investment in order to speed up the detection and diagnosis of the UK's deadliest cancers.

The LSCT represents six less survivable cancers, lung, liver, brain, oesophageal, pancreatic and stomach, with an average five-year **survival rate of just 16%** due to a legacy of neglect and underfunding. Together, these 'less survivable cancers' make up half of all common cancer deaths in the UK.

The LSCT is made up of Pancreatic Cancer UK, Roy Castle Lung Cancer Foundation, The Brain Tumour Charity, Action Against Heartburn, Guts UK, and British Liver Trust.

A new report from LSCT highlights the overwhelming evidence that late diagnosis of cancer leads to poorer outcomes and that less survivable cancers are far more likely to be diagnosed at a late stage.

Around one third of patients with a less survivable cancer will only be diagnosed after an emergency admission to hospital. This delay accounts, in part, for the unfortunate prognoses for thousands of people each year. For other common cancers, the proportion diagnosed at such a late stage is just **15% and the average five-year survival rate is markedly higher at 69%.**

The report explains that the reasons for later diagnosis are varied but a significant factor is that symptoms of less survivable cancers tend to be non-specific and most of the general public are unaware of them.

For brain tumours for example, two of the most common symptoms are headaches and nausea. This ambiguity often means that patients delay seeking medical help.

Victoria, 23, from Dundee, was diagnosed with a low grade brain tumour when she was 11. She has now been in remission for 10 years and has a degree from one of the top art schools in Scotland, runs her own photography business and is about to embark on a degree in teaching.

But Victoria faced many obstacles trying to access the appropriate medical help. **Victoria suffered from persistent localised headaches from the age of four years old, as well as unexplained weight gain.**

"On a weekly basis, my parents took me to our local GP in Dundee, where time after time we were told it was nothing to worry about. The GP said it was probably to do with my diet, or growth pains - at one point I was even told I was attention seeking. Not once was a scan offered".

"After seeing our GP for five years with the same symptoms, we were eventually sent to a Neurologist in Aberdeen, who also couldn't find a reason for my headaches. My parents had had enough, and turned to the private sector so I could have an MRI scan".

"I will never forget the day I was diagnosed with a brain tumour. I was 11 years old and terrified. I was in an MRI machine, and my mum was dancing to make me smile during the scan, and then all of a sudden her face dropped. I could tell something was wrong."

"I want to help improve early diagnosis in children - because if my tumour was found earlier, things could have been very different."

Closing the gap

The LSCT is also concerned that screening programmes for less survivable cancers are limited or non-existent in the UK and fast routes to diagnosis aren't clear for GPs.

The Taskforce shared data this year showing that the UK ranks as one of the world's worst countries for diagnosing and treating less survivable cancers.

In addition to this, research has shown that the COVID-19 pandemic has further delayed the diagnosis of all cancers and exacerbated an already dire situation. This is simply unacceptable and we are proud to stand together with these other charities behind this call for urgent action.

The report makes a number of recommendations to close the deadly gap on cancer inequality:

- A restart of cancer awareness campaigns, with a focus on raising

- Awareness of symptoms of less survivable cancers

- An increased focus on early diagnosis and ensuring GPs are well equipped to recognise the vague and non-specific symptoms of the less survivable cancers

- Rapid Diagnostic Centres (RDCs) should be rolled out across the UK, working closely with GPs, to ensure people with non-specific symptoms that could be cancer have access to fast and efficient diagnostics

- A clear strategy should be implemented by the NHS in England, Scotland, Wales and Northern Ireland for surveillance of people with liver disease for liver cancer

- Targeted screening for lung cancer should be rolled out across the UK

- UK governments and research institutes should support trials into early diagnosis

- UK governments should work with research partners to speed up the trials of Cytosponge and roll out its usage, to help diagnose Barrett's oesophagus and reduce pressure on endoscopy backlogs

Anna Jewell, of the Less Survivable Cancers Taskforce said:

"Less survivable cancers have been left behind for far too long and the time from diagnosis to death for anyone who has one of these cancers is brutally short. Our evidence of better outcomes for people diagnosed with more survivable cancers shows that it is possible to increase life expectancies but we urgently need a whole system approach to diagnosing the less survivable cancers earlier and faster".

"In addition to increased public awareness of symptoms, GPs need support in terms of resources and equipment as well as access to rapid diagnostic centres for their patients".

"The situation is critical. The COVID-19 pandemic has put an enormous strain on our health service but we must continue to act for people affected by these devastating diseases and give them a fighting chance".

"We are urging ministers, health service leaders, researchers and healthcare professionals to work with us and our patients to make the recommendations in this report a reality."

The LSCT aims to double the survivability of less survivable cancers to 28% by 2029.

The LSCT is made up of Pancreatic Cancer UK, Roy Castle Lung Cancer Foundation, The Brain Tumour Charity, Action Against Heartburn, Guts UK, and British Liver Trust. It is supported by: Pancreatic Cancer Action, OCHRE, Brainstrust, HCCUK, Heartburn Cancer UK, OG Cancer NI, Brain Tumour Research, Barrett's Oesophagus

Article courtesy of The Brain Tumour Charity

THE POTENTIAL OF LIGHT THERAPY FOR PARKINSON'S

Could light hold the key to help manage Parkinson's symptoms or even have a protective effect on brain cells? This article explores the research evidence and what the future might hold.

Light has a huge impact on life — from sustaining the plants we eat to allowing us to see, everyone of us is dependent on the power of light.

The power of light has been investigated in many conditions, and although it is still very much an experimental technique, there is research to suggest that light therapy can have protective and restorative properties. There is also evidence that light can alter our sleep, mood and behaviour.

So why is light relevant to Parkinson's?
In Parkinson's it is the loss of dopamine producing brain cells that cause both movement symptoms and other symptoms — known as non-motor symptoms — such as problems sleeping, depression, and loss of motivation.

Research is being done to look at whether treatment using light could offer protection to struggling brain cells to potentially slow down the progression of Parkinson's. And research is also looking into how light, in various forms, could be used to directly manage the symptoms of Parkinson's.

This is a fascinating topic as researchers try to unpick why cells that sit in the middle of the brain, in complete darkness could be protected, or even 'healed', by light. How do cells in the eye signal to the deepest parts of the brain? Or is it that light is being absorbed by specific components in cells activating and providing energy for the body to promote brain cell survival, protection or regeneration?

Let's explore some of the ways light is being looked at with regard to Parkinson's research.

Natural sunlight

The body makes vitamin D when the skin is exposed to direct sunlight, as well as small amounts being present in certain foods. Vitamin D helps regulate the amount of calcium and phosphate in the body. These nutrients are needed to keep bones, teeth and muscles healthy.

Research has been done looking at vitamin D and Parkinson's, including research that focuses on exposure to sunlight and how this might be associated with the risk of developing Parkinson's. This research, alongside other studies looking at supplements for vitamin D, have found that higher vitamin D levels are linked to a lower risk of Parkinson's.

In addition, studies have indicated that people with Parkinson's with higher vitamin D levels tend to have better mobility. This research has been done in rats and mice indicating that vitamin D may have protective properties. However, the authors called for more studies in people to confirm these potential benefits.

Bright light therapy

Bright light therapy, as the name suggests, uses a bright lamp to mimic natural light. The intensity of light, the duration and time of day that the therapy administers are all carefully controlled. Bright light therapy is probably most famous for its use in Seasonal Affective disorder (SAD), a form of depression linked to the change in seasons, where decreasing levels of light in the winter months triggers low mood.

But in controlled trials of bright light therapy in SAD, there are mixed conclusions. It seems that it's down to the individual whether bright light therapy is helpful. There are similar studies and mixed results when looking at bright light therapy and bi-polar disorder. But despite the overall conclusions not being clear cut, one of the more consistent observations, is that bright light therapy can help to improve sleep.

In Parkinson's trouble sleeping is a common symptom alongside feelings of anxiety, low mood and depression. So, if bright light therapy can potentially improve sleep and other symptoms in other conditions, can it help in Parkinson's?

There is some evidence in people with Parkinson's that bright light therapy can improve mood and decrease symptoms associated with depression and anxiety. But like previous studies in other conditions, the evidence

is not clear cut. The most recent study in 83 participants with Parkinson's, either receiving a control light or bright light therapy, showed that there was no significant change in overall depression scales. However, mood and sleep improved.

These results are supported in other studies looking particularly at sleep. Bright light therapy seems to help those that struggle to sleep and those that found themselves over-sleeping in the day. This clinical trial was done in 31 people with Parkinson's receiving bright light therapy, twice a day, for two weeks. These observations suggest benefits of light therapy can happen quickly.

As well as indications that there may be potential for light therapy in managing non-motor symptoms, there is also research to suggest that bright light therapy can potentially improve movement symptoms such as tremor and rigidity. But research is limited in this area and therefore further investigation is needed to assess the impact of bright light therapy on movement symptoms. There is some evidence that bright light therapy may help struggling brain cells in Parkinson's. There are theories that light therapy increases dopamine levels in the brain. This could explain why some individuals receiving light therapy are able to reduce their medication. This is supported in rat models in the lab, where dopamine producing cells can respond to light. More research is needed to further explore this — we'll discuss the power of red-to-near-infrared light as a way to protect brain cells later in the blog.

Evidence so far shows that the effects of bright light therapy on people with Parkinson's is variable and more large scale trials are needed to assess the long term benefits. The research so far has used different methods such as 'doses' and duration of light therapy, therefore, finding a consistent method would be useful for future research. On the other hand, it could be argued that light therapy needs to be tailored to the individual to have the best results. And unfortunately, there has been little research done into understanding why bright light therapy may be having an impact in Parkinson's.

Near-infrared light therapy

There are many names for near-infrared light therapy — Low-level laser therapy (LLLT) or photobiomodulation to name a couple — this is going to use the term near-infrared light therapy.
Light has different wavelengths. When light falls within what is known as the visible spectrum, the wavelength impacts the colour we see the light. The spectrum of visible light goes from the near-infrared range with long wavelengths, to the other end, where you find ultraviolet light with short wavelengths. Near-infrared light therapy uses light that has a relatively long wavelength, between 600–1070 nm. In comparison bright light therapy uses light from the 460–525 nm region of the spectrum.

Different parts of our cells can absorb different wavelengths of light. The longer wavelengths, like the red to near-infrared end of the spectrum, are thought to be better absorbed by specific components within the cell such as those that help control the cell's energy levels. There is increasing evidence in many different conditions that near-infrared light therapy has protective properties and restorative properties.

So, is there evidence that near-infrared light therapy is protecting brain cells in Parkinson's? The answer is yes, but it comes mainly from research in the lab in cell-based and animal models of Parkinson's. Nevertheless, the results look promising, where near-infrared light therapy decreases stress in brain cells, protects dopamine producing cells and shows improvement to movement symptoms.

The knowledge so far suggests near-infrared light therapy is more beneficial when applied directly or in close proximity to target cells. This poses a problem in Parkinson's as the cells implicated in the condition sit deep in the mid brain. To get round this, some researchers suggest using an optic fibre device, that can be surgically inserted into the brain, would have the most potential to directly impact cells in Parkinson's.

There is a particularly interesting research study in animal models that uses the optic fibre device to look at near-infrared light therapy in Parkinson's. The therapy was shown to be beneficial to the mice, rats and monkeys and interestingly shows a potential link between light therapy and an increase in a growth factor in the brain called GDNF. This is particularly topical as a recent clinical trial of GDNF showed that directly infusing the growth factor into a specific area of the brain in people with Parkinson's could have protective and regenerative effects on dopamine-producing brain cells. Therefore, could light therapy offer an alternative way to boost GDNF in the brain and protect brain cells? It will be interesting to see further research on this topic.

There has been limited investigations of near-infrared light therapy in clinical trials in people with Parkinson's. One study, in 8 people with Parkinson's, showed that near-infrared light therapy after 2 weeks may improve speech, cognition and freezing when used as a non-invasive therapy, so using the light source outside of the body. But larger trials are needed. In addition, results from a study of 36 people with Parkinson's found that an intranasal device led to an improvement of Parkinson's symptoms over a course of 10 days. There is a larger trial in the US about to start looking at135 people with Parkinson's using intranasal near-infrared light therapy. It will be interesting to see the results from this larger **trial.**

There is also news of 'red light helmets' being investigated in Tasmania and Australia. These helmets were inspired by research done in mice, where near-infrared light therapy was administered via helmet like devices and shown to improve the Parkinson's-like symptoms. The news relates to an imminent clinical trial wanting to test these red light helmets in people with Parkinson's. There are no details, as of yet, about this trial but this is something we will keep an eye on to see how it progresses.

Should people try near-infrared light therapy?

Although light therapy is thought to be safe with minimal side effects, we don't advise people seek out this therapy as a treatment for Parkinson's. There needs to be more research into the long term impact of near-infrared light therapy and the benefits to people with Parkinson's. The research so far has used various techniques and each needs to be investigated in larger, longer, controlled clinical trials. Any changes in managing Parkinson's should be discussed with a medical professional.

ARE YOU AFFECTED BY A LIFE AFFECTING ILLNESS? (Cancer, Heart Disease etc)

Living with a life affecting illness is always challenging both for the individuals concerned and their loved ones. Life limiting illnesses can leave people facing uncertainty and challenges they never planned for. SBS is a charity and social enterprise dedicated to providing support, counselling and information to people who are affected by life limiting illnesses.

THE SUPPORT SBS OFFER...

- **We offer confidential support by phone or in person**
- **Meet with one of our counsellors at a time or place convenient for you**
- **Provide information and support you in accessing services that could benefit you**
- **Financial counselling to unlock money and benefits available to you and your family**
- **Access to tax-free pension funds under terms available to people with life limiting illnesses**
- **Expert help with releasing money from life insurance and critical illness plans**
- **Assistance with lasting powers of attorney, will writing, estate planning and minimising longterm care costs**

WE ARE HERE TO HELP

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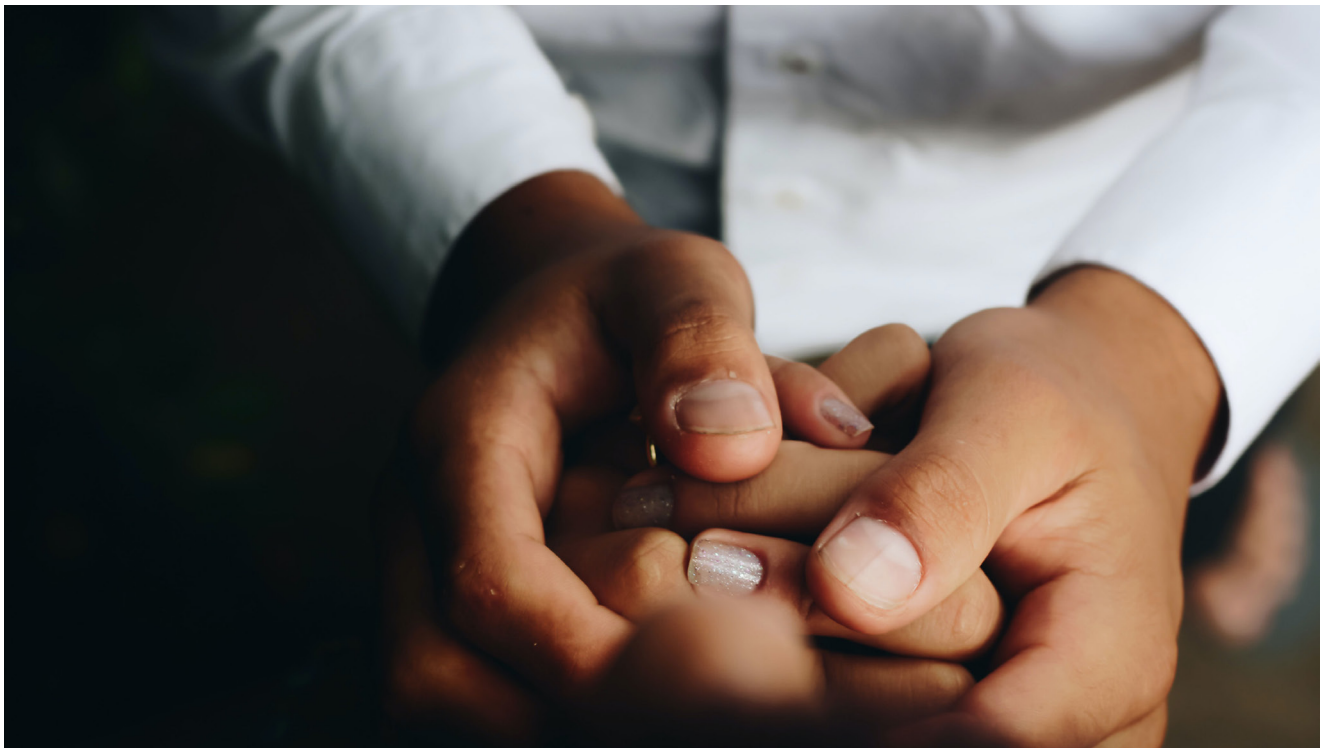

Image by Matheus Ferrero

For further information about St Bernard Support or to support our charity's work by advertising in Moving Forward please contact:

Mr Chris Bates
St Bernard Support
Broadstone House
Broadstone Mill
Broadstone Road
Reddish
SK5 7DL

Tel: 0800 772 0723
E-mail: admin@s-b-s.org.uk