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Destigmatising Multiple Sclerosis

"...exercise is associated with improved mental health and function, both of which are key in MS."

Despite efforts to spread awareness and educate people about Multiple Sclerosis (also known as MS) there is still an unacceptable amount of misunderstanding, misinformation and stigma surrounding the disease.

What is Multiple Sclerosis?

Multiple sclerosis, the neurological and autoimmune disease that impacts millions of people around the world, is on the rise. As a degenerative disease, multiple sclerosis patients experience worsening symptoms over time, requiring more care and more comprehensive treatment as the disease progresses.

Because MS targets and impairs the function of the nervous system, symptoms of the disease often become widespread around the body as more neurons are damaged. Causing widespread and diverse symptoms that can impact a person's senses, muscular function, vision, digestive system, urinary function, and cognitive capabilities, patients diagnosed with MS often experience profound changes to their day-to-day lives the longer they are living with the disease.

Motor symptoms are just the tip of the iceberg

When most people think about MS, they commonly think about the motor symptoms that become more apparent as the disease progresses. And while changes in a person's motor function definitely have a major impact on their day-to-day routines, there are a variety of other symptoms that also have a profound impact on their quality of life. Commonly referred to as a ***metaphorical iceberg***, the extent of MS symptoms is much, much deeper than many people can even imagine.

Diagnosing and appropriate treatment of MS can be challenging and the international guidelines recommend, referral and review by a Neurologist.

Types of Multiple Sclerosis

MS currently is categorized into four main types. Learn more about each one below.

Clinically Isolated Syndrome: first clinical presentation of neurological symptoms, lasting 24 hours or more.

Relapsing-remitting MS: Characterized by relapses followed by periods of remission.

Secondary Progressive MS: disease stage that follows RRMS, in which symptoms steadily worsen, even if the individual experiences no relapses.

Primary Progressive MS: progressive form of MS in which progression starts right from disease onset.

How is Multiple Sclerosis treated?

"The aim of treatments in Multiple Sclerosis is to ensure a good quality of life for as long as possible. That means prevention of attacks as well as the minimisation of inflammation with the neural system." Dr Avidesh Panday, Neurology and Neurophysiology Consultant at Eric Williams Medical Sciences Complex.

"This is done by the initiation of preventative medications known as **Disease Modifying Treatments** which can be oral, intramuscularly/subcutaneously or intravenously. The aims of these medications are to reduce inflammation and thus prevent attacks or the accumulation of injury in the nervous system. Different medications have different side effect profiles as well as efficacy. In the event that a patient has an acute attack, we sometimes use steroids administered intravenously. However, this is but one facet of the treatment of MS. We need to maintain overall wellness and this includes attention to mental and physical health for which exercise is critical," Dr Panday shared.

Is there a role for exercise in MS?

"Exercise is beneficial for all organs and overall health. However, it is specifically useful in forming part of a comprehensive MS strategy. Exercise improves cardiovascular fitness and exerts an anti-inflammatory effect which is useful in attack prevention. Additionally, exercise, particularly stretching and flexibility exercises are useful in the recovery phase of MS as it improves balance and strength. Most importantly, exercise is associated with improved mental health and function, both of which are key in MS."

Local Research on Multiple Sclerosis in Trinidad and Tobago

A recent study of MS in T&T conducted by Dr Henry Bailey and Dr Avidesh Panday of UWI showed that 75% of the patients are females and over 50% are in the 25-44 age group. MS patients in T&T tend to be highly educated, and more likely to be living in urban areas. The study found that MS patients in T&T were more severely affected by physical than by mental and emotional effects of MS and that males were more severely affected than females.

Historically it was believed that MS was associated more with the caucasian population than with afro populations. This thinking is changing as new studies show that prevalence in afro- populations may actually be equal to- or even higher than- that for caucasian populations in some age groups.

The prevalence of known cases in T&T is just under 8 cases per 100,000 people compared to 36 per 100,000 internationally. This suggests that there might be people in T&T who have the illness but are unaware of it.

The T&T study will soon be published and it will include a detailed analysis of the quality of life associated with MS among patients in T&T using quality of life measures that have been used with MS patients in developed countries.

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What you need to know about Haemophilia

"Living with haemophilia can be restrictive. Patients may not be able to attend or perform certain activities due to the increased risk of bleeding."

Haemophilia is usually an inherited bleeding disorder in which the blood does not clot properly. Blood contains many proteins called clotting factors that can help to stop bleeding. People with haemophilia have low levels of either factor VIII (8) or factor IX (9).

The severity of haemophilia that a person has is determined by the amount of factor in the blood. The lower the amount of the factor, the more likely it is that bleeding will occur which can lead to serious health problems.

There are several different types of haemophilia. The following two are the most common:

- Haemophilia A (Classic Haemophilia) - This type is caused by a lack or decrease of clotting factor VIII.
- Haemophilia B (Christmas Disease) - This type is caused by a lack or decrease of clotting factor IX.

Common signs of haemophilia include:

- Bleeding into the joints. This can cause swelling and pain or tightness in the joints; it often affects the knees, elbows, and ankles.
- Bleeding into the skin (which is bruising) or muscle and soft tissue causing a build-up of blood in the area (called a hematoma).
- Bleeding of the mouth and gums, and bleeding that is hard to stop after losing a tooth.
- Bleeding after circumcision (surgery performed on male babies to remove the hood of skin, called the foreskin, covering the head of the penis).
- Bleeding after having shots, such as vaccinations.
- Bleeding in the head of an infant after a difficult delivery.
- Blood in the urine or stool.
- Frequent and hard-to-stop nosebleeds.

How is Haemophilia diagnosed?

Many people who have or have had family members with haemophilia will ask that their baby boys get tested soon after birth.

About one-third of babies who are diagnosed with haemophilia have a new mutation not present in other family members. In these cases, a doctor might check for haemophilia if a new born is showing certain signs of haemophilia.

To make a diagnosis, doctors would perform certain blood tests to show if the blood is clotting properly. If it does not, then they would do clotting factor tests, also called factor assays, to diagnose the cause of the bleeding disorder. These blood tests would show the type of haemophilia and the severity.

Treatment

The best way to treat haemophilia is to replace the missing blood clotting factor so that the blood can clot properly. This is done by infusing (administering through a vein) commercially prepared factor concentrates.

"The standard for care today for persons with severe haemophilia is Prophylaxis." World Federation of Haemophilia, 2023.

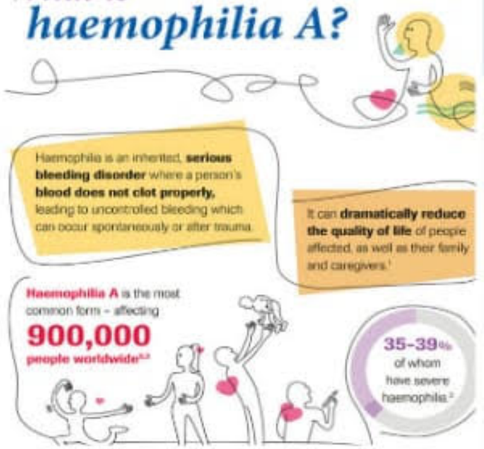
Inhibitors

About 15-20 percent of people with haemophilia develop an antibody (called an inhibitor) that stops the clotting factors from being able to clot the blood and stop bleeding. Treatment of bleeding episodes becomes extremely difficult, and the cost of care for a person with an inhibitor can skyrocket because more clotting factor or a different type of clotting factor is needed. People with inhibitors often experience more joint disease and other problems from bleeding that result in a reduced quality of life.

Holistic Support is Key

Living with haemophilia can be restrictive. Patients may not be able to attend or perform certain activities due to the increased risk of bleeding. This inability can have negative effects on one's psychological health and cause feelings of sadness, anxiety, or anger. Haemophilia can also influence a patient's mental health. In addition to medical care, a holistic approach should be taken and emotional support when needed.

For more information:



Through the lens of a caregiver

-a nurse, a wife and a mother

I am a Registered Nurse specialised in Paediatric Haematology/Oncology. I work in the field of Haematology at present. Having a husband with a blood disorder and given the challenges we encounter has made me a better nurse. Empathy is second nature to me because I live the caregiver role. I understand my patients' concerns, fears, frustrations, and tears because I live it too.

This is part of my husband's story with Haemophilia…

My husband and I met over 22 years ago, through a mutual friend. He never disclosed his illness to me until his illness became serious. He had a hip injury that made him unable to walk and affected his mobility.

We have had so many challenges over the years. Having prompt and efficient emergency care was and still is a problem. Challenges also present in acquiring blood donors and blood products for timely treatments.

Over time he has developed inhibitors to factor replacement therapy and the treatment, which is a bypassing agent that would work for patients with inhibitors. It stopped working for him. This makes treating his injuries and bleeds more difficult and challenging. Our hospital presently does not test for inhibitors levels at the public hospitals labs. We have to pay for his inhibitors levels at a private lab every 2-3 months.

Due to multiple hip, knee, elbows and ankle injuries, this led to haemophilic arthropathy in all his major joints. As a result, medications which would normally reduce bleeding, swelling and inflammation were not working for him, resulting in enduring sleepless nights and intense pain, which made daily living very difficult. His condition has made it almost impossible for him to maintain a normal 8-4 pm job because of the multiple joint deformities.

He has 2 dental extractions still to be done, just imagine having a tooth ache for 9 years. He endures pain and agony ever so often due to the constant decaying of the teeth. This procedure has been delayed because of the local unavailability of medications for patients with inhibitors and are unresponsive to other treatments.

After losing his uncle and his younger brother a few years apart from complications of a haemophilia crisis, it gave us a new perspective and appreciation for life and family. We do not take time, nor each other for granted.

My advice to all caregivers is to take care of yourself. Your health is also important. Try to have a balance in life. God first and mankind after. Take a little time for yourself, do something you like doing. It is not selfish, its healthy. Enjoy today, because tomorrow is not promised. We are grateful for the support system around us that continues to inject hope everyday into our lives.

We live in the moment and enjoy the moment because we know all too well how precious and fragile life can be.

We wrestle with the thought of him having a serious injury or a major emergency and what will be his fate.

There is so much more I can share, but I hope those who can change the deficits, pay attention.

We hope more can be done to improve the availability of the necessary investigations and accessibility to effective treatment.

If in doubt, treat! If you think you have a bleed, get treatment even if you are not sure. NEVER wait until a joint is hot, swollen, and painful. Do not worry that you may "waste" a dose of factor.

When should treatment be given?

The standard of care today for people with severe hemophilia is **prophylaxis**. Prophylaxis is the regular administration (intravenously, subcutaneously, or otherwise) of factor or non-factor replacement treatment with the goal of preventing bleeding (especially life threatening or recurring joint bleeding) in PWH.

On-demand treatment is the administration of factor only when there is active bleeding. It is given for:

- Bleeding into a joint
- Bleeding into a muscle, especially in the arm or leg
- Injury to the neck, mouth, tongue, face, or eye
- Severe blows to the head and unusual headaches
- Heavy or persistent bleeding from any site
- Severe pain or swelling in any site
- All open wounds requiring stitches, and
- Following any accident that may result in a bleed.