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movingforward

News for people affected by Life Limiting Illnesses





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ST BERNARD SUPPORT HELPS CLIENT QUINTUPLE THE VALUE OF THEIR PENSION LEFT TO BENEFICIARIES

It may sound incredible that one of our charity's representatives could help a client increase the value of their pension by 500% but it shows what can happen when clients explore the pension options available to them.

Sheila from Crawley came to our charity seeking information about the options available to her regarding her pensions. Sheila was single with no children and no dependents. Sheila had been diagnosed with a terminal illness and had not vested her pensions as she was below retirement age.

One of her pension arrangements, a paid-up final salary pension offered death benefits of **approximately £2000** which equated to her pension contributions plus interest. As Sheila had less than **12 months' life expectancy** she was eligible to opt for her pension to be paid as a tax free serious ill health lump sum. Her pension arrangement offered a sum of approximately **£11,000 as a tax free serious ill health lump sum.**

Another option available to Sheila was transferring her final salary pension to a personal pension. The transfer value of her pension was **approximately £60,000.** This was over five times the amount offered to Sheila as a tax free serious ill health lump sum, and thirty times greater than the death benefits offered by her existing final salary pension.

Independent financial advice is necessary for the transfer of any **final salary pension greater than £30,000.** Sheila received independent advice from an FCA authorised and regulated financial adviser. Sadly Sheila passed away in May 2020 but not before transferring her pension and ensuring that her beneficiaries benefit from a significantly enhanced estate.



RESEARCH ON HOW COVID-19 AFFECTS PEOPLE WITH MULTIPLE SCLEROSIS

The coronavirus pandemic has generated an enormous amount of research, with over 40,000 papers published in the first six months of 2020. The MS Trust have been sifting through the research up to the end of June to bring you a round-up of the studies that give an idea of what coronavirus means for people with MS.

Most of the studies so far have reported data on single cases or on small numbers of people. They do give a general indication but we need to interpret them with caution. Around the world, registries have been set up to capture information supplied by neurologists and people with MS. Analysis of data from larger numbers of people will give us a better picture of how people with MS are affected by coronavirus and Covid-19. The UK MS Register has launched a survey to look at how people are coping with guidance from the government as well as to capture data on confirmed or unconfirmed cases of Covid-19 in people with MS. Whether you have had symptoms of Covid-19 or not, you can contribute your experiences by signing up for the survey.

DOES MS AFFECT YOUR RISK OF CATCHING CORONAVIRUS

As coronavirus began to spread globally, one of the first questions to be asked was would people with multiple sclerosis be more likely catch coronavirus. Based on an understanding of the biology of MS, MS Trust would not expect someone who has MS, and is otherwise healthy, to have a greater risk of becoming infected compared to the general public; MS does not weaken your immune system. At this stage, MS Trust don't have data from sufficiently large numbers of the population to absolutely confirm this, but there's been no indication that people with MS are more likely to catch coronavirus.

DOES MS AFFECT THE SEVERITY OF COVID-19?

Italy was the first European country to see a rapid rise in the number of people with Covid-19. Italian researchers set up an online registry to record and collect data about people with MS who have been diagnosed with Covid-19 or have developed symptoms (suspected Covid-19). MS neurologists across Italy were asked to input data and share patient outcomes.

Their preliminary data included 232 people with MS who tested positive for Covid-19 (57 people) or had suspected Covid-19 (175 people). 211 were taking a disease modifying drug (DMD).

THE DATA RECORDED THE SEVERITY OF COVID-19 IN THESE PEOPLE:

- 222 (96%) HAD A MILD INFECTION
- 4 (2%) HAD A SEVERE INFECTION
- 6 (3%) HAD A CRITICAL INFECTION

Of those who were critical, one person recovered and five people died. The people who died tended to be older (50+) and have other health conditions.

A French registry has also published data on people with MS with confirmed or highly suspected Covid-19. Of the 347 people in the study, 73 (21%) needed hospital care and there were 12 deaths (3.5%). Age, disability and obesity were most strongly linked to a more severe course of Covid-19.

Although the numbers reported are fairly small, they suggest that having MS doesn't increase your likelihood of a more severe Covid-19 infection and that the majority of people with MS who do develop Covid-19 are likely to have a mild infection, the same as the general population.

Data gathered from the wider population has identified other factors which can increase the risk of having a more severe course of Covid-19, such as an older age and having underlying health conditions, particularly those affecting the heart or lungs. If you are more severely affected by MS, for example if you have difficulty with swallowing, clearing your lungs or are prone to chest infections, you will also be at greater risk of developing complications from Covid-19.

DO DISEASE MODIFYING DRUGS AFFECT THE RISK OF CORONAVIRUS OR SEVERITY OF COVID-19?

Disease modifying drugs (DMDs) work by damping down your immune system in a number of different ways, so there is a possibility that they might make you more susceptible to infection with coronavirus or affect the course of Covid-19. Much of the research published so far has focused on this aspect of coronavirus and MS.

At the beginning of the pandemic, teams drew on expert opinion to publish recommendations on starting, continuing or suspending DMDs. Guidelines from the Association of British Neurologists have formed the basis of advice in the UK.

Data from around the world is now being published and this may lead to refinements to the initial guidelines. The Italian and French registry studies assessed the impact of DMDs on the course of Covid-19. In the Italian study, 211 people (91%) were taking a DMD; in the French study, 284 people (82%) were taking a DMD. In both studies, taking a DMD did not appear to cause more severe Covid-19 but both research groups

acknowledged the small number of people taking any one drug made it difficult to draw firm conclusions. A further set of data on the risk of Covid-19 in people with MS has been collected by neurologists in China. A survey reported details of 1,836 people with MS, of whom 882 (49%) were taking a DMD. None of those taking a DMD were diagnosed with COVID-19.

Finally, a number of studies have reported outcomes for individuals or a small number of people who developed Covid-19 while taking one of the DMDs (including Ocrevus, Tysabri, Gilenya, Lemtrada, Aubagio). In all of these, there has been no evidence to suggest that taking a DMD increases your risk of developing more serious complications.

Taken together, these studies provide reassurance that taking one of the DMDs does not lead to a more serious course of Covid-19. Combining data from registries and carrying out further, detailed analyses will shed further light on the impact of coronavirus and Covid-19 on people with MS.

Article courtesy of the MS Trust





FINDING NEW WAYS TO TREAT COPD AND ASTHMA

Maria, a clinical data scientist at University College London, is working on a project to identify subtypes of COPD and asthma.

There's an increasing number of studies that suggest Asthma and Chronic Obstructive Pulmonary Disease (COPD) aren't mutually exclusive conditions but form part of a group of airway conditions. This means the conditions have different causes but people with the conditions share similar symptoms. This makes diagnosis and treatment challenging.

WHY SUBTYPES OF COPD AND ASTHMA ARE IMPORTANT?

The project Maria is working on is investigating if it's possible to discover condition subtypes (different categories or groupings) in COPD and asthma. Maria and her colleagues are using an approach called cluster analysis. This method groups patients together based on their characteristics such as other conditions they have, smoking status or the number of drugs they take. Patients in the same group - called a cluster - are more similar than patients in other groups.

Cluster analysis has been used before for asthma and COPD, but on a much smaller scale. We're fortunate to have access to a large number of detailed electronic health records for patients with airways disease,

allowing us to understand the subtypes of these conditions on a population scale.

The ultimate aim of the study is to help health care professionals make better decisions for the treatment of people with COPD and asthma, as patients who belong to a particular subtype may require different care. Overall, our research is designed to find ways to give people living with these conditions a better quality of life.

Maria highlights that 'thanks to the British Lung Foundation (BLF), my research can make a real difference. The potential difference we can make to lives is why this project excites me. I'm putting my experience of working with patient data and machine learning methods to good use in this challenging project. As an early career researcher, I'm very grateful to the British Lung Foundation for its financial support for this project – I wouldn't be able to do this work without them. The BLF takes an active interest in this work and has also given me the opportunity to present my findings at scientific meetings'.

Article courtesy of the British Lung Foundation





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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