About us
The Penang MS Support Group Association was established on 1 April 2009. It started with an initial 11 members and has grown to 193 strong today. The Association’s mission is to create awareness about MS, to provide counselling and look after the welfare of MS patients.

World MS Day 2016
Venue: Auditorium A, KOMTAR
Date: 15 May 2016
In conjunction with World MS Day, the Penang MS Support Group Association organised a get-together to welcome new members/volunteers to the group. Members who were patients of MS were given a token of support in the form of Wargai MS, a medical assistance fund of RM 100 each sponsored by the state government.

Charity Fund Raising Dinner 2016
Venue: Rainbow Paradise Beach Resort Penang
Date: 13 September 2016
This charity event was organised by Dalat International School together with the Family Hope Welfare Association and the Penang MS Support Group Association. Apart from a sumptuous buffet dinner, the chances were treated to an evening of song and dance by the students and members of both associations.

Membership:
Membership to the Penang Support Group Association is open to all Malay
sian aged 18 and above. MS patients are exempt from membership fees. Individuals of the public and medical students are welcomed to join us.
Annual fees: RM 24
Joining fees: RM 60

Contact details
PENANG OF MULTIPLE SCLEROSIS SUPPORT GROUP ASSOCIATION
No 22-10, Taman Putra Biru, Jalan Terengganu, 10450, Penang, Malaysia.
Tel: (Office) 04-281 4505
(Mobile) 013-484 5522
email: penang.msasy@gmail.com

Multiple sclerosis
Multiple sclerosis (MS) is a chronic and often disabling disease affecting the central nervous system (CNS), which is made up of the brain and spinal cord. It mostly occurs in young adults in their 20s to 40s, and is more frequently found in women than in men. In Malaysia, approximately 2 out of 100,000 people are estimated to have MS.1

What causes multiple sclerosis?
MS is caused by an abnormal immune reaction in which the body’s immune system attacks the outer layer of the nerve fibre called myelin. This results in inflammation and loss of myelin. The symptoms that appear in an individual person depends on the location and severity of myelin loss.1 Numbness or tingling, weakness, muscle spams, bladder or bowel problems, and visual disturbances are some of the common symptoms of MS.2

Multiple sclerosis and the eyes
The optic nerve is a bundle of nerve fibres connecting the eyes to the brain. It is one of the commonest sites involved within the CNS during the early stages of MS.1,3 In MS, any part along the optic nerve pathway can be damaged, causing the flow of signals to be disrupted or blocked.3 This can give rise to a variety of problems in how MS patients see the world and how their eyes move together.5

Problems with sight
- Blurred vision
- Visual field defect (blind spots)
- Diplopia (double vision)
- Distorted vision (straight lines look wavy)
- Floaters, sparks

Problems with eye movement
- Gaze palsy (Figure 1)
- Unequal eye alignment
- Nystagmus (jerky eye movements)
- Impaired pupil constriction to light

Figure 1: In gaze palsy, the eyes do not move together when looking to the side.

References:

What the experts say

Associate Professor Dr Suhailah Abdullah
(Consultant Neurologist, University Malaya Medical Centre)
- MS typically begins with a rapid onset of visual disturbances that worsens over a few hours or days.
- MS can affect different patients in different ways, with symptoms ranging from blurred vision to complete loss of sight.
- As the inflammation of the optic nerve subsides, recovery is generally good and vision returns to near normal over time.
- However, recurrent attacks with incomplete recovery can lead to vision loss and blindness.

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References:
Nystagmus

Nystagmus is an involuntary, rapid, jerky movement of the eyes. These movements can be from side to side, up and down, or in a slanted motion. It is a common symptom in MS, affecting about 30% of patients.

Nystagmus can be symptomatic. Patients with MS may not be aware that they have nystagmus because it can have little or no effect on their vision.

In some patients, nystagmus can be the cause of uncomfortable and disabling symptoms, such as oscillopsia (i.e., a sensation in which objects appear to be moving back and forth), difficulty holding their gaze on an object and unstable gait.

Homonymous hemianopia

Homonymous hemianopia is a visual field defect involving the same halves of the visual field of both eyes (Figure 6). It is a very rare manifestation of MS which occurs in 1-2% of patients.

Double vision

Within the optic nerve, there is another group of nerve fibres that carry signals in the opposite direction, i.e., from the brain to the eyes. These nerve fibres are responsible for controlling the eye muscles and coordinating movement.

When this pathway is affected by MS, the eyes cannot align or focus together. This results in double vision or diplopia (Figure 5).

Double vision is usually associated with other symptoms such as dizziness, vertigo (a spinning sensation) and problems with balance. Recovery is usually good and occurs within weeks or months.

Treatments

Treatment

- Early treatment of acute relapses with corticosteroids, especially methylprednisolone, hastens the recovery of visual disturbances associated with MS.
- The recommended treatment is with intravenous methylprednisolone for 3-5 days, followed by a tapering dose of oral prednisolone over the next 9-11 days.
- For patients who responded poorly to initial corticosteroid therapy, plasma exchange (a procedure that filters antibodies from blood) is used as second-line treatment.
- The use of disease-modifying therapy, such as interferon beta injections, during the early stages of MS prevents disabling relapses.

Avoid aggravating factors

Uthoff’s phenomenon is the temporary worsening of symptoms when the body temperature rises. Patients with visual disturbances may find that their vision tends to worsen in certain conditions, such as hot weather. These changes are caused by unstable electrical impulses in a previously affected nerve and do not indicate fresh nerve damage.

- Avoid hot baths
- Exercise early in the morning or late evening
- Conserve energy to avoid fatigue
- Fever may indicate an underlying infection (e.g., urinary tract infection) and should be treated.

Peter’s story

Peter was working as an art director at a print agency when he started to have double vision. At first, he thought it was caused by staring at the computer for too long. Objects appeared blurry and his surroundings looked dim. Even more worrying was the fact that he was finding it difficult to differentiate colours, which was an important aspect in his line of work.

When the symptoms did not go away, Peter decided to seek treatment. A series of tests and CT scan was done. However, the doctors were unable to find the cause of his vision problems. He was subsequently referred to a neurologist. It was then that Peter first heard of multiple sclerosis. His vision problems were to be the first of many acute episodes over the next 10 years.

Although Peter’s symptoms improved after a course of intravenous steroids, his vision was still unstable. One month after the diagnosis, he lost his job and fell into depression. At that time, his wife had just given birth to their first child. There was no cure for MS and he was also worried that he would not be able to provide for his young family.

It took several months for Peter to accept his condition and rebuild his life. He reached out to his friends and was able to find employment as an office administrator, IT specialist, and then as a marketing executive over the years. He continued to do graphic design as a hobby and took on freelance jobs when the opportunity arose.

Peter shared some tips for adjusting to life with MS. “I discovered that certain situations would trigger my symptoms. For example, when I was stressed with work or exposed to hot weather, my vision would become dimmer. It usually gets better after I take a break.”

“Peter is the president and founder of the Ranui MS Support Group. Over the years, his passion for helping people with multiple sclerosis has been evident. To learn more about the support for people living with MS and their families, contact Peter at 011-4849522.”
What is multiple sclerosis?

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Figure 1: In gaze palsy, the eyes do not move together when looking to the side.

Optic neuritis

Optic neuritis (ON) is the medical term used to describe inflammation of the optic nerve. It is often the earliest symptom of MS in 15–20% of patients. One out of every two patients with MS will experience some form of ON during the course of their disease. More than 90% of patients with ON have blurred vision (Figure 2); whilst total blindness occurs in 3% of cases.7

What the experts say

Professor Dr Tan Chong Tin
(Consultant Neurologist University Malaya Medical Centre)

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Associate Professor Dr Suhailah Abdullah
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- ON usually occurs in one eye, but can affect both eyes in rare cases. It typically progresses over hours to days, with improvement or recovery seen in 75% of patients by 1 month
- More than 90% of patients who develop ON experience eye pain that is worsened by movement.
- ON is commonly associated with visual field defect, often described as a smudge or a hazy layer of thin film in your field of vision (Figure 3).
- Patients can also experience impaired contrast and colour vision, i.e. images appear darkened or less vivid compared to the unaffected eye (Figure 4).
### Double vision

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Nystagmus can be asymptomatic. Patients with MS may not be aware that they have nystagmus because it can have little or no effect on their vision.

In some patients, nystagmus can be the cause of uncomfortable and disabling symptoms, such as oscillopsia (i.e. a sensation in which objects may appear to swing back and forth), difficulty holding their gaze on an object and unsteady gait.

### Homonymous hemianopia

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Figure: Homonymous hemianopia
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**Professor Dr Tan Chong Tin**  
(Consultant Neurologist, University Malaya Medical Centre)

**Vision aids**

- Choose large-print books or use a magnifying glass for reading
- Cover one eye with an eye patch to reduce double vision
- Corrective lenses with prisms reduce diplopia by bringing the eyes back into alignment
- Wear telescopic eye glasses to suppress nystagmus.

**Modifying your environment**

- Use a larger computer monitor, large-print keyboard and screen enhancement software
- Add lighting to your computer or work desk
- Get phones with large keypads or voice-activated functions
- Replace clear glass utensils with coloured ones that are easier to see.

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**Peter’s story**

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It took several months for Peter to accept his condition and rebuild his life. He reached out to his friends and was able to find employment as an office administrator, IT specialist, and then as a marketing executive over the years. He continued to do graphic design as a hobby and took on freelance jobs when the opportunity arose.

Peter shared some tips for adjusting to life with MS. “I discovered that certain situations would trigger my symptoms. For example, when I was stressed with work or exposed to hot weather, my vision would become dimmer. It usually gets better after I take a break.”

“*When I discovered that my vision was affected by stress, I found that listing out my most important daily tasks helped me cope with my vision problems,*” Peter explained. “*Always do what is important for the day and leave the unfinished tasks for tomorrow.*” Living with MS also required adjustments in other daily functions, such as driving. “*I can get around on my own during the day but driving becomes more challenging at night as I cannot see clearly. I will get my wife or friends to drive me around instead.***

Peter has some advice for people who are undergoing career uncertainties because of MS. “*Be positive towards change and talk to the MS society in your country. Be open to new ideas, have the courage to try something new when given the opportunity. Most importantly, don’t give up! There is always hope around us.***

Peter is the president and founder of the Penang MS Support Group Association. The Association aims to provide assistance and support to MS patients. One such assistance is helping patients with disabilities apply for financial support from the Penang Social Welfare Department. Anyone who is keen to know more about the application for state welfare assistance are welcomed to contact Peter at 013-4045532.
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Contact details:
Penang of Multiple Sclerosis Support Group Association
CO-22-U1, Kompleks Masyarakat Penyebayang, Jalan Utama, 10450 Penang, Malaysia. Tel: (Office) 04-281 4055 (Mobile) 013-484 5522
Email: penang.mssg@gmail.com

Upcoming events:
21 May 2017: MS Walk 2017

The goals of the Society are:
• To provide a support network for patients with MS
• To increase public awareness about MS
• To encourage earlier diagnosis and treatments before the condition becomes adverse
• To seek government assistance in approving the availability of medicine to patients who cannot afford to buy the same because the medicine is costly
• To purchase a building for the Society’s office and activities

References:

This newsletter is endorsed by the MS Society Malaysia and Penang MS Support Group Association.

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